‘NEGOTIATING SELF-WORTH’ IN THE CONTEXT OF RHEUMATOID ARTHRITIS: A GROUNDED THEORY STUDY

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by

Evelyn Siobhánn McManus

DECLARATION

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SUMMARY

‘NEGOTIATING SELF-WORTH’ IN THE CONTEXT OF RHEUMATOID ARTHRITIS: A GROUNDED THEORY STUDY

Background: Rheumatoid Arthritis (RA) is a chronic condition with an auto-immune pathology which may present at any age. Since its recognition in the mid-nineteenth century medical science has been at the forefront of extensive investigations searching for effective treatments. At the end of the twentieth century pharmacotherapies and specific treatment strategies were identified to alter the immune response, thus improving the physiological outcomes in terms of increased functionality and longevity for individuals affected. RA is a biopsychosocialspiritual condition and therefore affects the whole person. Studies prior to advancements in treatments revealed that living with the condition was perceived as suffering, a burden and impacted upon selfhood. It was not known what the people who live with RA (PLRA) considered as their main concern since the treatment advances.

Aim: The overall aim of this study was to generate a substantive grounded theory that explained how the participants processed their main concern when living with RA.

Methodology: Grounded theory (GT) as developed by Strauss and Glaser (1967), and specifically Glasserian Grounded theory (GGT) as established by Glaser (1978) was used to identify how the participants processed their main concern. Participants who had RA for longer than three years were invited to participate. Twenty-nine (29) in-depth interviews were conducted in various community settings in the Northwest of Ireland. Further data was also collected from a recently published book about the lives of PLRA. Selective coding and theoretical sampling were used, in conjunction with the constant comparative method to identify a core category and subcategory that fitted with the data. Continuous memoing supported the ongoing analysis and memo sorting helped to identify the theoretical codes.

Findings: The main concern for the participants in this study was identified as a *Fear of Declining Self-Worth*, which emerged in response to a confirmed diagnosis of RA, which signalled to the participants that they were going to become unable and dependant on others which negatively influenced their self-worth. The core category *Negotiating Self-Worth* explained how the participants continuously processed their main concern. *Negotiating Self-Worth* was operationalised in different awareness contexts which the participants created. The closed, limited, and open awareness contexts were further influenced by critical junctures of Flux, Vulnerability and Secure. These psychological states were the drivers in relation to awareness context, disclosure and progression over the three stages of the process.

Insulating Self-Worth represents the first sub-core category. When participants enter this stage they are in a psychological state of Flux and are consumed with the psychosocial considerations of RA. The ongoing demands of concealing and repeated flare-ups, in addition to normal social concerns, become too much and a psychological state of Vulnerable was entered, at which point participants progressed to the second sub-core category *Scoping Self-Worth*. Progression in this stage was supported by psychosocial resources, which assisted the participants in increasing self-awareness and personal comfort with exploring previous knowledge of RA and problem solving. A high level of engagement supported the participants to reach a critical juncture of Secure and they progressed to the next stage *Scoping Self-Worth*. When there was a low level of engagement, the participants returned to the previous stage of *Insulating Self-Worth* and entered the FASP (Flurry of Activity and Self Pity cycle). Re-entering *Scoping Self-Worth* occurred when the participants gained insight into their cycle of behaviours. The engagement with psychosocial supports increased their self-confidence. This was key in the progression to *Bolstering Self-Worth*. The participants brought the insights and possibilities for being and living gained in *Scoping Self-Worth* into this final stage. Supportive Relationships and Positivity enabled the participants to reframe their ideas for living and, moreover, strengthened the psychological processes which stabilised and empowered the participants to maintain their new vision. At this point RA was placed in the context of their whole life, that is, alongside the other aspects of living.

Conclusion: The theory that emerged emphasises that sociocultural understandings about chronic conditions do not alter in response to advances in science. For people diagnosed with a chronic condition, those previously held understandings will prevail until they are sought out and addressed with appropriate supports. This study clearly demonstrates that with supports PLRA can find purpose and meaning beyond their diagnosis. Societal approaches to chronic conditions must, therefore, acknowledge the impact of the psychosocial perspectives and find ways to support people in achieving a fulfilled life. *Negotiating Self-Worth* is a three staged process with critical junctures and illustrates variation enabling it to be understood as a Basic Social Psychological Process (BSPP).

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I would like to dedicate this thesis to all the people who have inspired me throughout my life. While these are many people, there are two groups in particular who inspired me either by their example or encouragement. My deceased parents Bernard and Kathleen and the many people I have had the privilege of being present with, at times of great need in their own lives.

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Finally, my sincere appreciation goes to the remarkable people who participated in this study. I have learned so much from your sharing and I endeavour to share this learning with others on their arthritis journey. Thank you for entrusting me with your experiences.

TABLE OF CONTENTS

List of Tables

List of Figures

Glossary of Acronyms

ACPAs	Anticitrullinated Protein Antibodies
ACR	American College of Rheumatology
AFLAR	African League of Association for Rheumatism
ANP	Advanced Nurse Practitioner
APLAR	Asia Pacific League against Rheumatism
BRADA	Belgian Rheumatoid Arthritis Disability Assessment
BSPP	Basic Social Psychological Process
CQRA	Commissioning for Quality in Rheumatoid Arthritis
CNM 2	Clinical Nurse Manager 2
DMARD	Disease-Modifying Antirheumatic Drugs
DoH	Department of Health
DoHC	Department of Health and Children
EULAR	European League Against Rheumatism
FASP	Flurry of Activity and Self-Pity Cycle
GGT	Glasserian Grounded theory
GP	General Practitioner
GT	Grounded Theory
HSE	Health Service Executive
ILAR	International League against Rheumatism
IRHPS	Irish Rheumatology Health Professionals Society
LDA	Low Disease Activity
MDT	Multi-Disciplinary Team
NCPR	National Clinical Programme for Rheumatology
NICE	National Institute for Health and Care Excellence
OMERACT	Outcome Measures in Rheumatology
PANLAR	Pan American League against Rheumatism
PLRA	Person Living with RA
PROMS	Patient Related Outcome Measures
RA	Rheumatoid Arthritis
RCT	Randomized Clinical Trials
RF	Rheumatoid Factor
RU	Rheumatology Unit
T2T	Treat to Target
TS	Theoretical Sensitivity
UK	United Kingdom
WHO	World Health Organization

CHAPTER ONE: INTRODUCTION AND OVERVIEW OF THESIS

Introduction

This study sought to discover the main concerns of PLRA and understand how they processed this concern. This endeavour culminated in the development of a theory which I have named *Negotiating Self-Worth*. This theory explains how PLRA process the main concern of *Fear of Declining Self-Worth*. It is a social process operationalised within an awareness context. The aim of this chapter is to introduce the reader to the substantive area and to give a broader background to this study. An overview of RA, its medical recognition, treatments and recognised support systems for PLRA are presented. As this study took place in the Irish context, the mechanism by which PLRA interact with healthcare is also outlined. The aims of the study are included here as an overall guide, together with an overview of the organisation of this thesis.

Origins of Arthritis

The word arthritis derives from Greek, Latin and Medical phraseology. *Arthri* is a derivative of *arthron*, a Greek term meaning 'joint'. The Latin translation is *articulus*, meaning the putting together of several distinct parts (Oxford University Press 2018). The term itis has Latin origins and in medical terms denotes inflammation. The literal meaning of arthritis refers to the inflammation of joints. While literal translation of the term is helpful in knowing that it is a disorder affecting joints, the term itis is misleading as inflammation, while a common feature, may not be evident or be the predominant characteristic. By contrast, everyday usage explicated by the participants in this study referred to any lingering joint ache or pain devoid of medical evaluation! As such this denotes a familiarity with the term with or without any underpinning knowledge. Within the field of medicine, arthritis is accepted as a global term ascribed to over 200 chronic joint disorders with Osteo and Rheumatoid typologies being the most prevalent (European League Against Rheumatism (EULAR) 2009).

Historical Presence

Studies by paleopathologists revealed that joints of skeletons indicated signs of wear and tear on long bones suggesting that arthritis in some form existed in prehistoric times (Bridges 1992). Additionally, malformation of joints is also suggestive of inflammatory activity in skeletons (Entezami *et al.* 2011). These studies were conducted prior to modern paleopathological methods and therefore are suggestive but not conclusive. Nevertheless, Entezami *et al.* (2011) conclude that sufficient evidence exists in ancient texts and artwork to support the view that arthritis always existed. The texts refer to the enduring nature of the condition and the pain. The artworks Entezami *et al.* (2011) refer to are the disfiguration of phalangeal joints in the Peter Paul Rubbins artwork “The Three Graces” and the anonymous painting of the “Temptation of Saint Anthony” where the beggar has structural displacement of the wrists. Despite its prehistoric existence knowledge of arthritic conditions only began to emerge in the twentieth century. The catalyst for contemporary understanding of arthritis as a medical condition originated in the nineteenth century and has evolved since then, making a continuing contribution to developments. It is appropriate to inform the reader of some more detail as it will assist in understanding the developments that have emerged over time.

Declaring Rheumatoid Disorders

Early recognition of inflammatory arthritis is accredited to the French surgeon Landré-Beauvais (1772-1840) who differentiated arthritis from the dominant eighteenth century gout (Landré-Beauvais 2001). Later in the mid-nineteenth century, Sir Alfred Garrod [1819-1907] advanced the pathological differentiation and coined the term RA (Symmons 2002). In 1927 a group of international physicians met in Paris and formed the International Committee Against Rheumatism (reorganised as the International League against Rheumatism (ILAR) (Engelman 1986). ILAR members recognised the need for conformity in medical practices. The ILAR members formed national societies and groups in their respective countries. The aim of these groups was to promote knowledge and research to support the implementation of standardised best practice in rheumatology internationally. The outbreak of World War II posed challenges to communication and regional groups were formed, all subordinate to ILAR. Figure 1 illustrates the development of professional groups since 1927.

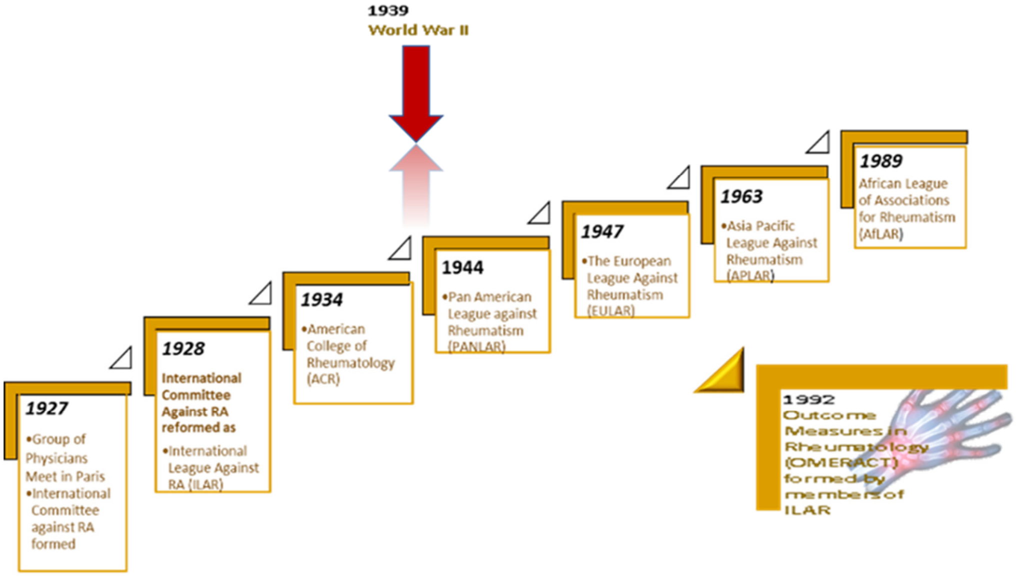
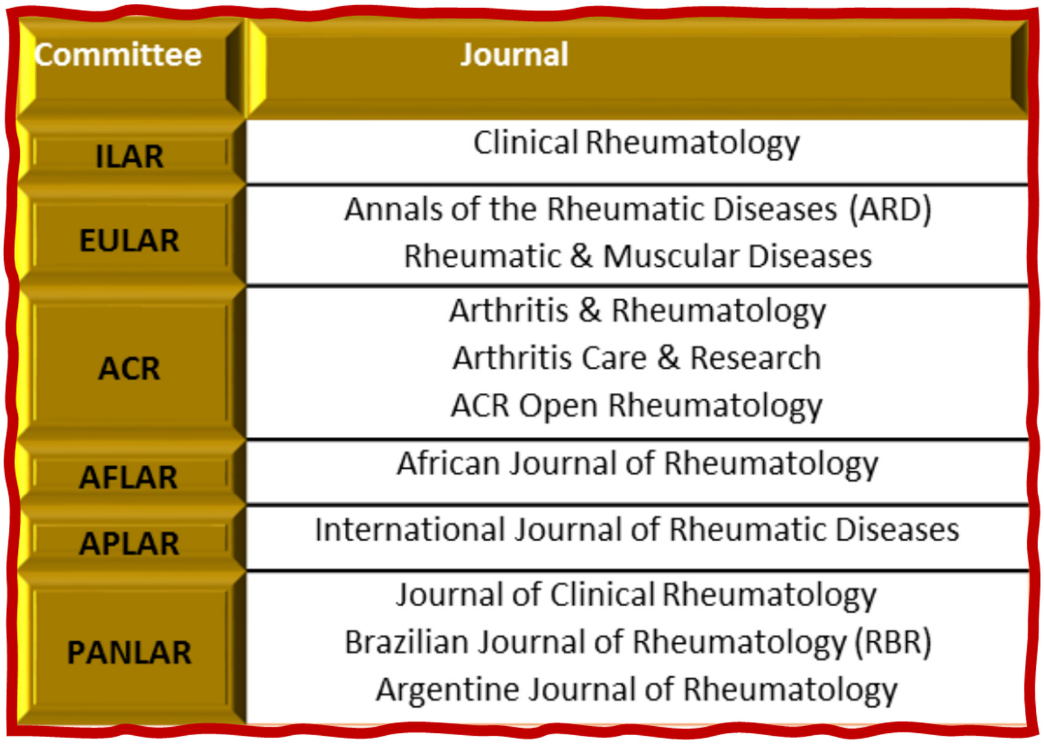


Figure 1 Professional Groups since 1927

This structure endures to the present day, with conferences providing a forum for professional collaboration leading to advances in research and best practice in relation to diagnosis and treatment internationally (Engelman 1986). For example, Outcome Measures in Rheumatology (OMERACT) formed in 1992, supports the identification of core outcome sets for specific aspects of rheumatoid treatments (Tugwell *et al*. 2007). OMERACT have extended their work more recently to include patient related outcome measures (PROMs) (Chiarotto *et al.* 2015). Randomized clinical trials (RCT) are supported by scholarships and bursaries by ILAR and the regional groups, namely, ILAR, EULAR, ACR, AFLAR, APLAR, and PANLAR. This international collaboration has ensured the work provides insights into the assessment, diagnosis, and treatment of rheumatological conditions. While the regional committees are non-governmental, the professional groupings render them a powerful group which influence not only national but international policy. The collaboration is enhanced by publication in the journals of the regional committees. Table 1 outlines the current journals. The international collaboration has created a ripple effect in individual nations. For example, within the United Kingdom (UK) a group called Commissioning for Quality in Rheumatoid Arthritis (CQRA) has been formed which functions within the National Institute for Health and Care Excellence (NICE) and develops metrics on NICE guidelines.



Committee	Journal
ILAR	Clinical Rheumatology
EULAR	Annals of the Rheumatic Diseases (ARD) Rheumatic & Muscular Diseases
ACR	Arthritis & Rheumatology Arthritis Care & Research ACR Open Rheumatology
AFLAR	African Journal of Rheumatology
APLAR	International Journal of Rheumatic Diseases
PANLAR	Journal of Clinical Rheumatology Brazilian Journal of Rheumatology (RBR) Argentine Journal of Rheumatology

Table 1 Rheumatology Journals

Arthritic Networks in Ireland

Within Ireland the Irish Society for Rheumatology was formed in 1973 for medical professionals. The Arthritis Foundation of Ireland was formed in 1981 (re-formed as Arthritis Ireland in 2000). Membership involves lay people and professionals who work on different programme objectives to educate the public about arthritis, to support those living with arthritis and contribute to ongoing research. In supporting the latter, Arthritis Ireland funds key Chairs of Rheumatology in two of Ireland's principal universities, namely, Trinity College Dublin and University College Dublin. The Irish Rheumatology Health Professionals Society (IRHPS) was formed in 1996 and members are allied health professionals working in the field of rheumatology. The Irish Rheumatology Nursing Forum was founded in 2004 and currently has 71 members. The first Advanced Nurse Practitioner (ANP) in Rheumatology was appointed in 2003. The appointment reflects the commitment and expertise in the development of rheumatological services in Ireland (Minnock & Ryan 2018).

About RA

Prevalence

Internationally, recording systems for chronic conditions differ and therefore precise estimates for adult RA are unobtainable. Most prevalence studies emanate from Northern Europe and North America, with a small number from Africa, Russia, Asia, and Southern Europe (Alamanos *et al*. 2006). This suggests that RA is an international phenomenon. The Health Service Executive (HSE) (2017a) estimate that 1 in 5 adults in the Irish population have some form of arthritis. Safiri *et al*. (2020), reporting on a systematic analysis of the Global Burden of Disease Study 2017, state the global incidence of RA between 1990 and 2017 has increased by 7.4% to 240 per 100,000 of the population. While the phenomenon of RA is international, treatment options have varied over time. The work of EULAR continues in an effort to standardise the assessment, diagnoses and treatment and achieve international equity (Smolen *et al*. 2020).

Causation

Causation was a key consideration for the participants in this study. There are no clear answers regarding causation. According to Alamanos and Drosos (2005) the occurrence, severity and genetic links while generally accepted is incompletely understood. Kurkó *et al*. (2013) refer to the pathogenesis of RA as the Bermuda Triangle, which acknowledges the contribution of genetic, environmental and auto-immune triggers that contribute to susceptibility of RA or its severity. The genetic and environmental investigation work is ongoing in relation to susceptibility and causation (De Roos *et al*. 2014). The higher incidence in women is considered to be linked to hormonal and reproductive factors (Oliver & Silman, 2009). The consumption of a lifelong diet rich in omega 3 is reported as reducing the risk of developing RA (Duncan 2015). Factors such as lifestyle and ethnicity are linked to RA but as yet these are inconclusive to both susceptibility and manifestation (Lee *et al.* 2019). A family history increases the risk and it is also suggested that some bacterial infections may trigger RA (Smolen *et al*. 2016). There is consensus that the risk, onset, and progression of RA are multifactorial and further epigenetic investigations are ongoing (Viatte *et al*. 2013; Gerlag *et al*. 2016; Sharma *et al*. 2020; Karami *et al*. 2020). For the participants in this study there is always hope that the links to lifestyle or environment will emerge as it has with other conditions, e.g., cancer.

Physical Manifestation and the Individual

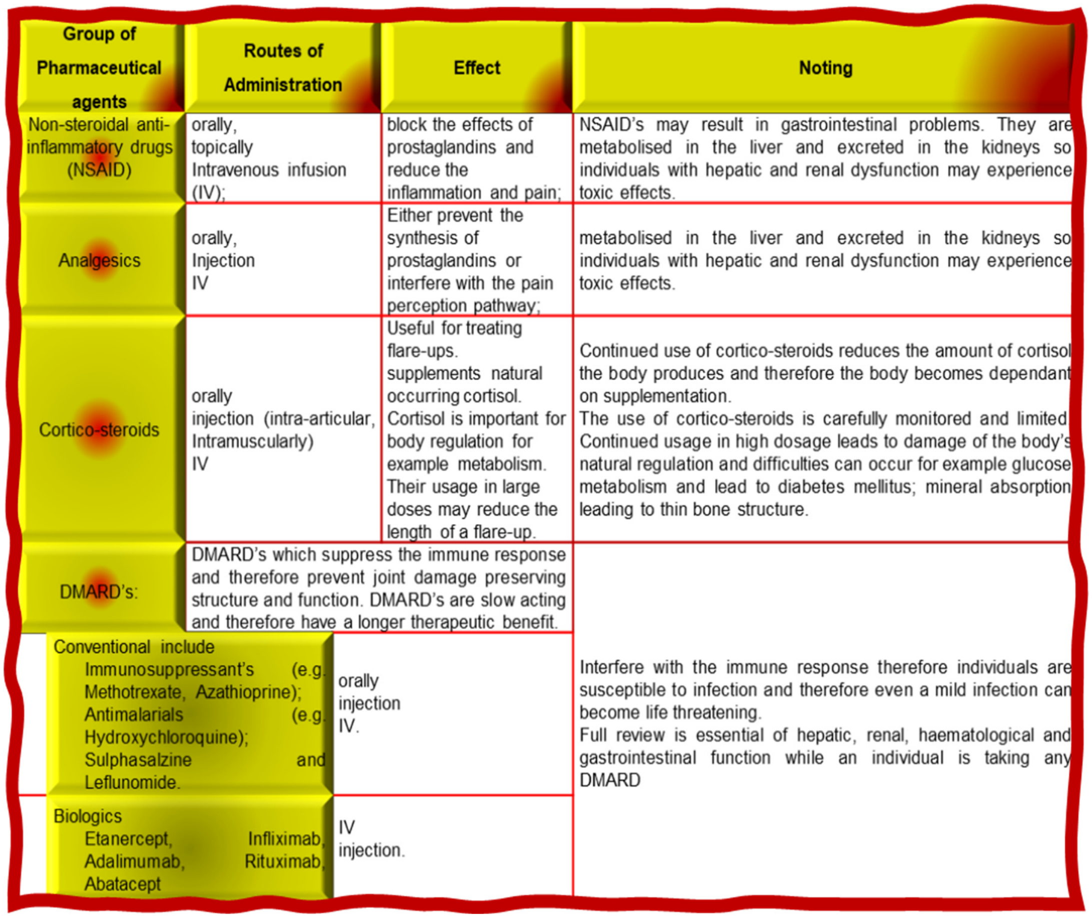
The complex phenomenon of RA has been defined and distinguished from other inflammatory processes in the group of diseases known as Inflammatory Arthritis for example, Psoriatic Arthritis, Fibromyalgia, and Ankylosing Spondylitis. For the majority of people with RA, the onset is notable in the swelling of small joints of the hands and feet due to leucocytes infiltration of the synovial space (Mc Innes & Schett 2017). The swelling is accompanied by pain and the joints are warm to the touch. Following periods of inactivity, affected joints become stiff. The inflammatory response is abnormal in RA, as the immune system produces autoantibodies which attack the body. Two of the most prominent of these are the rheumatoid factor (RF) and anticitrullinated protein antibodies (ACPAs). The inflammation continues, and tendons and joint capsules become eroded leading to malformation of the joint. Progression may involve other joints and incur systemic co-morbidities (Smolen *et al*. 2016). The serum level of auto-antibodies RF and ACPAs assist in clinical evaluation of diagnosis and specifying disease activity. The pain and swelling all have a negative effect on joint function and contribute to fatigue. The auto-immune activity continues and without pharmaceutical intervention will affect the body, leading to other systemic co-morbidities. The pattern of auto-immune activity is one of flare ups and remission (Aletaha & Smolen 2018). Flare-ups have no predictability and may subside but without pharmaceutical intervention will not be sustained. In summary, RA eventually effects the whole physical body (Mahoney 2017). Treatments can alter this progress but bring unwanted side-effects. The consequences of auto-immune activity and treatments impact upon the physical functioning of the body and consequently on the biopsychosocial being that lives with RA. As indicated, treatment regimens while they incur unwanted effects are important in RA so an overview is important.

Treatment

Historically people with RA used various traditional cures and remedies in the hope of eradicating the ailment (Hart 1976). Medical treatments emphasised rest and pain relief. Steroids and gold treatments afforded some relief but emergent side effects such as toxicity curtailed their usage (Davis 1988; Yan & Davis 1990). However, ongoing experimentation with gold and steroid therapy have increased knowledge regarding their usage. The development of pharmacotherapies since the 1990's (specifically disease modifying anti-rheumatic drugs (DMARD's) have improved clinical symptom management (Smolen *et al*. 2010; Steunebrink *et al*. 2016).

Contemporary Treatment and Strategies

Contemporary strategies (called Treat to Target (T2T) aim to achieve low disease activity (LDA) or clinical remission, to limit the development of comorbidities arising from the disease pathology or drug therapies and to support the PLRA in managing the RA (Smolen *et al*. 2016). Contemporary treatments (see table 2) are dependent on delivery by the multi-disciplinary team (MDT). Gul *et al*. (2020) maintain that evaluation of disease status should be multi-dimensional, and person centred.



Group of Pharmaceutical agents	Routes of Administration	Effect	Noting
Non-steroidal anti-inflammatory drugs (NSAID)	orally, topically Intravenous infusion (IV);	block the effects of prostaglandins and reduce the inflammation and pain;	NSAID's may result in gastrointestinal problems. They are metabolised in the liver and excreted in the kidneys so individuals with hepatic and renal dysfunction may experience toxic effects.
Analgesics	orally, Injection IV	Either prevent the synthesis of prostaglandins or interfere with the pain perception pathway;	metabolised in the liver and excreted in the kidneys so individuals with hepatic and renal dysfunction may experience toxic effects.
Cortico-steroids	orally injection (intra-articular, Intramuscularly) IV	Useful for treating flare-ups. supplements natural occurring cortisol. Cortisol is important for body regulation for example metabolism. Their usage in large doses may reduce the length of a flare-up.	Continued use of cortico-steroids reduces the amount of cortisol the body produces and therefore the body becomes dependant on supplementation. The use of cortico-steroids is carefully monitored and limited. Continued usage in high dosage leads to damage of the body's natural regulation and difficulties can occur for example glucose metabolism and lead to diabetes mellitus; mineral absorption leading to thin bone structure.
DMARD's:	DMARD's which suppress the immune response and therefore prevent joint damage preserving structure and function. DMARD's are slow acting and therefore have a longer therapeutic benefit.		Interfere with the immune response therefore individuals are susceptible to infection and therefore even a mild infection can become life threatening. Full review is essential of hepatic, renal, haematological and gastrointestinal function while an individual is taking any DMARD
Conventional include Immunosuppressant's (e.g. Methotrexate, Azathioprine); Antimalarials (e.g. Hydroxychloroquine); Sulphasalzine and Leflunomide.	orally injection IV.		
Biologics Etanercept, Infliximab, Adalimumab, Rituximab, Abatacept	IV injection.		

Table 2 Pharmaceutical Treatment Options

Pharmacological Treatments

Methotrexate is recognised as the gold standard in treatment (NICE 2018). Individuals respond to different combinations of these pharmaceutical agents (De Cock *et al*. 2015). For example, an individual may not respond to oral Methotrexate but respond to an injection, and yet another person may require intravenous administration to gain a therapeutic effect; another individual may not respond to Methotrexate and require

DMARD's. There is no specific prescription that will work for all. While pharmaceutical treatment options have expanded and are successful in achieving LDA, the individual is placed at risk of developing serious side effects (see noting column in table 2). Regular review to detect these is essential (Williams & Goodfellow 2013).

Non-pharmacological treatment

Non-pharmacological treatment focuses on supporting the PLRA to manage and live with their condition. This treatment involves education about RA and medication, exercise, activity tolerance levels, and pain management (Vliet Vlieland & Van den Ende 2011).

RA can be described as a chronic condition. Chronic refers to abnormal changes in the human body for which no treatment is available to permanently correct or eradicate. In the case of RA, that trajectory alternates between periods of active and LDA. Active disease (flare-ups) are times when the body is acutely assaulted by inflammation and clinicians rigorously attempt to arrest the inflammation and achieve T2T goals (Geenen & Dures 2019). Flare-ups can occur at any time without warning and while some PLRA achieve T2T goals and achieve relief from the features of acute inflammation other PLRA do not and experience the impact on a continuous basis (i.e. fatigue, pain, work impairment, anxiety and depression (van der Woude & van der Helm-van Mil 2018). Therefore in the latter case, RA is always present either acutely or in lingering less obtrusive and obvious ways, it is ever-present to some extent.

The complexity of the pathophysiology and treatments may detract from another important aspect of RA that is the PLRA and indeed society. RA does not occur in a vacuum it impacts upon the person who has the condition and consequently upon society as the PLRA may no longer be able to contribute to society as previously. Therefore, all of society is impacted as one of its members can no longer contribute in the same way to the functioning of that community (Nerenz *et al.* 2021). This means that RA is an issue for society and the societal response should be evident in robust, meaningful policies. A lack of policy or non-implementation of policy can have negative consequences for all citizens.

Access to Healthcare for People Living with RA

In Ireland individuals' access health services through a two-tier system. A financial assessment identifies the level of access. Individuals with a low income may gain a medical card, which gives entitlement to free health care, or people with a slightly higher income may qualify for free General Practitioner (GP) visits and investigations. While other individuals identified as having reached the income level, pay for GP consultations and tests. Individuals requiring regular medications may apply for inclusion on the Drug Payment Scheme. Under this scheme the individual pays a maximum of €124 per month for drugs. Alternatively, people may have health insurance which may cover part of or all of their health costs depending on the type of insurance policy. There is also a Long-Term Illness Scheme entitling individuals with specific long-term illnesses to free medical care however, this does not include RA (HSE 2017b). It is worth noting that the financial assessment does not take all expenses into account. Therefore, a person who is working may be earning just above the limit permitted for a medical card or GP visit card and find it very difficult to balance the needs of family, living, GP visits, monthly blood tests, and medications. This may curtail activities that the individual could do to support them psychosocially in dealing with living with RA e.g., swimming. It may also impact on the ability to follow treatment regimens. People aged 70 years and above automatically receive a GP visit card. A revised strategy for a Universal Health Insurance, giving all Irish citizens equitable access to healthcare was envisaged (Department of Health (DoH) 2012). However, an economic crisis and estimated costs of meeting this ideal have led to a strategic shift in healthcare provision and a focus upon widening access to quality healthcare (Burke *et al*. 2016).

Policy

In Ireland the publicly funded healthcare system is undergoing significant structural and process reform (Burke *et al*. 2016). The restructuring addresses issues such as inequity of access, provision of person centred responsive health services and increased economic efficiencies. Chronicity, as a significant part of this development, was addressed from 2008. EULAR and the World Health Organization (WHO) have been raising issues regarding chronicity and the impact of RA on the person and society for years (WHO 2003, 2005; EULAR 2012).

The first specific framework in relation to chronic conditions recognised the need for a focused response to the 'burden' of chronic illness upon society (Department of Health and Children (DoHC) 2008, p.9). The core of the publication focused on lifestyle induced chronic conditions and their prevention. However, clear management principles were suggested to achieve integrated, focused, responsive health care to support individuals living with any chronic condition. The ideology of this framework was integrated in the subsequent health strategies (DoH 2012, 2016) which aimed to achieve a healthy Ireland, to reduce inequalities in health care provision and to facilitate progression toward service provision at primary care level. The ultimate aim was to support the achievement of improved health and wellbeing for all citizens by way of empowerment and reforms to support the realisation of this strategy were implemented (HSE 2014, 2015).

Deficits in relation to managing chronic conditions were highlighted by Darker *et al.* (2015) in relation to ability to pay and waiting times for specialist appointments. The subsequent Irish strategy statement (DoH 2016) advanced the ideology of integrated service delivery with a plan for improving primary care services and equal access for all citizens. The all-party report (DoH 2017) demonstrates the commitment of the Irish government to the development of primary care and equity of access. The development of a framework to support the identification of health goals and clinical effectiveness in health provision is noteworthy (DoH 2018). The reforms are ongoing, and no doubt will experience interruption from the intrusion of the COVID-19 pandemic. However, they are adventurous and give promise for much needed reform and delivery of equitable care to address population health needs in an integrated manner (Stets *et al.* 2018). Specific plans to address chronic conditions emerged during this reformation process as illness specific national programmes (HSE 2017a).

National Clinical Programme for Rheumatology (NCPR)

The NCPR (HSE 2017a) sought to address the requirements outlined in the national framework (DoHC 2008) with some specific challenges needing to be addressed. These challenges included: increase in referrals to rheumatology; insufficient Rheumatologists to deal with the increased demand; disparity in service provision across the country; implementation of the T2T for all PLRA (increase in intensive review) and lack of sufficient physiotherapy to meet demand. So, the framework was essentially developed to address the demands and the cost of service provision, as opposed to a needs assessment from the PLRA perspective. For the PLRA, this position emphasises the burden that the population with RA put upon Irish society. Nevertheless, the framework does acknowledge the challenges of providing high quality care in a timely manner while aspiring to holistic management through specialist tertiary centres and close co-ordination between primary and secondary care (HSE 2015). The goal is to achieve evidence based therapeutic standards in accordance with best practice internationally (HSE 2017a). There is a recognition of the challenges and how these can be addressed in delivering a person centered responsive service, for example, addressing the length of waiting lists and the lack of specialist nurses and insufficient numbers of physiotherapists. It is noteworthy that the DoH responded in November 2017 by announcing 22 ANP positions for rheumatology (DoH 2017). Taking a lead role in completing reviews for T2T, the ANP assists in reducing waiting list times for new referrals (Minnock & Ryan 2018).

The NCPR guideline places emphasis on accessing professionals who will manage physical symptoms, the provision of supports for PLRA to manage the physical and psychosocial dimensions of living with RA and increase economic efficiencies in the service provided. A strong lynchpin for successful implementation is the integration of primary and secondary care with an expectation that primary care will deal with more physiological aspects of RA. It is difficult to envisage how the development of primary care will be managed in light of ongoing GP recruitment difficulties (HSE 2015). The NCPR guideline proposes the development of an action plan with each individual PLRA which lends the opportunity for the identification of diverse individual needs in an action plan and is reflective of a humane response. However, it is unclear who would develop the action plan with individuals (Borgermans & Devroey 2017). The specific examples of supports in the guideline are also good and reflect current evidence in relation to unmet needs in the noughties era (Taylor *et al*. 2016). The development and use of technologies in supporting equity of access within large geographical and rural areas is one example where more detail could have been given (Taylor-Gjevre *et al*. 2017; Tomlinson *et al*. 2019). Overall, the guideline points to particular areas of relevance to professionals and some to PLRA. However, there is very little of the detail explained that would be expected in a guideline. The guideline is very clear on promoting the empowerment of individuals to manage their condition through education which will be addressed in the next chapter.

Interaction with Healthcare

The health care trajectory pathway is outlined in figure 2. For the PLRA, the initial attendance at the Rheumatology Unit (RU) is an appointment via a referral by a GP. At the first appointment a thorough review is undertaken with the associated assessments and laboratory tests to support the specific diagnosis. Following the achievement of a clinical diagnosis, treatments are commenced. The ANP will specifically engage and follow the progress of the person who has been newly diagnosed for a six-month period. A variety of treatment regimens may be commenced and the ANP closely monitors the person for response to treatments and makes suggestions to the PLRA for appropriate consultations with other members of the MDT.

The aim of RA treatment is to achieve LDA which is the state when the PLRA should experience none or few physical symptoms (Aletaha & Smolen 2018). Achieving LDA requires carefully agreed therapeutic plans between the PLRA and the Rheumatology team.

At this point the reader will understand that RA is a chronic condition with the possibility of an attack anywhere in the physical body and hence this has influenced the dominance of medical science (disease model). In addition to the physical impact, there is the impact upon psychosocial dimensions including families, communities, and society and hence a shift toward a more holistic, person-centred model of care (Reich *et al*. 2010).

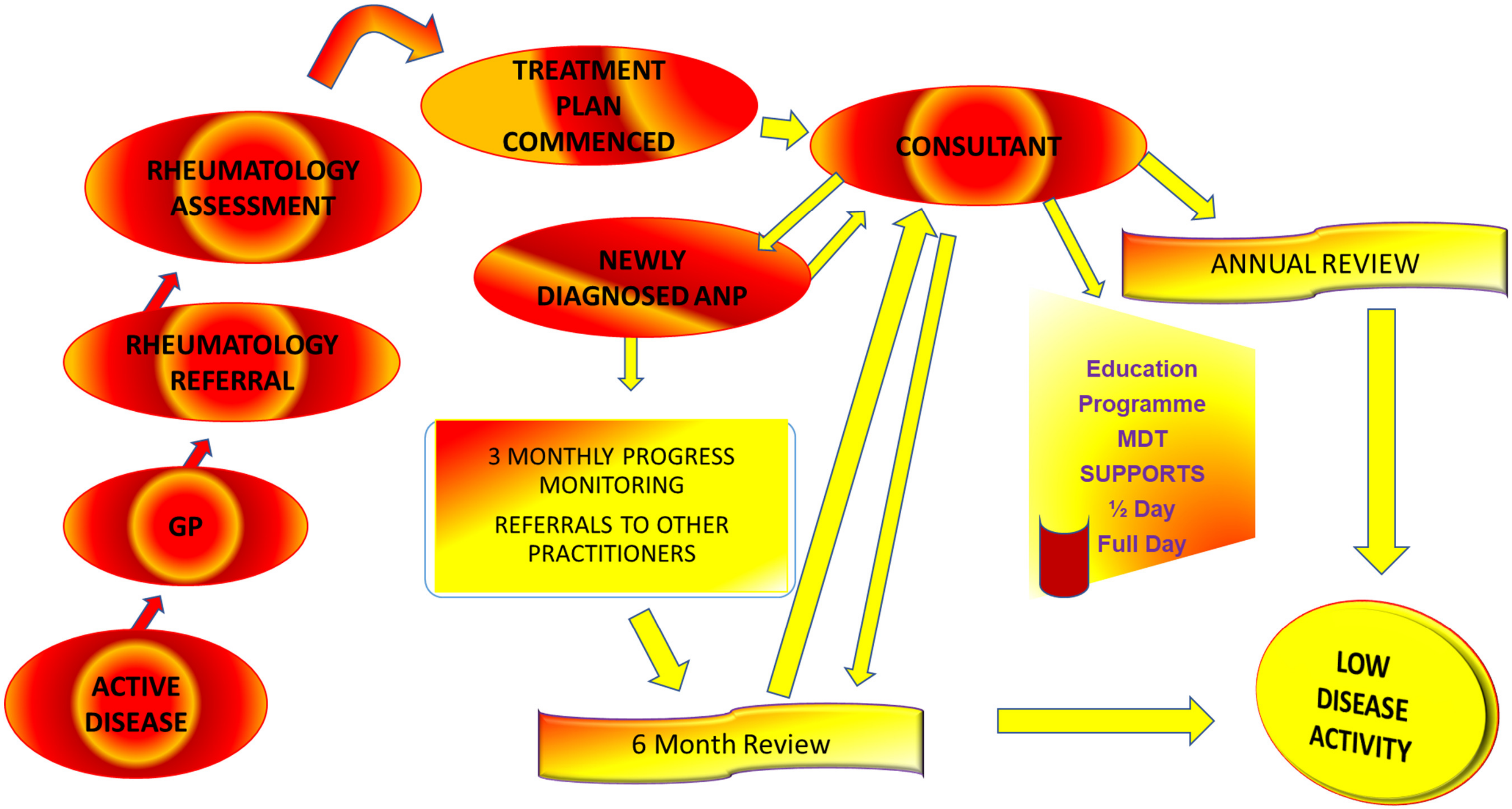


Figure 2 Health care trajectory for PLRA

Research Topic and Method Selection

In my personal life I have had family with RA and also my professional background in nursing gave me the privilege to be part of the lives of PLRA. For the most part this was in institutional settings when the PLRA required acute care. I understood the physiological dimensions of the condition, but the psychosocial focus was minimal as acute care needs dominated. These experiences left me with an abiding memory, not of suffering, but of bravery and a certain confidence in the faces and reactions of PLRA. As a young nurse this flummoxed me. So, when the opportunity came up to do some work in the area of arthritis, I sought to understand more in an effort to build on the holistic approach with which I relate with students in my role as a lecturer. As a nurse and academic I found that the concept of caring has become more significant and the understanding that it is embedded in the relatedness of persons is an essential component. So, it is not surprising that I would approach this inquiry wanting to discover what participants wished to tell me. But I did not want to do a narration I wanted to make a difference to the professional caring response so this influenced an exploration of the GT method. As will be evident in the subsequent chapters, I had little real understanding of GT in the beginning and the journey of learning the minutiae was at times a struggle. What I have achieved in this study reflects the patience and tolerance of GT experts as they responded to my questioning. Additionally, despite the research in the substantive area, a theoretical framework which explained the main concerns of people living with RA could not be located in the literature. Where qualitative research existed, it did not provide an in-depth understanding of the concern of people living with RA but was rather dominated by biomedical discourse.

Aim and Objectives of this study

The research aims influenced the choice of GT and this approach emphasises entering a research field and later identifying the specific aims of the study. Therefore, to adhere to the rigors of academia I initially developed quite general aims and objectives:

The aim of this study was to develop a grounded theory which explored the experiences of people who lived with RA.
The objectives of the study were:

- To explore experiences of living with RA.
- To identify the main concerns of people living with RA
- To identify the psychological and social processes that people with RA use to process their concerns

Format and Writing Style of the Thesis

Note about Style

In the writing of this thesis, I have chosen to use the language that is reflective of my personal perspective of the person as a social being and the belief that as a society many great things can be achieved with mutual collaboration and respect. It is the unity of all that can support the achievement of possibilities for others. With this in mind words that do not reflect this position are for the most part not used e.g., disease. In chapter seven to respect the anonymity of research participants I have allocated numbers instead of names. When the contributions came from a book source the first name as given in the publications is used.

Organisation of the Thesis

This thesis is divided into nine chapters. While I was aware of some of the context, I needed to sensitise myself fully to the substantive area. The next chapter will give a broad overview of the literature which helped me achieve sensitisation. I have also included some additional discussion on policy, as it relevant for the context of this study. Chapter Three provides some discussion on the nature of knowledge and the various viewpoints that influence the discovery and recognition of knowledge. In addition, chapter three discusses how GT has evolved. Three of the most frequently used GT methods are discussed in some more detail. Finally, the chapter provides the reader with insights and the rationale for the choice of GGT for this study. Chapter Four presents a detailed discussion on how GGT was operationalised in this study. Chapters Five, Six and Seven relate specifically to the theory that emerged using the GGT method. Chapter Five provides discussion on the main concern the *Fear of Declining Self-Worth* and how the participants continuously processed this in a theory named as *Negotiating Self-Worth* (core category). Here there is a brief introduction to the core category of the theory and the continuous resolving of the concern through the medium of an awareness context which the participants created and controlled. An in-depth discussion is provided in chapter six on the substantive multi-variate theory that emerged in the processing of the main concern. Chapter seven is divided into three sections with each section detailing a specific sub-category of the main theory. Chapter eight presents a discussion of the literature as it relates to the theory of *Negotiating Self-Worth*. Chapter nine explores the implications arising from this study and some recommendations for policy development, education, health care professions and research are presented. The final section of the chapter provides some more information indicating how quality was assured in this study.

CHAPTER 2: LITERATURE AND RHEUMATOID ARTHRITIS

Introduction

The purpose of this chapter is to provide an overview of the literature in the substantive area of RA. A full critical review of the literature was not completed as I was of the opinion that such a robust literature appraisal would restrict my openness to hear and conceptually analyse the main concern of the participants. However, a broad scoping of the literature was undertaken which gave an overview of the substantive area and this increased my sensitivity to the topic of RA and brought insights into general matters of discussion and relevance to the wider rheumatology community. In the previous chapter I outlined the historical context within which the chronic inflammatory condition of RA is situated. In this chapter I provide an overview of how the historical dimensions have influenced, and continue to influence, the development of the assessment, diagnosis and management of RA as a chronic medical condition. The immuno-pathology of RA has proven to be very difficult to detail and differentiate and, therefore, investigations into the disease pathway and pharmacological treatments continue to dominate medical science. This biological discourse influenced the broader RA investigations evident in the literature and I include an overview in this chapter. The majority of studies were quantitative in nature and the topics were clinical, for example, exploring fatigue, stress, supports and medication non-adherence. The pre-identification of topics prior to these studies limited the possibility of discovering what was of concern to PLRA and furthermore retained the emphasis on the biological dimensions of RA. Nurses are now recognised as having an important role in rheumatology. Therefore, the final part of this chapter looks at the role of nurses and how they contribute to service provision for PLRA. While reviewing the literature, it became evident that, whereas there was a focus on important areas of concern for professionals, the contribution the PLRA could make to knowledge and clinical practice development tended to be forgotten. To begin this chapter, I account for the reasoning to undertake a narrative review and not a critical literature review.

Literature Reviewing and the GT Method

A critical review of current literature provides a researcher with good insights into what is already known and what questions remain unanswered on a subject of interest (Gray *et al.* 2017). Therefore, the question formulation for proposed studies is dictated by the gap in the current literature. Additionally, the literature reviewing process supports the researcher in making methodological choices concerning how the unknown may come to be known

(Crawford 2020). In the reviewing process the researcher gains knowledge, insights and particular ways of looking at topics which inform the research question or propose a theoretical framework to underpin a study (Deering & Williams 2020). For example, the gap may consist of information about a population sample and therefore a descriptive research approach which would reveal quantifiable information would fill this gap. Another example might be that little is known from a subjective perspective on a topic of concern and therefore a qualitative approach revealing more in-depth knowledge would be appropriate. While the process of reviewing the literature can give further enlightenment, it can also limit a researcher's ability to view a subject or phenomenon afresh (Deering & Williams 2020). In a sense the researcher may be blinkered by in-depth knowledge of what is already there. This blinkering is not intentional but occurs subconsciously.

Studies using GT method want to view reality as it really is without influence from the literature or other theories (Gibson & Hartman 2014). It is for this reason that the co-founders of GT, Glaser and Strauss (1967) advocate that reviewing literature for a study is delayed until after data collection and analysis has been completed. This is not to be confused or interpreted as a researcher approaching a study as a tabula rasa (Giles *et al*. 2013). The purpose of delaying is to avoid contamination, that is, the researcher enters the field with no ideas of what they are going to study from existing theories (Glaser & Strauss 1967; Glaser 1992). Glaser and Strauss (1967) argue that if categories are used from an existent theory then the study may be another form of data collection. Consequently, the researcher is trying to make the data fit the category and therefore the study is not particularly well applied to the area of investigation. The fresh, in-depth consideration of existing literature can restrict the researcher's openness to discovering what is going on in the data and can lead to an unintentional contamination constraining the emergence of unique positions or features from a participant viewpoint (Gibson & Hartman 2014). The GT method advocates searching for latent psychological and social processes, which reveal an issue of concern. This issue of concern may also be unknown by the people being researched and therefore requires the researcher to view the behaviours in various different pattern expression (Glaser 1978). It is this viewing of behaviours in abstract ways that enables the researcher to understand what the concern is without any influence from apriori knowing. It is of course impossible to approach a study without any prior knowledge (Holloway & Gavin 2017). Every researcher brings knowledge to a study which is pre-existent knowledge from their professional or personal lives (Thornberg & Dunne 2019). This knowing too is to be acknowledged and recognised. In chapter four I discuss how I dealt with my professional and personal influences in this study.

While Glaser and Strauss (1967) advise the avoidance of prior in-depth study in the substantive area, they recommend broad reading in different literature to increase sensitivity. I conducted a broad narrative review of the literature in the expansive area of RA while preparing the proposal for this study. This scoping, my professional background in nursing and my personal influences, I believe helped me become theoretically sensitive to the substantive area. I wanted to develop a theory of how PLRA processed their main concern. Therefore, it was important to be sensitive to the substantive area on which that theory would develop. Theoretical sensitivity, an analytical process, affords the capacity to understand what is going on in the substantive area, gives meaning to data and also enhances the ability to be able to identify what is important for the theory and what is not relevant (Holton & Walsh 2017). Delaying the study of literature until there is certainty about the core category assures the researcher that the issue of concern has emerged during analysis of the data and not from extant literature (Gibson & Hartman 2014). As an academic with previous research engagement I was conscious of an urge to review literature. Being aware that the main concern of PLRA was unknown was probably the most helpful thought in containing this urge, and that this concern could only emerge if the researcher was open to recognising the behavioural patterns.

The literature has a very important role within the GT method, but the utilisation is different to other research methods (Gibson & Hartman 2014). Literature may be used in directing the researcher to further sampling for data to extend or modify the core category (Glaser 1992). In this process gaps in the current literature become obvious and it is possible to situate the developed substantive theory and thereby identify the contribution for the substantive area (Gibson & Hartman 2014). If a formal theory is the outcome of the research this is compared to existing theories beyond the substantive area of the research and therefore the contribution may be well beyond the area of study (Glaser 1992; Holton & Walsh 2017). As indicated above, I did a narrative review to increase theoretical sensitivity to the substantive area. The remainder of this chapter will outline broadly the key issues in the substantive area. Medical science proceeded the development of knowledge in arthritis and it at this useful point I start the discussion.

As indicated in the previous chapter, it was the enthusiasm of key individuals in 1927 which initiated mutual international collaboration in the area of inflammatory arthritis. This collaboration has continued to the present era, with conferences providing a forum for professionals to share knowledge and engage in discussion leading to advances in research and best practice (Smolen *et al.* 2016). This international scientific movement has focused upon and grappled with exploring the biological understanding of RA and the subsequent treatments. Therefore, the advances may not be as significant when compared to other chronic conditions e.g., asthma where the pathological understanding is known, and attention has been devoted to other aspects, i.e., the prevention of attacks.

The biological struggle has been dominated with research into the complex auto-immune response that occurs in the condition (Smolen *et al*. 2020; Gul *et al*. 2020). While the inquiry into the auto-immune response continues, evidence-based standards have been developed in three areas:
1) Diagnosis - achieving an accurate diagnosis; investigations to support accurate diagnosis (Aletaha & Smolen 2018);
2) Assessment - development of standarised tools to assess disease status, assessing joint damage and impact of disease on activities of living and quality of life (Joshua *et al*. 2019; Harrold *et al*. 2020);
3) Treatments and achieving LDA (Kurkó *et al*. 2013; George *et al*. 2020, Gul *et al*. 2020; Smolen *et al*. 2020).

Best practice standards are developed by national and international fora from research evidence principally RCT's. For example, OMERACT supports the identification of core outcome sets for specific aspects of rheumatoid treatments, e.g., measures to assess disease activity (Tugwell *et al*. 2007). However, specific measures of assessing disease activity, while being supportive for the decision-making regarding treatments, have been at odds with PLRA evaluation (Oude Voshaar *et al*. 2019). Studies revealed that reliance on specific physiological disease measures to indicate remission were incongruent with the experience of PLRA who stated they were not in remission (Braddock *et al*. 1999; Suarez-Almazor *et al*. 2001; Khan *et al*. 2012; ten Klooster *et al*. 2019). OMERACT have extended their work to include patient related outcome measures (PROMs) which are now an essential component of clinical consultations with PLRA and importantly are recognised as an essential outcome in RCT's (Smolen *et al*. 2020; Gul *et al*. 2020). Furthermore, EULAR guidelines have been developed to support remission treatment regimens, address the disparity of treatment and advance a patient centered approach as dictated by OMERACT and PROMs (Smolen *et al*. 2017). While the struggle with discovering the underlying pathology continues, evidence-based standards have been developed and are recognised as best practice internationally in the field of rheumatology. The inclusion of PROMs is significant albeit dictated by the RCT methodology.

Contemporary pharmaceutical treatments aiming to prevent progress of RA and prevent irreversible joint damage are dependent on early and accurate diagnosis, prompt commencement on treatment and regular follow up during disease activity (Home & Carr, 2009, Smolen *et al*. 2016; Joshua *et al*. 2019). Treatment options differ and correlate to the individual patient clinical condition, requiring regular follow-up to appraise effects, potential side effects and ascertain patient observance of precautions (Smolen & Aletaha 2015; Sacristán *et al*. 2019). The T2T has now been extended to targeting all persons with evidence of active disease (Smolen *et al*. 2016). All of these aspects are important, and the work is ongoing. However, the focus is on the clinical management of the physical dimensions of the disease. RCTs dominate the scientific endeavour, although some qualitative work informs RCTs (Oude Voshaar *et al*. 2019). For example, Sanderson *et al*. (2010) asked PLRA to identify the outcomes they felt were important in relation to outcomes for pharmaceutical treatments and these were subsequently used in RCT's on treatment outcomes. The identification of PROMs, while significant, continues to be restricted to measurement which negate the psychosocial dimensions of living with RA (Falzer 2019; Guimarães *et al*. 2020; Benham *et al*. 2021).

RA has proven to be a condition which is difficult to understand from a biological perspective and has totally engaged the scientific community (Gul *et al*. 2020). In the early stages pre- and post-World War II, it would have been difficult to have included the person with RA. The work of the EULAR groups would have involved travel which may have physically challenging for PLRA. Also the biological and academic discussions might not have been perceived to be appropriate for a lay audience. Regardless, the dominant philosophy within professional discourse in that period would not have included the patient perspective (Frank 2019). Therefore, the endeavour to find solutions remained with the biological focus and, while the total answer to RA has not been achieved, significant progress has been made in relation to assessment, diagnoses and management of symptoms within the field of medicine (Smolen *et al*. 2020). As an example, the knowledge of osteoarthritis has progressed faster. Pathophysiological mechanisms are now better understood and treatments aiming to lessen the speed of development have been introduced (Vreju *et al*. 2019). The pathophysiological understanding of RA is still subject to much investigation possibly due to the complex pathophysiology processes which are emerging (Smolen *et al*. 2016, 2020; George *et al*. 2020). The focus therefore remained intensive in relation to the biological perspectives of RA and the psychosocial dimensions have not received the same attention.

In the second half of the twentieth century sociological knowledge emerged which recognised the value of the patient contribution and strengthened the discourse in this area (Frank 2013). The initiative for patient involvement in arthritis was addressed by EULAR in the late 1980s when people with arthritic disorders were invited to join the social league of EULAR and participate in their work (People Against Rheumatism in Europe (PARE) 2012). Since then, the formation and work of national groups have made a significant contribution in creating awareness, providing support to individuals with arthritis and assisting in research projects. Lay groups promoted the First World Arthritis Day in 1996 which has become an annual event in October (PARE 2012). There is a genuine desire by professionals to involve PLRA in ongoing work in relation to RA. The quest to let the PLRA have a voice is obvious. However, defining participation and involvement have proven to be more challenging. Currently PLRA participate through the work of OMERACT and contribute in the development of RCTs. In Ireland PLRA fulfil the roles of supporting others and increasing awareness of RA (Minnock *et al.* 2018).

Studies in the twentieth century have brought more appreciation of the pathophysiology, the pharmacokinetics and, more recently, the impact on the quality of life of individuals with RA (Coty *et al.* 2017) and they continue to seek solutions to a rather complex condition. The voice of the patient is gaining more prominence albeit from a measurement perspective (McPherson *et al* 2001; Frank 2019). The research project Patient Voice in Arthritis Research is a serious attempt to encourage PLRA to become actively involved in research and ultimately aims to identify the concerns of the individual (University College Dublin 2018). Therefore, my study supports this work but also will inform future development in relation to how the voice of the PLRA can be captured and shared with the international professional community.

Early work on Life with RA

RA has always existed and therefore it is reasonable to assume that people had some cultural or personal meaning albeit unknown attached to it (van Eijk-Hustings *et al.* 2014). Early studies prior to developments in pharmaceutical treatments sought to capture this meaning. Two key studies were identified that sought to capture the perspective of the person with RA (Weiner 1975; Bury 1982). Weiner (1975) used a GT approach with PLRA attending either an out-patient clinic or were in-patients in a health facility participated. For these people, living with RA was theorised as a burden and the psychological strategy of hope for remission was retained and gave strength to PLRA as they attempted to balance their life. Social strategies of covering up, adjusting life to accommodate the increasing physical demands from RA and learning to live with the uncertainty of the disease were also part of the burden of living. Bury (1982) was studying chronic illness from a sociological perspective and examined the experience of 30 participants who were attending a rheumatology clinic for the first time. Bury (1982) conceptualised that RA disrupted the physical, psychological and social dimensions of the participants' lives. For the participants the meaning of chronic illness provoked practical questions about adjustment, identity, and adaptation within the uncertainty of the RA trajectory. Only one of the participants in Bury's study (1982) has a subsequent confirmation of RA. The work of Weiner (1975) was the earliest attempt that gave recognition to people living with RA and therefore is significant. Some of the terms used by Weiner are perhaps reflective of the professional discourse in medicine in that time period (i.e., arthritic, victim). Weiner's study was also part of a wider health care project looking at the nursing response to pain. Nevertheless, the study gave recognition to the experience of the patient and to how qualitative data could be robustly analysed using the GT general method.

Dildy (1996) examined suffering and chose to study this concept with 14 participants diagnosed with RA. PLRA were deemed to have an equivalent or greater suffering than people who may have another enduring illness. Dildy (1996) revealed that suffering was related to life transitions of loss of independence and inability to function. Shaul (1995) with a female population revealed a phasing transition from initial dismissal of symptoms to mastery in managing. When mastery at managing the symptoms was achieved, the individuals had a sense of control. The theoretical framework of transitioning informed the data collection and analysis. The studies of Weiner (1975) Bury (1982), Shaul (1996) and Dildy (1996) highlight the person perspective of living with RA which was lacking consideration in formal studies.

Contemporary treatment supported by protocols and guidelines became available subsequent to the above studies. The evidence indicates relative success in relieving physical symptoms and achieving LDA (Kiely *et al*. 2009) and work is continuing to involve PLRA in the assessment and treatment of the condition. Despite the positive response to contemporary treatment some PLRA continue to have physical dimensions of active disease (and have been referred to as difficult to treat) (Taylor *et al*. 2016). The exact reasons for an ineffective response continue to be explored from immunological and pharmacokinetic perspectives (de Hair *et al*. 2018). Furthermore, a multi-dimensional criterion for evaluating remission which includes the PLRA perspective may be more informative to clinicians in defining remission (Gul *et al*. 2020). De Hair *et al*. (2018) advocate a discussion with PLRA about the beliefs they hold in relation to their illness. While this may be revealing, without in-depth knowledge of the sources of those beliefs and what interventions might support the PLRA in gaining other perspectives such discussions may not be fruitful. RA is a holistic invasion, therefore, investigation into the psychosocial response is equally as important and requires attention in as much depth as the biological mechanisms (Dominik *et al*. 2004; Dixon *et al*. 2007; Orhan *et al*. 2018).

When scoping the literature, I observed that there is an abundance of quantitative studies evaluating aspects of the assessment, diagnosis and treatment of RA and fewer qualitative studies investigating the patient experience. While reading the qualitative studies, it became evident that later studies did not reveal any changed perspective on living with the illness since the seminal work of Weiner in 1975. While studies were undertaken recognising the subjective experience of living with RA the focus was on physiological features of RA, namely, pain, fatigue, mobility and disability, rather than the holistic experience of the condition. Daker-White *et al.* (2014) in a meta-ethnography of qualitative studies further conclude that later studies focus on describing experiences and not theorising about them. The development of theoretical frameworks from existing medical science literature (notably aspects which could be measured) therefore could be said to have influenced later studies. This present study therefore was warranted, and the outcome will inform professionals and PLRA about a real concern when living with RA. This is not to devalue the in-depth work of professionals already completed but rather to inform it by including the PLRA perspective in ways that can influence the research agenda and therefore achieve more holistic investigation into a holistic condition. A broad review of key issues is now presented and as will be noted there is a strong focus on the physical dimensions of RA.

Fatigue

Fatigue as an aspect of living with RA was identified in qualitative studies (Hewlett *et al.* 2005; Nicklin *et al.* 2010; Kilic *et al.* 2016). It was not until fatigue was highlighted by PLRA at a patient perspective workshop and subsequently added by the OMERACT group as a core outcome measure in clinical trials that fatigue was fully recognised and accepted by medical scientists as an important feature of RA (Kirwan *et al.* 2003, 2007; Hewlett *et al.* 2011; Parenti *et al.* 2020). Since then an increasing amount of work has sought to gain more knowledge of fatigue in terms of causes, assessment, impact, and management (Parenti *et al.* 2020). Fatigue is estimated to affect up to 70% of PLRA (Repping-Wuts *et al.* 2008; van Hoogmoed *et al.* 2010; Nikolaus *et al.* 2013; Matura *et al.* 2018). Considerable discussion is evident on scales to measure fatigue, with no agreement on a comprehensive valid and reliable tool that could be utilised in clinical trials (Hewlett *et al.* 2007; Dures *et al.* 2013; Santos *et al.* 2019). The investigations into fatigue identify that it is a complex concept with physical, cognitive, and emotional dimensions which may be inter-related (Hewlett *et al.* 2011; Nikolaus *et al.* 2013; Feldthusen *et al.* 2013; Santos *et al.* 2019). Fatigue also has consequences for living (van Hoogmoed *et al.* 2010). Figure 2 identifies some of the complexity of fatigue. I have added

"Life" to the original figure to illustrate the complexity that living has on fatigue and vice versa. Therefore, it is reasonable to suggest that the management of fatigue may be challenging.

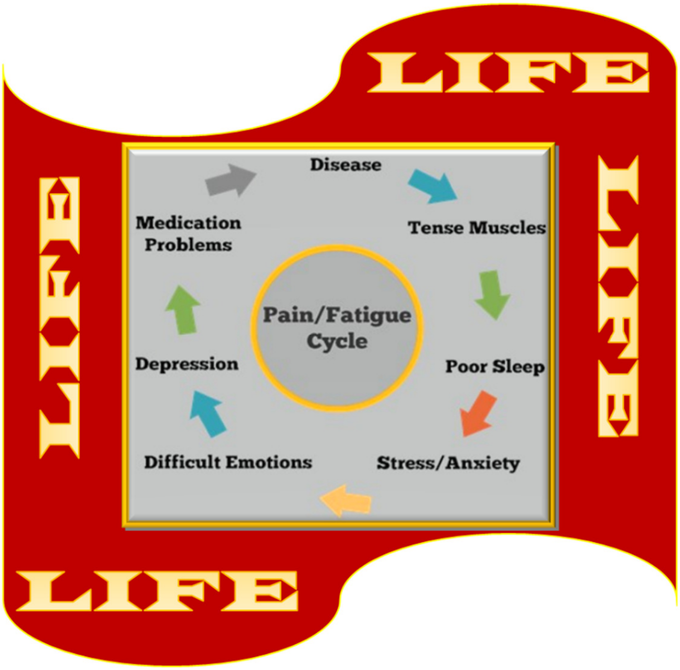


Figure 3 Complexity of Fatigue. Adapted from Arthritis Ireland (2020)

Management of Fatigue

A survey by Repping-Wuts *et al*. (2008) compared knowledge and clinical practice of fatigue management among British and Dutch rheumatology nurses. The advice given for fatigue management varied and only 31 nurses (n = 285) used a scale to measure fatigue. Hewlett *et al*. (2011) conducted an RCT which revealed that group Cognitive Behavioural Therapy improved the impact of fatigue and overall wellbeing. Feldthusen *et al*. (2013) in a qualitative study involving 25 PLRA (20-60 years) sought to discover how individuals handled fatigue. The participants felt that the fatigue of RA was different to other tiredness and it was overwhelming. Fatigue influenced their self-image, induced negative emotions and impacted upon their overall activity. The participants also found it difficult to communicate their fatigue to others. They felt that they were responsible for managing the fatigue themselves. It is interesting to note that in a systematic review of RCTs examining the impact of non-pharmacological interventions for fatigue (physical; psychosocial; herbal medicine; reflexology; Omega 3 supplementation; Mediterranean diet; provision of health tracker information), only minimal physical and psychosocial improvements were reported (Cramp *et* *al*. 2013). By comparison Richardson *et al*. (2014) identified that interventions by physiotherapists and occupational therapists impacted moderately on the experience of fatigue. The terms minimal and moderate needed some more clarification. However, this could be remedied with further studies as both Cramp *et al*. (2013) and Richardson *et al*. (2014) were reviews with a specific focus upon non-pharmacological and exercise interventions (Geenan & Dures 2019; Salmon *et al*. 2019).

The complex nature of fatigue and the individual factors which may impact upon it make it difficult to address (Hewlett *et al*. 2011; Geenan & Dures 2019; Carpenter 2020). A systematic review by Almeida *et al*. (2016) concluded that contemporary treatment may have an impact on fatigue. The inconclusive outcome is due to different scales being used to assess fatigue as an outcome measure in RCTs. Also fatigue was not a primary outcome for any of the studies included. It is therefore difficult to disentangle lessening of fatigue from the physical alteration in the disease process achieved in contemporary treatment, e.g., improvements in pain levels or a decrease in inflammatory levels. In a more recent analysis, Michaud *et al*. (2019) reaffirmed that fatigue levels impacted upon daily activity. What is clear is that fatigue is a dimension of RA. It seems it is as difficult to understand as the pathology that underpins RA itself (Geenan & Dures 2019). As each person is individual and complex as a social being, it would perhaps be more appropriate to address fatigue on a case-by-case basis (Geenan & Dures 2019). The search to develop a valid scale to measure fatigue indicates that it is now accepted by professionals as a dimension of living with RA (Ene 2013). Metabolic profiling discussed by Surowiec *et al*. (2016) included in the standard medical assessment would also increase validation of fatigue. It is interesting that Surowiec *et al*. (2016) discovered strong associations between fatigue and oxidative stress in PLRA suggesting that either the RA pathology or the psychosocial dimensions of living with RA leads to stress.

Stress and RA

A longitudinal descriptive Canadian Study by Melanson and Downe-Wamboldt (2003) investigated the stressors of 48 persons diagnosed with RA since midlife and revealed that physical limitations caused by the condition were a stress. An Irish quantitative study by Curtis *et al*. (2004) with 59 females investigated the extent to which psychological stress predicted wellbeing. The findings revealed that a higher perceived stress was associated with poor emotional adjustment. Avoidant coping strategies were positively associated with depression and rumination which increased negativity. Some qualitative enquiry in the Curtis *et al*. (2004) study may have assisted in gaining more insights particularly as the sample were identified as being in a LDA state. Dirika and Karanci (2010) demonstrated in a cross-sectional study that PLRA do experience distress and highlight that more exploration is required to understand coping strategies employed and the supportive interventions that might be beneficial. In a Japanese study using mixed methods, Otake *et al.* (2013) examined stressors over a 30-year period and pain was the strongest stressor over this time period. Patients who were treated with contemporary treatment had a significant decrease in pain however, despite the pain reduction anxiety levels increased over the time period which suggests that other factors of living with RA are challenging. Congruent with Melanson & Downe-Wamboldt's (2003) findings Otake *et al.* identified that physical limitations encountered with RA were identified as stressful. This suggests that the physical ability to participate in life activities is important for PLRA.

Santos *et al.* (2019) in a descriptive exploratory study with 62 participants confirm that inability to undertake life activities increased stress. Stress engenders an auto-immune response and for the PLRA, the immune system is already dealing with RA and therefore stress for these people can have negative health consequences (de Brouwer *et al.* 2014). The results of a small study by de Brouwer *et al.* (2013) suggest that stress training for PLRA can be beneficial. Rice *et al.* (2017) confirm in their cross-sectional study that pain is related to the perception of stress and suggest that interventions for pain are tailored to specific groups. While contemporary treatment has some success in relieving inflammatory pain, this may be insufficient (McWilliams and Walsh 2016). Other factors impact upon the perception of pain (emotional, physical (including co-morbidities) and psychosocial dimensions) and it seems reasonable to suggest that if those factors are not discovered and fully understood as PLRA define them then treatments and interventions will not be effective in addressing the experience of pain. Currently the Disease Activity Score 28 (DAS 28) in conjunction with a Visual Analogue Scale are used to assess pain and McWilliams and Walsh (2016) assert that these measures are not sufficiently specific to understand the emotional and psychological dimensions of living with RA. The findings of a longitudinal meta-analysis concur with this analysis and indicate that while the disease activity has improved, pain, fatigue and functional disability did not have similar improvement (Carpenter *et al.* 2020).

When compared to other chronic health conditions psychological distress is higher in PLRA and the reasons for this are unclear (Dickens *et al.* 2002; Isik *et al.* 2007; Matcham *et al.* 2013). It is generally accepted that PLRA who have psychological distress (ie depression) have poorer disease outcomes and increased pain and reduced health related quality of life (NICE 2009; Silva *et al.* 2019). Zhang *et al.* (2020) in a meta-analysis showed that PLRA who experience depression have a lower quality of life and more active disease but no significant difference in pain or functioning compared to PLRA who did not have depression. Zhang *et al.*

(2020) noted the differentiation in the application of the standardised questionnaire SF-36 used in the studies which limited the meta-analysis (Zhang *et al*. 2020). Similar to fatigue, stress and depression are complex and may arise for many reasons including the biological/immunological mechanisms and impact of living with RA (Lwin *et al*, 2020). It is interesting to note that despite the relative success of treatments, stress continues to impact upon PLRA (Taylor *et al*. 2016). It perhaps signifies that the current assessment of mental health needs to be revisited and assessed in a more detailed format (Lwin *et al*. 2020). I postulate that investigations have not really focused on listening to PLRA and therefore the real concerns are not being revealed. This is not implying that investigators have not been interested to uncover concerns, but it is intimating that research approaches which name concerns and focus on measuring those named concerns may not be able to perceive dimensions of real concerns to PLRA.

Medication Adherence

Medication non-adherence is identified by professionals as one reason for the ineffectiveness of contemporary treatment in achieving LDA (Pasma *et al*. 2013; Lin *et al*. 2017; Heidari *et al*. 2019). An overall adherence rate of 30-80% is equivalent to the average rates for all chronic conditions (López-Medina *et al*. 2019). A higher adherence rate is noted with some medications above others and in PLRA over 60 years (López-Medina *et al*. 2019). PLRA do not adhere to prescribed regimes for multiple reasons (Horne *et al*. 2018; Murage *et al*. 2018). Gaining insight into those reasons requires professionals to look at different ways to capture that information. Perhaps this is more than developing inclusion criterion for measurement as indicated by Kelly *et al*. (2018). The lack of detailed information from PLRA has led to variation in the assessment of non-adherence (Gossec *et al*. 2019). Gossec *et al*. (2019) recommend assessment of non-adherence with broad guidance on aspects to question the PLRA with no further recommendations for any particular communication strategies that might facilitate such a discussion, i.e., sensitivity (de Hair *et al*. 2018; Forbes *et al*. 2018). Currently the only contact with PLRA is at review appointments in Out-Patient Clinics. In these situations time constraints do not permit such in-depth conversations (Heidari *et al*. 2018). Appointments with other MDT members, e.g., Physiotherapists, Occupational Therapists, Clinical Nurse Specialists, may provide other opportunities for sharing about treatments regimes (Carandang *et al*. 2016). Supporting PLRA gaining knowledge is recognised as one way of increasing adherence to treatment regimens. This is more successful if done incrementally and repeated as necessary (Larsson *et al*. 2010). Larsson *et al*. (2010) identified that PLRA felt a sense of power, autonomy and security having had their medication knowledge attainment facilitated by nurses. As nurses are often the professionals who actually spend the most time with PLRA, they may have a different relationship and better insights into what type or methods of knowledge facilitation might be successful (Nieuwlaat *et al*. 2014). Abourazzak *et al* (2009) and Galo *et al*. (2016) advocate a tailored approach to facilitation, as there is no evidence to support any particular intervention. Therefore, there is scope for the development of software apps which may have more potential for supporting the PLRA (Song *et al*. 2019; Grainger *et al*. 2020). However, social policy may impact upon the ability of the PLRA to adhere to treatment regimens (Heidari *et al*. 2018). A clinically identified ineffective response to the standard treatment indicates that for some reason an effective response has not been achieved. When non-adherence is specifically and clinically reasoned as the root cause of an ineffective response, then the non-adherence warrants focused attention from the perspective of the PLRA. A dual recognition of non-adherence would assist professionals in considering regimes and implementing interventions which support the PLRA.

Support for the Person Living with RA

Boonen & Severens (2011) emphasise the need for supportive interventions. The Health Assessment Questionaire (HAQ) and the Belgian Rheumatoid Arthritis Disability Assessment (BRADA) are two of many questionnaires seeking to discover disease status, impact upon the PLRA and quality of life (Cooper *et al.* 2017; Lempp *et al*. 2020). Questionnaires assist professionals to identify the type of supports that the PLRA might find useful in helping them to achieve low disease status and maximise functioning in social roles. Questionnaires highlight functioning. Their inclusion in RA patient evaluation is significant and supports the desire to actively engage the patient in managing their RA. While not minimising the contribution that such questionnaires make to desirable holistic person-centered interventions, focusing on support from a functioning perspective reduces the experience of living with RA. Furthermore, emphasis is given to functioning in activities of living, intimating that functioning and performing are of utmost importance and neglecting what is of concern to the PLRA (Rendas-Baum *et al*. 2014). While functioning and performance may be a concern, the enduring mental health challenges suggest that it may not be the main concern for PLRA (Hewlett *et al*. 2011; Poh *et al*. 2015; de Hair *et al*. 2018).

Supports for those living with the complexity of RA are provided by the MDT (NICE 2018) but the evidence supporting their effectiveness is limited. Dissanayake & Bertouch (2010) in a systematic review of RCT’s from 1981-2009 revealed evidence to suggest some benefit for the PLRA when supported by disclosure therapy and cognitive behavioural psychotherapy

(CBP). Fiest *et al*. (2017) identified a small number of psychological intervention studies targeting anxiety and depression and identified an urgent need for intervention studies. Coty *et al*. (2017) identified that psychological well-being was affected by the psychosocial variants of self-efficacy and social roles. While the results of Coty *et al*'s (2017) descriptive study are tentative due to the study limitations, no other studies examining psychosocial dimensions are available, suggesting a lack of attention given to these important dimensions. Psychological interventions for PLRA have not received the attention warranted (Taylor *et al*. 2016; Prothero *et al*. 2018). Dalili *et al*. (2019), using an experimental design, demonstrated that mindfulness based CBP can have an impact on well-being. Zhou *et al*. (2020) and Jerling and Heyns (2020) identify how guided imagery and music therapy (GIM) can impact upon self-efficacy. One early study using GIM revealed significant improvements in the quality of life of PLRA (Jacobi 1994). Zhou *et al*. (2016) propose that nurses and medical staff address the mental health needs of PLRA. Prothero *et al*. (2018) advocate that professionals trained in the field of psychology are best placed to support PLRA in addressing the psychological dimensions of living with RA.

Exercise and physical therapy are important management features for PLRA with benefits not only for affected joints but overall mental and physical health (Harkcom *et al*. 1985; Evans *et al*. 2010; Cooney *et al*. 2011; Osthoff *et al*. 2018). Harkcom *et al*. (1985) demonstrated the benefits for joint improvement and overall health in an exercise programme for females. In a two-year exercise programme, Hakkinen *et al*. (2003) identified significant improvement in muscle strength. Bilberg *et al*. (2005) in an RCT demonstrated improvement in muscular endurance following a hydrotherapy intervention. The hydrotherapy session occurred twice weekly over a period of twelve weeks. PLRA displayed sustained muscle benefits at three months follow up. There are a limited number of studies published on the outcomes of hydrotherapy. However, the limited evidence is suggestive of benefits for the PLRA which warrant further study (Al-Qubaeissy *et al*. 2013). McKenna *et al.* (2019) in a survey identified that physiotherapists were aware of the importance of prescribing an exercise programme for PLRA. However, only 68% of the population of physiotherapists surveyed stated that physical activity was safe for PLRA, thus indicating that closer MDT liaison is warranted to enhance understanding of the balance of activity with rest and joint protection. PLRA find it difficult to participate in exercise consistently (Salmon *et al*. 2017). Nessan *et al*. (2019) in an exploratory study identified specific techniques of communication used by physiotherapists that can enhance participation of PLRA. Davergne *et al*. (2019) acknowledge potential use of assistive technology which may support PLRA to participate in exercise. In comparison to the focus on biological / immunological investigations, there is a scarcity of studies in physical therapy, which hinders the development of supportive interventions for PLRA.

Supportive exercise programmes may help PLRA to participate in paid work (Sverker *et al.* 2015). The ability to fulfil such roles may be protracted due to the disease activity and the consequent impact on their physical and psychosocial health. PLRA may experience difficulties in overcoming physical, social or contextual barriers and derive some benefit from Occupational Therapists by way of assistive devices, guidance, education and counselling (Steultjens *et al.* 2002; Malcus-Johnson 2005). Nevertheless, work disability among people with RA varies between 29-50% (Burton *et al.* 2006; Hallert *et al.* 2012; Sverker *et al.* 2015). Despite the success of contemporary treatment in treating RA, PLRA experience limitations in relation to employment, which suggests that sociological and psychological dimensions of work participation need more focus (Gwinnutt *et al.* 2020).

The development of PLRA interest groups at national and European levels indicate that individuals have an opportunity to share the experience of living with RA. Such groups provide an important support for the individual with RA (Phillips & Rees 2018). Within Ireland, Arthritis Ireland is a medium for a broad spectrum of supports. While there are locally organised groups, these too stay with a broad agenda (Participant 1 contribution for this study). This was exemplified by Renoe when she spoke at the launch of the photovoice project (Donnelly 2020). For Renoe, participation in the Photovoice Project meant she engaged with others who were living with RA. While she had RA for some years, she had never done this previously. For her this was an important support as the group met consistently and repeatedly during the project duration.

There are supports available to the PLRA. However, the evidence into their effectiveness needs strengthening. When compared with the body of research into the biological aspects of the disease, the evidence is much less. Perhaps this pertains to the prominence given to research in medical science. What this suggests is that medical science research is more important than another body of knowledge. The literature suggests that all knowledge is important when addressing the complex and chronic reality that is RA. However, within the speciality of rheumatology, it is incumbent on every professional in the MDT to conduct research in their specific area of professional practice. In this way they can contribute more fully to the working of the MDT and influence the development of innovative interventions to support the PLRA. Nurses as members of the MDT have an important role in the development of a responsive and effective service to PLRA.

Nursing and RA

Nurses have always been involved with PLRA in a variety of undefined but nevertheless important roles, e.g., co-ordinating care and communication. The role of nurses within rheumatology has evolved over time, partly due to the requirements of a new model of care delivery and the constraints experienced with the lack of medical practitioners to support same (Bech *et al*. 2020; Oliver *et al*. 2020). Variation in the roles and education of nurses internationally is evident. Within Europe recommendations are available to support the health service provider in the development of specific roles (van Eijk-Hustings *et al*. 2014). Nurses consistently have been identified as supporting PLRA by exhibiting empathy, creating a familial atmosphere and providing emotional support (Arvidsson *et al*. 2006; Bala *et al*. 2010; Primdahl *et al*. 2011; van Eijk-Hustings *et al*. 2013; Bala *et al*. 2018). Rheumatology nurses are now fulfilling the important role of reviewing progress for PLRA within the new treatment policy of T2T. The fulfilment of these roles compares favourably with medical staff (Garner *et al*. 2017). Furthermore, PLRA perceived that Nurse Led Clinics improved their self-efficacy, which may be attributed to the expert communication skills nurses develop through their professional education and career (Bala *et al*. 2018). Nurse led clinics and nurse led interventions have also been proven to be cost effective in achieving service targets for quality delivery (Mourgues *et al*. 2018). While making a valuable contribution within the MDT, nursing has a unique role (Minnock *et al*. 2018). Minnock *et al*. (2018) reviewed the OMERACT outcomes. They identified specific nursing sensitive outcomes which recognise the unique contribution that nursing brings to rheumatological nursing. This is significant work, albeit restricted to the current OMERACT outcomes, which are dominated by biological perspectives with some inclusion of the PLRA perspective. The nursing profession have always maintained a person-centred philosophy and over time these values will further infiltrate the OMERACT outcomes (Tschudin 2010; Sabatino *et al*. 2014; Williams *et al*. 2017; Reed 2020). The current focus is perhaps reflective of the broader literature on RA with the voice of the PLRA gaining meagre attention.

The discourse in the literature reverberates biological perspectives of living with RA. Nevertheless, there are studies which earnestly seek to gain the PLRA perspective. Two UK qualitative studies were conducted seeking to gain the outcomes that PLRA want from pharmacological treatments. These studies aimed to support the development of PROM's in RCT's. The descriptive analysis of the focus groups (n = 5) in Carr *et al*.'s (2003) study identified that the participants wanted treatments to relieve the symptoms experienced. Not surprisingly fatigue and pain were the common symptoms noted. Participants stated they also wanted a return to normality. The analysis of 23 in-depth interviews conducted by Sanderson *et al*. (2010) revealed 63 outcomes. A core category of minimising the personal impact of RA was identified. For these participants their experience of symptoms influenced how they felt overall. They wanted to relieve the symptoms so they could continue living and have a life that they could enjoy. The coping with illness sub-category included coping with the health system. Landgren *et al*. (2020) in a longitudinal qualitative study with 31 participants with disease duration of ≤1 year and treatment 3-7 months sought to discover their preferences for treatment outcomes. The analysis revealed that, while initially the participants wished to return to a life without RA, this changed over time to living with a quality of life at 12-20 months treatment duration. Duration of illness in the samples of these studies may account for the priority outcomes they selected. However, further exploration would have been helpful.

