



Men's experiences of rheumatoid arthritis: An interpretative phenomenological analysis

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Men's experiences of rheumatoid arthritis: An interpretative phenomenological analysis

ABSTRACT

This study qualitatively explores the psychological impact of rheumatoid arthritis, from the perspective of men who have the disease. Whilst previous research has focused specifically on women's experiences of rheumatoid arthritis, research examining men's experiences of the disease is lacking. Thus, the aim of this study is to gain insight and understanding of how men experience rheumatoid arthritis and its treatment. Utilising a combined phenomenological and ethnographic approach, semi-structured interviews were conducted via email with four men who have been diagnosed as having rheumatoid arthritis. Their data was subjected to an interpretative phenomenological analysis. Themes considered to represent men's experiences of living with rheumatoid arthritis are presented as Striving for Control, Finding Solace, Challenging Misconceptions and The Need for Purpose. The findings suggest that males' experiences of the disease have similarities with previously reported females' experiences, but are also individualistic. The men's personal perceptions, interpretations and the meanings they attach to their illness form an integral part of their experience. It is concluded that although rheumatoid arthritis necessitates some psychological adjustment, men are able to find opportunities for personal growth following their diagnosis.

KEY WORDS:	EMAIL INTERVIEWS	RHEUMATOID ARTHRITIS	MEN	ETHNOGRAPHY	INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS
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Introduction

Rheumatoid arthritis (RA) is a systemic auto-immune disease of which the cause remains unknown. Although it is characterised by swollen, damaged joints, the disease can affect the heart, lungs, eyes and skin (Arthritis Research Campaign, 2006). RA is a chronic, progressive condition causing pain, fatigue and disability, and impacts on an individual's life such that they may be unable to perform everyday tasks, participate in 'normal' activities and may require extensive surgery to replace damaged joints. The disease can present at any age and is more prevalent in women than men (Panayi, 2009). At present there is no cure for RA; medical intervention aims to reduce inflammation and slow down progression of the disease, thus drug treatment is continuous and complex with a potential for serious side effects (The Kings Fund, 2009a). Whilst the physical symptoms associated with RA are extensive, the psychological impact is also considerable (Dixon, Keefe, Scipio, Perri & Abernethy, 2007). Thus, the disease which affects approximately 1% of the UK population can be challenging to live with (Sinclair & Blackburn, 2008).

The biopsychosocial model proposes that the physical symptoms experienced by individuals with RA are influenced by crucial biological, psychological and social factors (Keefe et al, 2002). Indeed, there is much empirical support for the model. Dixon et al's (2007) meta-analysis has maintained that psychosocial therapies have a beneficial effect in RA populations not only on psychological variables such as anxiety and depression, but also on physical variables such as joint swelling and pain. Similarly, another meta-analysis has advocated psychological interventions as an effective adjunct to conventional drug therapy in RA (Astin, Beckner, Soeken, Hochberg & Berman, 2002). These studies have highlighted how biological and psychosocial factors are interrelated and that both affect the symptoms of RA, demonstrating the complexity of this illness.

In addition, previous research has established a link between RA and psychological health. However, many studies have utilised quantitative methodologies resulting in data that arguably lacks depth. For example, Neugebauer, Katz and Pasch's (2003) longitudinal research examined the relationship between physical function and psychological well-being in individuals with RA and found that reduced physical function was associated with both decreased ability in leisure and social activities and increased unfavourable social comparisons; this predicted low satisfaction with abilities, which in turn was associated with increased depression. Thus, the findings indicate a complex, indirect relationship. Indeed, Neugebauer et al (2003) conceded that their study illustrated how the subjective meaning people attach to their reduced physical function (how satisfied they are with their physical ability), rather than their actual physical impairment affects their psychological health. Indeed, there is further support for the claim that the subjective beliefs and meanings individuals attach to their RA influences their well being. Previously, Schiaffino, Shawaryn and Blum (1998) have demonstrated how patients' beliefs about the seriousness of RA interact with illness severity in predicting levels of depression. Similarly, perceptions of RA have been associated with depression and life satisfaction, whilst self consciousness has been related to anxiety, pain and fatigue (Treharne, Kitas, Lyons & Booth, 2005). Recently, Graves, Scott, Lempp and Weinman (2009) examined the relationship between RA related beliefs and disability and quality of life; they found that whilst stronger beliefs about control over

one's RA and its treatment was related to improved physical and psychological functioning, beliefs did not correspond to clinical markers of disease activity. This finding is significant as it indicates that beliefs may influence functioning regardless of disease severity. However, as Graves et al (2009) concluded, there is wide variation amongst individuals with RA; the researchers conceded their study did not indicate how beliefs and RA representations may change over the course of this progressive and unpredictable disease. Indeed, Treharne et al (2005) have argued that disease duration may be a factor in moderating the psychological impact of RA, especially when considering the influence of RA beliefs. In particular, the relationship between perceptions of RA and psychological functioning has been shown to be strongest amongst individuals who are in the early stages of the disease (Treharne et al, 2005).

In addition to personal beliefs and perceptions of RA, evidence suggests that numerous psychosocial variables affect both the disease process and psychological adjustment to RA. For example, a recent study suggests that wider beliefs and attitudes may be significant factors; Devins et al (2009) have shown that despite high illness intrusiveness, participants whose cultural attitudes emphasise autonomy and equality display less emotional distress regarding their RA than individuals with more collectivist attitudes. This relationship was particularly evident in young and middle aged participants. Devins et al (2009) concluded that variables such as age, beliefs and cultural attitudes need more in depth investigation. Treharne et al (2005) have reported significant interactions between disease duration and perceived social support and optimism in influencing well being. Other studies have focused specifically on social support and its effect on both psychological and physical health. Riemsma et al (2000) found 'positive' social support was associated with decreased depressive feelings whereas 'problematic' social support was associated with increased depressive feelings. Additionally, Holtzman, Newth and Delongis (2004) have demonstrated that dissatisfaction with social support was related to increased pain. Conversely, Curtis, Groarke, Coughlan and Gsel (2005) have claimed that perceived social support was not related to depression or anxiety but was associated with social activity. These studies have demonstrated how subjective attitudes towards social support rather than actual support can influence well being and quality of life within RA samples. In addition, Keefe et al's (2002) review has argued that the effects of stress appear to be an important factor in affecting RA disease activity; increased subjective stress has been linked to increased pain and joint swelling. Furthermore, Curtis et al (2005) have noted that whilst RA disease status did not predict emotional or social adjustment, perceived stress was related to depression. Other factors which appear to be significant in the personal impact of RA include learned helplessness, pain coping and self efficacy (Keefe et al, 2002). However, although Keefe et al's (2002) review concluded that these factors are significant, how they are experienced and therefore, arguably how and why they may be important remains unclear. Debatably, quantitative methodologies do not capture the complexity of the personal response to the disease.

