Exploring the Impact of Fatigue on Work Ability of People with Rheumatic Diseases.

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Coláiste na Tríonóide, Baile Átha Cliath
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HOSPITAL
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Table 1: Abbreviation list

ANOVA	Analysis of variance
AWS	Arthritis Work Spill-over
AS	Ankylosing Spondylitis
EQ5D-VAS	EQ-5D Visual Analogue Scale
MFI or MFI-20	Multidimensional Fatigue Inventory
MFIGF	MFI General Fatigue Subscale
N=	Number of participants
NDA	National Disability Authority
NVIVO	Nudist Vivo version 10 (NVivo) software analysis for qualitative data
OA	Osteoarthritis
p	p-value or probability value
PMR	Polymyalgia Rheumatica
PsA	Psoriatic Arthritis
PtGA	Patient Global Assessment of Disease Activity
r	Rho or pearson product-moment correlation coefficient
RA	Rheumatoid Arthritis
SLE	Systemic Lupus Erythematosus
SSc	Systemic sclerosis
SPSS	Statistical Package for Social Sciences
±SD	±Standard Deviation
Statistical Significance	p-value
WRF	Work Role Functioning Questionnaire
WRFWSD	Work Role Functioning Work Scheduling Demands
WRFOD	Work Role Functioning Output Demands
WRFPD	Work Role Functioning Physical Demands
WRFMD	Work Role Functioning Mental Demands
WRFSD	Work Role Functioning Social Demands

Executive Summary

Rheumatic diseases such as arthritis are one of the leading costs of work disability throughout the western world. In Ireland, the cost of lost productive time for those with Rheumatoid Arthritis has been estimated at €1.6 billion (Arthritis Ireland, 2008). The Employment Equality Acts 1998-2011 outline the legal obligations employers have to reasonably accommodate employees with a disability. Fatigue is reported in up to 90% of people with rheumatic diseases and therefore must be considered in any study of work disability and productivity (Norheim et al., 2011). This study, which was funded by the National Disability Authority, was carried out to explore the impact of fatigue in people with a rheumatic disease. The specific aims of the study were to:

- Examine the impact of fatigue on work-related activities for those with rheumatic diseases.
- Examine the impact of fatigue on the interrelationship between arthritis and work.
- Explore people’s experiences of the impact of fatigue on their work ability
- Investigate the range of strategies used by people in the work place to manage their fatigue

The majority of people in the study have Rheumatoid Arthritis, are working fulltime in non-manual jobs, in the private sector or self-employed. The average level of disease activity was 4.66 out of a maximum of 10. Those with higher levels of disease activity also have higher levels of fatigue, have more difficulties in work and lower quality of life. This indicates that disease activity interferes with many aspects of a person’s life. Age was related to work performance with the younger participants having significantly more difficulties in work. Perhaps older participants have reduced their work hours, changed jobs or have developed strategies manage the demands of their work. This indicates the importance of early interventions to assist those with a newly diagnosed rheumatic disease to manage work effectively.

The majority of respondents were female. On comparison with the male participants, the female participants had significantly higher levels of fatigue, significantly more difficulty managing the majority of their work demands, and reported lower quality of life. Those with third level education reported significantly more difficulty with the mental and social aspects of their work than those who achieved up to second level education, however the reasons for this are unclear.

Work characteristics have an impact on study participants’ disease, fatigue and quality of life. Those working part-time have significantly higher disease activity than their full time counterparts. They also have significantly higher levels of fatigue in the majority of fatigue domains. Although not significant, they had more difficulty meeting the demands associated with their work. The exception to this was that full-time workers have significantly more difficulty with the physical demands of work. Further studies are required examining other characteristics of part-time workers that might explain these differences.

The majority of study participants have severe fatigue with physical fatigue being the most problematic. In the qualitative phase some participants identified a pattern to their fatigue while others reported no discernible pattern and described their fatigue as unpredictable. This unpredictability makes fatigue more difficult to manage.

Those with severe fatigue have significantly more difficulty fulfilling the demands of their work, their arthritis impacts more severely on their work and vice versa, and they have a lower quality of life. This demonstrates the debilitating nature of fatigue for people with rheumatic diseases and how it impacts on a range of work activities. In the qualitative phase of the study, participants discussed how fatigue also causes cognitive difficulties in work which leads to emotional problems. There are a range of fatigue management strategies that could be implemented in the workplace including prioritising work activities, pacing activities across the day and the week, making ergonomic changes to work stations and taking short breaks throughout the day. The participants in this study also recommended that employers and co-workers are educated on fatigue in rheumatic diseases and how it differs from regular fatigue. Health professionals have a role to play in providing such education.

Just under half of participants reported moderate or extreme anxiety/depression. This could be related to many factors such as having a diagnosis of a chronic disease; experiencing pain and fatigue, or having difficulty balancing the management of the symptoms of their disease with meeting the demands of their work. Some of the participants in the qualitative phase of the study discussed difficulty telling their employers about their diagnosis as they feared this would impact on the security of their jobs or promotional opportunities, although such discrimination would be illegal under the Employment Equality Acts. It is vital that employers appreciate the importance of creating an environment that facilitates those with rheumatic diseases to feel safe in disclosing their diagnosis. Otherwise this could ultimately impact on employees’ mental health which will increase absenteeism in the workplace.

In this study 40% of participants reported having multi-morbidity. That is they have at least one other chronic disease in addition to their rheumatic disease. In comparison to those without any other chronic condition, those with multi-morbidity have

- significantly higher levels of fatigue,
- significantly more difficulty in fulfilling work-related demands,
- their arthritis impacts more severely on their work; and
- they have significantly lower quality of life.

These findings demonstrate the consequences of multi-morbidity within and outside the workplace. This indicates the need for early identification of people with multi-morbidity as they appear to be at higher risk for work-related difficulties.

Conclusion

Fatigue is a pervasive symptom of rheumatic diseases and it impacts on many elements of work performance. Those with severe fatigue have significantly more difficulty in work than those without severe fatigue and they also have a lower quality of life. Employers therefore need to accommodate employees with severe fatigue to enable them to meet the demands of their work. Interventions are required early in the disease trajectory to assist people to effectively manage fatigue related to Rheumatic diseases.

1. Introduction

Rheumatic diseases are common in the general population. They are painful conditions usually caused by inflammation, swelling, and pain in the joints or muscles. Examples of rheumatic diseases include Osteoarthritis, Rheumatoid Arthritis, Ankylosing Spondylitis and Systemic Lupus Erythematosus. Some rheumatic diseases like osteoarthritis occur as result of ‘wear and tear’ to the joints. Other rheumatic diseases, such as Rheumatoid Arthritis, are believed to be caused by an autoimmune reaction whereby the immune system attacks the linings of joints, causing joint pain and swelling. Due to the range of symptoms in rheumatic diseases, all aspects of a person’s life can be affected.

Rheumatic diseases are one of the main causes of physical disability, contribute to societal and economic costs and lead to loss of productivity in the workplace (Bevan et al, 2009). They are also one of the leading costs of work disability throughout the western world. In Ireland, the cost of lost productive time for those with Rheumatoid Arthritis was estimated at €1.6 billion (Barlow et al., 2001). Barlow et al., (2001) explored preventing work disability in people with rheumatologic diseases and reported that anxiety, depression and negative mood increased in those not fulfilling their full employment potential. Higher levels of pain and depression have been found in people with rheumatologic diseases when they are experiencing instability in employment (Barlow et al., 2001). A European wide ‘Fit for Work’ study investigated the impact of musculoskeletal disorders (MSD), including Rheumatoid Arthritis(RA) and Ankylosing Spondylitis (AS), on work loss of Irish workers and estimated that MSD’s cost in the region of €750m (Bevan, Magee and Quadrello, 2009). They also estimated that unemployment rates for people with AS are three times higher than the general population.

Research has found that work gives people a sense of identity, a role in society and a sense of independence (Boonen et al., 2001). Work provides purpose to a person’s daily activities, gives people the opportunity to be productive, provides financial support to themselves and their families and provides regular social interactions. In addition, work can be a distraction from health problems and can even give a person the chance for regular physical exercise that helps minimise symptoms of the condition (Gignac et al., 2014). Therefore, when people are unemployed or they are finding it difficult to participate at work, their psychological well-being may be affected and research has found that depression and poor self-esteem are associated with unemployment (Dooley et al., 2000).

Fatigue is reported to affect up to 90% of people with rheumatic diseases and must be considered in any study of work disability and productivity (Norheim et al., 2011). An improved understanding of the connection between a person’s life, work, rheumatic disease and fatigue, can assist in identifying individuals at risk of difficulty with maintaining employment. This information will also help health professionals to make recommendations for clients on how to manage their rheumatic diseases in the workplace (Gignac et al., 2014). Gignac et al., (2014) identified research priorities for rheumatic diseases. These included a need for further exploration of factors and symptoms that impact on work performance in the workplace and that limit and/or improve work outcomes.

2. Context of the Research

2.1 Societal and Economic Cost

Rheumatic diseases are one of the main causes of work disability in people of working age in Ireland. Each year in Ireland seven million working days are lost due to symptoms of rheumatic diseases. This results in a €750 million cost to the economy (Bevan et al., 2009). Work disability has been found to be more prominent in those with Rheumatic diseases than in the general population (Barrett et al., 2000). For example Boonen et al. (2001), found that people with Ankylosing Spondylitis (AS) are three times more likely to withdraw from work than the general population. Fit for Work is a pan-European project which has a particular focus on supporting people with musculo skeletal disorders, including arthritis and other rheumatic conditions to get back to and continue in employment.[1]

2.2 Irish employers' rights and responsibilities

The Employment Equality Acts (1998-2011) apply to all employees (full, part-time and temporary) in the public and private sector. The key legal provisions are:

- Employers must not treat employees less favourably in employment, training or promotion as a result of their disability. Dismissal is not permitted unless an employee cannot meet the essential duties of the job
- By law a person with a disability is considered fully competent and capable of undertaking any duties, if the person would be fully competent and capable when reasonably accommodated by the employer
- Employers must take 'appropriate measures' to meet the needs of people with disabilities in the workplace, except if in doing so, a 'disproportionate burden' is imposed on the employer.

'Appropriate measures' are helpful and practicable actions employers should choose to suit workers with a disability (Equality Authority, 2011). The overall objectives of appropriate measures are to ensure the person with a disability is regarded equally as other employees when applying for work, in work and when applying for promotions or training. Some examples of appropriate measures are:

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[1] http://www.fitforworkeurope.eu/research.htm

- Adjust premises and equipment such as ergonomic seating and equipment at a desk space
- Flexible working hours
- Allocate work activities to suit workers with disabilities
- Provide training and other resources that might help recovery or transition back to work.

'Disproportionate burden' is unreasonable pressure, either financially or due to the size of the business, on employers who are trying to carry out 'reasonable accommodations'. However, before employers can claim 'disproportionate burden' they must enquire about obtaining public funding or grants which may provide the extra assistance needed to make the accommodations possible (Equality Authority, 2011). The National Disability Authority in Ireland has published good practice guidelines for employers on how to retain and support employees with disabilities in the workplace. They suggest that employers have clear written policy to include the following reasonable accommodations:

- Provide early intervention to help employees with disability remain in employment after absence from work
- Keep in touch when an employee is absent from work
- Provide employees with an assessment of work ability before return to work
- Make a plan for returning to work
- Discuss with employees what supports they need put in place before their return to work
- Give employees an option for phased return to work
- Discuss with employee what they would like to tell their colleagues about their condition
- Inform and educate line managers on appropriate supports their colleague now needs
- Encourage persons with a disability to continue to pursue career goals
- Monitor work performance against career goals
- Offer redeployment to a suitable vacancy when someone is unable to do their job anymore.

Rheumatic diseases can present a number of challenges for those in paid employment. There are many symptoms of the disease including pain and fatigue that contribute to these challenges. However, employers are legally obliged to reasonably accommodate workers who experience these challenges. Therefore, this study aims to explore work-related challenges related to symptoms of Rheumatic diseases and the reasonable accommodations that people with Rheumatic diseases need to get from employers to maintain productivity levels in the workplace.

3. Literature Review

3.1 Introduction

This brief review of the literature discusses the impact of Rheumatic diseases on the ability to work with a specific focus on the impact of fatigue on work ability.

The term Rheumatic diseases covers over 100 various conditions such as Rheumatoid Arthritis (RA), and Osteoarthritis (OA) and other auto-immune conditions such as Ankylosing Spondylitis (AS), and Spondyloarthropies, Systemic Lupus Erythematosus (SLE), Fibromyalgia and Systemic Sclerosis (SSc) (Sangha, 2000). In Ireland approximately 915,000 people have a Rheumatic disease with RA, OA and Fibromyalgia being the most common (Arthritis Ireland, 2013). A worldwide report on prevalence of arthritis and rheumatism found the prevalence of OA to be between 8-16.4%, RA between 1-6%, Ankylosing Spondylitis to be between 0.1-0.5% and autoimmune conditions such as SLE SSc and Sjögren's to be between 0.1-0.5% (Wong et al., 2010).

Dadoun et al. (2014) carried out a study on 813 people of working age with newly diagnosed Rheumatoid arthritis (RA). They found that work productivity is affected negatively in the first three years after diagnosis. Also identified from this study was that absence from work, along with poor physical and mental health, can result in reduced work productivity. A study by Barlow et al, (2001), with 133 people with Ankylosing Spondylitis (AS) found that work loss and disability can lead to loss of identity, lower or depressed mood and lower self-esteem.

3.2 Challenges in work

Research has found that Rheumatic diseases are one of the most common chronic conditions to affect a person's ability to remain in paid employment (Burton et al., 2006). Work disability and loss are related to the challenges that people with Rheumatic diseases have in the workplace. These challenges can be related to three areas: Firstly, some symptoms associated with Rheumatic diseases such as fatigue and pain can pose issues for people in work with regards to productivity levels and absenteeism. Secondly, challenges occur related to being fully able to participate in work activities due to the symptoms. Some people experience particular challenges within their work environments and issues with other colleagues. Finally, challenges occur in relation to the emotional impact of work disability on the person with the Rheumatic disease (Lacaille et al., 2007, Gignac et al., 2011).

A study by De Croon et al. (2005) on work ability of 78 employees with early RA found that predictors of low work ability include fatigue, use of manual strength at work, and a lack of support, autonomy and participation in decision making. Another qualitative study by Lacille et al, (2007) identified fatigue as the main symptom of arthritis that caused the most difficulty at work. Participants identified a lack of awareness of colleagues and employers of fatigue due to it being an invisible symptom. This made it more difficult for people with arthritis to disclose information about fatigue and identify accommodations they may need. Therefore it was recommended that fatigue in the workplace needs to be addressed through medical and employment interventions such as medications that can help reduce fatigue levels and education on self-management strategies to cope with fatigue in work.

3.3 Work disability in rheumatic diseases

Work disability is prevalent in those with rheumatic diseases and has substantial costs from a personal, societal and economic view (Bevan et al., 2009). Work disability in Rheumatic diseases is a multidimensional concept that encompasses more than just employment, it includes: reduction in employed hours, loss of prospects of being promoted, more frequent use of sick leave, increased employment changes and early retirement (Allaire et al., 1996). Learner et al., (2002) found that Osteoarthritis is the leading cause of work disability in adults (Lerner et al., 2002). Similarly, research into work disability in RA has found that people with RA are more likely to discontinue work than the overall population (Barrett et al., 2000).

A 10-year longitudinal study of 1,235 people with early RA reported that pain and fatigue (low vitality) predicted work loss (McWilliams et al., 2014). Tillett et al., (2015) conducted a large multicentre UK study into factors that influence work disability in people with Psoriatic Arthritis (PsA). Three hundred and eighteen participants were assessed in the study of which 26% were unemployed. They identified that work disability was correlated with older age, disease duration of 2 to 5 years and poorer physical ability. Previous research also investigates how fatigue impacts on work disability in people with PsA (Wallenius et al., 2009). A similar study carried out by Barlow et al., (2001), into work disability in Ankylosing Spondylitis (AS) found that fatigue was one of the main challenges contributing to work disability for people with AS. The impact of fatigue on work for the study participants also filtered into other areas of their lives such as home, family and leisure activities. This shows that fatigue in the workplace is a multi-dimensional issue affecting a variety of areas in people’s lives.