Flurey *et al*. (2014) identified the struggle that RA participants in their UK study undergo to manage their flares ups. A European study conducted in the UK, Netherlands and Austria identified that PLRA described their remission experience as a return to normality in their life (van Tuyl *et al*. 2015). A sense of normalisation was revealed in a qualitative descriptive study in the UK by Sanderson *et al*. (2011). Normality was dependent on the disease status. Disrupted normality was inconvenient, and the patient struggled with symptomology. Strategies to maintain normality discovered by Weiner (1975) and Bury (1982) were evident in this study. Feddersen *et al*. (2019) conducted a meta-analysis to identify how women with RA managed their different roles (work, motherhood and managing their illness). Six studies met the inclusion criteria and the analysis revealed that for these women work and motherhood were dominant, with managing their illness given least attention. However, the unpredictability of their illness resulted in sometimes paid work being dominant and on other occasions motherhood.

The above studies allude to life with RA as influenced by personal or societal expectations. The emphasis is placed upon contributing to society and being self-sufficient. The increase in success rates achieving LDA (Stoffer *et al*. 2016) suggest the possibility of a change in life for the person with RA. However, the findings of the above studies are at variance with the success rates in low disease activity. This is quite interesting and one possible reason for this anomaly is the previewing of existing literature. Therefore, the possibility of other life challenges may not emerge. In this study I sought to reveal the main concern of the participants and how the participants processed this concern, which emphasises the significance of openness essential to hear what the participants are identifying as their main concern as opposed to the concern being influenced by current literature or professional discourse.

Conclusion

This chapter has given a narrative of the key issues relevant to the substantive area of RA and supported the achievement of a sensitivity for this study. The normal standard of a full critical review of the literature was not undertaken, following the advice of experts in the GT methodology (Glaser & Strauss 1967; Glaser 1992; Gibson & Hartman 2014). Critically reviewing literature in a substantive area can influence albeit in a subconscious manner the process and conduct of a research study. In this study I wished to capture the main concern of PLRA without any contamination. However, I needed to be sensitive to the issues in the substantive area and for this reason this narrative review was undertaken. As has been evident in this chapter, RA knowledge acquisition has been dominated by medical science in trying to find answers to the chronic problem of RA. The research into these aspects is continuing, although some progress has been achieved in relation to assessment, diagnosis and treatment. The dogged determination of medical science has enabled developments in pharmacotherapies which have increased the rates of LDA. While there is a focus on biological aspects, there was also a desire for the involvement of PLRA. However, the inclusion has been limited to supporting and participating in research. Nevertheless, new incentives are in progress which give a voice to PLRA.

The domination of the biological perspectives has influenced the ability of others to view RA differently and in this respect, there is a paucity of research into the experience of living with RA. There is also a limited number of studies investigating interventions that might support the person living with RA. Rheumatology nursing has had and continues to have an impact in this substantive area by the roles they fulfil and how they fulfil those roles. Nurses bring with them their holistic expertise and skills and this is recognised in the evidence from reviews garnered from PLRA.

The literature on RA is mainly quantitative and is in response to the biological nature of the discourses around RA. The quantitative approaches prompt a reductionist perspective on an illness, that is, the clinical features are focused upon as opposed to the holistic experience. The majority of studies were approached with pre-identified areas of concern. Since contemporary treatment commenced in the 1990s, no studies could be located which asked PLRA what their concern is. This study, therefore, was timely and can contribute to the overall task of understanding the experience of RA through the development of a theory that explains how participants process their main concern when living with RA. The theory developed then has strong explanatory power in terms of understanding the lives of people living with RA.

RA does not dissipate, and, no panacea has been discovered. Therefore, RA is termed a chronic condition and, contrary to common belief, may be evident in early childhood, adolescence, adulthood, and old age. Against this background, this study sought to engage with people with RA and discover what their concern/s were. The next chapter discusses the various options the researcher has when approaching research. A discussion is advanced on the ontological and epistemological perspectives of the investigative endeavour. The GGT approach selected to underpin this current study is also discussed in detail.

CHAPTER 3: METHODOLOGY UNDERPINNING THIS STUDY

Introduction

In this chapter I will address some of the wider issues in selecting GGT as the methodology for this study. Doing research is essentially about gaining new knowledge and commences with defining the focus and intentions of the inquiry in ontological and epistemological decisions (Burkholder *et al.* 2020). Such decisions should also address the personal position of the researcher and the focus of the research.

Research has been dominated by a positivistic view of ontology and epistemology and it is from this standpoint that the general methodology of GT is introduced (Gibson & Hartman 2014). Various authors have aligned GT methodology with the philosophical positions of objectivism and constructionism (Mills *et al.* 2007; Nathaniel 2011; Clarke 2019). In this chapter a discussion is offered by way of situating the claims made in relation to objectivism and constructionism. GT does not follow the recognised linear research process and therefore is more complex and, for the neophyte researcher, this can be challenging particularly if the researcher has been steeped in other research traditions. Another element adding to the complexity of GT is how it has evolved over time with different philosophical positions advanced and concomitant variations in methods (Gibson & Hartman 2014). In this chapter, I will discuss the most commonly used variations of GT prior to identifying the key pillars and essential elements of the selected method GGT used in this study. The chapter concludes with personal views about knowledge identification and attainment in relation to the research question and the choice of GGT as a suitable methodology for this inquiry.

Ontology and epistemology

Paradigmatic or worldviews differentiate research designs (Crotty 1998; Silverman 2013). Denzin & Lincoln (2018) exemplify paradigms as comprising of three key elements of ontology, epistemology, and methodology. Ontology refers to the philosophical study of the nature of being and existence with epistemology referring to the theory of knowledge and how such knowledge can be known and validated. Methodology refers to the application of the ontological and epistemological perspectives within a paradigm. In essence these considerations govern the inception and the processes selected for the design and conduct of a study and ultimately guide the researcher in achieving the ethical standards expected of any research study (Creswell & Creswell 2018). Research does not take place in a vacuum. Knowledge exists and therefore the researcher considers what the nature of that knowledge is and how it can come to be revealed, i.e., ontological and epistemological considerations.

Unravelling Ontology and Epistemology

Historically, the nature of reality or being and the origin, nature and scope of knowledge has been debated in philosophy circles since the time of Plato. Philosophers such as Aristotle, Descartes, Bacon, Kant, Hagel, Russel, Comte, Locke, Berkeley, Moore, and Hume amongst others all made valuable contributions to the ongoing and intense debates regarding knowledge sources, the reliability of knowledge and questioning philosophical and theological sources (Moser 1999). Scientific knowledge sought to oppose the philosophical and theological traditions. Sarantakos's (2013) account acknowledges a growing inclination toward empirical science and over time an increasing superiority of scientific knowing. Up to the 1950s positivism propounded by the French philosopher Auguste Comte [1798-1857] was the accepted inductive scientific method by which to identify and verify universal laws. According to Crotty (1998), Comte's quest was to have the same essential scientific methods applied in the human sciences. This was achieved in the early twentieth century through the work of a group of philosophers known as the Vienna Circle. Philosophers such as Russell [1872-1970] and Wittgenstein [1889-1951] advanced the introduction of the methods to the social sciences. The Vienna Circle are identified with the development of what is coined logical positivism and the verification of facts (Crotty 1998). Scientists Neils Bohr [1885-1962], Werner Heisenberg [1907-1976] and the Austrian born British philosopher Karl Popper [1902-1994] cast doubts upon the accepted epistemological claims of scientific knowledge achievement. They highlighted the ambiguity of experimentalism, the influence of the scientist and questioned the absoluteness of scientific knowledge (Crotty 1998). Popper had difficulties with the inductive methods for establishing general laws. Instead of accumulating data and inducing a general law by verification, Popper proposed falsification and the hypothetico-deductive method (Creswell & Creswell 2018; Lincoln & Guba 2013).

Thomas Kuhn [1922-1996] went beyond rejecting absolute knowledge and challenged the very nature of scientific theory (Hammersley 2008). According to Crotty (1998), Kuhn identified that science had a particular set of beliefs which restricted its development and the furtherance of theory as the old was rehashed and new insights stymied. This point is advanced by the Austrian philosopher Paul Feyerabend [1924-1994] who challenged the elitism of scientific knowing and espoused that science needed to look afresh at conceptual ideas and challenge existing theories.

These intense positivistic debates have progressed knowledge identification, knowledge sources and verification. At the same time within the social sciences the deductive approach was rejected, and considerable debate was taking place regarding how the social world could come to be known and understood with different methodologies emerging (Creswell &

Creswell 2018). Denzin and Lincoln (2008) name this the period of paradigmatic wars and, while initially the paradigmatic contentions were anti- positivism alluded to above, these then progressed into differences between interpretivism and constructionism. By the 1990s there was some acceptance that knowledge is value laden, is not apolitical, may be subjective and is influenced by various dimensions of history and culture (Flick 2014). Therefore, research studies should delineate the ontological and epistemological underpinnings and furthermore demonstrate application in discussions on rigour (Saunders *et al.* 2015). Some authors assert that GT is aligned with either a positivistic or a subjectivist ontology (McCann & Clark 2003; Kelle 2005; Åge 2011; Nathaniel 2011; Simmons 2011; Ralph *et al.* 2015; Holton & Walsh 2017). To examine the validity of these assertions, objectivism and constructionism as the fundamental principles will be examined.

Objectivism

Objectivism originated within the philosophical position of realism. The ontological perspective is that reality can be conceived separately to the individual consciousness and is governed by natural laws (Guba & Lincoln 2005). This independent existence of a reality lends itself to objective measurement. Epistemologically this reality can be measured independently of other realities including the researcher (Clarke & Braun 2013). Absolute principles govern objectivism (Weaver & Olsen 2006). The object exists and awaits discovery and having been discovered with appropriate methods reveals an objective truth. The stringent application of agreed rules and procedures which are purported to eliminate bias and other errors produce objective knowledge of the object under study (Paley 2011). The starting point is an apriori theory and subsequently the development of a hypothesis, then using the process of deduction, systematic objective measurements are completed to explain causal links between variables (Denzin & Lincoln 2018). Therefore, the objectivists view of knowledge is that an objective truth exists. This realist view restricts the study of phenomenon to that which can be observed, manipulated and measured independently of the researcher and other variables (Denzin & Lincoln 2018). From this perspective therefore objectivity reveals the truth, and this truth can be replicated in other studies and generalisations can be made. Thus, a universal truth is exposed (Martin & Félix-Bortolotti 2014).

From an epistemological perspective the researcher and the researched cannot be considered value free and therefore attempts to reveal an ultimate or universal truth are futile. Such views are partly accepted in contemporary understanding with knowledge being offered in a spirit of tentativeness. However, the attempts to produce objective knowledge continues (Loughlin 2008, Williams 2014, Corry *et al.* 2019). Objectivity appears to have retained its superiority and is often placed in opposition to subjectivity[1] (Loughlin 2008, Munro & Hardie 2019). Constructionism offers a different dimension on knowing and engaging with reality. One that sees truth emerging from engagement with reality. Engagement with social reality gives meaning to existence and therefore meaning is not discovered but constructed. This is worthy of further discussion as it is a key aspect frequently ascribed to GT.

Constructionism

Identifying that knowledge is constructed is a radical departure from the reductionist and objectivist perspectives of realism (Gibson & Hartman 2014). The terms constructivism and constructionism are somewhat confusing in the literature. Denzin & Lincoln (2008) define constructionism as a research paradigm. Gibson & Hartmann (2014) note that there are different versions of constructivism and distinguish between Kant's view of construction from the sense experience and the actual social construction of knowledge by society. Constructivism is used by Gibson & Hartmann (2014), Strong (2015) and Van Bergen & Parsell (2019) as a general construct which seems that it could be used interchangeably with constructionism. Additionally, Van Bergen & Parsell (2019) identify that constructivism is a broad term with many different types.

According to Mackenzie and Knipe (2006), constructionism emerged from the work of German philosopher Edmund Husserl[2] [1859-1938]. Husserl's interpretation of reality categorically emphasises the bracketing of all knowledge (consciousness) to become conscious of reality. Later philosophers such as Heidegger, Merleau-Ponty and Sartre developed and modified this philosophy and emphasised intentionality not toward reality but intentionally related to being in the world (Crotty 1998). Constructivism has a specific meaning when used by Crotty (1998) to refer to the meaning making that individuals do as conscious human beings. In Crotty's view knowledge is constructed by the person actively engaging with reality and living in the real world and immersed in political, cultural and social realities (Crotty 1998; Lee 2012). So, any meaning and knowledge that is gained is influenced by the reality in which the person has been engaged and therefore is socially constructed (Burr 2015). Crotty (1998) defines constructionism as "the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world and developed and transmitted within an essentially social context" (p. 42). Andrews (2012) purports that social constructionism is a theoretical stance

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[1] Subjectivity is a sociological concept that acknowledges the determination of a phenomenon as experienced by the individual.

[2] Edmund Husserl was a German philosopher accredited with redefining phenomenology as a transcendental-idealist philosophy.

that emanates from sociological theory and alludes to the way in which meaning is constructed.

Sociologists Berger and Luckmann (1966) are accredited with introducing the term constructionism into the social sciences. Berger and Luckmann[3] acknowledge the influence of the German philosopher and social phenomenologist Alfred Schütz [1899–1959] who in turn had liaised with Husserl (Barber 2018). Schütz's main concern was with the social nature of knowledge and how it was created within pre-existing social structures (Burr 2015). For Berger and Luckmann people and groups interact within a social system. In this interaction they form meaning and this meaning becomes routinised and shared with others eventually becoming institutionalised in society. It is in the institutionalisation that the knowledge is embedded as routine and forms "a general store of knowledge" (Andrews 2012, p. 41).

This institutionalisation has layers of interpretation and this may over time be objectively viewed and regarded as truth, i.e., constructed as an objective reality (Crotty 1998). Therefore, questions arise concerning *what* and *whose* reality is being constructed. Each person is born into a culture filled with social meaning and persons engaging in this world become familiar, internalise and assume cultural ways and meanings. Meanings therefore do not just exist as a distinct objective reality. They are constructed by others in a particular context in a particular time and therefore are relative to the culture in which a person was raised (Gibson & Hartmann 2014). In this sense they exist *apriori*. However, they are not objectivist. Similarly, they are not subjective, as meaning is not created about them.

Social constructionism according to Crotty (1998) is both realist and relativist. It is real in the sense that construction and what is being constructed is reality. It is relativist in the sense that what is constructed can claim to be a truth but not an absolute truth. It is the truth as constructed by the individual in a particular time period in a particular context (Edley 2001). Social constructionism has been criticised for not recognising objective realities and limiting construction to language (Andrews 2012). Andrews reaffirms that social constructionism does accept the existence of an objective reality and this fact may have been misrepresented or misunderstood by researchers. He asserts that researchers in their research activity may produce a tension between realism and relativism. This arises from the researcher viewing that they are constructing their own social world as a researcher and not focusing on representing the reality of the researched. Hammersley (1992) advocates a subtle realist

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[3] Luckmann was a student of the phenomenologist Alfred Schütz [1899–1959].

approach when researchers give representation of the social phenomena that exist independently of the research process.

In summary, from a social constructionist perspective knowledge about existence, therefore, is not objective and cannot exist independently, but has multiple realities that are subjected to change with the passage of time and development of culture. Culture is very powerful in the development of knowledge. One example is the concept of illness which has been enlightened by culture and societal developments over time. A very different knowledge of illness is evident in the twenty-first century in comparison to the eighteenth century (Conrad & Barker 2010). This knowledge is not an objective truth but knowledge that is constructed in the process of living and interacting within a social context.

Origins of Classic Grounded theory

GT was developed by two sociologists Barney Glaser [1930-] and Anselm Strauss [1916-1996]. Glaser, working at Columbia University attained a rigorous background in quantitative methodology and sociology of science under the leadership of Lazarsfeld[4] [1901-1976] and Merton[5] [1910-2003] (Bryant & Charmaz 2007). Glaser (1998) acknowledges the contribution of sabbatical studies in Paris where he trained in the explication de text. He explains thus:

> ..reading closely line by line to ascertain what exactly the author is saying without imputing what was said, interpreting it or reifying its meaning. I also became more and more interested in the concepts and the patterns of behaviour in which the characters in these novels found themselves, rather than the seductive charm of the descriptive narratives (Glaser 1998, p. 24).

By contrast Strauss achieved a strong background in symbolic interactionism and ethnographic methodology in the Chicago traditions under the leadership of Bloomer[6] [1900-1987]. It was by “an ironic conjunction of career” that they met in the University of California in the 1960s and a research collaboration began (Glaser & Strauss 1967, p. vii). Their individual career development enabled a different research approach to emerge and advance. In the professional context of sociology there was growing concern regarding the inadequacy of empirical and analytical deductive processes and their usefulness in sociological enquiry

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[4] Paul Lazarsfeld was an Austrian-American sociologist and the founder of Columbia University's Bureau of Applied Social Research.

[5] Robert Merton was an American sociologist and Professor at Columbia University. He is accredited with founding the sociology of science.

[6] Herbert Bloomer was an American sociologist who coined the term symbolic interactionism and supported the development of social research methods.

(Kenny & Fourie 2014). Bryant & Charmaz (2007) assert that both Glaser and Strauss disputed the influence of objective research methods and aimed to advance the credibility of qualitative inquiry and equate its recognition to that of quantitative[7] endeavours. Glaser recognised the necessity of systematic analysis in the research endeavour and Strauss acknowledged social processes and the complexity of life achieved through his schooling in symbolic interactionism.

In essence the collaboration of Glaser and Strauss brought together two divergent ontological perspectives (Glaser 1998). The serendipitous discovery of GT occurred during their research collaboration studying the experience of dying in hospitals. The publication of the study "Awareness of Dying" heightened their awareness of what they had discovered (Glaser & Strauss 1965). Having gained some insights into future possibilities for theory development "The Discovery of Grounded theory " was written as a reference text for other academics (Glaser & Strauss 1967). The method they discovered was different from the certitude of prevailing ontological and epistemological perspectives on knowledge and knowledge identification (Thomas & James 2006). Such a striking divergence required acceptance by others that the method had value. Glaser's many writings have a powerful and fervid tone particularly on aspects pertaining to verification and theory generation that deviated from the scientific norms of the 1960's (Glaser & Strauss 1967). Such energetic writings gained the attention of the academic community and particularly within the social sciences. Thomas and James (2006) opinion that Glaser and Strauss activated and advanced discussions in the social sciences regarding knowledge and social research methods. The subsequent volume of studies and the usage of the GT methodology across the behavioural, social and biological sciences is a testimony to its acceptance (Givon & Court 2010; Walsh 2014). It is not surprising that the originators coming from two very diverse backgrounds should have some disagreement on various aspects of the method. Rather than resolving the disagreement both Glaser and Strauss while remaining friends never reached a satisfactory theoretical resolution. However, both continued to develop GT from their own theoretical perspective[8] (Glaser 1998). Not surprisingly the academic community were critical of GT, but Glaser did not compromise and wrote prolifically and remained consistent on the importance of GT and laterally GGT and its different elements. This stance increases I believe the confidence of others in the method and its ability to theoretically explain reality. At this juncture it is appropriate to give some concrete details of the Glasserian GT method (GGT).

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[7] The terms qualitative & quantitative are often polarised as they relate to research approaches emanating from different ontological and epistemological stances. Quantitative from an objectivist and qualitative from a subjectivist.

[8] The theoretical perspective of Strauss is discussed later in the chapter under evolution of GT.

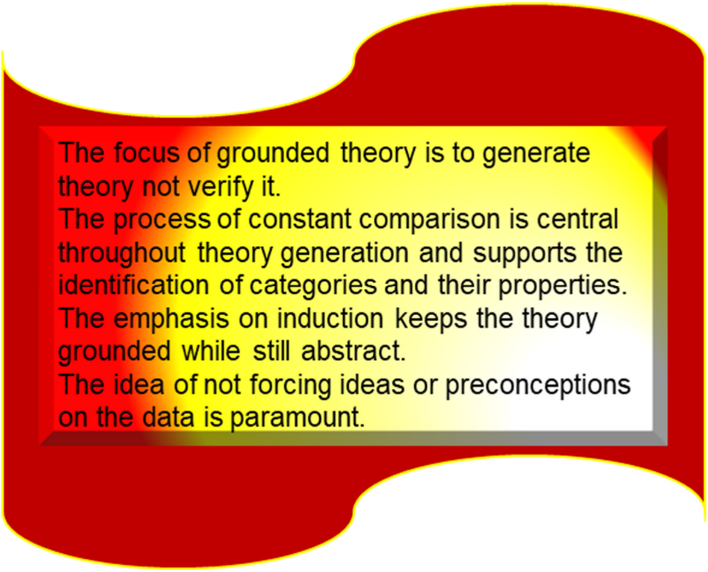
Philosophical Assumptions and Glasserian Grounded theory (GGT)

Some writers identify objective assumptions underpinning GGT (Charmaz 2014a, James 2017, Smith-MacDonald *et al.* 2019). Principally these comments are alluding to the detachment of the researcher from the subjective experience of participants and the notions of verification and rigour. Charmaz (2014b) and referring to the origins of GGT states: “He [referring to Glaser] imbued the method with dispassionate empiricism, rigorous codified methods, emphasis on emergent discoveries and its somewhat ambiguous specialized language that echoes quantitative methods” (p. 9). Similarly, James (2017) and Åge (2011) assert that GGT related to objective facts existing independently of the researcher. Glaser (1998) insists that the researcher should not be influenced by *a priori* knowing and this increases the notion of an objective reality. In *a priori* knowing he is referring to the wide practice of engaging with key literature to the extent that it influences the nature of the subsequent inquiry (Glaser 2002). However, there is an important caveat in that Glaser does not believe the researcher should be naïve but is theoretically sensitive (discussed later in this chapter) to the substantive area. Refraining from engaging intensively in the literature in a focused manner, the researcher is able to focus (objectively) on the data that is gathered. Glaser (1998) is insistent that what emerges fits with the data and explains what is going on in the substantive area which could equally be declared as objective as it implies that some reality exists and awaits discovery (James 2017).

The principle of objectivity extends to careful sample identification which enables generalisability of the findings to a wider population. This is entirely different in GT which emphasises modifiability of the findings in light of new knowledge being gained (Glaser 1998). The sampling techniques of GGT are to develop concepts and categories within the developing theory. While there are some objectivist perspectives in GGT, these do not represent the whole methodology. Glaser (2009) insists that GT is a general method and not equated with any particular philosophical position. However, he acknowledges the contribution of his formative studies and Strauss’s background in symbolic interaction in developing ideas in the method (Glaser 1992). Nevertheless, some authors provide a cogent argument for situating GT within a particular philosophical position either by way of career influences or distinct usage of terms (Ralph *et al.* 2015; Holton & Walsh 2017). It is worth noting that Glaser acknowledged that the research community were not ready for a different research approach when GT was developed. He stated that “[the] forcing methodologies were too ascendant” (p. 21), indicating the indifference that might ensue from other academics (Glaser 1998). Some more contextual detail is helpful here to understand Glaser’s comments.

Sociological Context of GT

Prior to the discovery of GT, the dominant research approach in sociology was the comparative method. This method was supported by two key texts *Patterns of Discovery* (Hanson 1958) and *Sociologists at Work* (Hammond & Bellah 1964). The sociologist Barry Gibson and the philosopher Jan Hartman have examined and compared these key texts with the seminal text *The Discovery of Grounded theory* (Glaser & Strauss 1967) and conclude that many of the methodological challenges identified in the earlier sociological texts became central elements in the general method written by Glaser and Strauss (Gibson & Hartman 2014). Gibson and Hartman (2014) argue that *The Discovery of Grounded theory* (Glaser & Strauss 1967) addresses some of the key challenges in the sociological method in specific detail and by way of illustration give the examples of preconception and forcing. However, Gibson and Hartman (2014) also acknowledge original aspects identified in figure 4.



The focus of grounded theory is to generate theory not verify it.
The process of constant comparison is central throughout theory generation and supports the identification of categories and their properties.
The emphasis on induction keeps the theory grounded while still abstract.
The idea of not forcing ideas or preconceptions on the data is paramount.

Figure 4 Original aspects of GT (Gibson & Hartman 2014)

While the accepted social science methods were recognised as deficient and insufficient, they were accepted and tolerated. The GT method challenged this acceptance and therefore, criticism and resistance from within social sciences was to be expected. GT was also challenging the elite methods of science and was perceived as challenging and unwelcome. Glaser and Strauss were sociologists and not regarded as members of the scientific community and, therefore, may have been viewed as outsiders making unwelcome critical comments and furthermore would not enjoy the esteem of physical scientists.

Quintessence of GT Method

Research studies generally follow a similar organisational template: a review of literature, research question/hypothesis/aim; sampling, data collection and analysis (Creswell & Creswell 2018). What is interesting is that this structure has not been altered in any of the paradigmatic developments and, furthermore, the adherence to this structure has remained rigid. While GT is equally rigorous, the organisational structure is different and, moreover, each of the dimensions have a very different conception (Denzin & Lincoln 2012). It is, therefore, salient to outline the key steps of the method and then discuss in more detail the fundamental pillars upon which the method of GT is contingent.

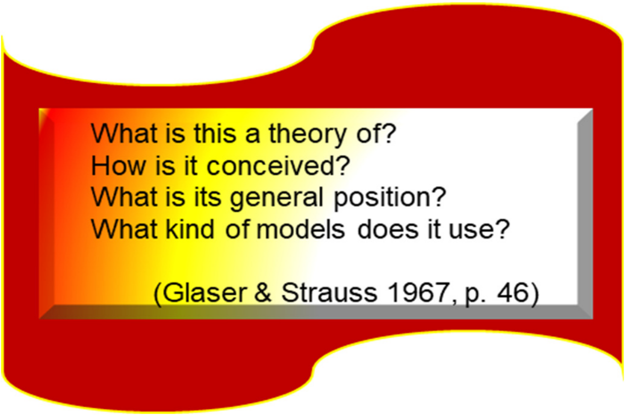
In Glaser's words 'The goal of GT is to generate a theory that accounts for a pattern of behaviour which is relevant and problematic for those involved' (Glaser 1978, p. 93). The researcher utilising an inductive approach is seeking to understand what the concern is for the participants by looking for "the underlying patterns" revealed in the process of constantly comparing data (Glaser 1992, p. 49). To allow the main concern to be evident, the research field is entered without any preconceived ideas. However, it is important that the researcher is theoretically sensitive to the substantive area and open to the many concerns that might be evident to the participants (Gibson & Hartman 2014). Ultimately, the researcher is aiming to identify the main concern of the participants. Data collection commences with an open question in an endeavour to discover concerns. The data collected (captured in field notes) is open coded, that is, incidents in the data are given labels known as codes. Constant comparison and memoing commences at this point also. Constant comparison is comparing incidents and codes for variation. Memoing refers to the researcher recording ideas about the incidents, the codes and relationships between incidents and codes. Data collection, open coding, memoing and constant comparison of incidents and codes occur simultaneously with the aim of identifying as many concerns as possible. Memoing assists with understanding how and in what ways these concerns vary between the participants. Memos too are regarded as data to be coded and analysed. The constant comparison enables the researcher to identify patterns in the data which suggest what the main concern might be (Dey 2007). The continuation of data collection, systematic coding and constant comparison of codes and their indicators enables the researcher to gain a more abstract view of what is happening in the data and in this way potential categories and their properties can be identified (Higgins *et al.* 2008). When the main concern has emerged, the researcher seeks to reveal the core category which explains how it is processed (Keogh *et al.* 2015). Through further data collection, analysis, memoing and memo sorting, the core category emerges. At this point the researcher starts to selectively sample and limits coding to the core category or properties that appear to be related to the core category (Holton & Walsh 2017). In the analytical process the researcher through deduction is guided as to what and where to collect further data in the process identified as theoretical sampling. Theoretical sampling is driven then by emergence from the data and assists in specifying and refining the properties of concepts and categories (Holton & Walsh 2017). The data collection, constant comparison and memoing raises the level of abstraction to a more conceptual level while also ensuring that the analysis remains firmly rooted in the data (Reed & Runquist 2007). In the process of theoretical coding the researcher explains the relationship between the constituent parts to integrate the theory.

The above descriptive overview indicates that the steps of the research process in GT differ from the accepted procedural steps of quantitative and qualitative approaches to investigations. Further detail is appropriate on the tenets included in the above description.

Pillars of GT

Main Concern & Core category

In GT the researcher enters the substantive area with no knowledge of the concern/s that are problematic for the participants. The main concern is the problem of relevance to participants in the substantive area and emerges from the analysis, i.e., coding, constant comparison and memoing (Glaser 1998). In the analysis the researcher is “fracturing” the data (Glaser 1998, p. 123). Fracturing refers to the line-by-line coding which is supported by questions that are asked of the data see figure 5:



What is this a theory of?
How is it conceived?
What is its general position?
What kind of models does it use?

(Glaser & Strauss 1967, p. 46)

Figure 5 Questions to ask of the data

The researcher, in examining the data, is looking for incidents which are the behaviours of the participants. Glaser (1992) identifies that it is key for the researcher to listen to the participants, suspend any prior knowing and engage in viewing the data from many different perspectives. It is the continuation of data collection, while simultaneously comparing, generating new codes and categories that the researcher can be confident that the concern identified is indeed the core concern (Glaser 1998). Glaser (1998, 2002a) and other experts in GT (Gibson & Hartman 2014; Holton & Walsh 2017) emphasise that those new to GT should trust in the process (coding, constant comparison, memoing) and the main concern will emerge. The concern is recognised by the identification of patterns of behaviour across all the data. As the researcher continues with the process the thinking becomes more abstract and it is this that makes the identification of patterns possible. The viewing of the data from many different perspectives assists the researcher in becoming more abstract (Glaser 1992). The constant comparing of the data, i.e. incident to incident, codes to incidents, code to code and memoing of theoretical ideas, reveals the latent patterns of behaviour indicating a main concern. Participants may not be consciously aware of this concern, but through the systematic coding and memoing the concern is evident to the researcher. The patterns of behaviour identifying the main concern also explain how that main concern is resolved or processed. The core category accounts for most of the variability around the main concern (Holton & Walsh, 2017). Therefore, it is the processing or resolving of the main concern that is termed the core category. Glaser (1978) alludes to the focus of the researcher in identifying the core category. In reality the researcher may identify many categories and it is the process of theoretically sampling and saturating each category that the core emerges.

The identification of the core category that is stabilised is central to the theory that is developed. The core must relate to many of the other categories; it must reoccur frequently in the data and account for most of the variation in the patterns of behaviour (Gibson & Hartman 2014). When the core category is identified, this leads the selective coding in identifying the relationship of the core to other categories (Glaser 1978).

Sampling in GT

Initial Sampling

The important questions in relation to sampling are guided by the research methodology and the research aim. Research wishing to measure or calculate a phenomenon will be aiming to achieve representativeness and generalisation of findings. Accordingly, probability sampling strategies would be utilised (Parahoo 2014). By contrast research wishing to inquire about phenomenon are aiming to reveal what they discovered not to generalise. The sampling frame for the latter is also rigorous but the emphasis is not on numbers but rather on inclusion and exclusion criterion that will address the research question (Harris *et al.* 2013). The aim of GT is to construct a theory from the evidence garnered in the substantive area. Therefore, the initial inclusion criterion is very broad to enable the researcher to explore the substantive area and later reveal what data is going to be collected and from whom. The researcher may gain ethical approval initially but may need to seek further approval as clarity is gained in relation to further data collection.

Theoretical Sampling

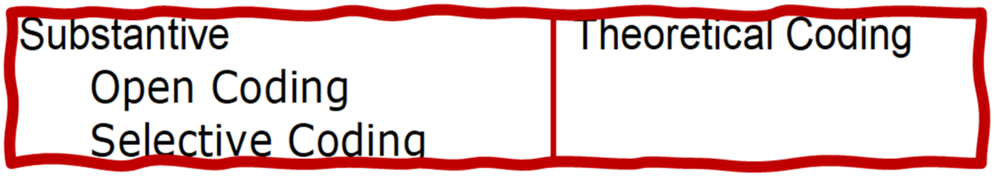
The criterion for sampling in GT is “theoretical purpose and relevance” (Glaser & Strauss 1967, p. 48). Accordingly, there are no set sample sizes or clear formulaic prescriptions for sampling (Bryant 2017). Sampling in GT has a very different intention, that is, to support the researcher in developing and processing a relevant concern (McCrae & Purssell 2016). Until a main concern becomes apparent in the analysis, the researcher has very little idea about what data to collect, or where and from whom such data can be acquired. Theoretical sampling then follows from theoretical sensitivity when the researcher is sensitive to what is happening in the substantive area. In the initial stages of theoretical sampling the task is to “..secure a wide variety of concerns and a number of perspectives from which to view these concerns” (Gibson & Hartman 2014, p. 123). The constant comparative analysis assists the researcher to identify the main concern and guides further data collection (Charmaz 2006, 2014b).

Sampling proceeds in different directions relevant to the emerging concepts. When a core category or a potential core category emerges, theoretical sampling become more selective and is guided by the emergent theory (Holton & Walsh 2014). Memo recording in the constant comparison of the data will direct the researcher where to go next to sample for data in order to develop the theory. Theoretical sampling is therefore enmeshed in the constant comparative analysis and its purpose is to support the developing theory (Conlon *et al.* 2020). The researcher may go back to original data as ideas and insights are gained in addition to continuing to gather new data.

The memoing of ideas supports the constant comparison, in that the links or possible links may be becoming evident, or hypotheses may be developing which are providing guidance on what data to look for and where to go next to look for data. Where to go next is referring to data slices and alludes to sampling for data in social units different to the substantive area. The main function of theoretical sampling is to garner a wide variation in categories in the developing theory (Gibson & Hartman 2014). This provides a focus for further constant comparison. This will permit comparison with existing concepts and refine development of the core category. Gibson & Hartman (2014) caution that the researcher should be careful not to theoretically sample too early by forcing early preconceptions about what is happening in the data, but rather remain alert to distinctions in categories that arise later in the analysis. Theoretical sampling, therefore, supports the emerging theory by providing a structure for data collection, in addition to supporting data analysis (McCrae & Purssell 2016). When the researcher recognises that the theory is dense then theoretical sampling ceases.

Coding

Coding processes with GT are of two types: Substantive and Theoretical.



Substantive	Theoretical Coding
Open Coding	
Selective Coding	

Table 3 Types of Coding

Substantive relates to the initial open coding of the raw data, and selective coding when the core category has emerged. Theoretical coding delineates the relationship between the facets of the theory. As indicated earlier coding is not linear. The interdependence within the analytical process creates a challenge and therefore some further discussion is appropriate (Holton 2010).

In a GT study the data is conceptualised through a process of coding. It is a precise way of putting order on data to expose theoretical inclinations and contribute to the emergence of a theory that addresses the main concern of the substantive area (Gibson & Hartman 2014). Essentially the researcher is breaking down the data into pieces known as incidents which are given labels (open coding) then, by comparing more data to this code and the codes to other codes and their data, more abstract codes are identified (Elliott & Jordan 2010). The researcher continues this coding until they have identified key fundamental aspects of a theory that is the main concern and how this concern is processed (core category). Coding at this point becomes focused upon codes that are considered to be part of the theory (selective coding) (Holton 2010). The point is achieved whereby there is certainty about the theory and the researcher then has to discover how and in what ways the different elements of the theory link together (theoretical coding). Coding is central to making sense of the raw data. However, the process of coding is dependent on the iteration between the data and the various codes. Therefore, coding makes sense of the raw data, and while it is core it is also dependent on the interrelationship with other aspects of the constant comparative analysis. From a theoretical development perspective coding without this interdependent relating would be meaningless (Holton & Walsh 2017). Accordingly, as data collection and analyses are concurrent, it is imperative that the one researcher undertakes both.

Open Coding

In open coding, the researcher examines the data line by line, comparing and looking for similarities and differences between the data and then to codes already given. Glaser (1978) refers to this as fracturing the data. He advises that the researcher has to continually ask questions of the data seeking to find out what is happening and what the data is indicating. Questioning the data in this fashion supports the identification of a core category (Glaser 1978). Instances of behaviour which indicate a pattern are known as incidents and these are given codes. These codes may be direct quotes or words of the participants (In-Vivo codes) or quoted in the language of the researcher to reflect the data (In Vitro codes). Initially the codes may be descriptive but, as constant comparison continues and the researcher gains more conceptual understanding, these are revised reflecting the conceptualisation (Elliott & Jordan 2010). Memoing is key to gaining conceptual understanding. The researcher's concern is not about the labels given in coding but rather what is happening in the data (Glaser 1992). This intimacy with the data supports the researcher in keeping the emerging ideas grounded in the data and additionally increases the confidence that nothing has been missed. The goal in open coding is to achieve as much variation as possible (Gibson & Hartman 2014). The continuous coding, data collection and memoing increase the conceptualisation which is key in the recognition of behaviour patterns indicating the main concern and how it is resolved or managed in what is termed the core category.

Selective Coding

Having discovered the core category, the researcher continues with data collection and constant comparison but engages in selective coding. Selective coding refers to delimiting coding to concepts that relate to the core category "in sufficiently significant ways to produce a parsimonious theory" (Holton & Walsh 2017, pp. 83-84). Consequently, if concepts do not relate to the core category they are not focused upon. It is at this point the researcher exercises vigilance to ensure that the concepts relate in meaningful ways to the core category. This relationship is captured in memos. The memo recording not only explicates the meaning but also assists the researcher in not ambushing the analysis with any preconceived or professional ideation (Glaser 1992; Elliott & Jordan 2010; Holton & Walsh 2017). As the analyses proceeds, the concepts become saturated or reach what some writers refer to as data sufficiency (Francis *et al.* 2010; Walker 2012; Nelson 2016). Saturation is defined by Holton & Walsh (2017) as the point at which no new properties or dimensions of the concepts are forthcoming from additional data. At this point the coding is further delimited to the concepts which are not saturated and continues with analyses until saturation is reached.

Theoretical Coding

Theoretical coding consists of the researcher identifying how the categories and subcategories relate to one another. This relationship is explicated in theoretical coding (Hernandez 2009). While open coding break down the data, the theoretical codes “weave the fractured story back together again” (Glaser 1978, p.163). Theoretical codes must not be pre-conceived but emerge from the data (Hernandez 2009; Glaser 2005). They can be implicit or explicit. The researcher, continuing to code, memo and being theoretically sensitive to what is occurring in the data, is able to identify implicit theoretical codes. Elliott and Jordan (2010) caution of the danger of trying to systematise the substantive codes into organised themes. Holton and Walsh (2017) indicate that some researchers do not progress and follow through with theoretical coding and, as indicated by Elliott and Jordan (2010), a thematic description is achieved. Therefore, identifying theoretical coding requires considerable skill and confidence (Bohm 2004). The identification of theoretical codes requires the researcher to look at the categories and identify the relationship between them and in this way the theory becomes a coherent, parsimonious whole (Belgrave & Seide 2019). Glaser (2005) offers a selection of theoretical codes that may be utilised as a guide for the researcher. The researcher needs to study and be familiar with as many theoretical codes as possible to assist in illuminating the code that explains how the elements of the theory relate to one another and become a whole (Glaser 2005). This is not to force a theoretical code onto the developing theory but to support the researcher in understanding the importance of theoretical codes in linking theory together to demonstrate how it explains the resolution of the main concern of the participants. At the point of theoretical coding, the researcher is working with concepts, properties and memos and as is obvious, the data is now in the background. The identification of a specific theoretical code is carefully achieved through sorting theoretical memos (Scott 2007). In this way, the theoretical code selected has earned its way into the analysis. A theoretical code cannot be thrust upon the categories. It must earn its relevance by showing in what way/s the categories and concepts relate to one another (Gibson & Hartman 2014). Therefore, theoretical coding requires the researcher to have identified a core category that fits and accounts for the variation in the patterns of behaviours. Theoretical coding is achieved through the sorting of mature memos and the writing of further memos.

Constant Comparative Analysis

The goal of GT is to generate a theory that explains in a conceptual manner the latent patterns of behaviour. Therefore, the goal of constant comparative analysis is primarily for theory generation. As stated by Glaser (1967), constant comparative analysis “is not used just to prove something as fact but is used to identify the properties and indicators of a category and help theory reduction by delimiting the theory's boundaries of applicability" (p. 24). This emphasis on generating theory over verification is what differentiates constant comparison from the comparative method of the social sciences. One of the major distinctions is the constancy of the comparisons throughout the method (Gibson & Hartman 2014).

The central thesis in the constant comparative method is comparing and conceptualising, yet remaining truthful to what is happening in the substantive area (Holton & Walsh 2017). So, the researcher compares incident to incident; incident to emerging codes and this comparison leads to the identification of codes that fit with the data; the researcher continues to compare concepts to concepts and properties of concepts emerge and tentative categories are emerging. Questions such as "What category does this incident indicate? What property of what category does this incident indicate? support the task of comparing. As the process continues over time, the same things are happening in the data and there is some pattern recognition. As the constant comparison continues and categories emerge the latent structure of behaviours emerge.

The analysis consists of four stages and while the following elucidates each stage individually the four are continuously being operated until completion of analysis (Glaser, 2008).

Comparing incidents applicable to each category

The researcher compares concepts (codes) which have been identified as elements of a tentative category. This involves comparing codes and their incidents with other codes. It is this comparison that leads to a sharpening of the codes, that is, identifying if the codes are doing what they are supposed to do which is to describe the patterns of behaviour in the data. It is at this point that the researcher is also comparing the codes with the tentative category with which they have been associated. The concepts are either stabilised or discarded. Theoretical sampling with new data supports this analysis and the overall development of the tentative category (Holton 2010). The data that is collected is compared to the tentative category and thus gives more clarity by identifying the properties and saturates the category (Glaser, 2008). The continuation of memoing is essential to support this process.

Integrating Categories and their properties

As the analysis continues the researcher moves from direct comparison of the data to comparing new data with categories and their properties (Holton 2007). This comparison gives greater clarity in relation to the properties. The researcher constantly returns to the data to particularise and situate the emerging concepts and categories. This process continues until there are no new properties emerging which is the point of theoretical saturation (Holton 2007).

Delimiting the theory

Delimiting the theory occurs at various levels helping to achieve more focus. The researcher identifies similarities in concepts and reformulates them into a small number of more abstract concepts. The researcher focuses on a core category and discards irrelevant categories and concepts. Thus, delimiting and reformulating reveals a more abstract level of theory development (Glaser 2008).

Writing the theory

When the researcher is confident of the substantive theory that has been developed, it is presented to others. Glaser (2002) asserts that when theoretical completeness occurs the creative sorting of memos is part of the writing up of the theory. Therefore, writing the theory is a vital part of GT.

Memoing

Memoing is an essential aspect of the GT method. It is a record of the researcher's observations and thinking on what is happening in the data. Therefore, memoing commences at the start of data collection and continues throughout the inquiry until the theory is developed. Memos capture the researchers thinking about the data. There is agreement with Glaser's (1978) dictum that memoing is of prime importance in GT (Birks *et al.* 2008; Levers 2013; Charmaz 2014a; Gibson & Hartman 2014; Holton & Walsh 2017). Glaser (2003) considers that memoing should be continuous and prolonged to permit the development of a theory. Glaser (1992) states that researchers who conclude memoing before theory is developed achieve conceptual description not theory (Glaser 1992). Glaser is clear on the function and use of memoing in the analytical process. During the analytical processes of constant comparison, the researcher is comparing all data while considering what the data may be revealing and recording memos about the comparisons.

Memoing is the researcher writing memos about the theorising of ideas about codes, similarities, differences, relationships of codes, properties and categories. Therefore, it supports the ongoing development of ideas for the theory and, importantly, directs the researcher regarding theoretical sampling (Glaser 1998). Memos need to be recorded accurately at the time or at the earliest opportunity as the idea or hunch or question may be lost very quickly. Memos are also considered as data and contribute to the development of the theory (Glaser 2003). Memo content is always related to what is happening in the data and accordingly the researcher's pre-conceptions or logical deduction will be obvious, as it will not be evident in the data (Gibson & Hartman 2014). Therefore, the content of memos will be a fit and will work for the data that is being analysed.

The recording of memos may be challenging at the beginning and the content descriptive (Holton 2010). Nevertheless the researcher pursues with memoing, as it will be unknown how the initial thinking may influence the development of ideas at a later stage (Schreiber & Noerager Stern 2001). Therefore, all memos are labelled and dated. As the researcher undertakes the analytical process, ideas come about the data concerning the possible relationships and these are recorded in memos (Montgomery & Bailey 2007). Earlier theoretical reading will be beneficial at this point, as it will increase openness for ideas and abstract thinking to support variation in the behaviour patterns. Ideas are captured in memos as they occur, preventing the loss of ideas which may transpire to support the creativity of the researcher as the analysis progresses (Glaser 1998).

Birks *et al.* (2008) suggest that memoing could be used to illustrate the decision-making trail in a qualitative study. The decision-making trail is viewed as evidence supporting the wider demands for rigour in inquiries conducted via qualitative methods and gives details for any decisions made during the conduct of a study (Koch 2006). Rigour is the accepted alternative in qualitative studies to reliability and validity which is the landmark of validating quantitative research studies. Discussions of reliability, validity and rigour are about researchers demonstrating that studies undertaken were systematically rigorous in their method and in accordance with expectations from the academic community (Parahoo 2014). Demonstration of meeting expectations are important for the acceptance of research studies (Roberts *et al.* 2019). Within quantitative research there are clear indicators which are adapted to any research study (Larson 2020). However, within qualitative research providing evidence of rigour can be more challenging (Nowell & Albrecht 2019).

Within GT, memoing records the deliberate thinking about the data and the ideas regarding data abstraction and do not focus so much on how the research is being done. Therefore, memo-recording to be an instrument of rigor would need to be adapted. It is possible that if they were used as a decision-making trail the researcher may be constrained in writing and perhaps some initial thinking of ideas may be lost (Holton 2010). As Glaser (2004) emphasises the key function of memoing is to record ideas about the code, indicators, concepts and ideas during the analysis. Memoing forces the researcher to concentrate on theory development (Gibson & Hartman 2014). According to Glaser (1978) theoretical memos are “the bedrock of theory generation” (p. 83). Memoing, therefore, is focused on theoretical development and to change that focus would in my opinion lead to a substantial change to the method.

Theoretical Sensitivity

Theoretical sensitivity is essentially the researcher having an attitude of openness to what is emerging and happening in a study. While participants in a study may have some similarities, each one is essentially unique. Therefore, openness enables the variation of each piece of data to be captured. This variation is in relation to the problem, how it is conceived and how it is processed (Glaser 1978). Therefore, theoretical sensitivity is a requirement from commencement to completion (write up) of a GT study and as Glaser (1967) states is “forever in a state of development” (p. 46). For Glaser (1978) the ability to be sensitive to the data is the lynchpin to rendering “theoretically the discovered substantive GT” (p. 1). Theoretical sensitivity is having the ability to be open and sensitive to what is happening in the data continuously. The developing of analytical skills and an attitude to remain open and sensitive without being influenced by professional concepts or reading is a conscious effort (Gibson & Hartman 2014). This effort is supported by the researcher entering the research field without the critical review of the salient literature and hence no theoretical framework to guide a study (Glaser 1992). As he states GT “must be free from the claims of related literature and its findings and assumptions in order to render the data conceptually with the best fit” (Glaser 1992, p. 32). Therefore, it is in service to the data analysis that the literature must not be studied. This does not mean that the researcher enters the research field as a tableau rasa but is open to what is happening in the field without being contaminated. The researcher must read widely beyond the subject matter of the research study to gain ideas about theory diversity and construction and, as Gibson & Hartmann (2014), state “... not only being steeped in the literature but also reading that literature in a particular way” (p. 107). Gibson and Hartmann are referring to engagement with theory to gain an appreciation of what constitutes theory, the different types, and, how in different fields of study, theory is constructed and related together as a theoretical whole. This assists the researcher to be open to the different ways in which theory is understood, and how different concepts and categories relate to one another.

Being aware of interests and preconceptions can support ongoing openness. Gibson & Hartman (2014) caution that preconceptions are often sub-conscious and can force meaning upon data. Key attributes of theoretical sensitivity include openness, analytical insightfulness and creativity. Reading of other theories assists the researcher to continue with the analytical process to the full development of theory. As Glaser (1967) cautions, the researcher can lose analytical insights or become insensitive to the data if they fix on an emergent concept as the theory. This fixation leads to voluminous conceptual description, but it is not GT (Glaser 1992). The attitude of openness is essential to the researcher having an appreciation for variability. It is this that assists the researcher to consider the relationships within the theory and, furthermore, how the theory fits with the reality of the substantive area.

Theoretical sensitivity, therefore, could be summarised as an attribute to theory development that contains the essential qualities of openness and creativity. It is the openness and creativity in conjunction with theoretical memoing, sampling and coding that lead to a theory that fits and works. Each of these aspects will be discussed later in the chapter.

Emergence vs Forcing

One of the key tenets of GT is to develop a theory that explains how a main concern in a substantive area is resolved or managed. To enable this to happen the researcher has to be able to capture what the concern is and how it is processed. Contrary to other research approaches, the researcher does not come with any preconceived frameworks to guide the study (McCann & Clark 2003). The researcher is a participant in society and has constructed their reality from the society and culture in which they have been immersed. However, Glaser (1992; 1998; 2003) in his writings, while using objectivist language, does not fully ascribe to the researcher a realist ontology. He acknowledges the researcher as a citizen influenced by society and culture and is fully aware of the influence of culture and traditions in academia and professional enterprise. In this mode I believe he asserts often in his writings that the researcher comes to the substantive area with preconceptions that may lead the analysis and therefore the expected issues are there. My understanding is that the researcher should be aware of preconceptions and the possibility of those preconceptions steering the analysis. The researcher purposefully sets out to be aware of any preconceptions but does not deliberately fill his/her subconscious with existing theories or research as this will influence the direction of the research. Gibson & Hartmann (2014) put the distinction succinctly when they state, “the distinction is between using preconceived notion and having preconceived notions” (p. 35). The researcher must be theoretically sensitive to the data and, while a scoping of the literature may contribute to the sensitivity, caution is taken not to permit this to influence the openness of the researcher toward the emergent or how it is processed. Glaser (1998) advocates that the researcher record preconceptions and, in this way, they can be used as more data in the constant comparison but not lead or hijack the analysis. There can be no forcing of concepts or ideas onto the data. The concepts must emerge from the data (Glaser 1998).

The research literature refers frequently to emergence, but no critical examination has taken place around its usage. Varpio *et al.* (2017) make a valid point when they state that the construct is misused in health research and explain that qualitative researchers use the term to increase legitimacy for qualitative work in more quantitative orientated fora. Some studies claim that findings emerged without any attempt to explain the underpinning process (Lo Cricchio *et al.* 2019; Diepeveen *et al.* 2020). Yezdani *et al*. (2015) assert that emergence has challenged existing ideas of describing “complex and counterintuitive ideas” (p. 307). Social phenomena too are complex. Dynamic processes occur that can be observed, but these must be given the space to emerge. Therefore, the attitude of the researcher is to be open to the emergence and observing those patterns. Watling & Lingard (2012) consider that emergence in this form is antiquated, as it ascribes to an objective neutral researcher which is not conceivable. Varpio *et al*. (2017) are sceptical also of emergence and argue that researchers obscure their own subjectivity and are influenced by the “pervasive linguistic influence” of GT (p. 43). Kelle (2005) concurs with the pervasiveness and the acceptance of GT. He maintains that the linguistic argumentation of Glaser is ubiquitous with objectivism and authoritarianism. The tones perhaps resonate the authority that dominated society at the time-period of GT origin and possibly are permeated with enthusiasm for changing the domination of verification and falsification. Emergence also contradicted the forcing of theoretical constructs which was part of the dominant method of comparison in the social sciences (Gibson & Hartman 2014). These insights help to explain and appreciate what Glaser was attempting to do. However, to the neophyte GT researcher it is a challenge to grasp emergence. Glaser (1978; 1992; 1998) emphasises that openness and trust must dominate the GT study to permit emergence. Glaser (1992) views emergence as the constituent in the analytic mode of the researcher. Forcing contradicts any possibility of emergence (Gibson & Hartman 2014). This issue of forcing in the initial stages of studies has dominated the literature. However, it can occur at other moments in the analytical process when the researcher does not stay close to the data, when the constant comparison of the data has not continued throughout a study or when recording of memos has not been continuous until the write up of the study.

Conceptualisation

Conceptualisation is a fundamental foundation of GT. Essentially conceptualisation is abstracting an idea or thought from a description to a higher level. To develop a GT Glaser (2002a) identifies two features of conceptualisation as: 1) concepts are abstract of time, place and people; 2) concepts have enduring grab. Concepts are names given to social behavioural patterns. Names are not randomly selected but carefully discovered through the constant comparative method. Initially the researcher may struggle to get the word that correctly identifies the emergent pattern, so concepts are renamed to fit with the emerging pattern (Elliott & Jordan 2010). Glaser (2002) defines fit as the word that "best captures its imageric meaning" (p. 4). I understand this to mean that the names of concepts should identify the patterns but in addition need to attract the attention of readers. Therefore, the researcher will need to use their imagination to identify the name that both fits and has grab. The goal in GT is to reveal what Glaser (1978) consistently refers to as latent patterns of behaviour. This is in stark contrast to other methods which seek to describe experiences or develop a thematic arrangement. People in a study may not be aware of, or able to recognise, the patterns as they are latent. They are captured by the researcher who carefully studies behaviours from many incidents and then views them as if at a distance to gain a broader picture of what is going on. This can be a very confusing picture and only with careful study will the pattern be evident. Holton (2010) refers to these skills as analytic temperament, that is, the ability to tolerate confusion and trusting in "preconscious processing for conceptual emergence" (p. 23). It is this broader picture or abstraction which is named as a concept. It is in the continuation of the constant comparison that the latent structure is evident, as Glaser (1992) articulates "…..tap the latent structure which is always there and drives and organizes behaviour and its social psychological aspects, all of which are abstract of objective fact" (p. 8). Consequently, the concepts are abstract of time, place or people. Thus, a GT is relevant in other substantive areas as it is an abstraction.

Holton (2010) explains that the ability to transcend description may be restricted by previous experience in other analytic methods. She also maintains that inexperience and over anxiety in missing something in the data may limit the skill of abstraction. She reiterates the advice of Glaser (1967, 1978) to trust in the process and persist with constant comparison. The continual asking of key questions of the data, capturing conceptual ideation in memoing and the subsequent revision of codes all support the development of abstraction. Concepts generated from disparate stories and thoroughly grounded in the data have enduring grab, that is, others who read the theory can understand what they mean. This continues over time according to Glaser, as they are recognised and preferred over conjectured or impressionistic concepts (Glaser 1992; 1998; 2002). In GT concepts are inductively derived with the ideation captured in the memoing of similarities and differences and in questions regarding relationships. Such questions are posed as hypothesis in the memos and the researcher goes back to the data to consider the hypothesis in the process of deduction.

Conceptualisation requires skill and time, without which the outcome is descriptive and, to use Glaser's (2002) term, "conceptual foppery" (p. 22). Conceptual description results when concepts have been identified and the constant comparison has not continued to permit categories and properties to emerge. The careful attention to line by line coding and comparison of incidents, concepts and properties engages the researcher in continual theorising (Holton 2010). Conceptual foppery results from the researcher's inability to compare many incidents and many concepts. The researcher cannot see the latent pattern. A theory grounded in data and developed through careful constant comparison and abstraction achieves fit and parsimony and has explanatory power (Gibson & Hartman 2014).

Divergence of GT

GT has gained popularity as a research method. Nevertheless, the language used to describe the method and the differences with other methods in its application have generated much discussion in the literature (Babchuk 1996; McCann & Clark 2003; Bryant 2017). Research methods usually align to a particular ontological and epistemological perspective. However, GT does not, and furthermore, Glaser refutes association with any particular philosophical position (Glaser 1998, 2002). This fact has influenced the literature discourse on the objective and subjective intentions of GT (McCann & Clark 2003, Bryant 2017).

The disagreement between the originators Glaser and Strauss on using induction and deduction to develop theory generated further discussion in the literature about the intentions of the method and the nature of the procedures (Rennie 1998). This had led to a number of reinterpretations. For example: Judith Wuest (1995) developed feminist grounded theory; and Kathy Charmaz developed constructionist GT (Charmaz 2006, 2014a). Straussian and Constructionist are the two formulations most frequently used and, therefore, discussion will focus upon these highlighting differences to the original discovery.

Straussian GT

The first digression emanated from a difference between the two founders regarding the development and recognition of theory. Glaser remained with the initial understanding that theory emerged through induction from the data. Strauss (1987) advocated that theory must be verified and be logically deduced, creating a coding paradigm with properties of conditions, context, consequence and strategising all of which emphasise the influence of Strauss's background in symbolic interactionism (Strauss 1987). Glaser (1992) viewed the reformulation as completely different to GT and requested that Strauss change the method or rename it. Strauss and Corbin (1998) reformulated the Straussian approach and included a broad research question to commence the study, adding axial coding and referenced one theoretical code. The inclusion of a broad research question to begin a study contrasts with GT method of entering without any preconceptions (Rieger, 2018). Within the analysis the use of professional experience in hypothesis generation contrasts with GGT when hypothesis is generated in the constant comparing of data (Rieger 2019). According to Holton & Walsh (2017), the addition of axial coding points alludes to theory verification. The aim of GT is to build theory from the data, not to test the theory (McCann & Clarke 2003). The reliance on one theoretical code contrasts with the suggested eighteen examples of coding families of GT. Theoretical coding links the categories of a theory together and is reflective of the relationships which will differ in theories. Therefore, one code forces the data in a particular direction which contrasts with GGT which emphasises the emergence of the theoretical code/s from the constant comparative analyses. it is important that the theoretical code emerges. Straussian GT as an analytical process is procedural, deductive and contrasts with induction the central tenet of GT (Rieger 2019). Melia (1996) and Kendall (1999) agree with Glaser and posit that the methodology proposed was lengthy and arduous and that the forcing of data was not congruent with the GT method. McCallin (2003) suggests that the clear descriptive steps may be advantageous to the new researcher in knowing the steps to follow, although Moore (2009) noted a challenge with implementation for her work as a neophyte researcher.

Constructivist GT (CGT)

CGT emerged from a rejection of the perceived objectivist epistemology of Glaser and Strauss and Corbin. Charmaz (2014a) reasons that there is no external objective world awaiting discovery. The reality for Charmaz is that the researcher and the researched construct the meaning of a reality (Charmaz 2006, 2014a). This construction is reflective of the engagement in the world and, therefore, this is present in the research endeavour (Gibson & Hartman 2014). Within GT the researcher composes hypothesis from the constant comparison, which contrasts with CGT when professional concepts from the discipline of the researcher or the literature may guide the inquiry. Charmaz does not view that such pre-conceptions might influence the analysis. She maintains that the researcher is interpreting the life of the participant and, therefore, these open up the inquiry (Charmaz 2014a). Using such preconceptions may compromise the openness of the inquiry and contrasts with this central tenet of GCT (Gibson & Hartman 2014). The focus of the theory may be on another subject not of relevance to the participant and therefore the outcome would not have the same explanatory power. The Charmazian approach then recognises the subjectivity and the co-construction of a theory to interpret the meaning of the participants as illustrated by the following:

> We are part of the world we study, the data we collect, and the analyses we produce. We construct our grounded theories through our past and present involvements and interactions with people, perspectives and research practices. (Charmaz 2014a, p.17).

This is very different to GGT which seeks to theorise what the concern of the participants are. Glaser (2002) asserts that GT is the development of theory, not a description of something but a theory that is induced from the data. Glaser does not dismiss the subjective considerations of Charmaz. However, he contends that the aim of GT is not getting an accurate description. He affirms that GT is directed toward theory development and that the researcher in analysing data goes beyond description to abstract conceptualisation (Glaser 2013). Gibson & Hartman (2014), while acknowledging the value of a constructivist approach, concur with Glaser and identify the significant impact subjectivism has on the initial inquiry and the subsequent analysis.

Cogency in GGT

The conduct and process involved in a research study are evaluated by others so they can gain confidence in the findings. The evaluation of quantitative[9] studies considers the reliability and validity, which is how well the methods have consistently and accurately measured the data within the study (Creswell & Creswell, 2018). According to Beck (1993), the rejection of reliability and validity as criterion for evaluating qualitative[10] studies gave rise to the concept of rigour and indicators of rigour, i.e., the accuracy, value and quality of the study in relation to the design and participants (Creswell & Creswell, 2018). Some or all of the suggested indicators by Lincoln and Guba (1985) are frequently used, i.e., trustworthiness, credibility, dependability, transferability. authenticity and confirmability (Johnson *et al.* 2020). GT studies do not neatly fit into the qualitative or quantitative domain (Wasserman *et al.* 2009). Therefore,

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[9] Quantitative methods are underpinned by the positivistic philosophy and the principle of objectivity employ numerical methods to investigate phenomenon.

[10] Qualitative methods are underpinned by post positivistic philosophy and the principle of subjectivity seeks to capture the views of individuals.

Glaser (1992; 1998) identified criteria for evaluating them as: fit, workability, relevance, modifiability, scope and parsimony.

Fit refers to the match of the concepts, i.e., do the concepts match the patterns in the data. This refers to the clarity of the categories in that they should be able to be utilised in future studies. It also indicates that the patterns match the data and are not forced (Glaser & Strauss, 1967). Workability refers to the concepts and the development of categories and to whether this accounts sufficiently for the way in which participants resolve or process their main concern. Concepts and categories should be abstract of the incidents that led to their development. Relevance refers to whether the theory deals with the concern of the participants and its importance to them. As Glaser states “Relevance, like good concepts, evoke instant grab” (1998, p. 18).

Modifiability refers to the ability of the theory to be changed as new data emerges. For Glaser, the more data that is analysed the more “plausible the generated theory*”* (Holton & Walsh 2017, p. 154). Parsimony refers to the ability of the theory to explain what is going on in the data in as few categories as possible.
These criteria are integrated into the method and support the refinement, parsimony and scope of the developed theory and for this study are evident in chapter five Operationalisation of GT.

Philosophy underpinning this study

I recognise that objectivity and a desire to gain definitive answers to questions in my professional field of nursing has influenced somewhat my personal philosophy. The subjective perspective was not neglected, as I recognised that individuals experienced ill-health, and this impacted upon their life. However, as I have matured and reflected upon my early experience of being and relating to people in nursing, I can identify that the patient voice was gained but in reality this was filtered through what I might call a clinical sieve of physiological knowledge. As I progressed on my professional journey, I recognise that the voice of the patient became a significant part of health knowledge and could support the development of future nursing know-how and health policy.
I was attracted to the GGT method and the emphasis it has on hearing the voice of the participant and not filtering it through any lens. The voice comes from a particular person influenced by biopsychosocialspiritual dimensions. Using GGT method the lens that the voice is being filtered through is the lens of many other people with RA and not a clinical or academic

one! I am merely the listener and analyst who is looking for the patterns that many people cannot see when they are close to their own story of life. My role is to assist them by identifying their concerns. Essentially it is about hearing what they are saying and bringing that to a wider audience. Therefore, GT is giving credence to that voice that for me was silenced on so many occasions for so many psychosocial reasons.

The idea that there is a reality that may be perceived and examined without any confluence from other realities or aspects of reality is an impossibility. All that is ever known is within some context, and therefore, it is influenced in some way by that context. What can be gained is a view of that knowing. I do not believe that another person constructs that knowing. It is the person who lives in that reality that has the power to construct that knowing. For this study, therefore, I am merely the conduit through which the participants share their experience. GGT was selected as the most appropriate method to gain the participants perspective, but to transcend and gain theoretical evidence that can be of value to others. From an ethical perspective, therefore, GGT respects the participants as individuals, and their sharing of their experience in an authentic and powerful manner.

Conclusion

This chapter discussed ontological and epistemological considerations when considering research design. Such discussions are helpful for deciding upon a research approach and how the selected approach will answer the research query. GT has been aligned with different ontological roots, despite one of the founders espousing vociferously that it is a general method and is not to be attributed to any one particular philosophical position (Glaser 1998). This chapter has provided some discussion on two philosophical lenses by which to view the identification of knowledge. While it is now accepted that naïve realism (objectivism) is no longer tenable or arguable the opposing view of subjectivism is not fully accepted either. It is evident that the search for objective truths remains. That said, studies operationalised within an objectivist ontology offer findings tentatively. The methodology of this study GT has been criticised for its objectivist leanings in the role of the researcher and the handling of the data gathered. Glaser (1998) advocates that the researcher approaches a study without completing a thorough and robust literature review. The researcher does not enter the field as a tableau rasa but is already influenced by their professional knowledge. As Glaser (2005) emphasises, openness in GT must be maintained:

“experienced people are more able to suspend their knowledge of literature and research field, based on their skilled, competent research ability to stay in control of perceptions and therefore stay open. They can spot preconceptions both substantively and TC (theoretical codes) quite easily since they are more aware” (p. 6).

The second lens for viewing knowledge discussed in this chapter was constructionism. This is the idea that knowledge is constructed by engaging in the reality in which we exist. A reality that is complex and operates within equally complex social entities. This reality has many layers of knowledge generated and embedded. This knowledge may become firmly nested in our knowing to the point of becoming somewhat objective knowledge. The researcher too belongs to this social world and, therefore, is a participant of socially constructed knowing. The method of GT recognises, I believe, objective and subjective knowing and ascertains evidence of knowledge. The task in GT is not to give meaning to or interpret the matters of the substantive area, but to reveal the patterns of behaviour that illustrate how a particular concern is processed. The task is to conceptualise these patterns through the constant comparative process. Here too the researcher is open and views the data from different perspectives to illustrate the variation in the patterns. It is not an objective truth but a truth that can be modified with more data. The discussion on the key pillars of GT highlighted the significance of the researcher remaining theoretically sensitive to what was happening in the data while being supported by the iterative process of constant comparison. Memoing supports the theoretical thinking and permit emergence and therefore the researcher will not be forcing their ideas or conjecturing what is happening in the data.

In the next chapter I discuss how the GGT was applied in gaining a substantive theory to explain how the participants processed their main concern of *Fear of Declining Self-Worth.*

CHAPTER 4: OPERATIONALISATION OF GGT METHOD

Introduction

The previous chapter outlined the major tenets of GT. This chapter will illustrate how the GGT methodology was applied in this study and the discussion reflects the methodological development of a neophyte GT researcher. The chapter begins by outlining the study aims and objectives and then proceeds to discuss elementary research aspects (recruitment and gaining access) including the profile of the participants. The application of GT within this study occupies the remainder of the chapter. Issues pertinent to fit, workability, relevance, modifiability, and parsimony are discussed throughout the chapter within the iterative processes. The ethical dimensions are discussed in terms of beneficence, non-maleficence, justice, and veracity. The research steps are presented here in a linear fashion for the reader. However, in reality the process was much more interwoven, as I took backward steps into sampling, data collection, coding and memoing as directed by the continuous constant comparison.

Aim and Objectives of the Study

The overall aim of this study was to generate a substantive theory that explained how the participants processed their main concern when living with RA. The following were the research objectives:

1. To explore the social and psychological process that occur when people live with RA.
2. To develop a theoretical framework that explains the processes used by the participants to address their main concern.
3. To situate this theoretical framework in the context of current understanding of living with RA.

Recruitment

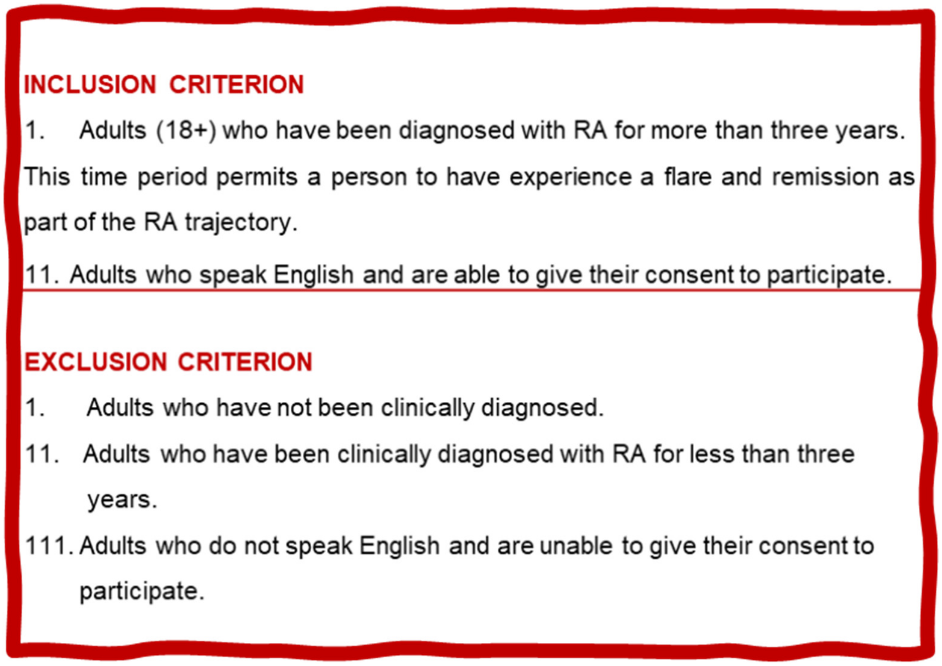
Accessing the research site and potential participants

The majority of the populations of previous qualitative studies in the substantive area of RA were what Daker-White *et al.* (2014) referred to as captive populations i.e., patients that were hospitalised. Therefore, I decided to sample participants who were community based to address this population gap. In Ireland, there are no national specific databases or formal recording systems for the population of people who have RA. People who have arthritic features are referred by their GP for specialist consultations to HSE managed Regional Centres for Rheumatology of which there are six in Ireland. These centres are located geographically matching the density of the population. I decided to gain access to the centre which serves the West and North-West of Ireland. The University I am employed in has links with this centre and, therefore, I considered this would be advantageous in gaining access and I could explore accessing the other centres later if the theoretical sampling of the study dictated. As it transpired, the population of the centre in the North West was sufficient to address the ideas of the emerging theory and accessing other centres was not necessary. People with different types of arthritis attend the RU clinics for consultation annually, biannually or quarterly depending on the status of an individual's arthritis.

Johl and Renganathan (2010) identify that the majority of published studies do not give much detail regarding accessing research sites. For me as the researcher, accessing the site was viewed as very important. I used both the formal and informal approaches discussed by Johl and Renganathan (2010). I believed that an informal approach initially gave an opportunity for clinical leaders to meet with myself and contribute to a discussion on the proposed study, thus respecting their clinical expertise. While I was somewhat familiar with the centre and the majority of the MDT, I wished to gain confidence that the proposed study would be perceived as adding to the quality of the service provided. I met informally with the leadership team (Director of Nursing, Lead Rheumatology Consultant, Clinical Nurse Manager) to propose the idea of a study. While I was aware of the limited studies focusing on the patient experience, I was unaware of what other studies were currently being undertaken and how many of the patient population with RA attending this centre might be involved in such studies. In addition to larger studies, staff in this Regional Centre undertake smaller research projects and audit work which would involve people using the service. It was important for me as a researcher to respect the individual lives of these people and not to overburden them. Clinical staff were delighted with the proposed study seeking to gain the RA perspective from people who were living with RA although they were not familiar with the GT method. Nevertheless, they could foresee that the study would add to their knowledge and practices within the Rheumatology services.

When ethical approval for the study was obtained, permission to access was sought formally from the site managers and clinical leaders. When permission for access was gained, a meeting was organised with the Rheumatology Consultants, ANP and Clinical Nurse Managers to inform them about the study. Staff in the Rheumatology Unit work as a MDT and contribute to the development of the quality of the patient service. Therefore, an information session was organised for all staff to be informed about the proposed study and to give them an opportunity to pose any questions they might have. While the majority of the staff would not be directly involved in the study, the participants whom they were caring for were and, so informing them recognised the contribution being made to the participants holistic health. Additionally, while I had organised some specific post interview services for participants, some may have chosen to speak with members of the MDT with whom they would be directly involved with. Therefore, it was important that they knew of the study and had some information on it.

The Director of Nursing as site manager and Data Controller delegated the Data Controlling role to the Clinical Nurse Manager 2 (CNM2). The CNM2 accessed records on my behalf and ensured that confidentiality was maintained in accordance with data protection legislation (Data Protection Commissioner 2007; Government of Ireland 1988, 2003, 2018). The CNM2 as gatekeeper fulfilled an important role in this study. Creswell and Creswell (2018) highlight the importance of a gatekeeper in any research study. Gatekeepers are usually people from within an organisation and thus are familiar with the culture of the study and have authority regarding participation in the research. This can be helpful for the researcher, but also create challenges e.g. have other work activities and insufficient time to support the identification of participants (McFadyen & Rankin 2016). For this study the CNM2 was included from the genesis of the study and regular face to face discussions took place which assisted in developing a respectful professional relationship. The CNM2 was given inclusion and exclusion criteria (see table 4 below) which she utilised to identify people as potential participants in the study. Over a six-month timeframe she used the criteria to select people who were scheduled for appointments in the Rheumatology Unit (RU). When she identified individuals, who met the criterion she attached an information pack to the individuals case notes.



INCLUSION CRITERION

1. Adults (18+) who have been diagnosed with RA for more than three years. This time period permits a person to have experience a flare and remission as part of the RA trajectory.

11. Adults who speak English and are able to give their consent to participate.

EXCLUSION CRITERION

1. Adults who have not been clinically diagnosed.

11. Adults who have been clinically diagnosed with RA for less than three years.

111. Adults who do not speak English and are unable to give their consent to participate.

Table 4 Inclusion and Exclusion Criterion

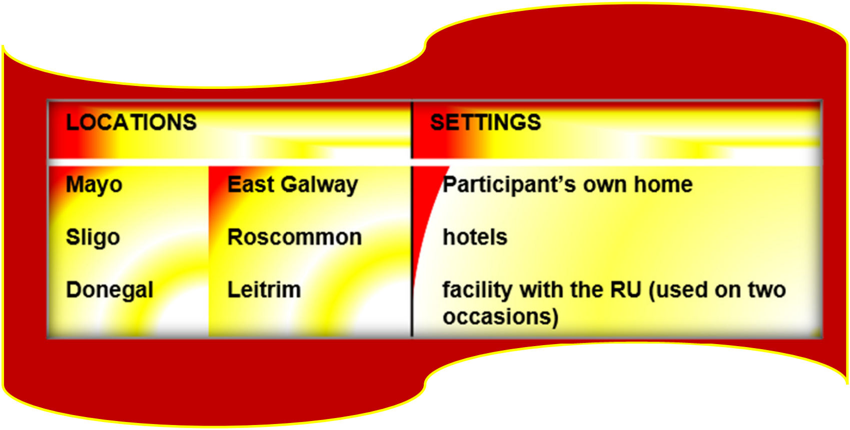
On the day of a participant's scheduled appointment the receptionist gave the pack to possible participants as they checked in for their appointment. She explained that the pack contained information about a study and the researcher was in the RU on that day if they wished to speak with her or if they had any questions. The study information pack consisted of a letter of invitation to the participants, an information sheet about the study, contact information for myself, and a question and answer sheet of anticipated questions participants might like to ask (Appendices 1 & 2). If people were interested in being part of the study, they were to contact me directly either by phone or email. While the receptionist distributed the information to potential participants, it was not known who was interested or who would agree to participate in the study. Information in poster format was also placed in different locations in the RU clinic to inform people about the study (Appendix 3). I attended the relevant clinics each week so that participants could ask questions directly from me. Respecting the privacy of those attending the clinic, I kept a low profile while wearing a badge signifying my first name and the title researcher. Thus, those who had opened and read the information in the pack would have known who I was if they wished to speak to me about their interest in the study. Some people greeted me on the day to tell me they would call me, while others came up to me and were eager to tell me about their RA in that moment. They were happy to provide me with their contact details so I could contact them. I asked them to read all the literature in the pack and I would contact them after one week to answer any questions that they might have or provide further information if they needed it. Eagerness to be involved surprised me and, therefore, I have included some discussion in the personal management section later in this chapter.

Recruitment of participants

Some participants contacted me directly, and I clarified information and re-confirmed that they were still interested in participating. For those who had given me contact details I contacted them after one week, clarified information and confirmed continued interest in study participation. For all people who had expressed interest in being part of the study I identified a date, time and location for the interview. I then booked a venue for the interview which was suitable to the participant. One week prior to the interview I contact the person to confirm their continued interest and that they were still available on the previously identified date and time. On the day prior to the arranged date I made contact to ascertain that the date was still suitable, and the individual felt well to meet with me. Flare-ups of active disease can occur in a short time space and I wanted to ascertain that they were not at the beginning of a flare-up. The majority of the encounters progressed as planned. A small number were re-arranged due to commitments that had arisen. For one person they were very anxious to be involved but I arranged to phone him on another occasion, as I felt on speaking to them that they may have been at the beginning of a flare-up and an interview would not have been appropriate. I did encounter him at a clinic later and identified that he was in a flare-up and other issues were present for him. We talked and agreed that he had too much going on in his life and it would be better not to be part of the study.

Location

The location and choice of setting (Figure 6) was influenced by the preference of the participant.



LOCATIONS		SETTINGS
Mayo	East Galway	Participant's own home
Sligo	Roscommon	hotels
Donegal	Leitrim	facility with the RU (used on two occasions)

Figure 6 Locations and Setting of Interviews

I was anxious to respect their privacy and time that they were giving to me. In the hotel and RU settings I had some control over aspects to increase comfort and privacy (quiet, do not disturb signage, refreshment). The participant was in control of these dimensions in their own home. However, on all occasions there was no disturbance during the interview. The Lone Worker Guidelines were very useful, as quite a number of the locations were in isolated areas (University of Dublin, Trinity College Dublin 2020). The interviews were spread out over nine months which supported the constant comparison, theoretical sampling and identification of the core category. I was challenged by some of the sharing that took place in the interviews and I have included some discussion regarding this later in the chapter.

Participant Profile

Thirty (n=30) participants expressed interest in participating in the study. However, pre-interview contact with 1 participant indicated the beginning of a flare-up and therefore 29 interviews were completed. All participants were taking regular medication specifically to manage the RA. Of the 29 participants 44.8% (13) gained the definitive diagnosis between 1970-1999 and 55.2% (16) between 2000-2008. One participant was diagnosed for 48 years, while two gained the diagnosis during their teenage years. Of the participants 51% were in the retirement age group. Of the 18 participants who were working, 14 were in full-time positions, 1 was on maternity leave and 4 were working part-time hours. In the working situations 41%(7) of work colleagues were unaware of the diagnosis and in 5%(1) selective others were aware. The participants identified the principal supports for them as medications, family/friend/spouse, lifestyle adjustments, exercise, rest, socialising, volunteering, keeping active, household aids, their own attitude, being positive, careful planning, RU staff, hydrotherapy, personal development, hobbies, balancing life, distractions, and arthritis support group. While all the participants identified that family were aware of their diagnosis, 27.6% (8) felt they did not have the support of family or friends, 10.3% (3) felt they received support sometimes and 62.1%(18) felt they had support of spouse/family/close friends.

Sampling

As discussed in the previous chapter, sampling in GGT has the specific intention of building up the understanding and nuances of the concepts within a theory. Initially inclusion and exclusion criteria were used to identify suitable participants and, while self-selecting to participate, the sample could be regarded as a purposive sample. The participants had RA for more than three years and, therefore, I envisaged that they would be information rich on the topic of living with RA. Marshall & Rossman (2016) identify that this such participants can provide a wide expanse of detailed information in relation to the topic area. This purposive sample supported the achievement of a sensitivity to the experience of participants and importantly a sensitivity to the concerns they had. As a GT study develops there is more clarity on what specific groups or populations need to be sampled. Directions for the development of sampling is achieved through the continuation of the inductive and deductive process captured in memos and referred to as theoretical sampling.