Nevertheless, taken together the results from previous quantitative studies give some indication of how RA may impact on an individual's life. However, the findings suggest that an individual's experience of RA may depend upon a diverse range of factors and as such one person's experience may differ considerably from another's. Furthermore, whilst quantitative research is undeniably valuable in highlighting which factors might be important in examining the psychosocial effects of RA, quantitative methodologies limit

what the participants can disclose, as the factors under investigation have been strictly predetermined by the researcher. Moreover, quantitative approaches do not reveal insight into the personal experience of living with RA. Thus, it is argued that existing quantitative RA data lacks full depth of meaning.

Research examining coping with RA has perhaps gathered richer data by conducting interviews but has then subjected the data to content analysis (Blalock, DeVellis, Holt & Hahn, 1993), thereby possibly reducing its meaning by neglecting to uncover the inherent meanings within the interview data. Nevertheless, such research has demonstrated that people with RA who use a wider range of coping strategies display improved psychological health. Consistent with this finding, a subsequent study employing a thematic analysis, has suggested that flexibility in coping strategies may enable individuals with RA to maintain psychological well being (Sinclair & Blackburn, 2008). Arguably, further research has employed content analysis in a more qualitative manner than earlier work (such as Blalock et al's, 1993) identifying and exploring themes related to social roles and identity (Lempp, Scott & Kingsley, 2006; Plach, Stevens & Moss, 2004a; Plach, Stevens & Moss, 2004b). Lempp et al (2006) have maintained that RA affects an individual's both public and private identity. Similarly, Plach et al (2004a) examined which social roles women with RA find most fulfilling and discussed how participants' perceptions of their competency in specific or traditional social roles influenced their self esteem. Additionally, researchers have argued that women with RA place great emphasis on their physical body in determining their perceived well being and the impact the illness has on their lifestyle (Plach et al 2004b). Moreover, Plach et al (2004b) have noted that women with RA try to hide their disability and acknowledged the distress their female participants felt when they were unable to do so. However, research examining men's social role experiences and perceptions of their physical body is lacking.

Several qualitative studies of the experiences of living with RA have noted recurring themes, including uncertainty (Brown & Williams, 1995; Schmidt, Brauer & Peden-McAlpine, 2003) and fatigue (Brown & Williams, 1995; Plach et al, 2004a). Searching for meaning has also been identified as a major theme (Brown & Williams, 1995), as has 'accepting limitations' and 'reframing the situation' (Sinclair & Blackburn, 2008). Role incompetence, dependency on others and inability to plan ahead due to unpredictable symptoms have been identified as important sub-themes (Brown & Williams, 1995; Repping-Wuts, Uitterhoeve, van Riel & van Achterberg, 2008). Hwang, Kim and Jun (2004) have reported themes centred on pain and negative emotions. More recently, Stamm et al (2008) have utilised a narrative biographic methodology to examine experiences of RA and have noted differences in how individuals respond to RA. According to Stamm et al (2008), some individuals resign themselves to RA and regard it as "something to get used to" (p664), whereas others appear to consider their RA as a basis for new challenges. This positive aspect, albeit observed in a very small sample, is in contrast to much of the previous literature. However, as Stamm et al (2008) reflexively conceded, the researchers went in search of positive experiences.

As discussed, quantitative research has demonstrated that the interaction of several psychosocial variables appears to be important in understanding the impact of RA. In other words, no single factor in isolation can account for or portray the effect of RA on an individual's life. Yet most qualitative studies have focused on investigating specific

factors such as identity (Lempp et al, 2006), social roles (Plach et al, 2004a), fatigue (Repping-Wuts et al, 2008), physical body (Plach et al, 2004b) and coping strategies (Sinclair & Blackburn, 2008) and as such, may have omitted to explore RA holistically. Indeed, Brown and Williams' (1995) and Hwang et al's (2004) research appear to represent the only studies in existing research literature, that have explored RA without explicitly focusing on any one preconceived issue. Whilst Brown and Williams (1995) utilised a UK female sample, Hwang et al's (2004) study focused on Korean women and therefore their findings may only apply to that culture. Also, perhaps more importantly, some of the intended meaning or depth of meaning may have been lost in translation. Therefore, it could be argued that further emphatically qualitative research remains necessary. Surprisingly, given the potential for serious side effects (Bruce, 2008) specific investigation into how individuals feel about and experience RA drug therapy and treatment is limited. A recent study examining treatment decision making represents the sole contribution; Schildmann, Grunke, Kalden and Vollen (2008) have stated that patients see decision making as an ongoing process consisting of discrete stages in which both themselves and their doctors have fluctuating involvement. Notably, the majority of participants expressed a desire to be more informed about alternative conventional treatments.

Other qualitative studies, whilst not focusing on any one limiting factor, have focused on specific sub-populations, for example, people with RA who exhibit a strong sense of well being (Schmidt et al, 2003) or females with RA (Brown & Williams, 1995; Hwang et al, 2004). However, there appears to be a deficiency in research exploring men's experiences of RA. Furthermore, almost all previous qualitative research has been conducted within a nursing paradigm (e.g. Brown & Williams, 1995; Hwang et al, 2004; Lempp et al, 2006; Plach et al 2004a; Plach et al 2004b; Repping-Wuts et al, 2008; Schildmann et al, 2008; Schmidt et al, 2003; Sinclair & Blackburn, 2008; Stamm et al, 2008) rather than solely within the psychological realm or from an 'everyday' perspective. Since those with RA feel that their condition is poorly understood by the general public (The Kings Fund, 2009b), it is perhaps important that they have the opportunity to relay their experiences in terms of what is relevant to them, to someone other than a nurse researcher or health professional. Research conducted within the context of health care systems has traditionally been executed within a medical model framework. However, as Stamm et al (2008) have maintained, some research findings appear to challenge the medical model. Stamm et al (2008) have advocated that the social model, which focuses on the disabling environment (Oliver, 1990) and medical model which focuses on the individual impairment need to merge as both have equal relevance in ongoing chronic illness such as RA where ongoing medical intervention is necessary but individuals actively participate in the management of their disease.

Whilst recent years have seen an increase in qualitative research relating to RA, the number of quantitative studies in this area still far outweighs the qualitative. Yet, qualitative methodologies may be necessary to capture the full complexity of living with RA from the perspective of those who have the disease. A recent consultancy report claims to have taken a patient -focused approach, employing both quantitative and qualitative methods of data collection (The Kings Fund 2009a, 2009b). However, whilst almost a thousand patients were surveyed along with over five hundred health care professionals, and eighteen clinicians were qualitatively interviewed, only a mere three focus groups comprising of just twenty patients were utilised. Despite this, the report

concluded that a more patient led model is necessary to improve the care and lives of those with RA. Furthermore the report maintained that patient experience should be central (The Kings Fund, 2009a).