Bevan, McGee and Quadrello (2009) carried out a study in Ireland as part of the European Fit for Work study examining the impact of musculoskeletal disorders (MSD) on work ability. MSDs include regional pain such as back pain, joint and limb pain. They also included people with Rheumatoid Arthritis (RA) and Ankylosing Spondylitis (AS). They reported that MSDs can impact on endurance, cognitive abilities and mobility in work and that this can severely affect a person’s ability to remain in work. Loss of work results in financial and psychological difficulties for people. Bevan, Magee and Quadrello (2009) therefore recommend a biopsychosocial model to support those with MSDs to remain in the workforce.

Baker and Pope (2009) identified that 32.4% of those with Systemic Lupus Erythematosus are work disabled due to psychosocial difficulties and symptoms of disease such as fatigue. They recommended further research into the impact of work disability on the person and possible interventions to help in the workplace (Baker and Pope, 2009). Previous research into work ability in women with Fibromyalgia and Systemic Sclerosis has found that greater work ability was associated with better ability to perform daily activities, increased satisfaction with ability to engage in activities, improved well-being and health (Sandqvist et al., 2008). Research in Trinity College Dublin found that work is an important and valued activity for people with SSc and that fatigue was one of the main issues that affected work ability along with effects on skin, pain and breathlessness (Mowlds et al., 2013). Therefore, further research is required to clarify barriers and facilitators to remaining in employment and the accommodations made by employers for people with a range of Rheumatic diseases.

3.4 Impact of fatigue on work

Fatigue is part of the inflammatory or disease process of the majority of rheumatic diseases (Norheim et al., 2011). Fatigue is one of the main predictors of challenges to work in rheumatic diseases and also is a factor in limiting people while in work (Gignac et al., 2006, Arthritis Ireland, 2008). Gignac et al. (2014), found that up to now there has been little research carried out into possible interventions related to the impact of fatigue on work and challenges to activity participation in work. Therefore, there is a gap in the knowledge on challenges people with Rheumatic diseases may have in managing fatigue in the workplace and if fatigue is a reason for giving up work temporarily or permanently. Even though OA is one of the most commonly diagnosed rheumatic diseases, recent research has found that fatigue in OA is not regularly evaluated in practice or in research (Power et al., 2008).

A Canadian study by Gignac et al, (2014), on 352 participants with a rheumatic disease found that fatigue can make it more difficult for a person to manage work, a family and social life balance. However, previous research has found that most people with RA do not discuss the impact of their fatigue with their health professionals because they either just accept it as a consequence of their RA or they feel it’s not addressed by health professionals (Repping-Wuts et al., 2008). Similar findings on communication of fatigue during medical appointments was found by Feldthusen et al. (2013) which left patients taking charge of managing their fatigue themselves. Therefore, there is a need to identify what specific challenges people with rheumatic diseases experiencing fatigue have in the work place, what they are currently doing to accommodate these challenges and what areas they would like strategies to help with work ability.

3.5 Conclusion

Rheumatic diseases impact on work ability, performance in work and contribute to loss of work. This is mainly due to the symptoms of the condition, with fatigue emerging as a symptom that impacts on all areas of life but particularly work. However, how exactly and what areas in particular people are having difficulties with are not yet defined. Therefore, research is needed to understand how different symptoms of rheumatic diseases particularly fatigue, affect work ability and performance.

4. Methodology

4.1 Study aims and objectives

The main aim of the study was to explore the perceptions of people with rheumatic diseases of the impact of fatigue on work ability.

The study objectives were to:

- Examine the impact of fatigue on work-related activities for those with Rheumatic diseases.
- Examine the impact of fatigue on the interrelationship between arthritis and work.
- Explore people's experiences of the impact of fatigue on their work ability.
- Investigate the range of strategies used by people in work to manage their fatigue.

4.2 Study design

A sequential exploratory mixed methodology approach was used in this study (Creswell and Plano Clark, 2011). Quantitative data were gathered using self-report questionnaires followed by semi-structured interviews and focus groups to generate qualitative data. The data from both approaches were analysed separately (Corcoran, 2006).

4.3 Data collection

Sampling

Two recruitment methods were utilised in this study. The primary method of recruitment was through weekly rheumatology clinics in St. James's Hospital. Participants were also recruited through the distribution of an online survey via arthritis-related voluntary organisations. The online survey was used in order to attempt a wide geographical representation beyond the catchment area of St. James's Hospital which typically deals with people in the greater Dublin area.

The inclusion criteria were that participants:

- had a definite diagnosis of a Rheumatic disease
- were between the ages of 18 and 65 years of age
- were currently in paid employment.

In relation to recruitment in the weekly rheumatology clinics, every person who attended the clinic and met the first two inclusion criteria were provided with a Participant Information Leaflet explaining the purpose of the study and what was involved in participating in the study. Those who agreed to participate in the study then approached the researchers who were present at the clinics and were provided with the questionnaires. On completion of the questionnaires, respondents were invited to participate in a focus group or interview which were held on a different day and arranged to suit respondents’ schedules.

Participants were also recruited through the distribution of an online survey by voluntary organisations for those with rheumatic diseases. The following organisations distributed the survey to their members:

- Arthritis Ireland
- Scleroderma Ireland
- Lupus group Ireland.

The diagnosis of all participants who attended the outpatient rheumatology clinics was confirmed by a chart audit, however it was not possible to confirm a diagnosis for those who were recruited via the online survey as all diagnoses for these participants were self-reported.

Recruitment Process

The recruitment process took place through two sources. The first was through St. James’s Hospital. Recruitment here took place over a 15 week period. During this time, 814 people attended the weekly clinics in St James’s Hospital. Of these 543 met the age and diagnosis criteria. Of these, 196 completed questionnaires and were currently working or had worked in the past 24 months giving a 36% response rate.

The second source of recruitment was through online questionnaires advertised through voluntary organisations for rheumatic diseases. One hundred and one participants accessed the online questionnaire, of these 86 completed the questionnaire. As the survey was distributed online via voluntary organisations it is not possible to determine the numbers of individuals the survey was distributed to in order to calculate a response rate. Table 2 shows a demographic comparison of the two groups.

Table 2: Comparison of St. James' and online survey group
(a) demographics

Recruitment group	St. James' Hospital		Online Survey	
	No.	%	No.	%
Age				
18-30	12	6%	17	20%
31-40	50	26%	32	37%
41-50	55	28%	27	31%
51-60	60	31%	8	9%
61-67	19	10%	2	2%
Gender				
Male	88	44%	5	6%
Female	108	56%	81	94%
Duration of disease				
Up to 5 years	76	39%	36	42%
6-10 years	56	29%	21	24%
10 years +	61	31%	29	34%
Did not say	3	2%	0	0%
Work hours				
Full-time	131	67%	53	62%
Part-time	52	27%	33	38%
Did not say	13	7%	0	0%
Job type				
Non-manual work	80	41%	59	69%
Mixed work	71	36%	25	29%
Manual work	36	18%	2	2%
Did not say	9	5%	0	0%

(b)Mean scores on different instruments

Instrument	Mean	SD	Mean	SD
Multi-dimensional Fatigue Inventory (MFI) - General fatigue	12.5	±4.1	16.5	±3.2
Work Role Functioning (WRF)	45.3	±17.9	63.8	±19.2
Arthritis Work Spill-over (AWS)	17.3	±6.1	22.0	±5.3
EQ-5D-VAS	63.7	±18.5	43.4	±19.0

Overall 282 people completed questionnaires. Of these 234 participants were currently working and 48 had been working in the last 24 months but were not currently working.

In terms of the qualitative phase, 62 respondents from the St. James' weekly rheumatology clinics provided contact details to participate in a focus group. Of these, contact was made with thirty-one people, with 11 individuals agreeing to participate. Ten people attended four focus groups and one person took part in an individual interview.

Forty-seven respondents of the online survey provided contact details. Contact was made with fourteen of these respondents. Of these, seven individuals agreed to participate with three people attending a focus group and four people participated in an individual interview. In total, 18 people took part in the qualitative phase of the study.

4.4 Data collection methods

Five questionnaires were used to collect quantitative data:

- A short demographic questionnaire designed by the research team
- Patient Global Assessment of Disease Activity (PtGA)
- Multidimensional Fatigue Inventory (MFI)
- Work Role Functioning (WRF)
- Arthritis Work Spill-over (AWS)
- EQ-5D-3L.

See Appendix 2 for a copy of these measures.

Patient Global Assessment of Disease Activity (PtGA)

The Patient Global assessment of disease activity (PtGA) is a single item scale that was originally designed for use with people with RA (Anderson et al., 2011). It was designed to measure a summary of how the disease affects the patient at a point in time. In this study the NRS was used ranging on a scale of 0 to 10. The higher the score, the higher the disease activity (Lassere et al., 2001). The PtGA has been found to have good test-re test reliability, validity and response to changes (Lassere et al., 2001).

Multidimensional Fatigue Inventory

The Multidimensional Fatigue Inventory (MFI-20) (Smets et al., 1995) is a 20 item self-report questionnaire that measures different aspects of fatigue over the past seven days. The MFI contains five domains: general fatigue, physical fatigue, reduced activity, reduced motivation and mental fatigue. Scores range from a minimum of 4 to a maximum of 20 for each domain. Higher scores indicate more fatigue. The MFI-20 has been used in previous research into fatigue in Rheumatic diseases and has been found to be a reliable and valid measure (Da Costa et al., 2006, Thombs et al., 2008, Van Tubergen et al., 2002, Reeves et al., 2005). A score of 13 or above in the general fatigue category indicates severe fatigue (Reeves et al., 2005).

Work Role Functioning Questionnaire

The Work Role Functioning (WRF) (Amick et al., 2004), questionnaire is a self-report questionnaire which measures the limitations a person experiences in work due to their health condition. It is a 27-item questionnaire that is divided into 5 subscales: work scheduling demands, output demands, physical demands, mental demands and social demands. Items are scored on a 5-point scale 1 (difficult none of the time) to 5 (difficult all of time) with each subscale being scored separately. A score is calculated by adding the response of each subscale, getting an average score and multiplying the score by 25 to get an overall percentage from 0% (have no problems meeting demands of the job) to 100% (always have problems meeting the demands of the job). This single summated score is calculated if a person is not missing 20% of the items. The WRF questionnaire has been used in previous research in people with Rheumatic diseases and is reliable and valid when used with other measures of work ability and impact of health conditions on work (Roy et al., 2011).

Arthritis Work Spill-over

The Arthritis Work Spill-over (AWS) is a 6-item self-report questionnaire which measures the degree to which the demands of arthritis impedes work performance and the degree to which work impedes the management of arthritis. The questionnaire is scored on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) (Gignac et al., 2006).Total scores range from 6-30 with higher scores indicating higher spill-over, or that arthritis is negatively affecting work between work and arthritis and vice versa (Gignac et al., 2006, Gignac et al., 2007).

EQ-5D- 3L

The EQ-5D-3L is a self-report measure of health status developed by the EuroQol group. It is a non-disease specific assessment for use in describing and valuing health related quality of life (Rabin and Charro, 2001). There are two parts to the measure: the descriptive category (EQ-5D descriptive system) and the Visual Analogue Scale (EQ-VAS). The descriptive category contains five elements: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression with each containing three levels: no problems, some problems and extreme problems. Participants mark the statement which is most relevant to their health state on the day. The VAS section of the measure is a vertical scale ranging from 0 ‘worst imaginable health state’ to 100 ‘best imaginable health state’. VAS is considered a valid and reliable measure for a range of chronic conditions (EuroQolGroup, 1990).

4.5 Qualitative Data Collection

Focus groups and semi-structured individual interviews were the qualitative methods used in this study. Both methods were based on pragmatic concerns in order to recruit as many participants as possible for the qualitative phase of the study. Individual interviews were offered to participants unable or unwilling to attend a focus group.

Semi-structured individual interviews collect detailed accounts of participants’ thoughts, attitudes, beliefs, and knowledge pertaining to a particular phenomenon and allow interviewers flexibility in questioning to further explore areas of interest

(Dillaway et al., 2006). Focus group interviews are a data collection method where participants express their views by interacting in a group discussion of the issues (Davidson et al., 2010, Carter and Henderson, 2005). Focus group interviews are useful for evaluating health care interventions and explaining quantitative findings as they provide both an individual and collective perspective (Liamputtong, 2010). Focus groups have been proposed as a particularly useful method of data collection when taking a qualitative descriptive approach and as counterpart to quantitative research to obtain a broad range of information about events (Sandelowski, 2000).

The purpose of both the interviews and focus groups was to explore participants' perceptions of fatigue and how it impacts on work and their ability to maintain paid employment. Another aspect explored was the issue of disclosure to employers and the accommodations, if any, provided/offered if they did disclose. The advantage of using a combination of these methods is enhancement of data completeness, as each method reveals different parts of the phenomenon of interest (complementary views) and contributes to a more comprehensive understanding (expanding the breadth and/or depth of the findings). For example, individual interviews may be used to explore personal experiences, whereas focus groups may be used to examine opinions and beliefs about the phenomenon (Lambert and Loiselle, 2008).

4.6 Data analysis

Quantitative

Data analysis was carried out using the Statistical Package for Social Science (SPSS) version 20. Initial descriptive statistics using frequencies, means and standard deviations were calculated. Pearson-Product Moment correlations were used to explore relationships between variables. Independent t-tests and one-way between groups analysis of variances were used to assess differences between the scores of sub categories of participants.

Qualitative

Both the interviews and focus groups were transcribed verbatim, then these transcripts were reviewed and were initially pre-coded manually, highlighting and marking quotes that stood out as significant and worthy of attention (Layder, 1998). Coding is the practice of grouping and labelling ideas and views so that the ideas generated then reflect wider perceptions. Once the codes are grouped they can form themes and viewpoints. These are then the findings of the qualitative method that provide responses to the research questions (Corcoran, 2006). In this study constant comparative analysis coding was used to analyse the qualitative interviews (Glaser and Strauss, 1967).

Following this provisional coding the transcripts were entered into Nudist Vivo version 10 (NVivo) software for analysis of qualitative data. Patterns in the codes were identified by re-reading the transcripts and then grouping together similar codes and descriptions into new categories (Stein et al., 2013). These new categories were then compared to one another and discussed by the researchers and given theme labels (Coffey and Atkinson, 1996).

5. Quantitative results

Overall 282 people completed questionnaires. Of these 234 participants were currently working and 48 were not currently working but had worked in the previous 24 months. However, not all participants completed all measures fully, therefore there are incidences of missing data. The demographic profile of those currently working (n=234) is presented along with the results of descriptive analysis, correlations between variables and finally differences in variables based on demographic and work characteristics.

5.1 Demographic profile

The majority of those working were women and aged between 41 and 50 years of age (table 3). Table 4 shows the demographic details of participants.

Table 3: Age and gender demographic variables

	Frequency (n)	**Percent (%)**
Age		
18-30	28	12
31-40	67	29
41-50	71	30
51-60	54	23
61-67	14	6
Total	**234**	**100**
Gender		
Male	69	30
Female	165	70
Total	**234**	**100**

Table 4: Demographic variables

	Frequency (n)	**Percent (%)**
Co-morbid condition		
One or more	91	39
None	137	59
Did not say	6	3
Total	**234**	**100**
Marital Status		
Single	77	33
Married	120	52
Separated/divorced	26	11
Widowed	8	3
Did not say	3	1

Total	**234**	**100**
	Frequency (n)	**Percent (%)**
Living Situation		
Living alone	42	18.0
Living with someone	188	80
Did not say	4	2
Total	**234**	**100**
Education level		
Up to Second level	92	39
College/ University	137	59
Did not say	5	2
Total	**234**	**100**

Table 5 and 6 present the main types of rheumatic diseases of participants and disease duration. The largest single groups were those with Rheumatoid Arthritis and those who had their condition for less than five years.