Theoretical Sampling

Theoretical sampling essentially is about theory generation (McCrae & Purssell 2016) and occurs when the core category has emerged. Therefore, data is sampled to saturate categories and concepts and to develop any new concepts that may fill the gaps[11] in the theory. Essentially data is collected, coded and compared with other data to discover behaviours and patterns of behaviours and the outcomes of the comparisons are recorded in the memos. The memos also contain any questions arising from the analyses and thoughts or further questions (hypothesis[12]) about the developing concepts or categories which guide the researcher in further data collection. Having identified what I thought was the core category on a number of occasions, I was theoretically sampling and saturating and then beginning again with another core. This difficulty could be explained by my usage of verbatim transcripts[13]. Engaging in theoretical sampling for these categories led me to question the core I had and, while this could be viewed at time wasting, it was ultimately rather helpful to the other processes of theoretical coding as I really felt I had a good understanding of how the participants were resolving their main concern. The specific core was elusive and eventually I was able to identify the core that brought it all together. Therefore, the interviews became more focused and I returned to preceding data to sample for additional data. I engaged in selective sampling for additional data on specific concepts that I considered were relevant to the emerging theory. Eventually I had sub core categories and I could identify that the participants were resolving their concern in a basic social psychological process (BSPP). However, the fit was not quite right. Eventually I was able to see that the participants were resolving by way of a BSPP but only in the context of awareness. This brought enormous relief as I felt that there was a BSPP, but it just was not coming together there was something missing I just could not see the perfect fit. The identification of an *Awareness Context* was the big discovery moment.

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[11] The gaps in the theory will be written in memos as hypothesis or questions.

[12] These hypotheses are not forced upon the data if they do not fit with further data collected, they are discarded (Glaser 1978).

[13] I had an enormous collection of codes which were preventing my thinking from becoming more abstract. When I had realised this, I stopped transcribing the interviews and wrote field notes only.

Theoretical sampling occurred throughout the analysis and this increased the density of critical junctures, categories and their properties (saturation). Data saturation remains problematic in research (Nelson 2017). When I was getting the same properties repeatedly, and the properties I had could account for the patterns in the data, I was confident that I had reached data saturation and this I considered to concur with Glaser's understanding (Glaser & Holton 2010).

Data Collection Methods

Interviews are the most common data collection method used in GT research (McCann & Clarke, 2003). I decided initially to conduct individual interviews and record memos about the environment. In 2019 "*My RA story*"[14] was published and I decided to use this as another source of data (Lynch 2019). I reasoned that these methods would be more suitable and less intrusive on each participant than reflective diaries or video recording. Interviews may be conducted as individual or in a group (focus group) and either structured, semi-structured or unstructured. Focus groups are beneficial in getting views and gaining discussion on broad issues which may not be so personal (Parker & Tritter 2006). Initially I was unaware of how individuals perceived their RA or how comfortable they would be in identifying and discussing any concerns in a group in which they had no previous relationship. When attending the RU in an introductory capacity, I had observed a silence and a hesitancy for any communication among the attendees and from this I reasoned that for some people discussion in a focus group may be threatening. I needed to ensure that all the participants felt safe to share and discuss without being threatened by the group or the topics of discussion. I decided that an individual in-depth unstructured interview would enable me to explore the concern of the participant.

I was cognisant of the power dynamics that might ensue in the interviews and had considered how I might manage the dynamics with the participants (Ryan *et al.* 2009). My earlier observation of silence in the RU had increased my anxiety and preparedness for facilitating what Glaser (1998) refers to as "instil a spill". I created a respectful relationship that recognised the participant as a person with their own story about living with RA. I respected their decision and choice regarding participation. Many people had indicated to me at the clinic that they were interested in being part of the study and gave me their phone number to contact them, while others were so keen they had wanted to relate their story on that day. For these moments I expressed my appreciation and said that I would be in touch with them within 1-2 weeks to

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[14] My RA Story is a collection of accounts of living with RA written by people who have been diagnosed with RA.

explore the opportunity to meet with them. Within the two weeks I telephoned all who expressed an interest in participating in the study to ascertain continued interest and to agree details for meeting. The phone calls commenced with explanations and an inquiry about the suitability of the moment for the call and their general health. I had an openness for any sharing about what might be going on in their life at that moment. For example, one man was tired, as he had been up all night with a cow calving. The cow had twins which was very exciting for him and I was conscious to link into his excitement and yet aware that the lack of sleep may have impacted upon what his physical body was experiencing that morning. For me building and facilitating relationships with each person was more important than gaining participants for the study. The points of contact in the meeting at the clinic, the follow-up phone calls (three to four) to ascertain interest, agree details for meeting and finally on the morning inquiring if they were well enough to participate were important foundation moments for developing a relationship of trust in me as the researcher with whom they were going to share their personal experience of RA.

When I met with each person for the interview, I greeted them by their first name and engaged in general conversation about the area or my observations while travelling. For example, one participant lived on the coast. I was able to admire the coastline, share how I walked the coast and talk about the comfort I gained from the waves and the differences in the scenery over the seasons. So, I shared personal information and gave the opportunity for the participant to get to know the stranger with whom they were going to engage in conversation about a personal aspect of their life. The sharing was reciprocal and helped to build rapport essential to every investigative conversation (Ryan *et al.* 2009). I found building rapport with all the participants easy and, perhaps because I originated from and lived in a rural setting, I was able to be more genuine in building rapport. A memo reflects some thinking on rapport shown here in figure 7:

Cautioning

August 18th 2018

I note a cautioning in participants. Secreting.....

The secreting evident in interviews - at the beginning until they grasped that I wanted to know about their RA and their life - until they grasped the genuine interest they were cautious - a hesitancy and a caution about movement in their posture: the crossed legs, the closed jacket buttons - the careful listening - also the responses - vague

What changed this? -

I think it was me: my posture, my body language, my attachment to what they were saying….the exploration and probing with sensitivity - I guess the genuineness of my interaction- they got this. Am I really getting the genuine honest how it really is response? How do I know that they are not sharing what they perceive to be safe to share? I know from the spill gained from the participant – the personal deep aspects of their lives that are so tied in with how they perceive and manage their RA on a daily basis. The sharing is so specific and detailed….. Would I share at this level myself? I am not sure….

Barney writes about getting the spill and that the encounters should be short! He would not be impressed by the length of my encounters……….. then again, a lot of time was taken to build the rapport and this has been rewarding.

Figure 7 Memo on Cautioning

After discussing and gaining consent and completion of the biographical data sheet (Appendix 4), I continued with general introductions about the research, the process of the interview and the reasons for looking at perspectives of those who living with RA. I commenced all interviews with a broad request ‘Tell me your story of living with RA’. I listened carefully to the participants story and let them lead the interaction. I jotted key words in my note pad as reminders for probing when appropriate as it would have been inappropriate and impacted upon their relating if I had interjected with probing questions for explanation or clarification while the participant shared. I continued to ensure that respect was maintained throughout the interview and this was possible because I had the intention that each interview was to gain the concern of the participant and not about doing research or gaining another interview.

Following the essential nature of GT the constant comparison commenced with the first interview and therefore specific theoretically focused questions emerged which I weaved into subsequent interviews. In this way, I felt I was not forcing an issue and compromising the openness of GT (Wimpenny & Gass 2000; Gibson & Hartman 2014). Therefore, later interviews could be loosely described as semi-structured, as some of the questions were related to concepts, categories and sub-categories which were being developed by the constant comparison approach. While respecting the participants story, it was important to gain sufficiently rich data to explain what was going on in the substantive area and inform the emerging theory. Being able to concentrate, jot notes down and listen attentively to the conversations was possible only because I had decided to digitally record the interviews.

While waiting in the clinic over the weeks, I made general observations of what was happening such as the environment, the general behaviours of staff and the patients, the communications that took place, the seating arrangements etc. What was interesting is that the seating plan was open, and the area was relatively small which meant that on some occasions there were not enough seats if the attendees were accompanied by others. The attendees made no attempt to communicate with other people and there was very limited communication with the person who attended with them. I decided to compare my observations to other health related clinics. When the core category had emerged, I observed in other areas where people were waiting –e.g. the train station waiting for the platform to be announced and the dentist waiting room. In observing I ensured that my presence and behaviours could not be noted by others. I made field notes on my observations. These field notes I included in data analysis. Latterly the observations were to look for general relevance outside of the RA substantive area.

Initially I considered that general observations and interviews would give sufficient data. The publication of the book *My RA Story* which contains the stories of 43 people in Ireland who live with RA decided were important to include (Lynch 2019[15]). The stories were used as more data and were coded and included in the comparative analysis.

The interview is an important focused intentional interaction for both the researcher and the participant (Mason 2018). To facilitate the process, I had a checklist of items to be attended to prior to each interview, which enabled me to relax into interviewing and be confident that the participant was given the best chance of total participation. I desired that the participants would be relaxed to share and therefore having the environment safe and comfortable was important. I also considered that if I was relaxed and comfortable this too would support the

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[15] This book is the 1st publication about RA completely written by people who have the condition and therefore is significant.

participants in sharing. The digital recording of interviews enabled me to focus on what the participants were saying and, as I was actively listening, I was able to respond more harmoniously with what they were relating. The attentive listening enabled me to focus on how the participants were describing their life and hearing the words they used enabled me to capture the meanings (McVey *et al*. 2016). Initially I did not know what they were going to share or what I was looking for, so I was keenly focused in early interviews. However, I was aware of this and attempted not to let this impact upon the sharing. As the interviews progressed, I had some ideas from the ongoing analysis of some aspects that I wished to find out about. The active listening enabled me to bring these aspects into the conversation in a natural way. At the same time, I was acutely aware that I did not want the conversations to become an interrogation of their life with RA or to control in a way that would constrain the participants (Mason 2018). It was achieving the balance between an everyday conversation and an intentional focused conversation of gaining their experience in a meaningful way which respected their life with a chronic condition that was important. It was this focus of the interview and the skills of communicating that brought, I believe, sincerity to the interview process. This encouraged the active sharing of the participants.

The interviews were well spaced to give time to the ongoing analysis. Mitchell (2011) refers to the emotional impact of interviews, which was one aspect which I had not really considered previously. In reality the sharing did have an emotional impact and I had to identify time for activities to deal with my emotional responses (discussed later in this chapter).

Digital recording of Interviews

I was aware of the arguments put forward by Glaser for not recording of interviews (Glaser 1998). Nevertheless, I lacked confidence in my ability to listen, concentrate and jot down notes during interview conversations. Interestingly others do not agree with Glaser and advocate recording (McVey *et al.* 2016). I felt confident that I had sufficient skills for using a digital recording device. However, I was apprehensive that the participants might experience fear in relation to being recorded. Therefore, I gave detailed information that access to recordings would be researcher only and following the writing of field notes they would be disposed of. This reassurance was sufficient as all participants consented to being recorded. Initially I decided to transcribe recordings. The interviews were time spaced to permit completion of transcription and also ongoing analysis. At the end of eight interviews, I was overwhelmed with codes and potential concerns. Having gained insights alluded to earlier I put aside the transcriptions and listened to the recordings and wrote field notes. This listening anew to the recordings was helpful in the constant comparison process. In Interviews 8-29 I continued to digitally record but wrote field notes only. Memos were written after each interview. My experience is an example of what Glaser (1998) warns about in his writing about recording and transcribing. He advises researchers that such practices lead to a false sense of security about capturing all the information and also generate an overwhelming amount of data which would not support a developing theory. Having endured the consequence, I learned an important lesson. Writing field notes supported the development of abstraction from the story to conceptualise what was happening in the data.

Data Management software

There is much debate about the usage of data analysis software packages in GT (Glaser 1998; Bringer *et al.* 2006; Liamputtong 2009; Holton 2010; Gibson & Hartman 2014; Holton & Walsh 2017). There are a number of packages including ATLAS.ti, QRS NVivo, Ethnograph, and MAXqda. The main contention with their usage is that the design of the packages restricts the researcher in the analysis and can force the data in a particular way, which is antithetical to GT. But as Gibson and Hartman (2014) maintain, software packages have evolved and are much more flexible in how they can be used. I had some experience at using NVivo previously and I considered that it would be a very useful tool for managing the data and documenting the analytical process. I undertook a training course to reacquaint myself with the programme and to update my skills. I envisaged having lots of Word documents with copious notes in margins and becoming overwhelmed amidst all the data and analysis. I was concerned that when doing the constant comparison of codes, concepts, memos and properties, I would not be able to make any sense of what I was doing. I was cognisant of the importance of staying open and letting the data lead the analysis. Therefore, I decided to use the NVivo Pro 11 software package. I was comforted by the fact that I would not lose any work and very importantly I could print work for hard copy analysis. While I would complete a lot of my professional work via different computer applications, I confess that I also like hard copies to read and browse over. I uploaded the field notes into NVivo and was able to code freely (node[16]). Each node was given a description which enabled other words or lines of data to be linked if the meaning was the same, or to be coded under another or new node if the constant comparison indicated. Being able to write descriptors of the nodes was important and assisted in developing the analysis and discovering what was a code, a property of a code or a category. Within NVivo I found it easier to compare pieces of data that were within a code, or property, or category. I found it easy to link a memo to a piece of data or code, or property and also to be able to write new memos. In reality I found that I printed off a lot of material and

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[16] Node is the NVivo term for code.

then wrote memos upon them which I later exported as pdf files to NVivo. Similarly, I recorded memos everywhere and these were in different formats. At the earliest opportunity I put these into the NVivo either as soft notes or exported as MP4 files onto NVivo. Memos which were digitally recorded, I later transcribed as it was easier for the constant comparison to have written text. Having read how Bringer *et al.* (2006) utilised NVivo I consider that my usage was very limited in comparison. However, I gained confidence that my work was safe, I could access previous work at any point, and the dates and times of work completed were automatic.

Main Concern and Core Category

I rigorously applied the inductive and deductive iterations associated with GGT, but I was quite unsure what I was doing initially. While I was still looking for the main concern, I sampled using the variants of the purposive sample[17] but none of these varied the concepts and categories. Gibson & Hartman (2014) advise that characteristics may be used provided that openness to other sampling is continued. Data from observations and the literature[18] were used as more data (data slices[19]) and assisted in keeping the openness required to gain multiple perspectives and variation in accordance with Glaser's "all is data" dictum (1998). Concerns did emerge and when they did not pattern out in the data, I realised they were not the main concern of all the participants (Appendix 5[20]). They were concerns of some of the participants, but not the main concern. According to Holton and Walsh (2017) the main concern must be allowed to emerge from the data and not from any pre-conceived ideas. When the main concern *Fear of Declining Self-Worth* emerged, I was elated and felt I could progress.

When the main concern i.e., the *Fear of Declining Self-Worth* was evident, I then focused on gaining clarity about how the participants were resolving this concern by identifying the core category. In essence the categories I had identified seemed to be pointing in one direction and on two occasions I felt I knew how the main concern was processed. So initially I considered that the participants were resolving the main concern by 'appeasing a frenemy' and then later I thought it was 'accepting the self'. In essence I had a doubt about these early categories, and it was not until I returned to the data and began to selectively code with the aim of achieving saturation that I knew they may be a category, but they were definitely not the core

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[17] From the biographical data collected I was aware of some characteristic variation in the purposive sample (age, gender, civil status, employment status, no of years diagnosed with RA, treatment information, geographical location).

[18] This refers to the publication of accounts of living with RA written by people who are living with the condition (Lynch 2019).

[19] Data slices and Data slicing is a technique that is used to identify where to go next to collect data. It can also be used to "create thought experiments with emerging categories to enable the researcher to test the general relevance of a category" (Gibson & Hartman 2014, p. 243).

[20] Memo exemplar identifying some early considerations of the main concern.

as they did not fit or have what Glaser (1998) refers to as “conceptual grab”. These categories did not bring the fractured parts of the story back together again, but I knew they were a part of the theory. This became more evident with the continuing analyses as I achieved more doubt about the core category I had identified (Appendix 6[21]).

As I continued with the constant comparison, I theoretically sampled with specific questions with further participants to saturate concepts and identify any new concepts. Theoretically sampling, memoing and sorting of memos assisted in the identification of the core as *Negotiating Self-Worth* and the identification of properties. *Negotiating Self-Worth* made sense, it fitted with the data and worked in that it accounted for most of the variation in behaviours conceptual indicators and, as Glaser (1978) emphasises, it processed the main concern. Now at last it made sense *Negotiating Self-Worth* related to other categories.

Coding

Open Coding

In the initial stages I understood that coding involved a fracturing of the story of the participants into incidents of behaviours i.e., focus on the action and what participants were doing (Gibson & Hartman 2014) This involved line by line coding. Glaser (1998) specifies three questions that analysts should use when coding data:

1. What is this a study of?
2. What category does this incident indicate?
3. What property of what category does this incident indicate?

I analysed the text line by line and identified labels for each piece of text. I had an enormous number of rather random codes which, while linked to pieces of data, were not making much sense. While I was memoing and trying to compare, I did not feel that there was much more clarity. I wrote the questions on A3 paper and put them on the wall in the hope that, somehow, I would understand more. Attending a GT seminar in 2018 I came to realise two important aspects. Firstly, Glaser did not intend literal line by line coding of field notes. Secondly, my codes were voluminous, descriptive, and reflective of the story of the participants (McManus 2018). These points are discussed by Glaser (1992) but somehow, I had not understood the significance of incidents as action behaviours, i.e., what the participants were doing. Line by line coding of verbatim transcripts had kept my analysis at a descriptive level and resulted in

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[21] Appendix 7 is a typical memo reflecting the thinking that was going on regarding the core category.

over conceptualization. I gained a fresh understanding that coding of incidents was important, not the line by line coding that I had become so diligent in doing. This was confirmed by Glaser (1992) when he wrote:

> during open coding the analyst starts with (1) line by line analysis (2) sentences or paragraphs, or (3) entire document. It depends on the type of data collected, the variation in data collector's skills, the kinds of interviews or observations etc, and the density /thinness of ideas in the data (p. 48).

The diligence in coding was reinforced by the fear of missing something important and my lack of trust in the analytical method. The verbatim transcription of interviews added to the confusion. Analysis in GGT is not a descriptive analysis but is a conceptualising of behaviours in codes, i.e., incidents of behaviours (Holton & Walsh 2017). As Gibson & Hartman (2014) affirm, it is the action in the excerpts that is being sought and, therefore, coding larger chunks of data may give the distance to be able to name the action. Another important feature identified by Gibson & Hartman (2014) was to code in many different ways, which helps to gain variation in the codes, concepts and categories. With these new insights I began to write field notes on interviews completed and code the incidents of behaviour. Memos recorded ideas about the coding and the comparisons of codes and indicators of codes. I was conscious of maintaining theoretical sensitivity and the endeavour to become more conceptual in coding (Holton, 2010). The coding in different ways assisted me in becoming more conceptual. I found questions posed by Glaser (1978) as helpful in maintaining theoretical sensitivity:

> What is happening?
> What is the data indicating as a main concern?
> What accounts for how the concern is resolved?

I discovered that as I continued to compare codes I was also renaming, and the codes were becoming more conceptual. The initial codes were not wrong. They were becoming more abstract and, therefore, needed more fitting labels (Elliott & Jordan 2010). The renaming of codes led me back into the data to look for other incidents and this assisted in the development of conceptual ideas about properties and categories. This process also signalled what data I was being sensitive to and where to look for more data. Furthermore, the interviews were becoming more focused with intense listening and comparisons to the data analysis completed. At the same time my categories were becoming refined and I felt were capturing most of the variation in the data. Iteration was quite a complex process. I had to trust amidst all the confusion the advice reiterated many times by Glaser (1998). Interviewing, coding, constant comparing and memoing continued. I could see the patterns of behaviours were indicating concerns. I was conscious of avoiding any forcing of my ideas onto the data. In hindsight I really did not initially understand what forcing really meant for this study, although the obsession supported my focus on the data.

Theoretical Coding

Theoretical coding was yet another challenge to understand. I think it was the term theoretical coding that increased my confusion. The reference to coding families did not help and no matter how many times I read Glaser (1992) I could not make much practical sense of it. I understood some but the practical application was elusive. I did understand that a theoretical code was what linked the aspects of the theory together into a whole (Hernandez, 2009). While up to this point the focus was on fracturing the data, theoretical coding is the point that Glaser (2009) refers to as bringing the data together again in a way that it is understandable by a wider audience.

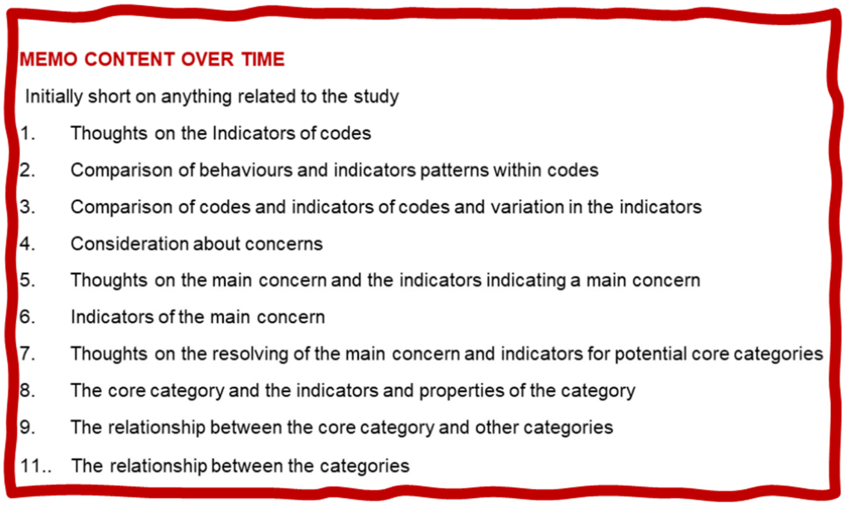
It was from this viewpoint that I started to sort memos and considered how the aspects related to one another, that is, how the concepts linked, the categories and what relationships made the different categories and concepts link together. Appendix 7 includes some diagrams revealing early attempts to establish theoretical relationships. These examples have some memos included to reveal how I juggled and struggled with identifying theoretical codes. In the sorting I realised that some of the concept labels needed further work and more clarity was needed in relation to properties and dimensions of categories. The fit did not seem right. At this point I was really conscious of remaining open and not forcing any theoretical framework upon the data. I returned to memos and field notes and theoretically sampled further for properties. Thus, I refined the categories and their properties and deleted what was not relevant. I also wondered was this delimited the theory which I had vaguely understood from reading. Going back to Glaser & Holton (2007), I gained more understanding of delimiting and realised that confining sampling and constant comparison was delimiting the theory and an important part of solidifying the theory.

I returned to sorting memos and deliberating on theoretical codes several times and eventually I established that this was a process theory, involving various stages. Critical junctures were reached, and this meant that the individual progressed to the next stage. Theoretical coding forced me to consider more clearly the critical junctures and how a person might progress in a stage. I still felt that something was missing. I was naming many conditions inappropriately which confused the process, making it very cumbersome and also unclear. It was at this point that I understood that the staged process took place only within an *Awareness Context*. Once this was recognised, I then was able to identify the typology of *Awareness Context*, the dimensions of disclosure and further specify the relationships between *Awareness Context*, disclosure and psychological states. The stages of the process and the critical junctures became clearer. More than one theoretical code was evident, but I considered the strongest theoretical code to be a Basic Social Psychological Process.

Memo Writing

Memos have an extremely important role in the development of theory (Gibson & Hartman 2014). Glaser (1998) states one golden rule for memoing and that is that the analyst interrupts whatever they are doing to memo. I engaged in memo writing from the outset of the study and recorded memos on anything related to the study but initially I did not really have any firm ideas about what the content should be. After attending the first GT workshop I gained some more insight into what the content of memos might be. Memos can be in any format as long as they are recorded (Holton & Walsh, 2017). Inserting the date, time and a heading enabled me to revisit the same memos later and make additions which reflected the continuing analysis. I carried paper, a pen and a digital recorder on my person so I could capture thoughts and ideas as they occurred to me.

Initially memos were short and descriptive with some ideas of possible participant concerns and ideas for exploring in subsequent interviews. From the hesitant recording initially, I advanced the memo writing on various dimensions of the analytical process which I have attempted to outline in table 5.



MEMO CONTENT OVER TIME

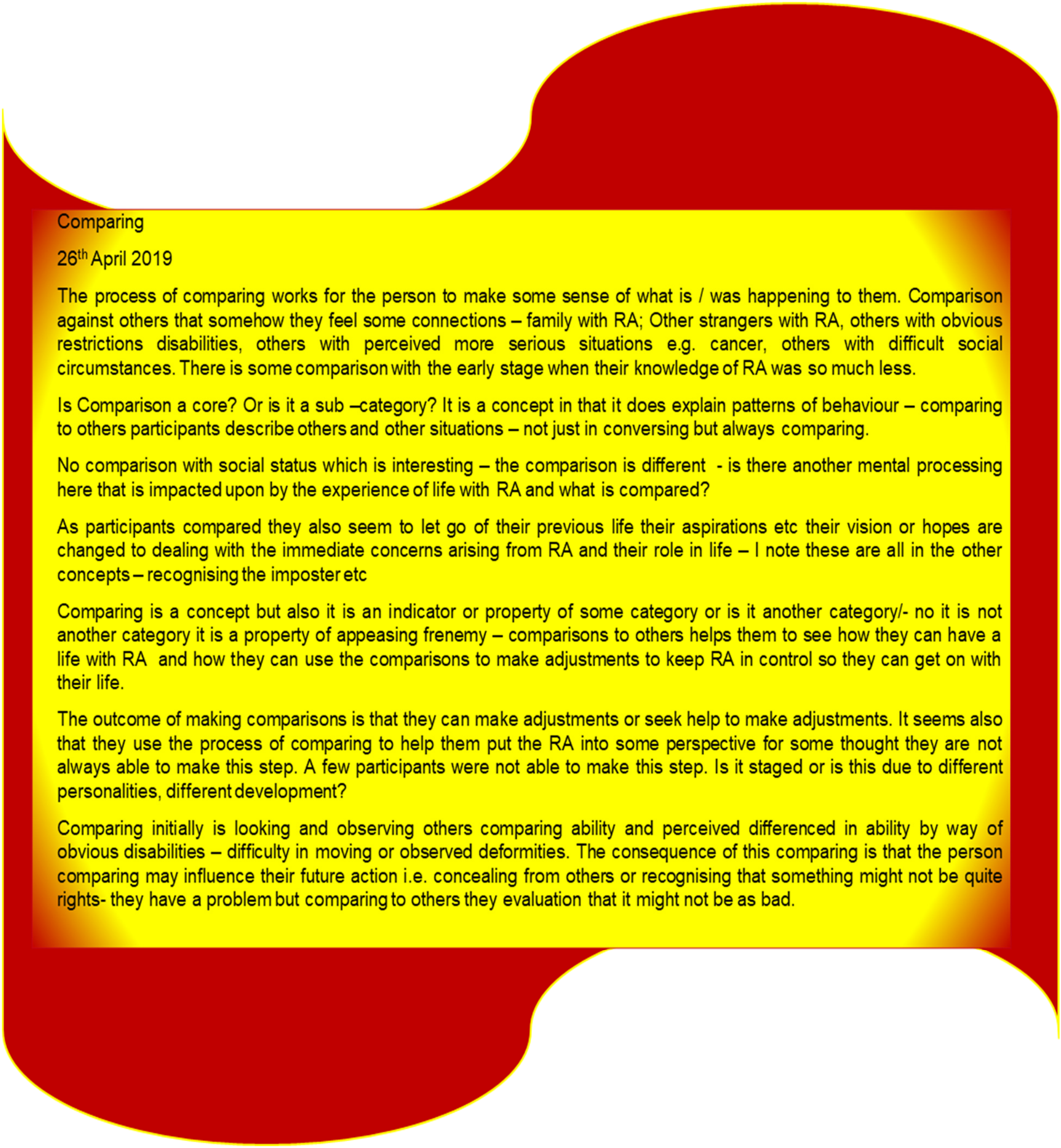
Initially short on anything related to the study

1. Thoughts on the Indicators of codes
2. Comparison of behaviours and indicators patterns within codes
3. Comparison of codes and indicators of codes and variation in the indicators
4. Consideration about concerns
5. Thoughts on the main concern and the indicators indicating a main concern
6. Indicators of the main concern
7. Thoughts on the resolving of the main concern and indicators for potential core categories
8. The core category and the indicators and properties of the category
9. The relationship between the core category and other categories

11.. The relationship between the categories

Table 5 Memo writing development

Some early memos (figures 8, 9, 10) illustrate some of the thinking that was happening during the constant comparison. The memos called Comparison and Pillaging illustrate the thinking as I compared indicators and codes. I was unsure what the indicators were indicating, and the thinking was attached to the story of the participants.



Comparing

26th April 2019

The process of comparing works for the person to make some sense of what is / was happening to them. Comparison against others that somehow they feel some connections – family with RA; Other strangers with RA, others with obvious restrictions disabilities, others with perceived more serious situations e.g. cancer, others with difficult social circumstances. There is some comparison with the early stage when their knowledge of RA was so much less.

Is Comparison a core? Or is it a sub –category? It is a concept in that it does explain patterns of behaviour – comparing to others participants describe others and other situations – not just in conversing but always comparing.

No comparison with social status which is interesting – the comparison is different - is there another mental processing here that is impacted upon by the experience of life with RA and what is compared?

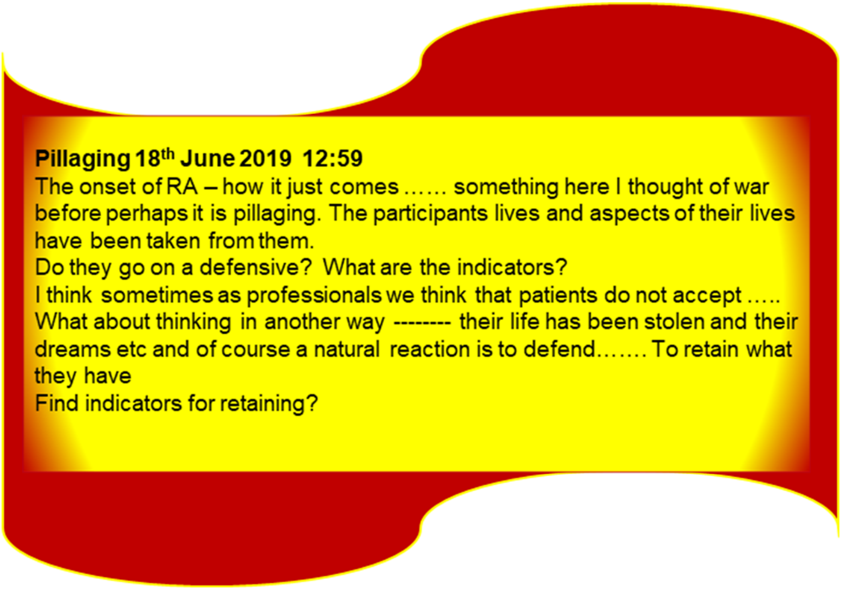
As participants compared they also seem to let go of their previous life their aspirations etc their vision or hopes are changed to dealing with the immediate concerns arising from RA and their role in life – I note these are all in the other concepts – recognising the imposter etc

Comparing is a concept but also it is an indicator or property of some category or is it another category/- no it is not another category it is a property of appeasing frenemy – comparisons to others helps them to see how they can have a life with RA and how they can use the comparisons to make adjustments to keep RA in control so they can get on with their life.

The outcome of making comparisons is that they can make adjustments or seek help to make adjustments. It seems also that they use the process of comparing to help them put the RA into some perspective for some thought they are not always able to make this step. A few participants were not able to make this step. Is it staged or is this due to different personalities, different development?

Comparing initially is looking and observing others comparing ability and perceived differenced in ability by way of obvious disabilities – difficulty in moving or observed deformities. The consequence of this comparing is that the person comparing may influence their future action i.e. concealing from others or recognising that something might not be quite rights- they have a problem but comparing to others they evaluation that it might not be as bad.

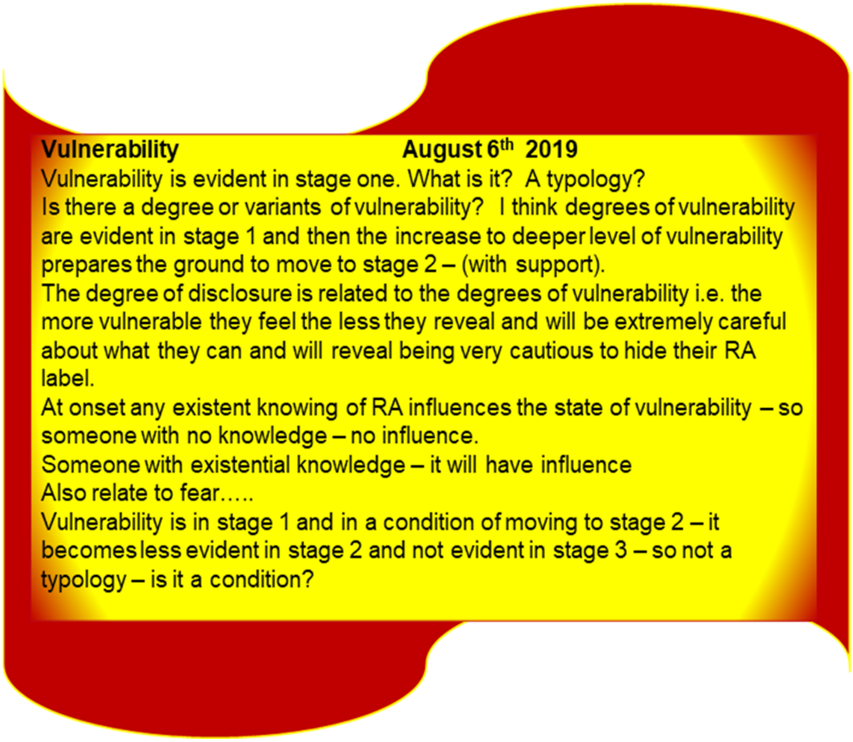
Figure 8 Memo on Comparing



Pillaging 18th June 2019 12:59
The onset of RA – how it just comes …… something here I thought of war before perhaps it is pillaging. The participants lives and aspects of their lives have been taken from them.
Do they go on a defensive? What are the indicators?
I think sometimes as professionals we think that patients do not accept …..
What about thinking in another way -------- their life has been stolen and their dreams etc and of course a natural reaction is to defend……. To retain what they have
Find indicators for retaining?

Figure 9 Memo on Pillaging

In the following memo entitled Vulnerability I was exploring vulnerability but as is evident my ideas around it were quite vague.



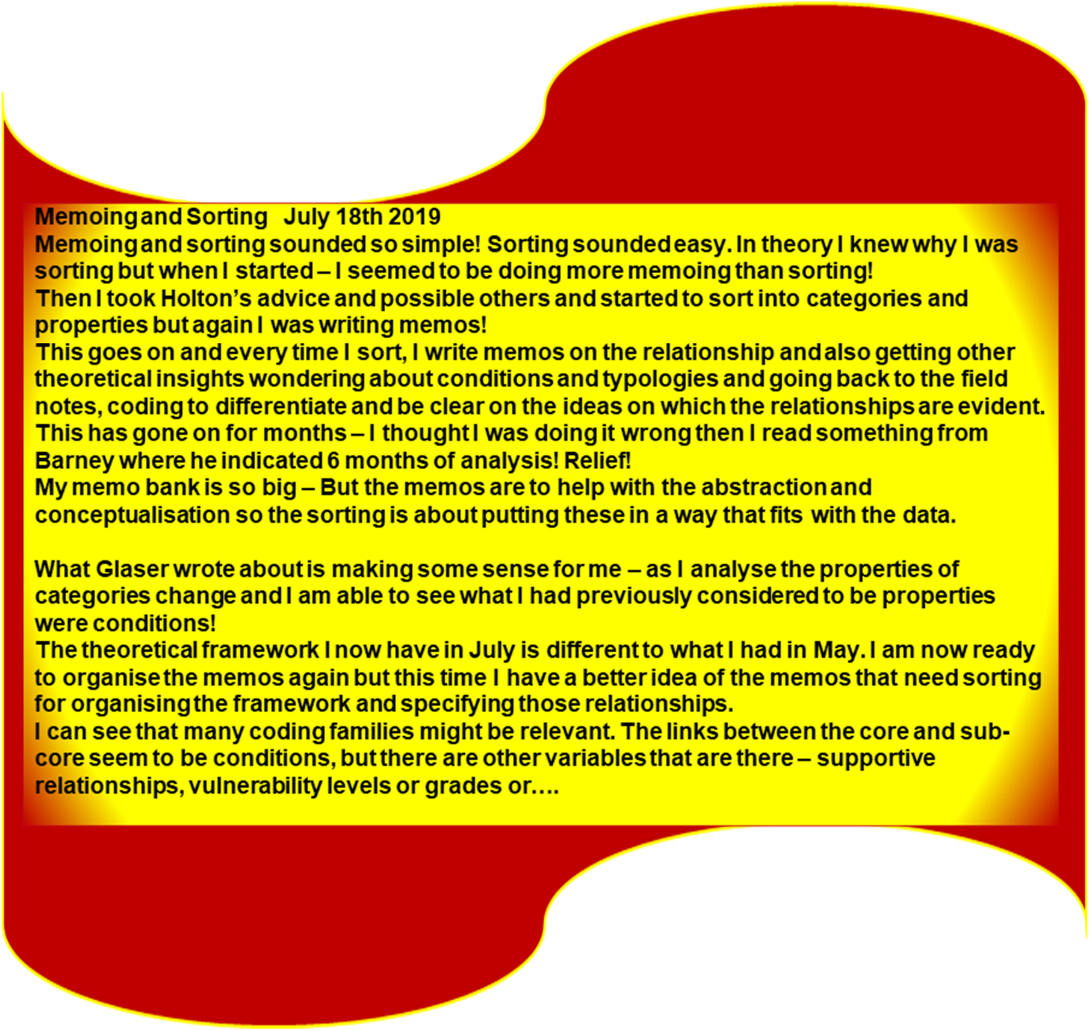
Vulnerability August 6th 2019
Vulnerability is evident in stage one. What is it? A typology?
Is there a degree or variants of vulnerability? I think degrees of vulnerability are evident in stage 1 and then the increase to deeper level of vulnerability prepares the ground to move to stage 2 – (with support).
The degree of disclosure is related to the degrees of vulnerability i.e. the more vulnerable they feel the less they reveal and will be extremely careful about what they can and will reveal being very cautious to hide their RA label.
At onset any existent knowing of RA influences the state of vulnerability – so someone with no knowledge – no influence.
Someone with existential knowledge – it will have influence
Also relate to fear…..
Vulnerability is in stage 1 and in a condition of moving to stage 2 – it becomes less evident in stage 2 and not evident in stage 3 – so not a typology – is it a condition?

Figure 10 Memo on Vulnerability

Memoing also assisted with saturating the categories. Memoing could be described as capturing ideas about the developing theory. However, such ideas needed thinking time to develop hence writing the date was useful for an initial idea but the exploring of the idea in the data and thinking about the idea in terms of social behaviours took time (Glaser, 1978). It was that thinking that took me from the descriptive level to abstraction.

Memo Sorting

Printing and sorting of memos into bundles of concepts and potential categories, enabled me to overcome the challenge I had of identifying the core category. I sorted and resorted many times and as I did, I wrote more memos identifying the theoretical thinking about the data. A memo captures some important aspects about the role and function of sorting.



Memoing and Sorting July 18th 2019

Memoing and sorting sounded so simple! Sorting sounded easy. In theory I knew why I was sorting but when I started – I seemed to be doing more memoing than sorting!

Then I took Holton's advice and possible others and started to sort into categories and properties but again I was writing memos!

This goes on and every time I sort, I write memos on the relationship and also getting other theoretical insights wondering about conditions and typologies and going back to the field notes, coding to differentiate and be clear on the ideas on which the relationships are evident.

This has gone on for months – I thought I was doing it wrong then I read something from Barney where he indicated 6 months of analysis! Relief!

My memo bank is so big – But the memos are to help with the abstraction and conceptualisation so the sorting is about putting these in a way that fits with the data.

What Glaser wrote about is making some sense for me – as I analyse the properties of categories change and I am able to see what I had previously considered to be properties were conditions!

The theoretical framework I now have in July is different to what I had in May. I am now ready to organise the memos again but this time I have a better idea of the memos that need sorting for organising the framework and specifying those relationships.

I can see that many coding families might be relevant. The links between the core and sub-core seem to be conditions, but there are other variables that are there – supportive relationships, vulnerability levels or grades or….

Figure 11 Memo Sorting

Towards the end of the study I had a bank of memos to sort. Having printed the memos, I cut them up and hand sorted around the core category trying to see where the ideas fitted together, that is how the other categories linked to the core category. I recorded memos on the organisation and links between ideas. I used a big room with large tables on which I found it easier to sort the memos. I used a marker and coloured paper to illustrate linkage between ideas and the organisation. I sorted in different ways around the core category, which helped to identify the emergent fit for the theory. This enabled me to see the variations in how the participants processed their main concern.

Learning GGT

My personal experience of applying the tenets of the GGT methodology was extremely challenging. There was no clear step by step process to follow. GGT proved to be very complex and required many processes occurring and reoccurring over the course of the study. I found Glaser's style of writing difficult to comprehend. As I tried to understand particular concepts I skipped between various key texts. This led to some confusion as I gleaned different perspectives on the same aspect. However, I was not to be swayed in my keenness to get a grasp of the methodology. I attended workshops on GT, and this helped in conjunction with the continued reading. However, it was not until I had started this study and brought some of the initial work to a GT Trouble Shooting Seminar that the nuances of the methodology began to really make sense. Over the course of this study I have attended five further workshops, which have increased my understanding and, I hasten to add, an appreciation for the writings of Glaser with which I struggled in the earlier years.

Ethical Dimensions

The Declaration of Helsinki, 1964 was the first guideline that identified ethical issues as important when considering a research study (Malik & Foster 2016). While these guidelines (and the updated versions) were to specifically support ethically responsive scientific research, they were the basis upon which other professions considered ethical dimensions of investigations involving human beings. These same principles governed the conduct of this study, that is, beneficence, non-maleficence, fidelity, justice, veracity and confidentiality (Beauchamp & Childress 2001). The researcher has the personal responsibility to apply the principles in a robust manner (Hammersley 2015). Guillemin & Gillam (2004) concord and argue that a robust ethics application supports the researcher in acknowledging cardinal issues but there is also an expectation of identifying and responding to ethical issues that occur in the practice of a research study.

Procedural Ethics

The local Research Ethics Committee (REC) within the geographical area of the RU gave ethical approval in January 2017 with a condition that a progress report be supported annually outlining progress of the study (Appendix 8). Approval was also gained from the Research Ethics Committee of the School of Nursing and Midwifery, Faculty of Health Sciences, University of Dublin, Trinity College in March 2017 (Appendix 9).

When I was completing the ethics application, I found that the participants did not match any of the vulnerability groups, but I considered them vulnerable as they were people who had an auto-immune chronic disease and were sharing their personal experience. Bracken-Roche *et al.* (2017) identified that in many policies governing research ethics consideration of vulnerability is restricted to issues regarding consent, marginalised or stigmatised groups. This leaves the researcher with the responsibility of identifying vulnerability within their own study and being acutely aware of what might constitute being vulnerable from the viewpoint of the participant (Shaw *et al.* 2020a). I was aware that when participants shared this may trigger unpleasant memories which may result in them experiencing stress (Parahoo 2014). Therefore, prior to the study I had sought out contact details for services in various locations that the participants could access. A recommendation was given to one participant. This lady had previously known and used the services and I encouraged her to contact the services again. As I was acutely aware in phone conversations and data collection that the participants were vulnerable, I maintained a heightened awareness throughout for any aspect that might increase their vulnerability or attack their sense of self-respect.

Beneficence

As suggested by Parahoo (2014), I informed the participants that there was no direct benefit from participating in this study, but they may benefit indirectly if the outcomes influence any development in service provision. The participants shared that generally the public have little understanding of RA. They were informed that publications and media interest following study completion may increase public awareness and understanding which would indirectly benefit the participants also. Furthermore, the publication of this study should influence other studies in this substantive area.

I gave a clear explanation of my role as researcher and how it differed from being involved in the day to day working of the RU. This made it easier for participants to understand that their participation would not influence any preferential treatment. Respecting the participants time, I did give a small token of appreciation at the end of the interview. Comments offered freely at the end of the interviews indicated that participants benefited from sharing their experience. I had not really anticipated this.

Non-maleficence

Guillemin & Gillam (2004) refer to the ethical situations that may be encountered in the reality of doing research. It is important that the researcher is always alert to possible ethical challenges in the context or conduct of a research investigation. For example, I observed a silence in the waiting areas of the clinics. Having reflected and reasoned upon this, I concluded that participants might feel vulnerable and exposed. Therefore, I took extra steps to reduce this vulnerability by ensuring that individuals were truly informed that only myself as the researcher would be able to identify them in the study.

I purposefully organised venues for interviews convenient to where participants resided to lessen disruptive travel and the possible consequences of tiredness or pain. In the venues I also requested some measures to increase comfort (heat, refreshment, privacy).

To protect against any misappropriation of data. information was kept in encrypted files with hard copies of consent forms and biographical data in a securely locked filing cabinet only accessible by the researcher. Initially the digital recordings were listened to by a transcriber with whom I had a confidentiality agreement. Later the transcribing was abandoned so the risk was eliminated.

Protection of personal data gained more formal recognition under the implementation of European General Data Protection Regulation (GDPR) 2016/679 (European Parliament & Council of the European Union, 2016) which was implemented into Irish legislation and enacted in 2018 (Government of Ireland, 2018). Commensurate with the requirements of the Data Protection Commission and University guidelines (University of Dublin 2019) a GDPR Impact Assessment was carried out in 2019 to determine the data protections risks in processing personal data and yielded a low risk.

Fidelity

While doing this research I was personally committed to its completion to respect the participants. Equally I was committed as a researcher to being faithful to the method and the process of undertaking an enquiry which was further influenced by my professional values from nursing. The evidence that had accumulated over the course of the study is evidence of completion. An important element of being faithful to the whole process is respecting the participants and myself as a researcher. One of the key issues in respecting participants was gaining consent freely. I felt for this population I had to be vigilant to the possibility that participants may be coerced into consenting. While there was no specific coercion, it was plausible that other factors may have subtly coerced participants (WHO, 2011). Two examples are my professional background as a nurse and the journey to the location to some of the venues. Generally, in Ireland nursing engenders a lot of respect and I did not want participants to feel they had to participate just because I was a nurse. The distance to some locations was two and a half hours drive and this I felt may perhaps have coerced the participants. On meeting at the location, I firstly thanked the participants for giving me a reason to come to that part of the country. At a different opportunity I made the participant aware that many nurses engage in research due to the fact that they learn much from people they nurse, and I was personally thankful for having the opportunity to learn from them about their experience. But their participation in a conversation with me did not mean they had to be part of the research. If participants selected not to be involved, I could access other participants. It was important for me that participants were aware and knew what they were consenting too. Working alone on this research project and travelling alone to isolated areas I followed the Lone Worker Guidelines (University of Dublin 2020).

Justice

Within the Irish context no previous study was found examining the concerns of people living with RA and, therefore, the research was justified. Uppermost in my mind was to respect the rights of the participants. The most salient issue was gaining an informed consent (Parahoo 2014). The participants were given detailed written information about the study and a question and answer sheet, with both written in lay language for clear understanding. Participants who were happy to continue and participate in the research were asked to give written consent (Appendix 10). The consenting process involved re-repeating study information and gaining reassurance that the participants understood what being part of the research involved. They were informed that they could withdraw from the research with no repercussions and that all information shared during the study would remain anonymous. As the initial interviews were transcribed by a person external to the study, a confidentiality agreement was signed to protect against any breeches. In addition, while I took care not to mention any names, I edited the digital recordings to remove the names prior to the transcriber receiving them. A separate verbal consent was gained to digitally record the interviews. Digital recordings and transcriptions, field notes, and analytical data were all encrypted with I alone having access.

Veracity

I informed the participants of the risks and benefits of being involved in the study. For example, I told them that there were no personal benefits to be gained from participating in the study. In participating they would be sharing their personal experience, but the risk attached to this was reduced by the explicit measures I put in to safeguard their anonymity. All publications referring to what was shared in an interview would be anonymised with a number. The participants were informed that they would be given a copy of an abbreviated version of the research report. A post study plan (Appendix 11) includes the presentation of the report. This study was conducted adhering to all research principles. I discovered in listening to the participants that I had to take some time to think about issues. I include some discussion from a reflective diary that I kept which illustrates the impact upon me and how I managed my thoughts.

Personal Aspects

In my early nursing career, I had nursed people with RA. I recalled that those people had a lot of joint problems and pain was a significant issue. I was eager to discover what the issues of concern for people living with RA in the noughties era. A naïve part of me forgot that it was through listening to the story of the person with RA that I would come to understand their concern/s. Initially I found the challenge quite difficult. I found myself reacting to some of the sharing and, while this was a private feeling, it seemed to dominate my thinking afterward. I had the impression that this would perhaps infiltrate the analysis and, therefore, I would perhaps force my views upon the analysis. I took some time to think about the stories I was hearing from participants. This was their story and I was not there to gather their stories or become embroiled in emotions arising from the stories. However, I did have to attend and give time to sort the emotions that were awoken in me in response to what I was hearing from participants. There was one particular interview when a participant was sharing some really difficult times in some detail. In the moments of the interview I asked if she wished to continue or if she would like to abandon the interview. I also offered to turn off the recording device. The participant's welfare was more important that the study at that moment and the recording was interrupted. The participant had some refreshment. I reasoned that as this participant was an adult they were able to make their own choices regarding what they were sharing. I did not need to take any action legally and I was not the participant's therapist. In the moment I could empathise, listen and recognise the difficulties. I had to take some more time afterward to consider why this story and this horrible situation was impacting upon me. I concluded that some people have circumstances and situations arising in their lives that for me seem so unjust, unfair and just horrible. Each adult person has choices to make in their lives and they choose what actions they are going to take. As a researcher my responsibility is to act ethically by respecting the story that is told with active respectful listening and where appropriate to offer contacts for further support.

Another issue which caused me to pause was the eagerness of participants to share their story. This was accentuated against the backdrop of the silence I had observed in the waiting area of the clinics. The eagerness also came through in the interview conversations. I acknowledge that my personal skills may have influenced the sharing and the eagerness to tell their story. Other contributing factors are the holistic, person centred care, authentic caring practices I had observed in the clinic. I do not believe they felt coerced as I had been careful to explain I was not part of the MDT and their participation would not be known by anyone except myself. In this study participants were very clear that society in general did not have any knowledge or insights into RA. Therefore this, I believe, influenced their eagerness to share with the assurance of anonymity and confidentiality.

Conclusion

In this chapter I discussed how I operationalised GGT in this study. Having started out with a clear aim and objectives, the cloud then descended as I tried to understand the coding processes, the constant comparison and memoing! The reality of applying this methodology was supported by participating in workshops facilitated by GT experts. This chapter has been presented in a somewhat linear fashion but the reality of doing coding, constant comparison and memoing has been convoluted and involved many turn arounds as I struggled to find the elusive main concern and then the core category. Sorting memos and resorting and returning to the memoing took time and thought. The memos that have been included illustrate the complex nature of this study. The final part of this chapter dealt with the ethical dimensions of conducting a study with other social beings. Finally, I allude to a vital learning curve for any researcher, that is, all humans are thinking and feeling and therefore the researcher is not disconnected from emotions during studies but do need to practice self-care. The next chapter describes the theory that emerged from the analysis and describes how participants manage their main concern *Fear of Declining Self-Worth.*

CHAPTER 5 MAIN CONCERN AND AWARENESS CONTEXT

Introduction

The previous chapter explained how GGT was operationalised in this study. The next three chapters give detail on the substantive theory that emerged. This chapter provides some discussion on the main concern and the awareness context which are fundamental to the theory of *Negotiating Self-Worth*. The awareness context emerged as the medium through which the core category *Negotiating Self-Worth* was processed. An introduction to the core category is included here as a preface to the discussion on the awareness context. The type of awareness context created and controlled by the participants was influenced by dimensions of disclosure and psychological states. Discussion is provided in this chapter on the myriad of ways by which these aspects influenced the type of awareness created. The main concern for this study remained elusive until there was acceptance of advice given by Glaser (1992) to trust in the process that it would emerge. Eventually the main concern emerged and was conceptualised as the *Fear of Declining Self-Worth*.

Main Concern: *Fear of Declining Self-Worth*

The aim of GT is to produce a theory from data that explains how the participants continually process a main concern. In this study, the main concern as expressed by the participants was their *Fear of Declining Self-Worth* and was processed in a theory conceptualised as *Negotiating Self-Worth*. The aim of this section is to provide an overview of the main concern. *Fear of Declining Self Worth* emerges in response to the participants' understanding of themselves as social entities who interact within a complex meaning filled world (Metz 2002). In this sense, people constructed personal meaning and gained a sense of purpose within the complexity of living (Metz 2016). It is in this process of living that the participants gained some perspectives on their worth and value as human beings (Metz 2002). This purpose was nurtured through social roles and ways of being as social entities within a cultural context. *Fear of Declining Self-Worth* explains how the participants believed that a diagnosis of RA and the perceived limitations of the condition negatively influenced their self-worth, requiring them to respond to protect and maintain their self-worth. For the participants in this study, RA was perceived as a condition that was attached to old age and loss of independence. This meant that once the diagnosis was confirmed, their *Fear of Declining Self-Worth* became more prominent with the participants consciously considering how the condition might impact on their concept of themselves, and also, how they would manage their social roles over time.

As the participants processed the *Fear of Declining Self-Worth*, at certain points they reached critical junctures of *Flux, Vulnerability* and *Secure.*[22] In each of these junctures the participants were confronted by their perceptions of RA, the impact of RA on their life and how they might respond to these personal internal debates.

In brief, the participants' main concern was identified as a *Fear of Declining Self-Worth*. This concern emerged from a definitive clinical diagnosis of RA which was perceived to threaten their worth and value as social beings. The response of the participants was conceptualised in *Negotiating Self-Worth*.

Processing of the main concern[23]: Negotiating Self-Worth

The core category *Negotiating Self-Worth*[24] explains how the participants responded to the *Fear of Declining Self-Worth*. This three-staged process describes how the participants initially went into the psychological state of *Flux* when the RA diagnosis was confirmed, that is, they were confused and in a state of disbelief and that for them, their worst fears had arrived. So, in desperation the participants initially *Insulated Self-Worth* and guarded the self-worth they had by non-disclosure. Non-disclosure masked the challenging experiences that they had, and thus they deliberately reduced possibilities of others gaining knowledge of their diagnosis or their life with RA. This concealing took energy and over time the response led the participants into a psychological state of *Vulnerability*. They had a diminished capacity to deal with the physical, psychological and social impact of living with RA. As the participants worked through their vulnerability within supportive relationships,[25] they moved to *Scoping Self-Worth*. *Scoping Self-Worth* gave them some hope, increased their self-awareness and they began to visualise other possibilities for themselves. Gradually they reached a *Secure* psychological state. In the *Secure* state they continued to increase self-awareness and address the challenges life with RA presented. At this point they have self-worth, and their *Fear of Declining Self-Worth* has resolved.

Negotiating Self-Worth is about carefully managing interactions, and the psychosocial environs within which they occur with the aim of eliminating any negative impact on the participants self-worth. The participants were aware of social interactions and the power of

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[22] A critical juncture is a cut-off point between one stage in the process and another. These are discussed in more detail in the following chapter.

[23] The identification of the main concern *Fear of Declining Self-Worth* required much deliberation as discussed in detail in the previous chapter.

[24] *Negotiating Self-Worth* is discussed in greater detail in the next chapter.

[25] Supportive relationships are a mechanism the PWRA use to manage their *Fear of Declining Self-Worth*.

that medium in conveying knowledge of their life with RA to others. Therefore, the biggest threat to the self-worth was others knowing and the implications of others knowing. This threat was very real. The participants engaged in an internal conflict and responded by entering a defence mode when they protected what they had. In the defence mode the participants engaged in interpersonal negotiation, that is, they haggled and debated about their response. This responding was also influenced by conscious consideration of the power of behaviours within social contexts, that is, they were considering how their behaviours would be perceived and interpreted by others. All of the interpersonal interactions were managed and controlled by the participants by creating an awareness context which I discuss in detail later.

Negotiating, therefore, was a very careful dimension of resolving their main concern and varied according to persons they encountered, the environs they were in and their own psychological state, i.e., *Flux, Vulnerable* or *Secure*. In summary, *Negotiating Self-Worth* was about the participants deliberating on variants of communication and their interpretation and giving in-depth consideration of how they would respond within any particular environ. The response was contingent on the ambience or the atmosphere the participants created. I have named this atmosphere the *Awareness Context*. When the participants created and controlled the *Awareness Context*, they were protecting the self-worth that they did not want to lose. Creating and controlling the *Awareness Context* is what added credibility to their communication. Figure 12 demonstrates the main concern *Fear of Declining Self-Worth* and the processing of this concern in *Negotiating Self-Worth* which were contingent on the *Awareness Context*. The *Awareness Context* could be likened to a base upon which *Negotiating Self-Worth* was supplied with energy. Further discussion of the *Awareness Context* is appropriate at this point.

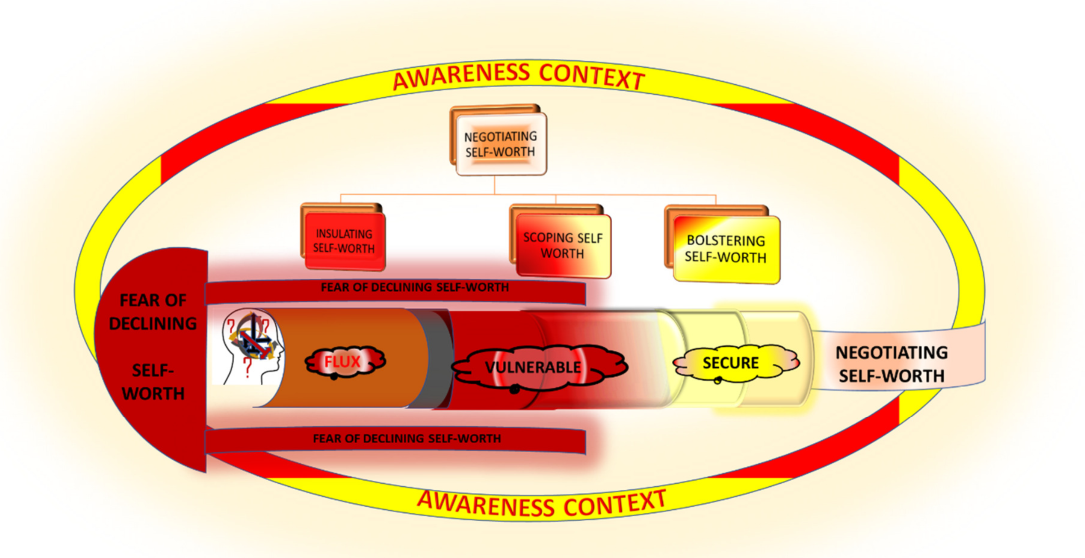

Figure 12 Processing of '*Fear of Declining Self-Worth*' within the Awareness Context.

Awareness Context

Awareness context was first identified by Glaser & Strauss (1965), who described it as a typology through which the findings of their study of dying in hospitals could be explained. The awareness context explained the various social interactions and behaviours of the people (doctors, nurses, family and the dying person) in the situation where a person was dying in hospital. In an earlier publication, Glaser & Strauss (1964) outlined the different types of awareness contexts and illustrated the variation and dynamic development of social interaction observed with different personnel in the hospital context. The four types identified were Open, Closed, Suspicion and Pretense. In a similar fashion, the awareness context of this present study explains the psychosocial behaviours of the participants as they processed their main concern *Fear of Declining Self-Worth*.

The participants had symptoms or features of RA that were not obvious to others. However, their ways of living and being may have suggested a health problem. The awareness context was the ambience or atmosphere that was created and controlled by the participants and was their attempt to be in control of the knowledge that may be attained by others. It was in the awareness context that the participants interpreted what was happening and based their behaviours on that interpretation. The participants response was an attempt to control information about their life with RA being available to others. Disclosure was regarded as the biggest threat to their self-worth and the participants carefully decided how and to whom they would reveal they had RA, as well as the amount and type of information that would be given. So, the participants controlled the information disclosed at any point in time to other people by creating an awareness context. The dimensions of the awareness context are closed, limited or open.

Closed Awareness Context

In the closed awareness context, there was no personal disclosure and the participants masked or concealed all personal knowledge. The participants were alert to the psychosocial behaviours that might indicate any knowledge of the self to anyone and discriminated between individuals to ascertain why a person might be wanting to know information and what the consequences of knowing might be for them as a person. Where it was judged that a person was ‘snooping’ rather than having a genuine interest in them as individuals, there was no personal disclosure. Equally if a person was perceived to have a limited capacity to understand there was no personal disclosure. There was careful consideration of any verbal or non-verbal communication that might reveal any information about the participants’ diagnosis which was a carefully guarded secret. There was emphasis on creating a veneer to give the distinct impression to others that the participants had no deficits, were healthy and possessed the ability to be self-reliant. This veneer was important regardless of the surroundings, i.e., the home, work or social environment. The veneer was important in masking and concealing the impact of the RA on the participants' human functioning. All the participants' energy was put into masking symptoms and suppressing how they really felt. The consequences were that the participants retained their sense of self and self-respect and furthermore they did not receive pity. Pity was to be avoided entirely as it undermined attempts to retain self-worth and self-respect. The participants perceived that they were viewed as worth less than others when they received pity and they struggled to defend the self-worth that they had. Thus, they decided to function as normal and conceal when they were not able to function to their known previous capacity. Contrarily, non-disclosure resulted in frustration at not being able to fulfil tasks unaided and there were no offers of help. In creating and maintaining a closed awareness context, the participants experienced an increase in symptoms of RA. The psychosocial behaviours contributed to them reaching a state of vulnerability. The closed awareness context was an important background for Insulating Self-Worth[26] which in essence was holding onto the self-worth they have.

Limited Awareness Context

In the limited awareness context, there was selective disclosure. The participants again deliberated about the enquiry about their life from another person. When the enquiry was deemed to come from genuine interest and they perceived that the individual had some capacity to understand, then some carefully selected information was given. The participants felt that they were being listened to and what they had to say was worthy of being heard. In this way they retained their respect and received empathy. They also received genuine offers of sympathy, some offers of help and suggestions for gaining further solutions. The limited awareness context was the background that supported them in *Scoping Self-Worth,*[27] enabling the participants to become more self-aware and gain insights into their own worth. The greatest outcome was that the individual retained a personal vision of being in control, of being capable to do tasks and activities, and had an energy to continue to consider who they were and what their life was about. The experience of all these outcomes contributed to them entering a *Secure* psychological state.

Open Awareness Context

The *Secure* psychological state was a condition of creating an open awareness context. The participants had regained a sense of self-worth and a perspective on RA and their life. There was full disclosure with people who had the capacity to understand and who were genuinely

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[26] Insulating Self-Worth is a sub-core category of the theory and will be discussed in more detail in the next chapter.

[27] *Scoping Self-Worth* is a sub-core category of the theory and will be discussed in more detail in the next chapter.

interested and respectful. These people did not need to know anything about living with RA previously as, through genuine interest and respect, that knowledge would be gained. The participants were open about sharing aspects of their life with RA and that sharing did not impact upon their self-worth. Disclosing was no longer a threat to their self-worth. The participants had made some self-discovery and realised that they were a person who had intrinsic value and that their previous perceptions of RA were distorted and were no longer valid. Their self-worth was more than their ability to do certain activities. They were aware that people differ. Some will be snoopy and have no interest, while others will have a genuine interest but may not be able to fully understand. Others will have a genuine interest and a capacity to actively listen and understand. For the participants the consequences of full disclosure with people who were respectful and had investment in them was that their respect was retained. Having investment in them meant having genuine empathy and interest in achieving the best for the participant. In this relationship the participants were honest about how life was and gained empathy, sympathy or support that enabled them to address challenges. In the spirit of respect and authenticity individuals also challenged the participants and supported them in addressing aspects of their living that may not be helpful. Consequently, the participants gained support to make changes that brought some advantages.

In the open awareness context, the participants were Bolstering Self-Worth[28]. With the self-awareness they had gained and in conjunction with supportive relationships, they were cementing the newly found self-worth and establishing it firmly for themselves. For example, one participant spoke about trying to do recommended exercises and found it tough to keep doing these every day. She was neglecting this important aspect of living with RA. She did not have the confidence to go to the gymnasium. Her friend went with her a couple of times and they both could see the benefit for the participant. Then her friend suggested she join a class and go on a regular basis. It was with the support of her friend that she was able to have the confidence to join and continue. Another participant shared that she was restricting herself to home and this was increasing the tension and anxiety of living with RA. She loved music and her friend explored options with her to further this love. She discovered a Pipe Band in another town and with the support of her friend she explored possibilities. She now plays a flute in the band and while she enjoys the music it is also benefiting her fingers with exercise. Table 6 below summarises the details of the type of awareness context created, the judging criterion and the consequences for the PWRA.

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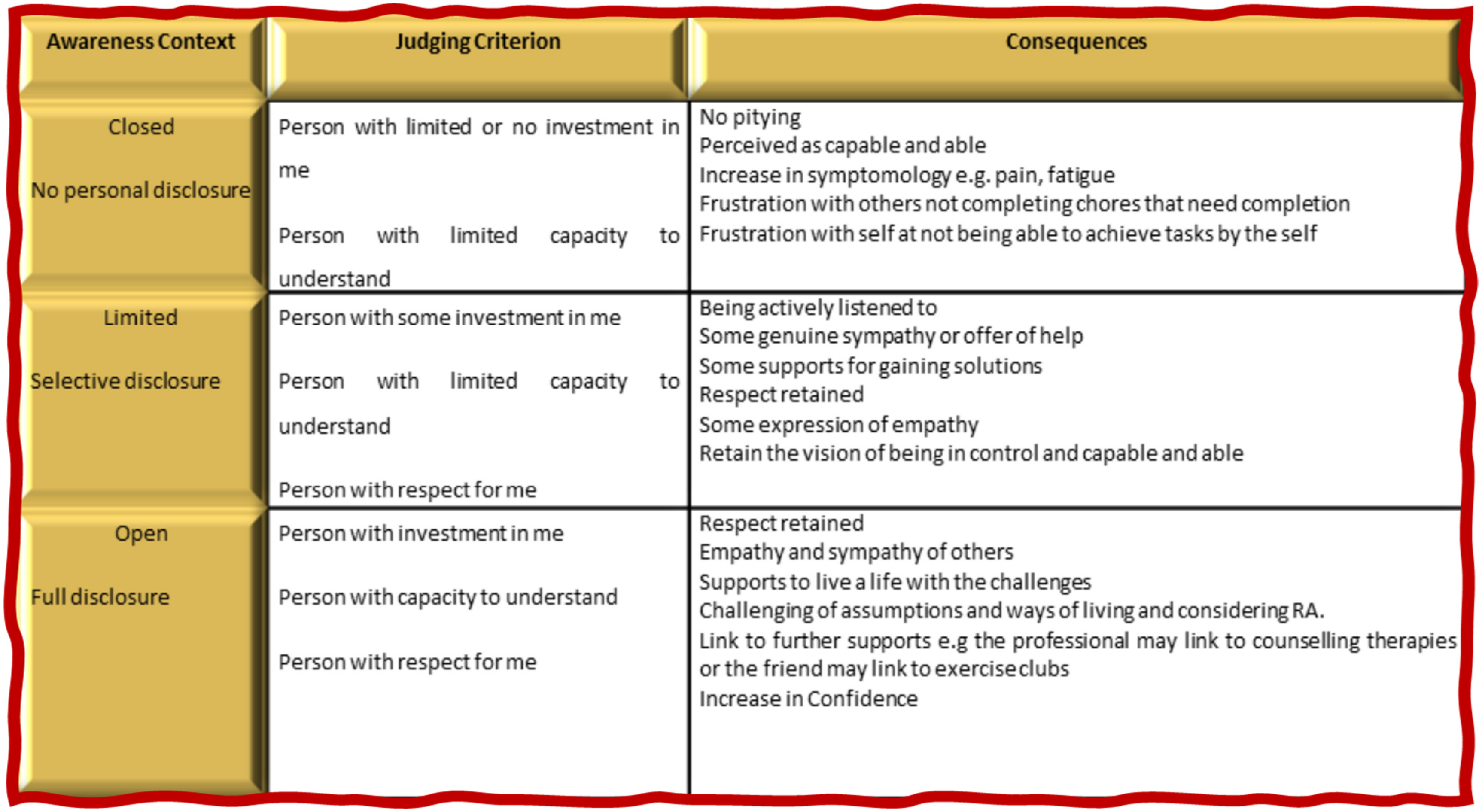
[28] *Bolstering Self-Worth* is a sub core category of the theory and will be discussed in detail in the next chapter.



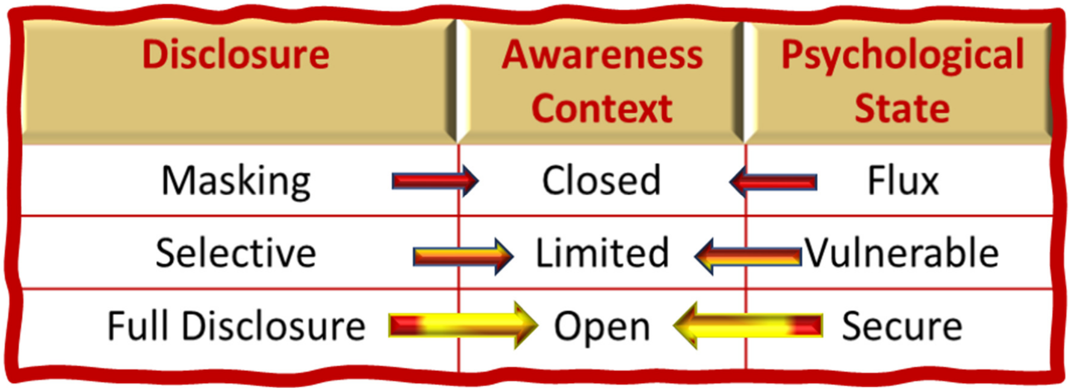
Awareness Context	Judging Criterion	Consequences
Closed No personal disclosure	Person with limited or no investment in me Person with limited capacity to understand	No pitying Perceived as capable and able Increase in symptomology e.g. pain, fatigue Frustration with others not completing chores that need completion Frustration with self at not being able to achieve tasks by the self
Limited Selective disclosure	Person with some investment in me Person with limited capacity to understand Person with respect for me	Being actively listened to Some genuine sympathy or offer of help Some supports for gaining solutions Respect retained Some expression of empathy Retain the vision of being in control and capable and able
Open Full disclosure	Person with investment in me Person with capacity to understand Person with respect for me	Respect retained Empathy and sympathy of others Supports to live a life with the challenges Challenging of assumptions and ways of living and considering RA. Link to further supports e.g the professional may link to counselling therapies or the friend may link to exercise clubs Increase in Confidence

Table 6 Details of Awareness Context

In summary, GT aims to identify the main concern in a substantive area. For the participants in this study, their main concern was identified as *Fear of Declining Self-Worth* which materialised because of a challenge to their understanding of themselves as social beings. The arrival of RA challenged their purpose and brought them into a confused state. The sociocultural meaning attached to RA was of disability and loss of independence. These perspectives along with the symptoms were perceived to have a negative influence on the participants self-worth. The confirmation of their diagnosis made the *Fear of Declining Self-Worth* very real. The processing of the main concern was conceptualised in the core category of *Negotiating Self-Worth.*

Negotiating Self-Worth is a three-staged process operationalised in an awareness context and explains how the participants defended their current perceived self-worth, scoped for new self-worth and finally bolstered their self-worth. One dimension of *Negotiating Self-Worth* was identified as disclosure. Disclosure was regarded by the participants as revealing their vulnerability and lack of self-reliance. The process of *Negotiating Self-Worth* was contingent upon the participants creating and controlling an *Awareness Context*. The *Awareness Context* was a carefully constructed medium through which the participants decided what knowledge of their life with RA was going to be revealed and to whom.

The type of awareness context created was dependant on the psychological state of the individual i.e., *Flux, Vulnerable* or *Secure*. In the closed context the participants were in psychological state of *Flux* and the goal was to conceal their life with RA and defend their self-worth. They did not reveal any of their life to avoid pity or be viewed as unable or incapable. Concealing resulted in negative consequences for the participants. They did not get the supports they needed and consequently living became too much, their reserves were depleted, and they became vulnerable. However, with the support of relationships with others they progressed to scoping their self-worth, which is the second stage in the process. They created a limited awareness context where they shared in a very narrow way initially and gradually as they began to experience positive consequences they shared some more. The sharing remained somewhat limited. However, as self-awareness increased they gained insights and confidence in sharing aspects of their life with RA. At this stage the participants were becoming more informed about RA and could visualise a life with RA and they began to feel more secure. In this secure state they could visualise a life while having RA. They created the open awareness context when they shared more openly about their life with RA. The participants' sharing remained careful but not because they wished to mask reality but rather because they decided that sharing would benefit themselves or their listener. The participants realised that they had worth and that previous perceptions were thwarted with misconceptions about life and living. They set about living and maintaining their new-found self-worth. Table 7 captures the link between Awareness Context, psychological states and disclosure.



Disclosure	Awareness Context	Psychological State
Masking	Closed	Flux
Selective	Limited	Vulnerable
Full Disclosure	Open	Secure

Table 7 Links between Awareness context, psychological states, and disclosure

The awareness context is the medium through which the participants processed the main concern. The type of awareness context the participants created was dependent upon the psychological state and influenced the disclosure that was engaged in. So, for example, if an individual is in a state of *Flux,* they created a closed awareness context that revealed no personal information. They manipulated the environment to create a pretence that they were self-reliant. They masked any features they were experiencing.

This chapter discussed the main concern of the participants *Fear of Declining Self-Worth* and the continuous resolving through *Negotiating Self-Worth*. The awareness context was acknowledged as the medium through which the participants processed their *Fear of Declining Self-Worth*, i.e., *Negotiating Self-Worth* was understood only within the medium of an awareness context. The type of awareness context created was further influenced by the *Flux, Vulnerable* and *Secure* psychological states. Decisions on disclosure were influenced by judgment of the individual with whom the participants were interacting, the context of interactions and the consequences of the disclosure on themselves. The next chapter will detail the overall theory and provide more substantial detail on the core category. The substantive theory is contingent on the awareness context.

CHAPTER 6 THEORY OVERVIEW AND CORE CATEGORY

Introduction

In the previous chapter the main concern of the participants was identified as a *Fear of Declining Self-Worth* and this was resolved in a process conceptualised as *Negotiating Self-Worth.* It was also established that *Negotiating Self-Worth* emerged as a process operated within a medium of an awareness context. Three different types of awareness context were created and controlled by the participants with disclosure and psychological states of flux, vulnerable and secure being the drivers for the type of awareness context created. In essence the theory of *Negotiating Self-Worth* operates from the foundation of the awareness context.

This chapter provides a discussion of *Negotiating Self-Worth* which is the GT that emerged in response to the participants' main concern. This substantive theory explains how the participants continuously processed their F*ear of Declining Self-Worth*. The theory is varied by stages, and categories, which enable it to be classified as a multivariate theory. The construct of a Basic Social Psychological Process (BSPP) explains how the patterns of social and psychological behaviour varied over time and how the participants having reached a critical juncture move from one stage in the process to another.

The Theory of Negotiating Self-Worth: Theoretical Explanation

The theory of *Negotiating Self-Worth* gave meaning to the latent patterns of behaviour which addressed their *Fear of Declining Self-Worth* and, therefore, can be called an explanatory theory. During the process of constant comparative analysis, it became evident that the latent patterns of behaviour were influenced and governed by various social and psychological processes and, therefore, the theoretical explanation may be termed as a Basic Social Psychological Process (BSPP). The term negotiating was chosen as reflecting the journey of the participants from the *Fear of Declining Self-Worth* to protecting and scoping self-worth, and subsequently having made a discovery of self-worth becoming skilled in maintaining and nurturing their discovery in *Bolstering Self-Worth*. The *Fear of Declining Self-Worth* did not arrive at a particular moment but began to emerge when a diagnosis of RA was suggested by their GP. This was sufficient to engage the participants in considering and ruminating upon the sociocultural meanings that they held regarding RA. When the diagnosis was authoritatively confirmed the main concern of *Fear of Declining Self-Worth* was pronounced and the participants questioned their worth as social beings. The theory of *Negotiating Self-*

Worth explains how the participants processed this main concern. The participants had no map or guide to assist them. It was an individual journey in which they as social beings engaged with the unknown. What participants had at the beginning of the journey was their own sociocultural understanding, which was that RA would negatively impact upon their self-worth. The theory describes the journey of *Negotiating Self-Worth*. This journey could be compared to a travel expedition to an unknown reported dangerous territory with varied directions from different people. Journey time would be unknown, and individuals experienced various encounters along the way, with safe arrival dependent on individual interpretation and engagement on route. Whatever directions were gained prior to commencing the journey, the apprehension remained until the destination had been reached. Similarly, participants were starting on a new adventure and they did not know where it was going to take them, but they were filled with fear that their self-worth would decline over time.

The theory of *Negotiating Self-Worth* explains the stages of the journey. It is not a linear journey, but one that is marked by primary and secondary routes and like any journey there are variations in the types of routes. The primary route is the core category *Negotiating Self-Worth,* and this links all of the different aspects of the journey together. These different aspects are called sub-core categories which are:

1. *Insulating Self-Worth*
2. *Scoping Self-Worth*
3. *Bolstering Self- Worth.*

Like a travel journey there is road variation and so the categories all vary with properties and the behaviours of the participants. In this instance this enabled the theory to be known as a multi-variate theory.

Core Category Negotiating Self-Worth

As mentioned, the core category was conceptualised as *Negotiating Self-Worth.* This category was selected, as it explained the processing of the main concern of the participants, and it related to and integrated all of the different aspects of the theory into a whole. *Negotiating Self-Worth*, therefore, explained how the participants continued to process their main concern. Self-worth was continuously being negotiated. Negotiating refers to the ongoing interpersonal and intrapersonal interactions and subsequent behaviours as elements of the process associated with the main concern. Negotiating was not an individual effort at any one point in time but required careful observation within a social context on a continuous basis, in addition to tremendous courage to face all the challenges. Each participant as a social entity held their own beliefs, values, and expectations, which were influenced by socio-cultural events over a lifespan and subsequently influenced the participants interpretation and response to the *Fear of Declining Self-Worth*. The participants responded in their own unique way and, therefore, the core category accounts for the variation in the patterns of behaviour. The participants were trying to find a place where they felt they were psychosocially more comfortable. In negotiating, the participants interpreted and gave meaning and subsequently selected a response that enabled them to fit in psychosocially. The response was delivered in an awareness context which the participant created. The core category then accounted for the variation in the patterns of behaviour through which the main concern *Fear of Declining Self-Worth* was continuously processed. The variations in behaviour patterns are accounted for in the properties of the core category.

The core category of *Negotiating Self Worth* has three distinct stages and these are identified as sub-core categories[29]: *Insulating Self Worth*; *Scoping Self-Worth* and *Bolstering Self-Worth* (see figure 13).

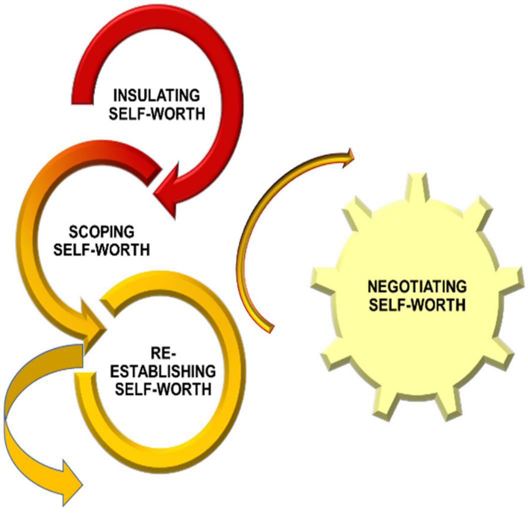


Figure 13 Overview of Core Category and Sub-Categories

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[29] The sub-core categories of Insulating Self Worth, Scoping Self-Worth and Bolstering Self-Worth will be discussed in detail in the next chapter.

Critical Junctures

While the sub-core categories of *Insulating Self Worth*, *Scoping Self-Worth* and *Bolstering Self-Worth* are identified as stages they are not independent as they relate closely to each other in processing the *Fear of Declining Self-Worth*. The participant enters one stage and progresses to another stage. The three stages are all part of the process of *Negotiating Self-Worth* and the participants must engage with each stage. However, there is no identifiable time dimension to any stage and the participant progresses at their own pace until they reach the next critical juncture. The movement between stages is marked by a critical juncture which is a particular psychological state. The movement maybe sequential, that is, the participants move from *Insulating Self-Worth* to *Scoping Self-Worth* and onward to *Bolstering Self-Worth*. Alternatively, the movement may be non-linear where the participants move from *Insulating Self-Worth* to *Scoping Self-Worth*, reverted back to *Insulating Self-Worth* and then to *Scoping Self-Worth* again. Movement between stages occurs when a critical juncture is reached (see figure 14).

