

Title: Living with Chronic Pancreatitis: A Qualitative Study.

Abstract

Objective: Recent literature acknowledges the impact of this progressive and debilitating disease on psychological and social well-being, but the plight of those with chronic pancreatitis remains unknown and hidden. The aim of this study was to develop an understanding of what it means to live with chronic pancreatitis.

Design: Qualitative study based on philosophical hermeneutics using multiple unstructured interviews.

Participants: Fourteen people with chronic pancreatitis and five relatives took part in 41 interviews in 2007-2008.

Setting: Tertiary clinic in Ireland

Results: The meaning of living with chronic pancreatitis for participants in this study is 'enduring disruption'. Enduring has a two-fold meaning; it symbolises the perpetual or permanent nature of disruption that occurs at physiological, social and psychological levels (i.e., 'suffering'). Enduring also means 'to tolerate' and encompasses how the participants and their families cope and manage the overall transition from well person to a person with chronic pancreatitis.

Discussion: This study offers an alternative perspective to previous quality of life research and presents a challenge to the emphasis on management of the pathophysiological processes and treatment of chronic pancreatitis that is decontextualised from the person's everyday living. Healthcare professionals need to understand and support people with chronic pancreatitis.

Key Words: Chronic Illness; Chronic Pancreatitis; Enduring disruption; Transition; Suffering.

Introduction

The purpose of this study was to develop an understanding and construct a meaning of living with chronic pancreatitis. Recent international literature acknowledges the impact of this progressive and debilitating disease on psychological and social well-being and efforts have been directed at assessing health-related quality of life. However, no comparable qualitative work exists and the plight of those with a diagnosis of chronic pancreatitis remains unknown and hidden.

Chronic pancreatitis (CP) is a chronic clinical disorder characterised by permanent damage to the pancreas, the development of histological evidence of inflammation and fibrosis and followed generally by progressive exocrine and endocrine insufficiency and sometimes calcification.^{1,2,3} It is a progressive and debilitating disease with a long-term prognosis that has been described as dismal.⁴ Throughout the illness trajectory there are significant challenges in relation to progression, treatment options and outcomes as well as debilitating intractable pain, steatorrhea, malabsorption, malnutrition, diabetes mellitus, an increased risk of developing pancreatic cancer and a range of other complications.^{3,5} About 50% of patients with CP will undergo surgery to manage their pain or complications; for many, however, despite apparent technical success no measurable improvement is seen in quality of life.¹

The prognosis of CP is variable and is affected by ongoing alcohol consumption. Continuous pain and continued drinking of alcohol in those with alcoholic CP have a negative influence on quality of life. The presence of symptoms and risks may lead to concomitant psychosocial problems, loss of work, narcotic addiction and consumption of health-care resources.³

Moreover, these life-changing events tend to occur in a population whose mean age is 40-50

years, although there have been incidences of CP developing in patients under 30 years and age-standardised rates are consistently higher in males than females.¹

Consequently, living with the condition creates a life-long demand on healthcare and social resources and presents various and continuing quality of life (QoL) challenges. Although there has been recent recognition of the wider impact of CP on patients' psychological and social well-being, and the burden of living with the condition has been recognised, it is not well documented.^{4,6,7}

In the majority of QoL studies, the focus was on measuring QoL before and after an intervention and not on comparing QoL in those with chronic pancreatitis and a healthy control group. This suggests that the primary goals for patients with CP are intervention-based, thus perpetuating the notion that interventions are a panacea for QoL issues. Consequently, the findings of these studies are of limited value in assessing the overall impact on those who live with the condition. More recent studies acknowledge the limitations of previous work and have attempted to evaluate quality of life in CP independent of therapeutic interventions.^{4,8,9} Some of these studies demonstrated that, regardless of treatment regime, patients with CP reported considerably lower scores in all SF-36 scales, with the most pronounced impairments in the 'role-limitations physical', 'role-limitations emotional' and general health perception.^{8,9} Pancreatic morphology changes were not significantly associated with any domain of health-related QoL and neither the type of pancreatic surgery nor endoscopic therapy were able to modify substantially the physical and mental domains explored by the SF-36.^{8,9} Fitzsimmons et al⁴ contend that patients with CP face a wider range of QoL issues such as fear of future ill-health and difficulty in

sleeping. Moreover, the identification of guilt about continued alcohol use or the burden of abstinence were issues of particular concern.