Table 5: Type of rheumatic disease breakdown

Rheumatic disease type	Frequency (n)	Percentage (%)
Rheumatoid Arthritis	100	43
Psoriatic Arthritis	24	10
Osteoarthritis	9	4
Systemic Lupus Erythematosus	19	8
Ankylosing Spondylitis	14	6
Fibromyalgia	12	5
Systemic Sclerosis	1	0.4
Gout	8	3
Polymyalgia Rheumatica	2	1
Other	16	7
Multiple Rheumatic conditions	28	12

Table 6: Duration of rheumatic disease

Disease Duration (n=234)	Frequency (n)	Percentage (%)
Up to 5 years	91	39
6-10 years	65	28
10 years or more	76	32
Did not say	2	1

5.2 Profile of employment

Participants provided information on the type of employment in which they are engaged. The majority of respondents are in full-time employment (70%) and in non-manual work (51%). Non manual labour consists of administrative, managerial, supervisory, office work and other professionals for example teacher. The disclosure question and job sector were both added to the questionnaire later in the data collection process and asked of just over half the sample (55%). Of these, three quarters (76%) had disclosed their rheumatic disease to their employer.

Table 7: Employment Details

	No.	%
Description of employment [2] (n=226)		
Non-Manual	120	53
Mixed non-manual and manual	80	35
Manual	26	11
Employment hours (n-234)		
Full-time	163	70
Part-time	71	30
Job Sector (n=153)		
Private Company/Self-Employed	82	56
Public Service	71	46
Disclosure (n = 157)		
Yes	119	76
No	36	23
Not applicable (Self-employed)	2	1

5.3 Descriptive Analysis of Outcome Measures

Disease activity

Participants were asked to rate their disease activity over the past week on a scale of visual analogue scale of 0 (no disease activity) to 10 (severe disease activity). The disease activity mean score was 4.7 (SD±2.6), with 225 people answering this question.

Impact of fatigue

The fatigue categories of the Multidimensional Fatigue Inventory (MFI) are: general fatigue, physical fatigue, reduced activity, reduced motivation and mental fatigue. Scores show that 'General Fatigue' has the highest mean score. General fatigue

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[2] Explanation of employment description terms:

- Non-manual work in this study covers administrative, managerial, supervisory office or other professional work such as a teacher.
- Mixed work in this study covers occupations such as sales and service occupations such as waitress, personal care attendant; patients care nurse, nurses' aide, or driver.
- Manual work consists of such as carpenter, roofer or loader.

includes global/broad statements about fatigue and was designed to encompass both physical and psychological aspects of fatigue and provides a general indicator of fatigue (Reeves et al., 2005).

Table 8: Mean fatigue scores according to the MFI (range 4-20)
(High scores indicate greater fatigue)

n=220	General Fatigue	Physical Fatigue	Reduced Activity	Reduced Motivation	Mental Fatigue
Mean Score	13.8	12.5	10.1	10.2	10.3
Standard deviation	SD±4.2	SD±4.3	SD±4.2	SD±3.5	SD±4.2

Work Ability

This section presents information on participants’ work ability as measured by the Work Role Functioning Questionnaire and the Arthritis Work Spill-over questionnaire.

The Worker Role Functioning (WRF) Questionnaire

The WRF questionnaire measures a person’s interpretation of how they are functioning in the workplace and has five subsections (Table 9). A high score indicates more difficulty. Participants’ mean scores indicated that participants perceived most difficulty in the physical demands of work, closely followed by difficulty managing work scheduling demands.

Table 9: Overall mean worker role functioning scores (range 0-100)
(High scores show greater difficulties)

n=212	Total	Work Scheduling Demands	Output demands	Physical Demands	Mental Demands	Social Demands
Mean scores	49.7	55.4	47.1	56.7	46.6	37.6
SD	±.19.0	±.25.8	±.22.1	±.27.9	±.22.5	±.17.7

The Arthritis Work Spill-over (AWS) Questionnaire

The AWS (score range 6-30) measures the degree to which the demands of arthritis effects work performance and the degree to which work effects the management of arthritis, where higher scores indicate more negative outcomes. The mean score was 18.3 (SD±.6.1), for 220 participants completing this measure. This indicates that there is a moderate level of spill-over between participants’ work and their arthritis.

Impact on quality of life

The EQ-5D assessed quality of life, under five headings (Table 10). The most frequently-occurring situations were some problems with mobility (53%), no problems with self-care (77%), some problems with usual activity (56%), moderate pain/discomfort (67%) and not anxious/depressed (52%). The mean EQ-VAS score, ranging from 0 for extreme difficulty up to 100, completed by 210 participants, was 59.5 (SD±.19.2).

Table 10: EQ-5D descriptive findings

EQ-5D Descriptive (n=223)	**No.**	**%**
Mobility		
No problems	96	41
Some problems	125	53
Confined to bed	2	1
Missing	11	5
Self-care		
No problems	179	77
Some problems	44	19
Unable to perform Self-care activities	0	0
Missing	11	5
Usual Activity		
No problems	86	37
Some problems	131	56
Unable to perform usual activities	6	3
Missing	11	5
Pain/Discomfort		
No pain/discomfort	36	15
Moderate pain/discomfort	157	67
Extreme pain/discomfort	30	13
Missing	11	5
Anxiety/ Depression		
Not anxious/depressed	121	52
Moderately anxious/depressed	92	39
Extremely anxious/depressed	10	4
Missing	11	5
	Mean	**Standard deviation**
EQ-5D- VAS (0-100) (n=210)	59.5	±.19.2

5.4 Correlations

This section examines the relationships between:

- Disease activity and the variables of fatigue, work functioning, arthritis work spill-over and quality of life
- Fatigue and the variables of disease activity, work functioning, arthritis work spill-over and quality of life

The relationships between variables were investigated using Pearson product-moment correlation coefficients. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. The strength of the correlations can be interpreted as follows (Cohen 1988, Pallant 2010)

- Range .10 to .29 – weak
- Range .30 to .49 – moderate
- Range .50 to 1.0 – strong

Disease activity and relationships with Fatigue, Work and Quality of Life

The relationship between disease activity and the following measures were investigated:

- Multidimensional Fatigue Inventory
- Work Role Functioning Questionnaire
- Arthritis Work Spill-over
- EQ-VAS

Statistically significant relationships are marked with an asterisk in Table 11 below. Significant positive correlations were found between disease activity and all domains of fatigue (general fatigue, physical fatigue, reduced activity, reduced motivation and mental fatigue), indicating that as disease activity increases so does fatigue. Disease activity was also significantly related to categories of Work Role Functioning (except managing the social demands of work) indicating that as disease activity increases difficulties in work functioning also increase. Another significantly positive relationship was found between disease activity and the AWS, indicating that arthritis-work spill-over increases when disease activity increases. A significant negative correlation was also found between disease activity and quality of life indicating that those with higher disease activity have a lower health-related quality of life.

Table 11: Correlations: Disease Activity and outcome measures

Variables	Disease Activity n=225	
	R	p-value
Multi-dimensional Fatigue Inventory (MFI) (n=220)		
MFI General	.543	.000*
MFI Physical	.448	.000*
MFI Reduced Activity	.322	.000*
MFI Reduced Motivation	.406	.000*
MFI Mental	.414	.000*
Work Role Function (WRF) (n=212)		
WRF Total	.347	.000*
WRF Work Scheduling Demands	.373	.000*
WRF Output Demands	.190	.006**
WRF Physical Demands	.430	.000*
WRF Mental Demands	.171	.014**
WRF Social Demands	.126	.072
AWS (n=220)	.440	.000*
EQ-VAS (n=210)	-.487	.000*

Significant at p≤0.01 indicating a 99% chance of the relationship being true
*Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Relationships between fatigue and (i) disease activity, (ii) work functioning and (iii) quality of life

Relationships were examined between the Multidimensional Fatigue Inventory and the following variables:

- Work Role Functioning
- Arthritis Work Spill-over
- EQ-VAS

Overall significant positive correlations, of varying strength, were found between all domains of fatigue as measured by the MFI and all aspects of work role functioning, as measured by the Work Role Functioning questionnaire. This indicates that higher levels of fatigue are associated with higher levels of difficulty in all aspects of work role functioning. Significant positive correlations, of varying strength, were also found between all MFI domains of fatigue and arthritis work spill-over. This indicates that higher levels of self-reported fatigue, across a number of domains, are associated with the extent to which arthritis impacts on work and vice versa. Negative correlations were found between all domains of the MFI and self-rated health as measured by the EQ-VAS. This indicates that higher levels of different types of fatigue are associated with lower levels of self-rated health as measured by the EQ-VAS. Significant relationships are marked with an asterisk in Table 12.

Table 12: Correlations: Fatigue and outcome measures (n=220)

Multi-dimensional Fatigue Inventory (MFI)	**MFI General Fatigue**	**MFI Physical Fatigue**	**MFI Reduced Activity**	**MFI Reduced Motivation**	**MFI Mental Fatigue**
Work Role Functioning (WRF)	R	R	R	R	R
WRF Total	.53**	.48**	.41**	.48**	.57**
WRF Work Scheduling Demands	.52**	.43**	.36**	.45**	.52**
WRF Output Demands	.42**	.36**	.29**	.31**	.45**
WRF Physical Demands	.48**	.49**	.41**	.48**	.35**
WRF Mental Demands	.37**	.36**	.31**	.37**	.58**
WRF Social Demands	.16*	.16*	.19*	.27**	.34**
AWS (n=220)	.54**	.45**	.32**	.41**	.41**
EQ-VAS (n=210)	-.57**	-.59**	-.46**	-.50**	-.42**

Significant at $p \leq 0.01$ indicating a 99% chance of the relationship being true. *Significant at $p \leq 0.05$ indicating a 95% chance of the relationship being true

5.5 Are there differences across severity, age, gender or other variables in disease activity, work role functioning, arthritis-work spill-over and quality of life?

This next section of the report presents the results of a statistical procedure, called the independent samples t-test, to ascertain if there are significant differences in disease activity, fatigue, work role functioning, arthritis work spill over and self-rated health between subgroups of:

- severity of fatigue
- age
- gender
- education levels
- co-morbidity
- duration of disease

The tables that follow present the average (mean) values for the subgroups on the various tests for these factors, along with a measure of how dispersed the values for the subgroup are around that average (standard deviation). The final column of these tables, the P value, is a measure of whether the groups are genuinely different or not – if it is below 0.05, the groups concerned show genuinely different characteristics that are highly unlikely to be due to chance.

Differences based on fatigue severity

Reeves et al., (2005) define severe fatigue as a score of greater than or equal to 13 on the MFI general fatigue subscale, and we have used this to divide the sample into severe and less severe fatigue groups. Table 13 presents the results. There were significant differences in scores for those with higher and lower levels of fatigue in all variables except for work role functioning – social demands. This indicates that those with severe levels of fatigue have higher disease activity, more difficulty in work functioning, higher levels of arthritis work spill-over, and lower self-rated health than those with less severe levels of fatigue.

Table 13: Differences in disease, work functioning and quality of life outcome measures between severe and non-severe fatigue

Outcome Measure	Fatigue Level	n	Mean for sub-group	Std deviation	P value
Disease Activity	Less severe	88	3.0	±2.0	.000**
	Severe	126	5.9	±2.3	
Work Role Functioning (WRF) Total	Less severe	82	40.1	±16.4	.000**
	Severe	122	56.5	±17.7	
WRF Work Scheduling Demands	Less severe	82	41.7	±20.7	.000**
	Severe	122	64.8	±24.1	
WRF Output Demands	Less severe	82	38.0	±16.7	.001**
	Severe	122	53.6	±22.4	
WRF Physical Demands	Less severe	82	43.0	±23.7	.000**
	Severe	122	66.0	±26.9	
WRF Mental Demands	Less severe	82	40.2	±19.8	.000**
	Severe	122	52.3	±22.2	
WRF Social Demands	Less severe	82	35.3	±18.4	.117
	Severe	122	39.3	±17.2	
AWS	Less severe	85	15.2	±5.8	.000**
	Severe	123	20.8	±5.0	
EQ5D-VAS	Less severe	82	71.1	±17.0	.000**
	Severe	119	52.2	±16.6	

Significant at $p \leq 0.01$ indicating a 99% chance of the relationship being true. *Significant at $p \leq 0.05$ indicating a 95% chance of the relationship being true (Pallant, 2010)

Differences in variables based on demographic characteristics

Impact of age

Independent samples t-tests were conducted to compare disease activity, fatigue, work role functioning, arthritis work spill-over and self-rated health for younger and older respondents. There were no significant differences in disease activity levels, fatigue levels, arthritis work spill-over and self-rated health. There were however, significant differences between younger and older respondents for overall work role functioning, and the mental and social demands of work, with younger participants having more difficulty in these areas (see Table 14 and 15).

Table 14: Differences in disease activity and fatigue levels between age categories (younger up to 50, older 51+)

Outcome Measure	Age	N	Mean for sub-group	Standard deviation	P value
Disease Activity	Younger	163	4.5	±2.6	.056
	Older	62	5.2	±2.5	
Multi-dimensional Fatigue Inventory (MFI) MFI General Fatigue	Younger	164	14.0	±4.1	.208
	Older	56	13.2	±4.4	
MFI Physical Fatigue	Younger	164	12.4	±4.2	.823
	Older	56	12.6	±4.7	
MFI Reduced Activity	Younger	164	9.9	±4.1	.490
	Older	56	10.4	±4.7	
MFI Reduced Motivation	Younger	164	10.1	±3.4	.717
	Older	56	10.3	±3.8	
MFI Mental Fatigue	Younger	164	10.5	±4.1	.373
	Older	56	9.9	±4.4	

Significant at $p \leq 0.01$ indicating a 99% chance of the relationship being true. *Significant at $p \leq 0.05$ indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 15: Differences in Work and Quality of Life between Age categories (younger up to 50, older 51+)

Outcome measure	Age	N	Mean for sub-group	Standard deviation	P value
Work Role Functioning (WRF) Total	Younger	153	51.5	±18.8	.023*
	Older	59	44.9	±19.0	
WRF Work Scheduling Demands	Younger	153	57.5	±25.0	.063
	Older	59	50.1	±27.4	
WRF Output Demands	Younger	153	48.6	±21.9	.115
	Older	59	43.2	±22.3	
WRF Physical Demands	Younger	153	57.4	±27.4	.584
	Older	59	55.0	±29.5	
WRF Mental	Younger	153	49.4	±22.7	.003*

Outcome measure	Age	N	Mean for sub-group	Standard deviation	P value
	Older	59	39.3	±20.3	
WRF Social Demands	Younger	153	39.6	±18.6	.006*
	Older	59	32.3	±13.6	
AWS	Younger	157	18.8	±5.9	.079
	Older	63	17.2	±6.5	
EQ5D-VAS	Younger	153	59.2	±19.7	.769
	Older	57	60.1	±17.7	

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Impact of Gender

Women had significantly higher levels of general, physical and mental fatigue, in comparison to men (See Table 16 and 17). Women also had significantly more difficulty in all categories of work role functioning than men, except for meeting the social demands of work where no difference was found. Females were also found to have significantly lower self-rated health than males.

Table 16: Differences in disease activity and fatigue levels between genders

Outcome Measure	Gender	N	Mean of sub-groups	Standard deviation	P value
Disease Activity	Male	63	4.6	±3.0	.817
	Female	162	5.7	±2.4	
MFI General Fatigue	Male	64	12.3	±4.0	.000**
	Female	156	14.4	±4.1	
MFI Physical Fatigue	Male	63	11.1	±4.2	.003*
	Female	162	13.0	±4.3	
MFI Reduced Activity	Male	63	10.0	±4.3	.302
	Female	162	10.2	±4.2	
MFI Reduced Motivation	Male	63	9.7	±3.3	.163
	Female	162	10.4	±3.6	
MFI Mental Fatigue	Male	63	9.1	±4.2	.007*
	Female	162	10.8	±4.1	

Significant at p≤0.01 indicating a 99% chance of the relationship being true.
*Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010).