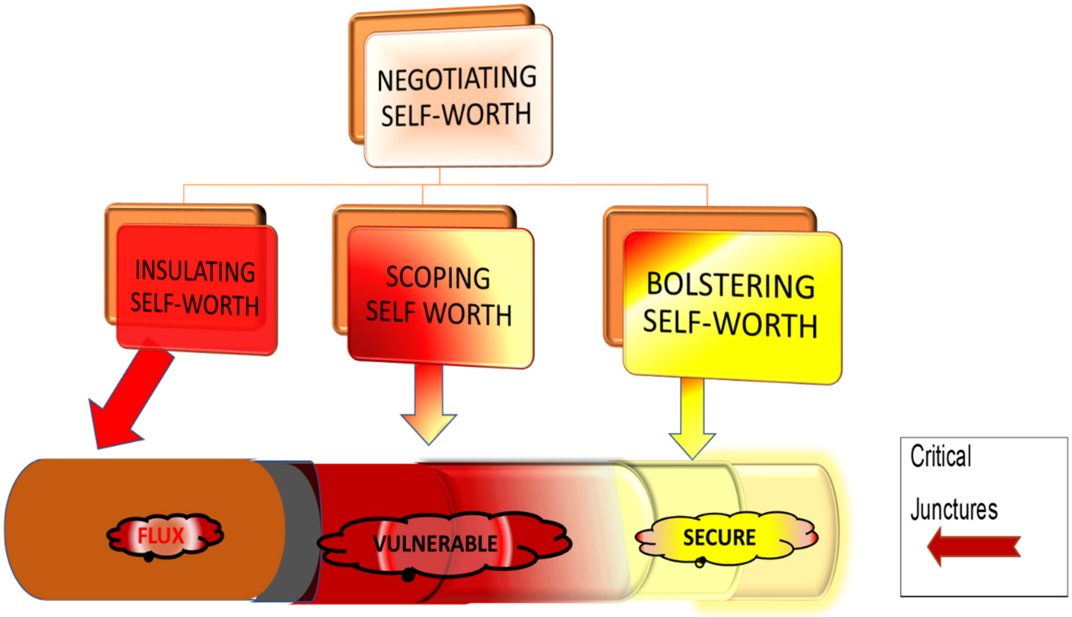

Figure 14. Stages of Negotiating Self-Worth and Critical Junctures

A critical juncture is a cut-off point between one stage and another. Strictly speaking, it is a significant position that the participants reach, making them halt. Upon reaching a juncture, progression was enabled by the participants engagement in relationships. The critical junctures are the psychological states of Flux, Vulnerable and Secure.

Critical Juncture – Flux Psychological State

A confirmed diagnosis of RA induced an emotional response for the participants. For some they experienced joy when they heard the diagnosis, as the name was to be preferred over what they had anticipated could be the health problem. For example, one participant thought the symptoms were pointing to a medical diagnosis of Multiple Sclerosis, and so it was relief to hear the diagnosis of RA. For other participants the diagnosis was a shock and they experienced internal conflict as they did could not believe they could have RA despite having lingering symptoms. While the initial diagnosis brought relief for some and shock for others, as the participants considered the diagnosis the emotional response became a flux psychological state.

For all participants when they considered the diagnosis their sociocultural understanding became paramount, that is, they considered RA as a condition of old age that led to dependency, infirmity and disability. This sociocultural understanding dominated their thoughts and, combined with the enduring symptoms the participants experienced, took them into a psychological state of flux. Flux was a state where the participants were unable to think about anything beyond their sociocultural beliefs about RA. The features of Flux were confusion, insecurity and uncertainty (see table 8). Confusion arose for the participants from hearing the diagnosis and understanding it was a condition of old age. They did not believe the diagnosis, and yet they had fatigue, unrelenting pain, which the participants described as the worst pain that could be imagined by any human being. The lingering symptoms and the confusion made the participants feel very uncertain about their ability to fulfil their normal life roles and this decreased their self-confidence. The participants experienced doubt in their ability and reasoned that if others discovered the diagnosis they would be viewed differently, and life would change forever. Some participants revealed the diagnostic name to a person they were close to and could trust to conceal, but no details were given. They did not trust anyone and, furthermore, they did not trust themselves not to reveal the diagnosis in their psychosocial behaviours. Therefore, in *Insulating Self-Worth* they were very careful to conceal their living and consequently became isolated. Participants entered *Insulating Self-Worth* in the flux psychological state, and this lasts throughout the stage. At a certain point their responses to the confusion, insecurity and uncertainty and the continuation of lingering symptoms became too much, and they became vulnerable.

Dimensions of Psychological States		
Flux	**Vulnerable**	**Secure**
Confusion Insecurity Uncertainty	Gross Uncertainty Insecurity Brokenness Defeated	Self-Confidence Hope for the Future Security

Table 8 Dimensions of Psychological states

Critical Juncture – Vulnerable Psychological State

In the psychological state of vulnerable the participants were broken and entered the stage of *Scoping Self-Worth* (see table 8). In their brokenness they engaged with compassionate others who related to them with understanding and compassion. This engagement took courage, as the participant began examining and addressing the internal conflict they were experiencing. For some participants this task was too much, and they reverted back to the previous stage. For other participants they continued to address the conflict and thus increased their self-awareness and the psychological energy to engage with resources. They started to examine what having RA meant for them as social beings. In these tasks the participants came to gain a different understanding about living with RA. The participants understood that they could have a life with RA, and that it was not the end of their world. They began to gain confidence in themselves and became more secure in the person they were becoming and entered the secure psychological state.

Critical Juncture – Secure Psychological State

In the secure psychological state, the participants enter stage 3 *Bolstering Self-Worth*. At this point they know that there is more to life than the RA. In their secure state the participants have confidence and hope for the future (see table 8). The participants have gained emotional energy to explore alternatives for living a fulfilled life and are no longer threatened by their diagnosis, others or the environment. In stage three *Bolstering Self-Worth* the participants continued to increase their self-awareness and boost their self-worth as social beings.

The psychological states of Flux, Vulnerable and Secure are a juncture that the participant enters and then progresses to another stage in the process of Negotiating Self-Worth. When the participant entered a stage, the psychological state remained but lessened as the participant progressed in the next stage as illustrated in figure 15.

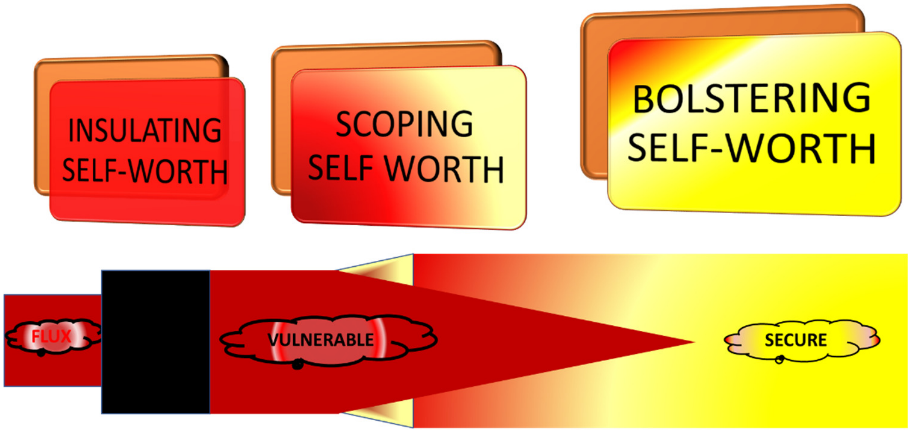

Figure 15 Psychological states through the stages of the Negotiating Self-Worth

In addition to the critical junctures, the movement between stages may be impacted upon by progress in a particular stage in the process. It is when the participants reach the critical juncture that they progress to the next stage. As indicated earlier, there is one distinction in movement between stages. When the participant progresses from *Insulating Self-Worth* to *Scoping Self-Worth,* they may revert back fully to *Scoping Self-Worth*. When they move from *Scoping Self-Worth* to *Bolstering Self-Worth,* they do not move back fully but they may glance back. The participants will only be in one stage at any particular time.

The defining characteristics of *Negotiating Self-Worth* are known as sub-categories. The sub-categories are the varying parameters that established *Negotiating Self-Worth* as core and enabled it to be understood as driving the whole theory. *Negotiating Self-Worth* has four sub-categories: *Relationships, Disclosure, Decision Making* and *Courage.* Each one increases the scope of the core category and therefore some detailed discussion is warranted.

Sub-Category of *Negotiating Self-Worth*: Relationships

In *Negotiating Self-Worth,* the participant interpreted observations about their social world and responded through relationships. The response was further influenced by the psychological state of the participant within each particular stage of the process. Different types of relationships were managed by the participant: *Unsupportive, Pseudo-Friendly, Semi-Supportive* and *Supportive*. In the context of living with RA the participants applied different attributes to the behaviours of others and also considered the possible impact and consequences of engaging in a particular type of relationship with them. It was within the context of awareness that they were able to manage the different relationships in limiting the negative impact upon their self-worth but also creating an impact that is helpful either physically, psychologically or socially. Relationships were key elements for the participants moving through the various stages of *Negotiating Self-Worth*. Table 9 below identifies the types of relationships and the defining aspects that supported the participants in their decision-making regarding responses.

The different types of relationships were evident in the stages of *Negotiating Self-Worth.* However, each stage was dominated by a particular type of relationship, with the domination being reflective of the psychological state of the participant. For example, *Unsupportive Relationships* dominated stage one *Insulating Self-Worth* when the participant was in a psychological state of flux. The different types of relationships are not linked to any particular social role of the other person. The relationships are determined by careful consideration of attributes that are observed and considered in conjunction with the consequences for the participant. When the participant deliberated on the attributes of the other person they responded. Careful decision making (discussed later), therefore, is an important sub-category of *Negotiating Self-Worth*. This is the ability to make the decision about an appropriate response to their impressions and observations. More detail on the four types of relationships is relevant at this point.

Unsupportive Relationships

Unsupportive Relationships can be with any person who has no vested interest in the participants. Such people display disinterest by being overly talkative and not listening. Even if the person asked a question, they were deemed as not really wanting or interesting in hearing a response. Another characteristic is that some people were perceived to be negative in their outlook in life. Negative thinking was deemed as not supportive of the participants in creating and maintaining the façade of self-reliance. The behavioural responses to persons who had no vested interest in the participants were to avoid communication or to change the subject of conversations.

Unsupportive Relationships dominated the stage of *Insulating Self-Worth* when the participant wanted to maintain a façade of self-reliance and capability. For the participants the consequences of unsupportive relationships were that façade continued, and they have concealed the psychosocial challenges of living with RA. Consequently, participants can become isolated and lonely on their RA trajectory. When the participants are in the stage of

Bolstering Self-Worth, Unsupportive Relationships were still evident, but they did not have the same impact. At this stage the participants were able to re-evaluate the individuals and their behaviours as characteristic of an ignorance of any chronic condition and did not attribute any more thinking to the behaviours they had observed. They just accepted that some people just are that way.

Pseudo-Friendly Relationships

Another type of relationship is *Pseudo-Friendly*. The participants recognised displays of disingenuous mannerisms such as glares or frustration at a slower pace of movement, and decided to respond in non-confrontational ways. The response was not a reaction to what they had observed or overheard. The participants responded in a friendly polite manner, creating the impression of being nice and oblivious to the hurtful behaviours that they had interpreted. In the stage of *Insulating Self-Worth,* the participants were deeply hurt, and their observations directly undermined their attempts to portray self-reliance. Simultaneously, this reinforced their resolve to hide their challenges more. Consequently, the participants did not receive any physical help with tasks when it would have been beneficial. *Pseudo-Friendly* was also evident in stage two *Scoping Self-Worth*, when the participants were hiding inabilities and not responding to inappropriate and hurtful behaviours. In the stage of *Bolstering* Self-Worth, *Pseudo-Friendly* relationships were still evident but did not have any impact as the participants discerned that behaviours indicated just how some people are.

Semi-Supportive Relationships

Another type of relationship is Se*mi-Supportive*. This type was attributed to family, co-workers, casual friends and professionals who were deemed to have no knowledge of RA. The behaviours of such people were evaluated as intentionally good, but they were not respectful. Examples might be doing things for the participant without asking. In the stage of *Insulating Self-Worth*, this was hurtful and was interpreted as disrespectful as it undermined the participants' façade of being self-reliant and prevented them doing what they could do without help. There was very careful observation for disingenuous conversations. The response also was very careful, with cautious selection of the amount and type of information that was revealed. The consequences of a semi-supportive relationship were an avoidance of pity which undermined the participants' attempts to insulate their self-worth. Another consequence of semi-supportive relationships was not getting support when it was needed. This created further repercussions as the participants endeavoured to find ways of doing things even at the expense of agitating the RA condition. In the stages of *Insulating Self-Worth* and *Scoping Self-*

Worth, there is a suspicion about relationships and just how genuinely supportive others really are. Hence, discernment of the participants was important.

Supportive Relationships

The final type of relationship is the *Supportive Relationship* which was perceived as bringing mutual benefits to interactants. The genuine interest was evaluated in the behaviours observed, such as active listening, and authentic comments articulated in a supportive way. These individuals were willing to engage and relate to the participants as a person regardless of any obvious deficiencies. Such people were identified as family, friends or professionals with knowledge of RA. Active respectful engagement permitted the participants to explore and consider suggestions, with no expectation of responses or acceptance of the elements of any conversations. This engagement did not release fear but rather gave participants confidence which enabled exploration of other options and other ways of looking at aspects of living while having RA. This type of relationship is evident in all stages of *Negotiating Self-worth*. However, in *Insulating Self-Worth*, the fear of disclosure was so powerful that the participants were unable to identify or engage in supportive relationships. In the stage of *Bolstering Self-Worth,* the participants on reflection were able to attribute *Supportive Relationships* as helping them to insulate and scope their self-worth. *Supportive Relationships* were always there but, because the participants were engrossed in their fear, they were unable to differentiate upon them. *Supportive Relationships* in the final stage of *Negotiating Self-Worth* brought consequences of active support in dealing with life issues. The participants felt understood and respected.

To summarise, relationships were identified as one sub-category of the core category *Negotiating Self-Worth*. The four types of relationships were evident throughout the three stages of the processing of the main concern. The participants evaluated the behaviours of others and their subsequent response was based upon that evaluation and the consequences for themselves. This evaluation was based on experiential learning of participants over their lifespan and not initially a conscious activity. However, it becomes a conscious act when the participants discovered that some relationships are very unhelpful and thereby to be avoided, and other relationship are supportive and should be nurtured.

Type of Relationship	With Whom	Associated Attributes	Associated Behaviours of Participants	Consequences for Participants
Unsupportive **Present in all stages of the process**	Individuals who are advice givers who know a lot about many things but really do not know anything or have much understanding of living with any chronic condition People who are negative and can give any conversation a negative connotation	Talkative Not good listeners Have a negative perception of everyone and everything	Avoid communication and sharing of any aspect of having RA. Change the subject of conversations quickly if the person cannot be avoided.	Relief Sometimes feel alone and isolated In *Bolstering Self-Worth* Participants accept people as they are and reason that such people do not know any different.
Pseudo Friendly **Present in:** **Insulating Self-Worth** **Scoping Self- Worth**	No-one in particular	Display of disingenuous mannerisms	Avoid glares at deformities, non-verbal communication indicating frustration in public places. Do not respond to glares or inferences about slowness or appearance. Non-information giving Change subject of conversation	Detract attention from limitations Feel hurt from the impatience of others or the perceived curiosity. In *Bolstering Self-Worth* accept people as they are. They do not know any different.
Semi-supportive **Present in:** **Insulating Self-Worth** **Scoping Self- Worth**	Family, co-workers, casual friends, Professionals (no knowledge of RA).	Wanting to do things for you without asking or knowing Ignoring and not offering to do tasks Asking questions but not really listening or hearing the answer	Select the amount and type of information revealed Find a way to do tasks for yourself even at the expense of agitating RA. Observe for disingenuous conversations and give only information as it is necessary.	Avoid pity. Frustration at not being understood o cared about In *Bolstering Self-Worth* accept people as they are. Individuals have the confidence to ask for physical supports and correct misunderstandings.
Supportive **Present in:** **Insulating Self-Worth** **Scoping Self- Worth** **Bolstering Self-Worth**	Family, Co-Workers, Friends and professionals with knowledge of RA.	Active listeners and observers Want to hear so ask questions If they do not understand they will say and ask more Will ask instead of offering support Will comment on what they observe Will challenge you in a supportive way Have a positive outlook Are respectful Are willing to engage with you and help you find the supports you need Know how to relate to you as a person	Engage in relationship. Explore possibilities for doing things. Confidence to make contact when needed.	The offer of physical help Active support for dealing with some o the issues Feel understood Feel cared for and respected Feel good about the self

Table 9 Types of relationships and defining attributes

Sub-category of *Negotiating Self-Worth*: Disclosure

Another important sub-category of *Negotiating Self-Worth* was disclosure. Disclosure required the participants to think carefully about revealing any information (see table 10):

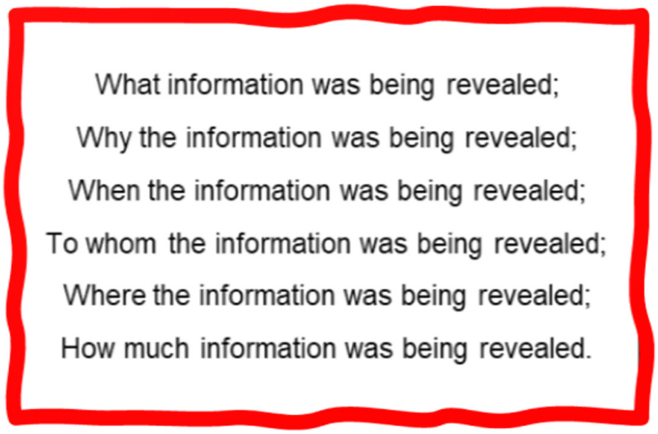
What information was being revealed;
Why the information was being revealed;
When the information was being revealed;
To whom the information was being revealed;
Where the information was being revealed;
How much information was being revealed.

Table 10 Disclosure considerations

There were consequences from disclosing details regarding life with RA and some are unwanted (see table 11).

Psychological State	Awareness Context	Judging Criterion	Disclosure Behaviours	Consequences
Flux	Closed	Person with no investment in me Person with limited capacity to understand	No personal disclosure Redirecting Masking	No pitying Perceived as capable and able. Increase in symptomatology e.g. pain, fatigue
Vulnerable	Closed	Person with limited investment in me Person with limited capacity to understand	Vague disclosure No suggestion of a problem Vaguing out Masking	Frustration with others not completing chores that need completion Frustration with the self as not being able to achieve tasks by the self
Vulnerable	Limited	Person with some investment in me Person with limited capacity to understand	Vaguing out Masking	Being actively listened to. Some genuine sympathy or offer of help. Some supports for gaining solutions. No expression of pity Some expression of empathy Retain the vision of being in control and capable and able.
Secure	Open	Person with investment in me Person with capacity to understand Person with respect for me	Full disclosure	Respect retained. Empathy and sympathy of others Supports to live with the challenges Challenging of assumptions and ways of living and considering RA Link to further supports e.g. the professional may link the person to counselling therapies or the friend may link the person to exercise club. Increasing confidence

Table 11 Consequences of disclosure

Therefore, the participants carefully judged to whom and what information they were going to disclose. Carefully judged disclosure protected against exposure of limitations and judgements regarding ability and prevented unwanted consequences. Initially no personal disclosure occurred. This progressed to full and open disclosure as the person became psychologically secure and was in stage three *Bolstering Self-Worth*. Disclosure, therefore, was influenced by the psychological state and vice versa. In the psychological states of flux and in a closed awareness context, there was no disclosure. This non-disclosure was portrayed in masking out, that is inattention to suggestions or comments of others, or redirecting attention to something else. While the consequences for the participants were no pitying and being perceived as self-reliant, participants experienced an increase in symptoms of RA. When the participant enters the psychological state of vulnerable and maintained a closed awareness context, the consequences increased, with personal frustration arising from inability to complete tasks.

When a limited awareness context was created, and the individual was in a vulnerable state, there was some selective disclosure to individuals who were perceived to have some interest in the participants and had a capacity to understand. The behaviours focused on avoiding unwanted intrusion into their RA by vaguing and masking observations, comments and questions. Vaguing and masking refer to the behaviours of the individuals by which they portrayed to others that they were oblivious to situations around them and in this way, they also concealed their real selves. The consequences of selective disclosure are that respect was retained and, the participants gained empathy and sympathy. They were also able to acknowledge supports, had no expressions of pity and, importantly for them, they were able to recognise that they had a sense of being in control and were perceived as being capable and able and therefore had some sense of their own worth.

Full disclosure occurs when the participant was in a secure psychological state. In this state the fear of disclosure no longer takes precedence and, therefore, the participant shared openly with individuals who had a genuine vested interest in them. Open disclosure with those who had a genuine interest in them increased their self-confidence in pursuing life activities and the achievement of *Bolstering Self-Worth*. *Bolstering Self-Worth* is not a pre-determined goal to be achieved but rather a state which required continuous nurturing. Therefore it is continually being processed, renewed and revitalised through supportive relationships and continued open disclosure. As self-worth becomes more firmly established, participants were no longer concerned about who knows what details about them and their life with RA. In addition, they perceived that others would benefit from their sharing. Disclosure and non-disclosure do not occur at random but are considered very carefully and are influenced by the type of relationships and the psychological state which they are in. Being able to control the disclosure gave the participants a sense that they had power over their own sense of self-worth.

Sub-Category of *Negotiating Self-Worth*: Decision Making

Decision making involved making choices about many aspects of living with RA. The essence of decisions made over the process of Negotiating Self-Worth altered and was influenced by the goal the participants had in each stage. In the stage of *Insulating Self-Worth*, the goal was to limit any disclosure. The outcome of decision-making was to maintain a facade of self-reliance and normality. The decision making was about types or aspects of psychosocial behaviours that would reveal anything about their having RA and therefore the participants selected behaviours that revealed self-reliance. In the stage of *Scoping Self-Worth*, the participants, having reached a vulnerable psychological state, began to realise that they can alter consequences if they think carefully about their choices of action or inaction. Initially in this stage they are still preserving the facade of self-reliance, but this gradually waned as they become more self-aware. The goal was to protect the self from physical consequences of poor choices. As they progressed in *Scoping Self-Worth*, the goal of decision making became more focused on improving their life with RA. Positive consequences from decisions re-enforced this goal. When they progressed to the final stage *Bolstering Self-Worth*, the goal centralised on improving their experience of living with RA. This included decisions about daily events and some longer-term aspects of living which would improve their quality of life. The decision making remained important and required input from supportive relationships to sustain their motivation for action. Decision making, while goal focused in all the various stages of *Negotiating Self-Worth*, was also influenced by life experiences, perceptions, sociocultural interpretation and personal development. In *Scoping Self-Worth,* the participants were beginning to realise the basis of their decisions and identify the various influences. It is in the final stage of *Negotiating Self-Worth* that the participants were able to identify the various influences on their decision making and critique these aspects. In *Bolstering Self-Worth,* the participants' ability to make more balanced decisions based on more reliable information was evident. Within the process of Negotiating Self-Worth decision making is a conscious activity.

Sub-Category of Negotiating Self-Worth: Courage

Initially in *Negotiating Self-Worth* courage was more akin to dogged determination not to reveal anything of their life with RA. The main driver was fear. However, determination alone was deficient in adequately responding to their main concern. Courage was a tremendous step that was required in each stage of the process of resolving their main concern. It consisted of: physical courage to go beyond many aspects including: the unwanted comments of others; the effects of the condition of RA; cautioning the effects of the treatments; continual observation of their RA status[30]; Social courage not to feel rejected by others either due to their disfigurement or inability to do some activity. Moral courage was required when their actions might not meet approval from others and emotional courage to cope with the negative emotions that were encountered during flare ups; spiritual courage to believe in the self. While the different dimensions of courage were evident in each of the stages, some are more prominent in some stages than others. For example, in *Insulating Self-Worth* social and moral courage were strong, and the other dimensions were weaker. Social and moral courage supported their decision making to continue to display self-reliance. Courage is the factor that enabled the participants to enact the choices decided upon in living and gave them confidence in their engagement in relationships. Courage was an important aspect in facing the reality of RA and the ability to proceed and finally *Negotiate Self-Worth.*

Conclusion

In conclusion, in this chapter the core category *Negotiating Self-Worth* was identified as the process through which the participants continuously processed their main concern of *Fear of Declining Self-Worth*. It is a BSPP, as the behaviours indicate social and psychological processes with varied properties. *Negotiating Self-Worth* was operational only in an awareness context, that is, the creation and control of an ambience through which the participants negotiated self-worth by selecting what information they would reveal to whom about various aspects of their life trajectory with RA. The participants created three types of awareness which were identified as closed, limited and open. In the closed context there was no disclosure, in the limited context there was some carefully judged information revealed and in the open context there was full disclosure.

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[30] Status of RA refers to two periods of disease activity: 1) period of active disease with pronounced physical symptoms and intervention is required 2) Inactive disease where the symptoms of RA are not obvious to the participants.

The awareness context and psychological states governed how the participants progressed through the stages of *Negotiating Self-Worth.* The participants negotiated their self-worth. Negotiation was a conscious activity that required careful consideration of relationships and the contribution toward the well-being of the participants. In negotiating they progressed through three distinct stages of *Insulating Self-Worth*, *Scoping Self-Worth* and *Bolstering Self-Worth*. Each stage was marked by a critical juncture which were the psychological states of flux, vulnerability and secure. Relationships were one sub-category of *Negotiating Self-Worth*, with four types of relationships evident in the processing of the main concern. Supportive relationships assisted the individual in negotiating and ultimately *Negotiating Self-Worth.* The variable that influenced responses in the different types of relationships was disclosure. Disclosure, therefore, was another important sub-category of *Negotiating Self-Worth.* The participants made very careful decisions about personal information they were revealing, with the aim of preventing unwanted consequences. Initially no personal disclosure occurred. The participants progressed to full and open disclosure as they became psychologically secure in the stage of *Bolstering Self-Worth*. Disclosure was influenced by the psychological state and vice versa. *Negotiating Self-Worth* involved making decisions about psychosocial behaviours and what they would reveal. Enacting those decisions required courage. Courage and decision making were identified as two further properties of *Negotiating Self-Worth* essential for enabling the participant to progress in the process.

Negotiating Self-Worth has subcategories of *Insulating Self-Worth; Scoping Self-Worth* and *Bolstering Self-Worth*. The next chapter is divided into sections which will detail each of these.

CHAPTER 7 PROGRESSION THROUGH THE PROCESS

Introduction

For the participants in this study living with RA brought challenges. While many challenges were evident, their main concern was their *Fear of Declining Self-Worth*. The participants processed this main concern by engaging in a three-staged process called *Negotiating Self-Worth*, which was operationalised in an *Awareness Context.* The three stages of the process are *Insulating Self-Worth, Scoping Self-Worth* and *Bolstering Self-Worth.* The discussion in the previous chapter identified that *Negotiating Self-Worth* was core to resolving the main concern and as such had key properties which enabled it to be understood as the core category. *Negotiating Self-Worth* is an all-consuming activity, requiring tremendous courage to navigate the different dimensions of the process. While the previous chapter provided some broad discussion on the core category, this chapter seeks to give more clarity on the sub-core categories of *Insulating Self-Worth, Scoping Self-Worth* and *Bolstering Self-Worth*. This chapter is divided into three sections for the respective categories. Exemplars from participant interviews are provided as illustrations with specific details anonymised to protect identity. As a preamble to the sub-categories a short summary of progression through the three stages of the process is useful.

Progression through the Process

Negotiating Self-Worth links all three stages of the process together. Figure 16 illustrates that *Insulating Self-Worth* (ISW), *Scoping Self-Worth* (SSW) and Bolstering *Self-Worth* (B*SW)* are contained within *Negotiating Self-Worth.* The properties that enable them to be contained are relationships, disclosure, decision making and courage, which is illustrated by the lines on figure 16 below, holding them as if in one container. The figure has a cover of *Negotiating Self-Worth* and from this cover come the properties of relationships, disclosure, decision making and courage.

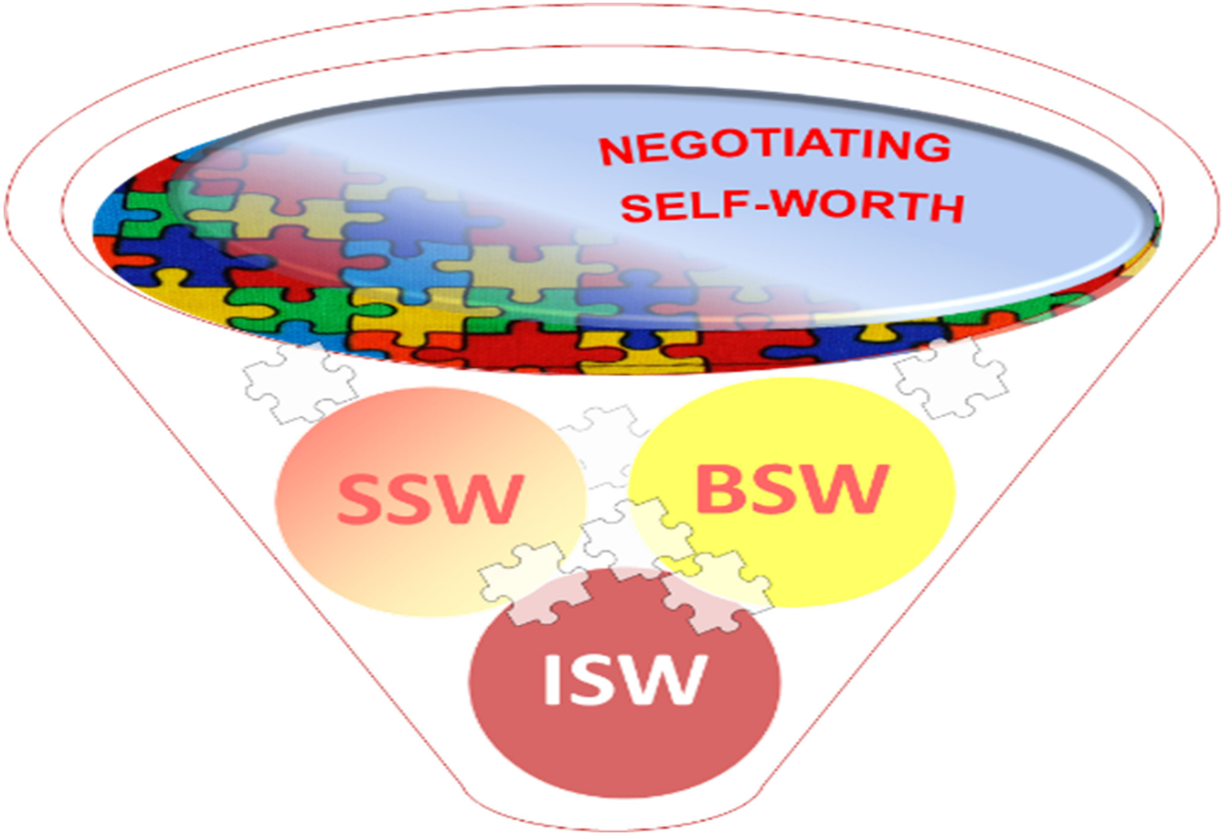

Figure 16 Negotiating Self-Worth

While all the stages are contained within *Negotiating Self-Worth*, each one is also a distinct stage within the process. In relation to progression the following features are significant:

- Progression is individually time related, that is each participant progresses in their own time;
- Progression though the stages is dependent upon the participant arriving at a critical juncture identified as *Flux, Vulnerable* and *Secure*;
- The stages are presented in a linear way however, the participants moved back and forth between the first two stages;
- Movement between the stages is dependent on the utilisation of supportive relationships to assist the participants in managing all the complexities of living
- When the participant enters the stage of *Bolstering Self-Worth*, they may glance back but do not fully move back to the previous stage of *Scoping Self-Worth*.

Figure 17 below captures the sub-core categories and the critical junctures which mark the movement across stages.

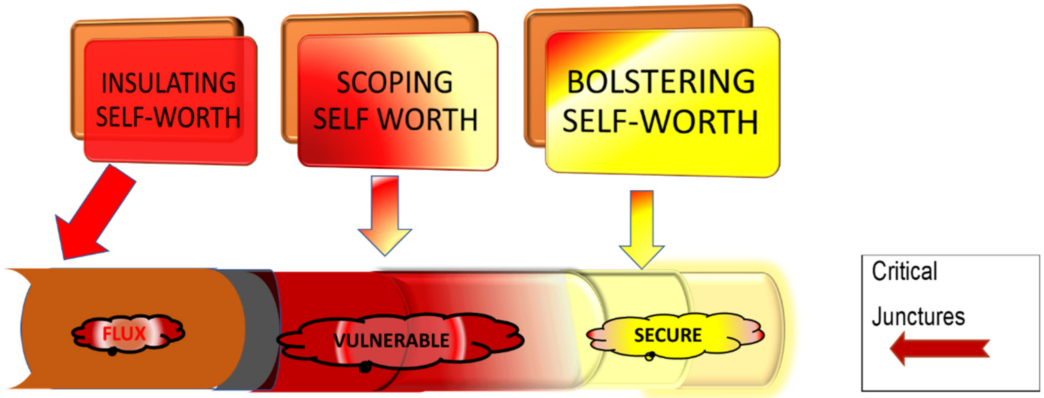

Figure 17 Sub-core categories and critical junctures

Critical junctures are the points at which the participant entered the next stage and are an important feature of progressing between stages. Therefore, it is useful to reiterate some of the points made previously. Flux happens to the participants when they receive a diagnosis of RA and relates to a psychological state of gross uncertainty and insecurity. This state is reinforced by the impact of the RA on the participants' whole being, combined with the impact of a definitive medical diagnosis which the participants associated with dependence and ageing. When the participants entered the stage of *Insulating Self-Worth,* there was engagement in conversations about the condition of RA and treatment regimens. A new and complex vocabulary was introduced, learned and relearned as the participants gained insight into the condition and the reality that there was no cure. At the same time, the participants tried to protect and retain their understanding and knowledge of themselves as social beings. For the participants the diagnosis directly conflicted with their desires for themselves and their lives. This internal, invisible conflict increased during the process of *Insulating Self-worth* and the participants became vulnerable. In the vulnerable state, the participants engaged with supports and resources and began the process of *Scoping* their *Self-Worth*. In the stage of *Scoping Self-Worth,* the participants increased their engagement with resources and supports and addressed the sources of conflict. For some participants the task of addressing the internal conflict became too much and they reverted to the previous stage of *Insulating Self-Worth.*[31] For other participants possibilities and glimmers of a different life was gained as the internal conflicts were worked through. They entered the psychological state of secure and progressed to strengthening the insights they had gained for a different life in the process of *Bolstering Self Worth.*

Critical junctures, therefore, are important points in the process of *Negotiating Self-Worth*. Reaching a juncture marks the passage from one stage in the process to another. The remainder of this chapter is divided into three sections, one for each sub-core category respectively.

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[31] Moving back is fully discussed in section 2 of this chapter Scoping Self-Worth.

Section One: Sub Core Category- *Insulating Self-Worth*

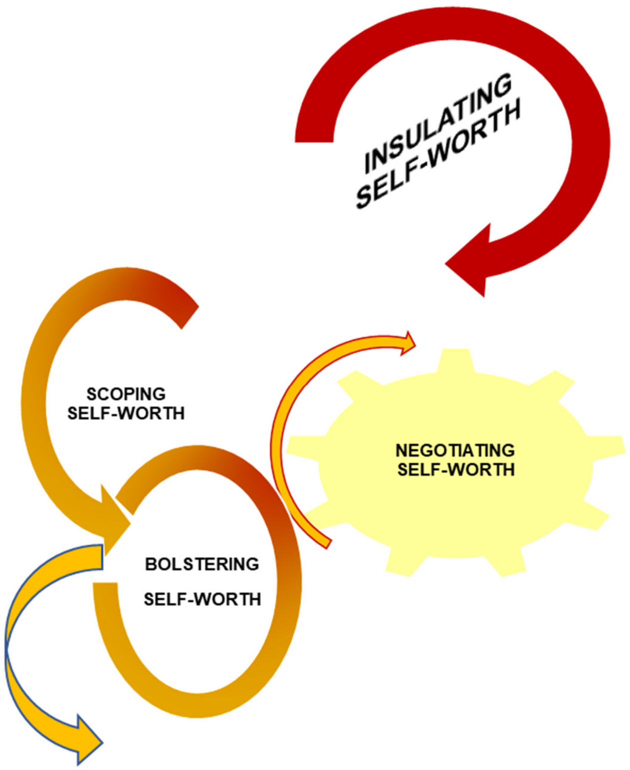

Figure 18 ***Insulating Self-Worth***

The sub-core category of *Insulating Self-Worth* is the first stage in the process of *Negotiating Self-Worth* (see figure 18). In brief, once the participants experience the symptoms of RA and gain a medical diagnosis, they place a protective layer around their self-worth to protect it against any further erosion. It could be compared to a robbery of a home where the homeowner put a lot of time and effort into the interior design. The homeowner realises that the robbery is taking place and as the destructive behaviours of the robbers continues to ruin the design and the furnishings, the owner, taking their precious belongings, manages to go to a hidden cellar and locks the door firmly. There was a similarity with the participants, as the robbery was very personal and was perceived to be taking away all they know about themselves and their lives and affected the very essence of their being. In a sense this stage is a reactive response as the participants attempt to halt the robbery and maintain the safety and security that they have known up to this point in their lives. The participants responded to the robbery by creating the illusion that everything was the same they did this through creating an Awareness Context.

Prior to receiving a definitive diagnosis of RA, self-worth was not given much consideration by the participants and typically was a taken for granted state of being in the world with their ability to be independent and conform with the norms of society and the culture in which they lived. Therefore, the participants felt a sense of belonging as social beings and experienced a sense of comfort and security with living and life. Participants reacted to the onset of the physical symptoms of RA in two ways. Either they were initially dismissive, in that the features were viewed as transient and would disappear, or they were totally overwhelmed. When the participants talked about the emergence of their condition before they were diagnosed, they described the severity and the seriousness of the symptoms they experienced. Pain, swelling, and stiffness were commonly reported as the primary symptoms. The participants talked about them with disbelief and hoped they would disappear. Their initial symptoms and reactions are captured in the following quotations:

> "…. went to get out of the car, I couldn't. I had …… seized up. It was the knees .. what's wrong with me? … I'm trying to straighten my legs and I can't. Then I'm thinking, ah don't be ridiculous so I'm rubbing them. ……I remember telling myself, cop on here. This couldn't be happening. I'm only what age, 24, like seriously what could be wrong." (Participant 10).

> "my legs were very swollen for no reason. I thought, what's wrong with me. Then my hands were really stiff, and my body was tired. The symptoms were all ….I didn't understand and I went to my own GP – not at the time but around 8 weeks later. ….You have to get on [continue with life] haven't you? I had a wife and a young family to support. But I did feel good enough, but I wasn't perfect. I thought maybe I'm imagining it." (Participant 2).

> " woke up one day with an extremely sore wrist – I just couldn't move - it felt like it was broken –but nothing had happened to it." (Participant 1).

> Took Disprin for pain "I'd get on with life", meaning she continued to work and live her life. She got married and then the Disprin were not effective in relieving the pain. At that point she went to her GP. The time period was over a year. (Field notes, Participant 7).

Participants who were initially dismissive of symptoms had hoped that the aches and pains would go away permanently, but when the pain continued and began to invade their ability to complete normal everyday tasks in life, medical advice was sought. For participants who experienced a sudden inability to move, medical advice was sought immediately either through their GP or at the Emergency Department. At the medical consultation all the participants were given some initial treatments for physical symptoms and had blood tests taken followed by a provisional[32] diagnosis of RA. This was followed by a period of waiting for an appointment with a Rheumatologist. While waiting the RA continued to make an impact requiring regular visits to the participants GP.

> "Nothing was showing up in the bloods ….that title [RA] was pushed out there as a possibility ….and that this could happen again maybe twice or three times and then boom, it could be full blown [referring to a flare-up]. So, they [GP] were preparing me for it." (Participant 7).

Being unable to move gave the impression to participants that a diagnosis of permanent paralysis was forthcoming. For these people a diagnosis of RA brought some relief:

> "I was lucky if you can be lucky –" (Participant 10).

> Despite the family history she thought she had MS because it was so difficult to move, and she was filled with fear and anxiety. She felt she could live with arthritis, but the thought of MS was really scary. When she was diagnosed, she was relieved as she had seen her mum and grandma just continue as normal so she thought she could do the same. (Field notes, Participant 11).

The experience of the ongoing features and the subsequent confirmation and diagnosis of RA challenged the certainty of the participants previously known lifeworld. This was principally because their sociocultural understanding of RA led them to believe that the diagnosis would negatively impact upon their social worth. Arthritis was viewed as a condition that affected old people and brought a dependence on others. Memories of old family relatives and stories relaying a stereotypical picture of old people with disfigured joints, suffering pain, being grumpy and requiring help for living were relayed by the participants. In addition, as some of the participants were young, this image and conceptualisation of RA conflicted with their perception of themselves as being relatively young.

> "One doctor said to me, you have arthritis. That's what he said to me. I thought he is mad I am not even 40 how could I have arthritis?" (Participant 8).

> her mother was "the arthritic burden" (Field notes, Participant 15).

> Recalls her mum having hands that were twisted but she never complained. (Field notes, Participant 21).

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[32] RA can be difficult to differentiate from other illnesses. A key feature is the presence of Rheumatoid factor in the blood (which may be absent initially) and an increase in other protein phases (referred to as inflammatory markers) factors indicating an inflammatory process.

> ..-seen an old lady with deformed feet and thought she would end up like that -fears that her hands will become as twisted. (Field notes, Participant 27).

In addition, the participants conceptualisation of arthritis conflicted with their own vision of their future selves and jeopardised this future. Participants did not want to surrender the life they knew, become dependent upon others or to be pitied by anyone. They did not want to become or to be known as the "arthritic cripple". For the participants the information was clear that there was no cure for RA, and this was reinforced by the lingering physical symptoms. The participants were in a period of great personal turbulence, the aspirations for their life that they so much desired were stolen and replaced with visions of old age associated with infirmity, disability, dependence and for some a shorter life span. The following examples illustrate some of the impact:

> "remember when I got the diagnosis I thought, oh my God. ….. because I knew somebody with rheumatoid arthritis. She was in a wheelchair and that's all I knew about rheumatoid arthritis." (Participant 10).

> "We bought our own home and life was good and then this started. it was very confusing, a*nd I* was in a bad place and I got quite down about the whole thing. I worried about my job and my career I could envisage myself being in a wheelchair for the rest of my life or maybe have a short life." (Participant 9).

> "I wasn't able to do anything…. I was so weak. I came out of the hospital ….on a Zimmer Frame [walking aid] and I was 55. [emphasising the age and Zimmer Frame in tone and facial expressions]..the most humiliating part was you couldn't go to the bathroom on your own. You couldn't shower on your own. You needed somebody with you." (Participant 3).

For the participants in this study, turbulence created by gaining an RA diagnosis and the stereotypical perceptions associated with it created great anxiety, worry and much confusion about themselves as social beings. The continuation of physical symptoms reinforced the turbulence and the participants' minds were consumed by the thought that their life and being no longer had any value, resulting in decreasing self-confidence, self-esteem and self-image. Thus, the self-worth that the participants had taken for granted began to erode. The participants' every thought was consumed by the burglar that was taking their self-worth and they retaliated by insulating what worth they had. The diagnosis and living with RA challenged the essence of the lives of the participants both physically and psychosocially and put them into the psychological state of flux. There was an acute realisation that a significant part of who they were, and their lives were being pillaged, but the participants were determined that they would retain their self-worth through being able-bodied independent social beings. The loss of self-worth was significant for the participants. They initially reacted by clinging to the known self-worth and protecting the self from further invasion by concealing the diagnosis and asserting control over their lives. *'Insulating Self-Worth'* is the name I have given to the strategies that the participants utilised to protect and actively defend their self-worth. The consuming thoughts of infirmity, disability and dependence provided the energy for *Insulating Self-Worth*. These thoughts were a significant factor recognised in this stage as a sub-category of *Insulating Self-Worth*. I have conceptualised this all-consuming activity and energy as *Captivity*.

Sub-Category of Insulating Self-Worth: Captivity

Captivity emerged as a consequence of a confirmed RA diagnosis, which brought into perspective the physical, psychological and sociocultural dimensions of a chronic disabling condition. RA dominated the participants thinking and penetrated every thought. It was difficult for participants to think about other things, that is, their minds were totally absorbed by their understanding of RA and the meaning that they attached to it. They were held captive as the following quotes illustrate:

> "not go on holidays - when we go away for a break, I find I cannot lift my mind off the RA" (Participant 14).

> "you wake up in the morning and think can I get up out of bed? am I able to put my clothes on? Am I able to wash? Am I able to make myself something to eat? Am I able to go out? Am I able to socialise?" (Participant 21).

In essence, the participants were consumed with the thought that their physical, psychological and sociological perspectives of RA would become real and thus they were motivated to insulate self-worth. For the participants various aspects of living accentuated the captive state. For example, comparison of their own previous abilities and the abilities of others highlighted to participants the impact that RA was having upon their wellbeing as evident in the following examples:

> ".. it affects your whole body and your mind and your sense of wellbeing. You feel different to everybody else. Even I sit at the front room and if you're looking out and you see people passing and flying up and down and you think, God they've no rheumatism." (Participant 5).

> "you would just hate to have to get out of bed and start to dress yourself. You would have to realise it's taking you that much longer to do things now too. What you would do in a half hour beforehand, it could take you an hour and a half to do it now". (Participant 12).

While participants were able to perceive the impact RA had on previous abilities, this was private and, therefore, they retained their self-worth. When others brought attention to their declining abilities this was hurtful as identified in the following field notes:

> hurt by the "low understanding and attitude" of others in shops or crossing the street. People "tutting" makes her feel angry when she is doing her best. "They do not understand how their reactions can be so hurtful. If they only knew how hard it is". She suppresses the emotions. (Field notes, Participant 11).

The participants perceived that generally others lacked any understanding of RA and therefore could not relate to them or their RA experience. At the same time, such experiences reinforced their thinking about the unwanted physical and psychosocial dimensions of RA, which increased their insulating behaviours. The participants desired supports as they felt hurt and isolated:

> "Sometimes you can feel isolated" (Participant 15).

For the participants RA was a condition that the participants had come to understand in the process of daily living. They reasoned that other people who did not have RA could not understand. In addition, the condition was not visible to others:

> "… maybe they would understand if you talked to them, but they don't…. because they can't see it. I think it's like any form of illness or sickness, unless you're going through it yourself, nobody understands it." (Participant 14).

The lack of visibility of the illness was a significant factor for all participants, which was further emphasised in family situations where the diagnosis was known. Because RA could not be seen, there was an expectation that social roles could still be fulfilled, and the RA was not factored into any requests. For example, in the following quote, the participant talks about how her son made requests to mind his children without asking how the participant was or if they were feeling well enough to assist:

> "He [son] knows I have it …– will you come up [referring to request for child minding]..There was no such thing as, are you fit to do it?" (Participant 5).

The lack of visibility of RA increased the isolation for the participants, as supports were not forthcoming and living with RA went unrecognised. This created some emotional challenges. Participants were challenged by the loneliness and isolation. However, their psychosocial and cultural perceptions continued to dominate the behavioural responses.

In summary, the participants were held captive on a number of levels, namely the physical symptoms, their negative beliefs about RA and the lack of support. This fuelled the need for the participants to insulate their self-worth. The stage of *Insulating Self-Worth* has two subcategories *of Concealing, and Asserting Control over RA.* These sub-categories will now be explained.

Sub-category of Insulating Self-Worth: Concealing

Concealing refers to how the participants retained all their personal information about RA and only revealed to others when it was safe and absolutely necessary. Participants considered that others having any knowledge of their RA was equated to losing what self-worth they had and, therefore, concealing was extremely important in *Insulating Self-Worth*. The participants had a fear of other people discovering information about their RA and were very cautious about the spoken word and behaviours that may directly state or infer that they had RA or indirectly imply their diagnosis. The participants concealed their diagnosis and information about their diagnosis through the use of four processes: *Managing Relationships, Managing Disclosure, Supremacing Medications* and *Guarding*.

Managing Relationships

The first process that the participants used to conceal their diagnosis was through the careful and skilful management of relationships. The participants managed their relationships by assessing them and making decisions about engagement and disclosure. Three types of relationships were identified. The participants evaluated the potential outcome from these relationships in terms of the level of interest and support that they might provide, which was not associated with gender or social roles. Key to these decisions was the participants psychological state of flux when insulating self-worth was paramount. The first type of relationship is ‘unsupportive’, where the participant evaluated people as having no vested interest in them. Some of the attributes of such people were described as snoopy, talkative, advice givers and not good listeners.

The participants found it difficult to listen to other people who made inappropriate reference to RA, as it seemed to undermine the participants' experience and life with RA. Participants suggested that some people would know about RA but portray ignorance and this was perceived as being snoopy. Participants also felt that others found it hard to believe the symptoms that the participants presented with and sometimes minimised them. The following examples illustrate these points:

> "..they haven't got a clue. .if I talk about it, people go on too much about things. They might say, why don't you drink this or why don't you take that. You drink too much coffee; you drink too much tea. It does my head in." (Field notes, Participant 8).

> "….'touch of arthritis' - if someone has not got RA they have no idea about the pain - no idea [emphasised in tone of voice and body language]-it is an awful pain in the acute flareups - people who have not got arthritis will complain of pain - they have no idea any little pain or ache is called arthritis and if they had the pain [of RA] they would not misuse the word." (Participant 18).

> "… some people might know a bit about RA but not know about it - some people …act as if they know nothing." (Participant 27).

> "..no matter what you tell them… they really do not understand and you can see this in their responses and in their eyes. Like they do not believe you." (Participant 21).

For all the participants, there were unhelpful conversations. They referred to these as either negative or the people had an attribute of being a 'moaner':

> too many moaners around - dislikes listening to other moaners - some of her family are real moaners ---moaning about the slightest thing (Field Notes, Participant 18).

The participants responded to unsupportive relationships by avoiding the person or changing the subject of the conversation if they could not avoid such people. However, continued avoidance or changing the subject of conversation was not an easy task for the participants. On occasions this made them angry and intolerant, as is evident in the following exemplars:

> "people can be negative, and this is hard work" (Participant 21).

> "..the term arthritis is misused by many people which is annoying. People use the term and they haven't a clue about what it really is" … she reacts to people who make comments about general pains and aches. She feels she is less tolerant. (Field Notes, Participant 1).

Participants experienced tension at the point when they recognised that others had no vested interest in them. When they successfully avoided individuals or had managed to change conversation topics this relieved the tension somewhat and the participants reasoned that others just do not understand RA. However, the participants experienced other personal consequences, for example the pain of not being understood, isolation and hurt:

> "…the hardest thing for me that nobody understands how I feel." (Participant 4).
>
> ".hurtful" Does not like to be viewed as someone looking for sympathy. (Field Notes, Participant 10).
>
> "my family know but are not supportive - they would not understand" (Participant 16).
>
> Feels that RA is isolating – does not go to pools or other activities. Not worth the effort and feels like the lack of understanding of others would take any enjoyment out of it. (Field Notes, Participant 11).

When participants evaluated people as not having any vested interest in them, they also engaged in another type of relationship which was a pseudo-friendly relationship. The participants recognised displays of disingenuous mannerisms, for example glares or frustration at their slower pace of movement and decided to respond in a non-confrontational way whereby they pretended to overlook these mannerisms. For the most part this referred to behaviours the participants encountered in public places with strangers, For example, on the bus, crossing the street or in the supermarket. Participants responded in a friendly polite manner, creating an impression of oblivion to the hurtful behaviours and concealing the hurt they experienced:

> "You don't know how people are going to react." (Participant 11).
>
> At the supermarket checkout she could hear the "tutting" behind her and the swearing. When she had finished packing, she looked down the que and said, "God I am sorry for being so slow, my head is all over the place today". (Field notes, Participant 27).

Participants wanted to avoid any confrontation. They reasoned that the best response was to either completely ignore the behaviours, i.e. pretend that they have not seen them, or to respond in a way that suggested the participants had been distracted by other things. The consequences for the participants were that they had detracted attention from their obvious limitations and decreased the possibility of increased negative reactions from others and continued to insulate their self-worth. Nevertheless, the hurt increased, as the comments and glances emphasised to the participants that they had RA. Others were getting frustrated with the behaviours of participants although not aware of the circumstances or context for those behaviours.

When individuals showed some interest in the participants, they were cautious about revealing their life with RA. When this occurred, they entered into a semi-supportive relationship with others. These individuals tended to be family, casual friends and professionals with very limited understanding of RA. In some respects, these people were individuals with whom the disclosure and avoidance strategies were not possible as responses. These people had to be endured in their life. However, the participants were resolute that there would be minimal sharing of their life with RA, as these individuals did not understand RA. Such individuals would do tasks for the participants without asking, while others ignored or did not offer to do tasks when the participants would have liked tasks done or had tendencies to ask questions while not listening to the replies. They portrayed an inauthentic interest in the participants and, therefore, it was better to conceal as much of their life of RA as possible. However, the behaviours were evaluated as intentionally good. Examples might be doing things for participants without asking:

> "some people can mean to be helpful but because they do not understand it can be hurtful when they do things for you that you can do for yourself" (Participant 11).

Good intentional actions were interpreted as disrespectful. They undermined the participants façade of being self-reliant and prevented participants doing what they could and wanted to do for themselves. Wanting to do and doing for the self was an important element of portraying to others self-reliance and, therefore, Insulated their Self-Worth. Participants, being aware that others do not understand RA, anticipated disingenuous conversations and observed carefully for these behaviours in others as indicated in this quotation:

> "they think they have the cure – they haven't got a clue [stated with force]. She [referring to his sister] thinks she does [understands]– great intentions but too much of it. .some [other people] would tell you it's in your mind it's your imagination you think you have it – drink this or that [referring to different nutritious drinks]." (Participant 8).

Participants recognised behaviours that indicated others were going to tell them what to do or what not to do. Therefore, when participants anticipated the conversations, they were less likely to react. The participants considered reacting to mean that they were accepting they had RA and their worst fear was becoming real. The participants were frustrated by insincere conversations but decided to view them as well-intentioned. Nevertheless, they felt frustrated. When they could not avoid them, the participants resolved to let the person continue to share the advice, but they would ignore what was being said. In this way the social norms of relationships and friendships would not be impacted, even if they were somewhat artificial. The participants continued to be very careful and cautious about the amount and type of information they shared, as they lacked security in the confidences of such people. The consequences of a semi-supportive relationship are an avoidance of pity. The participants perceived that pity undermined their attempts to conceal their life with RA not only from others but also from themselves. Another consequence of semi-supportive relationships is not getting the support when it is needed. This created further repercussions, as participants endeavoured to continue to carry on doing tasks for themselves even at the expense of agitating the RA condition.

> "I would be sore now from driving tractors or the jeep. Even driving the jeep now, I have to get out. When I'm walking, I'm ok but it's the driving." (Participant 8)

> Finds it hard to adjust work. Has her own standards of completing work to a "high standard". Feels she was raised with a philosophy of working hard and doing everything well and continues with this. "I know it after a day at work" [experiences symptoms of RA activity]. (Field Notes, Participant 21).

Managing Disclosure

For the participants concealing their diagnosis of RA was further buttressed by *Managing Disclosure*. *Managing Disclosure* represents the skilled practice of knowing how to deflect conversations and exhibit behaviours that participants believed would enable them to be recognised by others as self-reliant and capable. The participants felt it was important to be recognised as being capable, self-reliant and non-complaining. Complaining was conceptualised by the participants as a way of being that was disliked by people in the environs within which they existed. Complaining also was perceived to be creating a possibility of others discovering the RA diagnosis. Therefore an important aspect of managing disclosure was not complaining about any aspect of living with RA. Participants perceived an intolerance to anyone who complained. Complaining was described as telling others what your problems were. The following exemplars illustrate the thoughts of participants:

> "…. people get fed up with complainers" (Participant 1).
>
> "….come back [from being hospitalised with RA] you're great now and you got the arthritis sorted out. [referring to comments from neighbours] You knew yourself you were actually going on red diesel [alluding to the powerful but temporary relief]. It's good to see you back out walking again, but they would not want to know anymore. You were sorted and that's the end of that story." (Participant 9).

The participants believed that telling others about health problems was fruitless, as other people would not understand. This was perceived as putting the participants at risk of being labelled as being weak, feeble and disabled. Therefore, not complaining was very important to the participants in concealing their RA condition and Insulate their Self-Worth. Not complaining was also reinforced by memories of others with RA and how they did not complain. The participants used this as a standard by which they gauged themselves:

> He reflects on his dad's experience of arthritis and how he had no treatment. He ponders on how much his dad must have suffered and did not say anything. Now he realises since he was diagnosed with RA himself. He describes being supportive to his dad in doing manual work, but he had no idea about the RA and how it was affecting him. (Field Notes, Participant 2).
>
> Describes how her mum had deformed joints and swollen hands. But her mother never complained, and she asks herself why should she complain? She thinks that her mother had it much worse so she therefore should have no reason to complain. (Field Notes, Participant 25).
>
> "… people who do not make the effort to get out and do things - continually moaning - so you get RA it is not the end of the world - worrying about it will not make it better only worse …people too much time on their hands and they worry too much … we had RA in the family and people were bedridden and now we have drugs sure why you would worry." (Participant 18).

For the participants, non-complaining equated to being self-reliant , portraying an ability to be independent and fulfilling all the roles in their life.

> Focused on all the changes he had to manage - took it all on and got on with it. Does not linger on what is happening just get on with life. (Field Notes, participant 23).
>
> ".. it is important to keep my mind active on the farm – helps distract from the arthritis. . motto is to keep going- keep active. Don't think about the arthritis just keep going…" (Participant 14).

The participants were influenced by memories and believed that this is how they should be behaving, i.e. not complaining. The participants considered three factors as important in supporting their effort to be non-complaining, namely, distracting the mind from the RA condition, keeping busy with practical aspects of life, and concealing an inability to do or complete tasks by using some excuse or other distraction. Participants also recognised the importance of others not seeing them as being unable to do tasks. So, keeping busy was a distraction, but also a visible sign to others that the participants were self-reliant. The participants also recognised that others could intimate when they were no longer able to do tasks from work situations:

> "a neighbour man called .. one evening …. I was foddering the cattle and scraping up the silage. ..he came in and was chatting and he said, are you able to be at that? I said, I am. So …he passed no remarks and was chatting away and then he left. … in 3 or 4 days …we were chatting. He said, you're a better-looking man this evening than the last evening I was talking to you. He said, I don't think you were able to be at what you were at that evening [foddering cattle]. He said, the look on your face frightened me – ….you were in desperate pain. Some people get to know you have it and are meeting you frequently and they know there's a difference in you at times." (Participant 2).

While participant 2 was experiencing symptoms, it was important for him that he continued to demonstrate that he was able. However, a further conversation revealed that this neighbour could identify without the participant stating that something was not right. For all of the participants there was a recognition that behaviours might indirectly imply or intimate that there was a problem. Therefore while verbally, they did not complain, they also sought, by their behaviour, to demonstrate ability and a sense of normality. It was important for the participants to complete any tasks or aspects of their role as proficiently as others, and, thus, divert attention away from themselves. The manner in which they completed tasks could not reveal to others any problems that they had. In this the participants were concealing any deficits and portraying a sense of normality to others. It was the awareness that others can pick up when there is a problem that supported the participants' decision making about behaviours and normality. Factors important for participants when deciding were the ability to complete the task, to complete it as proficiently as others, to conceal any body language indicating discomfort or modification of the task, for example, facial grimace or handling equipment in a different way. If participants were unable to complete tasks, they deflected conversations and implied another acceptable reason for being unable. One participant referred to this as bluffing her way through work:

> "……. may sound very silly but I hide it and I'm not like …..I get through work by bluffing." (Participant 4).

> [conversation with work colleagues] ..”I say I am going to bed early tonight; I get so distracted in films “ [referring to the fatigue]. (Participant 25).

Participant 25 admits being tired to work colleagues and implies that this resulted from engaging in social activities and going to bed late. The participant cleverly concealed the fatigue being experienced and managed the information work colleagues received. In this situation suspicion was not aroused in work colleagues and they were unaware of the real reason for the tiredness or the extent of the fatigue. Deflecting was a frequently used strategy to manage disclosure. For some participants they managed disclosure by enduring the symptoms and getting on with tasks.

> Does not speak of her symptoms gets on with the tasks - -walking helps to deflect the anguish of not being able to speak the truth. (Field Notes, Participant 19).

While participant 19 gets on with the task, she acknowledges the impact upon her person. For most participants maintaining disclosure was more important than considering the impact on self. Some participants deflected attention from their RA by changing work patterns to deal with periods of fatigue or to manage clinic appointments as illustrated in the following examples:

> Takes a day off work (Annual Leave) to attend clinic appointment.
> (Field notes, Participant 8).

> If she finds the fatigue getting too much, she will find some family excuse and do a swap of shift pattern with a colleague to a shift where there are fewer heavy tasks to be completed. (Field Notes, Participant 14).

Managing Disclosure was essentially about the participants restricting what information was gained by others and, therefore, protected their fragile self-worth. The task of *Managing Disclosure* was continuous and needed energy to identify potential instances for disclosure and planning for deflecting behaviours.

Supremacing Medications

Supremacing medications was an important process in concealing the participants’ diagnosis and life with RA. The word supremacing signals the significance of medications to the participants. The participants experienced physical and psychosocial dimensions while living with RA. While the participants concealed their RA by managing communication and relationships with others, they were very aware that they needed the assistance of medications to continue concealing. Medications enabled them to overcome the fatigue, the increased pain experienced after completing strenuous tasks and the exhaustion when they attempted to continue with physical activities, all of which never relented. Medications gave participants a way of dealing with the ongoing symptoms, which enabled them to continue concealing their diagnosis from others and living life as they normally would.

Initially participants were cautious about taking medications due to the side-effects. All participants hesitantly started to take the medications and then discovered the impact that the treatments had on the symptoms they experienced. For many of the participants, the medications brought relief of their physical symptoms and permitted them to do normal things:

> “.. I can put my foot out any time of the day or night on the floor and be able to walk like a normal person, that’s brilliant.” (Participant 10).
>
> “just magic! it is "brilliant" I don’t know what I will do if I cannot have it. The Methotrexate [specific drug] just makes such a difference.” (Participant 20).

For some participants discovering the medication that relieved their particular symptoms took longer. The time period of trying a medication, realising it was not working and then trying another drug was challenging. The participants experienced relief when the medication that worked for them was discovered, which enabled them to get on with their life.

Initially participants engaged with professionals to gain practical knowledge about the drugs, for example, the different regimens, how to get the repeat prescriptions and how to store the drugs. These details were important, as the participants wanted to continue with the medication that brought them relief and supported them in living normally. While some of the medications were in tablet form, others were given by injection. For all of the participants this was a new skill that had to be learned but this was embraced. While some participants would have given injections to animals, they found that initially it was different injecting the self. However, as the participants gained confidence and the skill became natural and any initial fears were relieved:

> “The first time I was a bit touchy with it. My partner said she would do it the first time. I didn’t want that because you’re waiting for someone so I done it. It’s just cleaning it up and washing ……. The first time with the needle, I had the button pressed. Then not a problem.” (Participant 8).

The participants were delighted with the impact the medications were having on their symptoms, as it was a return to normal life and no-one would discover their diagnosis.

However, the arrival of the symptoms again was a reminder that the RA was still present [33]:

> “The symptoms started to come back the pain, the stiffness.” (Participant 29).
>
> “it wasn’t working so anyway they changed me onto Enbrel so I have been on that … ten years.” (Participant 1).

For the participants the re-arrival of symptoms shattered the illusion that the RA had been mastered. They realised that the reality was that RA condition consisted of quiet periods and flare-ups was clear. The continued experience of flare-ups provided occasions when the participants increased their learning about different drugs, as the medical team endeavoured to identify another drug that would halt the active phase. As the knowledge of the names of drugs increased so did the knowledge of side effects:

> “I suppose the biggest part with Methotrexate is this nausea. ..love to get sick and be done with it …. very debilitating.” (Participant 10).
>
> “Desperate headaches ..I rang them [referring to clinic] and said stop it. Then he [Consultant] put me on the Arava then …it was the first real relief from pain.” (Participant 2).
>
> “They put me on Enbrel and I thought I was doing great on that …came in one day and he [Consultant] said, I have to change it. My blood cells were too low.” (Participant 3).
>
> “I realised that there’s an awful lot of foods I don’t like anymore… blamed the Abatacept injection .. All foods I loved… “ (Participant 25).
>
> “… were always thinking of the damage it was doing to my liver. Getting blood check every 3 months to see if all is ok.“ (Participant 23)
>
> “I would be careful about infections now -especially the chest and the kidneys.” (Participant 22)

Participants were familiar with any drug that they had been prescribed from the time they were diagnosed. This familiarity was in part due to person centered care delivery by professionals and also because the participants did not want to be prescribed a particular drug again either because it was no longer effective, or they had experienced side effects.

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[33] RA is marked by variation in pathological activity. Medications may alter this activity and the person would experience less symptoms. When medications are no longer effective to halt the pathological activity the person experiences symptoms. RA never goes away it is either in an active or inactive state.

Participants also supplemented their regular medications with over-the-counter analgesia when they experienced niggles of pain in muscles or joints. While this assisted them in maintaining some comfort, there was also something important in identifying niggles. Participants had to distinguish between niggling pains and the onset of a flare-up. Knowledge of flare-ups gained already assisted them in detecting or being suspect of a flare-up. The first line of attack on a flare-up is a group of medications known as steroids and these are prescribed by a medical practitioner. While participants took supplemental medication, they observed its effectiveness and when the symptoms were not being relieved, they sought professional help, as they were aware that early intervention was important in managing a flare-up:

> "..Paracetamol if I felt some niggles in my joints. I would not take them every day just when I needed them but maybe 3 times per week. More comfortable when I take them." (Participant 21).

> "On occasions I would take Ibuprofen – good for keeping all quiet – but if it got really worse, I would ring the clinic if I wasn't going for an appointment in the next week or so." (Participant 18).

> "Sometimes I would take Paracetamol but if that was not working or I felt the twinges were getting worse I would go to the GP as I might need steroids – just to try and avoid a bad flare-up." (Participant 15).

Medications were very important because of the impact they had on the features of RA. Nevertheless, the prescribing, administering and monitoring of these medications were different to other drugs and required some adjustment in the participants lives. The adjustments, while inconvenient, were tolerated and viewed as part of the process of being able to live a normal life. Some examples illustrate the adjustments:

> "bit of a nuisance if you're going abroad – need letter from the Doctor and keep it [drugs] cool" (Participant 26).

> "You go to the chemist – you get a sharps box [hard plastic box for needles]…. get that collected when it is full … ring the HSE ….they come and take away the full one and give you a new one. [referring to the process with needles and syringes] ..you just get your medicines from the chemist but it is a different kind of prescription .. the consultant has to give you …..one of those high tech ones .. …go to the same chemist because the chemist is named on it …" (Participant 5).

> "..have to go to GP and get the bloods done and ring for the results" (Participant 16).

The treatment process did incur additional expenses and for participants who were in receipt of a medical card they were relieved as identified in the following quotation:

> "I am very fortunate to have a medical card. I could not do it otherwise" (Participant 19).

For other participants the expenses incurred had to be balanced with other expenditure. The medications were given priority in budgeting finances over other expenses as indicated in the following examples:

> "€114 every month –every time you go to the GP it costs and the bloods [referring to having blood tests every three months].. not included on the long term illness scheme....it annoys me – … diabetes ..it's on the long term illness list – .. don't have to pay …I am working I have kids going to college –a squeeze ..have to pay for everything -.. it's not right that when you are landed with something that is life long - like you are never going to get away from this [RA]." (Participant 11).

> Sometimes to manage the finances she will skip some medications so they will last longer. (Field Notes Participant 11).

> "I have a medical card. I am lucky. But I have a low income and paying for blood tests, administration charges and other living bills is hard. The deciding factor is What is essential? I need extra heating to make living easier. So winter is more costly. Also lack of public transport means having a car and balancing the cost – asking the question "What is important for me to live in comfort? then that sometimes help with making decisions." (Participant 15).

This was difficult when holidays and children's college education had to be considered. Participants considered that finances should be made available to support living with RA, making it possible to do other activities that might help living with RA or help with supporting the joints e.g., regular swimming, or massage. Balancing available funds with specific needs was a challenge.

Overall, medications were important for the participants, as they enabled them to get on with living a normal life. In the stage of *Insulating Self-Worth,* the medications made it possible for the participants to conceal that they had RA. Initially when the participant was prescribed the medication that relieved their symptoms, they imagined that the RA was being dealt with until they experienced a flare-up. The reality of RA as a long-term condition with physical and psychosocial dimensions became very real again. Despite having to learn new skills and knowledge, encountering side-effects, making life adjustments and managing expenditure, medication remained significant and, for the participants, an essential element in the process of concealing.

Guarding

Guarding enabled the participants to continue to live normally and detract any attention from any of the symptoms they were experiencing. I have conceptualised all the behaviours that the participants undertook to continue to live life normally and conceal their life with RA as *Guarding*. Participants needed energy to be able to continue to fulfil normal work routines and tasks. Acute episodes of fatigue could present at any moment either in low disease states or acute flare-ups, draining the participants energy resource needed for other activities. Fatigue was an ongoing feature that just became more acute. Medications[34] that the participants were taking to manage the RA influenced their experience of fatigue. So, when participants were due to have their next dose of medication, the fatigue would be more pronounced and would not respond to resting as highlighted in the following exemplars:

> The tiredness is not linked to anything she has done – it just "hits" her. (Field Notes, Participant 1).
>
> A day or two before her next infusion [the Intravenous administration of medication] she feels she could sleep for 24 hours and still be drained. (Field Notes, Participant 11).

All the participants guarded against becoming over tired and dealt with the fatigue in a variety of ways. For the most part the participants planned their day spreading their energy levels across all the activities that they had to do, thus preventing over-tiredness. Over-tiredness and increased pain resulted in nausea and exhaustion. All of the participants managed their energy levels in different ways. For some participants periods of rest during the day helped to buttress their energy levels and were seen as important, whereas others kept going until the weekend and then rested as illustrated in the following exemplars:

> On occasions she can feel physically sick with the tiredness. She manages the tiredness by having "power naps" Power naps are having a lie down which reenergises her -this could range from ten minutes to half an hour. Power naps release the horrible feeling and might give her some energy, but the horrible rotten feeling of sickness is gone. (Field Notes, Participant 1).
>
> She keeps going during the week - talks herself through the week but is absolutely exhausted on Friday. (Field Notes, Participant 10).
>
> Takes a lie down to relieve the fatigue. He works around this in his life making sure, he has sufficient rest to be able to continue in his full-time work. This is his normal routine. (Field Notes, Participant 2).

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[34] Medications are administered in various ways: tablet, injection (self-administered) or by intravenous infusion (given into a vein). People who get intravenous infusions general refer to these as infusions.

> Has a nap every day for 20 mins in the chair – just falls asleep and feels the better of it – feels he has more energy. No matter what loud noise surrounds him, he just falls asleep. (Field Notes, Participant 13)
>
> ..does get tired so rests often to re-energise (Field Notes, Participant 26).

For participants it was important that others outside their immediate inner circle of family and close friends remained unaware that they were taking naps. This was very important for concealing their RA and protecting the image they wished to portray of being able and self-reliant.

All participants concealed the presence of any of the features of RA in their life. For some participants joints would be swollen and or deformed. Participants used clothing to hide the obvious deformities and concealed the swelling. Thus, it detracted attention of others from glaring or asking questions.

> She describes the challenges of hiding her hands and showed me her hands which up to this point in the interview were somewhat concealed by the sleeves. The joints are disfigured on both hands. She feels it is easy to disguise her hands except when they become more swollen. During the interview she continues to have the sleeves over her hands. (Field Notes, Participant 17).

When ankle joints were disfigured this was more challenging to hide, as inevitably it affected walking. However, participants invested in good shoes which assisted with posture and walking and also trousers hid the obvious deformity. For other participants guarding involved taking medication to enable them to continue with various aspects of life roles:

> "I would be taking painkillers at lunch break just to get myself geared up for going out for the PE in the afternoon. PE would be part of the curriculum and I was always very conscious…..PE would be one of the most difficult subjects I would have had to teach because of my mobility, and I was not going to let it be said that the children missed out on their PE because I had arthritis." (Participant 9).

Fulfilling normal roles in life was extremely important for the participants as an element of concealing their RA and, therefore, insulating their self-worth. For the participants the continuation of symptoms and restrictions in living together with the struggle to appear normal was challenging. Participants felt that they were losing control over their life. The next sub-core category of *'Insulating Self-Worth'* describes how they responded by actively asserting control over their life.

Asserting Control over RA

The arrival of symptoms, the ultimate definitive diagnosis and the participants psychosocial understanding seemed like the declaration of the robbery of their life. The participants were not willing victims and, therefore, they were determined that RA was not going to achieve control. The participants actively resisted any ownership or acceptance of the RA and sought to be in control of their life. I have conceptualised this as *Asserting Control*, wherein the participants denied the existence of RA and equipped with the urge to be in control of their life proceeded to live with no modifications. Denying and continuing to live as normal created the illusion that they were in control and not requiring any supports or help from others in living. Psychologically being able to manage the symptoms and function in their normal routine helped participants believe that the RA was not in control and in living their life they could address the issues and get on with living. The participants had an urge to self-manage:

> [referring to fatigue] “I have all this will power [urge] myself to do things and to do things more than let somebody else do it.” (Participant 2).
>
> “I want to do everything that a person my age can do, I want to do. Now I don’t want to run marathons, I’m too lazy but I want to do everything else.” (Participant 10).

The participants perceived that taking medications was sufficient adjustment in their life and any further change or regulation was not needed, as they were in control of their life. The participants perceived that they could manage without the assistance of others including professionals and support groups. For example, the following illustrates how physiotherapy acknowledged by health professionals as an important support was not deemed to have any additional value:

> "I am walking 2 days a week around marts [animal trading] Why would I need physiotherapy? (Participant 14).
>
> “Not need support groups - my mother joined Arthritis Ireland [national support group] - looking for a cure - herbal remedies.” [referring to when she was diagnosed as a child]. (Participant 15).

Asserting Control over RA was about the participant making their own decisions about living. Considering others was a form of distraction that permitted the participants to live the illusion of control, as a distracted mind did not have time to consider the self and the RA. Psychologically, the participants aimed to do this, but the symptoms of RA presented:

> "Care about others – other people are important, and you have to help others – then think about yourself. Then again you can get very tired and a bit of pain" (Participant 17).
>
> If she does any activity that she does not do every day, she will get very sore. (Field Notes, Participant 27).
>
> Does gardening and sometimes does too much - feels tired and sore. (Field Notes, Participant 21).

Asserting Control was portrayed in living life as it was prior to diagnosis and in distracting activities, both of which decreased the participants capacity for considering RA as taking over their life. Therefore, they maintained the illusion that they were in control and they were not going to become dependent or disabled. The participants regarded that they were in control of their RA and therefore made choices that they wanted for their life gave little attention to the RA. But as the above examples allude the symptoms kept presenting and some further adjustment was necessary. The participants dealt with these situations by taking extra rest periods and taking medication for pain. For one participant at this stage she adjusted her life as illustrated by the following:

> ..so she avoids and leave housework undone. For the most part she will do all the work but will do so more slowly. (Field Notes, Participant 27).

Some participants, anticipating pain, will take medication prior to activities. Portraying an image of self-reliance increases the confidence that other people cannot discover the big secret that they have RA and participants considered that they were in control of their life.

This situation is upset when a flare-up arrives. The participants realise that they cannot manage the symptoms and they are very unwell. In the flare-ups they get a sense of how controlling this RA is:

> "That was really bad and I came back and I came in for a week (inpatient in Clinic facility). That really helped me." (Participant 24).

All the participants realise that medications assist them in maintaining the illusion of normality and being in control of their life. Flare-ups of active disease were frightening physically with very severe symptoms and on occasions required acute hospital treatment. The flare-ups were devastating psychologically, as the participants faced the reality that they did not have control of their life despite all their efforts to live normally and ignore the RA. This also accentuated the fear that the RA was going to negatively impact upon their social worth. When flare-ups were managed[35] and the RA was brought back into an inactive state again, the participant returns to trying to *Asserting Control*. This cycle was repeated until eventually the participant was no longer able to conceal their diagnosis or assert any control upon their life and living.

Conclusion

Insulating Self-Worth represents the first stage in the process of resolving the main concern of *Fear of Declining Self-Worth*. Participants are in a psychological state of flux when they enter this stage. The stage was defined by the state of *Captivity* which was a preoccupation with the psychosocial considerations about RA by creating an Awareness Context through which they considered how and in what ways they would behave within different environs and different people. In *Insulating Self-Worth* the participants respond to the threats emanating from the psychosocial dimensions of RA. The categories of *Concealing* and *Asserting Control* explained how participants processed the main concern in this stage.

Concealing was very strong and was enforced by the psychological state of flux. Participants resisted the diagnosis and anything that suggested the existence of limitations to others. In this stage participants yearned for the old normality of living. However, the participants experienced pain and restrictions in living, increasing the fear that the RA was going to get worse and therefore engaged in maintaining the life they had prior to their diagnosis. Participants concealing their actual experience and were mindful not to be complaining. Conversations, therefore, are on general everyday topics, with avoidance of any personal health details. The consequence of circumventing health conversations is avoidance of pity or the undermining of physical ability through kindness or lack of knowledge of RA. Being pitied and being viewed as unable undermined their person and ultimately what participants were trying to do which was to defend their self-worth and resist the existence of RA. Participants do not disclose aspects of their diagnosis or life with RA except with some very carefully selected individuals. Non-disclosure served to protect from the verbal and physical expressions of pity from others. Expressions of pity have two outcomes. One outcome is that it challenged the participants' ability to resist the threat to self-worth. The second outcome is that pity

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[35] When an acute attack of RA presents a variety of medications are used to decrease the symptoms and bring the RA into an inactive state.

undermines participants' aspiration to fulfil their normal role in life as defined by the social units they belong to. Both of these are to be avoided.

As the knowledge grows and the individual has more flare-ups,[36] the psychological state starts to become vulnerable. Participants increased their knowledge regarding medications, as they were viewed as very powerful in relieving the symptoms and, therefore, supported their efforts in portraying that they were self-reliant and able. The arrival of flares-ups, the limited effectiveness of medications and the experience of side-effects reminds them that the RA is still active and has control of their life. The energy levels to continue insulating are diminishing as they cope with normal life events in combination with living with RA.

Other major life events also do not go away (family concerns, other health concerns) and may combine with RA trajectory to increase the vulnerable state. Participants began to question who or what their life is all about. Living becomes too much and the participant enters a vulnerable psychological state. The desire to go beyond RA prevents participants from remaining in stage 1 indefinitely and they move to stage 2 *Scoping Self-Worth.*

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[36] The RA pathology is marked by periods of inactivity and active states (also known as flare-ups). In the inactive state where there is no identifiable increase in inflammation, whereas in the active state the increase in inflammation results in an increase in symptomology.

CHAPTER 7 SECTION 2 SCOPING SELF-WORTH

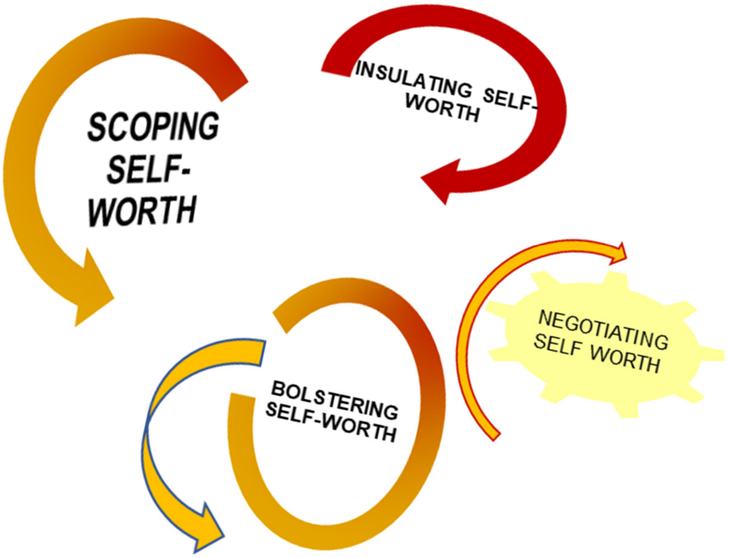


Figure 19 ***Scoping Self-Worth***

Introduction

The previous section identified that *Negotiating Self-Worth* was a three-staged process by which the participants processed their main concern, which was their *Fear of Declining Self-Worth*. The participants, having reached a critical juncture of flux, vulnerable or secure, proceed through the process. In the first stage, *Insulating Self-Worth*, it was established that the participants were in a psychological state of flux and were consumed by the thought that RA was going to negatively impact upon their self-worth. In that stage the participants reacted and responded to insulate their self-worth.