As previously noted, several qualitative studies have exclusively reflected women's experiences of RA (Brown & Williams, 1995; Hwang et al, 2004; Plach et al 2004a; Plach et al 2004b; Sinclair & Blackburn, 2008). In addition, remaining studies have utilised samples in which the vast majority of participants are female (Lempp et al, 2006; Schildmann et al, 2008; Schmidt et al, 2003; Stamm et al, 2008; Repping-Wuts et al, 2008). This has perhaps occurred as females with RA outnumber males by a ratio of 3:1 (Panayi, 2009). However, it is argued that the minority experience is equally valid and as such men's experiences of RA should be represented in the research literature. Moreover, research suggests that there may be some differences between men's and women's illness perspectives. For example, Hurd-Clarke, Griffin and The PACC Research Team (2008) have shown that chronic illness has a differential effect on older men's and women's body image. Additionally, in Stamm et al's (2008) biographic study, the male participants (two out of a total sample of ten) were both in the same typology of RA as "something to get used to" (p664) whereas six of the eight female participants were in the other typology of RA as a source of new challenges. Lempp et al (2006) have noted that their female participants spoke about their frustration relating to partner relationships and concerns about passing on RA to their children, whereas the male participants did not. These findings indicate that males and females may experience aspects of RA somewhat differently, although further research is needed to establish exactly how men experience RA.

Thus, the present research aims to provide a contemporary, first hand account of living with RA from a male perspective. As new drug therapies are emerging (Bruce, 2008), the study focuses in part on this issue by exploring how men experience RA treatment. However, as an exploration of the psychological impact of RA, the study also examines how individuals experience living with their disease, how they feel it has affected their lives and the meanings they attach to their illness. Thus an interpretative phenomenological approach is necessary and fits in with the research philosophy of attempting to understand how individuals make sense of their entire RA experience.

Methodology

Approach and rationale

The current study is concerned with the psychological impact of RA as deemed by men who actually have the disease. A qualitative approach is necessary in order to explore and interpret how individuals experience RA. Previous qualitative research has been conducted within a medical paradigm and as such has focused on how individuals with RA can be helped to cope with or adapt to their illness. The present study is interested in understanding the lived experience of RA and how it might subjectively affect wider daily life.

An interpretative phenomenological approach was undertaken as the study aimed to capture men's subjective experiences of RA and the inherent meanings within those

experiences. Langdridge (2007) has maintained that individual accounts of a specific experience facilitate understanding of that experience. In order to obtain rich, detailed accounts, semi structured interviews were implemented. As Smith and Osborn (2003) have asserted, this is the optimum method of gathering such data. The research also utilised an ethnographic methodology since I have RA and am a member of the internet forum from where participants were recruited. I considered that this approach would provide suitably rich and valid data.

The study was conducted via the internet, thus the interviewees participated in their own homes. This may be an important factor for people with RA; it may enable those who would otherwise find it difficult, due to their health and/or disability issues, to take part in research (Sixsmith & Murray 2001). However, it is acknowledged that this was also a suitable research design for me, as a researcher who has RA. Nevertheless, as Murray and Sixsmith (1998) have advocated, email provides a suitable medium for conducting qualitative interviews. Email correspondence may allow participants to reflect on their thoughts and experiences and consider their responses in a way that may not be possible in a face to face interview. Furthermore, responses may be less influenced by the researcher's role as a 'virtual' interviewer than they might be in the actual presence of the interviewer. Thus, the data may have greater ecological validity. Email interviews may be particularly appropriate with RA populations; due to the unpredictable nature of the disease and the tendency for fatigue to occur easily, participants can respond during a 'good' time or day, as and when they feel able. Another potential advantage of email interviews is that they facilitate the discussion of any sensitive issues without embarrassment (Murray & Sixsmith, 1998); this may have some relevance for RA populations.

Sampling strategy and participants

Previous qualitative research has focused specifically on women's experiences of RA. Yet studies of men's experiences of RA remain lacking. Although RA is more prevalent amongst women than men (Panayi, 2009), it is argued that the minority experience is equally valid and as such, should be communicated. As Murray and Sixsmith (2002) have maintained, researchers have an obligation to relay the experiences of those who wish to be heard. Thus, an all male sample was considered appropriate. The male participants were recruited via self-selection convenience sampling from an internet discussion forum used by members of a national RA charitable society. I considered that a self-selected sample obtained from such a website was likely to consist of participants who are comfortable with discussing their experience of the disease and who therefore may disclose suitably rich, in depth data. All participants self reported that they had a medical diagnosis of RA. Four males participated in this study. Their ages ranged from 51 – 69 years and time since confirmed diagnosis ranged from 2 to 35 years. The men live in different geographical locations within the UK. Thus, they attend various hospitals with regard to the treatment of their RA.

Data collection and ethical issues

The current research was conducted in accordance with the British Psychological Society's (2006; 2007) ethical guidelines; ethical approval was granted from Liverpool Hope University (Appendix 1). In addition, I considered any ongoing ethical issues

throughout the research process. Indeed, the study was modified to take account of potential participants' views and preferences. Specifically, I had intended to utilise some of the internet forum's documentary discussion posts as data (in addition to the interview data). However, being immersed within the culture of the forum, I felt somewhat uncomfortable with this, as it felt intrusive. Thus, with the interviewees' approval, I decided to use the discussion data to merely inform the interviews, in part. As Murray and Sixsmith (2002) have argued, health researchers have an ethical responsibility to implement innovative research techniques in order to access all voices. Therefore, I deemed that utilising the discussion data in this way enabled access to the views of those who were unable to take part in an interview, whilst being minimally invasive.

At the outset of the research process, I contacted the RA society which hosts the aforementioned forum, to inform them of my research intentions and obtained their approval. In order to recruit interviewees, I accessed the discussion forum and posted a thread inviting male forum members to participate in a study exploring men's experiences of living with RA. The invitation included a brief introduction and the participant information sheet (Appendix 2). The participant information sheet outlined details of the research and participants' rights, including the right to decline to discuss anything with which one might be uncomfortable and the right to withdraw from the study. Additionally, participants were informed that their data would remain secure, confidential and anonymous. As I do use the forum, I was careful to maintain a distinction between research use and personal use. Therefore, I used more formal language in conveying the details of the study and used my Hope email account as the contact address. Potential participants, having read the invitation post and participant information sheet, contacted me via email to register their interest in taking part.

Written informed consent was obtained in accordance with the British Psychological Society's (2007) supplementary ethical guidelines (focused specifically on conducting research on the internet). Thus, a consent form (Appendix 3) was emailed to each participant; participants subsequently 'signed' the consent form and emailed a copy back to me. In addition, at regular intervals throughout the interview I asked the interviewees (via email correspondence) if they were still comfortable and happy to continue with the interview. I considered that this was appropriate in the absence of being able to observe interviewees' body language. In addition, I remained alert and sensitive to their responses.

As per BPS (2007) guidelines, all reasonable steps were taken to ensure confidentiality and anonymity. In respect of confidentiality, emails were accessed solely by me and were deleted once a transcription copy had been obtained. In addition, computer files were password protected. To ensure anonymity, pseudonyms were used in replace of real names. I have also taken steps to ensure that the discussion forum is not easily identifiable. In any case, the forum is password protected and can only be accessed by members. Other potentially identifying information such as place names have been altered.