Table 17: Differences in work and quality of life between genders

Outcome Measure	Gender (n)	N	Mean of group	Standard deviation	P value

Outcome Measure	Gender (n)	N	Mean of group	Standard deviation	P value
Work Role Functioning (WRF) Total	Male	63	43.5	±19.1	.003*
	Female	162	44.9	±19.0	
WRF Work Scheduling Demands	Male	63	47.3	±27.4	.004*
	Female	162	58.6	±24.5	
WRF Output Demands	Male	63	41.6	±22.5	.024*
	Female	162	49.3	±21.7	
WRF Physical Demands	Male	63	50.6	±29.0	.044*
	Female	162	59.1	±27.2	
WRF Mental Demands	Male	63	38.4	±19.9	.001**
	Female	162	49.8	±22.7	
WRF Social Demands	Male	63	36.8	±20.8	.680
	Female	162	37.9	±16.4	
AWS	Male	63	17.2	±5.9	.088
	Female	162	18.8	±5.8	
EQ5D-VAS	Male	63	63.8	±17.5	.035*
	Female	162	57.7	±19.6	

Significant at p≤0.01 indicating a 99% chance of the relationship being true.
*Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Impact of education

Those with education up to second level had significantly higher disease activity levels than those with university level education. Those with university level education had significantly more difficulty in managing the mental and social demands of work role functioning than those with education up to secondary level (Tables 18 and 19).

Table 18: Differences in disease activity and fatigue for levels of education

Outcome Measure	Education Level	N	Mean of sub group	Standard deviation	P value
Disease Activity	Up to 2nd level	88	5.2	±2.7	.020*
	3rd level	135	4.3	±2.5	
MFI General Fatigue	Up to 2nd level	83	13.2	±4.2	.078
	3rd level	135	14.2	±4.1	
MFI Physical Fatigue	Up to 2nd level	83	12.4	±4.6	.757
	3rd level	135	12.6	±4.2	
MFI Reduced Activity	Up to 2nd level	83	9.9	±4.3	.511

Outcome Measure	Education Level	N	Mean of sub group	Standard deviation	P value
	3rd level	135	10.2	±4.2	
MFI Reduced Motivation	Up to 2nd level	83	10.6	±3.6	.264
	3rd level	135	10.0	±3.5	
MFI Mental Fatigue	Up to 2nd level	83	10.0	±4.2	.411
	3rd level	135	10.5	±4.2	

Significant at $p \leq 0.01$ indicating a 99% chance of the relationship being true.
*Significant at $p \leq 0.05$ indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 19: Differences in work and quality of life between levels of education

Outcome Measure	Education Level	N	Mean of sub group	Standard deviation	P value
Work Role Functioning (WRF)	Up to 2nd level	81	47.1	±19.5	.096
	3rd level	128	51.6	±18.6	
WRF Work Scheduling Demands	Up to 2nd level	81	52.3	±28.1	.135
	3rd level	128	57.8	±24.2	
WRF Output Demands	Up to 2nd level	81	44.0	±22.2	.088
	3rd level	128	49.4	±22.0	
WRF Physical Demands	Up to 2nd level	81	56.9	±29.9	.972
	3rd level	128	57.0	±27.8	
WRF Mental Demands	Up to 2nd level	81	42.2	±21.5	.021*
	3rd level	128	49.5	±22.8	
WRF Social Demands	Up to 2nd level	81	34.1	±16.4	.018*
	3rd level	128	40.1	±18.2	
AWS	Up to 2nd level	86	17.4	±6.1	.052
	3rd level	130	19.0	±6.0	
EQ5D-VAS	Up to 2nd level	80	57.9	±17.8	.443
	3rd level	126	60.0	±20.1	

Significant at $p \leq 0.01$ indicating a 99% chance of the relationship being true.
*Significant at $p \leq 0.05$ indicating a 95% chance of the relationship being true (Pallant, 2010)

Impact of co-morbidity

The next two tables (Tables 20 and 21) examined if there were differences between those with co-morbidity (multiple condition) in comparison to those with a single rheumatic disease (no co-morbidity). Those with co-morbidity had significantly higher fatigue in all domains except fatigue related reduced motivation. Those with co-morbidity also had significantly higher difficulty in overall work role functioning, managing work scheduling demands and had higher levels of arthritis-work spill-over.

Significantly lower levels of self-rated health were found in those with co-morbidity in comparison to those with a single rheumatic disease.

Table 20: Differences in disease activity and fatigue levels in co-morbidity

Outcome Measure	Co-morbidity	N	Mean of sub-group	Standard deviation	P value
Disease Activity	Yes	89	5.3	±2.9	.003*
	No	130	4.2	±2.5	
MFI General Fatigue	Yes	85	14.8	±3.8	.005*
	No	129	13.1	±4.3	
MFI Physical Fatigue	Yes	85	13.4	±4.2	.007*
	No	129	11.8	±4.23	
MFI Reduced Activity	Yes	85	11.0	±4.5	.005*
	No	129	9.3	±3.9	
MFI Reduced Motivation	Yes	85	10.6	±3.5	.092
	No	129	9.8	±3.6	
MFI Mental Fatigue	Yes	85	11.3	±4.0	.003*
	No	129	9.6	±4.1	

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 21: Differences in work and quality of life in co-morbidity

Outcome Measure	Co-morbidity	N	Mean of sub group	Standard deviation	P value
Work Role Functioning (WRF)	Yes	85	52.7	±18.7	.039*
	No	123	47.2	±18.8	
WRF Work Scheduling Demands	Yes	85	60.5	±25.4	.013*
	No	123	51.5	±25.4	
WRF Output Demands	Yes	85	50.4	±23.5	.055
	No	123	44.5	±20.7	
WRF Physical Demands	Yes	85	59.2	±26.2	.275
	No	123	54.9	±29.4	
WRF Mental Demands	Yes	85	49.7	±21.2	.071
	No	123	44.1	±22.6	
WRF Social Demands	Yes	85	37.6	±16.7	.950
	No	123	37.5	±18.4	
AWS	Yes	90	19.3	±6.0	.034*
	No	126	17.5	±6.1	
EQ5D-VAS	Yes	83	55.5	±19.5	.013*
	No	123	62.4	±18.7	

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Impact of disease duration

There were three categories of disease duration therefore a one way between-groups ANOVA was conducted to examine the impact of disease duration on disease activity, fatigue levels, work role functioning and self-rated health. A statistically significantly difference was found in fatigue-related reduced activity and fatigue-related motivation for the three disease duration groups. Post-hoc comparisons using the Tukey HSD tests were carried out. They indicated that those with disease duration of less than five years were significantly less active as a result of their fatigue than those with longer disease durations. Also it was found that those with disease duration of less than five years were significantly less motivated as a result of their fatigue than those with longer disease durations (Tables 22, 23 and 24).

Table 22: Differences in disease activity and fatigue levels for disease duration: ANOVA

Scale	Under 5 years Mean	SD	6-10 years Mean	SD	10 years or more Mean (±SD)	SD	P value
Disease Activity	4.7	± 2.6	4.4	± 2.7	4.8	± 2.6	.669
MFI General Fatigue	14.2	± 3.8	13.3	± 4.5	13.4	± 4.3	.466
MFI Physical Fatigue	13.1	± 4.0	11.7	± 4.4	12.4	± 4.7	.143
MFI Reduced Activity	11.0	± 4.2	9.0	± 3.9	9.8	± 4.5	.012*
MFI Reduced Motivation	11.0	± 3.8	9.7	± 3.48	9.6	± 3.1	.023*
MFI Mental Fatigue	10.5	± 4.3	10.2	± 4.2	10.2	± 4.1	.832

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 23: Differences in work functioning and quality of life for disease duration: ANOVA

Scale	<5 years Mean	SD	6-10 years Mean	SD	10 years+ Mean	SD	P value
Work Role Functioning (WRF)	49.2	±19.1	47.9	±15.8	51.7	±21.3	.513
Work Scheduling Demands	55.7	±26.54	53.5	±24.2	56.6	±26.5	.778
Output Demands	47.4	±19.8	44.0	±19.2	49.4	±19.2	.395
Physical Demands	55.4	±26.7	55.3	±27.6	59.5	±29.8	.588
Mental Demands	46.8	±22.1	44.7	±19.4	48.0	±25.3	.712
Social Demands	36.8	±18.3	36.3	±15.1	39.6	±19.0	.502
AWS	18.9	± 6.4	17.6	±6.3	18.1	±5.4	.400
EQ-VAS	60.0	±18.4	60.8	±20.1	57.7	±19.5	.627

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 24: Disease Duration and outcome measures ANOVA (post hoc test)

Dependent Variable	Disease duration (i)	Disease duration (j)	Mean Difference (i-j)	Std. Error	P
MFI Reduced Activity	Less than 5 years	6-10 years	2.0	.69	.073
		10 years+	1.2	.67	.040*
	6-10 years	Less than 5 years	-2.0	.69	.073
		10 years+	-.8	.73	.984
	10 years or more	<5 years	-1.2	.67	.040*
		6-10 years	.8	.73	.984
MFI Reduced Motivation	Less than 5 years	6-10 years	1.3	.58	.073
		10 years+	1.4	.56	.040*
	6-10 years	<5 years	-1.3	.58	.073
		10 years+	.1	.60	.984
	10 years or more	<5 years	-.4	.68	.040*
		6-10 years	-.1	.74	.984

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

5.6 Differences in variables based on employment characteristics

Differences were analysed between disease activity, fatigue levels, work role functioning, arthritis work spill-over and quality of life in the following employment characteristics:

- Working hours
- Job type
- Job sector

Working hours

An independent samples t-test was conducted to compare work role functioning, arthritis work spill-over and self-rated health between those working full-time and part-time. Employees working part-time had significantly higher disease activity, general fatigue, physical fatigue, fatigue-related reduced activity and fatigue-related reduced motivation in comparison to those working full-time. Employees working full-time had significantly higher levels of difficulty in meeting the physical demands of work functioning. No differences were found in other aspects of work role functioning or self-rated health (Table 25 and 26).

Table 25: Differences in disease activity and fatigue levels between different working hours

Outcome	Working hours	N	Mean	SD	P value
Disease Activity	Full- time	155	4.3	±2.6	.001**
	Part-time	70	5.5	±2.3	
MFI General Fatigue	Full-time	153	13.4	±4.1	.023*
	Part-time	67	14.8	±4.2	
MFI Physical Fatigue	Full-time	153	12.1	±4.3	.030*
	Part-time	67	13.4	±4.4	
MFI Reduced Activity	Full-time	153	9.7	±4.1	.040*
	Part-time	67	10.9	±4.4	
MFI Reduced Motivation	Full-time	153	9.7	±3.6	.001**
	Part-time	67	11.3	±3.2	
MFI Mental Fatigue	Full-time	153	10.1	±4.2	.212
	Part-time	67	10.8	±4.1	

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 26: Differences in work and quality of life between different working hours

Outcome Measure	Working hours	N	Mean	SD	P value
WRF	Full-time	142	48.6	±19.2	.242
	Part-time	70	51.8	±18.6	
WRF Work Scheduling Demands	Full-time	142	54.9	±25.3	.685
	Part-time	70	56.4	±27.0	
WRF Output Demands	Full-time	142	46.4	±22.2	.524
	Part-time	70	48.5	±22.1	
WRF Physical Demands	Full-time	142	53.2	±27.3	.008*
	Part-time	70	63.9	±28.0	
WRF Mental Demands	Full-time	142	46.3	±22.4	.768
	Part-time	70	47.3	±22.7	
WRF Social Demands	Full-time	142	38.5	±18.6	.313
	Part-time	70	35.8	±15.7	
AWS	Full-time	150	17.9	±6.0	.187
	Part-time	70	19.1	±6.1	
EQ5D-VAS	Full-time	144	60.8	±19.9	.144
	Part-time	66	56.6	±17.3	

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Job Type

A one way between-groups ANOVA was conducted to examine the impact of job type on disease activity, fatigue levels, work role functioning, arthritis work spill-over and self-rated health. A statistically significantly difference was found in managing the mental demands of work functioning between the three job type groups. Post-hoc comparisons using the Tukey HSD test indicated that non-manual workers had higher difficulty in managing the mental demands of work in comparison to manual workers (Tables 27-29).

Table 27: Differences in disease activity and fatigue levels for job type: ANOVA

Scale	Non-manual		Mixed		Manual		P value
	Mean	SD	Mean	SD	Mean	SD	
Disease Activity	4.7	±2.4	4.3	±2.6	5.6	±3.2	.184
MFI General Fatigue	14.3	±4.3	13.5	±3.9	13.2	±3.9	.288
MFI Physical Fatigue	12.7	±4.3	12.3	±4.3	11.8	±4.5	.591
MFI Reduced Activity	10.5	±4.3	9.6	±4.3	9.9	±3.9	.409
MFI Reduced Motivation	10.2	±3.6	10.0	±3.5	10.8	±3.2	.606

Scale	Non-manual		Mixed		Manual		P value
MFI Mental Fatigue	10.8	±4.2	9.7	±4.12	10.4	±3.8	.252

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 28: Differences in work and quality of life for job type: ANOVA

Scale	Non-manual		Mixed		Manual		P value
	Mean	SD	Mean	SD	Mean	SD	
WRF total	50.6	±18.4	49.3	±20.7	48.8	±16.6	.829
WRF Work Scheduling Demands	57.7	±24.2	53.3	±26.8	52.7	±29.7	.447
WRF Output Demands	48.3	±22.3	45.5	±21.6	48.7	±23.6	.673
WRF Physical Demands	54.7	±26.1	59.5	±30.9	59.2	±27.4	.480
WRF Mental Demands	49.7	±22.0	45.4	±24.5	37.2	±15.0	.035*
WRF Social Demands	38.9	±15.6	39.9	±21.5	35.6	±14.4	.442
AWS	18.2	±6.1	18.2	±6.1	19.3	±6.1	.676
EQ-VAS	59.4	±19.7	58.4	±19.4	63.6	±16.1	.554

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 29: Job Type and outcome measures ANOVA (post hoc test)

Dependent Variable	Job Type (i)	Job Type (j)	Mean Difference (i-j)	Std. Error	P value
WRF Mental Demands	Non-manual	Mixed	-3.0	2.7	.510
		Manual	1.3	4.0	.942
	Mixed	Non-manual	-4.4	3.4	.391
		Manual	8.2	5.3	.265
	Manual	Mixed	-8.2	5.3	.265
		Non-manual	-12.6	5.0	.034*

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Job Sector

An independent samples t-test was conducted to compare disease activity, fatigue levels, work role functioning, arthritis work spill over and self-rated health between those working in the public sector and those self-employed or working in the private sector. Those working in public service had significantly higher levels of mental fatigue, difficulty in overall work functioning and managing the physical demands of work (Tables 30 and 31).