Unsuccessful attempts to control RA, combined with other life challenges, for example financial issues, health, relationships and experiences of loss, contributed to the psychological state of vulnerable. The participants experienced a difficulty in identifying what possible meaning life could hold for them and they perceived that becoming old, dependent and a burden upon society was becoming a reality. Their *Fear of Declining Self-Worth* was at its pinnacle. The repeated flare-ups, the energy taken to conceal the diagnosis and assert control, combined with normal life events, became too much. The participants moved to the next critical juncture and became vulnerable. At this point they enter the second stage of the process which was conceptualised as *Scoping Self-Worth.*

The intention of the participants in *Scoping Self-Worth* was to investigate what possible meaning they could have in their life and they carefully pursued knowledge to help them gain some insights. Essentially in this stage the participants had a yearning for a different life. Nevertheless, they were cautious. In their vulnerable psychological state, they were hesitant to explore the possibilities that might give them some answers. As the participants became less hesitant and engaged with resources, they followed two parallel processes of *Discovery* and *Deliberating.* In these processes the participants discovered more about the condition of RA and increased their own self-awareness to the point where they acknowledged the self as worthy of recognition. In *Deliberating*, the participants considered the knowledge of RA and the relevance this had for how they lived their life. In *Scoping Self-Worth,* the participants came to understand that it was their acknowledgement of the self and their attitude to living that would bring some meaning to their life. They also discerned that having a positive attitude was an important ingredient to support the process. For some participants the journey through this stage was too much and they reverted back to *Insulating Self-Worth* to return to *Scoping Self-Worth* at another time.

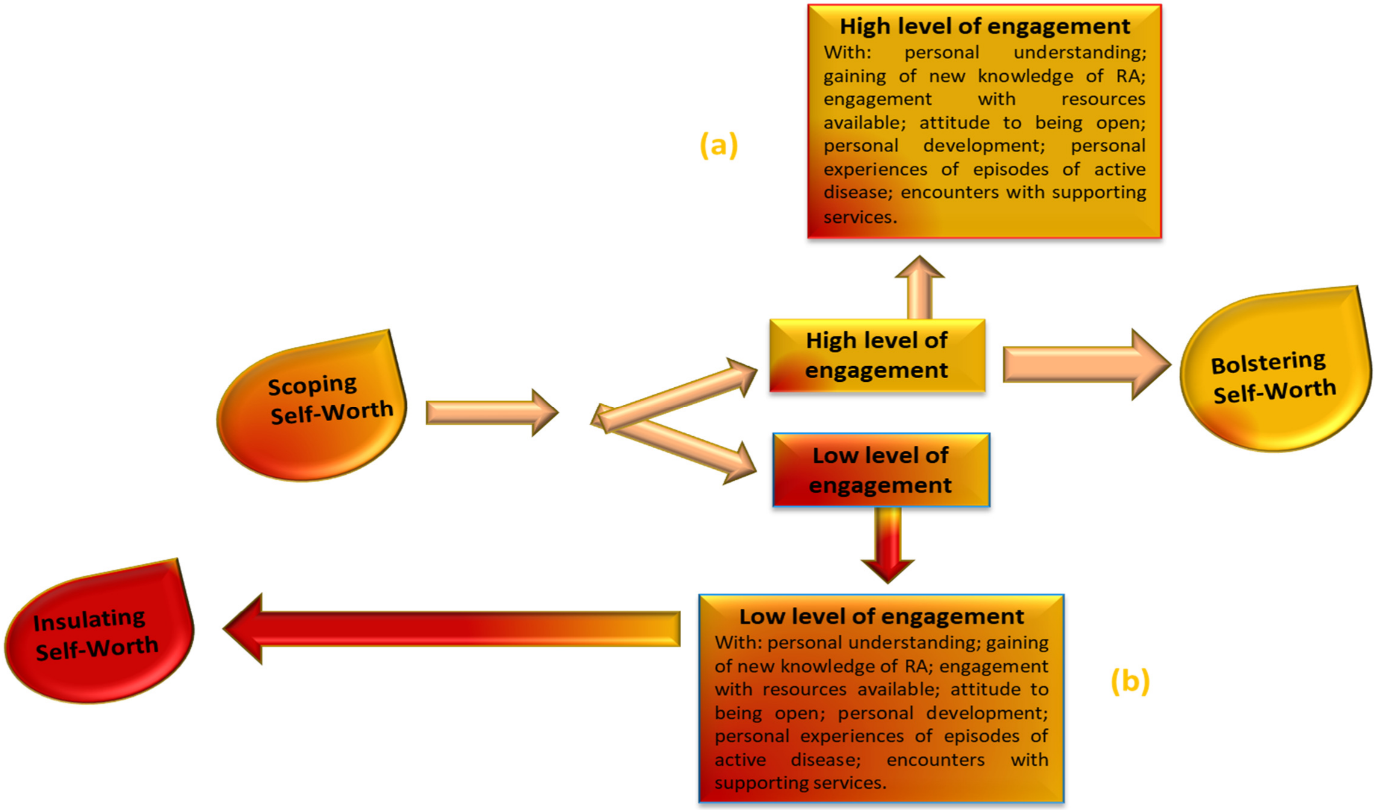
In *Scoping Self-Worth,* the participants considered the meaning of life for them as individuals and as social beings. In the process engaged with others in relationships, gained knowledge about RA, and became more self-aware. They engaged in thinking about all the knowledge they had gained and what it meant for them. The process took courage. When the participants entered this stage in the process they were in a vulnerable psychological state and their thoughts were dominated by RA as a disabling and disarming condition. Such suppressive and oppressive thoughts initially restricted any opportunity to consider any other meaning. However, the participants had a zest and a yearning for something different. *Scoping Self-Worth* signalled a difficult internal struggle for participants as they increased their awareness of the self and recognised self-inhibiting behaviours which contradicted with their new understandings of RA and prevented them from finding alternative ways of being. It was the yearning for something different that brought an energy to the endeavour of *Scoping Self-Worth*. The participants remained in this stage for different lengths of time, with progress dependent upon personal skills of self-awareness, thinking ability (critical and creative), attitude to increasing knowledge of RA and engagement in interpersonal relationships. Engagement with resources during this stage supported the participants in gaining some ideas about a different life for themselves. *Scoping Self-Worth* is characterised by the properties of *hesitancy* and *engagement* and the two subcategories of *Discovering* and *Deliberating*.

Sub-Category of Scoping Self-Worth: Hesitancy

The art of *Scoping Self-Worth* was characterised by hesitancy which indicated that the participants thoughts and actions were considered and cautious. The participants retained an attachment to their desires and hopes for the future. However, they were confused as the future was very unclear. This confusion emerged when all their efforts of insulating their self-worth had been unsuccessful and they were hesitant to embrace a world which they recognised as unrelenting loss in all aspects of their life. In *Scoping Self-Worth,* the participants encountered more information about RA and listened hesitantly as they perceived that this knowledge was not entirely relevant for them. The participants remained hesitant and cautious to take any new steps in their life which might have improved their quality of life or the management of the RA. However, the participants did with some hesitation try new things upon the suggestions from others with whom they had a supportive relationship with. The flare-ups characteristic of RA persisted. The participants understood that all knowledge was relevant and thus they became eager to engage. As they hesitantly tried out new ways of living and doing things, they learned more about themselves as individuals and their approach to life. Additionally, when there was a positive result from an action, the participants gained confidence to try new approaches in other aspects of their life. As the participants progressed in *Scoping Self-Worth* the hesitancy waned, and their confidence began to grow. Supportive relationships helped the participants progress from hesitancy to confidence.

Sub-Category of Scoping Self-Worth: Engagement

In the vulnerable psychological state, the participants gradually engaged with resources and relationships which assisted them in exploring life and living, i.e., *Scoping Self-Worth*. They played an active role in consultations with the professionals and education programmes. Resources refers to any accessible form of support. Some examples would be professional consultations (for example, physiotherapy, pharmacist, nurse doctor); specific therapies (for example, medication, exercise, counselling, yoga, hydrotherapy); administration (for example, being able to gain consultation with professionals); social supports (for example, club memberships). The participants remained in a vulnerable state but retained a desire to find a solution to their problem. However, the participants were unable to visualise or articulate any answer to their yearning for something different to the life they had. This desire fuelled an openness and eagerness towards engagement in their search for an undefined and undetermined solution. Initially it was a cautious engagement. Engagement occurred at two levels (high level of engagement and low level of engagement) as illustrated in figure 20.



High level of engagement
With: personal understanding; gaining of new knowledge of RA; engagement with resources available; attitude to being open; personal development; personal experiences of episodes of active disease; encounters with supporting services.

Low level of engagement
With: personal understanding; gaining of new knowledge of RA; engagement with resources available; attitude to being open; personal development; personal experiences of episodes of active disease; encounters with supporting services.

Figure 20 Engagement in Scoping Self-Worth

Participants who had a high level of engagement (a) with resources and engaged in meaningful dialogue progressed in *Scoping Self-Worth* until they reached a critical juncture of a secure psychological state. Meaningful dialogue refers to specific relationships with others who had an invested interest in them as persons. The participants identified such people as compassionate and understanding. They understood that genuine engagement led to new insights about RA and their life with RA. Participants described how engaging with professionals and interacting with resources was very beneficial to them in finding some meaning for what they were experiencing in their life with RA. The following exemplars illustrate that engaging with resources at the clinic was helpful for the journey of addressing the yearning for a different life:

> “They convinced me to stay because whatever tests they wanted to do – if they had brought me back to a clinic later … if there was something going on that they needed to find out then – so bloods and things like that.” (Participant 1).
>
> “All part of the whole programme. They do the relaxation classes. They did physio and we went to the pool. Maybe if I had to do it right in the beginning, it would have been better. [referring to earlier years when she did not relate to others].” (Participant 3).
>
> Feels the clinic is the biggest support for RA. They know and understand and this needs to continue. They look at the whole picture – this makes living possible. (Field notes, Participant 11).

Individuals who had a low level of engagement (b) struggled in this stage and their eagerness for engagement dwindled. The participants did not view that the resources would give them anything different for their life with RA. They felt that living with RA gave them knowledge about RA and, in a sense, there was no more knowledge to be gained. They could not see any benefit from engaging with professionals or any of the resources that were available. These participants still denied the presence of RA as a chronic condition and, not engaging was one way of supporting that denial. These participants had limited self-awareness and were unwilling to invest time in discovering their own person. The following examples illustrate:

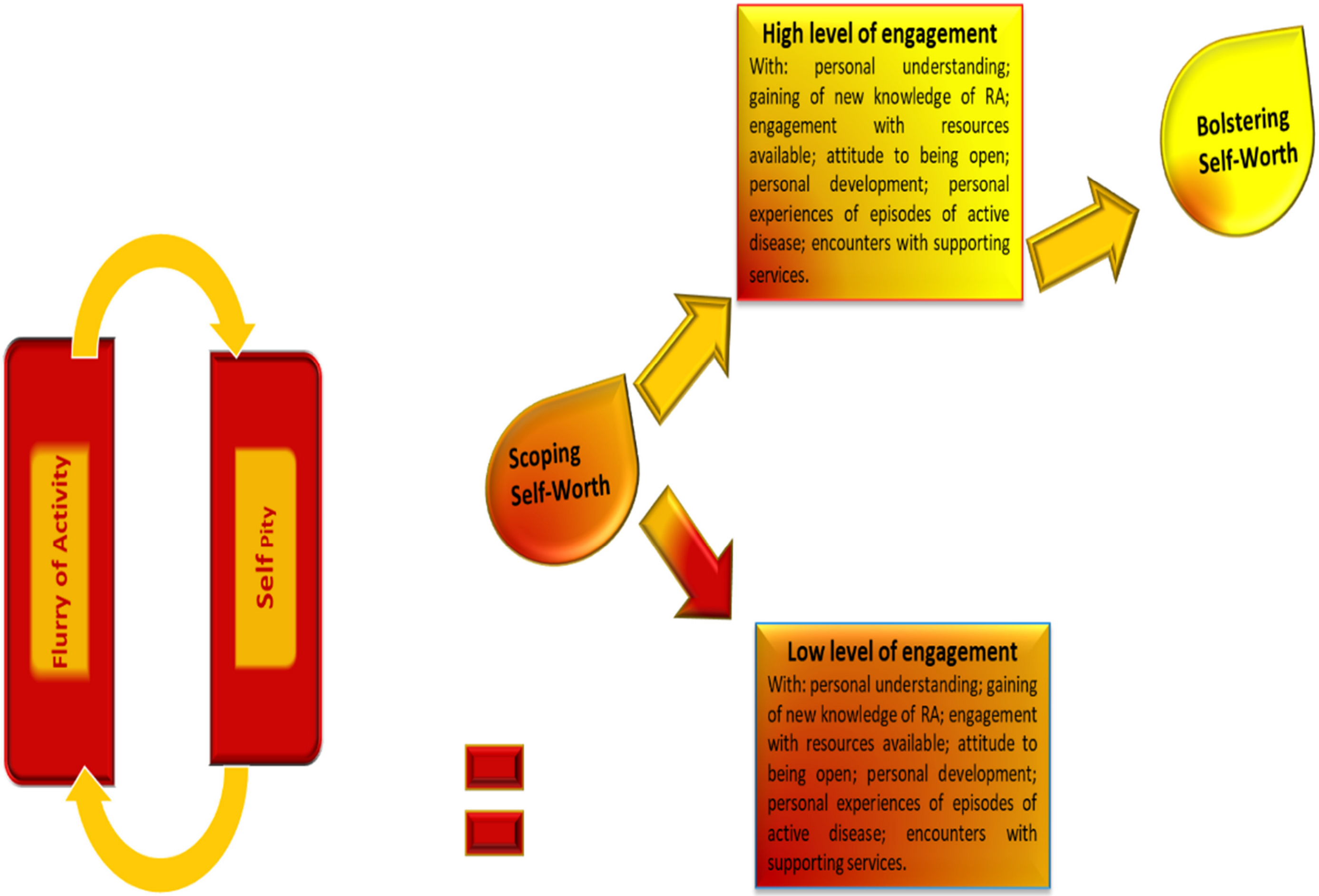
> Does not feel it is worth the effort to have the conversation with others regarding support and she feels this is probably because she wants an easier life and no hassle [referring to changing lifestyle and going for appointments with other members of the Health Care Team]. (Field Notes, Participant 23).

> Finds it hard to go to pool on your own - even if it is worthwhile. Feels exercises are of benefit but hard to keep doing on your own. (Field Notes, Participant 26).
>
> Not aware of Arthritis Ireland - did hear of a meeting in xxxx [location 30 miles distant] Offered the opportunity to go on a pain management course but felt she could manage her pain. (Field Notes, Participant 21).
>
> He [friend] offered to help with tasks but the participant refused as he considered he had to push himself in doing … (Field Notes, Participant 2).
>
> [After a flare up and referring to work] "…the doctor said, you have to get this right. You can't go back. Do you want to end up the same? xxx [partner] would say, you're mad to go back to work. You can't go back. I said, I'm going and that's it and away I went" [returned to work]. (Participant 6).

The struggle in this stage represented an inability to transcend the oppressive thoughts of RA as a disabling chronic condition. The participants were unable to visualise any acceptable social role and perceived that they were going to become dependent on others. To connect with resources equated to accepting that they had RA, that it had control over their life, and also, that they were, in a sense, giving the RA permission to take control over their life. The participants resolved this situation by reverting back to the stage of *Insulating Self-Worth*. A quotation from Peter's account is useful here to illustrate just how difficult life becomes for the person with RA:

> "With no job, the money disappeared ….. I had no disposable income as I had to rely on handouts and benefits. I hated this. …. I was a burden on society, I was useless and on a personal level all I had to look forward to was pain, immobility"…(Peter, p.39).

The participants decided not to engage with supports. They then reverted back to *Insulating Self-Worth* and consequently indulged in a flurry of activity (FA) and self-pity (SP), which I have named the FASP cycle. The FASP cycle reflects a behaviour pattern of a flurry of activity self-pity. The FASP cycle was only evident when the participants reverted back to *Insulating Self-Worth*. The FASP cycle is captured in figures 21 and 22 below.



High level of engagement

With: personal understanding; gaining of new knowledge of RA; engagement with resources available; attitude to being open; personal development; personal experiences of episodes of active disease; encounters with supporting services.

Low level of engagement

With: personal understanding; gaining of new knowledge of RA; engagement with resources available; attitude to being open; personal development; personal experiences of episodes of active disease; encounters with supporting services.

Figure 21 Entering the FASP Cycle

Figure 22 FASP Cycle

When the participant recognised that they were indulging in self-pity, they perceived that they were accepting the RA and so they addressed this by engaging in a flurry of activity. This action while important to distract the participants thinking also indicated to them that they were able and self-reliant and were not permitting the RA to have control. Contrarily, this aggravated the RA and more symptoms were experienced and at this point the participant reverted to self-pity. The FASP cycle continued until the participant gained insights into what was happening, i.e., they visualised a pattern in their repetitive behaviours, as illustrated in the following excerpt from a conversation with one participant:

> “back to work .. I shouldn’t have went back. I had to be ..working all the time.. no-one else could do the work. Running and racing what I was at was mad and sure it was making the whole arthritis thing worse … I worked harder to cover up and then I thought to myself what am I at? (Participant 3).

Engaging with supportive relationships enabled participants to gain insight into the FASP cycle. The participants remained vulnerable but, once they gained this insight, they were ready to re-enter the stage of *Scoping Self-Worth* which is illustrated in **(1)** figure 23.

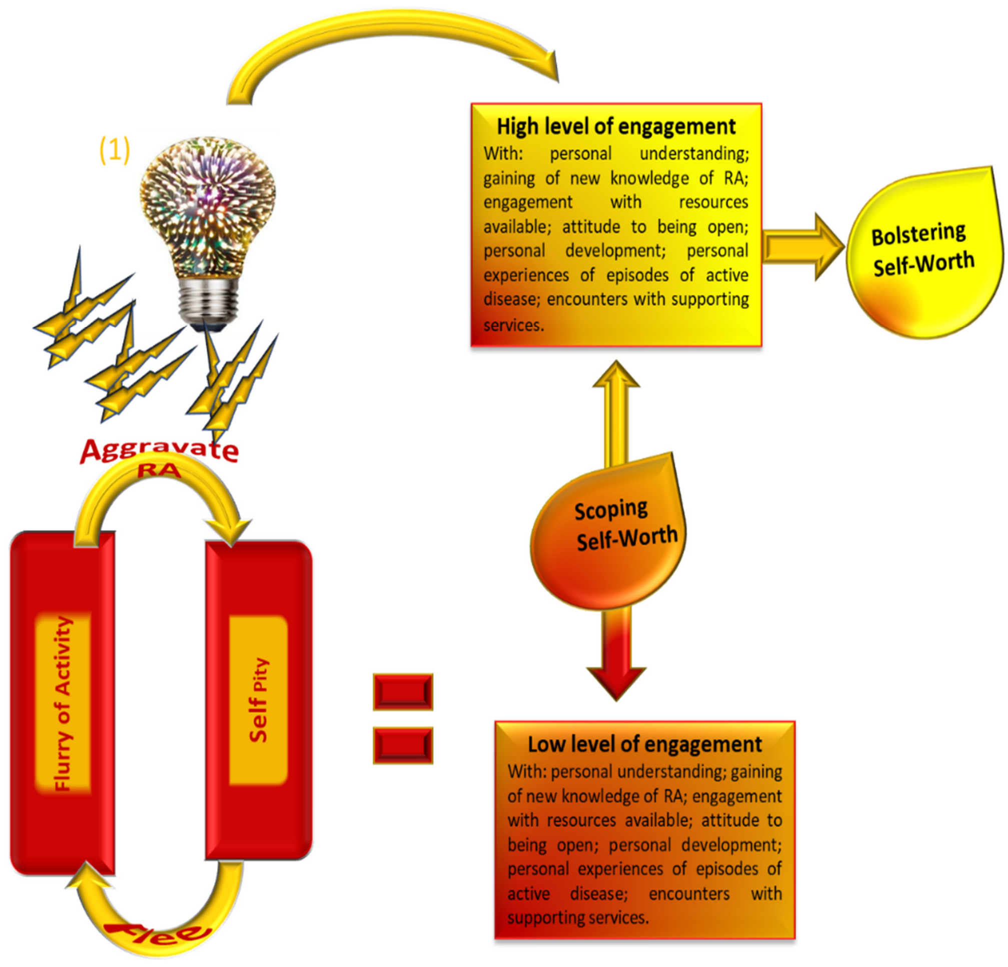


Figure 23 FASP and insights

Scoping Self-Worth has two sub-categories of *Discovering* and *Deliberating.* These categories are parallel processes which the participants engaged in to find some meaning for their life. While I will describe each category individually, they are interconnected, in that each process has a direct influence on progression in the other process.

The participants entered *Scoping Self-Worth* in a vulnerable psychological state and their attempts to eradicate RA had been unsuccessful. They continued to experience the physical and psychological dimensions of RA as described by Ken:

> I hated the way I was and what this disease was doing to my head. For years I'd just pretend to be ok, but putting up with …… destroys your confidence and the person you used to be. (Ken, p. 59).

The participants had put a lot of energy into concealing the diagnosis. It seemed like their worst nightmare had come through and they are going to become dependent, infirm and a source of pity. But in their vulnerability, they had a zest for something different. This is what motivated the participants to reach out and discover possibilities. The engagement with resources[37] gave them the energy to respond in their vulnerability and they began a journey of Discovery.

Category of Scoping Self-Worth: *Discovering*

Discovering is essentially the participants gaining an awareness of themselves as social beings. Previously, the participants had some knowledge of different health personnel and resources, but in *Scoping Self-Worth*, there was an increased understanding, awareness and active engagement with them. It was in this engagement that participants gained a fuller understanding of how and in what ways resources could be of benefit to them. In the process, they gained insights into the self as a thinking, feeling, social being. Discovery has three sub-categories of *Exploring Relationships*, *Acquainting with Compassionate Others* and *Acknowledging the Self*.

Exploring Relationships

The sub-category of *Exploring Relationships* was essentially about the participants beginning to gain a different perspective on relationships and engaging cautiously with

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[37] Resources are discussed below.

others in their vulnerability. The cautious connecting with others was evident in the pseudo-friendly relationships engaged in, which were more prominent when they first entered the process of *Scoping Self-Worth*. In their vulnerable psychological state participants were longing for help yet they very cautious. Others who had a vested interest in them reached out to the participants with compassion and this triggered the beginning of an openness to relationships. For the participants this created a possibility of considering the intentionality of others for conversations and not instant dismissal as Participant 12 identified following an encounter he had:

> "..the end of any session she'd say ….. are you able to get into the car on your own? Will I go down and give you a hand to get into the car? which told the tale that she's a really nice person and there was nothing meant by it." [referring to a comment made previously]. (Participant 12).

The participants began to realise that their evaluation of others having no interest in them was incorrect, as some people offered some insightful and respectful comments or assistance. These insights prompted some doubt around the previously held certainty that all individuals were insincere and snoopy. These experiences enabled the participants to increase their openness to others as evident in the following exemplar:

> "I am lucky …. they [work colleagues] don't ask. They see me going to move, ….and my laptop and all is down. ..I don't have to ask. I'd say, I'm fine. You're not fine [reply of colleagues]. (Participant 10)

The insights the participants had gained prompted them to reassess how they viewed relationships. The genuine interest was evaluated in the behaviours observed, such as active listening and authentic comments articulated in a supportive way. These individuals were willing to engage and relate to the participants as a person and to respect their abilities regardless of any obvious deficiencies, as illustrated in the following quotation:

> ".. off to do something and let me ask for help. …different when I was pregnant, they were protective and told me to look after myself" (Participant 15).
>
> "the practice nurse she has made a huge difference to me as a person…..I am not just an number coming in to get bloods done - she has an absolute interest in me - all the aspects of my health." (Participant 21).

Others who engaged with the participants in a respectful manner gave them permission and the opportunity to explore and consider suggestions for dealing with aspects of RA, or just for general living and life with the condition of RA. In the engagement the participants perceived that others had no expectations of responses or acceptance of any elements of the conversations. The other person in the conversation was compassionate, open to supporting and focusing on the agenda of the participants. It was the connection and expression of authentic concern that helped the participants to engage in supportive relationships, In the process, they gained valuable insights about themselves and the condition of RA. Supportive relationships began to become evident at the end of the stage of *Scoping Self-Worth*.

Acquainting with Compassionate Others

Acquainting with Compassionate Others was significant and identified a specific element of how others related to the participants. The relating referred to the knowing, understanding and compassionate manner which was evident to the participants in the communications. The most important and significant resource for the participants were other people who related to them in this way. The others could be close friends, spouse or partner or health professionals. These others may have some knowledge and understanding of RA and may use this to connect with the participant. However, the participants identified that these others also know that they cannot fully understand without listening to them. It was the active listening and wanting to know what it is that the participant is experiencing that made the compassion real. Previous experiences of disingenuous relating emphasised also the genuine compassion of others. Maeve put the importance of listening with compassion succinctly when she wrote:

> Re-directing the conversation to some distant unknown is not what a person with RA needs. … hoping for a compassionate ear. …… Éist do bhéal, [listen with your mouth]. (Maeve, p.151).

When participants first entered the stage of *Scoping Self-Worth*, other people were limited to professionals, i.e., GP or staff at the rheumatology clinic, while a small number identified a person with whom they had a long close relationship as fulfilling this role, namely. their spouse or partner. The spouse or partner played a significant role in understanding the symptoms of RA and how this impacted upon the person with RA. They were supportive with realistic expectations as Participant 10 explains:

> “xxxx (partner) comes with me and .. I could be in the shop .. and he’d say, there’s the keys to the car. I’d say, why. You’re green, so he knows”. [referring to his way of saying she is not looking ok and needs to rest up]. (Participant 10).

For many of the participants they felt that there was no-one with whom they had a close relationship, or who really understood the challenges of living with RA. For these participants the General Practitioner (GP) and the professionals in the clinic were the only compassionate other they had. For some participants the GP played a significant role[38]. The significance of an understanding GP was evident in the following quotations:

> I found a lovely GP and she immediately referred me ….. An immense relief. (Mary, p.21).
>
> I have a brilliant GP. He just knows… he really understands… You can see it in how he talks to you he knows how hard it is he is absolutely brilliant. (Participant 19).
>
> ..I was scared he'd [GP] dismiss it all and say it was in my head. I found myself crying as I was telling him my symptoms, finally letting all my fears and concerns out, thankfully he was wonderful. (Breda, p.157).

Similar to the GP experience, the participants described how the professionals in the clinic engaged with them in their state of vulnerability. These professionals specialised in rheumatology. While it is not known if any of them have experienced RA personally, they have studied RA and have professionally engaged with many people who have RA, and therefore, could be regarded as having expert knowledge. The RA trajectory entailed various appointments consulting with the professionals and, therefore, gave opportunities for familiarisation over time. While the participants acknowledged knowing individual staff members, they emphasised how these professionals engaged and interacted with them. It was the connection that was made by the staff that mattered most to the participants, as indicated in the following:

> He talked a lot about the personal support in the clinic and it is obvious he has a very good relationship with all the staff. He has connected with staff and in the connection has been able to get different perspectives on himself and on his life. (Field Notes, Participant 12).
>
> "They know and understand." (Participant 11)

For participants it was important that all healthcare professionals understood RA from a biopsychosocial viewpoint. The participants indicated that the professionals not only knew but also had insights into the experience of living with RA, which secured the relating connection in the relationship. The connection was a pivotal point for the participants starting the discovery journey. It was important for participants that staff

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[38] Within the RA trajectory the GP had an important role initially. This dwindled when a definitive diagnosis was achieved but the GP retained an important role with acute episodes of RA (flare-ups).

connected with them and that it was evident to the participants that they were genuinely concerned about and for them. For some participants who did not experience compassion within their family or very close friends, the staff in the clinic were very important as the following examples identify:

> Cannot depend on own family and has known this. (Field Notes, Participant 25).
>
> "…vital to know that the professionals are genuinely concerned about you and how you are." (Participant 15).
>
> I would recommend being very open and honest … about the impact on you. (Dee, p.47).

The connection enabled an identification with the experience of the participant that is the experience was heard and understood as real. From this fundamental point participants were able to share honestly about how their RA was and significantly about their life with RA. This contrasted with their previous perception. When they were speaking of their experience, they were complaining, and this brought further isolation and they felt as if they were unable, infirm, and becoming dependant. The connected conversations became a starting point for professionals to assist the participants in addressing the many physical, psychological and social concerns they experienced in their life with RA. For many participants the initial professional was the consultant or the nurse, but the participant came to know other members of the caring team through various appointments. In this way other professionals came to be regarded as very important in assisting the participants in living with their RA. Each connection provided an opportunity to suggest other professionals[39] that might be helpful to the participants. For the participants *Acquainting with Compassionate Others* was the first step in identifying that they could safely relate to specific others authentically. It was the first significant step in the process of discovering other possibilities. The connections with compassionate others in confidence enabled the participants to feel psychologically safe. This safety created the opportunity for the participants to acknowledge their own feelings which they had been suppressing.

Acknowledging the Self

Acquainting with compassionate others exerted indirect pressure upon the participants to consider their own person and transcend the normal mantra of symptoms and identify

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[39] This refers to professionals who would not frequent the clinic for example social workers, psychologists.

their feelings as social beings living with RA. The essence of *Acknowledging the Self* was having intrapersonal conversations when the participants asked difficult questions of themselves about their life with RA. It was in tangling with their responses to these questions that the participants increased their self-awareness and came to understand how they made choices about their life. In a sense, the participants were viewing their RA from a distance and got insights about themselves in the process. In this they were not abandoning the RA but giving themselves as the bearers of RA some true recognition.

This very different focus took time, as the participants had to first acknowledge their personhood, and then identify and acknowledge the feelings they experienced. The time was related to the influence of sociocultural beliefs regarding the self and the ability of the participants to identify and engage with what they had previously held as perceived truths about social roles and functioning within society. For the participants the engagement started with asking questions about why they should have this condition which was perceived as awful and why not someone else.

> Why me? I would have thought I had enough with xxxx and xxx [referring to other substantial health events with family]. (Participant 23).
>
> ..a 35year old dad crying in pain and wondering why, why me, why not the guy next door or the person in the next street? (Robert, p.118).

It was this questioning that assisted the participants to continue to explore and ask the question: why not me? It was the responses to these questions that participants continued exploring the self and discover more about who they were and how they lived their life. The participants engaged in many difficult questions about their approach to life and their expectations about life and living. Having engaged with those difficult questions, the participants were able to acknowledge the limitations they had and the extraordinary expectations they had from the self as the following quotations illustrate:

> “Everything was upside down [relating to the confusion she experienced] and I was very tired. Even though I was tired I tried to keep going it took me years to get that into my head” [to rest]. (Participant 3).

> “keeping oneself from stress– let the hustle and the bustle pass by. Stress needs to go” [emphasised in tone]. Previous work was a lot of stress and now she can see this and that she needed to listen to her body and appreciate what was happening. Mental health was also very important – identifies that she has resilience and now views that she was able to cope for a long period when she was younger. “my health and body screamed at me – the pain, I needed to go to a dark place and then identify how to get out of the dark place” (Field Notes, Participant 15).

Continuing to engage with difficult questions gave the participants further insights into motivations for life choices, their behaviours and the emotional impact of behaviours as illustrated in the following exemplars:

> I was becoming a pain to live with. I was on edge all the time; my wife could not talk to me without getting a short-tempered remark back. (Robert, p.117).
>
> One time I would have tried to please everybody, and I don’t do that anymore. (Participant 21).

The participants understood that in living with RA they had got caught up in concealing and being self-reliant. They had not previously considered how this impacted upon their behaviours or how their behaviours had impacted upon others. These questions brought further questions. Participants discovered that the RA had changed their life and their hopes for the future. They recognised that they possessed a hatred for RA which influenced the life choices they made, for example, having a negative attitude toward exercise or not having any interest in knowing what RA was all about. As the participants continued to pursue difficult personal questions, their feelings toward RA altered and they began to look at the influences upon their choices. The following quotations give some indication of the changing perception toward RA:

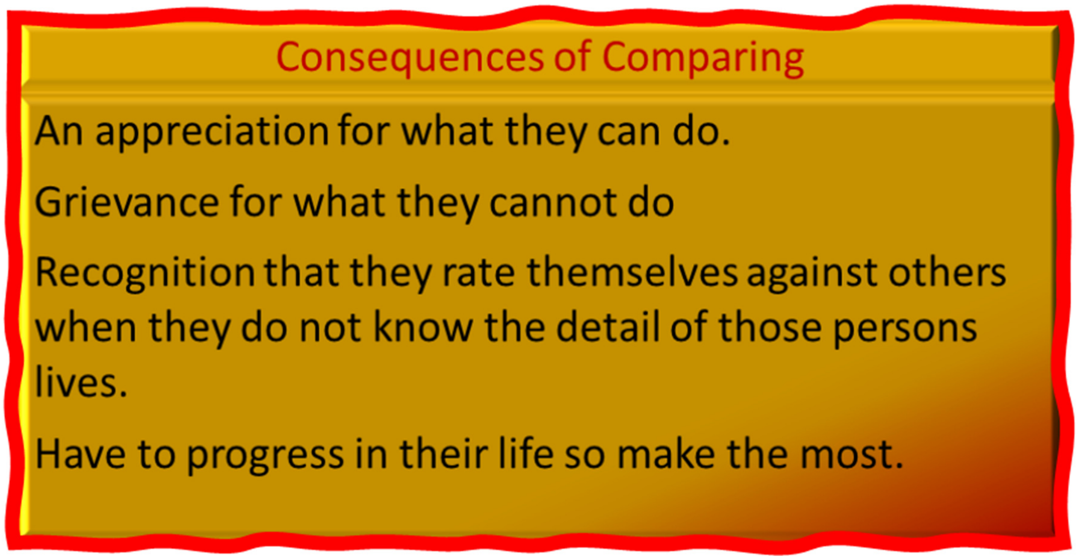
> “Sure, I have RA but someone else has some other ailment. Everyone seems to have something…….. So I have RA get on and deal with it “….. (Participant 28).
>
> “As you go on, you learn more about yourself really”. (Participant 5).

The participants wrestled with the inability to fulfil social roles and the inability to meet not only the expectations of others but also their own. Participants experienced resentment about lost opportunities, and guilt when they did not meet normal expectations as outlined in the following quotations:

> "…I have come to really resent, that I lost so many weekends. My youngest would have been 10 and I'm thinking, she really doesn't know what normal Mammy is like because this is normal to her. Normal Mammies can go out and do a lot more at the weekend" (Participant 10).

> "I meet my friends and by the third shop my lower back, knees, ankles have gone into a full-on screaming tantrum burning, severe pain, tiredness. Stubbornness kicks in…. No not today I am not missing out. …sitting on the bench… I tell my dearest friend about my new meds, physio".. (Pamela, p.75).

Examining regrets and guilt supported the participants in increasing their self-awareness. They gained valuable insights about themselves and their motivations for reasoning and actions. Similarly, participants compared with various social and work situations. They acknowledged that in these situations they were either concealing their inability or overcompensating for limitations. The participants realised that while they had a fear of being labelled as unable, and that they were not being honest with themselves. These insights increased their yearning to find ways of being that enabled them to have a fulfilled life and to be more authentic with the self. Participants compared themselves to other individuals who experienced restrictions with other conditions and concluded that they were doing good. Comparison enabled the participants to put their RA into perspective as outlined in table 12.



Consequences of Comparing

An appreciation for what they can do.

Grievance for what they cannot do

Recognition that they rate themselves against others when they do not know the detail of those persons lives.

Have to progress in their life so make the most.

Table 12 Consequences of Comparing

In summary, the participants understood the significance of acknowledging the self and whatever they were experiencing. Gradually participants accepted that they as persons were important and therefore, they sought to implement this thinking into their actions. Participants entered the stage of *Scoping Self-Worth* in a vulnerable psychological state. They were broken and had a yearning for something different, but not sure what the something would be. Participants responded to their broken state by engaging with compassionate others and began a journey of discovering who they were as persons. In acknowledging the self, the participants also engaged in some interaction about RA. Interacting about and with RA is the next category, which I have named as *Deliberating*.

Category of Scoping Self-Worth: *Deliberating*

Deliberating was a parallel process to *Discovering* and the processes interacted, as outcomes from one process influenced the other. *Deliberating* refers to the response of the participants to their yearning for something different to the life they had lived previously (evident in stage 1 *Insulating Self-Worth*) and indicates the focused intention on attainment of knowledge and the meaning of this knowledge for their life. In essence the participants were motivated, investing energy and time in increasing their knowledge about the condition of RA. The participants responded to the increased understanding by considering how they would implement this new knowledge in their living and how they would situate RA in their life. This category has sub-categories of *Knowing,* and *Hesitant Ownership.*

Knowing

The participants had experiential knowledge of living with RA which was underpinned by anecdotal, cultural and social knowledge. In deliberating, the participants had a readiness to engage in new learning on four specific aspects: (1) Knowledge of the RA condition; (2) Knowledge of the pharmaceutical treatments; (3) Knowledge of the physical self with RA. and (4) Knowledge of the supports available. The readiness of the participants to gain knowledge resulted in a deeper and more nuanced understanding of RA from a multitude of perspectives.

Participants compared pre- and post-diagnosis knowledge and sought to expand and refine that knowing in an attempt to limit the impact RA had upon their life. This comparison enabled the participants to consider some perspectives on RA beyond their personal experiences. The participants compared themselves with others who had RA, for example, ancestors, parents, siblings, individuals in their communities and people they met at the clinics. Comparing with close relations and others whom participants knew had RA helped them to evaluate that contemporary treatment was better as indicated in the following example:

> “my father was bad with arthritis ….. I didn’t realise how bad he was with it and there was nothing at that time that there is now” [referring to treatment options].(Participant 2)

When comparing current treatments to historical treatments there was also an appreciation for the developments, especially with the expanding range of drugs. When a drug was no longer effective, the participants discovered there were alternatives. While finding the drug that worked for them took some time, it was very hopeful as this quotation illustrates:

> “.. I switched to a new biologic. Different medicines work differently for different people, …important not to be despondent if a certain medicine does not work … lots of treatments and sometimes it is by trial and error then you come to the right one.” (Liam, p.114).

When participants examined their life and recognised that the interpretation and meaning they gave to it was based on their comparison to others and about meeting the expectations of others, they changed and placed focus upon the RA, themselves and their life. To assist them in changing focus, the participants centered upon gaining knowledge about the condition of RA and their experience of it in their body. Specifically, they concentrated upon flare-ups, medications and being attentive to what was happening in their physical body. This was a new way of focusing on the RA and the learning was deep and nuanced. The participants acknowledged that only they know what is happening in their body and so they became more attentive to all the physical features, i.e., pain, stiffness, tiredness. The participants recognised that the RA was a difficult condition to understand. They understood it quite simply as the body attacking itself as participant 22 explained:

> “it’s one of these auto-immune and the body for some reason attacks itself. But I would love to know what is happening in the cells – see it under a microscope” (Participant 22).

All of the participants were clear that RA did not just attack the joints. Some they came to a deeper understanding when another auto-immune disorder made its presence in their life,or example, Sjögren’s syndrome, which affects the tear and salivary glands. The participants realised that being attentive to what was happening in any part of their body was important, and, therefore, should be noted and discussed with professionals. When the participants understood that the body was attacking itself and that the flare-up attacks could come spontaneously, they sought answers as to how they could halt or alter them. The participants increased their knowledge of flare-ups and the importance of identifying an active state quickly to prevent joint damage. The participants made it their business to know what a flare-up involved as indicated in the following field note:

> She knows how to identify a flare-up in detail - knees feet and hands and shoulders - able to say she does things that make the shoulders more painful. (Field Notes, participant 18)

Flare-ups were identified as horrible with features which were very difficult to deal with. Moreover, getting the RA back into a low disease state was challenging as indicated by the following quotations:

> “Flare-ups are horrible. The fatigue is so bad -… sleep all night and after two hours feel as if you never have been in bed.” (Participant 24).
>
> “My body is actually screaming out in pain [flare-ups] and the drug is just not hitting it.” (Maretta, p.67).
>
> “When the RA flares the bed feels hard”. She is disturbed by stiffness and soreness.” (Field Notes, Participant 5).
>
> The ankles were swollen up and the hands. (Field Notes, Participant 8).
> “The worst part of flare-ups is.. never get the same speed back in your life or the same strength .the worst symptoms of pain and restrictions you could imagine.” (Participant 9).
>
> “Flare ups are worst …dread them” – feels the drugs are preventing flare-ups and keeping the RA under control – “flare ups very bad”.
> (Field Notes, Participant 15).
>
> Gets a flare-up every year when his disfigured hands and feet become very painful. (Field Notes, Participant 18).

All the participants identified that preventing flare-ups was important and they recognised the tremendous difficulties involved in bringing the RA into a low disease state. In flare-up the physical body experiences many symptoms at the most severe level and requires various drug treatments to attempt to stop the flare-up. Finding the drug or combination of drugs that achieves this task takes time as it is patient specific. The whole experience impacts upon the mental health of the participant.

All the participants encountered experiences of flare-ups and agreed that each occasion of a flare-up takes a little more strength from the body. The early identification of a flare-up was, therefore, key in maintaining current levels of strength in addition to protecting the joints. Extreme vigilance was needed to detect the indicators that a flare-up might be imminent. While the participants were able to identify general indicators of a flare-up over time, they identified specific signs relevant for them as outlined in the following quotations:

> ".. little flares … I know I am a little more tired and little tiny twinges in my fingers. I take Paracetamol and rest more that day and maybe the next day and hope it will go – and it does most times." (Participant 25).
>
> On some days when he would not be in form, he would not do a lot. What he identified as a mini flare-up that could progress to a full flare-up. (Field Notes, Participant 13).

Not only were the participants able to be specific about the features of a RA flare-up for them, but they were also able to identify activities or experiences that they felt could influence the development of a flare-up. While exercise and over-work were the most common activities associated with flare-ups, stress was acknowledged by all the participants as the precursor to a flare-up:

> "keeping oneself from stress." (Participant 15).
>
> "I have noticed that if I am worried or stressed over anything, it could bring on a flare-up." (Annette, p.105).

Knowledge about the impact of stress led the participants to find out how to deal with stress and thus prevent a flare-up. Participants identified various activities that worked to relieve their stress, such as walking, swimming, reading, meditation, but all emphasised it was whatever activity worked for the individual with the emphasis on dealing with the stress and preventing the impact of stress upon the body.

Participants did take some risks while living with RA. For some the risks were to skip a medication, which was sometimes influenced by financial restrictions. For others the risks involved continuing to live their life with no modification, i.e., no adjustment on work/life balance. As participants experienced the consequences of this risk-taking and their knowledge increased, they became more selective and were supported by the careful consideration of the consequences. Selective risk-taking was dominated by overdoing activities. The participants recognised when they had done this and dealt with it so as not to experience a flare-up as identified in the following Field Notes:

> Can do everything but is careful about how much. When he does too much, he rests the next day. (Field Notes, Participant 22).
>
> Pain sometimes get severe and he will take Nurofen. (Field Notes, Participant 14).

> ".. take Paracetamol for a little flare - last a day or two - and sometimes Difene" – Rests for a few days. (Field Notes, Participant 25).

The participants described how they were observant of their physical body and their moods. They adopted their daily lives to respond to their observations of what the RA was doing. They came to regard RA as the enemy but one that had to be treated as a friend (Frenemy). Therefore, the participants had to be consciously aware every day of agitators, and in living each day they attempted to keep the frenemy quiet by resting up and keeping the mind at peace. For all of the participants they encountered ongoing stressors which impacted upon their RA experience. Some examples are included in the following Field Notes:

> when her son was terminally ill the RA flared up. (Field Notes, Participant 18).
>
> had personal issues and her mum had cancer – a lot of stress affected sleep. (Field Notes, Participant 22).
>
> Daughter died 13 years ago - her eldest child died very suddenly as adult and her husband died young and so was a sole parent -felt bereavements and the stress affected the RA. Symptoms were worse. (Field Notes, Participant 27).

All participants identified that stressors were not to be ignored and advocated that anyone with RA should participate in some form of preventative stress reliever. They gave examples as walking, walking by the sea, talking to a good friend, accessing counselling or a relationship with a higher power. Participants were of the view that stress was part of life but, for the person with RA, it was essential that the stress was dealt with.

In the category of knowing, participants became acquainted with the supports that were available. All the participants identified that specific supports delivered by specialised practitioners were very important. This included, for example, physiotherapy, occupational therapy, hydrotherapy and pharmacotherapy. While the service given was a support, the participants identified that it was the professionals who made a respectful connection with them that was important. This was contrasted by supports given by other professionals not specialised in rheumatology as indicated by Participant 15:

> Going to RA clinic is compared to going to a family not for a medical appointment. She appreciates the support – to her it is vital to know "that the professionals are genuinely concerned about you and how you are. Critical that caring [emphasised] and if you do not have this at home it is vital in the clinic –good advice and support" (Field Notes, Participant 15).

Gaining knowledge of all supports was very important learning for the participants. Supports were powerful in assisting the participants to live their life while having RA. This support might come from significant others in their life completing various tasks or just knowing that other individuals were happy to support them if needed. The following excerpt acknowledges the availability of support:

> One colleague in particular was very helpful offering to do tasks and telling him to take it easy. If he needed help he would be happy to ask him. (Field notes, Participant 12).

The participants appreciated support from others and increased their knowing about human supports. The participants used their learning to help them gauge when they could safely ask for help and whom they could ask. In discerning about RA, the participants identified that it was the support from meaningful others that was most helpful. Meaningful others were people that could be trusted and were respectful, but who did not aim to pacify the participant. These people challenged the individual on aspects of their life in a supportive and respectful way. It was this element that participants identified as most important in assisting them in looking at their life and how they were living as illustrated in the following examples:

> Feels his sons are brilliant as they are reliable… and his wife is "exceptional in understanding his illness". She "really understood" the suffering he was in – she encouraged him to get help. She kept pressure on him. He feels she completely understands. She can "really empathise". (Field Notes, Participant 13).

> "I have a friend… she asked me well why don't you take the exercise? Why not join the gym? I laughed but she was serious. Ah sure maybe deep down you don't want to help yourself…. She made me think…. later I joined the gym and she did too and since then I have continued to be a member and go three times a week and swim…. Brilliant…" (Participant 22).

Hesitant Ownership

The second sub-category of *Deliberating* is *Hesitant Ownership. Hesitant Ownership* is a process when the participants, yearning for a different life, considered the meaning of having RA and reached the point where they embraced it and claimed the RA as their own. Essentially in this process the participants began to accept that they had RA and that it was they who had to deal with it in their lives. The participants were clear that a positive attitude was the key to them being able to take some ownership of the RA and gain a life apart from the RA.

As the participants engaged with compassionate others and increased their knowledge their main concern, the *Fear of Declining Self-Worth* was being replaced with possibilities. The participants gained increased awareness of their physical body and their life and were able to identify some irritating practices, such as, overwork or overexertion, as well as gaining insight into other activities that they could try out. These were critical insights which influenced the participants' attitude toward RA and permitted the consideration of ownership to enter their life. This was evident in the increased ability to resist living life as before and attempt new activities that have been recommended by close friends and professionals. An example might be going walking or exercising. When the participants identified benefits from the new activities, they routinely include them as part of their life. Participants realised that increasing activities which support the RA also benefit them as social beings as illustrated in the following:

> Daily exercises and walking - the exercises and the walking are really helping - …….the walk by the coast - so much to look at and peaceful believes this helps her mental health and is able to think about many things (Field Notes, Participant 20).
>
> "I love going to the gym, doing yoga, going for walks or hikes with friends, swimming, and stretching. And I know my body and my mind thank me for it". (Dee, p.47).
> "But I am also listening to my body and doing as it tells me by not overdoing things". (James, p.50).

In the process of acquainting and engaging with supports, the participants come to gain a different perspective on their life with RA, which increased their insights about their relationship with the RA and the subject of ownership. The participants identified that previously they were motivated by the desire to eradicate RA and to communicate self-reliance to others. This is now changed, and the participants desired more self-honesty. They wanted to see life with RA as it really is for them, not as how they imagine it to be. The supportive relationships with the professionals and close friends helped them to discuss and identify how things really were. Such discussions helped the participants process the various personal and sociocultural perspectives that were hindering them in being self-honest. The participants were able to consider the meaning and their relationship with RA in the context of living their life. For participants this step was difficult initially. It took courage to accept that the reasoning for choices was so dependent on the perceptions of others. Supportive relationships helped participants to make sense of this reasoning and to identify and manage self-criticism.

The processing of the truth around the various dimensions of living with RA prompted the participants' consideration of how they should view RA. They considered that RA had to be claimed and owned. They contrasted ownership with toleration. Ownership was about claiming the RA as their own, whereas toleration was perceived to be tolerating and reacting to the changes required to manage RA, as identified by Participant 15:

> Her RA plan is personal not a ritual of orders – she is in control or owns it – she describes how she has RA as a part of her life not her life. (Field Notes, Participant 15).

For the participants, ownership was perceiving RA in a different way with a positive view. Ownership involved making decisions about how they as individuals with RA managed their life and their RA. Therefore, participants were interested in what was happening with their RA, i.e., the stage it was at, the treatments they were receiving and taking responsibility for how the RA was managed as explained in the following:

> "it is like work - you get a job you don't like and then the foreman making it hard - and then they realise what you can do and leave you alone- the same with arthritis you don't like it but you have to work with it" (Participant 16).

> He is now at a stage where he is reliant on neighbours for support particularly with calving cows. This is an important hobby for him and does not have any other interests. Considers this a better option than sitting down and thinking about his RA. The help is mutual and also a form of socialising with neighbours who have the same common interest. (Field Notes, Participant 2).

The ownership was fuelled by positive thinking ,i.e., always some good to be gained. In situations it was about being resolute to find the good. Participants believed that searching for different solutions to the challenges and having the courage to ask for supports to find different answers was important.

> "There is always something to change things maybe a different drug or a different way to relieve symptoms or simple distracting with other activities". (Participant 29).

The participants came to realise that positivity, i.e., the state of being positive was very important. Positivity was accentuated in living with and owning the RA. Through positivity, they understood that many aspects of life are challenging but when something positive about life was discovered the challenges did not seem so hard or impossible. Positivity did not mean that the participants were ignoring, minimising, or denying the existence of RA. Instead, they were holding the RA in abeyance, looking more intently at other aspects of life and living, and focusing on finding something they could evaluate as good. This created an energy that they did not have previously and increased the possibility of looking at RA as their own.

At the same time the participants, having gained more understanding about RA and their life with RA, began to visualise a different perspective on their life. They progressed to implementing their new understandings into their life by planning carefully what they were going to do, with whom, when and under what conditions, with the aim of keeping the RA in a peaceful state and having some quality in living. The participants strategised and used their accumulating knowledge of RA in conjunction with careful decision making about many different aspects, including lifestyle, activities, disclosure, medications, going for appointments, socialising and working. The following examples indicate how the strategies were influenced by the accumulating knowledge:

> "..found this new to me very strange. It has been a huge learning curve and I've gained an appreciation of what one can endure and overcome." (Bernadette, p.154).
>
> "I've quit (smoking). When I have pain, I think I would just like to sit down with a cigarette, but I just put it off". (Participant 4).
>
> He works around fatigue in his life. So, he makes sure, he has sufficient rest to be able to continue in his full-time work. This is now his normal routine. (Field notes, Participant 2).
>
> ..we only go away for a week, ….and I'm back and the first night I'm back I take it [injection] but I never go back to work straight away. (Participant 4).

Initially the participants were concerned with preventing exposure to others and the physical consequences of poor choices. For some participants, disclosure about inabilities continued to be an issue. They compensated for this by carefully strategising about what they would or would not do. For some participants the vulnerable psychological state impacted upon their capacity to consider possibilities and choices, which they overcame by engaging in supportive relationships. The interactions in supportive relationships engaged them in thinking about their reasoning around their strategies in living. They evaluated that their reasoning may be faulty. In the following example the participant concluded that she had to use goals as a strategy for living:

> ..her friends help to keep her grounded …. has to be goal focused to get most out of life - planning holidays, visits. (Field notes, Participant 22).

All the participants used strategies to help them become positive and remain positive. They searched out situations and people to assist them in remaining positive. Situations and people which impacted on their ability to remain positive were actively avoided.

Positivity was a key attitude that supported participants in viewing possibilities for their life beyond the physical dimensions of RA. Participants realised that life was more than existing from day to day, but involved investing the time and energy in considering what they could do with their life. They were accepting that only they could own the RA. The journey with RA varies, but as the next quotation illustrates it does not define life with RA:

> "You will have bad days and weeks but they do not last .. with the treatments they will go…. enjoy the good days …. Make the most of everything." (Participant 17).

The participants recognised that having a changed attitude was not easy. The transition was supported by engaging in supportive relationships on an ongoing basis. The transition was harder for some participants as explained in the following Field Note from Participant 3:

> She recognises that while she has changed it was "hard to change a life of living with a particular approach" [referring to becoming and staying positive]. (Field Notes, Participant 3).

In the sub-category of *Deliberating* participants responded to their yearning for something different for their life. By increasing their knowledge of RA more intently, they gained new insights into the possible meanings that RA brought to their life. This knowing supported the participants in understanding that RA was not an object to be feared, but was a condition that had to be owned. In owning, the participant acknowledged that this included the responsibility for making choices that respected all aspects of their life, not solely the condition of RA. The participants were adamant that positivity was essential for living with RA.

Conclusion

This section focused upon *Scoping Self-Worth* the second stage in the process of addressing the main concern of *Fear of Declining Self-Worth.* In Stage One, *Insulating Self-Worth*, the participants in a state of captivity protected their self-worth by concealing and asserting control over RA. Their efforts were futile. They progressed into a psychological state of vulnerable and they entered the stage of *Scoping Self-Worth.* The experiences of Stage One and their vulnerable psychological state made the participants hesitant to engage with others or to try out new ways of doing things. The participants knew they wanted something different to the life they had lived with RA. Progress in this stage was dependant on engagement with resources. When there was a high level of engagement, there was progression on toward the next stage. When there was a low level of engagement, the participants reverted back to the previous stage and entered the FASP cycle of self-pity and activity flurry. Re-entering *Scoping Self-Worth* occurred when the participants gained insight into their cycle of behaviours.

The participants engaged in pseudo-friendly and semi-supportive relationships initially in *Scoping Self-Worth*. In pseudo-friendly relationships participants displayed a pretence of friendliness, which protected the self from exposure to others. Semi-supportive relationships, while providing some active support, also helped participants to scope meaning for their life. As the participants' confidence grew, they engaged in supportive relationships, which were most evident in the latter part of the stage.

Discovering and *Deliberating*, the two sub-categories of *Scoping Self-Worth*, described the processes of responding to the yearning for something different for a life with RA. *Discovering* revealed that the participants became acquainted and engaged with compassionate others, which supported them in gaining insights into and acknowledging the self as a social being living with RA. The process of *Deliberating* accounted for the development of knowledge about RA and the management of the condition. The participants understood that RA should be owned, but ownership did not equate to toleration. In the process of deliberating on ownership the participants identified that an attitude of positivity was essential. Essentially, in this stage the participants gained a lot of insights about what life with RA was about and how the new way of viewing RA might impact upon living.

Having engaged in Scoping Self-Worth participants now recognise that they have a life and have worth as social beings. From implementing some changes in their approach to living they can visualise that life can be different. At this point they are uncertain as to what else might transpire, but they accept that they have a role, can contribute to society, and are ready to focus more intently on this. The participants have reached a secure psychological state. The next section outlines the process that participants embark upon in *Bolstering Self-Worth.*

CHAPTER 7: SECTION 3 BOLSTERING SELF-WORTH

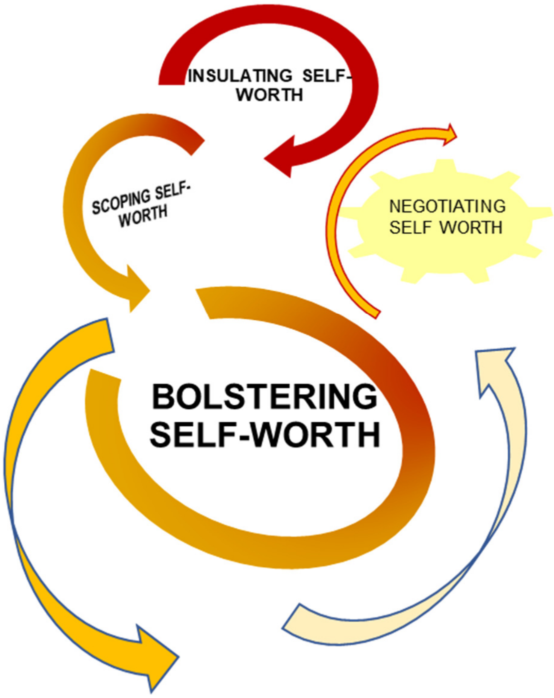


Figure 24 ***Bolstering Self-Worth***

Introduction

Bolstering Self-Worth is the third and final stage in the basic social psychological process through which the participants in a secure psychological state processed their main concern of *Fear of Declining Self-Worth*. In the first stage, *Insulating Self-Worth*. the participants were consumed with the psychosocial considerations of RA, which was reinforced by two major enduring physical features of relentless pain and fatigue. The participants were in a psychological state of flux and responded to the threat of losing their self-worth by concealing their diagnosis from others and asserting control over the RA. The attempts were futile, and the participants entered a vulnerable psychological state. However, they had a yearning for something different for their life. At this critical juncture they entered the second stage of the process *Scoping Self-Worth* and began to explore the meaning of their life with RA. Engagement with compassionate understanding others assisted the participants in becoming acquainted with their own person, leading to an increased self-awareness. Simultaneously the participants increased their knowledge of the management of RA. The increased self-awareness and knowledge of RA empowered them to implement some changes into their living and their life with RA. They came to understand that a positive attitude to living enabled them to own the RA and intuited that their life was worth "more". In a secure psychological state, they entered the third stage of the process *Bolstering Self-Worth* when they sought to reveal the "more". When they entered this final stage, they had clarity on one aspect which was that they were not going to become "an arthritic burden[40]", as this term was representative of personal worthlessness as social beings. The participants had experienced favourable outcomes in the previous stage when they had changed their perception, knowledge and management of RA in some aspects of their life. In this stage of *Bolstering Self-Worth* they wished to pursue more of what they had found and embed it into their life. They did this by changing the way they viewed the RA (*Re-Framing RA*) and created their own personal vision for their life with RA (*Personal Visioning*). *Bolstering Self-Worth* was characterised by properties of supportive relationships and positivity.

Supportive Relationships

Bolstering Self-Worth was achieved through the establishment and maintenance of relationships that were perceived by the participants as supportive. These supportive relationships could be with friends, family members or health care professionals. Through *Supportive Relationships*, participants were enabled to further develop self-worth which they experienced in *Scoping Self-Worth,* that is, they had gained a sense of themselves as persons separate to the condition of RA. In *Bolstering Self-Worth,* the participants expanded this experience and affirmed their own sense of worth as social beings. *Supportive Relationships* were the medium through which they achieved this. *Supportive Relationships* signified authentic relationships with another person/s who were present for participants and were deemed to be consistently available, honest and realistic. Such people had a dynamic interest in the participants demonstrated by investing time and energy in the relationship. The relationship was centered around the needs of the participants, as evident in the quotations below. It is worth noting that the person who fulfilled the supportive role may have been a professional however being a professional, while advantageous, was not regarded by the participants as fundamental.

> "Consultant was very supportive and gave good reassurance." (Participant 10).

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[40] Arthritic Burden is an invivo code.

> "My GP was very supportive, and I acknowledged and offloaded all the feelings onto him and to a professional counsellor." (Ger, p.176).

The initial step in *Supportive Relationships* taken by the participants was being their authentic selves. They gave recognition to themselves as persons and acknowledged what they were experiencing as real and was worthy of attention. It was from this perspective they engaged with others in *Supportive Relationships.* The other in the relationship needed to be listening actively to hear and understand what the participants were trying to make sense of and how they were doing the sense-making. The other had to be a genuine partaker in the relationship and this supported the participant to continually be their authentic self. *Supportive Relationships* then were important in helping the participants identify and respond to their own feelings about events in their life. Being able to relate their experiences to another who actively listened also helped the participants to give it the acknowledgment it needed:

> "I had an employer at the time who was appalling in how they treated me. I had to give up work and thought I would never work again. …. Chatting to my GP, we felt that maybe going back to a desk job might suit me better". (Claire, p.125).

For Claire her experience had a negative effect on her recognition of herself as a person who could contribute to society. The experience resulted in her considering that, not only was she not able to fulfil the role she was in, but she was incapable of ever working again. It was an attack on her self-confidence as a member of society and a person. The experience had an impact on her person. She alone reached the conclusion that her social worth as a citizen was gone from her. Subsequently in the supportive relationship with her GP, solutions were suggested to her, which she tried out. This achieved a good outcome for her, as she stated:

> "..five and a half years later and I am still with the same company" (Claire, p.126).

The experience of being able to work again bolstered Claire's self-worth and established for her that she had a social role. What was also important in the conversation with the GP was the connecting not only with the loss of employment but also with the impact the experience had on her as a person. She had formed the view that she would never work again. By discussing this with another interested person she was able to acknowledge her own physical limitations but not let them lead to a feeling of complete defeat. In this way the *Supportive Relationships* were important in *Bolstering Self-Worth.* The key purpose of *Supportive Relationships* was to assist the participants in making sense of their experiences, but yet maintain some realism in considering solutions. The sharing enabled them to gain other perspectives on the issues that affected them. *Supportive Relationships* were the means through which the participants were able to discuss their challenges in living with RA but also to find solutions that would help deal with ongoing issues.

Supportive Relationships are not to be confused with people being kind to each other. While there was kindness and gentleness evident, it was appropriate according to what was being shared. There were times when the participants needed just that kindness and understanding when they could openly share the challenges and the other would listen:

> "Surround yourself with positive people who will listen when you're not feeling well." (Annette, p.105.)

> Being involved with others is important. Has a lot of friends – each one has their story and this gives an opportunity to let go of her own concerns and have a laugh. (Field Notes, Participant 19).

For the participants *Supportive Relationships* were a means of expressing the physical and psychological dimensions they were experiencing. This sharing was a form of support. It helped them deal with the issues, to transcend the challenges even for a short while, and engage in humour. Again, the active listening and engagement with the participant was important.

In *Supportive Relationships* the other in the relationship demonstrated the ability to be sympathetic and empathetic and ask pertinent questions to help the participants understand more of the experience. There was no fear in asking questions. These people were also able to know when it was appropriate to challenge the participants.

Persons who fulfilled the supportive role were described as being skilled in taking a firm position, but also respectful in giving participants time to consider issues and the action/s they might consider. A further skill was supporting the participants to enact decision/s. This was identified as an important element of the supportive relationship in that the participants were held accountable for decisions they made about their life.

> it is regular 2 hours every other week. Feels she has made a commitment with her friend so that makes her go. (Field Notes, Participant 11).

Holding to account was not threatening but done in a way that respected the participants' choice-making for the life they wanted to live. These persons would have known the participant well and, therefore, were aware of when and how they should communicate. *Supportive Relationships* were important for dealing with matters of living, and sustained participants in remaining open to possibilities, instead of being trapped with problems or issues which may lead to indulgence in self-pity and powerlessness. In this way the participants were sustained] on their journey of *Bolstering Self-Worth*:

> Has 2 very close friends who motivate her to do different things – she does aqua aerobics, goes to the gym and yoga. They will go with her. She is delighted she has these friends - they talk things through - what to do -how to go about it – all the things to keep her "body and mind healthy. (Field Notes, Participant 22).

Through supportive relationships the participants continued to find and stabilise psychologically their self-worth. The participants were enabled to implement some changes that supported their ongoing development of self-worth in a positive way. It was this that led them to conclude that all human beings should participate in supportive relationships on the journey of life and emphasised this.

Positivity

Another characteristic of *Bolstering Self-Worth* was *Positivity*. *Positivity* represented a way of thinking that enabled participants to actively engage with the newly established self-worth and sustained them to remain in that reality. Positivity was an active state where the participants sought positivity in every circumstance. The participants reasoned that the active state was reinforced by a positive attitude as evident in the following quotation:

> "Being positive and not let depression get in - don't stop laughing". (Participant 12).

Participants were aware that living with RA could impact upon the psychological health of the person. They were resolved to live life in such a way that clinical depression would not become an issue for them. Hence, positivity was very strong with all participants, but it was realistic in the sense that they were real to what was happening in their lives, not ignoring or evading it. Participants practiced positive self-coaching and actively sought situations and people that assisted them in remaining positive. The following Field Note illustrates:

> Has a mantra “I’m not going to be in a wheelchair” She coaches herself with positive thinking. Knows the RA is progressing and unable to do all she could do but keeps positive and compares herself to others who have not done so well. (Field Notes, Participant 10).

Conversely, negativity consumed psychological and physical energy. The participants actively avoided being in negative environs, including the company of others who had pessimistic outlooks. The participants identified that avoidance of negativity was extremely important on days when life was more challenging. The following quotation highlights the challenges in negative environs:

> “being around people who are negative is really difficult … it is draining and serves no purpose - no good for anyone”. (Participant 19).

Contrarily, on good days, participants acknowledged assisting others to be positive in outlook which reinforced their own positivity.

The characteristics of *Supportive Relationships* and *Positivity* supported the participants in their endeavour to *Bolster their Self-Worth. Bolstering Self-Worth* had two subcategories: *Re-Framing and Personal Visioning.* These two sub-categories describe the process by which the participants, having gained some glimpses of self-worth, confidently continued the discovery of that worth, and established the conditions through which they stabilised it.

Re-Framing RA

In *Scoping Self-Worth,* the participants gained a glimpse of some positive outcomes when they viewed RA differently. *Re-Framing RA* describes the process by which participants continued to increase that different perspective. The participants, through *Supportive Relationships* and *Positivity*, were able to change the way they viewed the experience of living with RA. Despite the ongoing biopsychosocial challenges, the participants had a clear determination to view life differently. *Re-Framing RA* was processed through the categories of *Remoting RA*, namely, *Choosing Gratefulness* and *Being in the Moment*.

Remoting RA

In *Remoting RA,* the participants distanced themselves from the immediacy of the condition of RA. Distancing was an important cognitive step. In essence this means that the participants, while being fully aware of what was happening, did not indulge or languish in the experience of the moment, but they transcended what they were experiencing, feeling and thinking. This is not to be equated with denial of having RA, but rather just allowing themselves the opportunity to consider other things and not let issues regarding RA dominate their thinking. Features of distancing were transcending thoughts about RA and having the capacity to identify the inconveniences and frustrations about other aspects of life. This distancing then required another step which was to give the same time and energy to living as was given to the RA. For the participants *Remoting RA* required a balance between acknowledging the features of RA; recognising self-pity and engaging in self-compassion as identified in the following examples:

> But she started to consider what she could do in living her life. She manages the pain and plans her life. No obsessing about RA or treatment. (Field Notes, Participant 15).
>
> “Get on with things - do not think or dwell on the RA ..took time to be like this - but it is the only way.” (Participant 18).

The behaviours in remoting RA were thought about in a matter of fact way and this entailed the participants relearning about how to be with their own personal timetable. Previously the participants having a plan for some RA treatments, would have permitted the anticipation to be present in their thinking until the treatment was over. In this new way of viewing their life, they plan and then get on with other aspects of living and hence, put a distance between their timetable and their life.

The participants engaged in *Supportive Relationships* to assist them in distancing. Positivity provided the energy for *Remoting RA*. The consequences of *Remoting RA* were a recognition of other possibilities that life had to offer and the identification of benefits that RA had brought to their life. Thus, participants were gaining opportunities for experiencing a different way of life that expanded and augmented their self-worth as identified in the following examples:

> “this place [house] for instance was my last project this was just a barn and car park - every bit of this I done myself” [some very fine craftmanship]. (Participant 15).

> “I just cannot sit in the house so when I am at home I go out and about and foother [colloquial term derived from fústar [meaning doing bit and pieces but nothing specific] about and meet people. I would go to the pub I am not really a drinker but chat to people”. (Participant 17).

> “I joined Pulse Triathlon club a year later and it was the best thing ever…… since joining I have completed many more sprint distance triathlons, but I’ve done two Olympic distances and in 2017, I did Ironman 70.3 in Dublin”. (Ken, p.61).

Remoting RA gave participants the opportunity to consider other aspects of life that might give them some enjoyment or sense of achievement. When they returned to consider the RA, they had a different view and were not burdened by the thought of what the RA was doing or not doing. They had altered their way of viewing the RA and, in the process, gained some achievements in other things. This helped to boost their self-worth.

Choosing Gratefulness

Choosing Gratefulness indicated the deliberate choice participants made to view all the events in their life through the eyes of gratitude, even if the circumstances were difficult. This choice was underpinned by the participant holding two fundamental beliefs: (1) Solutions to problems will come and (2) Out of every life event there is something to be gained. This is not to be confused with accepting life as it is, but rather in each situation intentionally seeking to uncover the benefits for themselves as social beings. In this way they could accept that they had worth in spite of having this chronic condition.

When difficulties arrived or problems occurred, the participants would have previously been fixated with finding a solution. When the participants choose gratefulness, they made a clear decision not to be fixated with finding solutions. This relieved the tension and anxiety they had previously experienced. The participants concluded that all things in life have meaning and that fixating may mean that a solution is forced upon a situation or problem. Therefore, it was about having patience for the solution to arrive. In choosing gratefulness, the participants recognised the disappointments, the hurts, and all the other difficulties that living and life brought. Rather than becoming defeated, the participants made a deliberate choice of gratefulness. *Supportive Relationships* and *Positivity* were very important in assisting the participants to maintain the attitude of gratitude. The participants searched for possibilities on how to live particular difficult moments or aspects and asked the fundamental question: What else can be gained from this experience or event? It was the response to this question that assisted the participants to identify and acknowledge aspects of their life which gave gratitude as evident in the following examples:

> "be thankful and grateful for what people are trying to do for you" (Participant 14)
>
> "health wise I am pretty good and I am really grateful for that." (Participant 21).
>
> By chance she developed a love of reading and is grateful that she can as her mobility is now limited and she cannot go out alone. (Field Notes, Participant 25)
>
> RA was beginning to affect her mentally, so she joined a flute band because she liked music. Gets great enjoyment out of playing the flute - feels that this helps her fingers - good exercise. going to band practices and painting brings her in contact with some very interesting people. (Field Notes, Participant 20).

The experience of having RA and engaging with issues in supportive relationships helped participants to see other possibilities for their living. It was these new ways of being and living that the participants were grateful for.

The participants identified aspects of living that were difficult which they evaluated as unfair and they as recipients should not be encountering. Making comparisons to other people and other situations helped them to put their situation into perspective, which motivated them to choose gratefulness above other mental processes such as complaining. The following quotation illustrates the outcome of choosing gratefulness:

> "I was lucky nothing ever happened my hands and I was able to continue working". (Participant 16).

The participants made a deliberate choice to have an attitude of gratitude in the midst of pain, suffering and hard life events. The participants considered that the meaning or relevance they uncovered in relation to life events was not attributable to the RA and that understanding this brought a sense of freedom to the individual. RA just is the condition, and everyone has life issues and challenges! Mary identifies a list of aspects she is grateful for and her list puts RA into the perspective of living:

> "I'm grateful that I did not have a more severe form of RA.
> I'm grateful that the menopause completely passed me because I attributed any symptoms to the RA.
> I'm grateful that I'm not an orchestra conductor/jogger/surgeon/tennis player etc because then this would be so much worse.
> I'm grateful that my passion is reading – it involves very little movement.
> I'm grateful for the invention of e-readers because they are easier to hold than a book.
> I'm grateful that I'm alive in the time of 'athleisure wear'. Thick soled ugly shoes are now edgy.
> I'm extremely grateful that my biologic [referring to type of medication] is paid for under the Drugs Payment Scheme.
> Most of all I'm grateful to everybody at St. Vincent's Hospital Rheumatology Unit I'd be a very sad human being without their care".
> (Mary, p.25).

Being in the Moment

Being in the Moment described an important focus that participants brought to their living. Participants described how *Being in the Moment* enabled them to fill their consciousness about thoughts for the moment they were living and, thus, they did not have time for other thoughts that would divert their thinking into negativity. When participants lived in another time span (past or future) they were not attentive to the self. It was at these times that consciousness slipped into thoughts of pity, shame, guilt, or remorse. Focusing attention on the events of the moment assisted the participants to sustain their endeavour in *Reframing RA*, that is, to view the RA differently. *Being in the Moment* required psychological discipline and focused attention as evident in the following example:

> "….. each day you may have the big plans – but you have [emphasised in tone] to be in the moment and stay in that moment of where you are at." (Participant 21).

Therefore, *Being in the Moment* was about restricting possibilities for mental anguish about life, what may or may not happen, or how they were going to deal with various challenges. The self therefore occupied the space of *Being in the Moment as identified by Participant 19:*

> Has a busy business. Takes life as it comes - never dwelt on the future - always hoping for the best. Speaks about the banter between himself and his sons as they tease him "if you live to 250 -still have work to do" Emphasises focusing on the present and being content with what is. (Field Notes, Participant 19)

The participants focused on being grateful and content with their life supplemented their intentions and possibility for *Being in the Moment*. Such focusing meant that behaviours and commentary of other persons did not immediately impact upon them. Other behaviours or commentary were not ignored but considered later and kept in perspective.

The participants were focusing on the self so behaviours, comments were evaluated in terms of helping the self with life issues. Comments from others that were evaluated as unhelpful were excused as others not knowing or understanding which was a situation to which they could easily relate.

Personal Visioning

On entering the stage of *Bolstering Self-Worth*, the participants have some more personal awareness and increased knowledge of the condition of RA. In *Scoping Self-Worth*, the participants had gained some insights that they could have a different life for themselves. *Personal Visioning* describes the processes that enabled the participants to create the life they desired and to be successful in that endeavour**.**

The sub-category of *Personal Visioning* has further categories of *Self-Compassion, Diffuse Thinking* and *Careful Planning*. In the first instance the participants recognised that they had to practice self-compassion and be forgiving toward the self for mistakes they made in living their life. *Personal Visioning* was about gaining a vision for their life with RA, while practicing self-compassion. This involved the participants thinking about their life and what they wanted and planning carefully to enable the plan to be fulfilled. *Careful planning* involved consideration of their RA status and thinking in a broad manner so as not to restrict possibilities for living. Essentially *Personal Visioning* was about the participants firmly establishing ideas for their adventure of living and therefore was an important element of *Bolstering Self-Worth*.

Self-Compassion

Self-Compassion enabled the participants to realise their personal vision for their life. *Self-Compassion* was non-existent in the first stage and weak in the second stage of processing their main concern. In this stage, *Self-Compassion* increased in strength as the participant progressed in the stage. This gave the participants energy and confidence to pursue a vision for their life and, importantly, to become comfortable with their new sense of self and their future life. The participants discovered that *Self-Compassion* was a foundation for *Bolstering Self-Worth* and was key in firmly establishing that worth. Self-Compassion has key attributes of acknowledgement of the self, self-acceptance, and self-belief. The participants continued to build upon their skills of acknowledging what was happening in their life from biopsychosocial perspectives. It was only when the participants acknowledge what was happening in their lives that they were then able to explore how to deal with it, for example, identifying hurt as hurt and owning that hurt. In self-acceptance the participants were accepting their humanity and their capability to make good and poor choices. They began to understand that berating the self for perceived wrong choices was not helpful and that self-forgiveness was important. The participants began to have belief in the self as a social being with strengths that enabled them to make decisions for their life. Believing in the ability of the self as a social being brought further confidence and bolstered the self-worth that was being cultivated. The participants could be self-critical, but the self-compassion gave balance to the criticism.

Self-Compassion enabled the participants to view mistakes or errors that they made as part of life. Rather than minimising the self or being disappointed or ashamed of something they had done, the approach was about identifying the action as inadequate or inappropriate, and, importantly, placing the self-evaluation in perspective. Participants referred to the fact that in the past they berated themselves for being unable to complete tasks or making wrong decisions. Being self-compassionate was about identifying they had made a mistake and then asking themselves if there something new for them to learn here. They considered why they made the mistake, so they would be able to identify what changes they might make for other decisions. If they really wanted to do the task, they considered how they would adapt the task or what other equipment they might use. In a sense, they put a positive perspective on mistakes or errors. When the participants were in a period of low disease activity, they may forget that they have RA and overdo activities. In these times the participants demonstrated that they had learned to forgive the self. A quotation gives some insights:

> “Then I do too much. I’d maybe change beds and I would wash everything and put it out on the line and have it in and up in the hotpress … The next day I would say, what was I at?” [jovial accentuation]. (Participant 3).

Participant 3 was able to have a joke at her own expense. She had overdone it, but rather than reprimand herself she chose to identify the mistake and her forgetfulness and have a chuckle to herself.

For the participants being *self-compassionate* was recognising the humanity of the self and identifying that errors in judgements is a fundamental part of being human. The participants stressed the importance of acknowledging shame, embarrassment, hurt or mistakes and moving on by turning the experience and the feelings into a learning situation. The learning that took place gave the participants enhanced skills for living, for example, how to be different, how to do things differently or just gaining insights into their own personal responses, which were all part of creating the personal vision for their life. The following example illustrates the adaptation that participants made in relation to work:

> He adapted his work as the RA progressed going from heavy work to less strenuous tasks - he adapted how he did things, so he was not using his painful joints. (Field Notes, Participant 16).

Being self-compassionate also meant acknowledging what tasks or activities they could not complete and asking others to do them or assist, as Participant 21 explains:

> “I think you need to let up on yourself and just ask people to do things for you and you would be surprised how people like to help.” (Participant 21).

For the participants asking for help was difficult initially, but when they brought some positivity into thinking about the request, they determined that the person who had been asked to give assistance might gain something and perhaps that they needed to be given the opportunity to do the task. This identified identifying an important function for them which assisted in *Bolstering Self-Worth.*

Supportive relationships were key for the participants in becoming self-compassionate and nurturing the self in living. In nurturing the self, they asked difficult questions, e.g., Who are you doing this activity for? Why are you doing this activity? The participants evaluated that motivations for action were often infiltrated with a desire for approval outside of themselves. The increasing self-awareness made them ask why they needed external approval from others. They distinguished between decision-making based on external approval and decision-making which was more congruent with their person and this influenced the choices. Participant 3 explains:

> “I’ll do what suits me. One time I would have tried to please everybody, and I don’t do that anymore.” (Participant 3).

Making choices based on personal outcomes resulted in a growth of confidence to the point where they recognised that they had worth as a person and a human being. Their life was no longer defined by conditions or circumstances. The participants had more internal unity and, while they could still be self-critical, self-compassion was increasing.

Diffuse thinking

The participants engaged in *Diffuse Thinking* to support them in expanding their personal vision for their life. Essentially for the participants *Diffuse Thinking* was broadening their thinking about life events, and in so doing realising the potential opportunities from each event. Initially, this was a deliberate activity influenced by supportive relationships, for example going to the shop for groceries, a task which had to be completed irrespective of the physical or psychosocial dimensions that it entailed. Rather than focusing upon the task, the participants considered in what other ways they might complete the task so they would gain some more personal satisfaction and joy. One participant explained how she had broadened her thinking in relation to the task of shopping. When she reached the town her first stop was a coffee shop where the coffee was excellent and the staff were friendly and welcoming. This refreshed her physically, but also increased her emotional energy. *Diffuse Thinking* was about participants being alert to possibilities that were available to them by permitting themselves to think differently about living and life. Day to day living including attending to the demands of the RA but it was in addressing those demands that *Diffuse Thinking* was employed for example, if the participant was feeling a little sore and needed to rest up. Resting their body was something they had to do, but it was an opportunity to read, phone friends or some other activity that they enjoyed. So resting was an enjoyable event. For some participants it also meant finding a new activity to do in these rest times This might be something they would not have contemplated previously. One participant shared that he started to do calligraphy writing.