Initially, I had a loose 'interview schedule' covering several areas I was interested in exploring. These were based on the existing literature, previous research findings and my own experience of RA (Appendix 4). In addition, some lines of enquiry were informed by discussion that was taking place on the forum at the time. However, the 'schedule'

and discussion forum merely provided some provisional structure and a starting point. The questioning remained flexible as I modified any probes according to each individual interviewee's responses. Following the recommendations of Smith and Osborn (2003) I aimed to construct open questions in such a way that they were not leading. Each email interview took place over the course of two to three weeks with the pace being dictated individually by the interviewees. I attempted to establish a rapport between myself and each interviewee; indeed the interviews were quite reflexive since I commented on my personal experience from time to time. However, I allowed each interviewee to direct the discussion and further explored any novel areas that emerged within any of the interviewees' accounts. Nevertheless, the interview data reflects an interaction between me and the interviewees. Stamm et al (2008) have argued that this 'inter-subjectivity' should be acknowledged and valued rather than denied or ignored.

Towards the end of the interviews, the interviewees were given the opportunity to add any comments they thought were relevant. During the debriefing, interviewees were invited to ask any further questions, reminded of their right to withdraw and informed that their data would be subject to my own interpretation. As the interview took place via email correspondence, the interviewees had a record of the interview data and agreed that I could contact them during the analysis process should I wish to clarify any interpretations. I reiterated that a copy of the written dissertation would be kept at the University where future students may have access to it. All participants confirmed that they were comfortable with this protocol. Participants were thanked for their time and effort and for sharing their experiences. They were reminded that they could contact me at any time via my email address and that a summary of the research findings would be available to them on completion of the study. All interviewees appeared to be genuinely interested and requested a copy of the findings. Moreover, all participants stated that they had found the interview process to be therapeutic and expressed satisfaction in relaying their experience to someone whom they felt showed interest and understanding. Participants reported that they had not had opportunity to do this before.

The textual data obtained via email was copied and pasted into transcription form (Appendix 5). This was repeated for each interviewee. Any spelling mistakes or grammatical errors were left uncorrected as I did not want to alter the interviewees' accounts unnecessarily. Pseudonyms were inserted in place of real names and any location or place names were altered in order to protect the men's identities.

Data analysis method

Aiming to understand how the interviewees made sense of their personal experiences of living with RA, I employed an interpretative, hermeneutic approach, focusing on the underlying meaning within the interview accounts. Thus, the data was examined using an interpretative phenomenological analysis (IPA). In accordance with Smith and Osborn (2003), I attempted to explore the interviewees' subjective experiences and the inherent meanings within their accounts of those experiences, whilst acknowledging my role as a reflexive researcher. Within IPA the emphasis is on interpretation (Langdrige, 2007) and it is acknowledged that analysis probably began before and continued after the following method was employed. Nevertheless, with reference to Smith and Osborn (2003), the initial 'stage' of the analysis involved my attempt to become immersed within the data; the transcripts were read and re-read several times until I was familiar with the

text and felt some understanding of what was being portrayed. During the next stage, the first transcript was read more slowly and the left hand margin was used to make preliminary notes. Some notes merely highlighted the actual words used by the interviewee whereas others commented on associations between the words or my own thoughts. In addition, notes were made between the lines of text, commenting on reoccurring words, emphasis or contradictions. This process continued throughout the whole transcript. Then, by simultaneously interpreting the written notes and referring to the interviewee's actual words, the core or overall essence of what was being said was recorded as initial themes or categories in the right hand margin (see Appendix 5). Next, these emerging themes were copied onto a separate piece of paper and any connections or similarities between them were identified (Appendix 6). Subsequently, any similar themes were clustered into provisional themes which were then merged into initial main themes (Appendix 7). The three remaining transcripts were then subjected to the same process, one by one. Thus, I recorded emerging themes for each interviewee (Appendices 8, 10, 12) which were next collapsed into provisional themes and subsequently merged into initial main themes (Appendices 9, 11, 13). During these analyses, I remained alert for further evidence of any themes that had emerged from the first or previous transcripts. Simultaneously, I was aware of any new themes emerging from any of the remaining transcripts. During the next phase of the analytic process, I studied the four provisional theme documents (Appendices 7, 9, 11, 13) looking for similarities that were evident across all four participants' initial main themes. Finally, the initial main themes were collated into major themes (Appendix 14). Thus, the presented major themes represent those themes that were salient across the majority of the transcripts. In collating and naming the final presented themes, I selected those themes I thought best highlighted the essence of the transcripts overall whilst omitting those that I felt were less representative; inevitably, this procedure encompassed reflexivity. However, throughout this entire interpretative process, the actual transcripts were continually referred to, in order to ensure that the themes did indeed relate to the interviewees' dialogues.

Participant profiles

Participant profiles are presented (before the analysis and discussion) in order to highlight how each of the men's accounts represents a unique personal, yet shared experience.

Adam

Adam is 69 years old and was diagnosed two years ago. Thus, his account reflects the viewpoint of someone who is relatively new to RA. Arguably, his diagnosis has occurred at a time when new and more effective treatments should be available. Adam lives with his wife and is retired. At present, his RA is being treated with a combination of several disease modifying drugs. However, these are losing their efficacy and Adam is currently awaiting assessment for biologic (anti-tnf) therapy.

Ben

Ben is 54 years old and was diagnosed with RA 6 years ago. He has a number of other diagnoses and considers himself to have a unique medical history. Ben claimed that his RA, rather than his other serious conditions, forced him into ill health retirement. Ben now works part time on a voluntary basis and lives with his wife and children. His RA is

currently well controlled with biologic (B cell depleting) therapy, a disease modifying drug and steroids.

Jack

Jack has had RA for over 20 years; he is 61 years old and lives with his wife. Jack stated that shortly after his diagnosis, he retired from a job he loved whilst he was in his forties. Having had RA for a considerable length of time, Jack has been on a succession of various disease modifying drugs and has experienced the emergence of new therapies. Jack's RA is now controlled with biologic (anti-tnf) therapy and steroids.

Peter

Peter is 51 years old and was finally diagnosed with RA in late childhood, after experiencing symptoms for a number of years previously. Peter lives with his partner. Peter's account represents the experience of someone who grew up with RA. He has a number of long standing RA related health complications and was ill health retired several years ago. Currently, Peter's RA is treated with a combination of disease modifying drugs and steroids.

Analysis and discussion

In exploring the personal accounts of the four men, a number of major themes became evident that illustrate the psychological impact of RA. The following themes are presented as indicative of the interviewees' lived experience of RA: Striving for Control, Finding Solace, Challenging Misconceptions and The Need for Purpose. Although the themes are presented separately, they are interrelated; they do not occur as distinct aspects within the men's lives but are unified as one experience within each man's biography.