Table 30: Differences in disease activity and fatigue levels for job sector

Outcome Measure	Job Sector	N	Mean	SD	P value
Disease Activity	Private or self-employed	81	4.7	±2.6	.795
	Public Service	71	4.8	±2.5	
MFI General Fatigue	Private or self-employed	80	14.1	±4.3	.159
	Public Service	67	15.0	±3.8	
MFI Physical Fatigue	Private or self-employed	80	13.0	±4.3	.558
	Public Service	67	13.4	±4.0	
MFI Reduced Activity	Private or self-employed	80	9.9	±4.0	.132
	Public Service	67	11.0	±4.2	
MFI Reduced Motivation	Private or self-employed	80	10.1	±3.6	.110
	Public Service	67	11.0	±3.2	
MFI Mental Fatigue	Private or self-employed	80	10.2	±4.4	.023*
	Public Service	67	11.8	±3.9	

Significant at p≤0.01 indicating a 99% chance of the relationship being true. *Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

Table 31: Differences in work and quality of life for job sector

Outcome Measure	Job Sector	N	Mean	SD	P value
WRF	Private or self-employed	80	49.1	±20.0	.024*
	Public Service	67	56.6	±18.8	
WRF Work Scheduling Demands	Private or self-employed	80	55.3	±26.7	.082
	Public Service	67	62.9	±24.4	
WRF Output Demands	Private or self-employed	80	47.2	±20.9	.245
	Public Service	67	51.5	±23.3	
WRF Physical Demands	Private or self-employed	80	54.6	±28.8	.014*
	Public Service	67	66.4	±27.3	
WRF Mental Demands	Private or self-employed	80	47.4	±22.9	.092

Outcome Measure	Job Sector	N	Mean	SD	P value
	Public Service	67	54.2	±24.0	
WRF Social Demands	Private or self-employed	80	37.1	±18.8	.076
	Public Service	67	42.6	±17.1	
AWS	Private or self-employed	80	18.0	±6.2	.088
	Public Service	67	19.7	±5.9	
EQ5D-VAS	Private or self-employed	80	60.9	±19.6	.133
	Public Service	67	56.1	±18.4	

Significant at p≤0.01 indicating a 99% chance of the relationship being true.
*Significant at p≤0.05 indicating a 95% chance of the relationship being true (Pallant, 2010)

5.7 Summary of Quantitative Results

The largest single categories in our sample of those working were female; with a diagnosis of Rheumatoid Arthritis; had had their condition for less than five years; and were between 41-50 years of age. The largest group of respondents were in full-time employment in non-manual type of work. Of those asked about disclosure, three quarters had disclosed their Rheumatic disease to their employer. The group had a mean disease activity score of 4.66.

Fatigue levels according to the MFI were highest in the area of general fatigue followed by physical fatigue. The total mean level of difficulty in work role functioning was 49.7% indicating that those working have difficulty with their work activities almost 50% of the time. Physical demands present the highest proportion of difficulty at 56.7%. The Arthritis work spill-over mean score was 18.3. The majority of those currently working identified some problems with mobility, no problems with self-care, some problems with usual activity, moderate pain/discomfort and some difficulty with anxiety and depression. The mean EQ-VAS (0-100) score was 59.5 with a standard deviation of 19.2

Relationships between variables

Significant relationships were found between disease activity and fatigue, work role functioning (except managing social demands of work), arthritis work spill-over and health related quality of life.

Significant relationships were found between all domains of fatigue and all aspects of work role functioning, arthritis work spill-over and health related quality of life.

Significant differences between variables

Significant differences were found between those with and without severe fatigue in all variables except for managing the social demands of work

There were also significant differences between younger and older respondents in overall work role functioning, in managing the mental and social demands of work, with younger participants having significantly more difficulty.

Demographic differences between fatigue, work and quality of life

Gender

Women had significantly higher levels of general, physical and mental fatigue, in comparison to men. Women also had significantly more difficulty in all aspects of work role functioning than men, except for meeting the social demands of work. Women also reported significantly lower health related quality of life than male participants.

Educational attainment

Those with education up to second level had significantly higher disease activity levels than those with university-level education.

Those with third level education had significantly more difficulty in managing the mental and social demands of their work than those with education up to secondary level. Although those with 3rd level education tended to have higher levels of fatigue, there were no significant differences between the two groups.

Co-morbidity

Participants with co-morbidities had significantly higher fatigue in all domains of the MFI except fatigue-related motivation than those with no co-morbidity.

Those with co-morbidity had a significantly higher proportion of difficulty in overall work role functioning, specifically in managing work scheduling demands. They also reported significantly higher levels of work/arthritis spill-over than those with no co-morbidity.

There was also a significantly lower level of health-related quality of life than study respondents with no co-morbidity.

Disease duration

Statistically significantly differences were found in MFI categories of fatigue-related reduced activity and fatigue-related reduced motivation, between those with a disease duration of less than five years and those with a disease duration of 10 years or more.

Work Characteristics

Working hours

Employees working part-time had significantly higher disease activity, and significantly higher fatigue levels in all domains (except mental fatigue) in comparison to those working full-time.

Part time workers scored higher (but not significantly) in all categories of WRF except for social demands. They also reported lower EQ-VAS scores than full-time workers.

Employees working full-time had significantly higher levels of difficulty in meeting the physical demands of work than part-time workers.

Job type

Non-manual workers had higher difficulty (but not significantly) in managing the mental demands required in work functioning in comparison to manual workers.

Job sector

Participants working in public service had significantly higher levels of mental fatigue, difficulty in overall work functioning and managing the physical demands of work than those in the private sector or self-employed.

6. Qualitative Findings

Overall 18 people participated in the qualitative phase: focus groups (n=13) and individual interviews (n=5). The majority were female (n=14) and had their diagnosis for less than 5 years (n=10). All participants were working with 12 working full-time and six part-time. Three worked in manual jobs, four in a mixed manual and non-manual job, and 11 worked in non-manual jobs. See Table 27 for a demographic, fatigue, work and quality of life profile.

The main topics discussed in the focus groups and interviews were:

- Descriptions of fatigue (patterns of fatigue and factors that increase fatigue)
- Impact of fatigue on daily function (cognition, mood and physical abilities)
- Fatigue management strategies
- Disclosure
- Recommendations for managing fatigue in work

Table 32: Demographic, fatigue, work and quality of life profile of focus group and interview participants

ID and gender*	Age category	Highest Education	Disease Duration	Job Type	Job hours	MFI general	WRFQ Total	AWS	EQ-5D VAS
P56 (M)	31-40	3rd level	Less than 5 years	Manual	Full time	18	56.5%	21	65
P26 (M)	41-50	2nd level	Less than 5 years	Manual	Full time	9	59.3%	18	Did not say
P11 (F)	18-30	3rd level	6-10 years	Mixed	Full time	14	60.2%	29	70
P127 (F)	31-40	3rd level	Less than 5 years	Non manual	Full time	18	43.5%	20	50
P88 (F)	18-30	2nd level	Less than 5 years	Mixed	Full time	10	25.0%	14	80
P99 (F)	51-60	3rd level	6-10 years	Non manual	Full time	16	39.8%	21	80
P139 (F)	31-40	3rd level	6-10 years	Non manual	Full time	19	48.2%	19	60
SM19 (M)	61-67	3rd level	10 years or more	Non manual	Part time	19	49.1%	10	40
SM68 (F)	41-50	3rd level	10 years or more	Non manual	Part time	20	91.7%	27	40
P181 (F)	51-60	3rd level	Less than 5 years	Non manual	Full time	13	60.2%	21	60
P150 (F)	41-50	2nd level	Less than 5 years	Mixed	Full time	15	64.8%	19	40
SM33 (F)	31-40	3rd level	10 years or more	Non manual	Part time	14	43.5%	18	70
P173 (M)	41-40	2nd level	6-10 years	Manual	Full time	12	54.6%	20	75

SM83 (F)	18-30	2nd level	Less than 5 years	Non manual	Full time	15	61.1%	27	40
SM35 (F)	41-50	3rd level	Less than 5 years	Non manual	Full time	13	56.5%	18	70
SM38 (F)	31-40	3rd level	Less than 5 years	Non manual	Part time	17	57.4%	26	60
SM92 (F)	51-60	2nd level	6-10 years	Mixed	Part time	12	53.7%	22	40
P153 (F)	18-30	3rd level	Less than 5 years	Non manual	Part time	16	68.5%	24	60

* M = male; F = female

6.1 Descriptions of fatigue

All participants experienced considerable fatigue *'I wake up tired every day'* (P56) and *'For me the fatigue is an absolute killer'* (SM68). Participants described the physical fatigue they experience in work: *'I feel like I'm shaking inside. But I look down at my hands and legs and they're not shaking'* (P153)

> *'I feel like there's porridge in my veins not blood. Everything is heavier and slower - and you're constantly dragging the next bit of you, whichever bit is most affected, around- so porridge blood.*' (SM33)

Descriptions of mental fatigue were also given. Participants' stated that when they experienced cognitive or mental fatigue in work it felt like their heads were *'muzzy'*. *'Brain fog'* was experienced by some participants when they were experiencing mental fatigue.

Patterns of fatigue

There was some discussion about patterns and lack of patterns of fatigue during the working week. For some participants their fatigue levels fluctuated on a daily basis.

> 'I think it's always there but it's just at different levels- like the way you see your scale from one to ten, but fatigue is just at different levels. But I think it's always there.' (P173)

A number of participants reported that their fatigue increased towards the end of the working week whereas others experienced no pattern to their fatigue and that it appeared *'out of the blue, it's quite unexpected.'* (SM68) Three participants described being able to predict the time of day or the day of the week that their fatigue was going to be worse. This was due to years of experiencing fatigue *'I think that's only after ten years now, I can recognise the signs myself.'* (P99)

Factors that increase fatigue

There was some discussion during focus groups and interviews about factors that increase fatigue such as pain, medications and for two participants, exercise. The relationship between fatigue and pain was discussed. For some *'Pain is what fatigues me mostly.'* (SM19) and for others pain and fatigue are unrelated:

> 'One doesn't lead to the other. I think of it as two channels in my body- one of them is for pain and one is the fatigue. They don't impact each other. I could be absolutely in agony but I could be sitting there reading, or doing whatever. I won't fall asleep just because of the pain.' (SM68)

How pain causes fatigue in work was discussed by participants:

> 'You mightn't think the fatigue is from an ache or a pain. But then you stand up and realise it's probably because you're after sitting for so long that the pain and fatigue are after kicking in from not moving around.' (P127)

Some participants discussed how activities they do throughout the week impact on their fatigue levels in work '*so if I overdo it I get fatigued in work.'* (P153) Others discussed how if they over-exert themselves with social activities during the week and weekends that this increases their fatigue at work *'Well if I do too much I'm exhausted. So it's just a question of just not doing it, or saying no to social things.*'(P99)

Another factor reported by two participants that increases fatigue levels are medications. Mixed views on the relationship between fatigue and medications were discussed. One participant found the medication increased fatigue levels *'I'm off my meds now and I don't seem to be as tired.'* (SM92) Whereas the other noticed that fatigue increased when medication was forgotten or when it came close to medication time:

> 'Just thinking about the physical fatigue I am currently on two weekly medications and when I remember both of them on the right day, and take them, the pain and physical fatigue are really well managed. But if I forget the first thing I notice is the physical slowness- the porridge blood.' (SM33)

Two participants talked about the impact of exercise and how it impacts on their fatigue levels and ability to work:

> 'I'd be exhausted after it. I still would feel better for doing it but I would wake up in the morning after exercising and feel really stiff, sore and tired. I just won't go in (to work) until ten o'clock- but I'm lucky I can do that.' (P99)

6.2 Impact of fatigue on daily function

Participants reported three main areas where fatigue impacts on function in their daily lives. These were impact on cognition, mood and physical abilities.

Impact of fatigue on cognition

Mental fatigue and its impact on work were discussed by 16 of the participants *'the mental fatigue side of it that would really impact on work'* (P99) Participants felt that mental fatigue made them work at a slower pace because '*I'm just shut down in my head.'* (SM68) This lack of concentration and focus contributed to more mistakes being made in their work *'the more mentally fatigued I get the more mistakes I make'* (P173). The mistakes resulted in participants' '*doubting'* (P152) themselves which lead to *'double-checking'* (P181) and re-doing work tasks already completed '*And I find myself having to go back to the beginning.'* (SM33)

Participants discussed cognitive issues in work and how they resulted in challenges when concentrating on a task or conversation, difficultly with problem solving, procrastination, and memory difficulties. Participants mainly described concentration difficulties in relation to focusing on written information in work:

> 'If I'm reading something I'm meant to be commenting on it and then I'm three pages in, I've read it all, I've read every single word and I haven't got a clue what they've said. So it's that sort of engagement that your brain sort of just switches off quicker.' (SM33)

Others noticed their lack of concentration when talking or interacting with work colleagues ‘In meetings sometimes I would find it very hard to concentrate and to keep listening. I’ve had people say to me “are you listening?’’’(SM92)

The most typical memory difficulties discussed by participants’ were difficulties with memory when planning or organising their work day, *‘Tiredness makes me very forgetful. I'd have to have my list- this is what I'm going to do today!’* (P26) Other memory difficulties which impacted on work performance were challenges in relation to remembering words, colleagues’ names, passwords, phone numbers and details of clients and their orders *‘Just walking into a room to do something and thinking ‘what did I come in here to do?’* (P11)

Impact of fatigue on mood

Some participants identified how their mood is affected by their fatigue. Participants described instances when fatigue made them irritable ‘*cranky- ‘it affects my mood being very tired*’ (SM38):

> ‘Your tolerance levels drop because you’re tired. There are days when things go wrong because I’m not in the right frame of mind for it. And it’s not fair on the other person then, it’s not their fault if things go pear shaped.’ (P99)

This irritable mood then impacts on relationships with other colleagues and clients/customers:

> ‘When I’m really tired it makes it more difficult to just ignore when people get a bit angry, or rant at you. It’s easier for me to take it personally when you’re already in a bad mood.’ (SM38)

Participants identified restrictions experienced in work from their fatigue which made them frustrated and this in turn increased their stress. Participants also discussed other emotions they experience as a result of the difficulties they encounter in work. These include guilt *‘I used to feel really guilty when I went for a nap I used to think I’m being really lazy. But now I know that I actually need it’* (P153), annoyance with themselves and others, embarrassment, feeling depressed ‘*I try to remain upbeat but there are days that I would be down, purely because I'm just exhausted.’* (SM83), reduced motivation with respect to their work *‘when I'm that tired I just don’t care. Even when people are talking to you it’s just “go away’’’* (P26) and a changed attitude to the standard of their work:

> ‘I've come to hate my trade, I really have come to hate it. I just don’t like it anymore, I'd rather be licking stamps and putting them on envelopes than actually having to go in and push yourself as hard as you have to push yourself, just to get through the day’ (P56)

Impact of fatigue on physical abilities

Participants described how physical fatigue or lethargy can impact on their abilities to engage in physical activities in the workplace. Some participants described how physical fatigue can impact on them being able to go on errands to get supplies for with workplace *'I might get up in the morning and I won't be going anywhere because physically I won't be able to walk- I'll be just too tired.*' (SM19)

Participants spoke about trying to avoid work activities or tasks that involve physical activities, going outdoors, moving heavy objects such as computers and lifting boxes of paper *'There would be carrying and lifting but I try to minimise it as much as possible. Like, get somebody to do it for me or use a trolley.'* (SM92).Two participants spoke of not being able to walk up or down stairs in their workplace without having to have a rest afterwards. This lead to feelings of embarrassment as they felt colleagues had a lack of understanding.

The issue of not wanting colleagues to see their stiffness after sitting for long periods of time was discussed. Participants' described having to look like they are *'springing'* (P181) up from their desk after sitting for long periods of time to avoid colleagues noticing their stiffness.

6.3 Fatigue management strategies

Participants discussed a range of strategies for managing, and coping with, fatigue in the workplace. Attitude to work, and how it impacts on work ability, was discussed. Participants discussed using coping strategies such as changing from negative to positive attitudes to help them get through the working day *'So I made a conscious decision to stop it and to make more of an effort myself and that makes it more bearable.'* (SM38) Other participants described pushing themselves in work which has negative consequences on their fatigue levels at the weekend:

> 'So while I am able to work I work as long as I can. I'd go in at eight in the morning and stay 'til seven, eight in the evening. And I'd keep on pushing through. Come Sunday it's like, you're zonked you're absolutely zonked after five days of doing that.' (P127)

Participants identified energy management strategies that helped them manage their fatigue over the working day and week. These included pacing, planning and prioritising tasks.