Diffuse Thinking contrasts with the focused problem-solving thinking of the past which restricted the visualisation of any other possibilities. The attributes of *Diffuse Thinking* are being open to the suggestions of others and recognising the advantages of a different approach to life and living. For example, the participants mentioned coming to the RU clinic for appointments and identified that this would be the main event of a particular day. The suggestions of others assisted the participations to use the day differently with RU clinic appointment as one aspect. The day would be planned so it would include various other activities, i.e., shopping or visiting places of interest. Some of the participants had a significant other with them and they viewed the travelling as time together and an opportunity for both of them. They no longer viewed the journey as a chore that had to be done or filled their anxiety either for the appointment itself or concerns for the journey. *Diffuse Thinking* was about the participants thinking creatively about their life and not being confined by their condition of RA. Initially this was a challenge which was cultivated in *Supportive Relationships*. Having persons around them who had a positive outlook influenced the participants in expanding their thinking outside of the normal routines with RA. Such thinking assisted them in concretely putting into action new insights about living, as evident in the following examples:

> “it is different now….sometimes xxxx (daughter) would bring me down (to RU clinic) … we would go to the shops in xxxx (town on route) and maybe have lunch. She takes the day off work … she has a hard job and she needs the day out too…. So we make the most of it and have fun … we have our chats in the car too… Before I would have been afraid to tell them I had to go ….. I would have been disrupting their life…. Now I know different.. Well we are having time together and it is hard to have time like this – it is a reason for going not just the RA – the appointment makes us go – we have a great time- I am getting to know my daughter too and maybe it is the same for her” (Participant 9)
>
> “… I will try and keep fit. I joined xxxxxxx (local facility) doing swimming 5 evenings a week, [and] aquarobics classes two evenings a week. Joined xxxxx [facility 30 miles distant] and I go swimming and [use] steam room”. (Participant 15).
>
> “Early to bed… exercise within your limits” (Siobhán, p.132).

Diffuse thinking was about participants giving themselves the freedom to consider alternative ways of thinking about life and what else would they gain in resolving a situation or in living. As the participants gave less time to thinking and ruminating about the RA, they became more creative about what they could do. Participant 9 had a long journey to the clinic and came to view the journey as an opportunity for spending time with her daughter. In the process they did some activities together, which the participant considered helped her daughter. In *Diffuse Thinking* life was viewed differently, and participants visualised new possibilities and, in this process, identified assumptions they made about other people. Again, Participant 9 assumed that previously she was disrupting others lives. However, with creative thinking, she understood that she was actually helping her daughter have some time away from her busy life. The participants recognised the absurdity of their previous assumptions, but were self -compassionate and understood that their previous ways of being and thinking were different.

The participants were adventurous and attempted new things and new ways of doing things with a simple goal of learning more about themselves and their lives. Having experienced the benefits of *Diffuse Thinking,* the participants continued to practice this and when they gained a successful outcome, they developed the change into habits:

> Thought she would try out a holiday. So, she went to visit her daughter in USA– brought medications. Totally enjoyed this and realised this is something she will definitely do again. (Field Notes, Participant 23).

Participant 23 went on her first holiday which involved a long international flight. *Supportive Relationships* helped her to reach the point where she considered the possibility of taking the holiday and crystallize the idea. This has helped her to envisage that holidays and taking flights were a possibility for her life.

Diffuse Thinking was an important element of creating a personal vision for their life. The art of implementing *Diffuse Thinking* supported the development of insights for their vision and helped the participant to recognise that they had self-worth and could have a different life of their choosing.

Careful Planning

For the participants *Careful Planning* related to making decisions about their life and living with RA. This involved not only vigilant observation and consideration of their RA status but extended to gaining a holistic sense of their life. The goal of *Careful Planning* was not to restrict them in living, but rather to achieve harmony within themselves on physical, psychological and social levels. While *Careful Planning* involved more structure scheduling of each day, this was not the key intention. Rather it was about planning each day to live in ways that they choose and that brought them satisfaction and fulfilment in line with the vision and plan they had for their life. The essential planning is evident in the following quotations:

> “We work it out together and we plan [partner and participant]. I mean, going to a wedding or going on holidays.” (Participant 10).
>
> “…planning setting goals and organise and get on and do it - you have to plan” (Participant 16).

Courage and persistence were an essential part of planning and carrying out the plan. The process of *Careful Planning* includes a personal self-commitment to living a life that they choose. The participant, therefore, is actively engaged in making that life happen, which involves them in communicating and working with other people. *Careful Planning* is a deliberate activity. The participant has to go consider and be clear on what they will or will not do in their life. *Careful Planning* involved the participants setting clear goals for what they wanted to achieve and identifying deliberate actions that would enable the goals to be achieved. Careful organisation was also essential for the achievement of goals. For the most part *Careful Planning* was done in advance, with limited spontaneity in living. As the participants became confident and skilled in considering how they could live, the process of *Careful Planning* happened much faster and, in this sense, participants were able to accept unexpected opportunities that would bring them fulfilment. As indicated by Participant 19, going for a walk was not an activity she participated in, but she was aware that exercise was recommended for RA. Because of circumstances she felt she had to look after a dog. The task required her to participate in walking. She planned the task carefully being aware that it would not do her body any harm. Initially she planned the walk so that it would fit in with the routine of her life and to ensure that she could psychologically cope with the task. She courageously started and persisted in walking to give the dog the essential exercise that it needed. The outcome for her was that she discovered enormous personal benefit that enabled her to do other activities that she had not done previously like long haul flights with the inconvenience of airport changes:

> "When I started walking this dog about 4 years ago, I could not walk too far. I inherited this dog from my son (RIP) so I had to walk this dog. I wasn't a walking person. I had never walked before. I went short bits each day. I increased the walking each day - at 8 weeks I was up to walk [ing] 3 miles each day. Made an awful difference to my ankles and hips limbered up. …It took practice to do it [walk] properly but it makes a difference. I have been out to xxxxxx and xxxxxxxx [trans-Atlantic journeys requiring change of flights] twice to both places on my own …. There is [are] good walks in the airports but I am fit now - would not have been able to do this years ago before walking the dog. (Participant 19).

Careful Planning required the participants to be courageous and say 'no' to some suggestions and say 'yes' to some other suggestions. Participants also needed courage to ask for certain aspects to be considered and managed, as well as persistence to find a way to achieve a goal. As noted by participant 19, she persisted with walking out of sense of duty to her son rather than choice. She knew it would not harm her physically, but she had not anticipated the psychosocial benefits that would emerge. By *Careful Planning* she gained a life that respected her worth as a social being. Therefore, knowing when to say 'no' or 'yes' was important, and when doubt was experienced it was important not to feel pressured to respond immediately but allocate time to consider the response. The next quotation illustrates the importance of considering the knowledge of RA in decision making and planning of each day:

> "When you have the full knowledge of RA use it. You will feel fatigued so what are you going to do with it? Planning ..not letting it rule your life – you rest – critically not become over tired – overburdened – not be dragged into other people's lives. Being comfortable to say no and not feel guilty". (Participant 15).

Careful Planning enabled the participants to be aware that their life had important meaning, and this gave focus for their life. This importance was enhanced through the *Careful Planning* of each day within the confines of the RA, but this should not be equated with just filling time slots. It was an intentional endeavour, in which the participant considered what was of relevance to them, what they wanted to achieve and therefore what supported the vision they were identifying for their life. This planning involved making decisions about the various demands and dimensions of demands and about the impact upon their life and their person. The act of planning enabled participants to feel that they were putting meaning into their life, and while they were gaining a vision for their life, they also *Bolstered Self-Worth*.

Conclusion

This section has described the third stage of *Bolstering Self-Worth.* The participants brought the insights and possibilities for being and living which they had gained in *Scoping Self-Worth,* the previous stage into this final stage. At this point the participants had visualised a glimpse of something different which they liked and desired to develop and actualise in their life with RA. I have conceptualised this process as *Bolstering Self-Worth.* The process demanded that the participants visualise their life and living with RA differently. *Supportive Relationships* and *Positivity* enabled the participants to actualise this vision. As such, *Supportive Relationships* and *Positivity* were important properties, which in addition to actualising the vision, strengthened the psychological processes which stabilised and empowered the participants to maintain their new vision. Therefore, the participants were enabled to reframe how they perceived RA. The participants chose to place RA in the context of their whole life, where it had a place alongside the other aspects of living. The participants engaged in acknowledging the features of RA, while not permitting any features to dominate the moment they were living as they perceived that indulging led to self-pity, worry, anxiety and stress which were not beneficial. In this engagement participants gained a positive energy to focus their interest on general life matters. The participants were not ignoring their RA features or other life concerns, but gaining distance from them. RA no longer had a prominent place in living.

In the process of *Remoting RA*, the participants compared their lives to others, ascertaining that they themselves had a lot to be grateful for in their life. The RA experience, while changing their life, had brought some positive aspects, with personal growth and development dominating. The participants concluded that all people have concerns and issues, and that viewing them as possibilities for learning was more beneficial for living. Learning was also about believing that every situation would be resolved in time. *Reframing RA* encouraged the development of *self-compassion* and, while the participants came to understand that human error was part of living, they also understood that the perception of an error needed broader analysis. For example. concealing[41] in this stage was viewed as an error in thinking and being with the condition of RA. The participants concluded that being vulnerable was important for other social beings, as others may benefit from seeing aspects of vulnerable behaviour and supporting someone who is vulnerable. Therefore, the participants were able to establish that the new self may contribute to the development of others and to humanity.

The participants had gained a renewed sense of purpose, engendered by a new sense of self. The challenge was permitting this person to live. The participants garnered a sense of realism that no-one has a perfect life and in realising that whatever is in your life just is. Having gained a sense of purpose, participants recognised that, while previously they fought to have control of RA, they came to understand that control is illusionary and that one is not really in control of anything or anyone! The only thing that the participants recognised they have control over is the self and supporting the self in gaining the most out of the life they have. They realised that control or attempting to control contributes to stress which is really unwanted and may bring RA into an active state. Hence, participants established what their life was about, and this task highlighted the choices for living. Becoming aware that there were always choices gave the participants a sense of freedom and an excitement about making choices, revealing also some control and a sense of having a purpose in life. The increasing awareness about choice led participants to carefully plan their life with the self at the centre of such planning, in an effort to achieve more harmony between the physical, psychological and sociological self.

In this stage of *Bolstering Self-Worth*, the participants engaged in a process to actualise a different vision for their life. This stage is not a definitive end in itself, but rather a continuing stage as the participants continually develop their person including their self-worth.

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[41] An important category in *Insulating Self-Worth* when the participants concealed any acknowledgement or identity with RA.

Summary of the theory of Negotiating Self-Worth

This study identified the main concern of participants as *Fear of Declining Self-Worth*. This main concern arose from the participants receiving a definitive diagnosis of RA and believing that this would negatively influence their self-worth. The core category identified to address this concern was *Negotiating Self-Worth*, which was operationalised within an awareness context. The awareness context was the ambience or the atmosphere that the participants created and controlled. It was essentially how they managed the disclosure of personal information to others. Participants created and controlled three types of awareness context: closed, limited and open. In the closed awareness context, there was no personal disclosure and, therefore, the participants were careful that behaviours did not give any indication of their diagnosis. In the limited awareness context, there was selective disclosure with persons whom the participant perceived had a vested interest in their welfare and were respectful to them. In creating the open awareness context, the participant engaged in full disclosure with people who had the capacity to understand RA, who had a vested interest and were respectful to them. With awareness context as the medium, *Fear of Declining Self-Worth* was processed through the core category of *Negotiating Self-Worth.*

Negotiating Self-Worth comprised of stages, categories, properties, critical junctures, all of which explained the variation in patterns of behaviours and enable it to be known as a BSPP. *Negotiating Self-Worth* comprised of three stages: *Insulating Self-Worth, Scoping Self-Worth* and *Bolstering Self-Worth* with the movement between stages signalled by the participant reaching a critical juncture of either flux, vulnerable or secure. Critical junctures were identified as critical points which the participant reached, and this signalled progression to the next stage. There was no time limit to any of the stages. While progression between stages could be linear, this deviated for some participants when they moved to the second stage and then reverted back to stage one. When the participants entered stage three, they did not revert back.

In the first stage, *Insulating Self-Worth,* the participants were consumed by the fear of the erosion of their self-worth, and they responded by concealing the diagnosis and asserting control over the RA. In the psychological state of flux, the participants were cautious to conceal any dimension or indicator that might reveal or intimate they had this RA which they believed to be a condition of the elderly and brought infirmity, disability and dependency. At the same time as the participants were concealing the condition, RA was making its presence felt with everyday symptoms and flare-ups and normal life events were continuing to make demands psychosocially. The participants had reached their limit when all their efforts achieved nothing, and they became very vulnerable. Having reached the critical juncture of vulnerable the participants moved into Stage Two, namely *Scoping Self-Worth*.

In *Scoping Self-Worth,* the participants in the psychological state of vulnerable were broken. While they were broken, they had a yearning for something more for their life. The participants brought a hesitancy with their yearning, making them cautious and this restricted engagement in opportunities to find meaning in their life with RA. They began to engage with compassionate others to discern what meaning they could have for living and their life. For some this was too much of a struggle and they reverted back to Stage One, where they engaged in the FASP cycle of activity flurries and self-pity, before eventually gaining insight into behaviour patterns and moving forward again to *Scoping Self-Worth*. The categories of *Discovering* and *Deliberating* described the processes the participants engaged in to respond their yearning for something else in their life with RA. These processes emphasised the participants gaining self-knowledge and coming to understand the self as a social human being. Gaining knowledge about RA management gave them further insights about living with RA.

The increased self-awareness and specific knowledge of RA management empowered them to focus on their yearning for something different and begin to envision what the something different might be. In *Deliberating*, the participants came to understand that RA has to be owned and not just tolerated. Owning RA enabled them to make life decisions, and not decisions based only on RA. From this perspective the participants started to implement the new learning into their life and gained glimpses of what that life should be. They entered a secure psychological state and considered that they wanted more of what they have gained a glimpse of. So, they moved into Stage Three, namely *Bolstering Self-Worth*.

In *Bolstering Self-Worth,* the participants, through supportive relationships and positivity, were enabled to expand what they had glimpsed and furthermore to maintain that vision. The participants reframed how they perceived RA. RA no longer dominated their life and the participants gave equal recognition to other aspects of their life and living. Through reframing, the participants gained a positive energy to focus their interest on general life matters and situate RA at a distance. Participants recognised that, while RA had changed their life, they could also acknowledge some positive aspects and in particular personal growth. Participants exhibited self-compassion and an understanding that, while everyone has issues and concerns, solutions would emerge. Participants, therefore, had achieved some internal peace and gained insights into how they could contribute to humanity.

At the end of this stage the participants had established that, while they had self-worth, it was not a definitive end stage, as they would continue to develop their person and their self-worth.

Negotiating Self-Worth described the process of resolving the main concern of the *Fear of Declining Self-Worth.* In the process the participants may not have achieved what they thought they wanted, but gained more than they could have dreamed of, that is, an understanding that they were social beings, worthy of self-consideration and, therefore, important members of society. Participants acknowledged that life now is so much better, not because of the RA, but because their whole attitude to life and living has changed.

CHAPTER 8: DISCUSSION

Introduction

The previous chapters examined the emergent '*Negotiating Self-Worth*' theory without any discussion in relation to existing theoretical literature. The aim of this chapter is to discuss the theory in relation to other existing empirical literature and thus increase the clarity of the theoretical constructs. '*Negotiating Self-Worth*' is situated within a social context that perceived RA as a chronic illness and, therefore, the chapter begins with a discussion of dominant discourses on chronicity. The remainder of the chapter will establish self-worth as entwined within identity and belonging, and thus revealing a broader conceptualisation. The discussion will draw upon other theories to assist in understanding how the participants processed their fear of *'Declining Self-Worth'* utilising social and psychological theories.

Dominant Discourses on Chronic Conditions

The dominance of biomedical science discourse in relation to RA has influenced developments in treatments and consequently PLRA are now experiencing symptomatic relief and increased functionality, which professionals equate to an inactive state (Kilic *et al.* 2016; Forestier *et al.* 2019). PLRA dispute the inactive clinical status and, therefore, a discrepancy exists (Kool *et al.* 2014; Santiago *et al.* 2017). This discrepancy has contributed to a desire by professionals to understand the perspective of the PLRA (Avis *et al.* 1995; Groenewegen *et al.* 2005; Carpenter *et al.* 2020). Esteemed writers such as Kleinman (1988); Charon (1996; 2005, 2011), Charon and Charon (2012), and Hurwitz and Charon (2013) have advanced the discourse on the discrepancy and advocated for the inclusion of psychosocial dimensions in medical science. This professional influence attributed to the development of various validated tools in an effort to understand the psychosocial dimensions of RA e.g., quality of life, fatigue, pain, depression, invalidation (Kool *et al.* 2014; Bacci *et al* 2017; Dalili *et al.* 2019; Carpenter *et al.* 2020). While such tools cannot capture nuances they do, nevertheless, contribute albeit minimally to the ongoing discourse on psychosocial dimensions.

Treatment successes have created other challenges: (1) a proliferation in costs for pharmaceutical agents; (2) an increase in the population with co-morbidities (PLRA develop co-morbidities as part of the condition or treatment sequela in addition to the ageing process) and (3) a growth in the population requiring supports to address psychosocial dimensions of life with RA (Scambler & Scambler 2010; Donnelly *et al.* 2020). These challenges are an international phenomenon. Governments have developed social policies with predominant strategies of health literacy and self-management promoted through education programmes (Turner & Kelly 2000; Nutbeam 2008). Underpinning the social policies are the assumptions that a person equipped with health knowledge and self-management skills would be empowered and enabled to manage their condition and, therefore, the burden upon society would be decreased (Coster *et al.* 2009). Such an assumption is pervaded with other presumptions. The following discussion highlights the contradictions that arise in education and self-management ideologies.

Education and 'Negotiating Self-Worth'

The majority of education programmes for chronic conditions follow the framework developed in the USA by Lorig *et al.* (2001) (Bury *et al.* 2005; Squire & Hill 2006; Stenberg *et al.* 2016). Such programmes are often devised by professionals with lay involvement in the development and delivery (Richardson *et al.* 2014; Morgan *et al.* 2017). A similar format is followed, i.e. details are given on the condition, skills for management and gaining some quality of life, all of which reinforce the biomedical perspective and minimise recognition of personal perspectives regarding the meaning of RA in their life (Walker *et al*. 2004; Bury *et al.* 2005; Bury 2010; Richardson *et al.* 2014; Stenberg *et al.* 2016; Lin *et al.* 2020). The effectiveness of educational programmes remains unclear and, therefore, education could be a mechanism whereby people are expected to follow guidelines and manage, all of which imply a decreasing need for supportive health services (Coster *et al.* 2009). Consequently, individuals may perceive an increased need for support service as a failure on their part to comply with the prescribed programme and, therefore, requests for support services would be reduced, but there may be an increase in distress for PLRA. From this perspective, education programmes could be another mechanism to reduce the demand for support services (Bury 2010; Greaney & Flaherty 2020; Charmaz 2020). Furthermore, as Greaney and Flaherty (2020) caution, the lack of identified supports may further the self-blame when individual targets are not achieved due to insufficient or absence of supports.

The participants in this study noted the benefit of education programmes in '*Scoping Self-Worth*' and *'Bolstering Self-Worth'*. In these stages the participants were motivated to engage and increase their understanding of RA and the subsequent application of new knowledge into their lives. In '*Scoping Self-Worth*' participants were hesitant to engage, but believed that there was something new to learn which they considered may unfold possibilities for positive influence in living with RA. The anticipated future gains, although undefined, increased their motivation for engagement. However, it was within the process of engaging that they encountered and gained experiential knowledge regarding the psychosocial dimensions of living with RA. The education programmes the participants took part in followed the general format referred to above, but there was an unwritten dimension which was equal to, or perhaps more powerful than, the biological dimension, as the participants gained insights into self-awareness. The participants felt supported to continue to increase their self-knowledge, which in turn increased their readiness to engage in the biological dimensions. When the participants entered '*Bolstering Self-Worth*', they continued to increase their self-knowledge and gained courage to identify the biopsychosocial supports they needed to live their life with RA.

By contrast, when the participants were in *'Insulating Self-Worth'*, there was a pre-occupation with concealing the diagnosis. The minds of the participants were captivated by the threat of RA to their whole existence and, therefore, the goal in *'Insulating Self-Worth'* was gaining information about how RA could be eradicated. Suggestions and encouragement from professionals influenced the participation in education programmes. The participants selectively focused upon aspects that they deemed important, i.e., the directions regarding medication and further clinic appointments. Limiting knowledge attainment to a medication regime and instructions to follow was linked to their personal goal of keeping the diagnosis a closely guarded secret and protecting their sense of self. Maintaining a sense of self by concealing also maintained their illusion that nothing had changed, but also restricted the possibility of others gaining any insights into their behaviours.

The participants in '*Scoping Self-Worth*' and '*Bolstering Self-Worth*' became empowered to live in ways that respected their whole person. From this perspective it is possible to draw some parallels with empowerment theory. Empowerment theory advocates individuals gaining control over their lives by acquiring the skills to gain solutions to issues in the wider social context (Rappaport 1984). In a sense, this is what occurred for the individuals, albeit at an individual level. There was an awareness of the wider social context, which is congruent with psychological empowerment as defined by Zimmerman (1995). Psychological empowerment can vary across social contexts and time, which was the experience of the participants. However, once they knew and experienced empowerment, the participants did not succumb to helplessness. Having to conceal aspects of the self in *'Insulating Self-Worth'* prevented the participants becoming empowered, which concurs with the findings of Fairweather *et al.* (2021) who studied empowerment in children with Cystic Fibrosis.

In summary, education programmes focusing on professionals' perspectives on health needs and engaging a passive approach may be limited in their success. The findings of this study raise questions about the timing and the content of education, and strongly suggest that generic programmes will not address specific needs (Wilson *et al.* 2007). The participants in this study were psychologically empowered in '*Scoping Self-Worth*' and '*Bolstering Self-Worth*'. The psychosocial supports they encountered enabled them to become empowered. This study emphasises that psychosocial needs are equally important to biological and functional aspects of living with RA, and thus in the initial stages the emphasis needs to be given to the meaning of the diagnosis to the participants and how this meaning impacts upon the self.

Self-Management and 'Negotiating Self-Worth'

For the participants in this research, self-management was ongoing and integrated into living and varied across the three stages. In 'Insulating Self-Worth' when the participants first gained a definitive diagnosis, they experienced conflict between what they had been told and their personal hopes and future plans. Realising that treatments were powerful in relieving physical symptoms and supported their endeavours in concealing the RA diagnosis the participants gave supremacy to medications. Therefore, the participants possessed strong motivations to self-manage medication, i.e., following regimens and instructions regarding ongoing monitoring. For some participants, the powerful relief of physical symptoms resulted in them engaging in reminder strategies for medication regimens, while others employed various schemes to self-manage the side-effects of medications, e.g., taking medications at night or on days off from work. Participants also managed their review appointment times to avoid clashes with work or other important commitments. These management strategies enabled the participants to live life as normal and conceal their diagnosis, and were successful until a flare-up was encountered. In the flare-up state it was difficult to engage in normality and maintain the façade. Repeated flare-ups brought the participant into a psychological state of *vulnerable*. For other participants there was a struggle to find the regimen that would lead the RA into an inactive state. The cyclical nature of active-inactive states was too much and a psychological state of *vulnerable* was reached. It is important to note that

RA management does not occur in a vacuum. It is one part of the life of the PLRA and in ‘Insulating Self-Worth’ the participants micromanaged life with RA to retain normality.

In *‘Scoping Self-Worth’* the participants were motivated to discover more about the strategies that could be utilised to manage the RA at a macro level. While they were still micromanaging aspects of their RA life, they were also discovering that psychosocial supports were important for managing their life. The encounters and engagement with psychosocial perspectives enabled the participants to begin a journey of discovery beyond RA, including the self and life meaning. In *‘Bolstering Self-Worth’* the participants were self-managing at a micro and macro level. This was communicated in holistic terms, no longer giving supremacy to the treatments but gaining a balance in living with RA as part of life. *‘Bolstering Self-Worth’* brought a different dimension to the idea of self-management and emphasised the importance of biopsychosocial dimensions inclusive of desires and capabilities for self-managing (Van de Velde *et al*. 2019). In ‘*Insulating Self-Worth’* when the participants encountered a period of intense activity of RA, there was some evidence of self-recrimination. In *‘Scoping Self-Worth’* combined with professional support, they engaged in problem-solving strategies and gained a more holistic perspective.

What this study demonstrates is that self-management plans which are dominated by physiological perspectives are insufficient and psychosocial perspectives must be included (Turner & Kelly 2000; Walker *et al.* 2004). There is a sparsity of literature on psychosocial dimensions in relation to chronic conditions. Donnelly *et al.* (2020) completed the one and only evidence synthesis of qualitative studies (1993 – 2019) in relation to self-management and RA, and sought to discover how people experience self-management and what aspects were regarded as most pertinent. From the 32 studies selected for review, six domains were identified: “cognitive-emotional, behavioural, social, environmental, physical, and technological” (p.1391). The cognitive domain, which included the dimension of the self and related to self-worth, was found in 90% of the papers reviewed, and emphasises the self as central to considerations of self-management. The findings of this present study, therefore, will be beneficial in understanding the assault on the self and how the participants managed that assault.

In summary treatment developments for RA have achieved good outcomes, namely, increased functionality and longevity, but consequently created fiscal demands. Healthcare policy developed to address this has focused upon self-management through education programmes from a biomedical perspective. While clearly there are important biomedical dimensions that need detailed consideration, of equal importance are psychosocial perspectives, which ultimately impact upon individual orientation to continue with physiological treatment regimens. In this study the participants in *'Insulating Self-Worth'* participated in education programmes through the encouragement of professionals and complied with treatment regimes. In 'Scoping Self-Worth' and *'Bolstering Self-Worth'*, when they possessed a psychological readiness to engage, they moved from compliance to self-management, which emphasises the need for strategies that are aligned with the needs of PLRA.

'Negotiating Self-Worth' and Sociological Perspectives

In the 1970s there was a fundamental shift in sociology toward chronicity and consideration of holistic perspectives in the management of chronic conditions. This shift in discourse influenced subsequent sociological studies (Strauss & Glaser 1975; Conrad & Bury 1997). Strauss and Glaser (1975) identified that chronic conditions have an impact on family. Wiener (1975) identified that PLRA carried a burden, as they encountered the physical aspects and engaged in living to maintain a sense of normality. Bury (1982) in the UK investigated the phenomenon of living with a chronic condition and identified that a diagnosis of RA brought a particular kind of biographical disruption which interrupted future plans. During the process of disruption people were concerned about who to tell and what to reveal in particular contexts. Bury (1982) identified that chronic conditions were an assault on the biological, psychological, and sociocultural aspects of people's lives which impacted upon engagement with others. Contexts and meaning, therefore, were an integral component of disruption that could not easily be separated (Bury 1991). The meaning of chronic conditions was further defined in terms of consequences in everyday life and the significance of meaning that is the symbolic meaning people attach to a diagnosis which, as Bury (1991) states, has a profound influence on the person and their life. Meanings do not remain stagnant, but rather may change across the trajectory and, as they do, people are therefore never certain of how they should respond.

The perspective of burden was obvious in '*Insulating Self-Worth'*, when the participants struggled to conceal their diagnosis and maintain the façade of normality. Disruption also was relevant to the experience of the participants, in that the RA experience disrupted all of their life but the psychological assault on their identity was much more emphasised. At the time period of both Wiener's (1975) and Bury's (1982) studies, PLRA would have encountered more frequent and lengthy periods of pathological activity in addition to the progressive physical consequences upon joints. By contrast, in the era of this study two aspects of treatment development impacted upon the physical dimensions, i.e., the development of pharmaceutical agents and T2T strategies. Thus, the immune response was altered, which decreased joint deformities, and intensive treatment of RA activity lessened the length of the immune response. Therefore, the focus of the participants was less physical (although this was present) and more upon the psycho-sociocultural meaning they attached to the RA and the impact upon their life. The RA did disrupt life plans and hopes for the future. The assault on the inmost being took away the very sense of self. This constituted a major burden for the participants. Similar to Bury's theory the participants had taken for granted assumptions about their life and these were given meaning when they could no longer be certain or know what their future was going to be. In this theory, the participants responded initially from a defensive perspective and therefore had concerns about who they could possibly tell. Keeping the RA, a secret was a self-protection strategy that was considered to protect the social self.

Later in *'Scoping Self-Worth'* the participants discovered that psychosocial perspectives were important for examining the meaning of life and recognised that gaining external affirmation had been an enormous influence in how they considered their life and living. These insights equipped the participants with a different psyche to consider their life and work. In *'Bolstering Self-Worth'* they cemented and built upon the insights they gained in *'Scoping Self-Worth'*.

Other sociologists have used narrative re-construction to look at the lived experience of chronic conditions (Williams 1984; Kleinman 1988; Frank 1995; Charon 2005, 2014a, 2014b). These narratives offer insight into the experience and disruption that is experienced in living. Kleinman (1988) brought some insights into the limitations of medical perspectives on chronic conditions while Frank (1995) offered a restitution narrative, bringing hopes for wellness and possibilities for transformation as people engaged with medical advances. Charmaz (1983, 1991, 2002) focused on the consequences of chronic conditions and identified assaults on selfhood. The loss of self was exhibited as individuals observed their previous known person crumbling and dissipating, which resulted in an undermining of the self-concept. Charmaz (1983) identified that this loss of selfhood was a tremendous suffering for the individual. The loss of selfhood was congruent with the events for the participants in this study, but what is striking is that the participants in this study were able to transcend the loss and find their worth. What enabled the participants to '*Negotiate Self-Worth'* was the engagement in supportive relationships, which not only assisted them in problem solving everyday concerns but also untangled their thought processes that undermined their sense of self.

'*Negotiating Self-Worth*' extends the thinking about the life of individuals with RA. A burden, disruption and loss of self-hood only partly explain the contemporary response, that is, they explain the behavioural responses in '*Insulating Self-Worth'* only. The participants did experience disruption and a loss of selfhood. However, the participants persevered in a fuller process to find meaning in their life and ultimately self-worth. The motivation to persevere was initiated and bolstered by professionals practicing through a holistic person-centred ideology and continuously engaging in psychosocial dimensions. This approach to being with the participants on their RA journey began to infiltrate the personal psychology of the participants. In *'Scoping Self-Worth'* the participants engaged tentatively, but in the *'Bolstering Self-Worth'* stage they progressed to full engagement achieving the perspective that psychosocial dimensions were extremely important in living with RA and from these insights sought to increase psychosocial resources for future usage. The literature acknowledges that RA brings social and psychological challenges (Benka *et al.* 2012; Xu *et al.* 2017; Dures *et al.* 2014). There is, however, conflicting evidence on the range of psychosocial interventions that may be useful to PLRA or how they might be accessed and utilised (McBain *et al.* 2019; Santos *et al.* 2019). Perhaps similar to education, psychosocial interventions should be tailored to individual needs, as each PLRA will have a perspective on what is helpful to them. The literature in relation to psychosocial dimensions alludes to the lack of recognition of the impact of psychosocial dimensions in living with RA and the needs for specialist services, i.e., expert clinicians who may focus on the development of these resources.

In summary, biomedical perspectives dominated the discourse on chronic conditions, having retained its superiority in relation to knowledge advancement (Frank 2013). In the seventies era sociology began to recognise and advance the idea that chronic conditions impacted upon the person beyond physiological perspectives (Conrad & Bury 1997). Two principal theories dominated the literature in attempting to understand how a chronic condition impacts upon the life of the individual. Wiener (1975) identified that living with RA was a burden and, despite this study being the first examining the experience of living with RA, there is little evidence in the literature acknowledging any impact in the subsequent years. This is, perhaps, an indication of the domination of the biomedical model in that era. Bury's work (1982) on a disrupted life had more influence from a sociological perspective. Other sociologists have further distinguished the experience of disruption in life with a chronic condition (Williams 1984; Frank 1995; Charon 2014a) and a loss of selfhood (Charmaz 1983). Bury's and Charmaz's work have dominated the literature, which, perhaps, is due to expansion of their work in further studies and publications. The advancements in treatments mean that physiologically RA is better controlled. This may have generated the belief that psychological and social burden were no longer an issue because the physical symptoms, such as deformity, were absent. However, there remains a burden, even if it is hidden by the reduction in physical symptoms. This present study extends the work of Bury and Charmaz, in that it explains how PLRA proceeded to gain a life that was not defined or controlled by RA but accentuated the significance of recognition of self-worth.

Impact on Self-Worth: Precursor to 'Fear of Declining Self-Worth'

Self-worth essentially refers to an individual possessing the knowledge that they are good enough and worthy of belonging and receiving affection from others (Rosenberg *et al.* 1995; Cast & Burke 2002; Stets & Burke 2014a). This subjective evaluation of the self gives an overall sense of self-worth (Myers 2009; Stets & Burke 2014b). To be able to evaluate the self an individual, therefore, would need to have a sense of who the self is (identity). That said, it is when a situation arises (either negative or positive) that an individual engages in in-depth conscious consideration about self-identity (Burke & Stets 2009). The first stage '*Insulating Self-Worth'* identified that the participants entered a reactionary psychological state of *flux* when they received factual information about their RA and the subsequent impact upon them. The information impacted profoundly upon the participants' identity as social beings, and they questioned the essence of their identity and the meaning for living. The term RA was understood as bringing negative connotations which were not included in the participants' considerations for life planning and, furthermore, undermined their current life choices of work and social role fulfilment. Prior to receiving the diagnosis, the participants understood their identity and knew they belonged and fitted into society. The RA diagnosis impacted upon those certainties. The participant fought to belong to the world they knew prior to the diagnosis. RA impacted upon their sense of being, their self-worth and belonging, as if they were drained of all they ever knew of themselves as social beings.

Lack of Belonging and the Contribution to Flux

The need for belonging is well established in social psychology as a human emotional need (Over 2016). Early work on motivational theory by Abraham Maslow [1908-1970] (1954) identified that individuals are motivated to proceed through levels of needs from physiological to transcendence. According to Maslow (1954), human beings have a need for belonging and acceptance in a wider context outside of the self and thus are motivated to address this important aspect through interpersonal processes within various social groups. Human nature, therefore, is conditioned to belong but does require social interaction to become real (Baumeister & Leary 1995; Brewer & Gardner 1996).

This partly explains the defensive behaviours of the participants when they were given the definitive diagnosis of RA as they considered that their belonging was threatened. The diagnosis brought negative connotations, which highlighted to the participants the ways in which they could not fulfil their own or other expectations of current roles and, therefore, no longer fulfilled the self-identified criterion for belonging in society. In addition, they perceived that negative connotations associated with RA would evoke the emotional response of pity which was understood as emphasising and increasing negative perspectives. The participants reacted by concealing the challenges and normalising their behaviours (Strauss & Glaser 1975). The concealing behaviours could be explained in three different strategies: (1) avoidance of situations or contexts in which their deficits may be implied or be obvious to others, i.e., social gatherings, (2) offering alternative excuses to explain nonattendance or non-participation in events or activities and (3) super-normalising by undertaking activities where they would encounter challenges to prove to others that they were capable and able, even at the expense of encountering increased physical symptoms. For the participants the RA diagnosis threatened their belonging in society. Strategising supported them in maintaining a façade that nothing had changed, but internally they experienced *flux* and questioned their personal identity and roles in society. When compared to Maslow's hierarchy, the participants were no longer having their physiological needs met and so were not engaging in reciprocal interactions necessary to feel they belonged. Ironically, the participants inabilities were emphasised to them through their own strategising and their visualising the capabilities of others. Moreover, the strategising brought consequences of isolation and loneliness which emphasised the lack of belonging. This made the participants question what their identity was.

Identity Re-conceptualisation and Careful Management of Disclosure

‘Insulating Self-Worth’ encompassed the participants experiences of initial symptoms, their struggle to come to terms with the confirmed diagnosis and the subsequent impact upon the self and their identity as a social being. Identity has over time been the subject of much theoretical discourse, with recognition of the contribution of American philosopher William James [1842—1910] as a key contributor in the subsequent discussions and debates (Gubrium & Holstein 2000). James theorised that the self as a conscious being was comprised of two dimensions “I” and “Me” (Woźniak 2018). The “I” was the subjective self who understands who the self is and has capabilities of thinking and reflecting upon the self, was capable of linking the past to the present, and cares with passion about the objective self the “Me” (Cooper 1992). “I” is mediated through the consciousness and cannot be considered to be an object of science (Green 1997). The “Me” dimension was the objective self which was understood as having elements of material, social, and the spiritual self. The material self was understood in terms of the belongings, e.g., possessions, i.e., the body, money, friends, family, esteem from various roles. The social self was based on social interactions within different contexts which bring recognition for the many social selves. Drawing from the work of James, in this study RA impacted on both dimensions of the participants sense of self. In the “I” dimension, the participants underwent a reconceptualization of who they understood themselves to be, namely a healthy individual, and replaced it with a conceptualisation of themselves as sick, disabled, dependent and old. The participants recognised the possible impact of this reconceptualisation on the “me” dimension and strived to protect it through various strategies, such as avoidance of health conversations and supernormalising activities.

There was tension between the “I” and the “Me” dimensions, necessitating strategies such as managing disclosure. The participants wanted to detract from the RA and communicate to others that nothing was different and thus they carefully managed disclosure through four different types of relationships, namely, *Unsupportive; Pseudo-friendly; Semi-Supportive* and *Supportive*. The type of relationship engineered was dependent upon the participants’ evaluation of the psychosocial behaviours of others and of the reasons these others had for demonstrating an interest in their condition. Consequently, when the participants evaluated people as having no vested interest in them, they deemed the relationship to be unsupportive and there was no disclosure. To minimise the threat of disclosure, the participants created a *closed awareness context.*

All their psychosocial behaviours demonstrate normality and the behaviours were focused upon maintaining a façade of self-reliance and capability. In *Pseudo-Friendly* relationships, the participants recognised a display of disingenuous mannerisms, such as glares or frustration at a slower pace of movement, and decided to respond in a non-confrontational manner. The response was not reactionary, but friendly and polite, creating the false impression of oblivion to the hurtful behaviours that they had interpreted and experienced. In the *Semi-Supportive* relationship, the behaviours were interpreted as intentionally good. The participants were very selective about what disclosures they would make and to whom, and thus did not become an object of pity. This protected their reconceptualisation of the "I" as unable, but they experienced conflict as they did not get support when they needed, which created further repercussions as the participants endeavoured to find ways of doing things for themselves, even at the expense of agitating the RA. In the *Supportive* relationship, genuine interest of others was evaluated in the behaviours observed, such as active listening, authentic comments articulated in a supportive way, which indicated that others were willing to engage and relate to the participant as a person regardless of any obvious deficiencies. At this point the participant was able to acknowledge their new reconceptualisation of the self and feel comfortable with disclosure. The consequences of these disclosures enabled further conversations, which supported the participants in developing self-awareness as well as exploring their core identity further and marking the beginning of decreasing the tension between the "I" and the "Me". *Supportive* relationships were more dominant in '*Bolstering Self-Worth'*. It seemed like the real self was emerging as the "Me" gained experiences which were mediated through the "I".

The Looking Glass Self a strategy within 'Insulating Self-Worth'

Charles Horton Cooley [1864 -1929], an American sociologist, proposed that identity is realised through socialisation. The human being is viewed as social in nature. Therefore, it is in the processing of interactions that individuals gain an identity, i.e., they interpret what is occurring in an interaction (Crocker & Wolfe 2001). Using the "looking glass self" idea proposed by Cooley, individuals imagined how they were perceived by others and the judgements others made about them based upon appearances and presentation (Belgrave & Charmaz 2015). For the participants in this study, Cooley's ideas are very pertinent. The participants used their sociocultural understandings of RA to make judgements about their presentation to others, and considered that presenting as normal was very important. However, this varied across the three stages of the theory. In '*Insulating Self-Worth'* and '*Scoping Self-Worth'*, the participants exercised caution and controlled the amount and type of information others would gain through social interaction. The participants, while being cautious about their own presentation, also interpreted in detail the responses of others through the lens of RA as a crippling, debilitating and ageing phenomenon and adapted their responses to maintain the façade of normality (Downey 2021). The participants were selectively using the looking glass ideas on an aspect of their life that was significant to them. In *'Insulating Self-Worth'* the participants were sceptical and suspicious of any inquiry regarding their health. This shaped their impressions of their own presentation and altered their behavioural responses. Later when they entered '*Scoping Self-Worth*', the participants rationalised that some people were being polite and friendly. In '*Bolstering Self-Worth'* the participants were less suspicious and cautious about their presentation, as they increased their self-awareness and acknowledged that responses of others have many influencing factors. Participants were using subjective interpretation and were imagining the responses or judgements (Leary & Acosta 2018). In *'Insulating Self-Worth'* and '*Scoping Self-Worth'* the participants were influenced by their own sociocultural understandings. As Crocker and Wolfe (2001) acknowledge, there is no way to know what others truly think and participants achieved this realisation in '*Bolstering Self-Worth'*. The idea of the looking glass self has considerable relevance, as it reflects exactly where all the participants were at the beginning of the arthritis journey in *'Insulating Self-Worth'*. The meaning that the participants gained emerged from their interpretations and cultural understandings.

The Challenges of Identity and Social Roles in 'Insulating Self-Worth and 'Scoping Self-Worth'

While the identity proposed by Cooley emerged from interpretation, an alternative idea is that the identity is created by an individual (Bauman and Vecchi 2004). It is the invention of self-identity that the social psychologist George H. Mead [1863–1931] gave his attention in what was later termed symbolic interactionism (Stryker 2008). For Mead, society was composed of symbols that individuals used to establish meaning, develop views about the world and to communicate with others. The individual, then, is a reflexive self that can interpret situations and modify symbols to respond. It is this interaction that forms and reforms society (Hogg *et al.* 1995). Stryker (1980) developed identity theory from structural symbolic interactionism, moving Mead's idea to a reciprocal relationship between the self and society leading to a particular identity (Stets & Burke 2014b). According to Stryker (1980) engagement with society occurs at two levels, namely, the family or work level and the larger structures within society e.g., clubs, institutions.

For the participants in this study, the roles they fulfilled in society gave them their identity. Some they selected because of their profession or roles they were elected to in different social groups, or some just emerged from their circumstances in life, e.g., carer or homemaker. Each role had a particular identity, and the participants lived their life from the expectations of such roles. When the participants had one role and applied their understanding of RA, they questioned their ability to fulfil the role. It seemed to be more devastating to their sense of self and hence *'Insulating Self-Worth'* was intense.
Stryker (1980) viewed that individuals had many identities and they selected which identity should have salience over another. The selection of a particular role identity was reflective of the commitment to particular roles and the social ties within society (Stets & Burke 2014b).

Burke (1991) questioned the idea that people acted in ways consistent with their identities. He proposed a theory of identity which was premised upon the view that individual identities are embedded in the social structure and the individual behaves in a way that corresponds to meanings evident in the evaluation of an identity. He revealed a verification process consisting of four central elements: (1) an identity standard, i.e., explanations and descriptions held by an individual which explain his/her role identity in a particular situation; (2) individuals' understanding of meanings within the situation; (3) individuals compare the identity standard with their perception of meanings within a situation; (4) an individual's behaviour equates to the difference between the identity standard and the individual's perception (Burke & Reitzes 1991; Burke 2016). In the process of self-verification, the individual attempts to achieve congruence between the identity standard and self-meanings by altering the current situation or creating new situations (Stryker & Burke 2000). It is, therefore, the internalisation of expectations associated with social roles that gives identity. Prior to receiving the diagnosis of RA, the participants felt they knew who they were. However, the arrival of the physical manifestations of RA and the subsequent confirmed diagnosis created a situation where they began to consider and question that identity.

In *'Insulating Self-Worth'* the participants were of the opinion that the identity they had was in question. They could not achieve congruence between the identity standard they had and the expectations held by others and were unable to alter or change their behaviours to achieve the identity standard. Consequently, the participants sought to retain the identity they knew through defensive strategies and, as noted by Wylie and Wylie (1957), defending was fuelled by the discrepancy in their identity. '*Insulating Self-Worth'* recognises the challenge for individuals as the interactions and social relations with which they were familiar were no longer a resource that they could use to reformulate a new identity or place in society. Additionally, new resources available as a consequence of their clinical diagnosis of RA were dominated by the biophysical aspects of RA.

As the participants progressed into '*Scoping Self-Worth',* they gained insight into the importance of psychosocial resources in discovering a different identity. Swann and Hill (1982) highlight that intrapersonal and interpersonal elements are required for a change in identity. The intrapersonal element of re-organising the self-view was achieved in '*Scoping Self-Worth'.* The participants scoped with the support of psychosocial resources to gain a new self-view and take ownership of same. As Swann and Hill (1982) maintain identify, this ownership may be contested if interpersonal elements do not confirm or support the new self which was evident when some participants entered the *FASP Cycle* within *'Insulating Self-Worth'*. This action may be explained by two factors:(1) they did not take ownership and retained doubts about a new identity and hence their behaviours verified their old self-concept and (2) their social environs did not support their new identity. The participants who owned their new self-identity and sought out and engaged in psychosocial resources gained the impetus to embed the new identity in their life in the process of '*Bolstering Self-Worth'*. At this juncture the chronic condition of RA did not define their identity, but on the contrary, assisted them in gaining a different perspective on their identity and, consequently, on life and living. The new self-identity was a *discovering* process when the participant, in interaction with others and with psychosocial support, began to create possibilities for their role and identity. For some this was an adaptation of work methods, or work details. Psychosocial supports enabled the participants' engagement with cognitive and affective dimensions involved, e.g., the homemakers discussed the completion of tasks and how those tasks could be completed differently or by others in the household. For other participants the task was about discovering a new identity that would bring financial reward and personal fulfilment. It was in the process of *deliberating* that participants engaged in increasing self-awareness and endeavoured to discover an identity which was broader than their current thinking about their role in life. '*Scoping Self-Worth'* was a demanding stage for all the participants as they engaged with interpersonal perspectives and continued to develop contemporary knowledge of RA and to establish the limitations of past understanding.

Self-esteem and Identity

Cast and Burke (2002) propose a theory of self-esteem based on the theory above. They assert that self-esteem has two important dimensions: competency (self-efficacy) and worth (personal feeling of value). Furthermore, they state that individuals are motivated to perceive themselves positively, a view that is confirmed by other theorists (Gecas 1991, 2003; Leary 2005; Leary and Accosta 2018). The process of verifying an identity accords an individual with competence and worth, i.e., the identity matches their meanings of that identity[42] to give them worth. Furthermore, the idea that they can affect situations gives a feeling of self-efficacy. An increase in self-esteem is experienced when an individual verifies their salient identity. This may occur, for example, when their behaviours in a work situation are deemed similar to the meanings they have of a particular work role. A decrease is experienced when the individual cannot confirm their identity to match the meanings they hold. An increase in self-esteem can be used as a buffer at a later time, to defend an individual when a verification is not achieved. Self-esteem may be accumulated and used in other instances, but needs to be replenished. When social changes are encountered an individual uses the stored self-esteem and, should these changes persist, the self-esteem becomes depleted.

In *'Insulating Self-Worth',* the participants were unable to verify all the identities they held. They strategised using non-disclosure in an effort to maintain their self-esteem, but in essence they were using the accumulated self-esteem and, finally, when it was not replenished, they became *vulnerable*. The individuals were no longer able to maintain a view of the self which would indicate their connectedness to others and their social worth. In later work Stets and Burke (2014b, 2018) explain a third dimension to self-esteem: authenticity. Authenticity refers to the standards by which an individual verifies their identity and whether these standards represent the true self. In *'Insulating Self-Worth'*, the participants concealed their true identity and, therefore, were not authentic, which lead to personal discontentment and further diminishing self-esteem. For all the participants at least one other was selected as a confidant. However, non-disclosure was

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[42] An individual has many identities. The salient identity refers to the identity which is relevant in a particular social situation at a particular point in time.

the prominent strategy for retaining self-esteem (Weisz *et al.* 2016; Ryan *et al.* 2017). Non-disclosure has been shown to have implications for personal health (Lempp *et al.* 2006; Newheiser & Barreto 2014). Furthermore, non-disclosure reduces possibilities for establishing social ties and the consequential loss of opportunities for psychosocial supports (Beals *et al.* 2009; Quinn *et al.* 2014; Quinn 2017). When the participants entered *'Scoping Self-Worth'* and engaged in self-awareness, they were able to discover and deliberate upon new identities. This engagement required *courage* and energy and psychosocial supports. The *hesitancy* that was evident initially in *'Scoping Self-Worth'* decreased and self-confidence increased boosting their self-esteem. In *'Bolstering Self-Worth*' the participants engaged in strengthening the foundations of their self-esteem.

In summary, the participants entered an identity vacuum when they received the definitive RA diagnosis. This identity vacuum was evident in *'Insulating Self-Worth'*, when the safe world the participants knew disappeared and they struggled to find their place in society. The participants reconceptualised their identity as being sick and unable, which conflicted with the verification of their social roles and increased the identity vacuum. The verification of identities, roles and fulfilment of roles was filtered by the participants through the sociocultural understanding which remained very strong in *'Insulating Self-Worth'*. Engagement in '*Scoping Self-Worth'* gave the participants new insights into their true identity.

Stigma and 'Insulating Self-Worth'

The behaviours of the participants in the first stage, '*Insulating Self-Worth'*, could further be explained using the dramaturgical theory of Erving Goffman [1922-1982], which proposed that life is a never-ending stage performance with people acting out different roles. The participants when acting on the front stage performed to suit their audience and the perception they wished to relay, which was that nothing had changed about their person or their life. It was only backstage that the participants could be their true self (Goffman 1959). The participants were what Charmaz refers to as supernormalising, that is, they were acting in particular ways to create a different impression from reality and thus were concealing the impact of the RA on their person and their social roles (Charmaz 1983; Glaser & Holton 2007).

Goffman's later work on stigma gives some more clarity on the motives for the behaviours of the participants in *'Insulating Self-Worth'* (Goffman 1963). Goffman (1963) identified that individuals may have an attribute which differentiates them from others, and they are viewed less favourably by society which provokes particular behaviours from others, ostracising them from social environs. Goffman (1963) identified stigmas associated with mental illness, physical deformation, and sociocultural characteristics such as religion or ethnicity. In general terms, the idiom 'arthritis' continues in the 21st century to incite a vision of pain, disability, deformity, old age infirmity and inability, all of which would alter the appearance and hence possible sources of stigmatisation. For the participants who had deformities they were careful to conceal deformed joints with clothing and footwear, thus limiting exposure to others and decreasing the social consequences of stigmatisation. However, in the constant comparative analysis, it was evident that the awareness of the stigma of RA even in the absence of obvious disfigurement or infirmity motivated the participants to conceal their diagnosis, with the exception of select others who could be trusted with the secret.

Thus, the word 'arthritis' engendered a mental image of a future where the physical features would be unfavourable to them, but in anticipating the stigma the participants were internalising the negative assumptions surrounding RA and believing that this was how they were going to become (Reuda *et al.* 2012). Therefore, the threat of the stereotypical stigma of infirmity and inability remained strong in '*Insulating Self-Worth'* and, hence, the RA diagnosis challenged their individual self-concept (Rosenberg *et al.* 1995). Contemporary treatment has improved the overall outcomes of RA. However, the stigma remains, which emphasises its power and endurance as a social construction (Millen & Walker 2001; Major & O'Brien 2005; Defenbaugh 2013). Internalised or felt stigma (Scambler 2018) is a known phenomenon with mental health disorders (Corrigan & Watson 2002; Boyd *et al*. 2014), but less so with predominantly recognised physical health disorders (Corker *et al.* 2016a). While felt stigma was obvious, the stigma related to chronic conditions was also evident (Millen & Walker 2001).

Stigma and Health

Historically stigmatisation has always existed, with stigma sources being anything that makes a person different from others in a particular time or culture. Hence, health deficits have always attracted stigmatisation (Pettit 2008; Defenbaugh 2013; Scambler 2018). The increased public awareness has both increased and decreased stigmatisation. Health conditions acknowledged as being outside of the control of the individual might attract less stigma, e.g., multiple sclerosis, while those which can be related to human behaviour have increased stigma e.g., obesity (Pettit 2008; Idemudia *et al.* 2018). Some studies have found evidence of stigmatisation in relation to RA (Looper & Kirmayer 2004;

Lempp *et al.* 2006; Corker *et al.* 2016b; Myung *et al.* 2019). Similar to the findings in this present study, a qualitative study by Lempp *et al.* (2006), primarily looking at quality within service provision, identified that people diagnosed with RA endured consequences in relation to personal and public identities. No investigations specifically looking at stigma in patients with RA were evident prior to Corker *et al.'s* study (2016b). This cross-sectional survey intentionally aimed to validate a modification of the Internalised Stigma of Mental Illness Scale for usage in PLRA populations. Internalised stigma was reported in 25% as moderate or severe and 49% as mild. While the sample size was small (100), this is the first study that attempted to quantify the existence of internalised stigma with PLRA. In this research the participants in *'Insulating Self-Worth'* and *'Scoping Self-Worth'* were trying to find meaning about their RA diagnosis. They accepted that RA equated to being old and infirm and in this way self-stigmatised themselves. In some public situations if they were unable to conceal the impact of RA upon their behaviours. They did experience some consequences which consequently impacted further upon their identity and their fragile self-worth. Stigmatisation is very real and, therefore, should not be underestimated due to the lack of overt physical features, but recognised in the holistic practices of health professionals. The acknowledgement of stigmatisation as a feature of living with RA is important. At this point it is worthwhile to consider how stigma affects the social being.

Stigma and the Social Being

According to Major and O'Brien (2005), stigma affects the stigmatised in four ways. Firstly, stigma results in negative treatment and discrimination. While RA is recognised as a chronic illness the supports and benefits available for other long-term illnesses are not available for PLRA and, therefore, the additional health expenses have to be subsumed by the individual themselves (HSE 2017b). Irish citizens may avail of the support of the National Drug Payment scheme and at 70 years old the General Practitioner visit card may be availed of (HSE 2017b). A medical card may be gained subject to a financial assessment. However, the employed person with dependants may have to manage the additional expenses of GP visits and ongoing investigations which are part of the contemporary treatment sequelae. All of this suggests that people with RA are treated differently to some other long-term chronic conditions. Secondly, stigma brings an expectancy confirmation process. This can be explained by the wider society having negative stereotypical perceptions and expectations of persons with RA which influences their behaviours toward them. It is these behaviours which directly affect the person with RA. They take ownership of the stigmas and believe what the stigma is inferring. Thirdly, a stigmatised group may activate stereotypical behaviours. This can occur even in the absence of discriminatory behaviours toward the group or individuals in the group. Anderson and Aleite (2020) personal accounts are two good examples. 4) Identity threat occurs when stigmas are internalised. The stigmas are given significance and meaning, and the stigmatised person mediates the response in the actions they take. Major and O'Brien (2005) identify that identity threat stigma may come from an actual experiencing of negative stigma or from their construal of environmental proceedings. Major and O'Brien (2005) indicate some people are more vulnerable to the threat of stigma than others, either because they are more sensitive to stigma language and meaning or they have an expectation of stigmatisation toward the group with which they identify. Individual goals and motives also influence how stigmas are perceived. When an individual is motivated to protect or enhance their self-esteem, stigma behaviours are evaluated in terms of the other, as opposed to an interpretation which is directly about them as stigmatised persons. It is reasonable to presume that to adopt this interpretation of stigma an individual would have a high level of self-esteem (Major & O'Brien 2005). This was evident in '*Bolstering Self-Worth'* when the participants evaluated the behaviours of others in terms of their lack of knowledge or insights into their own person. At this point the participants had gained self-awareness, understood that others may not be self-aware and forgave them for their offending behaviours. The participants were grateful that they had this new knowledge and could see life and behaviours authentically.

The participants in this study all accepted that they were a burden upon society. In the first two stages of the process, '*Insulating Self-Worth'* and *'Scoping Self-Worth'*, participants felt powerless and did not share their diagnosis except to very select others in an effort to avoid and minimise possibilities for stigmatisation at both personal and public levels. However, the non-disclosure did also impact as illustrated when a participant who did not share their diagnosis with co-workers and were not participating in the different aspects of their work role. Colleagues stigmatised the participant as lazy and unwilling to work. They became known in the environment as lazy and consequently relationships became damaged. In reality the inability to attend to work roles was due to lack of muscle strength and fatigue and in this case the invisibility of RA contributed to the stigmatisation (Thompson *et al.* 2019). The consequence for the participant was alienation from work colleagues. In '*Bolstering Self-Worth'* participants were more open about their diagnosis, but they remained firm that they were a burden on society.

The politicising of chronicity has been advanced in Irish society through the identification of chronic conditions as a "burden". The mass media has been successful in delivering the message of burden in explicit socioeconomic terms upon society (Ring & Von

Radowitz 2012; Corcoran 2016; Kastner *et al.* 2018). When internalised, such stigma threatens the identity of individuals, their subsequent self-worth and self-esteem (Conrad & Barker 2010; Salih & Landers 2019). This is a good example of the power of stigma in infiltrating the lives of the stigmatised (Link & Phelan 2014). Such a politicising of chronic conditions has been acknowledged as an outcome from an assent to globalisation and the acceptance and activation of a neoliberal agenda internationally (Thomas 2012; Scambler 2018; Charmaz 2020). The neoliberal agenda is "rationalized by a culture ideology of consumerism, emphasises the virtue and significance not of state responsibility but of personal responsibility" (Scambler 2006, p. 292). Thus, the neoliberal agenda places emphasis on the individual to self-manage their condition, which is reinforced by policies in relation to chronic conditions. The latest policy on chronic conditions in Ireland continues to place emphasis on the biophysical perspectives which further reduces the value of the person and reinforces stigma (Weiss *et al.* 2006; HSE 2020). Furthermore, this policy inhibits the development of holistic services, leading to more evidence of people having unmet healthcare needs (Ryan *et al.* 2013; Poh *et al.* 2015). Stigmatisation is powerful and can impact the lives of individuals and groups. As indicated above, it can lead to disempowerment of the individual, which may ultimately impact on self-esteem and consequently on health outcomes for the individual (McGonagle & Hamblin 2014; Major & Schmader 2018).

In summary, stigmatisation is a powerful phenomenon and disarms people with chronic conditions of their self-worth. The participants in this study did not want to be perceived as different to others. Most of the stigmatisation in relation to RA emanates from the era of limited treatment and the consequences of obvious disfigurement of joints. This historical fact remains strong despite the success of pharmaceutical agents arresting joint disfigurements in the past 35 years. It could be postulated that in 50 years some of the stigma surrounding RA as disabling will lessen. What is somewhat surprising is that new sources of stigma are arising, i.e., the concept of being a burden to society supports the conclusion that stigmatisation will remain evident for as long as differences are not accepted or appreciated or the possibilities for a more fraternal society are not grasped. Individuals with chronic conditions such as RA encounter biopsychosocial dimensions and stigmatisation will increase the demands made upon their personal resources.

Coping and ‘Negotiating Self-Worth’

An alternative theory which is frequently referred to in relation to chronic conditions is coping and adaptation. The psychologist Richard Lazarus [1922 –2002] proposed the idea that in relating to a situation an individual actively constructed meaning, based on their own values and beliefs and the outcome of this appraisal was psychological stress (Lazarus 1974, 1991, 1999; Krohne 2002). Later working with Folkman, a transactional theory of stress and coping emerged which centred on two fundamental process: continuous appraisal which may be primary or secondary, and coping, which is the response to the appraisal (Lazarus & Folkman 1984). Primary appraisal involves the assessment of a situation and determining the interaction with personal values, or goals and whether the outcome is benign, irrelevant, or stressful (Smith & Lazarus 1993; Lazarus 1999). A benign outcome may exert a positive effect on wellbeing, whereas an irrelevant outcome has no significance. When a transaction is perceived as stressful, secondary appraisal occurs, which involves determining options for dealing with the situation and the potential for coping (Chesney *et al.* 2006). Coping may be problem-based (PBC), focusing on managing the stress or emotion-focused, (EFC) concentrating on regulating emotions or future expectancy (FEC) considering the potential for future alterations (Biggs *et al.* 2017). Cognitive reappraisal occurs continuously aiming to change stressors to benign or irrelevant however continuous nonachievement with coping strategies employed impacts negatively both psychologically and physically (Biggs *et al.* 2017).

Comparison of the stress and coping theory of Lazarus highlights similarities with the theory of ‘*Negotiating Self-Worth’*. The confirmation of RA was subconsciously appraised as a threat to the core of the participants’ existence, that is, their self-worth. The participants engaged in familiar coping strategies, together with insights and knowledge of situations aiming to successfully master the stressors. Thus, coping was a process the participants engaged in, and by which they made alterations to strategies according to their reappraisal of the context. This is consistent with Lazarus and Folkman’s position that individuals are constantly changing their cognitive and behavioural efforts to manage demands (Lazarus & Folkman 1984; Schoenmakers *et al.* 2015). In *‘Insulating Self-Worth’* the coping was focused upon protecting the self-worth they had. Reappraisal was continuous, and when behaviours were deemed unsuccessful, participants adjusted and readjusted behaviours to conceal the diagnosis from others, that is, they used both PBC and EFC. Some examples of PBC and EFC included worrying, ruminating, not going out, continuing to do the same daily work activity, diet therapy, concealing deformities, walking, praying, selective support seeking, and going to faith healers, all in an effort to eliminate or modify the stressor of RA. The coping efforts were insufficient to meet the demands and impacted upon the participants psychological well-being, as result of which they became distressed and psychologically *vulnerable* (Skinner *et al.* 2003; Biggs *et al.* 2017).

Distress is one outcome of the stress and coping theory. Another outcome and a later development of the Lazarus and Folkman's theory is that distress can provoke meaning focused coping (MFC) (Folkman 1997; 2008). Essentially this means that the individual reappraises distress and brings into that appraisal "beliefs (e.g., religious, spiritual, or beliefs about justice), values (e.g., ''mattering''), and existential goals (e.g., purpose in life or guiding principles)" (Folkman 2008, p. 8). It is in this process that different perspectives or new meaning is gained, evoking positive emotions which provide motivation for the restoration of coping abilities (Folkman 2008). Five categories of MFC were identified as benefit finding: benefit reminding, adaptive goal processes, re-ordering priorities, and the infusion of ordinary events with positive meaning (Folkman & Moskowitz 2007). This means that individuals may garner some positivity from an essentially negative coping analysis (Helgeson *et al.* 2006). Gruszczyńska & Knoll (2015) found that MFC was critical in managing the acute pain experienced with a flare-up of RA.

In this present study MFC corresponds with what occurred in '*Scoping Self-Worth'* when the participants began to explore possibilities for living with RA, that is, they were exploring the meaning of their life with RA, albeit initially with some apprehension. The participants recognised that their previous vision of RA was limited. With determination and psychosocial supports, they gained a different perspective, in addition to confidence in their endeavours, which brought them into a *secure* psychological state and enabled them to enter *'Bolstering Self-Worth'* where they further bolstered the meaning of RA in their life. However, some participants were unable to sustain the meaning exploration in *'Scoping Self-Worth'* and returned to '*Insulating Self-Worth'* and entered the *FASP Cycle* where they engaged in a cycle of *activity flurry* and *self- pity.* It might be postulated that, had the participants had further intense engagement with individualised psychosocial supports, they may have enabled progression in *'Scoping Self-Worth'* (Affleck *et al.* 1987; Been-Dahmen *et al.* 2017; Akkaya, & Kiyak 2018). In a longitudinal study, Strating *et al.* (2006) noted higher satisfaction with emotional support was associated with less distress in both the short and long-term. As identified by the participants in this study, the goal of supports need to be person centered and holistic as opposed to concordance with treatment regimens (Brooks *et al.* 2014; Dures *et al.* 2014; Kostova *et al.* 2014; Shim *et al.* 2017; Chaleshgar-Kordasiabi *et al.* 2018).

The coping theory of Lazarus and Folkman (1984) conveys an understanding of an individual coping alone. However, some participants in this present study recognised the importance of a significant other in coping with the biopsychosocial dimensions that presented. This is recognised in the construct of communal coping originally proposed by Lyons *et al.* (1998) and developed by Helgeson *et al.* (2018), who advanced the idea of shared responsibility comprising a shared appraisal and collaboration with a close partner. A number of participants stated they could not cope without the support of significant others, which is congruent with communal coping. However, the majority of participants highlighted the impact of RA and, as described by Rolland (1994), an imbalance in the relationships was identified, which possibly increased the stress for the participants and their perception of decreasing self-worth.

There is another important caveat in this present study. RA is a chronic condition and, as highlighted earlier, occurs in the social context of increasing fiscal demands upon society and addressed in policies advocating self-care management. These two elements co-occurring present persistent biopsychosocial stressors, placing much demand upon coping abilities (Martin 2007; Finkelstein-Fox *et al.* 2020). In *'Negotiating Self-Worth'* the participants discovered and developed coping strategies with psychosocial supports. This differs from my understanding of Lazarus and Folkman's (1984) idea of coping which gives less emphasis to how coping strategies and skills are developed. *'Negotiating Self-Worth'* acknowledges the significance of psychosocial supports in the development of resilience, which enabled the participants to gain the skills and ability to cope. Resilience is important in improving biopsychosocial health outcomes (Penley *et al.* 2002; Earvolino-Ramirez 2007; Ong *et al.* 2010; Schetter & Dolbier 2011; Garcia-Dia *et al.* 2013; Bauer *et al.* 2016; Rojas *et al.* 2018). In *'Insulating Self-Worth'* the participants were hesitant to engage with psychosocial supports, which may be explained by the impact of self-stigmatisation. For the participants their engagement with psychosocial supports would be evidence of being a burden. Therefore, the participants believed that they had the skills to manage alone, but their attempts were unsuccessful (Strating *et al.* 2006). The participants became *vulnerable*. It was at this point they engaged with psychosocial supports. This engagement increased over time thereby enhancing their resilience and enabling them to continually cope with ever changing demands (Rutter 2006; Montpetit *et al.* 2010; Musich *et al.* 2019; Shaw *et al.* 2020). Congruent with this study, Shaw *et al.* (2020) identify positive emotions as very important in gaining a different perspective on coping with life challenges. While positivity was somewhat evident in *Scoping Self-Worth*, it was a very strong emotion in *Bolstering Self-Worth.*

Positivity: Key Dimension of 'Bolstering Self-Worth'

Positivity was a key construct in *'Bolstering Self-Worth'* and had an enduring transformative power. Healthcare in the area of chronic conditions emphasises negative perspectives, i.e., relief of physical symptoms, suffering and finding the causes of illness (Eaton *et al.* 2014). The literature reveals an increasing positive approach, particularly in the area of chronicity (Gilbert *et al.* 2017; Zhang *et al.* 2020). Positive psychology has influenced this ideological shift, with Seligman advancing the idea of capitalising on positive thought processes that enable an individual to have a fulfilled life in the face of adversity (Seligman & Csikszentmihalyi 2000; Seligman 2019).

Positivity has been shown to have an impact on the perceptions of various elements of living with RA (Strand *et al.* 2006; Kreis *et al.* 2015). Some of the participants acknowledged that they had a natural tendency toward positivity in living and embraced what Prati & Pietrantoni (2009) call dispositional optimism, that is, they always expected the positive. However, the diagnosis and subsequent life and living with RA did challenge that perspective. For these participants their personal re-appraisal revealed that their positivistic outlook had changed, and they actively sought psychosocial supports to enable them to regain and maintain their positive perception. It was their self-awareness that enabled them to do this. Other participants would have naturally defaulted to a negative evaluation of any event and always expected negative outcomes. Considering that RA may bring continuous biopsychosocial challenges, this default to negative evaluation, in addition to the negative perspective of evaluating, put these participants at risk of emotional distress (Krishnadas *et al.* 2011; Broomhall *et al.* 2017; Xu *et al.* 2017). In '*Scoping Self-Worth'* some of these participants engaged with the psychosocial supports available and gained self-awareness. Consequently, this influenced the appraisal of situations. They gained further supports and achieved other perspectives, thus giving them hope for the future and increasing their resilience (Kreis *et al.* 2015). Some participants returned to *Insulating Self-Worth*, as they were unable to gain a different perspective. Perhaps if more intensive psychosocial supports had been accessible, they may have progressed and gained a different perspective. As RA is a progressive illness, gaining hope is significant in enabling the participants to identify that there is more beyond the confines of this disease (Xu *et al.* 2017).

‘Bolstering Self-Worth’ was distinguished by the sub-category of positivity. The participants viewed life from a positive perspective. While such a view has often been criticised for ignoring the negative or devaluing the negative, this was not the case for the participants (Eaton *et al.* 2014). The participants endured many negative events, e.g., physical and psychological aspects of living with RA, major family events and consequently experienced negative emotions. The focus was not to eliminate negative events or negative emotions, but to bring positive thought processes into the appraisal of situations. This permitted the participants to gain more benefits both psychologically and physically (Eaton *et al.* 2014). The ability to intelligently consider events in this manner could be equated to using emotional intelligence (Mayer *et al.* 2004). Although emotional intelligence has gained popularity, the science behind the construct has been contested (e.g., Epstein 1998; Becker 2003). Zeidner *et al.* (2008) define emotional intelligence as “a set of competencies for identifying, processing, and managing emotion” (p. 64). Thus, it is essentially about the interaction between intelligence and emotion. Cherry *et al.* (2014) identify the key components of emotional intelligence as: self-awareness, self-regulation, social skills, empathy, and motivation. Although emotional intelligence is distinct from other intelligences (social, personal), the majority of people intertwine these intelligences to make sense of situations and influence subsequent actions (Mayer *et al.* 2016). For the participants, using emotional intelligence was key to them being able to gain from the negative emotions and experiences, in that they would examine situations and not make any assumptions or presumptions which would impact further upon their feelings and subsequent actions. Emotional intelligence supports the development of resilience which is significant in living with any chronic condition (Armstrong *et al.* 2011). *Choosing Gratefulness* and *Self-Compassion* were very important concepts of *‘Bolstering Self-Worth’* and demonstrate the EI work of the participants (Lowry 2016).

When a participant was being self-compassionate, they were recognising the hurt within. They were interpreting the hurt and shielding the self from other emotional states which would impact upon their psychological well-being. In having gratitude, the participants were aware of their emotions and developed this further by identifying lists of items for which they were grateful, thus demonstrating the desire to regulate the emotion and to develop it further by acknowledging ways in which they were supportive of others. These behaviours demonstrate what Buck (2004) refers to as higher level moral emotion, in that they were able to acknowledge the gifts they had (e.g., the ability to continue working), and had the humility to accept that others could do tasks for them. Furthermore, the participants were clear that the expression of gratitude was a felt emotion and was genuine. Gratitude has been identified as being positively correlated to life satisfaction and hope, which would further build resilience in the presence of a chronic condition like RA (McCullough *et al.* 2002; Bryant *et al.* 2021). Rash *et al.* (2011) examined the efficacy of a four-week gratitude intervention and found a positive correlation between gratitude and physical health. Further study with larger samples would be pertinent and perhaps also recognise the influence of culture upon gratitude. The participants discussed gratitude in such profound and authoritative tones, suggesting that more investigative work on gratitude with this population would be useful. Perhaps overall gratitude increased their self-esteem and sense of worth, which would be congruent with the conclusions of Wood *et al.* (2010) in their critical review.

The participants in this study worked hard to develop emotional intelligence with psychosocial supports. Some participants participated in the practice of mindfulness to focus on sensations and feelings and to achieve complete relaxation (Shapiro *et al.* 2006). Mindfulness has gained popularity and studies have shown favourable outcomes using the mindfulness-based stress reduction (MBSR) program in the management of chronic conditions (Kabat-Zinn 1982; Baer 2003; Bonadonna 2003; Lau *et al*. 2006; Zhangi *et al.* 2012; Nyklíček *et al.* 2015; Phillips & Harris 2019; Pei *et al.* 2021). The favourable outcomes have encouraged professionals to implement mindfulness-based therapies in relation to RA. While larger studies are still needed there is promising success (Zhou *et al.* 2020; Lindauer *et al.* 2021). Despite the favourable outcomes, the mechanism of the psychological pathway has not been fully detailed to date (Bawa *et al.* 2015; Zhou *et al.* 2020).

Negotiating Self-Worth' in the Irish Sociological Context

In this study self-worth was key to having a life. Not possessing self-worth impacted upon the participants' goals for living. In the absence of self-worth, attempts at developing person-centered therapeutic life goals achieve nothing more than a ritualised goal setting performance and disengagement (Arends *et al*. 2016). Furthermore, this perpetuates problems with adherence and treatment regimens (Colls *et al.* 2021; Studenic & Aletaha 2020; Myung *et al*. 2019). Success rates with T2T[43] emphasise the need for the

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[43] T2T is a treatment focus giving intensive holistic treatment to achieve low disease activity

development of agreed therapeutic goals with individuals (Lempp *et al.* 2020). Within Ireland reforms to address needs of people with chronic conditions are evident (DoH 2012, 2016; HSE 2017a, 2020, 2021).

In this study psychosocial supports were identified as key pillars for *'Negotiating Self-Worth'*. As noted previously, healthcare policy promotes a neoliberal agenda, emphasising self-care management and lacking clear exposition of self-care. Accordingly, the implementation of this policy has not gained the resources to enhance the skills of professionals. Professionals supporting individuals are challenged to practice within their professional values (e.g., holistic care) and to operate according to healthcare policy. The literature reflects the attempts of professionals to support the development of self-care (for example: Richardson *et al.* 2014; Chaleshgar-Kordasiabi *et al.* 2018). The more recent literature reflects that psychosocial dimensions need attention if self-care is going to be actualised (Zuidema *et al.* 2015; Been-Dahmen *et al.* 2017; NICE 2018; Toye *et al.* 2019; Lempp *et al.* 2020). For the participants, the expectation that they would be self-caring was equally troublesome and may have added to their '*Fear of Declining Self-Worth',* as they were unable to be self-caring due to the ongoing physical symptoms they experienced, the lack of abilities to do what they would normally do, and their perception that they were not the person they thought they were.

Social prescribing in some ways acknowledges the psycho-social needs of individuals living with a chronic condition. This policy framework (HSE 2021) views that these needs will be addressed by other individuals in the wider community. This dividing out of such important aspects of health care further emphasises the scientific reductionist perspective and the superiority of addressing physical dimensions of chronic conditions (Helgeson *et al.* 2018). For the people in this study psycho-social dimensions were equally or more important than physical perspectives. It could be argued that this was influenced by the clear policy in relation to addressing the physical dimensions of RA (HSE 2017a). The social prescribing policy devalues the skilled professionals who are educated to deliver holistic health care and have built relationships with people which are key foundations to the identification and addressing of psycho-social needs.

'Negotiating Self-Worth' **– Personal Perspectives**

It is widely acknowledged in academic discourse that any researcher will impact upon the conduct of a research study. In some methodological approaches, the researcher spends time considering how the impact may be limited, while other approaches acknowledge the combined efforts of the researcher and the researched in the conduct of a research study (Charmaz 2000). There is acknowledgement that a researcher gains knowledge and insights for their future practices (Staley *et al.* 2017). However, the impact of the conduct of a research study is less understood (Staley 2017).

I had previously understood that I was fairly well informed about the impact of psychosocial dimensions of ill health. In essence my professional background in general nursing had a strong influence upon this perception. While in my professional practice I had developed empathy skills and the ability to be empathetic in a sensitive and appropriate approach, I can now appreciate that this practice was limited and presumably impacted upon by the very nature of the acute healthcare settings where I worked. I really had never considered the full impact of the stigma in relation to chronic conditions. Conducting this study has reframed my vision of what is often broadly termed psychosocial aspects of nursing.

At the root of this reframing is the understanding of the impact of contexts upon a person with a chronic condition and how the individual develops the capacity to visualise the possibilities for living despite the many challenges. What was most significant for me was the enthusiasm with which the participants made the transformation in their personal lives, despite the challenges presented with their social situations. Interviewing participants in their homes in various parts of the North West of Ireland increased my awareness and insights into the challenges presented from a geographical perspective. I can now appreciate that inclusion within nursing education curriculae would enable learners to develop and deliver psychosocial dimensions that would support people in identifying how they are perceiving their chronic condition and how this can be managed to enable people to progress and find meaning for their life. Similarly, prior to this study, I considered I understood the political context of healthcare. Conducting this study has given me an appreciation of the socio-political context of healthcare. This has contributed to personal frustration in relation to the focus upon systems and not on the people for whom the systems should serve. However, I have to admit that I too contributed to this limitation by not being involved in the development of healthcare policies.

Conclusion

The aim of this chapter was to discuss the theory of *'Negotiating Self-Worth'* as it relates to other theoretical literature. The relevant theories spanned the fields of psychology and sociology. While I had been somewhat aware of the different theories, studying these in-depth gave the impression that I was expanding and explaining the theory of *'Negotiating*

Self-Worth'. I found this chapter challenging mainly due to the three stages in *'Negotiating Self-Worth'* and the many psychosocial theories that were worthy of discussion. I restricted the discussion to self-worth, as this was the most salient and significant for the participants.

This chapter began with a brief discussion on the context within which the theory of *'Negotiating Self-Worth'* emerged. This gave a deeper understanding for the main concern 'Declining Self-Worth' and of the socio-political forces that may be increasing the experience of declining self-worth. Psychosocial dimensions of chronic conditions only began to emerge in the seventies with Wiener's seminal study on suffering (1975) and the work of Strauss and Glaser (1975) demonstrating the impact of chronic conditions on kinfolk. However, no significant impact was realised until Bury (1982) published work demonstrated that a chronic condition disrupts the life of the person. Bury's study gained the recognition and support of other writers, including Williams (1984) Kleinnman (1988) Frank (1995). Charon (2005, 2014) added to these discussions, gaining the attention of her medical colleagues. The discourse broadened to include an acceptance that living with a chronic condition does have an impact upon the life of the person. Charmaz (1983, 1991, 2002) added to these discussions when she focused upon the consequences of chronic conditions and the loss of selfhood. *'Negotiating Self-Worth'* extends the thinking of these earlier sociological theories by capturing the actions of PLRA in response to the challenges that emerge when living a life with a chronic condition. A key contribution to the negotiation were psychosocial supports. Engaging widely with key audiences will be important for the development of *'Negotiating Self-Worth'* as a theory, but also for application in wider professional fields.

Self-worth was defined in the discussion as a subjective evaluation of the self, based on some understanding of identity as a person. A person needs to feel they belong to society. The definitive diagnosis of RA threatened the belonging of the participants. The theory of Baumeister and Leary (1995) added further explanation as to why the participants felt threatened and defensive when they were diagnosed with RA. The participants felt they no longer belonged because the identifying features of belonging were taken from them. Focusing on identity the work of James [1842-1910] and Cooley [1864-1929] explicated how identity comes to be recognised and lived. Using James' theory I understood that the participants, having experienced tension between the "I" and "Me", re-conceptualised themselves from being a healthy person to a sick disabled being. This explained the approaches taken to manage disclosure which protected the re-conceptualised "I". The theory of the looking glass self helped to explain how the participants used their sociocultural understandings to make judgements of others and deliberate on their presentation, which was particularly evident in *'Insulating Self-Worth'* and *'Scoping Self-Worth'* (Belgrave & Charmaz 2015).

Social identity theory (Stryker 1980; Burke 1991) assisted further to understand how the participants gained social identity and the psychosocial processes that they utilised to maintain a social identity. This helped to explain the significance of the *vulnerable* psychological state, when the participants could no longer sustain their previously known identities as a social being. The significance of psychosocial resources in *'Scoping Self-Worth'* to support the discovery of a new identity was supported by Swann and Hill (1982). The theory of stigmatisation (Goffman 1963) helped to explain how the participants had internalised the stigma of RA as a crippling old person's ailment. The work of Major and O'Brien (2005) assisted in identifying how self-stigmatisation impacted upon the participants. Stigma was recognised as enduring and powerful and reinforced by the representation of chronic conditions as a burden.

That the participants were able to gain a life despite the impact of stigma on their person was significant. To do this they needed psychosocial supports to enable them to increase their self-awareness and examine their own social worth. Coping theory (Lazarus & Folkman 1984) offered some more explanation for the behaviours of the participants in '*Insulating Self-Worth'* and *'Scoping Self-Worth'*. The later development of coping theory to include meaning focused coping (Folkman 2008) explained how the participants moved from *'Scoping Self-Worth'* to *'Bolstering Self-Worth'*. It was using dimensions of beliefs, values and existential goals that enabled the participants to find other meaning in their situation. It was this meaning that was significant for them in finding a life that included but was not defined by RA. The embedding of the significance of the meaning helped them to develop and use emotional intelligence and resilience.

The concluding section of this chapter provided a discussion about how the development of 'Negotiating Self-Worth' challenged my personal acknowledgement of psychosocial dimensions of chronic conditions across my career. I concluded that across my career with a focus was upon evidence-based practice, and miniscule attention to the psychosocial dimensions of living with a chronic condition.