The impact of pathological changes associated with CP can be devastating. Intractable pain, malnutrition and/or maldigestion and diabetes mellitus could each, in their own right, be considered a chronic illness and each demands significant life adaptations. Add to these the uncertainty of the natural course of the disease, the ambiguity associated with treatment options and outcomes, and the ultimately poor prognosis and there is a significant cumulative effect in respect of patients' physical, psychological and social well-being. Furthermore, although recent studies have reported that the prevalence of heavy alcohol consumption is lower (45-50%) than the previously reported 70-90%,^{10,11,12} it is incumbent on all those with a diagnosis of CP, including those who have a history of alcohol abuse to abstain. Moreover, not only has smoking been confirmed as an independent risk factor for the development of CP^{11,12,13}, a significant association between co-existing very heavy alcohol consumption and cigarette smoking and CP has also been established^{11,12}. Given the known alcohol-smoking relationship the findings of these studies have implications for disease progression and quality of life in those who drink alcohol and smoke. For many of those who have idiopathic CP, there is a sense of helplessness associated with not knowing how or why they have developed this condition.

No aspect of QoL has been examined amongst patients with CP living in Ireland. Yet, an understanding of living with chronic pancreatitis is important because of the physical, psychological and social burdens placed on individuals so diagnosed. This group may have needs and concerns common to other chronic illnesses but it is the manner in which these are particularised that necessitates explication. Furthermore, the impact and burden on immediate

or close family and informal carers is not known. Although people with CP can spend significant periods of time in the acute hospital setting, in keeping with many chronic illnesses much of the management is undertaken by the individual and their family in the community. Identifying the collective burden for patients and their relatives may assist with the development and implementation of strategies that can maximise the potential for self-management of this condition.

The Study

Aim

To develop an understanding and construct a meaning of living with chronic pancreatitis and, in so doing, to:

- illuminate the everyday contextualised and culturally situated lives of the participants, and
- explicate the meaning of living with chronic pancreatitis as a basis for understanding and interpretation by others.

Methodology

As the focus of the study was on interpreting and understanding what it means to live with chronic pancreatitis, a qualitative methodology was selected and hermeneutics, the science and art of interpretation, provided an appropriate philosophical underpinning. In this study, the philosophy of Gadamer¹⁴ informed and directed the study.

Participants and Study site

The sample for the study was purposeful as all potential participants were living with chronic pancreatitis. The sample was drawn from a population of all patients (approximately 75) who, at the time of the commencement of the study were under the care of a hospital-based pancreatic specialist in Ireland. [Participants were recruited to the study through the clinical nurse specialist \(CNS\) or the Pancreas Data Controller employed for the service. The CNS distributed 14 invitations to patients with a diagnosis of CP over a period of 8 months. Four participants were recruited by this means. The Pancreas Data Controller identified persons with a primary or secondary diagnosis of CP \(using ICD-9 codes\) through the Hospital In-Patient Enquiry \(HIPE\) database. As records were limited to the preceding two years, those with CP who had not been an in-patient during that time were precluded from participating. The data controller sent 33 invitations by post and 10 further participants were successfully recruited to the study \(Table 1\).](#)

[Participants' ages](#) ranged from 26-58, with 7 aged 40 years or under. Six of the participants were married (4 male, 2 female), the remaining 8 were single. Five of these lived with family or friends, 3 lived alone. Seven of the participants had been diagnosed with CP for 2 years or less, 4 for 2-5 years and 3 for more than 5 years. Eight of the 14 had been referred from regional hospitals located outside the immediate hospital locality. [Further details are included in Table 1.](#)

[Table 1: Participant Profiles](#)

Ethical considerations

Ethical approval for the study was obtained from the hospital site. Participants were informed of the aims of the study, that participation was voluntary and they could withdraw from the study at

any time without explanation. Written consent was obtained. All data were anonymised and kept on a password-protected computer.