Participants reported that pacing strategies included ensuring to take scheduled breaks such as a lunch break. They also discussed taking short rest breaks in-between tasks *'What I do is when I know I'm tired I just stop for about five or ten minutes.'* (SM35) and taking short movement breaks about the office such as going to get a glass of water, make a coffee or go to the bathroom *'I'll get the wave of tiredness so I go to the bathroom. Or, I'll have a cup of coffee, or I'll do something to try and wake myself up.'* (P181) The benefit of resting in the work day '*I'd go and have a nap during my lunch break.'* (SM38) was identified by 15 participants '*ten minute breaks are great.*' (P26). Another pacing technique used was changing tasks when concentration is waning *'Just do a paragraph, just focus on that paragraph, "is there anything there?" Stop, do something else and come back to it.'* (SM33)

Planning ahead was another energy conservation strategy that participants identified as being beneficial to manage their fatigue in work. Participants spoke about planning and organising their work routine according to their fatigue levels:

> ‘I work full time and by Thursday evening I’m not worth tuppence. So, I always plan to keep Friday as quiet and as calm as I can because I know I’m not going to function well on Friday.’ (P99)

One participant identified a useful strategy as planning a rest day in-between working days, *‘Planning a rest day I found that helps.’* (P139)

Strategies were also discussed in relation to participants’ reducing their working hours or beginning to work flexi time due to fatigue levels. Six participants had changed to part time work. Two participants described splitting their working days up as a result of fatigue:

> ‘Yeah, I’ve gone job sharing this year it’s a split week so it’s Thursday, Friday and then the weekend and then Monday, Tuesday Wednesday. So I never work more than 3 days in a row.’ (P153)

Participants also discussed other strategies for their workload such as making lists, organising emails, delegating tasks to other workers *‘get someone else to do it for me’* (SM92) and spreading tasks throughout the week instead of doing them all in the one day:

> ‘I know I’ve just got so much to do it fills three days and more. So I go in and I’ve got my list and I just work through it. So it’s being organised and just keeping going – not too fast, as you say taking it easy, but keeping moving on things.’ (SM33)

6.4 Disclosure

Fifteen participants’ had disclosed to their employer about their Rheumatic disease: *‘I’ve been open from day one. I think if I'm open with them, they can be open with me.’* (SM83) Some participants reported being uncomfortable telling their employers about their arthritis but felt it was necessary to explain frequent absences from work. The majority reported that their employer was supportive of the physical aspects of their disease and offered them appropriate accommodations, such as ergonomic assessments:

> ‘And they got in an ergonomic specialist to make sure that everything was within reaching distance for me so that I wasn’t over stretching and everything was in the right place.’ (P127)

However, some participants discussed a lack of understanding of fatigue from employers and colleagues upon explaining their fatigue with responses such as *‘are you tired again?’* (P26), or ‘*Oh I’m tired too’* (SM83) or *‘make sure you get a good night’s sleep tonight’* (SM35) This lead to it being difficult for participants to disclose information about their fatigue levels:

> ‘They don’t understand the scale of the tiredness. A lot of people don’t realise- nobody really gets it.’ (SM83)

Some participants reported mixed responses with regards to support from their managers:

> ‘It was mixed, between different people. Like, the person over my area, he was like- “how can we help you?” But I don’t find the person I report directly to as positive or as helpful.’ (SM92)

This lack of understanding had led to confusion for participants on what accommodations are reasonable for employers to offer with regards to managing fatigue at work:

> ‘It’s like if you had a headache you could go in and say “oh I’m really suffering with a bad headache now, I need to go home!” But you can’t go in and go “I’m really, really tired, I need to go home”.’ (P153)

As previously discussed some participants were offered reduced hours and flexi time which helped with managing fatigue. This demonstrates that some employers are providing accommodations to people with Rheumatic diseases. For those participants whose employers and colleagues were supportive, they felt reassured by the fact that there was awareness of their condition in the workplace *‘But the fact that work are so good, and they do know, I feel I don’t have to pretend I’m okay, when I’m not okay’* (P99).

Only three participants had not told their employers about their rheumatic disease. When asked why not, they gave a number of reasons. One participant explained how he was on a probation period and if he told his employer about his condition he was worried that he would be made redundant. Another participant, who has difficulty breathing, said he wouldn’t tell his employer or his colleagues as he believes they would observe him constantly. He also discussed that he believes that they would think that he should not be at work as he might have an accident *‘But I wouldn’t tell my boss something like that because you're afraid. What if they think that you're just not able for it and you shouldn’t be there.’* (P56) Two manual workers said that their employers were more interested in having the work completed than in their employees’ health.

6.5 Recommendations for managing fatigue in work

Discussions occurred about how to better inform employers and colleagues about fatigue and the impact of their rheumatic diseases on their work. Participants spoke about the role of health professionals’ in *‘empowering’* people with arthritis to inform their employers and colleagues about fatigue and their rheumatic disease. One suggestion to achieve this was to bring a health professional to meetings of disclosure with their employers.

> ‘But also there’s a bit of work there with us and thinking about how you tell people. I wouldn’t have told people in my previous job until things got really bad. And it

> was only that experience and it going down so well that then allowed me to be just completely open about it when I came here. So there's almost giving us permission and thinking about what you can do with people with arthritis themselves to empower them to say "I'm actually going to do this". I'm going to take this information or I'm going to encourage my OT (Occupational Therapist) to come with me to tell my employer.' (SM33)

Other suggestions for educating employers' and colleagues were having leaflets to give to employers, having discussions with colleagues and employers about fatigue in rheumatic diseases to help their understanding:

> 'Education sessions explaining about fatigue and how it can affect employees and what they (employers) could possibly do to help them.' (P181)

An interesting suggestion in relation to general awareness and education of the public was to have an arthritis awareness day education campaign:

> 'See the way they have the daffodil day and stuff like that. And there's huge awareness around those. So have an arthritis day- an advertisement campaign. Because you don't really see it on telly, or media or anything like that. So just to have a little bit more of a higher profile of it.' (P127)

Some discussion occurred related to health professionals' awareness of fatigue and its management: '*Nobody says* "*what are you doing for the fatigue*?" *The health professionals don't understand how to treat it either'* (P153).

> 'I've never had anybody sit down and say to me, "here's what you need to do". And I'm going "how do I cope?" And nobody's bridging that gap!' (SM19)

Participants believed that sometimes health professionals did not recognise fatigue as a symptom and that further education of health professionals on fatigue and its impact on daily functioning is needed.

6.6 Summary of Qualitative findings

The qualitative findings identified a number of themes. Participants described their experiences of physical and cognitive fatigue, the patterns, and possible triggers. Some participants reported their fatigue increased towards the end of the working week, some experienced daily fluctuations in fatigue levels, and others could discern no pattern. Participants described how fatigue can impact on concentration and focus at work, can lead to increased irritability, and can affect the ability to do physical tasks at work. Participants discussed coping strategies at work including pacing themselves, planning and prioritising tasks, taking breaks, or working part-time. Most participants had disclosed their condition to their employer, but while most were positive and accommodating, others found that colleagues or line managers could lack understanding and insight into the effects of the condition. Participants felt that greater awareness of rheumatic conditions and their impact would be helpful.

7. Discussion

For this study, participants were recruited through two different sources, the Rheumatology Department in St. James Hospital and an on-line survey distributed through three arthritis-related voluntary organisations.

Based on the chart reviews of those attending the St. James' rheumatology clinics, 543 people met the inclusion criteria of being between the ages of 18 to 65 years and having a definite diagnosis of a Rheumatic disease. All 543 people were invited to complete the fatigue and work related questionnaires if they were currently working. Of these, 196 people completed the questionnaires of which 148 are currently employed. In addition to the 196 people recruited through St. James, 86 people who were currently working completed the online survey. This gave a total number of 234 people currently in employment who were included in the study. Of these, the majority were female, married, and aged between 31 and 50 years. The most common arthritis was Rheumatoid Arthritis (RA) diagnosed less than five years. The majority of participants in employment were working full time (70%). This is slightly lower than the national rate for full time employment being 77% (Central Statistics Office, 2015). Just over half of study participants were in non-manual type employment (51%). This is perhaps unsurprising given the physical demands of manual jobs and that a primary symptom of RA is joint pain.

The participants in the qualitative phase had a similar profile. The majority were female and split equally between the age categories of 31-40 and 41-50 years. The most frequent Rheumatic disease was RA diagnosed less than five years. The majority were in non-manual jobs (61%) and worked full time (67%).

Disclosure

The majority of survey respondents and participants of the focus group and interviews had informed their employers of their diagnosis. The focus group and interview participants stated they felt obliged to inform their employers in order to explain time taken away from work to attend medical appointments. Most of the focus group and interview participants reported that their employers were supportive when informed. Those who did not inform their employers explained this as being fearful of their employment being terminated or being disadvantaged for promotional purposes. Such actions by employers could constitute discrimination and be contrary to the Employment Equality Acts. The issue of how to disclose to employers was discussed by the participants in the qualitative study. They suggested input from health professionals on the benefits of disclosure and discussed challenges and strategies for disclosing a Rheumatic disease to employers.

Employers are legally obliged to reasonably accommodate their employees with a disability where the cost of so doing is not disproportionate. Participants of the qualitative phase identified accommodations provided by employers such as ergonomic assessments of the work environment, providing assistive technology and flexible or reduced working hours as beneficial. Those would generally come under the heading of ‘reasonable accommodations’ set out in the Employment Equality Acts. It would be important that workers who have a rheumatic disease would understand their rights and what their employer’s obligations are under this legislation.

However, focus group/interview participants identified that on disclosure they did not always receive support or understanding from their colleagues or co-workers. Therefore it is important that colleagues would be aware and supportive of what a worker would need to accommodate their disability and manage their symptoms at work.

Previous research has found that interventions targeting co-workers can help with improving work ability in employees with rheumatic diseases. However, this combination is only effective if co-workers have a clear understanding of the difficulties people with Rheumatic diseases have in relation to work productivity (De Croon et al., 2005). Previous research has found that employees with RA who received support and understanding from their supervisors and co-workers report higher work performance than employees who do not receive such support (De Croon et al., 2005).

Disease activity

As a group, participants’ disease activity was moderate with a mean score of 4.74, however scores ranged from the minimum score of 0 to the maximum score of 10. Disease activity was significantly associated with higher fatigue, increased arthritis work spill-over, increased difficulty in work role functioning and lower self-rated health. These findings are in line with previous research which has demonstrated that higher levels of disease activity are associated with reduced work performance (Bansback et al., 2012, Chaparro del Moral et al., 2012, Zhang et al., 2010, Pollard et al., 2006, Dagfinrud et al., 2005a).

The WRF questionnaire measures the proportion of difficulties a person experiences in their work role. It examines five different elements of work. In the survey, the physical demands of the job resulted in the greatest amount of difficulty for the respondents. This was also identified in the focus group with participants describing difficulties encountered with specific physical elements of their work. Work scheduling demands, which includes being able to work without taking breaks and working the required number of hours, was the second highest category of difficulty for participants. Again, this was also identified in the focus groups and interviews. As RA was the most frequent condition reported, and it causes stiffness particularly in early morning, this could explain the need for frequent rest breaks. The impact of participants’ arthritis on their work, and how their work impacts on their arthritis was measured with the Arthritis-Work Spill-over questionnaire (AWS). The high mean score on this scale supports the findings from the WRF. The AWS questionnaire demonstrates the difficulty in identifying the direction of cause and effect between arthritis and work.

Fatigue and work

In the Multidimensional Fatigue Inventory (MFI) a score of 13 or above is considered severe fatigue (Smets et al., 1995). Overall study participants had severe levels of fatigue with the majority, (54.5%), scoring 13 or above on the fatigue measure (MFI). Estimates of prevalence of fatigue for Rheumatic diseases are not conclusive due to differences in fatigue measures used and study inclusion criteria; however, previous research indicates that fatigue is reported in up to 90% of people with rheumatic diseases (Norheim et al., 2011). A study of fatigue levels in those with RA found that 40% of individuals experienced persistent severe fatigue (Repping-Wuts et al., 2008). The results of the current study are in line with this figure demonstrating that fatigue is a pervasive symptom in employed individuals with rheumatic disease.

Fatigue was significantly associated with both of the work-related questionnaires (WRF and AWS), thus showing that high levels of fatigue are associated with difficulties in work related activities. On examining the associations between different types of fatigue and the five WRF categories, mental fatigue had the strongest associations with three of the five WRF categories. This means that mental fatigue is significantly related to difficulties in meeting the scheduling, output, and social demands of work. Physical fatigue had the strongest association with the AWS.

Those with severe fatigue had significantly more difficulty in meeting the demands of their work as measured by the WRF. Their arthritis also impacted significantly more on their work and vice versa. Given these findings, it is not surprising that those with severe fatigue had significantly lower self-rated health than those with non-severe fatigue levels. The present study's findings are consistent with previous quantitative research which has found that fatigue is one of the main factors contributing to work disability and challenges in work functioning and that those with higher fatigue levels have more difficulty in work ability (Boonen & Severns 2011, Gignac et al., 2013) Qualitative studies of employed adults with RA also found that participants viewed fatigue as the aspect of their condition most limiting their employment and impacting on many aspects of work functioning (Lacaille et al., 2007, Feldthusen et al., 2013). The qualitative results supported these findings with all participants reporting considerable fatigue and the consequent impact this had on their work functioning. Addressing fatigue through work-based interventions by health professionals and provision of appropriate accommodations by employers may help to validate fatigue experiences, improve self-management of symptoms and enhance work functioning. It is important to target those early in their disease who are experiencing severe levels of fatigue as these groups appear to experience particular difficulty.

Patterns of fatigue and factors that increase fatigue

The experience of fatigue appeared to be individualised for participants, with many commenting on the unpredictable nature of this symptom. In contrast, some of the focus group and interview participants identified the constant nature of fatigue, but that its severity fluctuates. Others identified sudden onsets of fatigue. This is similar to other qualitative studies of fatigue where individuals experienced fatigue as mainly unpredictable (Feldthusen et al., 2013, Connolly et al., 2014). This unpredictability makes it a difficult symptom to treat, however, perhaps an increased awareness of this feature of fatigue may help people to manage it better. This current study included individuals with a mix of rheumatic diseases rather than focusing on a single disease. It may be that those with inflammatory type disease experience patterns of fatigue in a different way to those with non-inflammatory diseases. Future research could explore differences in fatigue patterns and experiences of those with different types of rheumatic disease.

Some differences were reported by the focus group and interview participants on factors which caused or exacerbated their fatigue. Many participants reported that pain increased their fatigue in work. They described how pain affects their work performance and how work tasks increase their pain. They all also described how pain affects their sleep and how all these factors combined has a significant impact on their mood and motivation for work. Other studies also reported that participants expressed a close relationship between fatigue and pain (Feldthusen et al., 2013, Lacaille et al., 2007). In the current study pain was prevalent among the survey participants with almost 80% reporting moderate or extreme pain. Other research has also identified a significant relationship between pain and fatigue (Pollard et al., 2006). This indicates a need for combined fatigue-pain interventions in order to manage the symbiotic relationship of these two symptoms.

The impact of fatigue on mood was a frequent theme within focus group and interview discussions. Participants described how when they are tired, they then become frustrated with themselves and irritable with their colleagues. This then results in feelings of guilt, increases their stress which in turn increases their fatigue. Difficulties with mood were also identified in the quantitative data with over 40% reporting moderate or extreme anxiety or depression. This could be due to many reasons such as pressures in work, fear of losing their jobs, and difficulty fulfilling roles outside of work. This therefore appears to be an area that needs to be assessed during hospital appointments and relevant referrals made to help with managing anxiety and stress.