CHAPTER 9: LIMITATIONS, IMPLICATIONS RECOMMENDATIONS AND EVALUATION OF NEGOTIATING SELF-WORTH

Introduction

People living with chronic conditions have various concerns, as do those living with RA. This research focused on the main concern of the participants. As far as I am aware this study has been the first to attempt this endeavour since contemporary treatments commenced at the end of the twentieth century. Based on the theory that emerged I will in this chapter present the recommendations for policy development, education, health care professional, and future research. The post-study plan (appendix 11) will highlight these recommendations to the people they directly relate to. The methodology underpinning this study has been most challenging and, while I grappled with and managed to use the methodology, there were limitations which I also include here. However, I do believe that I applied the methodology robustly and include here some of the ways in which I met the criterion for appraising a GCT.

Limitations

The aim of this study was to conceptualise the main concern of the participants however I have identified the following limitations:

- Data collection was via individual interviews initially and perhaps I could have completed some focus group interviews or completed some observations which may have shown other variations in the patterns of behaviours. However, the patterns emerged through memos, field notes and the constant comparative process and have been continuously supported by the individual interviews.
- I learned about GCT by doing it. I believe this was good, but it lengthened the time of the interviews, the constant comparison, and the study overall.
- The participants in this study lived in the West of Ireland and accessed the same RU and subsequently the same service. Therefore, the main concern might have differed had the population been attached to another RU. However, the stories of participants included in the publication “My Arthritis Story” which I also used as data would have been accessing services at other RU’s

throughout Ireland. Despite this, the core category and sub-categories are supported by the literature.

- The analysis was grounded in the perspective of PLRA and, therefore, is limited to their perspectives.
- Potentially useful concepts and a substantive theory have been generated, the theory remains at the descriptive level because this is the first GGT I have done.

Implications and Recommendations

What is already known about living with RA has been fragmented. This theory brings together the different processes to explain how the participants processed their '*Fear of Declining Self-Worth'*. The power of psychosocial supports in supporting the individuals on their difficult journey to *'Negotiate Self-Worth'* brings to the fore the holistic perspectives which are often minimised at policy level, but are an important endeavour for healthcare professionals in their everyday roles. Therefore, dissemination of this theory is important for informing professionals about the concern identified as relevant to PLRA but also advancing the discourse of holism within influential arenas which would ultimately influence government agenda. The post-study plan (appendix 11) outlines different publication strategies in an effort to influence the public health agenda and socio-political conversations that ultimately influence the life of the PLRA. The recommendations arising from this study are presented under the headings of policy development, education, and health care professionals.

Policy Development

Health care policy

Health care policy in relation to RA should be reconsidered with the following suggestions:

- Acknowledge in meaningful ways the importance of self-worth as a key pillar of health.
- Re-write policy to reflect the holistic, humanistic and cultural dimensions of self-care.
- Identify clearly operational plans for implementation of self-care and self-care management within health care

- Consider the potential of persons with RA to contribute to society in meaningful ways and recognise how this can contribute to other policies e.g., education of young people.
- Consider adding RA to the long-term illness scheme which would help PLRA feel they are not being treated unfairly.

Education

Professional programmes:

- Professional undergraduate education should include modules of study in relation to chronic conditions e.g. RA and have a focus upon sociological and psychological perspectives.
- Specific post graduate health related programmes to give equal weight to the psychosocial and biological dimensions of chronic conditions such as RA.
- Identification of Continuing Professional Development (CPD) for all healthcare professionals in the area of RA with a focus on the sociological and psychological perspectives. Such CPD to be mandatory for healthcare professional working in an area where they would be engaging with people with RA.

Health care professionals

It is recommended

- That professionals consider how much weighting they give to psychosocial aspects of chronic conditions such as RA and how they could actively support the development of psychosocial interventions in their area of practice. Professionals should consider what tools they use to identify the negative impact of active RA on self-worth.
- That professionals consider what CPD would enhance their skills and competence to support people in find meaning in their life following a diagnosis of RA.
- That professionals consider the provision for psychosocial supports where they work and, furthermore, examine how and in what ways they might influence the development and provision for increased availability. This would be in addition to individual professionals incorporating psychosocial dimensions in their everyday practice.

- That professionals consider the development of specific support groups for people with RA which are easily accessible and are supported by healthcare professionals.
- That professionals consider their involvement in increasing awareness of RA by the general public and how this might be improved at local and national level to reflect the changed trajectory of RA.
- That professionals consider the ideology of social prescribing PLRA and deliberate on how a positive impact may be achieved in relation to PLRA (HSE 2021).

Research

To supplement the tremendous continuing work on the biological dimensions further research in the following areas will support the develop of healthcare practice and hence support the person living with RA:

- Further research is needed to build on the constructs of the theory identified from this study. The following are inquiries that might be addressed
    - How might *Insulating Self-Worth, Scoping Self-Worth* and *Bolstering Self-Worth* be evaluated?
    - What are the standards which people with RA appraise their worth?
- Further research is recommended to explore the cultural understandings of Irish people with RA. It would be important to identify how and what factors vary cultural understandings.
- Further research is recommended regarding the psychosocial supports that people with RA find beneficial.
- Studies are needed to investigate the uptake and effectiveness of virtual psychosocial supports. The population in this study were geographically spread out and this may have impacted upon their accessing and using supports available.
- It is recommended that studies investigating both the person with RA and health professionals understanding of self-care management be undertaken.
- Further research is needed in relation to the competencies required by healthcare professionals to meet psychosocial needs of people who live with RA (Dures *et al.* 2017).

Evaluation the quality ‘Negotiating Self-Worth’

As discussed previously in Chapter Three, quality is a major issue in relation to research inquiry and researchers are careful to demonstrate the various ways in which they achieve the expected standards (Creswell & Creswell 2018). From a personal perspective achieving standards is important. However, I consider this to be a moral endeavour as much as it is a quality issue, in that the researcher permits the ethical self to influence the planning and conduct of a study (Hammersley & Traianou 2012). Quality is but a statement of how the method was applied, and without the moral self it could become a tick box exercise and fail to respect the people involved in the study. Formal inquiry is evaluated against set criteria and, thus, if a study meets that standard the possibility that the outcomes will be accepted is increased.

While qualitative research is evaluated against measures of rigour, quantitative research is measured against validity and reliability (Creswell & Creswell 2018). GT aims to permit the emergence of a theoretical explanation of latent patterns of social behaviour in a substantive area and, thus, the criteria of rigour, validity and reliability would not be appropriate (Glaser 1992; Holton & Walsh 2017).

More suitable evaluation criteria have been identified as fit, workability, relevance and modifiability and the discussion that follows will demonstrate their application to this study (Glaser 1992, 2007; Smith-MacDonald *et al.* 2019).

Fit

Fit refers to how or whether or not the concepts and categories express the patterns in the data. It is the careful studying of the patterns, the naming of patterns and renaming of patterns to fit with the data (Glaser 2011). As highlighted in Chapter Three, fit can only be achieved by retaining an openness to the data and what is emanating from the data (Kelle 2005). I had become concerned about forcing and initially this could be attributed to a limited understanding of what forcing was actually all about. I found that discussion of the issues with other GT experts and enthusiasts combined with a re-reading of pertinent Glaserian and other texts helpful (Glaser & Strauss 1967; Glaser 1992, 1998; Charmaz 2008; Gibson & Hartman 2014; Holton & Walsh 2017). Achieving fit is about recognising the patterns in the data and, over time, allowing different patterns to emerge which might challenge previous thinking. The continuous recording of memos assisted with the openness required to permit what was happening in the data to emerge. Thus, memos included ideas about meaning, behaviours, possible patterns, and relationships. Subsequently, when I thought something else was emerging, I questioned if these emanated from my own preconceptions. Therefore, I looked for evidence of patterns and theoretical ideas in memos. This happened on a few occasions when I felt I knew what the pattern was. For example, at one point I thought the pattern was about being a friend to the RA and treating it accordingly. The constant comparison and theoretical sampling revealed that the participants were indeed alert to the physical changes in their body, but not with the goal of keeping the RA in a quiet state. The awareness of the RA state was to inform their future actions and decision-making. The memos recorded reflected the various decisions about patterns and further data collection and thus the memos directed the theoretical sampling. This ensured that the theory emerged from the data, and, hence the naming of patterns reflected what was emanating from the data. The process of constant comparison and memoing was a cyclical continuous process. While it may appear to be quite simplistic, it was quite convoluted and required deep concentration and immersion in the analysis. I believe the continuation of constant comparison in conjunction with memoing enabled me to maintain the openness toward the emerging patterns. I was able to identify when the theoretical idea sounded good and fitted with some data, but did not account for the variations in the patterns of behaviour. Having a supervisor who was expert in GGT also enabled me to discuss the emergent patterns and further challenge my thinking about ideas, patterns, and relationships. Participating in advanced GT workshops on four occasions with other enthusiasts and GT experts also enabled a clearer understanding of fit and achieving fit.

Workability

Workability refers to how well the theory explains the variations in the behaviours in the substantive area. In the case of *'Negotiating Self-Worth'*, the three stages of the process provide an explanation of how '*Declining Self-Worth'* was processed within the context of the chronic condition of RA. The concepts within each stage demonstrate the variation in the patterns of behaviour. In essence it was when I gained an abstract view that I was able to identify the variations in the behaviours of the participants. They were all doing the same thing but differently. However, getting to the stage of naming patterns of behaviours required a lot of constant comparison, memo writing and selective coding, as I took the emerging ideas into more interviews. In some instances, I dropped the theoretical idea, as it did not pattern out in the new data. For example, I considered one behaviour pattern to be hiding the diagnosis. I termed this as 'secreting' and I considered this to be subcategory at one point. As the constant comparison, selective coding and memoing continued, I knew it did not work for all the behaviour patterns. I was also able to recognise that secreting was but one behaviour pattern in '*Insulating Self-Worth'.* The memos provide evidence of the variations in behaviours. The renaming of patterns identifies how I have attempted to have congruence between names and patterns. I have named and renamed to find the labels that most fits with the patterns of behaviour. Other researchers may, however, use different variations of the names of patterns but in essence I do not believe they will gain dissimilar theory.

Relevance

Relevance refers to the core category fitting and its usefulness to others. Participants living with RA know at some level what they are doing. The abstract view identified in the theory of *'Negotiating Self-Worth'* gives more information regarding the conceptualising of behaviours, the patterns of behaviours, and how behaviours are processed. This is very relevant for the participants, as they can expand their current knowledge and self-awareness about their behaviours, which may influence how they respond to encounters in the future. The theory is also relevant for healthcare practitioners who are involved in the trajectory of the person with RA. Efforts to support the person have not focused on psychosocial supports, which were demonstrated in this theory to be a key factor for participants.

Modifiability

When a theory is developed, it is not right or wrong. It is a theory of what is. When new data has emerged, the theory can be modified (Glaser & Tarozzi 2007; Nathaniel & Andrews 2010). Nathaniel and Andrews explored the relevance of the theory Awareness of Dying some 45 years after it has been first published (Glaser & Strauss 1965). In the analysis Nathaniel and Andrews perceived that, in some areas of healthcare, knowledge had advanced, and the evidence might only be partly supportive of the theory, e.g., palliative care settings. However, for the vast majority of situations in healthcare, awareness of dying remained clouded in secrecy. The theory was still very relevant to the situation in hospitals in 2010. Had the evidence been available that would support the modification, this would not have eliminated the theory but rather enriched it by continuing to make it relevant. Similarly, the substantive theory of *'Negotiating Self-Worth'* is only relevant for the present but can be modified with new evidence. New evidence would enrich the theory.

Summary and Conclusion

In this chapter I have presented limitations for the approach and conduct of this study. I have also given recommendations based on the theory that emerged. Finally, I looked at the specific measures that demonstrate how this study could be evaluated as rigorous. This thesis has presented the theory that emerged from the application of the GGT method in a population of people who lived with RA. *'Negotiating Self-Worth'* emerged as a process explaining how the participants with RA managed their main concern '*Fear of Declining Self-Worth'*. While it is particularly relevant for the population of people who are or may in the future be diagnosed with RA, it may also be relevant to other populations with chronic conditions which impact upon their very being. This theory is presented with the hope that those people who are in a position to support the development of policies and subsequently psychosocial resources will overcome obstacles and be successful in implementing robust psychosocial frameworks and resources to enable PLRA achieve their full potential as social beings.

References

Abourazzak F., El Mansouri L., Huchet D., Lozac'hmeur R., Hajjaj-Hassouni N., Ingels A., Chalès G. & Perdriger A. (2009) Long-term effects of therapeutic education for patients with rheumatoid arthritis. *Joint Bone Spine* **76**(6), 648-653.

Affleck G., Tennen H. & Pfeiffer C. (1987) Appraisals of control and predictability in adapting to a chronic disease. *Journal of Personality and Social Psychology* **53**, 273-279.

Åge L.-J. (2011) Grounded theory methodology: positivism, hermeneutics, and pragmatism. *The Qualitative Report* **16**, 1599-1615.

Akkaya F. & Kiyak E. (2018) Evaluation of the loneliness, social support and quality of life in patients with rheumatoid arthritis. *International Journal of Caring Sciences* **11**(1), 457-463.

Alamanos Y. & Drosos A.A. (2005) Epidemiology of adult rheumatoid arthritis. *Autoimmunity Reviews* **4**(3), 130-136.

Alamanos Y., Voulgari P.V. & Drosos A.A. (2006) Incidence and prevalence of rheumatoid arthritis, based on the 1987 American College of Rheumatology criteria: a systematic review. *Seminars in Arthritis and Rheumatism* **36**(3), 182-188.

Aletaha D. & Smolen J.S. (2018) Diagnosis and management of rheumatoid arthritis: a review. JAMA *Journal of the American Medical Association* **320**(13), 1360-1372.

Almeida C., Choy E.H., Hewlett S., Kirwan J.R., Cramp F., Chalder T., Pollock J. & Christensen R. (2016) Biologic interventions for fatigue in rheumatoid arthritis (Review). *The Cochrane Database Systematic Review 2016*, *Issue 6*, No. Cd008334. DOI: 10.1002/14651858.CD008334.

Al-Qubaeissy K.Y., Fatoye F.A., Goodwin P.C. & Yohannes A.M. (2013) The effectiveness of hydrotherapy in the management of rheumatoid arthritis: a systematic review. *Musculoskeletal Care* **11**(1), 3-18.

Anderson L. & Aleite A. (2020) Community divided: never mind sticks and stones, it's the words that hurt. *Arthritis Today* **34**(1), 44-45.

Andrews T. (2012) What is social constructionism? *Grounded Theory Review.* **1**(11), 39-46.

Arends R.Y., Bode C., Taal E. & van de Laar M.A. (2016) The longitudinal relation between patterns of goal management and psychological health in people with arthritis: the need for adaptive flexibility. *British Journal of Health Psychology* **21**(2), 469-89.

Armstrong A.R., Galligan R.F. & Critchley C.R. (2011) Emotional intelligence and psychological resilience to negative life events. *Personality and Individual Differences* **51**(3), 331-336.

Arvidsson S.B., Petersson A., Nilsson I., Andersson B., Arvidsson B.I. Petersson, I.F. & Fridlund B. (2006) A nurse-led rheumatology clinic's impact on empowering patients with rheumatoid arthritis: a qualitative study. *Nursing and Health Sciences* **8**(3), 133-139.

Ashcraft L.E., Quinn D.A. & Brownson R.C. (2020) Strategies for effective dissemination of research to United States policymakers: a systematic review. *Implementation Science* **15**(1), 1-17.

Avis M., Bond M. & Arthur A. (1995) Satisfying solutions? A review of some unresolved issues in the measurement of patient satisfaction. *Journal of Advanced Nursing* **22**(2), 316–322.

Babchuk, W.A., (1996) Glaser or Strauss? Grounded theory and adult education. In *Proceedings of the 15th Annual Midwest Research-to-Practice Conference in Adult, Continuing, and Community Education*, Lincoln, Nebraska, October 17-19, 1996, pp. 1-6.

Bacci E.D., DeLozier A.M., Chen-Yen L., Gaich C.L., Xiang Z., Rooney T., de Bono S., Hoffman R., Wyrwich K.W., Lin C.-Y. & Zhang X. (2017) Psychometric properties of the single-item measure, severity of worst tiredness, in patients with moderately to severely active rheumatoid arthritis. *Health and Quality of Life Outcomes* **15**, 1-10.

Baer R. (2003) Mindfulness training as a clinical intervention: a conceptual and empirical review. *Clinical Psychology: Science and Practice* **10**(2), 125-143.

Bala S.-V., Forslind K. & Månsson M. (2010) Self-reported outcomes during treatment with tumour necrosis factor α inhibitors in patients with rheumatoid arthritis. *Musculoskeletal Care* **8**, 27-35.

Bala S.V., Forslind K., Fridlund B., Samuelson K., Svensson B. & Hagell P. (2018) Person-centred care in nurse-led outpatient rheumatology clinics: conceptualization and initial development of a measurement instrument. *Musculoskeletal Care* **16**(2), 287-295.

Barber M. (2018) Alfred Schutz. In *The Stanford Encyclopedia of Philosophy* (Winter 2018 Edition). Retrieved from https://plato.stanford.edu/entries/schutz/ on December 6th 2018.

Bauer H., Emeny R.T., Baumert J. & Ladwig K.H. (2016) Resilience moderates the association between chronic pain and depressive symptoms in the elderly. *European Journal of Pain* **20**(8), 1253-1265.

Bauman Z. & Vecchi B. (2004) *Identity*. Polity, Cambridge.

Baumeister R.F. & Leary M.R. (1995) The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin* **117**(3), 497-529.

Bawa F.L.M., Mercer S.W., Atherton R.J., Clague F., Keen A., Scott N.W. & Bond C.M. (2015) Does mindfulness improve outcomes in patients with chronic pain? Systematic review and meta-analysis. *British Journal of General Practice* **65**(635), e387-400.

Beals K.P., Peplau L.A. & Gable S.L. (2009) Stigma management and well-being: the role of perceived social support, emotional processing, and suppression. *Personality and Social Psychology Bulletin* **35**(7), 867-879.

Bearne L.M., Byrne A.M., Segrave H. & White C.M. (2016) Multidisciplinary team care for people with rheumatoid arthritis: a systematic review and meta-analysis. *Rheumatology International* **36**(3), 311-24.

Beauchamp T. & Childress J. (2001) *Principles of Biomedical Ethics*. Oxford University Press, Oxford.

Bech B., Primdahl J., van Tubergen A., Voshaar M., Zangi H.A., Barbosa L., Boström C., Boteva B., Carubbi F., Fayet F., Ferreira R.J.O., Hoeper K., Kocher A., Kukkurainen M.L., Lion V., Minnock P., Moretti A., Ndosi M., Nikolic M.P. & Schirmer M. (2020) 2018 update of the EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. *Annals of the Rheumatic Diseases* **79**(1), 61-68.

Beck C.T. (1993) Qualitative research: the evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research* **15** (2), 263-6.

Becker T. (2003) Is emotional intelligence a viable concept? *Academy of Management Review* **28**, 192-195.

Been-Dahmen J.M.J., Walter M.J., Dwarswaard J., Hazes J.M.W., van Staa A. & Ista E. (2017) What support is needed to self-manage a rheumatic disorder: a qualitative study. *BMC Musculoskeletal Disorders* **18**, 1-9.

Belgrave L. & Seide K. (2019) Coding for grounded theory. In *The SAGE Handbook of Current Developments in Grounded theory*. (Bryant A. & Charmaz K. eds), Sage, Los Angeles, pp. 167-185.

Belgrave L.L. & Charmaz K. (2015) George Herbert Mead: meanings and selves in illness In *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*. (Collyer F., ed), Palgrave Macmillan, Basingstoke, pp. 107-124.

Benham H., Chiu H., Tesiram J., Mehdi A., Landsberg P., Grosman S., Harrison A., Nash P., Thomas R., Langbecker D. & Van Driel M. (2021) A patient-centered knowledge translation tool for treat-to-target strategy in rheumatoid arthritis: patient and rheumatologist perspectives. *International Journal of Rheumatic Diseases* **24**(3), 355-363.

Benka J., Nagyova I., Rosenberger J., Calfova A., Macejova Z., Middel B., Lazurova I., van Dijk J. & Groothoff J. (2012) Social support and psychological distress in rheumatoid arthritis: a 4-year prospective study. *Disability and Rehabilitation* 34(9), 754-761.

Berger P. L. & Luckmann T. (1966) *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Penguin Books, New York.

Biggs A., Brough P. & Drummond S. (2017) Lazarus and Folkman's Psychological Stress and Coping Theory. In *The Handbook of Stress and Health.* (Cooper C.L. & Campbell Quick J. eds), John Wiley & Sons, Sussex, pp. 349-364.

Bilberg A., Ahlmén M. & Mannerkorpi K. (2005) Moderately intensive exercise in a temperate pool for patients with rheumatoid arthritis: a randomized controlled study. *Rheumatology* **44**(4), 502-508.

Birks M., Chapman Y. & Francis K. (2008) Memoing in qualitative research: probing data and processes. *Journal of Research in Nursing* **13**(1), 68-75.

Böhm A. (2004) Theoretical coding: text analysis in grounded theory. In *A Companion to Qualitative Research*. (Flick U., von Kardoff G.P. & Stein A. eds). Sage, London, pp. 270-275.

Bonadonna R. (2003) Meditation's impact on chronic illness. *Holistic Nursing Practice* **17**(6), 309–319.

Boonen A. & Severens J. (2011) The burden of illness of rheumatoid arthritis. *Clinical Rheumatology* **30**, 3-8.

Borgermans L. & Devroey D. (2017) A policy guide on integrated care (PGIC): lessons learned from EU project INTEGRATE and beyond. *International Journal of Integrated Care* **17**(4), 1-12.

Boyd J.E., Adler, E.P., Otilingam, P.G. & Peters T. (2014) Internalized stigma of mental illness (ISMI) scale: a multinational review. *Comprehensive Psychiatry* **55**, 221-231.

Bracken-Roche D., Bell E., Macdonald M.E. & Racine E. (2017) The concept of 'vulnerability' in research ethics: an in-depth analysis of policies and guidelines. *Health Research Policy and Systems* **15**(1), 8.

Braddock C.H. 3rd, Edwards K.A., Hasenberg N.M., Laidley T.L. & Levinson W. (1999) Informed decision making in outpatient practice: time to get back to basics. *Journal of American Medical Association* **282**(24), 2313-2320.

Brewer M. & Gardner W. (1996) Who is this "we"? Levels of collective identity and self representations. *Journal of Personality and Social Psychology* **71**, 83-93.

Bridges P.S. (1992) Prehistoric arthritis in the Americas. *Annual Review of Anthropology* **21**, 67-91.

Bringer J.D., Johnston L.H. & Brackenridge C.H. (2006) Using computer-assisted qualitative data analysis software to develop a grounded theory project. *Field Methods* **18**(3), 245-266.

Brooks A.T., Andrade R.E., Middleton K.R. & Wallen G.R. (2014) Social support: a key variable for health promotion and chronic disease management in Hispanic patients with rheumatic diseases. *Clinical Medicine Insights: Arthritis and Musculoskeletal Disorders* **7**, 21-26.

Broomhall A.G., Phillips W.J., Hine D.W. & Loi N.M. (2017) Upward counterfactual thinking and depression: a meta-analysis. *Clinical Psychology Review* **55**, 56-73.

Bryant A. & Charmaz K. (2007) *Grounded theory Research: Methods and Practices*. Sage, Los Angeles.

Bryant A. (2017) *Grounded theory and Grounded Theorizing: Pragmatism In Research Practice.* Oxford University Press, Oxford.

Bryant F.B., Osowski K.A. & Smith J.L. (2021) Gratitude as a mediator of the effects of savoring on positive adjustment to aging. *International Journal of Aging & Human Development* **92**(3), 275-300.

Buck R. (2004) The gratitude of exchange and the gratitude of caring: a developmental-interactionist perspective of moral emotion. In *The Psychology Of Gratitude* (Emmons R.A. & McCullough M.E.E., eds), Oxford University Press, New York, pp.100-122.

Burke P.J. & Reitzes D.C. (1991) An Identity Theory Approach to Commitment. *Social Psychology Quarterly* 54(3), 239-251.

Burke P.J. (1991) Identity Processes and Social Stress. *American Sociological Review* **56**(6), 836-849.

Burke P.J. (2016) Identity control theory. In *The Blackwell Encyclopedia of Sociology*, (Ritzer G. ed.). Retrieved from https://doi.org/10.1002/9781405165518.wbeosi002 on July 10th 2019.

Burke P.J. & Stets J.E. (2009) *Identity Theory*. Oxford University Press, New York.

Burkholder G.J., Cox K.A., Crawford L. & Hitchcock J. (2020) *Research Design and Methods. An Applied Guide for the Scholar-Practitioner.* Sage, California.

Burr V. (2015) *Social Constructionism*. Routledge, Hove.

Burton W., Morrison A., Maclean R. & Ruderman E. (2006) Systematic review of studies of productivity loss due to rheumatoid arthritis. *Occupational Medicine* **56**(1), 18-27.

Bury M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* **4**(2), 167-182.

Bury M. (1991) The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness* **13**(4), 451-468.

Bury M. (2010) Health, emotion and the body. *Sociology of Health and Illness* **32**(3), 502-503.

Bury M., Newbould J. & Taylor D. (2005) A rapid review of the current state of knowledge regarding lay led self-management of chronic illness. *Chronic Illness* **2**(4), 249-61.

Carandang K., Pyatak E.A. & Vigen C.L. (2016) Systematic review of educational interventions for rheumatoid arthritis. *American Journal of Occupational Therapy* **70**(6), 1-12.

Carpenter L., Barnett R., Mahendran P., Nikiphorou E., Gwinnutt J., Verstappen S., Scott D.L. & Norton S. (2020) Secular changes in functional disability, pain, fatigue and mental well-being in early rheumatoid arthritis. A longitudinal meta-analysis. *Seminars in Arthritis and Rheumatism* **50**(2), 209-219.

Carr A., Hughes R., Mitchell H., Ryan S., Carr M. & Kirwan J. (2003) Rheumatology outcomes: the patient's perspective. *The Journal of Rheumatology* **30**(4), 880-883.

Cast A. & Burke P.J. (2002) A theory of self-esteem. *Social Forces* **80**(3), 1041-1068.

Chaleshgar-Kordasiabi M., Enjezab B., Akhlaghi M. & Sabzmakan I. (2018) Barriers and reinforcing factors to self-management behaviour in rheumatoid arthritis patients: a qualitative study*. Musculoskeletal Care* **16**(2), 241-250.

Charmaz K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness* **5**(2), 168-195.

Charmaz K. (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*. Rutgers University Press, New Brunswick, NJ.

Charmaz K. (1995) The body, identity, and self: adapting to impairment. *The Sociological Quarterly* **36**(4), 657-680.

Charmaz K. (2000) Grounded theory : objectivist and constructivist methods. In *Handbook of Qualitative Research*, 2nd edn. (Denzin N. & Lincoln Y.S. eds), Sage, Thousand Oaks, pp. 509-535.

Charmaz K. (2002) The self as habit: the reconstruction of self in chronic illness. *Occupational Therapy Journal of Research* **22**(Supplement 1), 31S-41S.

Charmaz K. (2006) *Constructing Grounded theory* . Sage Publications, London.

Charmaz K. (2014a) Grounded theory in global perspective: reviews by international researchers. *Qualitative Inquiry* **20**(9), 1074-1084.

Charmaz K. (2014b) *Constructing Grounded theory* . Sage Publications, London.

Charmaz K. (2020) Experiencing stigma and exclusion: the influence of neoliberal perspectives, practices, and policies on living with chronic illness and disability. *Symbolic Interaction* **43**(1), 21-45.

Charon R. (1996) Literature and ethical medicine: five cases from common practice; introduction. *Journal of Medicine and Philosophy* **21**, 243-247.

Charon R. (2005) Narrative medicine: attention, representation, affiliation. *Narrative* **13**(3), 261-270.

Charon R. (2011) The novelization of the body, or, how medicine and stories need one another. *Narrative* **19**(1), 33-50.

Charon R. (2014a) Narrative and interprofessional education: writing toward transparency, mutual respect, and trust. *Clinical Scholars Review* **7**(2), 92-93.

Charon R. (2014b) Narrative reciprocity. *Hastings Center Report* **44**, S21-24.

Charon R. & Charon R. (2012) The reciprocity of recognition--what medicine exposes about self and other. *New England Journal of Medicine* **367**(20), 1878-1881.

Cherry M.G., Fletcher I., O'Sullivan H. & Dornan T. (2014) Emotional intelligence in medical education: a critical review. *Medical Education* **48**(5), 468-478.

Chesney M.A., Neilands T.B., Chambers D.B., Taylor J.M. & Folkman S. (2006) A validity and reliability study of the coping self-efficacy scale. *British Journal of Health Psychology* **11**(3), 421-437.

Chiarotto A., Deyo R., Terwee C., Boers M., Buchbinder R., Corbin T., Costa L., Foster N., Grotle M. & Koes B. (2015) Core outcome domains for clinical trials in non-specific low back pain. *European Spine Journal* **24**(6), 1127-1142.

Clarke A. E. (2019) Situating grounded theory and situational analysis in interpretive qualitative inquiry. In *The Sage Handbook of Current Developments in Grounded theory* . (Martin V. & Gynnild A. eds), Sage, London pp. 3-48.

Clarke V. & Braun, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners*. Sage Publications, London.

Colls J., Lee Y., Xu C., Corrigan C., Lu F., Marquez-Grap G., Murray M., Suh D. & Solomon D. (2021) Patient adherence with a smartphone app for patient-reported outcomes in rheumatoid arthritis. *Rheumatology* **60**(1), 108-112.

Conlon C., Timonen V., Elliott-O'Dare C., O'Keeffe S. & Foley G. (2020) Confused about theoretical sampling? Engaging theoretical sampling in diverse grounded theory studies. *Qualitative Health Research* **30**(6), 947-959.

Conrad P. & Barker K.K. (2010) The social construction of illness: key insights and policy implications. *Journal of Health and Social Behavior* **51**, Supplement, S67-79.

Conrad P. & Bury M. (1997) Anselm Strauss and the sociological study of chronic illness: a reflection and appreciation. *Sociology of Health and Illness* **19**(3), 373-376.

Cooney J., Law R.-J., Matschke V., Lemmey A., Moore J., Ahmad Y., Jones J., Maddison P. & Thom J. (2011) Benefits of exercise in rheumatoid arthritis. *Journal of Aging Research* ID 681640 pp. 1-14.

Cooper C.L. & Campbell Quick J. Eds. (2017) *The Handbook of Stress and Health A Guide to Research and Practice*. John Wiley & Sons Ltd, Chichester.

Cooper W.E. (1992) William James's theory of the self. *The Monist* **75**(4), 504-520.

Corcoran J. (2016) Report lays bare alarming cost of our poor lifestyle. *Independent*, May 22nd 2016. Retrieved from https://www.independent.ie/irish-news/health/report-lays-bare-alarming-cost-of-our-poor-lifestyle-34735833.html on April 26th 2018.

Corker E., Henderson R.C., Lempp H. & Brown J.S.L. (2016a) Internalised stigma in people with rheumatoid arthritis: a cross sectional study to establish the psychometric properties of the ISMI-RA. *BMC Musculoskeletal Disorders* **17**(1), 244.

Corker E., Brown J. & Henderson C. (2016b) How does self stigma differ across people with psychiatric diagnoses and rheumatoid arthritis, and how does it impact on self-esteem and empowerment? *Psychology, Health and Medicine* **21**(8), 993-1005.

Corrigan P.W. & Watson A.C. (2002) The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice* **9**(1), 35-53.

Corry M., Porter S. & McKenna H. (2019) The redundancy of positivism as a paradigm for nursing research. *Nursing Philosophy* **20**(1), e12230.

Coster S., Li Y. & Norman I.J. (2009) Cochrane reviews of educational and self-management interventions to guide nursing practice: A review. *International Journal of Nursing Studies* **46**(4), 508-28.

Coty M.-B., Salt E.G., Myers J.A. & Abusalem S.K. (2017) Factors affecting well-being in adults recently diagnosed with rheumatoid arthritis. *Journal of Health Psychology* **22**(4), 493-504.

Cramp F., Hewlett S., Almeida C., Kirwan J., Choy E., Chalder T., Pollock J. & Christensen R. (2013) Non-pharmacological interventions for fatigue in rheumatoid arthritis. *The Cochrane Database of Systematic Reviews 2013*, Issue 8. No.: CD008322. DOI: 10.1002/14651858.CD008322.

Crawford L. (2020) Conceptual and theoretical frameworks in research. In *Research Design and Methods. An Applied Guide for the Scholar-Practitioner.* (Burkholder G., Cox K., Crawford L. & Hitchcock J. eds.) Sage, California, pp. 35-48.

Creswell J, & Creswell D. (2018) *Research Design Qualitative, Quantitative, and Mixed Methods Approaches,* 5th edn. Sage Publications, London.

Crocker J. & Wolfe C.T. (2001) Contingencies of self-worth. *Psychological Review* **108**(3), 593-623.

Crotty M. (1998) *The Foundations of Social Research. Meaning and Perspective in the Research Process*. Sage, London.

Curtis R., Groarke A., Coughlan R. & Gsel A. (2004) The influence of disease severity, perceived stress, social support and coping in patients with chronic illness: A 1 year follow up. *Psychology Health and Medicine* **9**, 456-475.

Daker-White G., Donovan J. & Campbell R. (2014) Redefined by illness: meta-ethnography of qualitative studies on the experience of rheumatoid arthritis. *Disability and Rehabilitation* **36**(13), 1061-1071.

Dalili Z. & Bayazi M.H. (2019) The effectiveness of mindfulness-based cognitive therapy on the illness perception and psychological symptoms in patients with rheumatoid arthritis. *Complementary Therapies in Clinical Practice* **34**, 139-144.

Darker C., Whiston L. and O'Shea B. (2015) *Chronic Disease Management in Ireland. Perspectives from Patients and Clinical Stakeholders – Implications and Recommendations for the Irish Healthcare System.* Department of Public Health & Primary Care, Trinity College Dublin, Dublin. Retrieved from http://www.adelaide.ie/wp-content/uploads/2015/04/Chronic-Disease-Management-overview-of-patients-and-clinical-stakeholders-implications-recommendations-for-Irish-healthcare-system-Darker-et-al.-2015.pdf on July 6th 2016.

Data Protective Commissioner (2007) *Data Protection Guidelines on Research in the Health Sector*. Data Protection Commission Retrieved from https://www.dataprotection.ie/documents/guidance/Health_research.pdf on July 29th 2020.

Davergne T., Pallot A., Dechartres A., Fautrel B. & Gossec L. (2019) Use of wearable activity trackers to improve physical activity behavior in patients with rheumatic and musculoskeletal diseases: a systematic review and meta-analysis. *Arthritis Care and Research* **71**, 758-767.

Davis P. (1988) Gold therapy in the treatment of rheumatoid arthritis. *Canadian Family Physician* **34**, 445-452.

de Brouwer S.J., van Middendorp H., Kraaimaat F., Radstake T., Joosten I., Donders A., Eijsbouts A., Spillekom-van Koulil S., van Riel P. & Evers A. (2013) Immune responses to stress after stress management training in patients with rheumatoid arthritis. *Arthritis Research and Therapy* **15**(6), R200.

De Cock D., Van der Elst K., Meyfroidt S., Verschueren P. & Westhovens R. (2015) The optimal combination therapy for the treatment of early rheumatoid arthritis. *Expert Opinion Pharmacotherapy* **16**(11), 1615-1625.

de Hair M., Jacobs J., Schoneveld J. & van Laar J. (2018) Difficult-to-treat rheumatoid arthritis: an area of unmet clinical need. *Rheumatology* 57(7), 1135-1144.

De Roos .J., Tamburic L., Davies H. & Brauer M. (2014) Proximity to traffic, ambient air pollution, and community noise in relation to incident rheumatoid arthritis. *Environmental Health Perspectives* **122**(10), 1075-1080.

Deering K. & Williams J. (2020) Approaches to reviewing the literature in grounded theory: a framework. *Nurse Researcher* **28**(4), 9-15.

Defenbaugh N. (2013) Revealing and concealing ill identity: a performance narrative of IBD disclosure. *Health Communication* **28**(2), 159-169.

Denzin N.K. & Lincoln Y.S. (2008) Introduction: The discipline and practice of qualitative research. In *Strategies Of Qualitative Inquiry*, 3rd edn. Sage Publications, Thousand Oaks, CA, pp. 1-43.

Denzin N.K., & Lincoln, Y. S (2012) *The Landscape of Qualitative Research*, 4th edn. Sage, London.

Denzin N.K. & Lincoln, Y. S (2018) The discipline and practice of qualitative research. In *The SAGE Handbook of Qualitative Research* (Denzin N. & Lincoln Y., eds), Sage, Los Angeles, pp. 1-26.

Department of Health (2012) *Future Health A Strategic Framework for Reform of the Health Service 2012 – 2015*. Stationery Office, Dublin.

Department of Health (2016) *Statement of Strategy 2016 – 2019.* Stationery Office, Dublin.

Department of Health (2017) *120 new ANPs will drive improvements in the delivery of our health services*. Announcement by the Minister for Health, Simon Harris TD, November 27th 2017. Retrieved from https://health.gov.ie/blog/press-release/120-new-anps-will-drive-improvements-in-the-delivery-of-our-health-services-minister-for-health/ on January 30th 2019.

Department of Health (2018) *Framework for Public Involvement in Clinical Effectiveness Processes*. Stationery Office, Dublin.

Department of Health and Children (2008) *Tackling Chronic Disease. A Policy Framework for the Management of Chronic Diseases*. Stationery Office, Dublin.

Dey I. (2007) Grounding categories, In *The Sage Handbook of Grounded theory*. (Bryant A. & Charmaz K., eds.), Sage Publications, London pp. 167-190.

Dickens C., McGowan L., Clark-Carter D. & Creed F. (2002) Depression in rheumatoid arthritis: a systematic review of the literature with meta-analysis. *Psychosomatic Medicine* **64**(1), 52-60.

Diepeveen S, van Haaften L., de Swart B. & Maassen B. (2020) Clinical reasoning for speech sound disorders: diagnosis and intervention in speech-language pathologists' daily practice. *American Journal of Speech-Language Pathology* **29**(3), 1529-1549.

Dildy S.P. (1996) Suffering in people with rheumatoid arthritis. *Applied Nursing Research* **9** (4), 177-183.

Dirik G. & Karanci A.N. (2010) Psychological distress in rheumatoid arthritis patients: an evaluation within the conservation of resources theory. *Psychology and Health* **25**(5), 617-632.

Dissanayake R.K. & Bertouch J.V. (2010) Psychosocial interventions as adjunct therapy for patients with rheumatoid arthritis: a systematic review. *International Journal of Rheumatic Diseases* **13**(4), 324-34.

Dixon K., Keefe F., Scipio C., Perri L. & Abernethy A. (2007) Psychological interventions for arthritis pain management in adults: a meta-analysis. *Health Psychology* **26**(3), 241-250.

Dominick K., Ahern F., Gold C. & Heller D. (2004) Health-related quality of life among older adults with arthritis. *Health and Quality of Life Outcomes* **2**, 5.

Donnelly S. (2018) Participatory Action Research: Using Photovoice to explore solutions to self-managing rheumatoid arthritis. Conference Proceedings: *Facilitating a Collaborative Approach to Arthritis and Rheumatic Disease*. University College Dublin, George Moore Auditorium, 02 November 2018.

Donnelly S., Manning M., Mannan H., Wilson A.G. & Kroll T. (2020) Renegotiating dimensions of the self: a systematic review and qualitative evidence synthesis of the lived experience of self-managing rheumatoid arthritis. *Health Expectations* **23**(6), 1388-1411.

Downey B. (2021). Looking Glass Self. In The Blackwell Encyclopedia of Sociology. (Ritzer G. ed.). Retrieved from https://doi.org/10.1002/9781405165518.wbeosl059.pub2 on July 6th 2020.

Duncan K. (2015) Nutrition and rheumatoid arthritis. *Today's Dietitian* **17**(3), 50-57.

Dures E., Almeida C., Caesley J., Peterson A., Ambler N., Morris M., Pollock J. & Hewlett S. (2014) A survey of psychological support provision for people with inflammatory arthritis in secondary care in England. *Musculoskeletal Care* **12**(3), 173-181.

Dures E., Fraser I., Almeida C., Peterson A., Caesley J., Pollock J., Ambler N., Morris M., Hewlett S. (2017) Patients' perspectives on the psychological impact of inflammatory arthritis and meeting the associated support needs: open-ended responses in a multi-centre survey. *Musculoskeletal Care* **15**(3), 175-185.

Dures E., Hewlett S., Cramp F.A., Greenwood R., Nicklin J., Urban M. & Kirwan J. (2013) Reliability and sensitivity to change of the Bristol rheumatoid arthritis fatigue scales. *Rheumatology* **52**(10), 1832-1839.

Earvolino-Ramirez M. (2007) Resilience: a concept analysis. *Nursing Forum* 42, 73-82.

Eaton R.J., Bradley G. & Morrissey S. (2014) Positive predispositions, quality of life and chronic illness. *Psychology, Health and Medicine* **19**(4), 473-489.

Edley N. (2001) Unravelling Social Constructionism. *Theory and Psychology* **11**(3), 433-441.

Elliott N. & Jordan J. (2010) Practical strategies to avoid the pitfalls in grounded theory research. *Nurse Researcher* **17**(4), 29-40.

Ene S. (2013) Faces of fatigue: ethical considerations on the treatment of chronic fatigue syndrome. *American Journal of Bioethics: Neuroscience 4*(3), 22-26.

Engleman E.P. (1986) International League Against Rheumatism. A brief history and update. *Arthritis and Rheumatology* **29**(7), 929-931.

Entezami P., Fox D., Clapham P. & Chung K. (2011) Historical perspective on the etiology of rheumatoid arthritis. *Hand Clinics* **27**, 1-10.

Epstein S. (1998) *Constructive Thinking: The Key to Emotional Intelligence*. Praeger, New York.

EULAR (2009) *10 things You Should Know About Rheumatic Diseases*. European League Against Rheumatism, Geneva. Retrieved from http://www.eular.org/myUploadData/files/10%20things%20on%20RD.pdf on December 28th 2018.

EULAR (2012) *Preventing Chronic Diseases For A Healthier Europe: The Case For Rheumatic And Musculoskeletal Diseases*. European League Against Rheumatism, Geneva. Retrieved from https://www.eular.org/myUploadData/files/EU_EULAR_EFORT_Prevention_Chronic%20Diseases_Agenda_2012_4C99DB3D-1F29-E788-9E7BCA4FC4633083.pdf on January 31st 2019.

European Parliament and the Council of the European Union (2016) Regulation (EU) 2016/679 of The European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC. *Official Journal of the European Union* 119/1. Retrieved from https://eur-lex.europa.eu/eli/reg/2016/679/oj on September 21st 2018.

Evans S., Moieni M., Taub R., Subramanian S., Tsao J., Sternlieb B. & Zeltzer L. (2010) Lyengar yoga for young adults with rheumatoid arthritis: results from a mixed-methods pilot study. *Journal of Pain and Symptom Management* **39**(5), 904-913.

Fairweather N., Jones F., Harris S., Deiros Collado M. & Shayle A. (2021) Thriving alongside cystic fibrosis: developing a grounded theory of empowerment in children and young people with cystic fibrosis during key life transitions. *Child: Care, Health and Development* **47**(4), 484-493.

Falzer P.R. (2019) Treat-to-target and shared decision making in rheumatoid arthritis treatment: is it feasible? *International Journal of Rheumatic Diseases* **22**(9), 1706-1713.

Feddersen H., Mechlenborg Kristiansen T., Tanggaard Andersen P., Hørslev-Petersen K. & Primdahl J. (2019) Juggling identities of rheumatoid arthritis, motherhood and paid work – a grounded theory study. *Disability and Rehabilitation* **41**(13), 1536-1544.

Feldthusen C., Björk M., Forsblad-d'Elia H. & Mannerkorpi K. (2013) Perception, consequences, communication, and strategies for handling fatigue in persons with rheumatoid arthritis of working age--a focus group study. *Clinical Rheumatology* **32**(5), 557-566.

Fiest K.M., Hitchon C.A., Bernstein C.N., Peschken C.A., Walker J.R., Graff L.A., Zarychanski R., Abou-Setta A., Patten S.B., Sareen J., Bolton J. & Marrie R.A. (2017) Systematic review and meta-analysis of interventions for depression and anxiety in persons with rheumatoid arthritis. *Journal of Clinical Rheumatology* **23**(8), 425-434.

Finkelstein-Fox L., Park C. & Kalichman S. (2020) Health benefits of positive reappraisal coping among people living with HIV/AIDS: a systematic review. *Health Psychology Review* **14**(3), 394-426.

Flick U. (2014) Mapping the Field. In *The SAGE Handbook of Qualitative Data Analysis*. (Flick U., ed), Sage, Los Angeles pp. 3-18.

Flurey C.A., Morris M., Richards P., Hughes R. & Hewlett S. (2014) It's like a juggling act: rheumatoid arthritis patient perspectives on daily life and flare while on current treatment regimes. *Rheumatology* **53**(4), 696-703.

Folkman S. (1997) Positive psychological states and coping with severe stress. *Social Science and Medicine* **45**(8), 1207-1221.

Folkman S. (2008) The case for positive emotions in the stress process. *Anxiety Stress and Coping* **21**(1), 3-14.

Folkman S. & Moskowitz, J. (2007) Positive affect and meaning-focused coping during significant psychological stress. In *The Scope of Social Psychology: Theory and Applications* (Hewstone M., Schut H., De Wit J., Van Den Bos K. & Stroebe M. eds.) Psychology Press, Hove, pp. 193-208.

Forbes C.A., Deshpande S., Sorio-Vilela F., Kutikova L., Duffy S., Gouni-Berthold I. & Hagström E. (2018) A systematic literature review comparing methods for the measurement of patient persistence and adherence. *Current Medical Research and Opinion* **34**(9), 1613-1625.

Forestier B., Anthoine E., Reguiai Z., Fohrer C. & Blanchin M. (2019) A systematic review of dimensions evaluating patient experience in chronic illness. *Health and Quality of Life Outcomes* **17**(1), 1-13.

Francis J., Johnston M., Robertson C., Glidewell L., Entwistle V., Eccles M. & Grimshaw J. (2010) What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology and Health* **25**(10), 1229-1245.

Frank A. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. University of Chicago Press, Chicago.

Frank A.W. (2013) The Wounded Storyteller: Body, Illness, and Ethics, 2nd edn. University of Chicago Press, Chicago.

Frank A.W. (2019) Not whether but how: considerations on the ethics of telling patients' stories. *Hastings Center Report* **49**(6), 13-16.

Galo J.S., Mehat P., Rai S.K., Avina-Zubieta A. & De Vera M.A. (2016) What are the effects of medication adherence interventions in rheumatic diseases: a systematic review. *Annals of the Rheumatic Diseases* **75**(4), 667-673.

Garcia-Dia M.J., DiNapoli J.M., Garcia-Ona L., Jakubowski R. & O'Flaherty D. (2013) Concept analysis: resilience. *Archives of Psychiatric Nursing* **27**(6), 264-270.

Garner S., Lopatina E., Rankin J.A. & Marshall D.A. (2017) Nurse-led care for patients with rheumatoid arthritis: a systematic review of the effect on quality of care. *The Journal of Rheumatology* **44**(6), 757-765.

Gecas V. (1991) The self-concept as a basis for a theory of motivation. In *The Self-Society Dynamic: Cognition, Emotion and Action* (Howard J.A. & Callero P.L., eds), Cambridge University Press, Cambridge, pp. 171-188.

Gecas V. (2003) Self-agency and the life course. In *Handbook of the Life Course. Handbooks of Sociology and Social Research*. (Mortimer J. & Shanahan M. eds.) Springer, Boston, pp. 369-388.

Geenen R. & Dures E (2019) A biopsychosocial network model of fatigue in rheumatoid arthritis: a systematic review. *Rheumatology (Supplement)* **58**(5), pv10-v21.

George R., Jyothi Y. & Khan S. (2020) Rheumatoid arthritis: an overview of epigenetics and pathogenesis. *Drug Invention Today* **14**(2), 248-255.

Gerlag D., Norris J. & Tak P. (2016) Towards prevention of autoantibody-positive rheumatoid arthritis: from lifestyle modification to preventive treatment. *Rheumatology* **55**(4), 607-14.

Gibson B., & Hartman, J. (2014) *Rediscovering Grounded theory*. Sage, London.

Gilbert E.K. Foulk T.A. & Bono J.E. (2017) Building positive psychological resources: the effects of mindfulness, work breaks, and positive reflection. In *The Handbook of Stress and Health A Guide to Research and Practice* (Cooper C.L. & Quick J.C. eds.), John Wiley & Sons Ltd., Chichester, pp. 427-433.

Giles T.K., & de Lacey S. (2013) The timing of the literature review in grounded theory research: an open mind versus an empty head. *Advances in Nursing Science* **36**(2), E29-E40.

Givon S. & Court D. (2010) Coping strategies of high school students with learning disabilities: a longitudinal qualitative study and grounded theory. *International Journal of Qualitative Studies in Education* **23**(3), 283-303.

Glaser B.G. & Holton J. (2007) Remodeling grounded theory. *Forum: Qualitative Social Research* 32, 47-68.

Glaser B. & Strauss A. (1964) Awareness Contexts and Social Interaction. *American Sociological Review* 29, 669-679.

Glaser B.G. & Strauss, A.L. (1965) *Awareness of dying*. Aldine Publishing, Chicago.

Glaser B.G., & Strauss A.L. (1967) The Discovery Of Grounded theory : Strategies For Qualitative Research. Aldine Publishing Company, Chicago.

Glaser B. & Tarozzi, M, (2007) Forty years after Discovery: Grounded theory worldwide. *The Grounded theory Review* Special Issue, 21-42.

Glaser B. (1978) *Theoretical Sensitivity: Advances in the Methodology of Grounded theory*. Sociology Press, Mill Valley, CA.

Glaser B. (1992) *Basics of Grounded theory Analysis: Emergence vs. Forcing*. Sociology Press, Mill Valley, CA.

Glaser B. (1998) *Doing Grounded theory: Issues and Discussions*. Sociology Press, Mill Valley, CA.

Glaser B.G. (2002) Conceptualization: on theory and theorizing using grounded theory. *International Journal of Qualitative Methods* **1**(2), 23-38.

Glaser B. (2003) *The Grounded theory Perspective 2: Description's Remodeling of Grounded theory Methodology*. Sociology Press, Mill Valley, CA.

Glaser B. (2005) *The Grounded theory Perspective III: Theoretical Coding*. Sociology Press, Mill Valley, CA.

Glaser B. (2008) The Constant Comparative Method of Qualitative Analysis. *Grounded theory Review* 7(3). Retrieved from http://groundedtheoryreview.com/2008/11/29/the-constant-comparative-method-of-qualitative-analysis-1/ on November 20th 2017.

Glaser B.G. (2009) Theoretical writing. *The Grounded theory Review* **8**(3), 1-18.

Glaser B. G. (2011) *Getting Out of the Data: Grounded theory Conceptualization*. Sociology Press, Mill Valley, CA.

Glaser B. (2013) Introduction: free style memoing. *The Grounded theory Review* **12** (2),1-12.

Glaser B. (2014) *Applying Grounded theory. A Neglected Option.* Sociology Press, Mill Valley, CA.

Goffman E. (1959) *The Presentation of Self in Everyday Life*. Doubleday, New York.

Goffman E. (1963) *Stigma Notes: On the Management of Spoiled Identity*. Prentice-Hall, Englewood Cliffs, N.J.

Gossec L., Molto A., Romand X., Puyraimond-Zemmour D., Lavielle M., Beauvais C., Senbel E., Flipo R.M., Pouplin S., Richez C., Saraux A., Mézières M., Gutermann L., Gaudin P., Wendling D. & Dougados M. (2019) Recommendations for the assessment and optimization of adherence to disease-modifying drugs in chronic inflammatory rheumatic diseases: a process based on literature reviews and expert consensus. *Joint Bone Spine* **86**(1), 13-19.

Government of Ireland (1988) *Data Protection Act 1988.* Stationery Office, Dublin.

Government of Ireland (2003) *Data Protection (Amendment) Act 2003*. Stationery Office, Dublin.

Government of Ireland (2018) *Data Protection Act 2018*. Stationery Office, Dublin.

Grainger R., Townsley H., Ferguson C., Riley F., Langlotz T. & Taylor W. (2020) Patient and clinician views on an app for rheumatoid arthritis disease monitoring: function, implementation and implications. *International Journal of Rheumatic Diseases* **23**(6), 813-827.

Gray J., Grove S. & Sutherland S. (2017) *Burns & Grove's The practice of Nursing Research. Appraisal, Synthesis and Generation of Evidence*, 8th edn. Elsevier, Missouri.

Greaney A.M. & Flaherty S. (2020) Self-care as care left undone? The ethics of the self-care agenda in contemporary healthcare policy. *Nursing Philosophy* **21**(1), e12291.

Green C.D. (1997) *The principles of psychology William James (1890). Classics in the History of Psychology*. Retrieved from https://psychclassics.yorku.ca/James/Principles/prin6.htm on November 8th 2018.

Groenewegen P., Sixma H.J., van der Eijk I, & Boerma W.G. (2005) What is important in evaluating health care quality? An international comparison of user views. *BMC Health Services Research* **5**(1), 5-16.

Gruszczyńska E. & Knoll N. (2015) Meaning-focused coping, pain, and affect: a diary study of hospitalized women with rheumatoid arthritis. *Quality of Life Research* **24**(12), 2873-2883.

Guba E. & Lincoln Y. (2005) Paradigmatic controversies, contradictions, and emerging confluences. In *The Sage Handbook of Qualitative Research* 3rd edn. (Denzin N & Lincoln Y. eds), Sage Publications Ltd, Thousand Oaks, CA, pp. 191-215.

Gubrium J.F. & Holstein J.A. (2000) The self in a world of going concerns. *Symbolic Interaction* **23**(2), 95-114.

Guillemin M. & Gillam L. (2004) Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry* **10**, 261-280.

Guimarães M., Pinto M., Resende G., Machado C., Vargas-Santos A., Amorim R., Gomides A., Albuquerque C., Bértolo M., Júnior P., Santos I., Giorgi R., Saciloto N., Radominski S., Borghi F., Bonfiglioli K., Silva H., Sauma M., Sauma M., Medeiros J., Pereira I., Castro G., Brenol C., Xavier R., Mota L., Castelar-Pinheiro G. (2020) Discordance between the patient's and physician's global assessment in rheumatoid arthritis: Data from the REAL study-Brazil. *PLoS One* **15**(3): e0230317.

Gul H., Eugenio G., Rabin T., Burska A., Parmar R., Wu J., Ponchel F. & Emery P. (2020) Defining remission in rheumatoid arthritis: does it matter to the patient? A comparison of multi-dimensional remission criteria and patient reported outcomes. *Rheumatology* **59**(3), 613-621.

Gwinnutt J., Leggett S., Lunt M., Barton A., Hyrich K., Walker-Bone K. & Verstappen S. (2020) Predictors of presenteeism, absenteeism and job loss in patients commencing methotrexate or biologic therapy for rheumatoid arthritis. *Rheumatology* **59**(10), 2908-2919.

Häkkinen A., Sokka T., Lietsalmi A., Kautiainen H. & Hannonen P. (2003) Effects of dynamic strength training on physical function, Valpar 9 work sample test, and working capacity in patients with recent-onset rheumatoid arthritis. *Arthritis and Rheumatology* **49**(1), 71-77.

Hallert E., Husberg M. & Bernfort L. (2012) The incidence of permanent work disability in patients with rheumatoid arthritis in Sweden 1990-2010: before and after introduction of biologic agents. *Rheumatology* **51**(2), 338-346.

Hammersley M. & Traianou A. (2012) *Ethics in Qualitative Research: Controversies and Contexts*. Sage Publications, London.

Hammersley M. (1992) *What's Wrong with Ethnography?* Routledge, London.

Hammersley M. (2008) *Questioning Qualitative Inquiry*. Sage Publications, London.

Hammersley M. (2015) On ethical principles for social research. *International Journal of Social Research Methodology* **18**(4), 433-449.

Hammond P. E, & Bellah R. N. (1964) *Sociologists at Work: Essays on the Craft of Social Research.* New York, Basic Books.

Hanson N.R. (1958) *Patterns of Discovery: An Inquiry into the Conceptual Foundations of Science*. Cambridge University Press, New York.

Harkcom T., Lampman R., Banwell B. & Castor C.W. (1985) Therapeutic value of graded aerobic exercise training in rheumatoid arthritis. *Arthritis and Rheumatology* **28**(1), 32-39.

Harris C., Kiger A. & Counsell C. (2013) Attitudes to brain donation for Parkinson's research and how to ask: a qualitative study with suggested guidelines for practice. *Journal of Advanced Nursing* **69**(5), 1096-1108.

Harrold L., Patel P., Griffith J., Litman H., Feng H., Schlacher C. & Kremer J.M. (2020) Assessing disease severity in bio-naïve patients with RA on treatment with csDMARDs: insights from the Corrona Registry. *Clinical Rheumatology* **39**(2), 391-400.

Hart F.D. (1976) History of the treatment of rheumatoid arthritis. *British Medical Journal* **1**(6012), 763-765.

Health Service Executive (2014) *Report from the Prevention of Chronic Disease Programme*. Health Service Executive, Naas.

Health Service Executive (2015) *Reform and the establishment of Integrated Care Programmes Charter*. Health Service Executive, Naas.

Health Service Executive. (2017a) *Model of Care for Rheumatology in Ireland*. Health Service Executive, Naas.

Health Service Executive (2017b) Guide to the Long-Term Illness (LTI) Scheme. Health Service Executive, Naas. Retrieved from https://www2.hse.ie/services/long-term-illness-scheme/long-term-illness.html on February 6th 2021.

Health Service Executive (2020) *National Framework for the Integrated Prevention and Management of Chronic Disease in Ireland 2020-2025.* Health Service Executive, Naas.

Health Service Executive (2021) *HSE Social Prescribing Framework*. Health Service Executive, Naas. Retrieved from https://www.hse.ie/eng/about/who/healthwellbeing/our-priority-programmes/mental-health-and-wellbeing/hse-social-prescribing-framework.pdf on September 10th 2021.

Heidari P., Cross W. & Crawford K. (2018) Do out-of-pocket costs affect medication adherence in adults with rheumatoid arthritis? A systematic review. *Seminars in Arthritis and Rheumatism* **48**(1), 12-21.

Heidari Z., Feizi A., Roohafza H., Rabiei K. & Sarrafzadegan N. (2019) Are dietary patterns differently associated with differentiated levels of mental health problems? Results from a large cross-sectional study among Iranian manufacturing employees. *British Medical Journal* Open 9, e020083.

Helgeson V., Jakubiak B., Van Vleet M. & Zajdel M. (2018) Communal coping and adjustment to chronic illness: theory update and evidence. *Personality and Social Psychology Review* **22**(2), 170-195.

Helgeson V., Reynolds K. & Tomich, P. (2006) A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology* **74**(5), 797-816.

Hernandez C.A. (2009) Theoretical coding in grounded theory methodology. *Grounded theory Review* **8**(3), 51-59.

Hewlett S., Ambler N., Almeida C., Cliss A., Hammond A., Kitchen K., Knops B., Pope D., Spears M., Swinkels A. & Pollock J. (2011) Self-management of fatigue in rheumatoid arthritis: a randomised controlled trial of group cognitive-behavioural therapy. *Annals of the Rheumatic Diseases* **70**(6), 1060-1067.

Hewlett S., Cockshott Z., Byron M., Kitchen K., Tipler S., Pope D. & Hehir M. (2005) Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. *Arthritis and Rheumatology* **53**(5), 697-702.

Hewlett S., Hehir M. & Kirwan J.R. (2007) Measuring fatigue in rheumatoid arthritis: a systematic review of scales in use. *Arthritis and Rheumatology* **57**(3), 429-439.

Higgins A., Barker P. & Begley C.M. (2008) ‘Veiling sexualities’: a grounded theory of mental health nurses’ responses to issues of sexuality. *Journal of Advanced Nursing* **62**(3), 307-317.

Hogg M., Terry, D. & White, K. (1995) A tale of two theories: a critical comparison of identity theory with social identity theory. *Social Psychology Quarterly* **58** (4), 255–269.

Holloway I. & Galvin. K. (2017) *Qualitative Research in Nursing and Healthcare*, 4th edn. Wiley Blackwell, Chichester.

Holton J. & Walsh I. (2017) *Classic Grounded theory. Applications with Qualitative and Quantitative Data*. Sage Publications, New York.

Holton J.A. (2007) The coding process and its challenges. In *The Sage Handbook of Grounded theory* (Bryant A. & Charmaz K. eds), Sage., Thousand Oaks, CA, pp. 265-289.

Holton J. (2010) The coding process and its challenges. *Grounded theory Review* **9**(1), 21-40.

Home D. & Carr M. (2009) Rheumatoid arthritis: the role of early intervention and self-management. *British Journal of Community Nursing* **14**(10), 432-436.

Horne R., Albert A. & Boone C. (2018) Relationship between beliefs about medicines, adherence to treatment, and disease activity in patients with rheumatoid arthritis under subcutaneous anti-TNFα therapy. *Patient Preference and Adherence* **12**, 1099-1111.

Hurwitz B. & Charon R. (2013) A narrative future for health care. *Lancet* **381**(9881), 1886-1887.

Idemudia E., Olasupo M. & Modibo M. (2018) Stigma and chronic illness: A comparative study of people living with HIV and/or AIDS and people living with hypertension in Limpopo Province, South Africa. *Curationis* **41**(1), e1-e5.

Isik A., Koca S., Ozturk A. & Mermi O. (2007) Anxiety and depression in patients with rheumatoid arthritis. *Clinical Rheumatology* **26**(6), 872-878.

Jacobi E. (1994) The efficacy of the bonny method of guided imagery and music as experiential therapy in the primary care of persons with rheumatoid arthritis. PhD Thesis, The Union Institute. Cincinnati, OH. Retrieved from https://www.proquest.com/openview/4ac66c53b4efc36b10c151378080a97a/1?pq-origsite=gscholar&cbl=18750&diss=y on June 6th 2020.

James F. (2017) Where are the grounds for grounded theory? A troubled empirical methodology meets Wittgenstein. *Educational Philosophy and Theory* **50**, 1-11.

Janssens X., Decuman S. & De Keyser F. (2014) Belgian rheumatoid arthritis disability assessment study group. Assessment of activity limitations with the health assessment questionnaire predicts the need for support measures in patients with rheumatoid arthritis: a multicenter observational study. *PLoS One* **9**(9): e106749.

Jerling P. & Heyns M. (2020) Exploring Guided Imagery and Music as a well-being intervention: a systematic literature review. *Nordic Journal of Music Therapy* **29**, 1-20.

Johl S. & Renganathan S. (2010) Strategies for gaining access in doing fieldwork: reflection of two researchers. *Electronic Journal of Business Research Methods* **8**, 42-50.

Johnson J.L., Adkins D. & Chauvin S. (2020) A Review of the Quality Indicators of Rigor in Qualitative Research. *American Journal of Pharmaceutical Education* **84**(1), 7120, 138-146.

Joshua F., Bailey C., Marabani M., Romas E., White R. & Wong P. (2019) Perceptions of doppler ultrasound for rheumatoid arthritis disease activity assessment and education. *International Journal of Rheumatic Diseases* **22**(1), 55-61.

Kabat-Zinn J. (1982) An outpatient program in behavioral medicine for chronic pain patients based on the practice of mindfulness meditation: theoretical considerations and preliminary results. *General Hospital Psychiatry* **4**(1), 33-47.

Karami J., Masoumi M., Khorramdelazad H., Bashiri H., Darvishi P., Sereshki H.A., Shekarabi M. & Sahebkar A. (2020) Role of autophagy in the pathogenesis of rheumatoid arthritis: latest evidence and therapeutic approaches. *Life Sciences* **254**, 17734.

Kareem O., Ahmad H., Ijaz B. & Altaf S. (2020) Frequency of depression in patients with rheumatoid arthritis. *The Professional Medical Journal*. **27**, 646-650.

Kastner M., Cardoso R., Lai Y., Treister V., Hamid J., Hayden L., Wong G., Ivers N., Liu B., Marr S., Holroyd-Leduc J. & Straus S. (2018) Effectiveness of interventions for managing multiple high-burden chronic diseases in older adults: a systematic review and meta-analysis. CMAJ: *Canadian Medical Association Journal* **190**(34), E1004-E1012.

Kelle U. (2005) "Emergence" vs. "forcing" of empirical data? A crucial problem of "grounded theory " reconsidered. *Forum: Qualitative Social Research* **6**(2), Art. 27.

Kelly A., Tong A., Tymms K., March L., Craig J., De Vera M., Evans V., Hassett G., Toupin-April K., van den Bemt B., Teixeira-Pinto A., Alten R., Bartlett S., Campbell W., Dawson T., Gill M., Hebing R., Meara A., Nieuwlaat R. & Shaw Y. (2018) Outcome measures in rheumatology - interventions for medication adherence (OMERACT-adherence) core domain set for trials of interventions for medication adherence in rheumatology: 5 phase study protocol. *Trials* **19**, 204-204.

Kendall J. (1999) Axial coding and the grounded theory controversy. *Western Journal of Nursing Research* **21**(6), 743-757.

Kenny M. & Fourie R. (2014) Tracing the History of Grounded theory Methodology: From Formation to Fragmentation. *The Qualitative Report* **19**, 1-9.

Keogh B., Callaghan P. & Higgins A. (2015) Managing preconceived expectations: mental health service users experiences of going home from hospital: a grounded theory study. *Journal of Psychiatric and Mental Health Nursing* **22**(9), 715-723.

Khan N., Spencer H., Abda E., Aggarwal A., Alten R., Ancuta C., Andersone D., Bergman M., Craig-Muller J., Detert J., Georgescu L., Gossec L., Hamoud H., Jacobs J., Laurindo I., Majdan M., Naranjo A., Pandya S., Pohl C., Schett G., Selim Z., Toloza S., Yamanaka H. & Sokka T. (2012) Determinants of discordance in patients' and physicians' rating of rheumatoid arthritis disease activity. *Arthritis Care and Research* **64**(2), 206-214.

Kiely P., Brown A., Edwards C., O'Reilly D., Ostör A., Quinn M., Taggart A., Taylor P., Wakefield R. & Conaghan P. (2009) Contemporary treatment principles for early rheumatoid arthritis: a consensus statement. *Rheumatology* **48** 7, 765-772.

Kilic L., Erden A., Bingham C., Gossec L. & Kalyoncu U. (2016) The reporting of patient-reported outcomes in studies of patients with rheumatoid arthritis: a systematic review of 250 articles. *Journal of Rheumatology* **43**(7), 1300-1305.

Kirwan J., Heiberg T., Hewlett S., Hughes R., Kvien T., Ahlmèn M., Boers M., Minnock P., Saag K., Shea B., Suarez Almazor M. & Taal E. (2003) Outcomes from the patient perspective workshop at OMERACT 6. *Journal of Rheumatology* **30**(4), 868-872.

Kirwan J., Minnock P., Adebajo A., Bresnihan B., Choy E., de Wit M., Hazes M., Richards P., Saag K., Suarez-Almazor M., Wells G. & Hewlett S. (2007) Patient perspective: fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. *Journal of Rheumatology* **34**(5), 1174-1177.

Kleinman A. (1988) *The Illness Narratives Suffering Healing and the Human Condition*. Basic Books, New York.

Koch T. (2006) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing* **53**(1), 91-103.

Kool M., van de Schoot R., López-Chicheri García I., Mewes R., Da Silva J., Vangronsveld K., Wismeijer A., Lumley M., van Middendorp H., Bijlsma J., Crombez G., Rief W. & Geenen R. (2014) Measurement invariance of the Illness Invalidation Inventory (3*I) across language, rheumatic disease and gender. *Annals of the Rheumatic Diseases* **73**(3), 551-556.

Kostova Z., Caiata-Zufferey M. & Schulz P.J. (2014) The impact of social support on the acceptance process among RA patients: a qualitative study. *Psychology and Health* **29**(11), 1283-1302.

Kreis S., Molto A., Bailly F., Dadoun S., Fabre S., Rein C., Hudry C., Zenasni F., Rozenberg S., Pertuiset E., Fautrel B. & Gossec L. (2015) Relationship between optimism and quality of life in patients with two chronic rheumatic diseases: axial spondyloarthritis and chronic low back pain: a cross sectional study of 288 patients. *Health and Quality of Life Outcomes* **13**(1), 1-6.

Krishnadas R., Mallon V., McInnes I. & Cavanagh J. (2011) Correlates of depression and quality of life in patients with inflammatory arthritides. *European Psychiatry* **26**, 383-383.

Krohne H.W. (2002) Stress and coping theories. *International Encyclopedia of the Social Behavioral Sciences* 22, 15163-15170. Retrieved from https://poliklinika-harni.hr/images/uploads/440/teorije-nastanka-stresa.pdf on July 10th 2020.

Kurkó J., Besenyei T., Laki J., Glant T., Mikecz K. & Szekanecz Z. (2013) Genetics of rheumatoid arthritis - a comprehensive review. *Clinical Reviews in Allergy and Immunology* **45**(2), 170-179.

Landgren E., Bremander A., Lindqvist E., Nylander M., Elst K. & Larsson I. (2020) "Mastering a new life situation" – patients' preferences of treatment outcomes in early rheumatoid arthritis – a longitudinal qualitative study. *Patient Preference and Adherence* **14**, 1421-1433.

Landré-Beauvais A.J. (2001) The first description of rheumatoid arthritis. Unabridged text of the doctoral dissertation presented in 1800. *Joint Bone Spine* **68**(2), 130-143.

Larson M.J. (2020) Improving the rigor and replicability of applied psychophysiology research: sample size, standardization, transparency, and preregistration. *Biofeedback* **48**(1), 2-6.

Larsson I., Arvidsson S., Bergman S. & Arvidsson B. (2010) Patients' perceptions of drug information given by a rheumatology nurse: a phenomenographic study. *Musculoskeletal Care* **8**(1), 36-45.

Lau M., Bishop S., Segal Z., Buis T., Anderson N., Carlson L., Shapiro S., Carmody J., Abbey S. & Devins G. (2006) The Toronto mindfulness scale: development and validation. *Journal of Clinical Psychology* **62**(12), 1445–1467.

Lazarus R.S. & Folkman S. (1984) *Stress, Appraisal, and Coping*. Springer publishing company, New York.

Lazarus R.S. (1974) Psychological stress and coping in adaptation and illness. *The International Journal of Psychiatry in Medicine* **5**(4), 321-333.

Lazarus R.S. (1991) *Emotion and Adaptation*. Oxford University Press, New York.

Lazarus R.S. (1999) *Stress and Emotion: A New Synthesis*. Springer Publishing Company, New York.

Leary M.R. & Acosta J. (2018) Acceptance, rejection, and the quest for relational value. In *The Cambridge Handbook of Personal Relationships*, 2nd edn. (Vangelisti A.L. & Perlman D. eds), Cambridge University Press, New York, pp. 378-390.

Leary M.R. (2005) Sociometer theory and the pursuit of relational value: Getting to the root of self-esteem. *European Review of Social Psychology* **16**(1), 75-111.

Lee C. (2012) Reconsidering constructivism in qualitative research. *Educational Philosophy and Theory* **44**(4), 403-412.

Lee M., Romero S., Velozo C., Gruber-Baldini A. & Shulman L. (2019) Multidimensionality of the PROMIS self-efficacy measure for managing chronic conditions. *Quality of Life Research* **28**(6), 1595-1603.

Lempp H., Baggott R., Scott D., Parker L., Bosworth A., Georgopoulou S. & Firth J. (2020) The value, impact and role of nurses in rheumatology outpatient care: critical review of the literature. *Musculoskeletal Care* **18**(3), 245-255.

Lempp H., Scott D. & Kingsley G. (2006) The personal impact of rheumatoid arthritis on patients' identity: a qualitative study. *Chronic Illness* **2**(2), 109-120.

Levers M.-J. (2013) Philosophical Paradigms, Grounded theory, and Perspectives on Emergence. *SAGE Open* **3**(4), 1-6.

Liamputtong P. (2009) Qualitative data analysis: conceptual and practical considerations. *Health Promotion Journal of Australia* **20**(2), 133-139.

Lin A., Vickrey B., Barry F., Lee M., Ayala-Rivera M., Cheng E., Montoya A., Mojarro-Huang E., Gomez P., Castro M., Corrales M., Sivers-Teixeira T., Tran J., Johnson R., Ediss C., Shaby B., Willis P., Sanossian N., Mehta B., Dutta T., Razmara A., Bryg R., Song S. & Towfighi A. (2020) Factors associated with participation in the chronic disease self-management program. *Stroke* **51**(10), 2910-2917.

Lin L., Yafei C., Rulan Y., Shengnan C., Qian Z., Haoyang, C. & Biyu, S. (2017) Medication adherence has an impact on disease activity in rheumatoid arthritis: a systematic review and meta-analysis. *Patient Preference and Adherence* **11**, 1343-1356.

Lincoln Y.S. & Guba, E. (1985) *Naturalistic inquiry*. Sage Publications. Thousand Oaks, CA.

Lincoln Y. & Guba E. (2013) *The Constructivist Credo*. Left Coast Press, Walnut Creek, CA.

Lindauer C., Speroni K., Godinez K., Lurz T., Oakley R. & Zakes A. (2021) Effect of a nurse-led, patient-centered, gratitude intervention on patient hospitalization experience. *JONA: The Journal of Nursing Administration* **51**(4), 192-199.

Link B.G. & Phelan J. (2014) Stigma power. *Social Science and Medicine* **103**, 24-32.

Lo Cricchio M.G., Lo Coco A., Cheah C. & Liga F. (2019) The good parent: southern Italian mothers’ conceptualization of good parenting and parent–child relationships. *Journal of Family Issues* **40**, 1583-1603.

Looper K.J. & Kirmayer L.J. (2004) Perceived stigma in functional somatic syndromes and comparable medical conditions. *Journal of Psychosomatic Research* **57**(4), 373-378.

López-Medina C., Moltó A., Gérald F., Dubremetz M., Grange L., Thibaud G., Charles B., Lafarge D., Beauvais C., Gossec L. & Dougados M. (2019) Assessment of the adherence to disease-modifying drugs in patients with chronic inflammatory rheumatic diseases: results of a survey of 1594 patients. *Joint Bone Spine* **86**(5), 610-614.

Lorig K., Sobel D., Ritter P., Laurent D. & Hobbs M. (2001) Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice* **4**, 256-262.

Loughlin M. (2008) Reason, reality and objectivity--shared dogmas and distortions in the way both 'scientistic' and 'postmodern' commentators frame the EBM debate. *Journal of Evaluation in Clinical Practice* **14**(5), 665-671.

Lowry N. (2016) *Examining the Relationship Between Emotional Intelligence and Interpersonal Forgiveness Among Internet Users*. PhD Thesis. Walden Dissertations and Doctoral Studies 2740. Retrieved from https://scholarworks.waldenu.edu/dissertations/2740 on October 20th 2020.

Lwin M., Serhal L., Holroyd C. & Edwards C. (2020) Rheumatoid arthritis: the impact of mental health on disease: a narrative review. *Rheumatology and Therapy* 7(3), 457-471.

Lynch B., (ed.) (2019) *My RA Story*. Arthritis Ireland, Dublin.

Lyons R.F., Mickelson, K. D., Sullivan, M. & Coyne, J. C. (1998) Coping as a communal process. *Journal of Social and Personal Relationships* **15**, 579-605.

Machin A., Babatunde O., Haththotuwa R., Scott I., Blagojevic-Bucknall M., Corp N., Chew-Graham C. & Hider S. (2020) The association between anxiety and disease activity and quality of life in rheumatoid arthritis: a systematic review and meta-analysis. *Clinical Rheumatology* **39**(5), 1471-1482.

Mackenzie N. & Knipe S. (2006) Research dilemmas: paradigms, methods and methodology. *Issues in Educational Research* **16**, 193-205.

Mahoney, Paul M (2017) *An Investigation of Methods for Predicting Rheumatoid Arthritis Patient Response in Clinical Trials from Clinical Biomarkers and Patient Characteristics.* PhD thesis, University of Sheffield. Retrieved from https://etheses.whiterose.ac.uk/21019/ on October 23rd 2020.

Major B. & O'Brien L. (2005) The social psychology of stigma. *Annual Review of Psychology* **56**, 393-421.

Major B. & Schmader T. (2018) Stigma, social identity threat, and health. In *The Oxford Handbook of Stigma, Discrimination, and Health* (Major B., Dovidio J.F. & Link B.J. eds), Oxford University Press, New York, pp. 85-103.

Malcus-Johnson P., Carlqvist C., Sturesson A.L. & Eberhardt K. (2005) Occupational therapy during the first 10 years of rheumatoid arthritis. *Scandinavian Journal of Occupational Therapy* **12**(3), 128-135.

Malik A.Y. & Foster C. (2016) The revised Declaration of Helsinki: cosmetic or real change? *Journal of the Royal Society of Medicine* **109**(5), 184-189.

Marshall C.R. & Rossman G.B. (2016) Designing Qualitative Research, 6th edn. Sage, Los Angeles.

Martin C.M. & Félix-Bortolotti M. (2014) Person-centred health care: a critical assessment of current and emerging research approaches. *Journal of Evaluation in Clinical Practice* **20**(6), 1056-1064.

Martin C. (2007) Chronic disease and illness care: adding principles of family medicine to address ongoing health system redesign. *Canadian Family Physician* **53**(12), 2086-2091.

Maslow A.H. (1954) A theory of human motivation. *Psychological Review* **50**(4), 370-396.

Mason J. (2018) *Qualitative Researching* 3rd edn. Sage, London

Matcham F., Rayner L., Steer S. & Hotopf M. (2013) The prevalence of depression in rheumatoid arthritis: a systematic review and meta-analysis. *Rheumatology* **52**(12), 2136-2148.

Matura L.A., Malone S., Jaime-Lara R. & Riegel B. (2018) A systematic review of biological mechanisms of fatigue in chronic illness. *Biological Research for Nursing* **20**(4), 410-421.

Mayer J.D., Caruso D.R. & Salovey P. (2016) The ability model of emotional intelligence: principles and updates. *Emotion Review* **8**(4), 290-300.

Mayer J.D., Salovey P. & Caruso D.R. (2004) Emotional Intelligence: Theory, Findings, and Implications. *Psychological Inquiry* **15**(3), 197-215.

McBain H., Bezzant M. & Bosworth A. (2019) The barriers and facilitators to requesting and receiving psychological support for people with rheumatoid arthritis and adults with juvenile idiopathic arthritis. *Rheumatology* **58**, Issue (Supplement 3), British Society for Rheumatology Annual Conference 2019 Abstracts, p. 2.

McCallin A. (2003) Grappling with the literature in a grounded theory study. *Contemporary Nurse* **15**(1-2), 61-69.

McCann T.V. & Clark E. (2003) Grounded theory in nursing research: Part 1--methodology. *Nurse Researcher* **11**(2), 7-18.

McCrae N. & Purssell E. (2016) Is it really theoretical? A review of sampling in grounded theory studies in nursing journals. *Journal of Advanced Nursing* **72**(10), 2284-2293.

McCullough M., Emmons R. & Tsang, J. (2002) The grateful disposition: a conceptual and empirical topography. *Journal of Personality and Social Psychology* **82**, 112–127.

McFadyen J. & Rankin J. (2016) The role of gatekeepers in research: learning from reflexivity and reflection. *GSTF: Journal of Nursing and Health Care* **4**, 82-88.

McGonagle A. & Hamblin L. (2014) Proactive responding to anticipated discrimination based on chronic illness: double-edged sword? *Journal of Business and Psychology* **29**(3), 427-442.

McInnes I.B. & Schett G. (2017) Pathogenetic insights from the treatment of rheumatoid arthritis. *Lancet* **389**(10086), 2328-2337.

McKenna S., Kelly G. & Kennedy N. (2019) A survey of physiotherapists' current management and the promotion of physical activity, in people with rheumatoid arthritis. *Disability and Rehabilitation* **41**(18), 2183-2191.

McManus E. (2018) Personal Notes from Grounded theory Troubleshooting Seminar. Personal Communication, December 13th 2018.

McPherson K., Brander P., Taylor W. & McNaughton H. (2001) Living with arthritis--what is important? *Disability and Rehabilitation* **23**(16), 706-721.