Data collection

Multiple, unstructured, audio-taped conversations were conducted with each participant over a period of several months, and one participant kept a diary. Biographical and contextual data were also collected. In addition, 5 close family members were interviewed (2 wives, 1 mother, 1 daughter, 1 sister). A total of 41 individual or joint interviews were undertaken, 39 of which involved the person who had a diagnosis of CP. The remaining two, one of which was a telephone interview, were with close family members. All interviews and diary entries were transcribed, and returned to participants for comment. Participants' involvement ranged from 3-5 months with approximately 4-6 weeks between each interview.

Data Analysis

The task of analysis was to translate the participants' experiences into a construction of the meaning of living with chronic pancreatitis. The 'texts' were complex and included interview transcripts, diary entries, recorded words, text messages, written comments and the interviewer's reflections and observations about the interviews, all of which were stored in NVivo Version 7. A data analysis cycle of 4 steps (Figure 1) was used, as outlined by Fleming et al.¹⁵. Initially each participant's story was written using all sources of data,¹⁶ following which inductive coding and thematic development was undertaken through a detailed analysis of all data using NVivo 7. Using a data management system facilitated transparency and auditability as it provided a permanent record of the decision-making process throughout analysis including the labelling of codes and themes that represented the experiences of all the participants. In order

to ensure the quality and integrity of the analytic process three 'texts' were blind coded by [PC] and [CB] and then compared and reviewed. Subsequently, the codes and themes were organised into three major unifying categories as outlined below. From this, a higher level conceptual representation of living with CP as 'enduring disruption' was constructed.

Figure 1: Steps of Data Analysis

Findings and Interpretation

In this study, the meaning of living with CP was represented as 'enduring disruption' with 'enduring' having a two-fold meaning. It symbolises the perpetual or permanent nature of disruption that occurs at physiological, social and psychological levels interpreted herein as 'suffering'. Enduring also means 'to cope with' and/or 'to tolerate,' and encompasses how the participants and their families cope with the perceived restrictions arising from the condition, their capacity to tolerate them and the strategies developed to manage them, within the overall transition from well person to a person with CP. Transition to being a person with CP is a process of assimilation and acceptance of a life permanently altered and a realisation that a return to their 'old' normal is no longer possible. Together, suffering and transition form the whole of 'enduring disruption'.

Suffering

Critical analysis of and reflection on the interrelationship between the three unifying categories of 'enduring physiological disruption,' 'enduring social disruption' and 'enduring psychological disruption,' and the configuration of themes and sub-themes therein led to the proposition that for those living with chronic pancreatitis 'enduring (perpetual and permanent) disruption'

represents 'suffering'. Although the concept has been variously represented in the literature, the meaning drawn upon herein is the contemporary view of it as occurring in the 'whole person as a state of distress induced by the threat of loss of intactness or disintegration from whatever cause'.¹⁷

Being disrupted from one's wholeness is common to all suffering¹⁷ and it is conceived as being evil and undesirable.¹⁸ Despite its malevolence, suffering is seen as a naturally occurring phenomenon that is part of life.¹⁷ It involves the assignment of an intensely negative meaning to an event or perceived threat.¹⁹ However, it is also a concept that can only be characterised, not measured, as it is subjective, individualised and multidimensional (physical, psychological and social).¹⁹ Nonetheless, three forms of suffering have been identified in the literature; suffering caused by illness and treatment, suffering caused by care, and suffering that relates to existence.¹⁸ In chronic pancreatitis, as explicated by this study, the three forms of suffering are clearly seen and could be said to constitute the 'what' of suffering.¹⁷ (Figure 2).