Medication was another factor identified as related to fatigue with participants having mixed views on this relationship with some believing medication to be important in managing fatigue and others reporting increased fatigue as a result of certain medications. Other studies have also found that individual participants believed that medication either reduces or increases fatigue (Power et al., 2008, Feldthusen et al., 2013). Increased exercise was attributed by some to increased fatigue levels. This variation of attributing factors indicates that education is required to increase people's awareness of the range of factors that may increase their fatigue. Further quantitative and qualitative research is also needed to understand factors causing fatigue and individual's experience of factors increasing fatigue for those with Rheumatic diseases in employment.

Impact of fatigue on work

Participants discussed the impact of fatigue on their cognition, mood and physical abilities within the workplace. Participants provided examples of difficulty concentrating during work tasks and interactions with colleagues, difficulty with memory and problem solving activities. They explained how these cognitive difficulties results in making mistakes and this increases their work load. Physical activities such as lifting work-related objects or managing stairs were problematic leading to embarrassment with colleagues. This is consistent with other studies which have found that fatigue has an extensive impact on work, interfering with cognitive, physical and emotional components required for work performance and engagement (Lacaille et al., 2007, Feldthusen et al., 2013, Norheim et al., 2011). It also supports the quantitative findings of this study on the negative impact of fatigue on managing all demands of work including scheduling, output, physical, mental and social.

It is also worth noting that over 56% of participants identified difficulties in performing their usual activities outside of work. It is important then to recognise that the experience of fatigue is multidimensional and the impact is multifaceted. Interventions for those with rheumatic disease which specifically address fatigue in the workplace are lacking. Enabling individuals to manage their fatigue and provision of emotional support may be crucial for individuals to remain in employment (Gignac et al., 2006). Advice on fatigue management needs to be individualised, collaborative and address a broad range of contributing factors in order to positively impact on work performance and participation (Feldthusen et al., 2013, Hewlett et al., 2005).

Fatigue management strategies

Participants of the qualitative phase of the study were asked to identify strategies they used for managing their fatigue in the work place. In order to cope with the demands of work and their fatigue, participants developed a range of techniques such as developing a positive attitude and using energy conservation strategies of planning and prioritising activities, pacing tasks and taking frequent short rest periods. These are all strategies that health professionals would recommend (Hammond, 2010). However participants felt that fatigue was essentially disregarded by health professionals. Similarly Reeping-Wutts et al., (2008) identified that fatigue is not routinely addressed by health professionals and that people with rheumatic diseases accept fatigue as a consequence of their condition. Participants of the current study discussed how they had to figure out how to manage their fatigue themselves. Connolly et al. (2014) also reported that fatigue management strategies were acquired through trial and error with no input from health professionals.

Some participants appear to have developed maladaptive strategies such as drinking large amounts of coffee, pushing themselves to complete work tasks, and carrying out all the important work tasks at the beginning of the week which resulted in severe fatigue at the end of the week. Similar findings on pushing through fatigue, and uncertainty on how to manage fatigue were discussed in previous research (Dagfinrud et al., 2005b). Hewlett et al., (2005) recommends that health professionals need to discuss fatigue as a legitimate and manageable symptom of Rheumatic diseases which will authenticate feelings of fatigue and aid understanding of how to manage fatigue effectively.

Focus group and interview participants reported that fatigue is difficult to explain to their employers, supervisors and co-workers as it is not a visible symptom of their disease. Participants spoke about employers and co-workers misunderstanding the difference between regular tiredness and the fatigue related to rheumatic diseases. This resulted in participants feeling unable to explain the fatigue they experience or to request accommodations to help with managing their fatigue in the work place. This study therefore shows the need for educating employers and employees about fatigue management strategies that can be used in the workplace. This may improve productivity and perhaps reduce work absenteeism. Fatigue management guidelines designed specifically for the workplace should focus on balancing activities, taking frequent rest breaks, correct positioning, work simplification strategies, problem solving, stress and pain management, and effective communication training. Further research is then required to examine the effectiveness of such work management strategies on work performance.

Risk factors for impaired work functioning

Demographic characteristics

The identification of work disability risk factors is important to guide the interventions and accommodations to enhance work participation and performance (Allaire et al., 2013). Research has been inconsistent in identifying risk factors predicting work disability in those with Rheumatic diseases. The majority of research has focused on work cessation, on individuals with rheumatoid arthritis, and has not included a broad array of risk factors such as demographic, health and work characteristics (Allaire et al., 2013, Bansback et al., 2012).

In terms of demographic characteristics a number of factors were found to be indicative of higher fatigue levels, impaired worker role functioning and poor self-rated health. Younger participants were found to have significantly higher levels of difficulty in work role functioning in comparison to the older participants. This could be because the older participants, who have their disease longer, have developed strategies to manage the demands of their work. No differences were found in the AWS which is in contrast to a previous study which found that younger individuals perceived more arthritis spill-over (Gignac et al., 2006). Similar to this current study, Bansback et al. (2012) found that older individuals with RA had less reduced work performance than younger individuals. While many previous studies of work disability have found that older patients have an increased chance of becoming work disabled, it is important to note that many studies have examined age in relation to work cessation as opposed to how older participants who are still in employment are functioning (De Croon et al., 2005). It may be that older adults view their difficulties as age normative and therefore report less difficulties than younger adults with rheumatic diseases (Mowlds et al., N.P Thesis). Inconsistent findings have been found when specifically examining age and work functioning in those currently working (Bansback et al., 2012, Utset et al., 2015).

Women had higher levels of general, physical and mental fatigue, increased difficulty in work role functioning and decreased self-rated health than men. A small number of previous studies have found that, in those currently working, women have higher levels of fatigue and more difficulties in functioning in work than men (Repping-Wuts et al., 2008, Haglund et al., 2013). Direct comparison of the consequences for males and females is difficult because of the difference in gender distribution of RA. Perhaps future research could have a more equal gender distribution to make a more accurate comparison.

In this current study, those with a university level education have significantly lower disease activity than those with up to second level education. However, they had significantly more difficulty in meeting the mental and social demands of work in comparison to those with a second level education. Perhaps those with third level education are more inclined to have jobs that involve greater mental demands. Further research is required to explain these differences.

Co-morbidity is becoming increasingly prevalent resulting in an increased burden on health services globally (Valderas et al., 2009). A limited number of studies have explored the impact of co-morbidity on work ability of those with a rheumatic disease (Schofield et al., 2014). It is therefore interesting to examine the prevalence of co-morbidity and its impact on work functioning. Forty percent of respondents identified having at least one chronic condition in addition to their rheumatic disease. In comparison to those with no co-morbidity, those with more than one other chronic condition had significantly (i) higher disease activity, (ii) more severe fatigue, (iii) more difficulties with worker role functioning, (iv) higher arthritis work spill-over and (v) lower self-rated health. Thus, the focus of policy makers and health professionals should not only be on one specific disease, but also identify those with co-morbidities who appear to be at higher risk for work related difficulties. Health care workers should monitor those with co-morbidity and perhaps prioritise this group for intervention (Gijsen et al., 2001). One study found no association between co-morbidity and work productivity (Bansback et al., 2012). However recent research indicates that the probability of being out of the labour force for those with rheumatic disease increases with higher numbers of co-morbidities (Schofield et al., 2014).

Those with a disease duration of less than five years had significantly higher fatigue-related reduced activity and fatigue-related reduced motivation than those with longer disease durations. Previous studies have found no association between disease duration and fatigue levels (Pollard et al., 2006). An interesting finding is that no significant association was found between disease duration and worker role functioning despite previous research showing that greater levels of work disability is related to longer disease duration (Tillett et al., 2015). A possible explanation for these results is that those who are experiencing higher fatigue levels in the early stages of their disease stop working, whereas those with a longer disease duration, who have managed to remain in work, develop effective strategies earlier in their disease to manage their fatigue. For example in the qualitative findings some participants described developing fatigue management strategies through trial and error over time. It is important therefore for those who are recently diagnosed to access interventions early to develop effective management strategies and maintain work productivity over time.

Work characteristics

Examining different worker profiles also provided some interesting findings. Those working in public service had higher levels of mental fatigue and difficulty in overall work functioning, in comparison to those self-employed or working in the private sector. While it appears previous research has not explored differences in work functioning based on job sector, other studies have found that having more control or autonomy in work activities are predictors of better work functioning (Bansback et al., 2012, Allaire et al., 2013). Perhaps those in the private sector have more autonomy in managing the demands of their work in terms of scheduling etc. and can adapt their work demands depending on their symptoms. Further research is needed to confirm this finding and to explore if there are differences in contextual factors between private and public sector employment which enable individuals with Rheumatic diseases to function better.

When compared to those working full-time, employees working part-time had significantly higher disease activity and significantly more severe fatigue in all the fatigue categories except mental fatigue. A possible explanation is that perhaps those who are working part-time are doing so as a result of their high disease and severe fatigue levels. There were no significant differences between working part-time and full-time in arthritis work spill-over, worker role functioning (except for managing the physical demands of their job) or self-rated quality of life. It therefore remains that inconsistent evidence exists regarding the impact of working hours on work ability and further research is warranted (De Croon et al., 2005).

There were no significant differences between the three categories of manual, non-manual, and mixed manual and non-manual jobs for arthritis work spill-over, worker role functioning (except for managing mental demands) or self-rated quality of life. On post-hoc analysis, it is the non-manual workers who had significantly greater difficulty in managing the mental demands of their work in comparison to manual workers. This is partially supported by the qualitative findings whereby participants described cognitive difficulties in work such as concentration and memory when fatigued. This may be reflective of the higher mental, rather than physical demands, required in such jobs. Inconsistent evidence exists on whether cognitively demanding jobs are associated with decreased work functioning with some studies suggesting that high psychological job demands, do not predict low work ability (Gignac et al., 2011) and others finding an association (Utset et al., 2015, Yelin, 2007). Future research could focus on examining factors relating to fatigue and work functioning in non-manual workers.

8. Conclusions

The majority of the study participants are working full time in non-manual jobs. The majority had informed their employers of their arthritis but those who had not feared the repercussions of this on their jobs and prospects for promotion.

In meeting the requirements of work, the physical demands, which involves activities such as moving around in work, lifting and carrying objects, and staying in the one position for long periods, cause the greatest amount of difficulty for those in employment.

Disease severity is significantly associated with the multiple demands of work, the level to which work and arthritis are inter-related and health-related quality of life for those with arthritis in employment.

The majority of people with Rheumatic Diseases, who are currently working, experience severe fatigue with physical fatigue being the most problematic. Fatigue is significantly related to difficulties in meeting the multiple demands of work, the extent to which work and arthritis are inter-related and self-rated quality of life.

Those with severe fatigue have significantly more difficulty in work, their arthritis impacts more severely on their work and vice versa, and they have significantly lower health-related quality of life. Interventions are required in the work place to reduce the impact of fatigue and assist those in employment to maintain employment.

Those with chronic diseases in addition to their arthritis have significantly higher levels of fatigue, significantly more difficulty in work, their arthritis impacts more severely on their work and they have significantly lower health-related quality of life. This group of people should be identified for early and regular interventions by health professionals. Policy makers need to be cognisant of the range of difficulties experienced by people with more than one chronic condition.

There are a number of demographic and work-related characteristics that impact on people with arthritis and their ability to participate in paid employment. Employers and co-workers need education on the impact of these characteristics on work performance.

The primary aim of this study was to investigate the impact of fatigue in rheumatic diseases on work ability. The findings show that people with rheumatic diseases are experiencing severe fatigue which interferes with several aspects of their work. Policies and interventions are therefore required to reduce the impact of fatigue on work to enable the people with rheumatic diseases to remain in employment.

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Appendix 1: Definition of terms

Term	Definition
95% confidence interval	The range of values within which we can be 95% sure that the true value lies for the whole population of patients from whom the study patients were selected (Cochrane Collaboration, n.d.) .
Analysis of variance (ANOVA)	Analysis of variance (ANOVA) is so called because it compares the variance (variability in scores) between the different groups (believed to be due to the independent variable) with the variability within each of the groups (believed to be due to chance) (Pallant, 2010).
Anklosing Spondylitis	Anklosing spondylisitis is one of a group of rheumatic disorders that affect the spinal column, the sacroiliac joints and the peripheral joints. It involves inflammation of the tissues attaching tendons, ligaments and joint capsules to bone and inflammation of the synovium (a thin layer of tissue that lines the joints) (American College of Rheumatology, n.d.).
Co-morbidity	Conditions that co-occur with an index condition of interest are considered to be co-morbid with the index condition, with the combination referred to as co-morbidity (Van den Akker et al., 1996).
Constant comparative method	The constant comparative method is a process used to analyse qualitative data whereby the researcher compare and contrasts data in a search for frequent consistencies (Creswell & Plano Clare, 2011).
Correlation	Correlation is a measure of the extent to which two or more variables vary together (Watson et al., 2005)
Disease activity (PtGA)	The Patient Global Assessment of Disease Activity (PtGA) is a one item scale that measures the overall way a Rheumatic disease affects an individual at a point in time. It involves the patient rating their disease activity on a visual

	analogue scale ranging from 0-10. The higher the score on the 0-10 scale, the higher the disease activity (Anderson et al., 2011)
Fatigue	Fatigue is a subjective symptom which may occur in patients with many different diseases including those with rheumatic disease. There is no consensus for a definition of fatigue in the literature Most authors define fatigue as an overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work (Repping-Wuts,van Riel & Achterberg, 2009).
Fibromyalgia	Fibromyalgia is a disorder of unknown cause characterized by widespread pain, abnormal pain processing, sleep disturbance, fatigue and often psychological distress. Fibromyalgia is a disorder of unknown cause that causes widespread pain and tenderness (sensitive to touch), sleep disturbance, fatigue and often psychological distress (American College of Rheumatology, n.d.).
Gout	Gout is a common form of inflammatory arthritis resulting from deposition of uric acid crystals in tissues and fluids within the body. This process is caused by an overproduction or under excretion of uric acid. Gout will typically manifest itself as an acutely red, hot, and swollen joint with excruciating pain (American College of Rheumatology, n.d.).
Independent T-test (Two sample T-Test)	Independent T-test (two sample T-Test) is the statistical test used to accept or reject the null hypothesis when comparing two means (Curtis & Drennan, 2013).
Mean	An average value, calculated by adding all the observations and dividing by the number of observation (Cochrane Collaboration, n.d.).
Multimorbidity	Having at least one other separate chronic disease in addition to rheumatic disease.
Normally distributed	Normal distributions are symmetrical bell-shaped curves with the greatest

	frequency of scores in the middle and lower frequency of scores at either extremity. A normal distribution is centred around the mean and the spread of the curve is determined by the standard deviation (Curtis & Drennan, 2013).
N-vivo	N-vivo is a qualitative software analysis package (Bazeley & Jackson, 2015).
Osteoarthritis (OA)	Osteoarthritis (OA) is a disease of the entire joint involving the cartilage, joint lining, ligaments, and underlying bone. The breakdown of these tissues eventually leads to pain and joint stiffness. The joints most commonly affected are the knees, hips, and those in the hands and spine (American College of Rheumatology, n.d.).
Pearson Product moment correlation (r or rho)	Pearson's correlation coefficient is denoted by r (rho). A value close +1 or -1 indicates a positive or negative linear relationship (Curtis & Drennan, 2013). The strength of the correlations can be interpreted using the guidelines proposed by Cohen (1988), weak correlations range from r=.10 to .29, moderate strength correlations range from r=.30 to .49, and strong correlations range from r=.50 to 1.0.
Polymyalgia Rheumatica (PMR)	Polymyalgia rheumatica (sometimes referred to as PMR) is a common cause of widespread aching and stiffness in older adults. The typical symptoms of PMR are aching and stiffness about the upper arms, neck, lower back and thighs (American College of Rhematology, n.d.).
Psoriatic Arthritis	Psoriasis is a disease in which scaly red and white patches develop on the skin. Psoriasis is caused by the body's immune system going into overdrive to attack the skin. Some people with psoriasis can also develop psoriatic arthritis, when the immune system attacks the joints as well, causing inflammation (American College of Rhematology, n.d.).
P-value	The probability (ranging from zero to one) that the results observed in a study

	could have occurred by chance (Cochrane Collaboration, n.d.).
Qualitative	Qualitative research is any form of data collection that generates narrative or non-numeric information and focuses on the meanings and interpretations of the participants (Bowling & Ebrahim, 2005).
Quantitative	Quantitative research focuses on measuring quantities and relationships between attributes, following a set of scientifically rigorous procedures.
Rheumatoid Arthritis	Rheumatoid arthritis is a systemic inflammatory disease which manifests itself in multiple joints of the body. The inflammatory process primarily affects the lining of the joints (synovial membrane), but can also affect other organs. The inflamed synovium leads to erosions of the cartilage and bone and sometimes joint deformity. Pain, swelling, and redness are common joint manifestations (Silman & Hochberg, 2001).
Sequential exploratory mixed methodology study design	A mixed methodology study design which involves an initial phase of qualitative data collection, followed by quantitative data collection and analysis. The findings are integrated in the interpretation phase.
Standard deviation	The standard deviation is a measure of dispersion based on the differences of values from the mean value (Cochrane Collaboration, n.d.).
Statistical Package for Social Sciences (SPSS)	Statistical Package for Social Sciences (SPSS) is a quantitative software analysis package (Pallant, 2010).
Statistical significance	Statistically significance refers to a result that is unlikely to have happened by chance. The usual threshold for this judgement is that the results, or more extreme results, would occur by chance with a probability of less than 0.05 if the null hypothesis was true. Statistical tests produce a p-value used to assess this (Cochrane Collaboration, n.d.).