McVey L., Lees J. & Nolan G. (2016) Reflective-verbal language and reverie in a qualitative interview. *Counselling and Psychotherapy Research* **16**(2), 132-140.

McWilliams D.F. & Walsh D.A. (2016) Factors predicting pain and early discontinuation of tumour necrosis factor-α-inhibitors in people with rheumatoid arthritis: results from the British Society for Rheumatology Biologics Register. *BMC Musculoskeletal Disorders* **17**, 337.

Melanson P.M. & Downe-Wamboldt B. (2003) Confronting life with rheumatoid arthritis. *Journal of Advanced Nursing* **42**(2), 125-133.

Melia K.M. (1996) Rediscovering Glaser. *Qualitative Health Research* **6**(3), 368-378.
Memel D., Kirwan J., Langley C., Hewlett S. & Hehir M. (2002) Prediction of successful application for disability benefits for people with arthritis using the Health Assessment questionnaire. *Rheumatology* **41**(1), 100-2.

Metz T. (2002) Recent work on the meaning of life. *Ethics* **112**(4), 781-814.

Metz T. (2016) Is life's meaning ultimately unthinkable? Guy Bennett-Hunter on the ineffable. *Philosophia* **44** (4), 1247-1256.

Michaud K., Pope J., Emery P., Zhu B., Gaich C., DeLozier A., Zhang X., Dickson C. & Smolen J.S. (2019) Relative impact of pain and fatigue on work productivity in patients with rheumatoid arthritis from the RA-BEAM Baricitinib Trial. *Rheumatology and Therapy* **6**(3), 409-419.

Millen N. & Walker C. (2001) Overcoming the stigma of chronic illness: strategies for normalisation of a 'spoiled identity'. *Health Sociology Review* **10**(2), 89-97.

Mills J., Chapman Y., Bonner A. & Francis K. (2007) Grounded theory: a methodological spiral from positivism to postmodernism. *Journal of Advanced Nursing* **58**(1), 72-79.

Minnock P., McKee G., Kelly A., Carter S., Menzies V., O'Sullivan D., Richards P., Ndosi M. & van Eijk Hustings Y. (2018) Nursing sensitive outcomes in patients with rheumatoid arthritis: a systematic literature review. *International Journal of Nursing Studies* **77**, 115-129.

Minnock P. & Ryan A.-M. (2018) Rheumatology Advanced Nurse Practitioners treat to target person centered care: Ireland's policy framework. *Annals of the Rheumatic Diseases* **77**(Supplement 2), 1812-1812.

Mitchell M. (2011) A reflection on the emotional potential of qualitative interviewing. *British Journal of Midwifery* **19**(10), 653-657.

Montgomery P. & Bailey P.H. (2007) Field notes and theoretical memos in grounded theory. *Western Journal of Nursing Research* **29**(1), 65-79.

Montpetit M., Bergeman C., Deboeck P., Tiberio S. & Boker S.M. (2010) Resilience-as-process: negative affect, stress, and coupled dynamical systems. *Psychology and Aging* **25**(3), 631-640.

Moore J. (2009) An exploration of the origin of classic grounded theory. *Nurse Researcher* **17**, 8-14.

Morgan H., Entwistle V., Cribb A., Christmas S., Owens J., Skea Z. & Watt I. (2017) We need to talk about purpose: a critical interpretive synthesis of health and social care professionals' approaches to self-management support for people with long-term conditions. *Health Expectations* **20**(2), 243-259.

Moser P.K. (1999) *Philosophy after Objectivity – Making Sense in Perspective* - Oxford University Press, Oxford.

Mourgues C., Blanquet M., Gerbaud L., Soubrier M. & Dougados M. (2018) Economic analysis of a nurse-led programme for comorbidities management of rheumatoid arthritis patients. *Joint Bone Spine* **85**(5), 573-576.

Munro E. & Hardie J. (2019) Why we should stop talking about objectivity and subjectivity in social work. *British Journal of Social Work* **49**, 411-427.

Murage M., Tongbram V., Feldman S., Malatestinic W., Larmore C., Muram T., Burge R., Bay C., Johnson N., Clifford S. & Araujo A. (2018) Medication adherence and persistence in patients with rheumatoid arthritis, psoriasis, and psoriatic arthritis: a systematic literature review. *Patient Prefer and Adherence* **12,** 1483-1503.

Musich S., Wang S., Slindee L., Kraemer S. & Yeh C. (2019) Association of resilience and social networks with pain outcomes among older adults. *Population Health Management* **22**(6), 511-521.

Myers D.G. (2009) *Social Psychology,* 10th edn. McGraw-Hill Higher Education, New York.

Myung G., Harada N., Fong S., Aquino-Beaton C., Fong C. & Fang M. (2019) Stigma and medication adherence in patients with rheumatic disease. *Journal of Psychosomatic Research* 125, Retrieved from https://www.sciencedirect.com/science/article/abs/pii/S0022399919306312?via%3Dihub doi: 10.1016/j.jpsychores.2019.109791.on February 20th 2021.

Nathaniel A. & Andrews T., (2010) The modifiability of grounded theory. *The Grounded theory Review* 9 (1), 65-78.

Nathaniel A. (2011) An integrated philosophical framework that fits grounded theory In *The Philosophy, method and work of Barney Glaser*. (Martin V. & Gynnild A., eds), BrownWalker Press, Florida.

NICE (2009) Depression in adults with a chronic physical health problem: recognition and management: Clinical guideline 91. National Institute for Health Care Excellence, London. Retrieved from https://www.nice.org.uk/guidance/cg91/resources/depression-in-adults-with-a-chronic-physical-health-problem-recognition-and-management-pdf-975744316357 on June 10th 2019.

NICE (2018) *Rheumatoid Arthritis in Adults: Management Guideline 100*. National Institute for Health Care Excellence, London. Retrieved from https://www.nice.org.uk/guidance/ng100 on July 10th 2019.

Nelson J. (2017) Using conceptual depth criteria: addressing the challenge of reaching saturation in qualitative research. *Qualitative Research* **17**(5), 554–570.

Nerenz D., Austin J., Deutscher D., Joynt Maddox K., Nuccio E., Teigland C., Weinhandl E. & Glance L. (2021) Adjusting quality measures for social risk factors can promote equity in health care. *Health Affairs* **40**(4), 637-644.

Nessen T., Opava C.H., Martin C. & Demmelmaier I. (2019) Physiotherapists' management of challenging situations in guiding people with rheumatoid arthritis to health-enhancing physical activity. *Physiotherapy: Theory and Practice* **35**(1), 31-39.

Newheiser A.-K. & Barreto M. (2014) Hidden costs of hiding stigma: ironic interpersonal consequences of concealing a stigmatized identity in social interactions. *Journal of Experimental Social Psychology* **52**, 58-70.

Nicklin J., Cramp F., Kirwan J., Greenwood R., Urban M. & Hewlett S. (2010) Measuring fatigue in rheumatoid arthritis: a cross-sectional study to evaluate the Bristol rheumatoid arthritis fatigue multi-dimensional questionnaire, visual analog scales, and numerical rating scales. *Arthritis Care and Research* **62**(11), 1559-1568.

Nieuwlaat R., Wilczynski N., Navarro T., Hobson N., Jeffery R., Keepanasseril A., Agoritsas T., Mistry N., Iorio A., Jack S., Sivaramalingam B., Iserman E., Mustafa R., Jedraszewski D., Cotoi C. & Haynes R. (2014) Interventions for enhancing medication adherence. *The Cochrane Database of Systematic Reviews 2014,* Issue 11. No. CD000011. DOI: 10.1002/14651858.CD000011.

Nikolaus S., Bode C., Taal E. & Laar M. (2012) which dimensions of fatigue should be measured in patients with rheumatoid arthritis? A delphi study. *Musculoskeletal Care* **10**(1), 13-17.

Nowell B. & Albrecht K. (2019) A reviewer's guide to qualitative rigor. *Journal of Public Administration Research and Theory* **29**(2), 348-363.

Nutbeam D. (2008) The evolving concept of health literacy. *Social Science and Medicine* **67**(12), 2072-2078.

Nyklíček I., Hoogwegt F. & Westgeest T. (2015) Psychological distress across twelve months in patients with rheumatoid arthritis: the role of disease activity, disability, and mindfulness. *Journal of Psychosomatic Research* **78**(2), 162-167.

Oliver J.E. & Silman A.J. (2009) Why are women predisposed to autoimmune rheumatic diseases? *Arthritis Research and Therapy* **11**(5), 1-9.

Oliver S., Tam L.S., Suet-Kei Kwok G., Fusama M., Nakahara H., Zhang C.Y., Yamamoto K. & Furtner D. (2020) The Asia-Pacific initiative for rheumatology nurse education: current gaps, programme development and future outlook. *Musculoskeletal Care* **18**(3), 397-403.

Ong A., Zautra A. & Reid M. (2010) Psychological resilience predicts decreases in pain catastrophizing through positive emotions. *Psychology and Aging* **25**(3), 516-523.

Orhan C., Van Looveren E., Cagnie B., Mukhtar N.B., Lenoir D. & Meeus M. (2018) Are pain beliefs, cognitions, and behaviors influenced by race, ethnicity, and culture in patients with chronic musculoskeletal pain: a systematic review. *Pain Physician* **21**(6), 541-558.

Osthoff A., Niedermann K., Braun J., Adams J., Brodin N., Dagfinrud H., Duruoz T., Esbensen B., Günther K-P., Hurkmans E., Juhl C., Kennedy N., Kiltz U., Keegan K., Nurmohamed M., Pais S., Severijns G., Swinnen T., Pitsillidou I., Warburton L., Zhivko Y. & Vlieland T. (2018) EULAR recommendations for physical activity in people with inflammatory arthritis and osteoarthritis. *Annals of the Rheumatic Diseases* **77**(9), 1251-1260.

Otake T., Ashihara M., Nishino J., Kato K., Fukaya S. & Yoshida S. (2013) Stressors and rheumatoid arthritis: changes in stressors with advances in therapeutic agents. *Rheumatology International* **33**(4), 887-891.

Oude Voshaar M., Vonkeman H., Courvoisier D., Finckh A., Gossec L., Leung Y., Michaud K., Pinheiro G., Soriano E., Wulfraat N., Zink A. & van de Laar M. (2019) Towards standardized patient reported physical function outcome reporting: linking ten commonly used questionnaires to a common metric. *Quality of Life Research* **28**(1), 187-197.

Over H. (2016) The origins of belonging: social motivation in infants and young children. *Philosophical Transactions of the Royal Society B: Biological Sciences* **371**, (1686), 20150072.

Oxford University Press (2018) *English Oxford Living Dictionaries.* Online version. Retrieved from https://www.lexico.com/definition/articulous on July 1st 2018.

Paley J. (2011) The fictionalist paradigm. *Nursing Philosophy* **12**(1), 53-66.

Parahoo K. (2014) *Nursing Research: Principles, Process and Issues*. Palgrave Macmillan, London.

Parenti G., Tomaino S.C.M. & Cipolletta S. (2020) The experience of living with rheumatoid arthritis: a qualitative metasynthesis. *Journal of Clinical Nursing* **29**(21/22), 3922-3936.

Parker A. & Tritter J. (2006) Focus group method and methodology: current practice and recent debate. *International Journal of Research and Method in Education* **29**(1), 23-37.

Pasma A., van't Spijker A., Hazes J., Busschbach J. & Luime J. (2013) Factors associated with adherence to pharmaceutical treatment for rheumatoid arthritis patients: a systematic review. *Seminars in Arthritis and Rheumatism* **43**(1), 18-28.

Pei J.-H., Ma T., Nan R.-L., Chen H.-X., Zhang Y.-B., Gou L. & Dou X.-M. (2021) Mindfulness-based cognitive therapy for treating chronic pain a systematic review and meta-analysis. *Psychology, Health and Medicine* **26**(3), 333-346.

Penley J., Joe; Wiebe, John S. (2002) The association of coping to physical and psychological health outcomes: a meta-analytic review. *Journal of Behavioral Medicine*. **25**(6), 551-603.

PARE People Against Rheumatism in Europe (2012) *With one voice. A brief guide to the role and work of the EULAR Standing Committee of People with Arthritis /Rheumatism in Europe*. Retrieved from https://www.eular.org/myUploadData/files/PARE%20BROCHURE_FINAL_290212.pdf on 30th January 2019.

Pettit M.L. (2008) Disease and stigma: a review of literature. *Health Educator* **40**(2), 70-76.

Phillips J. & Harris P. (2019) Helping people to help themselves: an eight-week mindfulness course for people living with a long-term inflammatory condition. *The Chartered Society of Physiotherapy UK Conference*, 19-20 October 2018, Birmingham, UK. *Physiotherapy* **105**, e151-e152.

Phillips T. & Rees T. (2018) (In)Visibility online: the benefits of online patient forums for people with a hidden illness: the case of multiple chemical sensitivity (MCS). *Medical Anthropology Quarterly* **32**(2), 214-232.

Poh L., He H., Lee C., Cheung P. & Chan W. (2015) An integrative review of experiences of patients with rheumatoid arthritis. *International Nursing Review* **62**(2), 231-247.

Prati G. & Pietrantoni L. (2009) Optimism, social support, and coping strategies as factors contributing to posttraumatic growth: a meta-analysis. *Journal of Loss & Trauma* **14**(5), 364-388.

Primdahl J., Wagner L. & Hørslev-Petersen K. (2011) Being an outpatient with rheumatoid arthritis - a focus group study on patients' self-efficacy and experiences from participation in a short course and one of three different outpatient settings. *Scandinavian Journal of Caring Sciences* **25**(2), 394-403.

Prothero L., Barley E., Galloway J., Georgopoulou S. & Sturt J. (2018) The evidence base for psychological interventions for rheumatoid arthritis: A systematic review of reviews. *International Journal of Nursing Studies* **82**, 20-29.

Quinn D. (2017) Issue introduction: identity concealment: multilevel predictors, moderators, and consequences. *Journal of Social Issues* **73**, 230-239.

Quinn D., Williams M., Quintana F., Gaskins J., Overstreet N., Pishori A., Earnshaw V., Perez G. & Chaudoir S. (2014) Examining effects of anticipated stigma, centrality, salience, internalization, and outness on psychological distress for people with concealable stigmatized identities. *PLoS ONE* **9**(5), e96977.

Rice D., Mehta S., Serrato J., Pope J., Harth M., Sequeira K., Morley-Forster P., Shapiro A. and Teasell R. (2017) Stress in patients diagnosed with rheumatoid arthritis compared to chronic pain. *Rehabilitation Psychology* **62**(4), 571-579.

Ralph N., Birks M. & Chapman Y. (2015) The methodological dynamism of grounded theory. *International Journal of Qualitative Methods* **14**(4), 1-6.

Rappaport J. (1984) Studies in empowerment. *Prevention in Human Services* **3**(2-3), 1-7.

Rash J., Matsuba K. & Prkachin K. (2011) Gratitude and well-being: who benefits the most from a gratitude intervention? *Applied Psychology Health and Well-Being* **3**, 350-369.

Reed P. & Runquist J. (2007) Reformulation of a methodological concept in grounded theory . *Nursing Science Quarterly* **20**, 118-122.

Reed P.G. (2020) Explanatory power and nursing theory. *Nursing Science Quarterly* **33**(3), 229-233.

Reich J.W., Zautra A.J. & Hall J.S. (2010) *Handbook of Adult Resilience*. Guilford Press, London.

Rendas-Baum R., Bayliss M., Kosinski M., Raju A., Zwillich S.H., Wallenstein G.V. & Koncz T. (2014) Measuring the effect of therapy in rheumatoid arthritis clinical trials from the patient's perspective. *Current Medical Research and Opinion* **30**(7), 1391-1403.

Rennie D.L. (1998) Grounded theory methodology: the pressing need for a coherent logic of justification. *Theory and Psychology* **8**(1), 101-119.

Repping-Wuts H., Uitterhoeve R., van Riel P. & van Achterberg T. (2008) Fatigue as experienced by patients with rheumatoid arthritis (RA): a qualitative study. *International Journal of Nursing Studies* **45**(7), 995-1002.

Richardson J., Loyola-Sanchez A., Sinclair S., Harris J., Letts L., MacIntyre N.J., Wilkins S., Burgos-Martinez G., Wishart L., McBay C. & Martin Ginis K. (2014) Self-management interventions for chronic disease: a systematic scoping review. *Clinical Rehabilitation* **28**(11), 1067-1077.

Rieger K.L. (2019) Discriminating among grounded theory approaches. *Nursing Inquiry* **26**(1), e12261.

Ring E. & Von Radowitz J. (2012) Drug offers hope to arthritis patients. *Irish Examiner*, June 9th 2012. Retrieved from Dublin Retrieved from https://www.irishexaminer.com/news/arid-20196790.html on August 17th 2017.

Roberts K., Dowell A. & Nie J.-B. (2019) Attempting rigour and replicability in thematic analysis of qualitative research data; a case study of codebook development. *BMC Medical Research Methodology* **19**(1), 1-8.

Rojas M., Rodriguez Y., Pacheco Y., Zapata E., Monsalve D.M., Mantilla R., Rodríguez-Jimenez M., Ramírez-Santana C., Molano-González N. & Anaya J.-M. (2018) Resilience in women with autoimmune rheumatic diseases. *Joint Bone Spine* **85**(6), 715-720.

Rolland J.S. (1994) In sickness and in health: the impact of illness on couples' relationships. *Journal of Marital and Family Therapy* **20,** 327-347.

Rosenberg M., Schooler C., Schoenbach C. & Rosenberg F. (1995) Global self-esteem and specific self-esteem: different concepts, different outcomes. *American Sociological Review* **60**(1), 141-156.

Rueda S., Chambers L., Wilson M., Mustard C., Rourke S.B., Bayoumi A., Raboud J. & Lavis J. (2012) Association of returning to work with better health in working-aged adults: a systematic review. *American Journal of Public Health* **102**(3), 541-556.

Rutter M. (2006) Implications of resilience concepts for scientific understanding. *Annals of the New York Academy of Sciences* **1094**, 1-12.

Ryan F., Coughlan M. & Cronin P. (2009) Interviewing in qualitative research: the one-to-one interview. *International Journal of Therapy and Rehabilitation* **16**(6), 309-314.

Ryan S., Lillie K., Thwaites C. & Adams J. (2013) 'What I want clinicians to know'--experiences of people with arthritis. *British Journal of Nursing* **22**(14), 808-812.

Ryan W.S., Legate N., Weinstein N. & Rahman Q. (2017) Autonomy support fosters lesbian, gay, and bisexual identity disclosure and wellness, especially for those with internalized homophobia. *Journal of Social Issues* **73**(2), 289-306.

Sabatino L., Stievano A., Rocco G., Kallio H., Pietila A.-M. & Kangasniemi M.K. (2014) The dignity of the nursing profession: a meta-synthesis of qualitative research. *Nursing Ethics* **21**(6), 659-672.

Sacristán J.A., Díaz S., de la Torre I., Inciarte-Mundo J. & Balsa A. (2019) Treat-to-target and treat-to-budget in rheumatoid arthritis: measuring the value of individual therapeutic interventions. *Rheumatology and Therapy* **6**(4), 473-477.

Safiri S., Kolahi A., Cross M., Carson-Chahhoud K., Hoy D., Almasi-Hashiani A., Sepidarkish M., Ashrafi-Asgarabad A., Moradi-Lakeh M., Mansournia M., Kaufman J.S., Collins G., Woolf A., March L. & Smith E. (2020) Prevalence, incidence, and years lived with disability due to gout and its attributable risk factors for 195 countries and territories 1990–2017: a systematic analysis of the global burden of disease study 2017. *Arthritis and Rheumatology* **72**(11), 1916-1927.

Salih M.H. & Launders T. (2019) The concept analysis of stigma towards chronic illness patient. *Hospice and Palliative Medicine International Journal* **3**(4), 132-136.

Salmon V., Hewlett S., Walsh N., Kirwan J. & Cramp F. (2017) Physical activity interventions for fatigue in rheumatoid arthritis: a systematic review. *Physical Therapy Reviews* **22,** 12-22.

Sanderson T., Calnan M., Morris M., Richards P. & Hewlett S. (2011) Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociology of Health and Illness* **33**(4), 618-633.

Sanderson T., Morris M., Calnan M., Richards P. & Hewlett S. (2010) What outcomes from pharmacologic treatments are important to people with rheumatoid arthritis? Creating the basis of a patient core set. *Arthritis Care and Research* **62**(5), 640-646.

Santiago M.G., Marques A., Kool M., Geenen R. & da Silva J. (2017) Invalidation in patients with rheumatic diseases: clinical and psychological framework. *Journal of Rheumatology* **44**(4), 512-518.

Santos E., Duarte C., Marques A., Cardoso D., Apóstolo J., da Silva J. & Barbieri-Figueiredo M. (2019) Effectiveness of non-pharmacological and non-surgical interventions for rheumatoid arthritis: an umbrella review. *JBI Database of Systematic Reviews and Implementation Reports* **17**(7), 1494-1531.

Sarantakos S. (2013) Social Research. Palgrave Macmillan, Basingstoke.

Saunders, M., Lewis P., Thornhill A. & Bristow A. (2015) Understanding research philosophy and approaches to theory development. In *Research Methods for Business Students* (Saunders M., Lewis P., Thornhill A. & Bristow A. eds), Pearson Education, Harlow, pp. 122–161.

Scambler G. & Scambler S. (2010) *New Directions in the Sociology of Chronic and Disabling Conditions: Assaults on the Lifeworld*. Palgrave Macmillan, Basingstoke.

Scambler G. (2006) Sociology, social structure and health-related stigma. *Psychology, Health and Medicine* **11**(3), 288-295.

Scambler G. (2018) Heaping blame on shame: ‘weaponising stigma’ for neoliberal times. *The Sociological Review* **66**(4), 766-782.

Schetter C.D. & Dolbier C. (2011) Resilience in the context of chronic stress and health in adults. *Social and Personality Psychology Compass* **5**(9), 634-652.

Schreiber, R. S. & Noerager Stern R. (2001) *Using Grounded theory in Nursing*. Springer, New York.

Scott H. (2007) The temporal integration of connected study into a structured life: a grounded theory . In *The Grounded theory Seminar Reader 2007.* (Glaser B.G. & Holton J. eds), Sociology Press, Mill Valley, pp. 145-162.

Seligman M. & Csikszentmihalyi M. (2000) Positive psychology: an introduction. *The American Psychologist* **55**, 5-14.

Seligman M.E.P. (2019) Positive psychology: a personal history. *Annual Review of Clinical Psychology* **15**, 1-23.

Shapiro S.L., Carlson L.E., Astin J.A. & Freedman B. (2006) Mechanisms of mindfulness. *Journal of Clinical Psychology* **62**(3), 373-386.

Sharma S., Mahajan A., Mittal A., Gohil R., Sachdeva S., Khan S. & Dhillon M. (2020) Epigenetic and transcriptional regulation of osteoclastogenesis in the pathogenesis of skeletal diseases: a systematic review. *BONE* **138**, 1-11.

Shaul M.P. (1995) From early twinges to mastery: the process of adjustment in living with rheumatoid arthritis. *Arthritis Care and Research* **8**(4), 290-297.

Shaw R.M., Howe J., Beazer J. & Carr T. (2020a) Ethics and positionality in qualitative research with vulnerable and marginal groups. *Qualitative Research* **20**(3), 277-293.

Shaw Y., Bradley M., Zhang C., Dominique A., Michaud K., McDonald D. & Simon T.A. (2020b) Development of resilience among rheumatoid arthritis patients: a qualitative study. *Arthritis Care and Research* **72**(9), 1257-1265.

Shim E., Song Y., Park S.-H., Lee K.-M., Go D. & Hahm B.-J. (2017) examining the relationship between pain catastrophizing and suicide risk in patients with rheumatic disease: the mediating role of depression, perceived social support, and perceived burdensomeness. *International Journal of Behavioral Medicine* **24**(4), 501-512.

Silva C., Duarte C., Ferreira R., Santos E. & Da Silva J. (2019) Depression, disability, and sleep disturbance are the main explanatory factors of fatigue in rheumatoid arthritis: a path analysis model. *Clinical and Experimental Rheumatology* **38**, 314-321.

Silverman D. (2013) *Doing Qualitative Research,* 4th edn. Sage, London.

Simmons O. (2011) Why classic grounded theory. In T*he Philosophy, Method And Work Of Barney Glaser*. (Martin V. & Gynnild A., eds), BrownWalker Press, Florida, pp. 15-30.

Skinner E.A., Edge K., Altman J. & Sherwood H. (2003) Searching for the structure of coping: a review and critique of category systems for classifying ways of coping. *Psychological Bulletin* **129**(2), 216-269.

Smith C.A. & Lazarus R.S. (1993) Appraisal components, core relational themes, and the emotions. *Cognition and Emotion* **7**(3-4), 233-269.

Smith-MacDonald L., Reay G., Raffin-Bouchal S. & Sinclair S. (2019) Patient-oriented research and grounded theory : a case study of how an old method can inform cutting-edge research. *International Journal of Qualitative Methods* **18**, 1-13.

Smolen J.S. & Aletaha D. (2015) Rheumatoid arthritis therapy reappraisal: strategies, opportunities and challenges. *Nature Reviews Rheumatology* **11**(5), 276-289.

Smolen J.S., Aletaha D., Bijlsma J., Breedveld F., Boumpas D., Burmester G., Combe B., Cutolo M., de Wit M., Dougados M., Emery P., Gibofsky A., Gomez-Reino J., Haraoui B., Kalden J., Keystone E., Kvien T., McInnes I., Martin-Mola E., Montecucco C., Schoels M. & van der Heijde D. (2010) Treating rheumatoid arthritis to target: recommendations of an international task force. *Annals of the Rheumatic Diseases* **69**(4), 631-637.

Smolen J.S., Breedveld F., Burmester G., Bykerk V., Dougados M., Emery P., Kvien T., Navarro-Compán M., Oliver S., Schoels M., Scholte-Voshaar M., Stamm T., Stoffer M., Takeuchi T., Aletaha D., Andreu J., Aringer M., Bergman M., Betteridge N. & Bijlsma H. (2016) Treating rheumatoid arthritis to target: 2014 update of the recommendations of an international task force. *Annals of the Rheumatic Diseases* **75**(1), 3-15.

Smolen J.S., Landewé R., Bijlsma J., Burmester G., Chatzidionysiou K., Dougados M., Nam J., Ramiro S., Voshaar M., van Vollenhoven R., Aletaha D., Aringer M., Boers M., Buckley C., Buttgereit F., Bykerk V., Cardiel M., Combe B., Cutolo M. & van Eijk-Hustings Y. (2017) EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update. *Annals of the Rheumatic Diseases* **76**(6), 960-977.

Smolen J.S., Landewé R., Bijlsma J., Burmester G., Kerschbaumer A., McInnes I., Sepriano A., van Vollenhoven R., de Wit M., Aletaha D., Aringer M., Askling J., Alejandro Balsa A., Boers M., den Broeder A., Buch M., Buttgereit F., Caporali R., Cardiel M., De Cock D., Codreanu C., Cutolo M., Edwards C., van Eijk-Hustings Y., Emery P., Finckh A., Gossec L., Gottenberg J-E., Hetland M., Huizinga T., Koloumas M., Li, Z., Müller-Ladner U., Mysler E., da Silva J., Poór G., Pope J., Rubbert-Roth A., Ruyssen-Witrand A., Saag K., Strangfeld A., Takeuchi,T., Voshaar M., Westhovens R. & van der Heijde, D. (2020) EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2019 update. *Annals of the Rheumatic Diseases* **79**, 685-699.

Song Y., Reifsnider E., Zhao S., Xie X. & Chen H. (2020) A randomized controlled trial of the effects of a telehealth educational intervention on medication adherence and disease activity in rheumatoid arthritis patients. *Journal of Advanced Nursing* **6**(5), 1172-1181.

Squire S & Hill P (2006) The expert patient's programme. *Clinical Governance: An International Journal* **11**, 17-21.

Staley K. (2017) Changing what researchers 'think and do': Is this how involvement impacts on research? *Research for All* **1**, 158-167.

Staley K., Abbey-Vital I. & Nolan C. (2017) The impact of involvement on researchers: a learning experience. *Research Involvement and Engagement* **3**(1), 20.

Stenberg U., Haaland-Overby M., Fredriksen K., Westermann K.F. & Kvisvik T. (2016) A scoping review of the literature on benefits and challenges of participating in patient education programs aimed at promoting self-management for people living with chronic illness. *Patient Education and Counseling* **99**(11), 1759-1771.

Stets J. & Burke P. (2014a) The Development of Identity Theory. *Advances in Group Processes* **31**, pp. 57-97.

Stets J.E. & Burke P.J. (2014b) Self-Esteem and identities. *Sociological Perspectives* 57(4), 409-433.

Stets J.E., Burke P.J. & Savage S.V. (2018) Exchange, identity verification, and social bonds. *Social Psychology Quarterly* **81**(3), 207-227.

Steultjens E.M., Dekker J., Bouter L.M., van Schaardenburg D., van Kuyk M.A. & van den Ende C.H. (2002) Occupational therapy for rheumatoid arthritis: a systematic review. *Arthritis and Rheumatology* **47**(6), 672-685.

Steunebrink L., Versteeg G., Vonkeman H., ten Klooster P., Kuper H., Zijlstra, T., van Riel P. & van de Laar M.A. (2016) 'Initial combination therapy versus step-up therapy in treatment to the target of remission in daily clinical practice in early rheumatoid arthritis patients: results from the DREAM registry'. *Arthritis Research and Therapy* **18**(60), 1-9.

Stoffer M., Schoels M., Smolen J. S., Aletaha D., Breedveld F., Burmester G. & Stamm T. (2016) Evidence for treating rheumatoid arthritis to target: results of a systematic literature search update. *Annals of the Rheumatic Diseases* **75**(1), 16-22.

Stoffer M., Schoels, M., Smolen J.S., Aletaha D., Breedveld F.C., Burmester G., Strand E.B., Zautra A.J., Thoresen M., Ødegård S., Uhlig T. & Finset A. (2006) Positive affect as a factor of resilience in the pain-negative affect relationship in patients with rheumatoid arthritis. *Journal of Psychosomatic Research* **60**(5), 477-484.

Strating M., Suurmeijer T.P. & van Schuur W. (2006) Disability, social support, and distress in rheumatoid arthritis: results from a thirteen-year prospective study. *Arthritis Care and Research* **55**(5), 736-744.

Strauss A. & Corbin J. (1998) Basics of Qualitative Research: Techniques and Procedures for Developing Grounded theory , 2nd edn. Sage Publications, Thousand Oaks, CA.

Strauss A. & Glaser B. (1975) *Chronic Illness and the Quality of Life*. C.V. Mosby, Saint Louis.

Strauss A. (1987) *Qualitative Methods for Social Scientists*. Cambridge University Press, New York.

Strong T. (2015) On being a social constructionist in a more than human world. In *Studies in Meaning. Perturbing the Status Quo in Constructivist Psychology.* (Raskin J., Bridges S. & Kahn J. eds.). Pace University Press, New York, pp. 91-118.

Stryker S and Burke P.J. (2000) The past, present, and future of an identity theory. *Social Psychology Quarterly* Special Millennium Issue on the State of Sociological Social Psychology. **63**(4), 284-297.

Stryker S. (1980) *Symbolic Interactionism: A Social Structural Version.* Benjamin/Cummings Publishing Company, Menlo Park, CA.

Stryker S. (2008) From Mead to a structural symbolic interactionism and beyond. The *Annual Review of Sociology* **34**, 15-31.

Studenic P. & Aletaha D. (2020) The slippery road of adherence in chronically ill individuals. *Rheumatology* **59**(1), 9-11.

Suarez-Almazor M.E., Conner-Spady B., Kendall C.J., Russell A.S. & Skeith K. (2001) Lack of congruence in the ratings of patients' health status by patients and their physicians. *Medical Decision Making* **21**(2), 113-121.

Surowiec I., Gjesdal C.G., Jonsson G., Norheim K.B., Lundstedt T., Trygg J. & Omdal R. (2016) Metabolomics study of fatigue in patients with rheumatoid arthritis naïve to biological treatment. *Rheumatology International* **36**(5), 703-711.

Sverker A., Östlund G., Thyberg M., Thyberg I., Valtersson E. & Björk M. (2015) Dilemmas of participation in everyday life in early rheumatoid arthritis: a qualitative interview study (The Swedish TIRA Project). *Disability and Rehabilitation* **37**(14), 1251-1259.

Swann W. & Hill C. (1982) When our identities are mistaken: reaffirming self-conceptions through social interaction. *Journal of Personality and Social Psychology* **43**, 59-66.

Symmons D.P. (2002) Epidemiology of rheumatoid arthritis: determinants of onset, persistence and outcome. *Best Practice and Research: Clinical Rheumatology* **16**(5), 707-722.

Taylor P.C., Moore A., Vasilescu R., Alvir J. & Tarallo M. (2016) A structured literature review of the burden of illness and unmet needs in patients with rheumatoid arthritis: a current perspective. *Rheumatology International* **36**(5), 685-695.

Taylor-Gjevre R., Nair B., Bath B., Okpalauwaekwe U., Sharma M., Penz E., Trask C. & Stewart S.A. (2017) Addressing rural and remote access disparities for patients with inflammatory arthritis through video-conferencing and innovative inter-professional care models. *Musculoskeletal Care* **16**(1), 90-95.

ten Klooster P.M., Oude Voshaar M.A.H., Fakhouri W., de la Torre I., Nicolay C. & van de Laar M. (2019) Long-term clinical, functional, and cost outcomes for early rheumatoid arthritis patients who did or did not achieve early remission in a real-world treat-to-target strategy. *Clinical Rheumatology* **38**(10), 2727-2736.

Thomas C. (2012) Theorising disability and chronic illness: where next for perspectives in medical sociology? *Social Theory and Health* **10**, 209–228

Thomas G. & James D. (2006) Reinventing grounded theory: some questions about theory, ground and discovery. *British Educational Research Journal* **32**, 767-795.

Thompson L., Ford H., Stroud A. & Madill A. (2019) Managing the (In)visibility of Chronic Illness at Work: Dialogism, Parody, and Reported Speech. *Qualitative Health Research* **29**(8), 1213-1226.

Thornberg R & Dunne C. (2019) Literature review in grounded theory . In *The Sage Handbook of Current Developments in Grounded theory* (Bryant A. & Charmaz K. eds.), Sage Publications, London, pp. 206-222.

Tomlinson P., Heaton H., Medcalf P., Campbell J. & Whiteside D. (2019) A nurse-led rheumatology telephone advice line: service redesign to improve efficiency and patient experience. *British Journal of Nursing* **28**(10), 619-627.

Toye F., Seers K., & Barker K. (2019). Living life precariously with rheumatoid arthritis - a mega-ethnography of nine qualitative evidence syntheses. *BMC Rheumatology* **3**(5) 1-13.

Tschudin V. (2010) Nursing ethics: the last decade. *Nursing Ethics* **17**(1), 127-131.

Tugwell P., Boers M., Brooks P., Simon L., Strand V. & Idzerda L. (2007) OMERACT: an international initiative to improve outcome measurement in rheumatology. *Trials* **8**(38), 1-6.

Turner J. & Kelly B. (2000) Emotional dimensions of chronic disease*. Western Journal of Medicine* **172**(2), 124-128.

University College Dublin (2018) Conference Proceedings: *Facilitating a Collaborative Approach to Arthritis and Rheumatic Disease*. University College Dublin, George Moore Auditorium, 02 November 2018, p. 2.

University of Dublin (2019) Data Protection Impact Assessment (DPIA). Trinity College, Dublin.

University of Dublin, Trinity College (2020) *University Lone Worker Policy and Guidance.* Revised 1.0 University of Dublin, Trinity College, Dublin.

Van Bergen P. & Parsell M. (2019) Comparing radical, social and psychological constructivism in Australian higher education: a psycho-philosophical perspective. *The Australian Educational Researcher* **46**(1), 41-58.

Van de Velde D., De Zutter F., Satink T., Costa U., Janquart S., Senn D. & De Vriendt P. (2019) Delineating the concept of self-management in chronic conditions: a concept analysis. *British Medical Journal Open* **9**(7), e027775.

van der Woude D. & van der Helm-van Mil A.H.M. (2018) Update on the epidemiology, risk factors, and disease outcomes of rheumatoid arthritis. *Best Practice and Research Clinical Rheumatology* **32**(2), 174-187.

van Eijk-Hustings Y., Ndosi M., Buss B., Fayet F., Moretti A., Ryan S., Savel C., Scholte-Voshaar M., de la Torre-Aboki J. & van Tubergen A. (2014) Dissemination and evaluation of the European League Against Rheumatism recommendations for the role of the nurse in the management of chronic inflammatory arthritis: results of a multinational survey among nurses, rheumatologists and patients. *Rheumatology* **53**(8), 1491-1496.

van Hoogmoed D., Fransen J., Bleijenberg G. & van Riel P. (2010) Physical and psychosocial correlates of severe fatigue in rheumatoid arthritis. *Rheumatology* **49**(7), 1294-1302.

van Tuyl L.H., Hewlett S., Sadlonova M., Davis B., Flurey C., Hoogland W., Kirwan J., Sanderson T., van Schaardenburg D., Scholte-Voshaar M., Smolen J., Stamm T. & Boers M. (2015) The patient perspective on remission in rheumatoid arthritis: 'you've got limits, but you're back to being you again'. *Annals of the Rheumatic Diseases* **74**(6), 1004-1010.

van Vollenhoven R., Lee E., Strengholt S., Mojcik C., Valdez H., Krishnaswami S., Biswas P., Lazariciu I., Hazra A., Clark J., Hodge J., Wang L. & Choy E. (2019) Evaluation of the short-, mid-, and long-term effects of Tofacitinib on lymphocytes in patients with rheumatoid arthritis. *Arthritis & Rheumatology* **71**(5), 685-695.

Varpio L., Ajjawi R., Monrouxe L., O'Brien B. & Rees C. (2017) Shedding the cobra effect: problematising thematic emergence, triangulation, saturation and member checking. *Medical Education* **51**, 40-50.

Viatte S., Plant D. & Raychaudhuri S. (2013) Genetics and epigenetics of rheumatoid arthritis. *Nature Reviews Rheumatology* **9**, 141–153.

Vliet Vlieland T.P. & van den Ende C.H. (2011) Nonpharmacological treatment of rheumatoid arthritis. *Current Opinion in Rheumatology* **23**(3), 259-264.

Vreju F.A., Ciurea P.L., Dinescu S.C., Cristina C., Rosu A., Chisalau B.A., Parvanescu C.D., Firulescu S.C., Dumitrascu R.M., Turcu-Stiolica A., Barbulescu A.L., Dumitrescu C.I., Radu L., Tusaliu M. & Dumitrescu D. (2019) The effect of glucosamine, chondroitin and harpagophytum procumbens on femoral hyaline cartilage thickness in patients with knee osteoarthritis -- an MRI versus ultrasonography study. *Journal of Mind and Medical Sciences* **6**(1), 162-168.

Walker J.G., Jackson H.J. & Littlejohn G.O. (2004) Models of adjustment to chronic illness: using the example of rheumatoid arthritis. *Clinical Psychology Review* **24,** 461-488.

Walker J.L. (2012) The use of saturation in qualitative research. *Canadian Journal of Cardiovascular Nursing* **22**(2), 37-46.

Walsh I. (2014) Using grounded theory to avoid research misconduct in management sciences. *The Grounded theory Review* **13**(1), 51-57.

Wasserman J.A., Clair J.M. & Wilson K.L. (2009) Problematics of grounded theory: innovations for developing an increasingly rigorous qualitative method. *Qualitative Research* **9**(3):355-381.

Watling C.J. & Lingard L. (2012) Grounded theory in medical education research: AMEE Guide No. 70. *Medical Teacher* **34**(10), 850-861.

Weaver K. & Olson J.K. (2006) Understanding paradigms used for nursing research. *Journal of Advanced Nursing* **53**(4), 459-469.

Weiss M.G., Ramakrishna J. & Somma D. (2006) Health-related stigma: rethinking concepts and interventions. *Psychology, Health and Medicine* **11**(3), 277-287.

Weisz B.M., Quinn D.M. & Williams M.K. (2016) Out and healthy: Being more "out" about a concealable stigmatized identity may boost the health benefits of social support. *Journal of Health Psychology* **21**(12), 2934-2943.

Wiener C.L. (1975) The burden of rheumatoid arthritis: tolerating the uncertainty. *Social Science and Medicine* **9**(2), 97-104.

Williams A. & Goodfellow R. (2013) Pharmacology in the musculoskeletal system. *Nurse Prescribing* **11**, 499-504.

Williams G. (1984) The genesis of chronic illness: narrative re-construction. *Sociology of Health and Illness* **6**(2), 175-200.

Williams L., Rycroft-Malone J. & Burton C.R. (2017) Bringing critical realism to nursing practice: Roy Bhaskar's contribution. *Nursing Philosophy* **18**(2), 1-19.

Williams M. (2014) Situated objectivity, values and realism. *European Journal of Social Theory* **18**(1), 76–92.

Wilson P.M., Kendall S. & Brooks F. (2007) The expert patient's programme: a paradox of patient empowerment and medical dominance. *Health and Social Care in the Community* **15**(5), 426-438.

Wimpenny P. & Gass J. (2000) Interviewing in phenomenology and grounded theory : is there a difference? *Journal of Advanced Nursing* **31**(6), 1485-1492.

Wood, A. M., Froh, J. J. & Geraghty, A. W. (2010) Gratitude and well-being: a review and theoretical integration. *Clinical Psychology Review* **30**(7), 890-905.

World Health Organization (2003) *The Burden of Musculoskeletal Conditions at the start of the New Millennium. Report of a WHO Scientific Group*. World Health Organization, Geneva, Switzerland.

World Health Organization (2005) *Preventing Chronic Diseases: A Vital Investment.* World Health Organization, Geneva, Switzerland.

World Health Organization (2011) *Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants*. World Health Organization, Geneva, Switzerland.

Woźniak M. (2018) “I” and “Me”: The self in the context of consciousness. *Frontiers in Psychology* **9**(1656).

Wuest J. (1995) Feminist grounded theory: an exploration of the congruency and tensions between two traditions in knowledge discovery. *Qualitative Health Research* **5**, 125-137.

Wylie R.C. & Wylie R.C. (1957) Some relationships between defensiveness and self-concept discrepancies. *Journal of Personality* **25**(5), 600-616.

Xu N., Zhao S., Xue H., Fu W., Liu L., Zhang T., Huang R. & Zhang N. (2017) Associations of perceived social support and positive psychological resources with fatigue symptom in patients with rheumatoid arthritis. *PLoS ONE* **12**(3), e0173293.

Yan A. & Davis P. (1990) Gold induced marrow suppression: a review of 10 cases. *The Journal of Rheumatology* **17**(1), 47-51.

Yezdani O., Sanzogni L. & Poropat A. (2015) Theory of emergence: introducing a model-centred approach to applied social science research. *Prometheus* **33**(3), 305-322.

Zangi H.A., Mowinckel P., Finset A., Eriksson L.R., Høystad T., Lunde A.K. & Hagen K.B. (2012) A mindfulness-based group intervention to reduce psychological distress and fatigue in patients with inflammatory rheumatic joint diseases: a randomised controlled trial. *Annals of Rheumatic Disease* **71**(6), 911-917.

Zeidner M., Roberts R. & Matthews G. (2008) The science of emotional intelligence: current consensus and controversies. *European Psychologist* **13**, 64-78.

Zhang K., Hannan E., Scholes-Robertson N., Baumgart A., Guha C., Kerklaan J., Hanson C.S., Craig J.C., Davison S.N., Hecking M. & Tong A. (2020) Patients' perspectives of pain in dialysis: systematic review and thematic synthesis of qualitative studies. *PAIN* **161**(9), 1983-1994.

Zhou B., Wang G., Hong Y., Xu S., Wang J., Yu H., Liu Y. & Yu L. (2020) Mindfulness interventions for rheumatoid arthritis: a systematic review and meta-analysis. *Complementary Therapies in Clinical Practice* **39**, 10168.

Zimmerman M.A. (1995) Psychological empowerment: issues and illustrations. *American Journal of Community Psychology*, **23**(5), 581-599.

Zuidema R.M., Repping-Wuts H., Evers A.W., Van Gaal B.G. & Van Achterberg T. (2015) What do we know about rheumatoid arthritis patients' support needs for self-management? A scoping review. *International Journal of Nursing Studies* **52**(10), 1617-24.

Appendix 1

University Learning in a Unique College Environment

St. Angela's College, Sligo
Coláiste San Aingeal, Sligeach
A College of NUI Galway

Lough Gill, Co Sligo, Ireland
T: +353 (0)71 91 43580
F: +353 (0) 71 91 44585
E: admin@stangelas.nuigalway.ie
www.stangelas.nuigalway.ie

Dear Sir/Madam,

This letter is being given to you on my behalf by the receptionist in the Rheumatology Unit which you attend.

I am a nurse and I am doing a study on Rheumatoid Arthritis. You may not know that in Ireland no study has looked at what life is like with Rheumatoid Arthritis. I want to find out what it is like to live with Rheumatoid Arthritis. So I am inviting you to be part of this important study. I am inviting other people also. The attached document will give you more information about the study. The study has been approved by the Research Ethics Committee and by the Rheumatology consultants in the Rheumatology Unit, Our Lady's Hospital, Manorhamilton, Co. Leitrim.

I do hope you will consider being part of this important study. I think it is important that people know what it is like to live with Rheumatoid Arthritis in Ireland.

Thank you for taking the time to read this letter and the attached information sheet.

It is important that you understand that you do not have to be part of the study and your care in the Unit will not be affected in any way.

Next steps

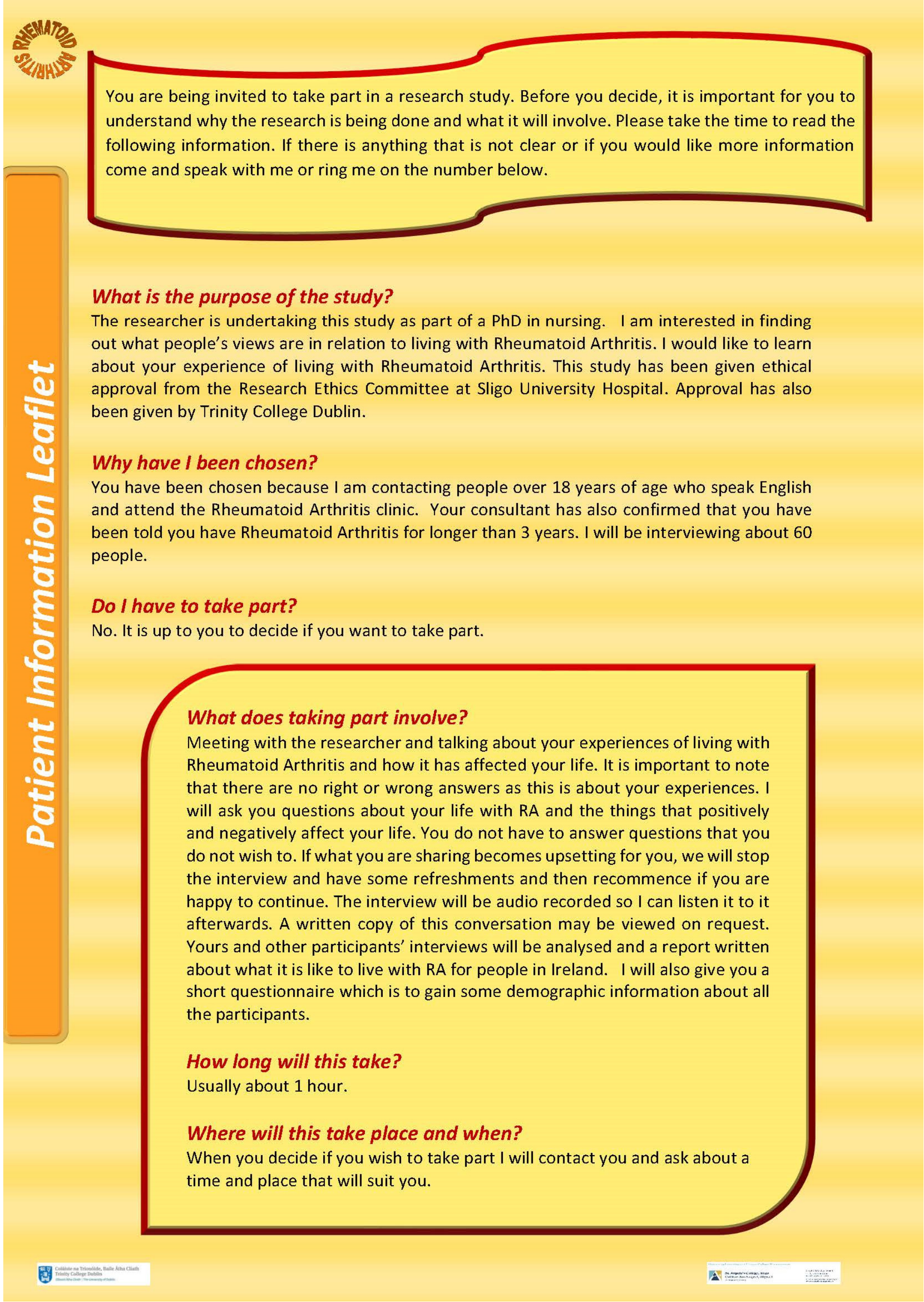
- **Read the information sheet and decide if you wish to take part in this study.**
- **If you have time, I am available in the waiting area to answer any questions that you have.**
- **Contact me at the phone number email address if you have any questions or if you want to take part.**
- **If you decide to take part, a convenient date, time and location for the interview will be arranged.**

I wear a name badge which has Evelyn, Researcher on it. Alternatively, you can ring me on the contact number on the attached sheet.

Yours Sincerely,

Evelyn McManus

Appendix 2



RHEUMATOID ARTHRITIS

Patient Information Leaflet

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information. If there is anything that is not clear or if you would like more information come and speak with me or ring me on the number below.

What is the purpose of the study?

The researcher is undertaking this study as part of a PhD in nursing. I am interested in finding out what people's views are in relation to living with Rheumatoid Arthritis. I would like to learn about your experience of living with Rheumatoid Arthritis. This study has been given ethical approval from the Research Ethics Committee at Sligo University Hospital. Approval has also been given by Trinity College Dublin.

Why have I been chosen?

You have been chosen because I am contacting people over 18 years of age who speak English and attend the Rheumatoid Arthritis clinic. Your consultant has also confirmed that you have been told you have Rheumatoid Arthritis for longer than 3 years. I will be interviewing about 60 people.

Do I have to take part?

No. It is up to you to decide if you want to take part.

What does taking part involve?

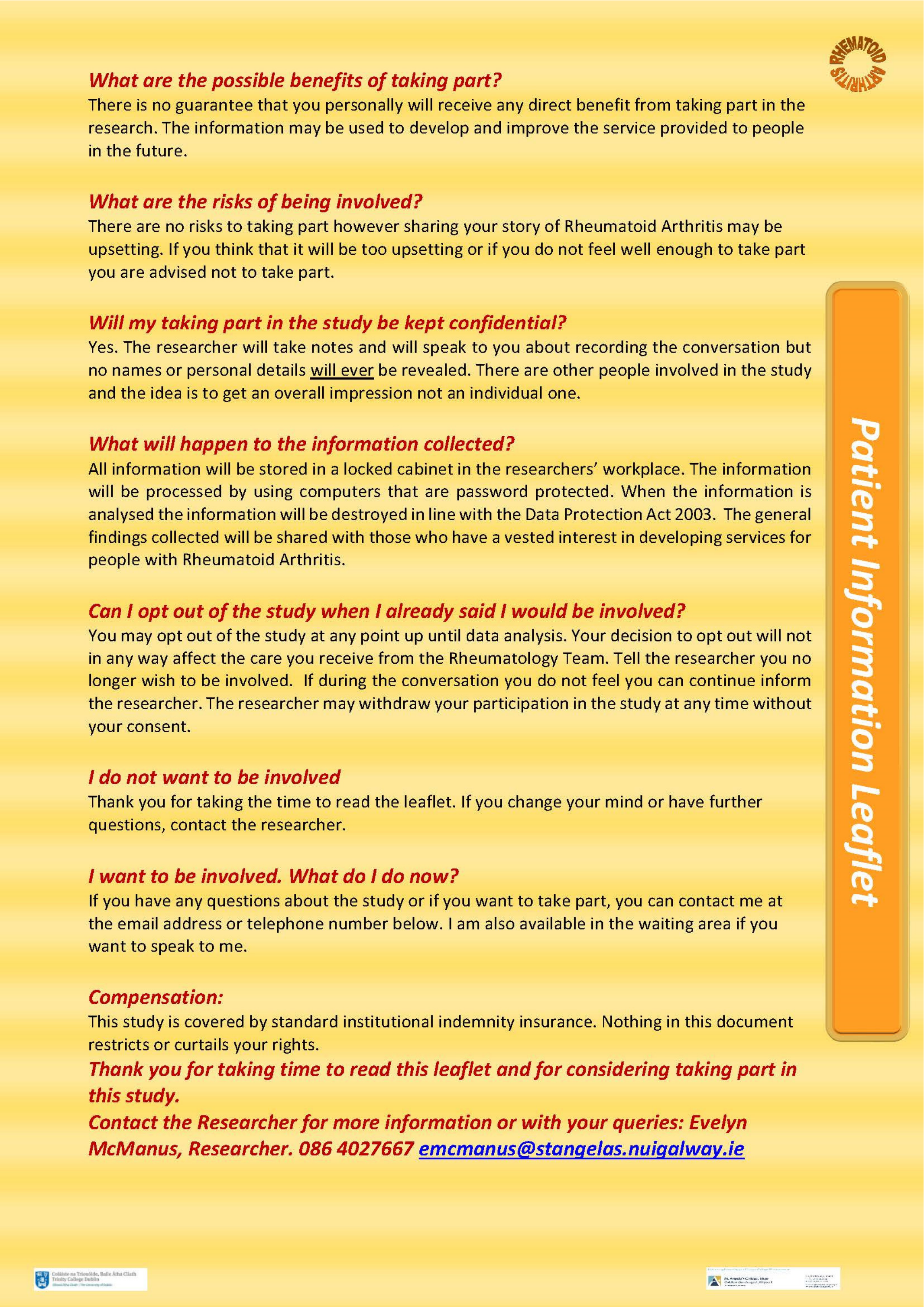
Meeting with the researcher and talking about your experiences of living with Rheumatoid Arthritis and how it has affected your life. It is important to note that there are no right or wrong answers as this is about your experiences. I will ask you questions about your life with RA and the things that positively and negatively affect your life. You do not have to answer questions that you do not wish to. If what you are sharing becomes upsetting for you, we will stop the interview and have some refreshments and then recommence if you are happy to continue. The interview will be audio recorded so I can listen it to it afterwards. A written copy of this conversation may be viewed on request. Yours and other participants' interviews will be analysed and a report written about what it is like to live with RA for people in Ireland. I will also give you a short questionnaire which is to gain some demographic information about all the participants.

How long will this take?

Usually about 1 hour.

Where will this take place and when?

When you decide if you wish to take part I will contact you and ask about a time and place that will suit you.



RHEUMATOID ARTHRITIS

What are the possible benefits of taking part?

There is no guarantee that you personally will receive any direct benefit from taking part in the research. The information may be used to develop and improve the service provided to people in the future.

What are the risks of being involved?

There are no risks to taking part however sharing your story of Rheumatoid Arthritis may be upsetting. If you think that it will be too upsetting or if you do not feel well enough to take part you are advised not to take part.

Will my taking part in the study be kept confidential?

Yes. The researcher will take notes and will speak to you about recording the conversation but no names or personal details will ever be revealed. There are other people involved in the study and the idea is to get an overall impression not an individual one.

What will happen to the information collected?

All information will be stored in a locked cabinet in the researchers' workplace. The information will be processed by using computers that are password protected. When the information is analysed the information will be destroyed in line with the Data Protection Act 2003. The general findings collected will be shared with those who have a vested interest in developing services for people with Rheumatoid Arthritis.

Can I opt out of the study when I already said I would be involved?

You may opt out of the study at any point up until data analysis. Your decision to opt out will not in any way affect the care you receive from the Rheumatology Team. Tell the researcher you no longer wish to be involved. If during the conversation you do not feel you can continue inform the researcher. The researcher may withdraw your participation in the study at any time without your consent.

I do not want to be involved

Thank you for taking the time to read the leaflet. If you change your mind or have further questions, contact the researcher.

I want to be involved. What do I do now?

If you have any questions about the study or if you want to take part, you can contact me at the email address or telephone number below. I am also available in the waiting area if you want to speak to me.

Compensation:

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

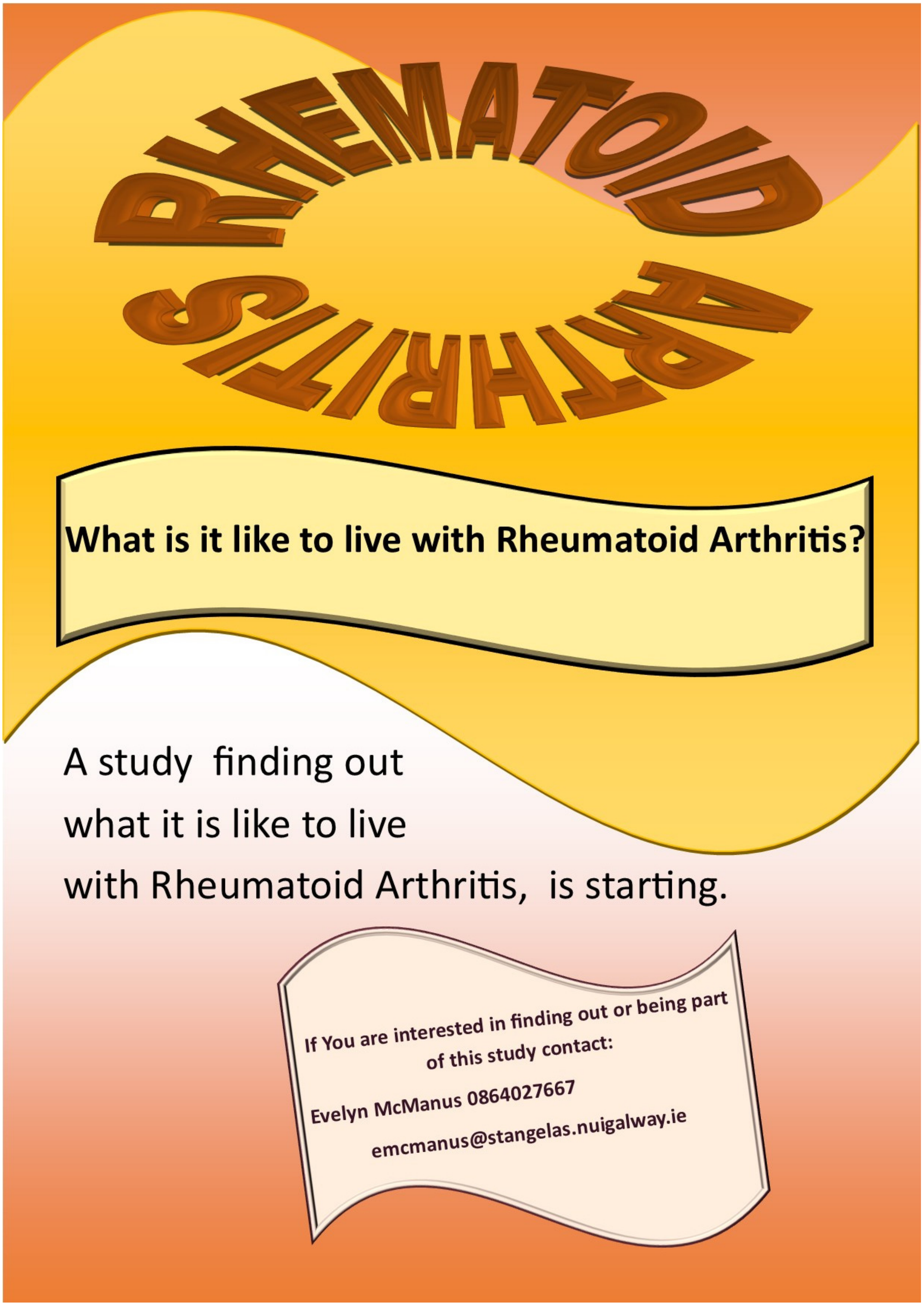
Thank you for taking time to read this leaflet and for considering taking part in this study.

Contact the Researcher for more information or with your queries: Evelyn McManus, Researcher. 086 4027667 emcmanus@stangelas.nuigalway.ie

Patient Information Leaflet

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Appendix 3



RHEUMATOID ARTHRITIS

What is it like to live with Rheumatoid Arthritis?

A study finding out
what it is like to live
with Rheumatoid Arthritis, is starting.

If You are interested in finding out or being part of this study contact:

Evelyn McManus 0864027667

emcmanus@stangelas.nuigalway.ie

Appendix 4

RHEMATOID ARTHRITIS

General Information

Biographical Data Sheet

All information provided will be treated confidentially.

Respond to the questions by ticking the box of filling in the information in the space provided.

1. **What is your gender?** **Female** ☐ **Male** ☐
2. **Which category includes your age?**

   20-30 ☐ **31-40** ☐ **41-50** ☐ **51- 60** ☐ **61-70** ☐ **71-80** ☐ **80+** ☐
3. **Do you: Live alone** ☐ **live with partner spouse** ☐ **live with other family members** ☐
4. **How long have you been living in Ireland?**

All my life ☐ **greater than 10 years** ☐ **5-10 years** ☐ **less than 5 years** ☐

5. **Have you lived in other countries?** **Yes** ☐ **No** ☐
6. **How long have you lived in other countries?**

Country	length of time

7. **How long did you have problems before you went to your Doctor?** ____________
8. **What year were you 1st diagnosed with Rheumatoid Arthritis?** ____________
9. **Are you currently taking any medication for your Rheumatoid Arthritis? Yes** ☐ **No** ☐
10. **What is your current work status?**

Full time work ☐ **Part time work** ☐ **On Leave** ☐ **Unemployed** ☐ **Retired** ☐

11. **What hours do you work on a weekly basis?**

    10-20 ☐ **20-30** ☐ **30-40** ☐
12. What type of work do you do or did you do? ____
13. Do close friends or family know that you have Rheumatoid Arthritis? **Yes** ☐ **No** ☐
14. Do work colleagues know that you have Rheumatoid Arthritis? **Yes** ☐ **No** ☐
15. What principle supports do you use to help you live with your arthritis?

    1. **4.**

    2. **5.**

    3 **6**
16. Do you feel family/friends are supportive toward you? **Yes** ☐**No** ☐

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St. Angela's College, Sligo
Coláiste San Aingeal, Sligeach

Appendix 5

The following memos indicate attempts to identify the main concern

Pillaging 18th March 2018 12:59
The onset of RA - how it just comes I thought of war before - perhaps it is pillaging. Their life and aspects of it has been pillaged - do they go on defensive? - I think sometimes as professionals we think that patients do not accept but what about thinking in another way - their life has been stolen their dreams etc and of course a natural reaction is to defend - to retain what they have. Is the main concern to defend or retain what they have?

5.06.18 Conflict
I am wondering if conflict or confrontation is what they are doing...... Firstly, they are dealing with conflict - they do not want RA - the fight / struggle with it in various ways when they do not win this battle and RA is still in evidence and still need to do this.
They then confront the issues. This happens in enlightenment when they are getting more knowledge and more insights in living - they try out some behaviours - I have called this risk taking. Is the overall theory on managing conflict or confronting?
In the end peace to an extent (or a resolution) is achieved when they dance with frenemy. Or is it just an end to the hostile thinking - they realise that being hostile is damaging them more that it is the RA. cannot seem to get away from frenemy - the word arriving from the comments of the participants.
Interesting though that i am now thinking conflict and confrontation and the word frenemy (being friendly despite having a strong dislike) has been in my mind for nearly a year. Are these features of war or combat?

Main concern memo July 4th 2018
Secreting is very important to all of them. Secreting is about concealing and hiding the fact they have RA and any of the symptoms and hiding the fact that they cannot do something someone else would do - include aspects of work or social or personal life. Is the main concern avoiding being discovered i.e. others knowing they have RA?

Main concern memo 23rd Aug 2018
Secreting is also linked to planning - planning your life well so you can manage. This also sounded like independence but with more comparison it is not independence it is about managing demands well so to lessen or avoid stress- so planning is thinking ahead what will be needed and how it can be managed or completed.

Main concern memo 6th May 2019
The secreting is part of decision making- careful decision making -it also includes selectivity – Is this is a property or dimension of careful decision making?
This is also linked to perception - how they are perceived by others. This changes over time and becomes less relevant. Is secreting their main concern the fear of someone else finding out that they have RA?

Main concern memo May 29th 2019
Secreting is an important part but only a part it is not the main concern. Secreting is one of the strategies they use. The main concern is about fear of limitations or fear of dependence. There is evidence to support maintain or retain independence - this links so much better in the analysis. i think it is to retain independence. To maintain suggests something being done to help to maintain - in the first instance the individual would have to recognise that they have something and possibly appreciate this then would lead to some actions to maintain. Retain on the other hand is to keep hold of - to keep

possession - hold on to - there is a threat with the diagnosis - the very words - they become defensive and start to resist - they are not going to be robbed.
in the data it seems like the very words have strong association with elderly and disability
When it is first diagnosed this is what comes across - the disbelief that something is not right - what they are saying cannot be right as it is conflicting with what they know and they do not view themselves in the old age and infirmity categories of life. They want to retain their independence - keep what they have - do not want to loose this.

Main concern: June 6th 2019 To Retain Independence
The data tells a story of wanting to retain independence but there is evidence in the data of them resisting and fighting against this imposter - do these behaviours indicate fear? i think yes fear and much more than the behaviours indicate retaining so the main concern is fear of future limitations. there is an aspect of wanting to retain what they have but the behaviours do not indicate - they indicate more fear....

Appendix 6

Core Category June 6th 2019

Comparing seems to happen all the way through. Is comparison the way they process their main concern?

When they compare, they recognise the RA the thing that they are not wanting to take their independence? They recognise that they are not as they once were – they gain an understanding about the enemy and realise that if they keep the enemy quiet they have a better life. Is the core category then appeasing frenemy?

Not sure that this fits there is something more

It occurs in stages it seems – a process

Something more is happening – the increasing self-awareness brings more enlightenment to their life – it is more than appeasing frenemy.

The behaviours are about appeasing frenemy, but what then is the conceptualisation of frenemy - what is it overall - dancing with frenemy to a certain extent they are careful to watch the steps of frenemy and listen to the music (what the RA is doing) and they respond to keep in line with their partner. The rhythms change so does frenemy and the person responds. Is appeasing the same as dancing with frenemy - it has similarities. So they appease frenemy but they then change their life the eureka moment where they say ok i keep you quiet BUT i am going to live. is the core more about finding a meaningful life or meaningful living? theory MEANINGFUL LIVING or MEANINGFUL LIFE or deciding to live?

i think it is not appeasing frenemy i think dancing with frenemy is probably better. They learn how to dance with frenemy they are attentive to the music, the moves, the twists and turns they learn what to do and not to do. In the dance you also make mistakes and correct your actions.

Ah now i am thinking that appeasing frenemy is a stage and then they move on to from reappraising - the stage where they look at their life and think revaluate what they do how they think

they then move to appeasing frenemy but to stay in this stage would be succumbing to the enemy - the enemy is in control

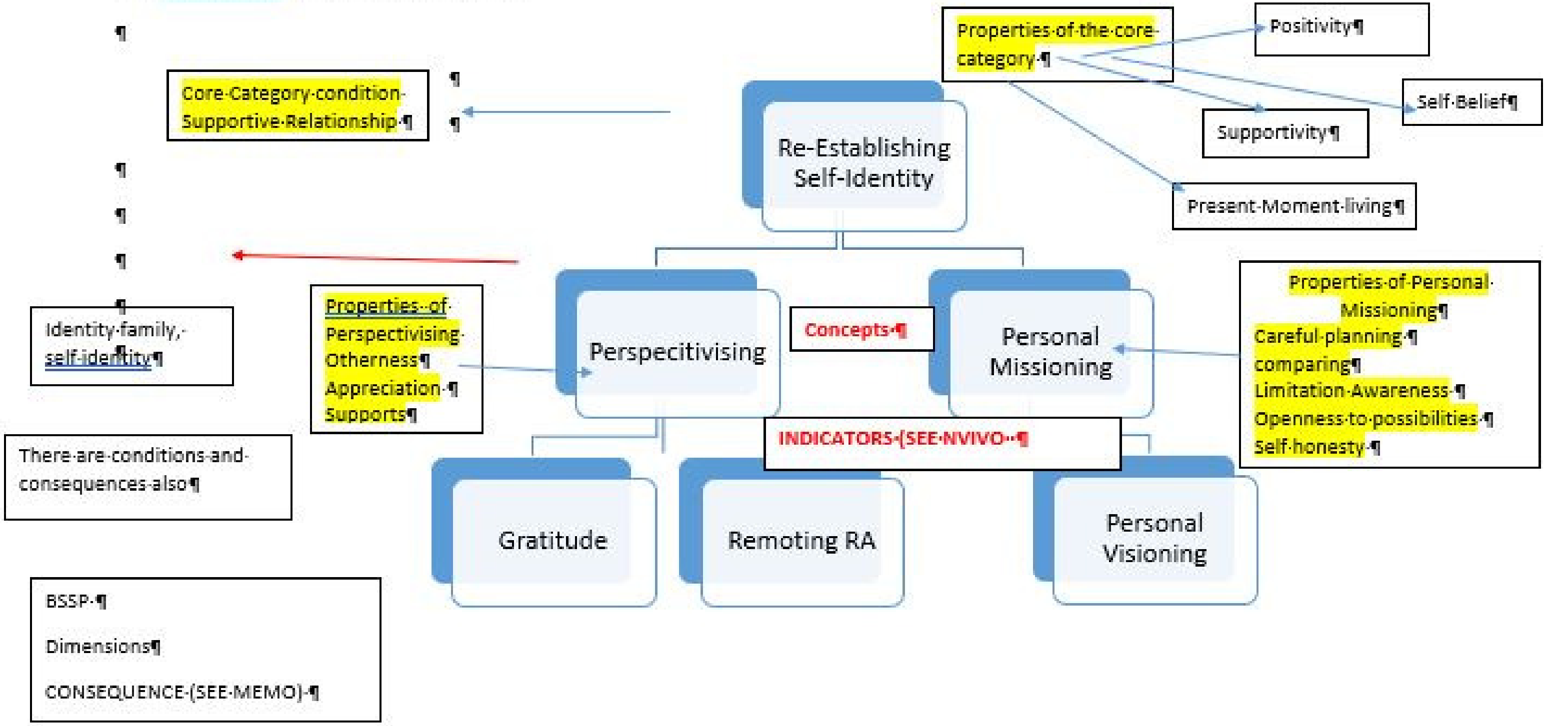
moving to dancing means that they are putting into practice what they have learned - learn new moves what works and what does not - very specific learning - when to get professional help but also what new moves they can learn

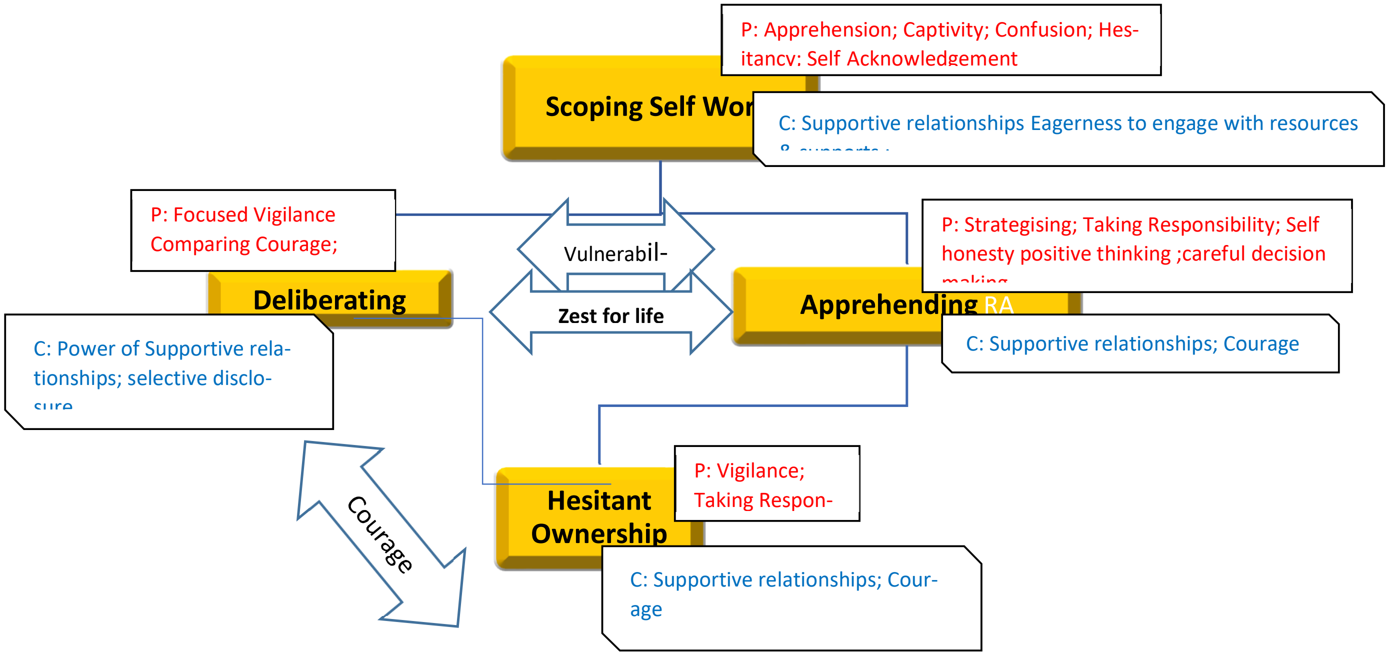
Advancing years is not what matters, it is the threat of increasing limitations/reducing capacity that looms. Is that the context that they are creating for themselves.. threatening?

Appendix 7

Fear of Future Limitations

Core Category Re-Establishing Self Identity





Scoping Self Wor

P: Apprehension; Captivity; Confusion; Hesitancy: Self Acknowledgement

C: Supportive relationships Eagerness to engage with resources & supports ;

P: Focused Vigilance Comparing Courage;

Deliberating

C: Power of Supportive relationships; selective disclosure

Vulnerabil-

Zest for life

P: Strategising; Taking Responsibility; Self honesty positive thinking ;careful decision making

Apprehending RA

C: Supportive relationships; Courage

Courage

Hesitant Ownership

P: Vigilance; Taking Respon-

C: Supportive relationships; Courage

Appendix 8

Research Ethics Committee
Sligo University Hospital
Chairman: Dr.John Williams
Admin: Mette Jensen Kavanagh

Ms. Evelyn McManus
Dept of Nursing, Health Sciences & Disability Studies
St. Angela's College
Lough Gill
Sligo

Jan 20th 2017

Re. Research Ethics Application

Dear Ms McManus,

The Research Ethics Committee (REC) at Sligo University Hospital has reviewed your submission for ethical review of the study "*An Investigation enquiring about the Main Concerns of persons who have Rheumatoid Arthritis in Ireland*".

The study underwent expedited review and the REC Chairman has given a favourable ethical opinion for the study for Sligo University Hospital.

Documents reviewed:

- REC Application Form
- Protocol
- Information Sheet
- Consent form
- Interview guide
- Questionnaire
- Letters to Rheumatology Dept
- PI CV

The REC requires that approved studies submit an annual report to the REC. The annual report for the above study is due on January 25 2018.

Yours sincerely,

Dr. John Williams
REC Chairperson

Mission Statement

Appendix 9

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Evelyn McManus
School of Nursing and Midwifery
Trinity College Dublin
24 D'Olier Street
Dublin 2

13th March 2017

Study title:
An Investigation enquiring about the Main Concerns of persons who have Rheumatoid Arthritis in Ireland.

Dear Evelyn

I am pleased to inform you that the above named study has been granted ethical approval from the deputy Chair of the School of Nursing and Midwifery Research Ethics Committee.

Yours sincerely,

Aileen Lynch

Dr Aileen Lynch
Deputy Chair of School of Nursing and Midwifery Research Ethics Committee

Scoil an Altranais agus an Chnáimhseachais
Dámh na nEolaíochtaí Sláinte,
Coláiste na Tríonóide,
Baile Átha Cliath,
Ollscoil Átha Cliath,
24 Sráid D'Olier.
Baile Átha Cliath 2, Éire.

School of Nursing and Midwifery
Faculty of Health Sciences,
Trinity College Dublin,
The University of Dublin,
24 D'Olier Street,
Dublin 2, Ireland.

+353 1 8962692
nursing.midwifery@tcd.ie
nursing-midwifery.tcd.ie

Appendix 10

University Learning in a Unique College Environment

St. Angela's College, Sligo
Coláiste San Aingeal, Sligeach
A College of NUI Galway

Lough Gill, Co Sligo, Ireland
T: +353 (0)71 91 43580
F: +353 (0) 71 91 44585
E: admin@stangelas.nuigalway.ie
www.stangelas.nuigalway.ie

Informed Consent Form

Research Project Title: An Investigation Enquiring About The Main Concerns of Persons Who Have Rheumatoid Arthritis In Ireland

Principal Investigator: Evelyn McManus

I volunteer to participate in a research project conducted by Evelyn McManus University of Dublin, Trinity College. I understand that the project is designed to gather information about living with Rheumatoid Arthritis. I will be one of approximately 60 people being interviewed for this research.
My participation in this project is voluntary. I understand that I will not be paid for my participation and that I may withdraw and discontinue participation at any time without penalty.
Participation involves being interviewed. The interview will last approximately 1 hour.
The researcher will be making notes during the interview.
I understand that most interviewees will find the discussion interesting and thought-provoking. If, however, I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to end the interview.
An audio recording of the interview will be made. If I don't want to be taped, I will tell the researcher and I will not be recorded. I understand that the researcher will not identify me by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

I understand that this research study has been reviewed and approved by the Ethics Committees of the University of Dublin, Trinity College and the Research Ethics Committee at SUH

DECLARATION:
I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

______________________ ______________________
Signature Date

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

______________________ ______________________
Signature of the Researcher Investigator Date

Appendix 11

Post Study Plan

This plan is not considered to be the step-by-step response or reaction to the findings of this study. The process of facilitating the uptake of the findings requires a practical intelligence and patience. In short it is considering the different audiences and how their curiosity may be peaked and sustained through various media options. The experience of the consequences of the recent pandemic i.e. fear, loneliness may in some ways contribute to the curiosity of others. What is key is using the various multi-media mechanisms to garner and sustain interest and thus make real changes for those who live with the chronic condition of RA. Forming links with others to raise the profile of RA and seek for a deeper understanding and recognition of the condition may be good investment for success. This may involve variously organised groups.

Presentation of findings within current nursing programmes

- Undergraduate
- Postgraduate

Presentation of Report

- Local to North West of Ireland
    - Presentation within the RU
- Arthritis Ireland
    - Summary of report as Podcast on the Arthritis Ireland website
- Presentation to Irish Rheumatology Nursing Forum

Professional conferences

- Annual conference Research and Education Foundation, Sligo 2021
- International Council of Nurses 2023
- Trinity Health and Education International Research Conference 2022
- RCN Education Forum National Conference & Exhibition 2023
- International Conference on Nursing, Self-Care and Chronic Diseases IC-NSCCD on May 17-18, 2022 in London, UK
- The Sociological Association of Ireland conference 2023
- EULAR 2022, the European Congress of Rheumatology 2022
- The International Conference on Rheumatology 2000

Publications:

- Local newspapers – short press release to gain interest
- Local professional publications
- National newspapers
- Professional Journals
    - Nursing Standard
    - Journal of Clinical Nursing
    - Journal of Advanced Nursing
    - European Journal of Public Health
    - International Journal of Caring Sciences
    - Research in Nursing & Health
    - Rheumatology
    - The Grounded Theory Review
    - Nurse Researcher
    - Arthritis Care and Research

Reports for specific professional groups i.e. OMERACT

Specific publications in nursing on the issues of developing and providing psychosocial supports.

Specific Reports

- Key people in the policy division in the DoH
- Meetings with key influential people in the DoH

Develop multimedia presentations for presenting to the wider public arena and link to different social media platforms
Develop stronger links with Arthritis Ireland identifying possibilities for further studies and collaboration with others
Develop relationships with others to influence a whole population information on RA
Develop a series of public engaging activities
Seek funding to support publication and also for further study e.g. the interventions of most benefit to individuals with a chronic condition.
Develop educational courses or units on specific psychosocial interventions.