Figure 2 Suffering in chronic pancreatitis

Enduring physiological disruption manifests itself as unpredictable daily disruptions, interspersed with episodes of escalating or salient physiological disruption. The enduring nature of the disruptions is evidenced by the reality that no participant experiences a day in which they are without some indication that the condition exists. Daily disruptions are concerned with intrusive pain, interrupted sleep, inability to eat, gastrointestinal disturbances and food intolerance, incapacitating fatigue, loss of physical strength, iatrogenic effects and complicating and co-existing pathologies.

'I feel some sort of pain everyday...at any given time I could be in pain for five minutes and the rest of the day is grand...another day, no relief whatsoever...' (5:2)

'Your ability to fight the pain goes downhill because you're run down and you're exhausted the whole time' (1:1)

Salient physiological disruptions are a feature of all participants' experiences although they vary in intensity and frequency. They are marked generally by escalating pain and severe uncontrolled vomiting and signify profound assault. I is during these times that participants are likely to feel the most severe decrement in their health. The unpredictable pattern of the symptoms in conjunction with the, sometimes, uncontrollable pain symbolises a threat to the integrity of the self.

'On the trolley that night getting all worked up...I felt myself choking, getting sick and everything'
(2:1)

'The blood was all over the place. My father was in the house and I was shouting for him and I keeled over. I don't remember feeling much pain then, I just remember being in shock because I thought I was dying, I thought, 'oh no, this is it,' (5:3)

All participants experienced enduring social disruption that encompassed their perception of voluntary or enforced alterations to their social roles, obligations and functioning. Enduring social disruption is explicated by the three themes of 'personal relationships', 'altered social

relationships', and 'altered economic circumstances'. When daily and salient physiological disruptions impact on the functional ability of the participants their roles as husband/wife, provider/worker, father/mother, and/or protector are compromised because they can no longer undertake the tasks that defined them in these roles. This seems to be based largely on their cultural and social beliefs and expectations of their role within the family. Relinquishing roles and being 'forced' to adopt a 'sick role' threatens self-identity and can also be a source of conflict.

'It's all to do with pride, going out and making a living and making your own way in the world'
(10:2)

Social isolation and withdrawal was present in the lives of all the participants, due to the limiting nature of physiological disruptions. As one participant's mother said, 'eating is such a chore for (participant's name) whereas for us eating is one of the pleasures of life' (Family Member: Mother). Another feature of marginal social engagement is related to the fact that the participants no longer consume alcohol.

'The fact that I don't drink – people in Ireland think that's weird' (1:2).

Many of the participants, particularly those (n=6) who are now unemployed and receiving disability benefits outlined how their financial position has been rendered more precarious, due to occupational disruption, economic constraints and financial vulnerability.

'I was an upholsterer...I haven't done any since I got sick...I don't have the strength to pull the cloth (2:1)

There are additional healthcare costs also because CP does not appear on the list of prescribed illnesses or disabilities that would entitle them to free medication, and sufferers cannot secure life insurance.

The unpredictable nature of the symptoms and the uncertain yet progressive illness trajectory provoke psychological and emotional responses to threat indicative of psychological distress.²⁰ Enduring psychological disruption is rooted in the participants' discernment of an altered self in illness, a sense of being different to the person they perceived they were before diagnosis. This difference is signified as disturbance in their cognitive and affective sense of normal. The sense of 'disturbed normal' is predicated on who they perceived they were before their illness, which was situated in their sense of self (defining 'me'), personal values, social milieu, social influences and life before chronic pancreatitis. Largely, the measure of the disparity was verbalised by elucidating their perception of their altered body and altered perception of self, which generates a series of emotional responses to their situation. such as 'being afraid', 'loss', 'feeling down', 'worry' and 'being angry'.

'I know probably the next bad dose could kill me...that's a fear I have' (6:1)

'At the moment I get very down...I could be on a high and suddenly the pain comes and it's like 'oh no, not again' (10:3)

Each person judges the meaning of their living with chronic pancreatitis within the context of their own lives and living, but for most it is evaluated negatively. Many feel they are no longer able to control their present and the future is unpredictable. Uncertainty and vulnerability that materialise as a consequence of tangible physical and social losses and psychological symbolic losses contribute to psychological distress and generate suffering related to existence.