Systemic Lupus Erythematosus (SLE)	Systemic Lupus Erythematosus is an autoimmune disease in which the immune system produces antibodies to cells within the body leading to widespread inflammation and tissue damage (American College of Rhematology, 2013).
Systemic Sclerosis(SSc)	Systemic Sclerosis (SSc) is a disease affecting the skin and other organs of the body. Scleroderma is one of the autoimmune rheumatic diseases, meaning that the body's immune system is acting abnormally. The main finding in scleroderma is thickening and tightening of the skin, and inflammation and scarring of many body parts leading to problems in the lungs, kidneys, heart, intestinal system and other areas (American College of Rheumatology, 2013).
Thematic analysis	Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within qualitative data (Braun & Clarke 2006)

Appendix 2: Questionnaire pack (quantitative phase)

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Consent form

Research team: Dr. Deirdre Connolly, Ms. Lynn O' Toole, Dr. Finbarr O'Shea, Dr. Michele Doran.

I have read and understood the participant information leaflet and I consent to taking part in this research study. I understand that agreeing to take part means that I am willing to complete the study questionnaires.

I understand that all information I give will be treated confidentially. I understand that if I participate in the interview phase the researcher will stop the interview if I become upset and will provide support or find the relevant support for me to access. I understand that I can withdraw from the study at any stage.

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.

Please fill in the following if you consent to take part in this research study:

PARTICIPANT'S NAME (PRINT PLEASE):

____

PARTICIPANT'S 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.

INVESTIGATOR'S SIGNATURE:

____

Date: ______________________________

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Participant information leaflet

Study title: An exploratory study of the impact of fatigue in Rheumatic diseases on perceptions to perform work and the effectiveness of workplace accommodations.

Research Team: Dr. Deirdre Connolly, Ms. Lynn O' Toole, Dr. Finbarr O'Shea, Dr. Michele Doran.

Why is this study being done?

This study is being carried out by the Discipline of Occupational Therapy, Trinity College, Dublin in collaboration with the Rheumatology Department, St. James' Hospital. Research indicates that Rheumatic diseases can negatively impact ability to perform work. Fatigue is a common symptom in those with Rheumatic diseases which can cause such difficulties. Employers are required by legislation to support those with such conditions to remain in the workplace. You are therefore being invited to participate in a study to explore the impact of fatigue in Rheumatic diseases on perceptions to perform work and the effectiveness of workplace accommodations. To be eligible for this project participants must have a confirmed Rheumatic disease, be aged between 18 -65 years and currently working.

What does the research involve?

This research involves two parts. The first part of the study involves completing five short questionnaires. These questionnaires include a demographic questionnaire and examine fatigue levels, the impact of fatigue on daily life, level of difficulty in common work-related activities and self-rated health.

The second part of this study requests those who complete the questionnaires to participate in a 30-40 minute focus group discussion with other individuals with Rheumatic diseases. Focus group questions will explore the impact of fatigue on work ability and perceptions of the barriers and facilitators to remaining in employment and the extent of and types of reasonable accommodations employers are providing. This focus group discussion will be audio-recorded and fully transcribed. You will have an opportunity to review the content and remove any of your comments which you don't want to be used in the study findings. If you are willing to participate in this group discussion, you can provide your name and contact details at the end of the questionnaires.

You can choose not to take part in any way in this study. You can also choose to take part in the first part of the study (completion of questionnaires) and not take part in the second part (group discussion). Either decision is entirely up to you and will not affect your current or future care in St. James' Hospital in any way.

Benefits of taking part:

Unfortunately, there are no direct benefits to you for taking part in this study. However, the findings of the study may be valuable in identifying strategies needed in assisting those with Rheumatic diseases in work.

Risks of taking part:

There are no anticipated risks to you in participating in this study. However, some issues could be considered sensitive as this study will examine your ability to perform work-related activities as a result of fatigue and/or your Rheumatic disease and experiences of workplace accommodations. If you do find any element of the study distressing you can withdraw from the study at any time without affecting your current or future care in St. James' Hospital in any way. Contact details for support organisations are provided at the end of this leaflet. You can also discuss concerns which you may have relating to your conditions impact on work with your rheumatology health care team.

Confidentiality:

The questionnaires you fill out are confidential and will only be seen by the research team. You are not required to put your name on these questionnaires. Your name will not be published and will not be disclosed to anyone outside the research team. Your participation in the research is voluntary, and you may withdraw at any stage without affecting your care in St. James' Hospital in any way. All hardcopy records of completed questionnaires and group discussion transcripts will be kept in a locked filing cabinet, and stored on a password protected computer. This information will be stored for five years, as considered best practice, after which time it will be destroyed.

How do you take part?

If you wish to participate in the first part of the study only, please complete the questionnaires that the secretary of the clinic gave you when you registered for the clinic today, and put your completed forms in the red box at the registration desk. If you are also willing to participate in the group discussion, please complete the contact details section at the end of the questionnaire before putting your completed questionnaires in the red box. Thank you very much for taking the time to read this information letter and for considering participating in this study. If you would like to get some further information about the study before making your decision you can contact Deirdre Connolly at the contact details below.

Dr. Deirdre Connolly

Discipline of Occupational Therapy,

Trinity College Dublin.

Tel: (01) 8963216

Email: connoldm@tcd.ie

Contact Details for Support Organisations

Samaritans 116 123

Arthritis Ireland 1890 252 846

Please complete the following questionnaires after reading the information leaflet and if the following apply:

You are aged between 18 and 65

You have a confirmed diagnosis of a Rheumatic disease

You are currently working **or** have been working in **paid employment** the past 24 months

Demographic Questionnaire

1.	Age (please check ✓ only one)	18 – 30 ☐ 31 – 40 ☐ 41 – 50 ☐ 51 – 60 ☐ 61 – 67 ☐	
2.	Gender	Male ☐ Female ☐	
3.	County of Residence		
4.	Rheumatic Condition Type	Rheumatoid Arthritis ☐ Psoriatic Arthritis ☐ Osteoarthritis ☐ Systemic Lupus Erythematosus ☐ Ankylosing Spondylitis ☐	Fibromyalgia ☐ Systemic Sclerosis ☐ Gout ☐ Polymyalgia rheumatica ☐ Other (please specify)__________________
5.	Other health conditions (not rheumatic)	Yes ☐ No ☐ Please specify: ____________________	
6.	Duration of Condition	Less than 5 years ☐ 6-10 years ☐ 10 years or more ☐	

7.	Disease Activity	Please circle a number below from 0-10 to indicate your overall assessment of your disease activity during **the last week** 0 1 2 3 4 5 6 7 8 9 10 None Severe
8.	Marital status (check✓ only one)	Single ☐ Married ☐ Separated/ divorced ☐ Widowed ☐
8.	Living situation	Living alone ☐ Living with other ☐
9.	Highest level of education	Primary ☐ Secondary as far as inter/junior cert ☐ Secondary to leaving cert ☐ College/University ☐
10.	Employment Status (please check ✓ only one)	Currently working ☐ Not working currently but worked in the past 12 months ☐ Not working currently but worked in the past 24 months ☐ Have not worked in the past 24 months ☐ Please Specify length of time not working: ______________________________________
11.	Please state your current or most recent employment: ______________________________________ Have you told your employer about your Rheumatic disease?	

	Yes ☐ No ☐ If no, why? ____________________________________	
12.	Check the box that best describes your current or most recent employment	Non-manual (e.g. administrative, managerial, supervisory, office and other professional, such as teacher) ☐ Mixed, non-manual and manual (e.g. sales and service occupations such as waitress, personal care attendant, patient care nurse, nurse's aide, driver) ☐ Manual with no supervisory duties (e.g. carpenter roofer, loader) ☐ Private company ☐ Public Service ☐ Self-employed ☐
	Please indicate your employment hours	Full-time ☐ Part-time ☐
14.	If you have stopped work in the past 24 months could you please indicate if you are:	Temporarily off-sick ☐ Unemployed ☐ Permanently stopped work due to condition ☐ Retired ☐

Multidimensional Fatigue Inventory - MFI

Below is a list of statements that describe how people sometimes feel. Please read each item carefully, then circle the number next to each item which best describes how true each statement has been for you in the **past 7 days.**

	Yes, that is true				**No that is not true**
I feel fit.	1	2	3	4	5
Physically, I feel only able to do a little.	1	2	3	4	5
I feel very active.	1	2	3	4	5
I feel like doing all sorts of nice things.	1	2	3	4	5
I feel tired.	1	2	3	4	5
I think I do a lot in a day.	1	2	3	4	5
When I am doing something, I can keep my thoughts on it.	1	2	3	4	5
Physically I can take on a lot.	1	2	3	4	5
I dread having to do things.	1	2	3	4	5
I think I do very little in a day.	1	2	3	4	5
I can concentrate well.	1	2	3	4	5
I am rested.	1	2	3	4	5
It takes a lot of effort to concentrate on things.	1	2	3	4	5
Physically I feel I am in a bad condition.	1	2	3	4	5
I have a lot of plans.	1	2	3	4	5
I tire easily.	1	2	3	4	5
I get little done.	1	2	3	4	5
I don’t feel like doing anything.	1	2	3	4	5
My thoughts easily wander.	1	2	3	4	5
Physically I feel like I am in excellent condition.	1	2	3	4	5

	Work Role Functioning Questionnaire (Amick et al., 2004) Please indicate the percentage of time you have experienced problems meeting the following work demands as a result of their physical and emotional health during the previous week. If you are not currently working, please consider the impact of these demands when you were working:	Difficult all the time	Difficult most of the time	Difficult half of the time	Difficulty some of the time	Difficult none of the time	Does not apply to my job
WORK SCHEDULING DEMANDS							
1	Work the required number of hours						
2	Get going easily at the beginning of the workday						
3	Start on your job as soon as you arrived at work						
4	Do your work without stopping to take extra breaks or rests						
5	Stick to a routine or schedule						
OUTPUT DEMANDS							
6	Handle the workload						
7	Work fast enough						
8	Finish work on time						
9	Do your work without making mistakes						
10	Satisfy the people who judge your work						
11	Feel a sense of accomplishment in your work						
12	Feel you have done what you are capable of doing						
PHYSICAL DEMANDS							
13	Walk or move around different work locations (for example, go to meetings)						
14	Lift, carry or move objects at work weighing more than 10 pounds						
15	Sit, stand, or stay in one position for longer than 15 minutes while working						

	Work Role Functioning Questionnaire (contd.) Please indicate the percentage of time you have experienced problems meeting the following work demands as a result of their physical and emotional health during the previous week. If you are not currently working, please consider the impact of these demands when you were working:	Difficult all the time	Difficult most of the time	Difficult half of the time	Difficulty some of the time	Difficult none of the time	Does not apply to my job
16	Repeat the same motions over and over again while working						
17	Bend, twist or reach while working						
18	Use hand-held tools or equipment (for example, a phone, pen, keyboard, computer mouse, drill, hairdryer or sander)						
Mental Demands							
19	Keep your mind on your work						
20	Think clearly when working						
21	Do work carefully						
22	Concentrate on your work						
23	Work without losing your train of thought						
24	Easily read or use your eyes when working						
Social Demands							
25	Speak with people in-person, in meetings or on the phone						
26	Control your temper around people when working						
27	Help other people to get work done						

Arthritis Work-Spill-over Questionnaire (Gignac et al., 2006).

Please indicate to what extent you agree with the following statements regarding your **Rheumatic disease** and your employment

In general...	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A
The demands of my job make it difficult for me to take good care of my Rheumatic disease	☐	☐	☐	☐	☐	☐
It takes a great deal of my energy and time to manage my work demands.	☐	☐	☐	☐	☐	☐
My Rheumatic disease suffers because of the demands of my work	☐	☐	☐	☐	☐	☐
The demands of my Rheumatic disease make it difficult for me to do as good a job at my work as I would like	☐	☐	☐	☐	☐	☐
It takes a great deal of my energy and time to manage the demands of my	☐	☐	☐	☐	☐	☐

Rheumatic disease						
The quality of my work suffers because of the demands of my Rheumatic disease	☐	☐	☐	☐	☐	☐

EuroQoL – 5D – 3L

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

Self-Care

I have no problems with self-care ☐

I have some problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

Usual Activities (e.g. work, study, housework, family or leisure activities)

I have no problems with performing my usual activities ☐

I have some problems with performing my usual activities ☐

I am unable to perform my usual activities ☐

Pain/Discomfort

I have no pain or discomfort ☐

I have moderate pain or discomfort ☐

I have extreme pain or discomfort ☐

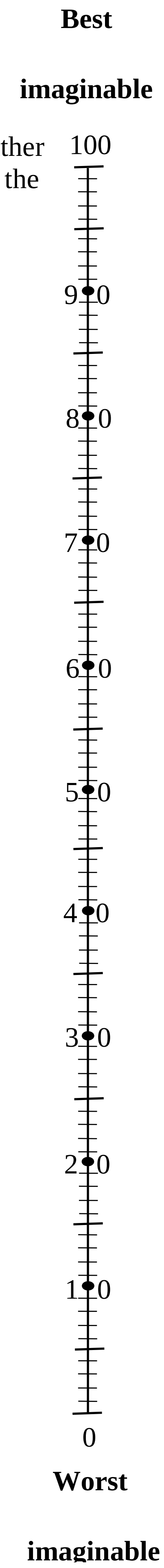
Anxiety/Depression

I am not anxious or depressed ☐

I am moderately anxious or depressed ☐

I am extremely anxious or depressed ☐

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.



TRINITY COLLEGE DUBLIN

DISCIPLINE OF OCCUAPTIONAL THERAPY.

Contact Detail Form.

Please leave your contact details below if you are willing to take part in a focus group discussion at a later date to further discuss the issues raised in this questionnaire. The researchers Dr. Deirdre Connolly or Lynn O' Toole will contact you to arrange a date to complete a consent form and group discussion.

Name:

Address:

Contact Telephone number:

Appendix 3: Focus group and interview schedule (qualitative phase)

Introduction (consent forms, introductions, aim of FG)

How does your arthritis impact on work? - the main effects.

How do you manage these issues?

What *supports* does your employer give you?

Have you *told* your employer and colleagues about your condition (disclosure)

Fatigue specific questions:

Is fatigue an issue for you in work?

How does fatigue impact?

How do you manage it?

What are the most effective strategies?

Have you had to make any changes to your work routine due to your fatigue?

> E.g. change to part time- if so how has the affected you (salary?)

Are your employers and colleagues understanding of your fatigue?