Striving for Control

The aspect of striving for control was continually evident throughout the interviewees' accounts. During the period leading up to, and at the time of diagnosis, the men experienced a sense of a lack of control. Most interviewees were shocked and expressed disbelief at their diagnosis. However, Peter recalled feelings of relief in finally obtaining an explanation for what had been happening to him. For Peter, who was diagnosed in childhood, the diagnosis may have signalled an end to the turmoil he and his family were experiencing. Peter recollected his parents' anxiety and how the medical profession initially seemed baffled by his symptoms:

"My RA started with my right hand swelling up like a balloon whilst I was still at school. I was about 10 or 11 years old. Of course my parents were worried stiff at what it could be and it was quite some time before I was referred to a consultant at the hospital. While all the symptoms pointed to some sort of inflammation, no one was prepared to say what it was. I even had an operation on the palm of my hand in case I had a foreign body in there."

(Peter, 6-13)

Peter's words reveal a sense of uncertainty which was salient throughout the men's accounts. This is consistent with previous research that has identified themes of uncertainty in women's experiences of RA (Brown & Williams, 1995) and in those individuals with RA who exhibit a strong sense of well being (Schmidt et al, 2003). Feelings of uncertainty may be prominent in RA due to the unpredictability of symptoms and fluctuating disease activity (The Kings Fund, 2009b).

RA can present at any age (Panayi, 2009), yet there is still a lack of awareness amongst general practitioners regarding early symptoms (The King's Fund, 2009a). Whilst Peter's age may have been a contributing factor in the pursuit for diagnosis, earlier research suggests that his experience is a common occurrence amongst RA patients of all ages (Brown & Williams, 1995). Peter's use of a simile (like a balloon) to describe his swollen joints is interesting as he and the other interviewees repeatedly used metaphors and similes in describing aspects related to their RA. [Although the present study does not include a discourse analysis, the technique is well established in health psychology research as a tool in understanding the meanings individuals attach to their illness (Morgan, 1999). The current use of metaphors and similes is highlighted as they were salient in the current data and give insight into how the present participants make sense of their RA.]

Preliminary feelings of a lack of control were echoed by Adam who described his shock and confusion at his diagnosis and how he felt a need to find out more about the disease:

"When first told I had RA I was feeling shocked and could not believe what the RA Specialist said –RA – what's that? I didn't know. The Hospital told me nothing or what to expect. My wife picked up a (name of website) leaflet at the hospital and I found out most about RA on there. I read the articles and I went through the past posts for hours trying to find out more."

(Adam, 9-14)

Nevertheless, after an initial period of bewilderment following diagnosis, it appeared evident that individuals attempt to gain some sense of control over their disease. One of the fundamental ways the men reclaim control is by equipping themselves with information and knowledge. This quest for information is particularly salient in Adam's account, reflecting his attempt to increase his knowledge of RA and the associated drug therapies. This is perhaps unsurprising since Adam is more recently diagnosed than the other interviewees. Nevertheless, for all the men, being informed seems to be a way of empowering themselves. Schmidt et al (2003) have claimed that by accessing information, patients can adjust their interactions with the environment thereby enhancing their sense of well being. Later, Adam reflected that he would have benefitted from more information being given by his medical team at the time of diagnosis:

"If I had been informed of all aspects of RA, I would have been in a better position to handle the RA. It's not knowing and then being affected (sic) that causes (sic) unnecessary pain and anxiety."

(Adam, 348-350)

Adam's complaint of the lack of information imparted in respect of his RA has similarities with previous research literature. Repping-Wuts et al (2008) noted that RA patients would have welcomed more information regarding fatigue at their initial consultation. Similarly, Schildmann et al's (2008) participants reported a lack of information and discussion with their consultant regarding treatment options. Research has shown that there is a need and desire for more information and access to resources especially amongst recently diagnosed individuals (The King's Fund, 2009b).

Indeed, the theme of striving for control was particularly evident when the current interviewees were discussing aspects of their treatment:

"Having been Dx (diagnosed) for over 20 years ago I had never been included in talks about side effects, effectiveness of medication etc, maybe that's my own fault for not (sic) pressing them as I personally felt that I was questioning their expertise of RA. Now I know different and I do ask these questions and because I have a new Nurse Practitioner I actually get answers and feel I am now a full part of the process."

(Jack, 167-172)

Jack's words exhibit a growing realisation that he himself is the expert in the experience of his RA. Stamm et al (2008) have argued that the medical and social model should be integrated to recognise that individuals can take responsibility for and an active role in medical decisions and treatment relating to their RA. Indeed, Jack's growing confidence is echoed by the other participants who have had RA for a considerable period of time. Ben, having previously equipped himself with knowledge of RA and its treatment now feels confident enough to contribute to medical discussion and decisions:

"As I 'grew' in knowledge with my determined research into RA and the drugs available, I came to a point where I would go into a consultation saying "I don't think MTX (methotrexate) is working on its own can we think about changing meds or adding Sfz (sulphasalazine) to the mix?" I do ask my Consultant's opinion on my suggestions based on my research. I'm also very confident about maintaining my level of input into all of our drug discussions – at the last consult, I asked about alternatives to oral steroids as this is an area I worry about."

(Ben, 425-431)

Jack and Ben's accounts support the proposal that decision making about treatment is a sequential process, rather than a single occurrence, in which patients may become more involved as time progresses (Schildmann et al, 2008). However, the level of involvement fluctuates in line with new treatment options and symptoms. This is unsurprising since RA is a progressive but unpredictable illness (Arthritis Research Campaign, 2006). Nevertheless, Treharne et al (2005) have claimed that the length of time an individual has had RA is an important factor in moderating the psychological effects of the disease. The present findings suggest that as time progresses, individuals may gain confidence in the self- management of their disease which enables a stronger sense of control.

Indeed, attempting to gain control of their personal situation appeared to be important for the men's physical and psychological health. Adam's description of his attempt to take control regarding his treatment indicates that feelings of not being in control may be detrimental to well being:

"I believe it is better to know than to remain ignorant until the side effect problems start, as this is far more worrying than not knowing anything. If I had known what to look out for I would not have been so anxious and could have prevented myself suffering pain. I don't mean the nurse reading from a leaflet – I can do that myself."

(Adam, 358-362)

Adam's experience offers support for the findings of recent research which has suggested that stronger beliefs relating to control are associated with lower disability and improved quality of life (Graves et al, in press). Moreover, autonomy has been found to moderate the emotional impact of RA (Devins et al, 2009). Thus, by striving for control individuals may maintain their psychological health.

However, achieving control is not a static situation. As the disease progresses and symptoms vary, control fluctuates; thus the men are continually striving for control. Sinclair and Blackburn (2008) have noted evidence of a similar process in women with RA and have attributed this to the construct of 'response shift', an adaptive coping strategy. According to Sinclair and Blackburn (2008), response shift may enable individuals to perceive higher levels of control which in turn facilitates well being. However, even when the present men are well informed and feel some degree of control, the reality of their disease is such that they may never be fully in control. Furthermore, current treatments carry considerable risks (Bruce, 2008) which may add to feelings of a lack of control. Peter's words illustrate the futility of statistical information:

"Even now I'm sure we don't know the full details and possible side effects of the drugs we take. The leaflets are all well and good but as they're written from the drug companies' perspective I'm sure they tend to downplay the possible bad effects. To say a side effect is rare when it effects (sic) one in a 1000 - well it might be - but when you're the 1 it's meaningless."