It is conceived that suffering as it is characterised in chronic pancreatitis is endless and likely never to be alleviated fully because of the nature of the condition and the potential for new problems associated with disease progression and further disruption in physical, social and psychological functioning. Furthermore, it is not a steady state and oscillates on a continuum from tolerable to intolerable. Thus, the three forms of suffering identified above may not occur simultaneously or exist in isolation or with the same degree of intensity. It is their particular configuration in the context of each individual's unique situation that ultimately determines perception of their tolerability.

Transition

For the participants and their families in this study, 'enduring', as a verb, is about how they cope, and are learning to live, with CP. Coping concerns the processes by which the participants and their families continually reappraise the demands placed on them and how they think or act in those situations. An important point is that coping or tolerating in the sense in which it emerged occurred within the overall health/illness transition from 'well' person to a person who lives with CP. This transition is explicated as comprising 'coming to know' and 'adjusting/managing'. The central thesis is that coping mediates the conditions in the transition experience. Therefore, progression is not a strictly linear process, but can fluctuate depending

on changes in the nature and severity of symptoms, perceived significance of the social impact of the condition and emotional and psychological responses to all that the illness entails.

Figure 3: Transition in chronic pancreatitis.

'Coming to know' as described by participants in this study, is a complex process that marked the beginning of the health/illness transition. Initially, participants were unaware that they had begun such a transition. Most considered that the information with which they left the hospital was inadequate in facilitating their understanding and management of the condition. It was only through attempting to assimilate CP into their everyday lives that its implications became evident. For example, despite following advice, most found that symptoms either did not resolve or recurred.

'I pretty much thought that if I never drank again, then I'd never feel ill again...then it came around acutely the second time' (4:1)

Participants reported differences in the information with which they were provided. Most sought information from other sources such as the internet, family and friends, books/articles/mass media, and fellow patients but all reported that there was little 'lay' knowledge available about the condition.

'I'm still caught between what I've read and what the specialists have told me' (4:2)

Although all knew that there was no cure for chronic pancreatitis and that the condition was a life-long one, few grasped fully the meaning of its progressive nature.

'No-one has told me exactly why my pancreas has decided to continue the progression of the disease even though I'm not drinking' (7:1)

Furthermore, most did not appear to have any knowledge of long-term complications associated with CP. 'Coming to know' was significant, as it constituted the foundation on which the participants based subsequent management of their CP. Factors such as personal values and beliefs about illness behaviour, situational factors and relationships with healthcare professionals were important mediators in facilitating or constraining their coping.

'You go to casualty, you've got this triage battle...having to fight your case like a barrister for admittance into the hospital' (1:1)

'No matter what I said about he doesn't drink...I always thought they didn't believe me...'
(Family Member: Wife).

'Adjusting/managing' is concerned with a number of complex, interrelated processes that define how the participants and their families manage and adjust to living with CP. It includes coping strategies adopted and resources mobilised as a result of 'coming to know' the condition. Thus, there is a direct, synergistic relationship between 'coming to know' chronic pancreatitis and adjusting to living with it.

'Adjusting/managing' encompasses the daily living activities participants engage in to minimise the impact of symptoms of CP and maximise their health potential. Following experimentation, trial and error and testing, participants increasingly adopted strategies based on self-knowledge and bodily responses. These included handling the pain, modifying lifestyle, self-monitoring, emotional coping, drawing on social resources and interacting with the healthcare system.

'If I get a pain and I have to take a tramadol, boom, there's your appetite gone. What I usually do now is eat as much as I can in the morning so if I know it's going to kick off at least I'll have something eaten before it does' (5:2)

All participants made life-style modifications, to minimise the impact of intrusive pain, gastrointestinal disturbances and food intolerance and incapacitating fatigue, which included 'abstaining from alcohol', 'adjusting diet', 'prioritising demands' and 'struggling to live well'. Continuous 'self-monitoring' provides participants with feedback on their body's response to illness and contributes to how they make decisions.