(Peter, 277-282)

The male participants in the present study acknowledged their past psychological distress and it appeared that a way to overcome this was by gaining a sense of control over the disease and ultimately their lives. Furthermore, in contrast to the two male participants in Stamm et al's (2008) study, the current men challenged their RA and did not passively accept the disease or its consequences. Thus, the men in the present study had more similarities with the women than the men in Stamm et al's (2008) research. However, disease status and disease activity may play a role in this. At least one of the men in Stamm et al's (2008) study had very active disease, thus was probably feeling rather ill at the time of the study being conducted, whereas the current participants, with the exception of Adam, stated that their RA is well controlled.

Finding Solace

Along with the continuing strive for control, the need for emotional support was evident throughout the interviews. RA is unpredictable and the amount of support that may be needed varies both within and between individuals. Most of the participants did not view their medical team as a source of support. In addition they did not think that their wider family, friends or the public appreciated the impact of RA on their lives. These feelings are consistent with previous research findings (Blalock et al, 1993; Hwang et al, 2004; The Kings Fund 2009b). The present men considered that only fellow 'RAers' can fully understand what it is like to have RA. Thus, the forum may be significant in acting as source of support. Indeed, the men considered the forum as a positive aspect of RA:

"The only positive aspect for me personally is finding (name of forum) and the marvelous people who do worthwhile work for us and the willingness of the members of all ages giving assistance not only to new members but instill the need to fight for the right to treatment for those who "don't like to cause a fuss" because if we don't cause a fuss, we get depressed and it is only a short leap from depression to taking your life (I really believe this)..."

(Jack, 298-303)

Jack's words demonstrate how important access to emotional support might be. Previous studies have linked perceived practical social support with depression (Reimsma et al, 2000), pain (Holtzman et al, 2004) and social activity (Curtis et al, 2005). The current findings suggest emotional social support may be equally important in influencing well being.

Indeed, the men utilised the forum as a place where they could find solace, information and humour:

"I have found out more about RA on the Forum and (name of web) site than I have from the hospital. At the hospital they never have time to discuss your problems or feelings about RA. Also there are some good comedians on the site which makes one smile and laugh in this painful world."

(Adam, 219-222)

Thus the forum serves a dual purpose for Adam; it enables him to access practical help in the form of information and also gives emotional support. The use of humour may influence both psychological and physical health in individuals with RA. Cognitive reframing such as attempting to remain positive has been associated with decreased depression and improved functioning (Holtzman et al, 2004). The forum also represented a place where the men found comfort in knowing others had experienced the same issues as themselves:

"There are times when dealing with RA you can feel alone and unsure of what's happening.....I look through the posts to see if anyone is experiencing similar problems either physical or mental."

(Peter, 154-158)

Finding others who have experienced RA may reduce the feelings of isolation that the men described intermittently. Sinclair and Blackburn (2008) have asserted that finding “fellow sojourners” (p225) is one aspect of the coping pattern they have termed ‘response shift’. The current men compared their own RA symptoms with those of other forum members:

“Also, there are those members who help me to realise that I’m not that badly affected by RA as I imagine (and as the medics say) - it’s a place where I can get some perspective of my lot as it were.”

(Ben, 314-316)

Ben appeared to find solace in the use of downward comparisons. Previous researchers (Plach et al, 2004a; Repping-Wuts et al, 2008; Sinclair & Blackburn, 2008) have also noted that individuals with RA make downward comparisons. Repping-Wuts et al (2008) have suggested that downward comparisons represent a method of coping with fatigue. Similarly, Sinclair and Blackburn (2008) have attributed downward comparisons to one aspect of the adaptive coping process.

In addition, the interviewees found solace in their close relationships. Peter ‘spoke’ of his partner’s support as being paramount to his well being. Ben and Adam both indicated that their wives’ kindness was reassuring. Jack found comfort in his role as a granddad.

“....yet my relationship with my 3 eldest grandchildren is now stronger than it has ever been.”

(Jack, 112-113)

Lempp et al (2006) have advocated that social roles and relationships become strained with RA; therefore individuals experience a sense of loss. Similarly, Plach et al (2004a) have noted feelings of inadequacy and guilt in respect of social roles. Jack’s words refute these claims, indicating that social role losses are not inevitable. Indeed, Jack is able to consider that his role as a granddad has benefitted from him having RA.

The theme of finding solace was also evident when the men specifically discussed their drug treatment experience. The men’s accounts illustrate that they view their treatment in terms of a benefit versus cost balance:

“I took a very rational approach (in my opinion) that I either lived risk-free of medication side-effects and have little or no quality of life. The alternative which I followed was to have a reasonable quality of life on medication with the full knowledge that I will experience some side effects and could end up dying sooner than I would have done without medication. Life is a game of balances. We choose a road that will give us the best journey. Luckily, the side effects I have (nausea, headaches, lung problems) are tolerable.”

(Ben, 64-71).

Ben’s acknowledgement that taking the drugs may shorten his life supports previous findings. Participants in a recent research study (The King’s Fund 2009b) explicitly discussed the trade off between length and quality of life. Ben’s use of a metaphor of life

with RA as a journey is noted. Other interviewees found solace in the efficacy of the treatment:

“Mostly my attitude has been the potential side effects are outweighed by the ameliorating effect of the drug.....I think that my RA is reasonably well controlled though there are days when a flare feels as though it's bubbling under the surface ready to erupt if you know what I mean.”

(Peter, 137-144)

Peter's use of a volcano metaphor highlights the uncertainty of the disease. It appeared that Peter was trying to convince himself that the drugs were effective. Adam appreciated the benefit in taking medication despite experiencing side effect problems. His evaluation of the benefit versus cost was initially stark:

“The choice is take these drugs and their potential risks or finish up a cripple..... As far as I can tell the medications have improved my quality of life. When I was first diagnosed with RA, I had to get up the stairs on my hands and knees. Now I can walk up the stairs although with difficulty. I do put the risks of taking the drugs to the back of my mind...”

(Adam, 59-69)

Adam's claim of trying to ignore the risks associated with the medication, contradict his assertions throughout the interview of wanting to know as much as possible and searching for information regarding his RA and its treatment. However, some of the other men did maintain that there were things they would rather not know:

“Frankly there are times I don't want to know, e.g. the fine details of a surgical procedure.....Other times I'll trawl the internet and find out far too much information that it can almost scare me but I think it's important to be able to see that what the doctor has told me is what I ought to know- but can (sic) help feeling that ignorance is bliss.”