'I've sort of made up my own diet...I've been eliminating anything that caused me to get sick' (6:1).

Most participants believe cessation of alcohol consumption is the single most important factor in their self-care. As a result, all participants attempted to stop drinking immediately following diagnosis, due mainly to fear of physiological disruption.

'I haven't had a drink in five years – I actually found it quite easy' (1:1)

'Adjusting/managing' also includes a range of coping strategies expressed here as 'emotional coping' and 'drawing on social resources' such as family, friends and professional agencies.

'When I go to [Alcoholics Anonymous] meeting, I don't think I am going because I am an alcoholic. I'm thinking of them as part and parcel of my daily routine of keeping well' (11:1)

'We're both very much in tune with how each other is feeling...she'll know when something is wrong'(3:2)

Participants also accommodated regular and necessary contact with the healthcare system for the purpose of ongoing monitoring and being treated including strategies for managing what they perceive as shortcomings within the system.

This representation of enduring disruption describes the process of transition from 'well person' to a person who lives with CP. According to Kralik et al²¹ transition is about how people respond to change over time. In this study, change was enforced by virtue of being diagnosed with CP. In 'coming to know' disrupted body and chronic pancreatitis, participants became aware of their permanently altered lives. Subsequently, in 'adjusting/managing', they came to know the nature of these alterations and mobilised coping strategies and resources to modify or minimise the impact on their current living whilst endeavouring to maintain or maximise their health potential for their future. Pivotal to this process was the distinction between awareness of a permanently altered life and knowing it as a result of living it. Adjusting and managing change through the use of self-management strategies not only indicates immersion in the transition process but is integral to it as these strategies essentially describe engagement with the process.^{22,23}

Discussion

This interpretation presents a new understanding of quality of life for the person who lives with chronic pancreatitis. Within the CP literature, research on quality of life has been confined to a medical discourse that focuses primarily on health decrements in life domains such as physiological, functional, social and emotional. Quality of life, however, is a multidimensional concept that encompasses a range of objective and subjective aspects that change in relative importance over time and in response to various life experiences.^{24,25} The adoption of the term health-related QoL is mainly a proxy for medicine's continued focus on health- and illness-related variables,²⁴ and thus, whilst there is recognition of the subjective elements of the concept of quality of life, the focus remains on achieving measurable outcomes.

The key concepts of enduring, suffering, and transition identified from the findings of this study have been the subject of an increasing proliferation of work within the realms of chronic illness. In respect of suffering, recent and contemporary empirical studies have strived to delineate the concept as it is perceived by the person experiencing it. Efforts have been directed at labelling and explicating 'expressions' of suffering as well as distinguishing the 'what' of suffering.^{17,18,26,27} Key expressions such as loss, threat, alienation, distress, feeling disempowered and loss of dignity are depicted in these studies as being reflective of the concept. Although these works have all been undertaken with persons with various chronic illnesses, their findings support the interpretation in the present study that the participants are suffering. In addition, Eriksson's representation of suffering (Figure 2) related to illness and treatment, suffering related to care and suffering related to existence¹⁸ provides an explanatory framework for the interpretation that enduring physiological disruption, enduring social disruption and enduring psychological disruption represent the of the suffering of chronic pancreatitis.

Moreover, ~~the finding herein~~ that suffering is more than 'suffering from' and encompasses existential threat is in keeping with its conceptualisation in Younger's²⁸ theory of alienation of the sufferer and Eriksson's²⁹ theory of the suffering human being.

Despite differences in theories and conceptualisations of suffering, an explicit commonality is the notion that suffering can progress to healing or transformation.^{17,28,29} Other conceptualisations, theories and research that do not specifically label suffering as the transformative factor describe a course of change or process triggered by chronic illness. Although characterised variously as adaptation,³⁰ biographical disruption,^{31,32} transformation,³³ transition²¹, and integration,³⁴ each describes what appears to be a common phenomenon associated with a process of adjustment to chronic illness. Embedded in this process is the notion of a response to the change enforced by chronic illness that is mirrored in the findings of this study.