(Peter, 316-322)

On the face of it, Peter's statement indicates that he finds solace in not knowing. Nevertheless, Peter's words also reveal inherent contradictions within his practice. He is torn between striving for control in the form of gaining information and finding solace in the form of ignorance. Whilst it might be considered that this internal conflict may cause some distress, similar interactions between opposing constructs have also been noted in RA patients who had previously displayed a strong sense of well being (Schmidt et al, 2003). Peter's use of another metaphor (of fishing for information) is again noted.

Challenging Misconceptions

In line with previous research findings (Blalock et al, 1993; Hwang et al, 2004; The Kings Fund 2009b) the present interviewees reported a lack of public awareness and understanding of RA. Public perceptions appeared to cause the men some anguish:

"When I was first diagnosed reactions like, 'you're swinging the lead, you don't look ill, you've become a SS scrounger' really upset me and 'your only problem is you're too fat'."

(Jack, 44-46)

The distress and frustration that the men experience in reaction to other people's perceptions inevitably causes them stress. This in turn may affect their health; the role of stress has been shown to be particularly important amongst individuals with RA. Curtis et al (2005) found that stress was related to depression. Additionally, Keefe et al (2002) have noted that stress may be instrumental in exacerbating symptoms of RA. The men expressed particular annoyance at instances where other people compared their own seemingly trivial symptoms to those of RA:

"I'm sure everyone who's had RA has had someone say, oh we all get twinges and aches and you know so much how different it is to a twinge. When you have no one who's experienced that sort of pain or fatigue you can feel alone."

(Peter, 178-181)

Indeed, research suggests that RA is not taken seriously by the public (The King's Fund, 2009b).

The women in Hwang et al's (2004) study discussed how they had difficulty in making those around them aware of the effects of RA. The current men described similar experiences:

"Sometimes I feel that not only am I fighting this illness but also fighting other people's perception of the illness."

(Peter, 198-199)

Peter's use of the metaphor of a 'battle with others' is interesting; Jack also 'spoke' of a 'battle with those in authority', whereas Ben's 'battle' was more personal. Ben concentrated on winning his battle against the disease. Indeed, in contrast to the public perceptions of RA, the men themselves placed RA at the top of their 'illness hierarchy'. Ben appeared to find RA more of a challenge than his other diagnoses:

"I have said on many occasions that the diagnosis of cancer in 1998 was much easier to accept. I knew there was a cure for cancer and also that I would win the battle. With RA, I was told quite candidly (on asking) that there was no cure, only management. Also, I knew about cancer (Hodgkin's Lymphoma) but knew nothing about RA."

(Ben, 134-138).

Although Ben's claim that his RA diagnosis was more difficult to accept than cancer might initially seem surprising, his words reflect the inherent uncertainties of RA. The aspect of uncertainty is salient throughout the existing research literature. Adam also compared RA unfavourably to cancer. However, for Adam the comparison related to the status of RA in the political arena:

"I do not begrudge any sick person getting the necessary drugs to cure or relieve the symptoms of an incurable disease. I find it difficult to understand why a cancer patient can have a £6,000 drug per month to prolong life for a few months and then a RA patient is refused drugs at £6,000 per annum to relieve the severe pains of this incurable and crippling disease."

(Adam, 299-304)

Support groups and organisations such as the one to which the current interviewees belong campaign to educate the public and raise political awareness of RA. Following an ongoing discussion on the forum, the men discussed how the name RA is a misnomer as it implies a similar condition to osteo-arthritis which is related to the wear and tear associated with ageing whereas RA is a systemic immune disorder (Arthritis Research Campaign, 2006). Interviewees thought the name rheumatoid disease or disorder might be more appropriate. However, Peter also offered a word of caution:

"Rheumatoid disease might mean it's taken more seriously but I think we have to be careful not to frighten off the very people who are affected by it. To call it by a name which sounds less threatening or serious might in fact suit some rather than acknowledge that it is a serious and sometimes life threatening illness."

(Peter, 207-212)

Peter's words illustrate the conflict that was evident throughout his account. He is aware of the seriousness of RA but at the same time he gains comfort from dismissing this. Nevertheless, the men claimed that they were often forthright in challenging other people's misconceptions of RA. However, Jack thought that until there was political change, misconceptions about RA would persist:

"It is my considered opinion that whilst politicians (of any party) in this country refuse to put RA on a par with MS, CF and other serious immune illnesses instead of the aches and pains that granny had this will not come about..."

(Jack, 248-251)

The Need for Purpose

The men's need for purpose in their lives was inherently evident within their accounts. Additionally, at times the men explicitly discussed this need. Since all of the participants in this study were now retired (three of them retired early on ill health grounds) they needed to find a substitute for paid employment, in order to fill their daily lives. Retiring very early due to ill health is a common occurrence amongst individuals with RA (The Kings Fund, 2009a). Work had obviously been an integral aspect of the current men's lives and employment is likely to be linked to self esteem. Some of the men found purpose through voluntary work and were particularly involved in helping others who have RA. This is highlighted in Ben's account:

"It's also a place where I can utilise many of my skills on disability and employment issues to good effect. I may be 'dead' in body but in mind and spirit I am very much alive and kicking.....It is important for me to realise that I can

still perform some function and be of use to society albeit in a restricted and voluntary sense. Prior to my voluntary work and my involvement in the Forum, I felt valueless and was of little use to society or my family and friends.”

(Ben, 309-316)

Previous research has identified role incompetence as a sub theme in women's experiences of RA (Brown & Williams, 1995). Plach et al (2004a) have asserted that perceptions of role competency influence self esteem. Ben is confident in his skills in advising on disability and employment issues. Therefore, using these skills is likely to improve his well being. However, evidence suggests that the loss of some roles may be more significant than the loss of others (Plach et al, 2004a). Indeed, research has shown that the loss of traditional roles may cause women with RA most distress (Brown & Williams, 1995; Plach et al, 2004a). The current study suggests that men too may be most affected by difficulties within their traditional roles. Whereas Ben 'spoke' about the loss of his role as breadwinner, Adam focused on difficulties with the traditional roles of 'sportsman' and 'handyman'. However, he acknowledges that advancing age, as well as RA, plays a part in this:

“Before, I was a very active person. As a youth and right up until I was 40 I played a lot of football, cricket and on occasions rugby. Then when age catches up with you as it does, one by one the sports got knocked on the head. I was still active with DIY, gardening and walking. Since RA all this has gone so now I class myself as inactive. Although now and then I try to do a little DIY but suffer for it the next day.”

(Adam, 261-267)

Adam's comment suggests that he expects negative consequences if he attempts to do DIY. Learned helplessness has been identified as an important factor in understanding the experience of individuals with RA (Keefe et al, 2002). Keefe et al (2002) have argued that learned helplessness is related to current and subsequent pain, disability and responsiveness to drug therapy.

The men found new purpose in their lives in different ways. Like Ben, Jack found purpose and satisfaction in helping others:

“I started making friends and when my treatment changed I found I could actually help others who were having problems and were struggling and that made me feel better.”