That coming to terms with illness is dynamic and continuous, and marked by alternating periods of balance and imbalance,³³ is reflected in this study where an uncertain body and an unpredictable illness trajectory mediate the participants' acceptance. As many of the participants became more proficient in self-management, there were indications of a sense of being in control and having more confidence in managing situational uncertainties. However, their unknown future remained a source of discomfort and distress and sustaining a positive outlook was difficult in the face of disequilibrium and instability. Acceptance wavered when progress was disrupted with the participants seeming to be continually re-ordering.

Acceptance or coming to terms with chronic illness also includes a deeper psychological incorporation of changes that facilitate a reorientation or restructuring of self.^{22,33} Coming to terms with being a person with chronic illness involves finding meaning in the experience³³ and redefining self-identity in the face of adversity.^{22,31} For the participants in this study, the reality of their situation was acknowledged but emotional acceptance of themselves as a person with chronic illness had not been achieved.

Transition to being a person who lives with chronic pancreatitis, and all that it entails, is a gradual process of assimilation. This resonates with the literature where reframing what is normal, relinquishing the hope for a return to a pre-existing state and the adoption of strategies to manage situational alterations are markers of the process.^{22,33,35} Whilst it is not being claimed that participants in this study will never achieve a meaningful reconstruction of their self-identity, at the time of the study and despite the passage of time none could be said to have completed this transition.

Implications for practice

Healthcare professionals need to know that people with chronic pancreatitis endure physiological, psychological and social disruption of their lives, and that they require the support and understanding of their carers. Negative attitudes towards patients, related to assumptions of their alcohol intake, are not helpful. People with CP live in a perpetual state of transition as they undergo the process of adjusting to living with chronic pancreatitis and strive for an acceptable, albeit changing, quality of life. In this endeavour, they need the insight of committed health professionals to encourage and assist them.

Limitations

The findings of this study identify that social support (information, practical, emotional) and resources or a lack of them, facilitate or constrain aspects of the participants' adjustment to and management of chronic pancreatitis. However, these findings are essentially particularised to this group and inferences about the weighting of various factors can only be made within these parameters, and cannot be transferred to other contexts or settings.

In addition, the participants' expositions are representations of their experiences at a particular point in their lives. Therefore, the interpretation proposed here could not be said to represent the whole of their living because subsequent experiences would influence their reflection and understanding.

Conclusion

This study, undertaken from an emic perspective supplements previous QoL research and expands understanding of the complex and multidimensional experience that is living with chronic pancreatitis. ~~The meaning of living with chronic pancreatitis is enduring disruption, with suffering and transition comprising its two constitutive concepts.~~ While ~~this particular~~this interpretation and representation is new, it sheds light ~~there are parallels with previous depictions of suffering and transition.~~ Previous research supports the interpretation that suffering is an appropriate concept to represent the enduring physiological, psychological and social disruption of chronic pancreatitis for the participants in this study. Moreover, these depictions shed light on suffering related to illness and treatment, care and existence that these participants experience. and offers further validation of Eriksson's model outlined above.

Explicating suffering in this way extends and offers a new perspective on life quality in chronic pancreatitis.

In addition, ~~previous research supports~~ the interpretation ~~that transition~~ captures the process of adjusting to living with chronic pancreatitis and reflects the efforts participants are making to strive for an acceptable quality of life. In this sense, the work of living with chronic pancreatitis is more than the behavioural work of disease management but encompasses the psychological, social, vocational and existential work within the person's context and situation. This study has begun to identify some of the active processes undertaken by people who live with chronic pancreatitis. Further research in this area is needed in order to specify the work of the illness experience of chronic pancreatitis as distinct from that undertaken in other chronic illnesses. Additionally, such research may provide direction for healthcare professionals in their assessment and designation of interventions that maximise the potential for achieving a life quality that is acceptable to the individual living with the condition.

Conflict of Interest Statement

The authors declare that there is no conflict of interest.

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