(Jack 188-190)

Schmidt et al (2003) have asserted that interdependence may be necessary for well being in individuals with RA. Jack is also active in spreading the word about the work of the RA charitable society which exists to educate and support:

“There is a need for the name (society) to be posted in every surgery and hospital to give those who think they are on their own to realise there is help out there...”

(Jack, 306-307)

In addition to helping others, Jack challenges authority as this gives him new purpose now that he considers his RA to be controlled:

“My RA has pretty much come under control with the Infliximab. I still get the flares (not so virulent) and the stiffness, I feel now the battle is more against the establishment than the disease.”

(Jack, 154-156)

It is interesting to note that in addition to the other interviewees, Jack also uses the metaphor of being in a battle. Having structure, purpose and challenge in daily life has been related to positive experiences of RA and described as a form of ‘mastering’ the disease (Stamm et al, 2008). Thus the need for purpose might be fundamental in the men maintaining well being.

Reflexivity

In the following account I discuss how in my position as the researcher, I influenced the construction, collection and analysis of the data. Other potentially relevant issues are also noted.

As previously mentioned, I have RA and am a member of the forum from where participants were recruited. I was curious to find out if males would report similar experiences to those previously recorded by women, and indeed my own. Thus, my own experiences and world view exerted their influence on the initial study design. As a member of the forum, the interviewees and I vaguely ‘know’ each other, albeit virtually. Consequently, I did not want to abuse my position as a co-member of the forum and become overly intrusive, hence I was careful to maintain a distinction between personal and research use of the forum. However, as I was utilising some of the forum discussion data to inform my questioning, a compromise existed between being suitably familiar with the discussion that was taking place and maintaining enough distance so as not to form any preconceived views of the interviewees or how they might respond.

Thus, I began to keep a reflexive diary at the beginning of the research process and used it to record notes throughout the study. This enabled me to keep a record of my thoughts and feelings, remain aware of how these may have influenced the study and acknowledge this in the written report. The reflexive diary also proved a useful tool as I became aware of the need to protect myself (as well as my participants) from psychological distress. At times in the research process, especially during the literature review, I was confronted with things that I found uncomfortable. For example, I discovered that some drug therapies (which I take/ have taken) are highly carcinogenic. Whilst I was already aware of this and similar risks, it somehow seemed more stark reading it in a published journal. I considered that the responsibility to protect myself lay with me. Thus, I found it therapeutic to note down my thoughts and feelings on any such issues in the diary.

Some of the interviews were conducted simultaneously. Whilst this was advantageous in terms of time management and the interviews cross- informing each other, I needed to

be organised in juggling the various replies and keeping track of who 'said' what. Unlike a verbal interview, I did not set a rough time limit on how long the interview should last. However, I copied the textual data into transcription form as and when I received the emails, as this allowed me to keep note of the data volume. I was aware from previous studies as to the approximate amount of data that is generated in an hour's verbal dialogue and used this knowledge to decide when to draw the interview to a close. Obviously, I did not end the interviews abruptly, continuing with any interesting, ongoing topics as appropriate. Therefore, the length of the interviews is not uniform. In particular, Ben's transcript is considerably longer than the other interviewees'.

One of the issues I was conscious of was that by utilising email interviews, I would be unaware of participants' body language, hesitations and tone of voice. Thus, I was apprehensive about approaching potentially sensitive topics. However, I did explore these to some extent and remained alert to participants' responses. Additionally, I feel that it was much more difficult to familiarise myself with the data than it has been in the past when I have transcribed audio recorded interviews. In the present study, I found myself constantly re checking the transcripts to verify which interviewee 'said' what, unlike verbal interviews whereby recollection and recognition of the participants' voices aids identification. I think this highlights how the actual transcribing of data facilitates familiarity and immersion within that data. In my defence, the volume of data was considerably more than I have negotiated in the past. In addition, I found the interpretation of the data more challenging than I expected. I considered that this is because, for me, the textual data obtained via email is more difficult to interpret than verbal data where tone of voice, emphasis and hesitations can be deciphered and used to aid interpretation. This is something I would give serious consideration to in any future research. The use of live, private chat facilities such as MSN may be a way forward, as this offers the same advantages over face to face interviews as email, but incorporate the use of features such as emoticons which enable the more accurate portrayal of emotions. However, some of the interviewees did use capitals or bold on occasion in their text, which I inferred denoted emphasis. Whilst analysing each transcript separately was relatively straightforward, collating and collapsing themes across transcripts was more problematic as I was unsure of some of my interpretations and found organising the various themes difficult. This might have occurred as I was conscious of not simply using data that corresponded with previous literature.

There were times during the analysis stage of the research process when I wished I had chosen a quantitative approach. How much easier it would have been to 'crunch a few numbers'. However, I reminded myself that a quantitative analysis would not have revealed the richness of the inherent meanings embedded within participants' dialogues. Furthermore, I was encouraged by the interviewees' willingness to share their personal experiences and felt an obligation to portray their accounts appropriately and with due consideration. I remain convinced that only a qualitative approach aids understanding of a lived experience.

All research is time and context dependent and I should make it clear that at the time of the research being conducted, I am taking RA drugs that are relatively new and as such the long term effects are unknown. This does cause me some anxiety and may be one reason why I explored drug therapy experience, although another reason is that research in this area is indeed limited. Therefore, this study is a product of my own RA

biography, thus my interpretation of participants' accounts may emphasise the inherent anxieties that were salient to me within their dialogues. Indeed, my interpretation as a whole was unavoidably influenced by my own experience of RA. Therefore, in choosing which themes to present, I may have selected themes which I myself could identify with and omitted any which I could not; although by being aware of this, I minimised this possibility.

Although I have struggled with this project, perhaps in part due to time management, I have found the experience valuable. I hope to be able to look back on the research process with some sense of achievement.

Conclusion

This study has qualitatively explored the experiences of four men who have RA. An interpretative phenomenological analysis revealed main themes of Striving for Control, Finding Solace, Challenging Misconceptions and The Need for Purpose. These themes were considered to represent the experience of RA from a male perspective. The present findings add to the research literature by supplementing the existing research findings of women's experiences of RA. It is evident that RA is a unique, yet shared experience. Whilst there were similarities between the current interviewees' experiences and those reported in previous studies, the men's accounts also revealed individual idiosyncrasies. In addition, the findings enrich the understanding of how the factors that have been demonstrated in quantitative studies such as beliefs, perceptions, perceived control and support are actually experienced. The current findings offer support for the biopsychosocial model as it was inferred that numerous psychosocial factors influence the men's functioning and well being. However, it is perhaps not the actual interaction of biological, psychological and social factors which affect the men's health, but their personal perceptions, interpretations and the meanings they attach to their RA that have most influence. Future research should aim to explore these factors in more detail.

To conclude, the men's experiences reflect neither predominantly negative nor positive experiences of RA but, just as would be expected in their wider lives, a mixture of the two. The men acknowledged that the diagnosis of RA necessitated physical and psychological adjustment but their accounts also demonstrate that they were able to find opportunity for personal growth following their diagnosis.

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