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THE EVERYDAY ALWAYS-THERENESS

of

Living with Rheumatoid Arthritis

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ABSTRACT

This study explores the phenomenon of 'living with rheumatoid arthritis'. Utilising a hermeneutic phenomenological methodology informed by the writings of Martin Heidegger and Hans-Georg Gadamer, the study provides an understanding of the meaning the phenomenon has for the participants and illustrates the impact it has had on their lives.

The participants in the study were twenty-five people who have varying experiences of the phenomenon. Eleven participants were people who have the disease, six were partners of people who have rheumatoid arthritis, and eight were adult-aged children whose mother or father has the disease. Drawing primarily on the stories shared by the participants, the study uncovers the everyday realities of living with rheumatoid arthritis and it reveals the taken-for-granted nature of the experience. The interpretation offered in the thesis raises new understandings of the complex phenomenon of 'living with rheumatoid arthritis'.

The findings of this thesis show that rheumatoid arthritis is always there in the lives of those who experience the phenomenon, whether as partners, adult children, or the person with the disease. In its always-thereness rheumatoid arthritis becomes part of the background familiarity of their lives. Those who live with rheumatoid arthritis take the experience with them into all other worlds. It permeates, to varying degrees, all aspects of their lives. In the presence of rheumatoid arthritis different things matter and things matter differently. Living with rheumatoid arthritis means finding a new way of being-in-the-world. It means developing and maintaining strategies for being-in-the-world with rheumatoid arthritis. As the strategies are developed, these people come to live in the world in an everyday way that in itself becomes taken-for-granted. They, as I suggest, come to live resolutely with the disease. However, living resolutely with rheumatoid arthritis is always tenuous and at the beck and call of the disease and a myriad of other influences. Resoluteness in the everydayness of living with rheumatoid arthritis can be lost at any time, in any way. Living with rheumatoid arthritis becomes a cycle of always working towards and maintaining the everydayness of resolute coping, while knowing it may be lost at any moment, which will necessitate coming again to pick up the strategies that bring one back to a taken-for-granted everydayness.

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CHAPTER ONE: Introduction and Overview

Disease happens in a life that already has a story, and this story goes on, changed by the illness but also affecting how the illness story is formed (Frank, 1995, p. 54).

Rheumatoid arthritis is a disease that affects the lives of many people in New Zealand and worldwide. People live with the disease for many years and experience it in the context of their everyday lives. The development of nursing knowledge that acknowledges, values, and focuses on personal experience of an illness such as rheumatoid arthritis is essential to nursing practice (Brown & Williams, 1995; Watson, 1985). Gerhardt (1990) suggests there is an onus on nurses to understand the patient's perspective, especially in chronic illness. By understanding the meaning of illness, nurses can be more responsive to people's unique difficulties (van Manen, 1999) and thus facilitate appropriate care. The research I report in this thesis explores the phenomenon of 'living with rheumatoid arthritis' and provides an understanding of its meaning in the lives of those who experience it.

Evidence of rheumatic disease has been found in skeletal remains from ancient Egypt and is represented in pictorial and graphical records. However, it was not until the mid 18th century that rheumatoid arthritis was first recognised as a sub-classification of rheumatic disease (Alarcon, 1995). Rheumatoid arthritis is a chronic, systemic inflammatory disease of the connective tissues. It is characterised by periods of remission and exacerbation and causes symmetrical synovitis resulting in destruction of the joints. It most commonly affects the peripheral joints but can also affect connective tissues throughout the body, including the lungs, eyes and blood vessels (Beare & Myers, 1994).

Rheumatoid arthritis has been described as "the most feared of the crippling rheumatic diseases" (Thompson, 1983, p. 11). It can range in severity, from the person who experiences one or two exacerbations only and is left with little residual joint destruction or functional impairment, to those for whom rheumatoid arthritis is life threatening (approximately 1% of the client group). For the vast majority the reality is between these two extremes - they experience chronic pain, chronic fatigue and functional impairment for a large part of their lives (Waterflow, 1992). As such,

rheumatoid arthritis has a “global impact” on the lives of people with the disease and their families (Ryan, 1998).

The cause of rheumatoid arthritis is unknown, although it has been hypothesised that autoimmune defects or infectious agents may trigger the disease in people with a genetic susceptibility (Beare & Myers, 1994; Moller, 1994). The disease can occur at any age, with 30 - 50 years being the most common age of onset. Three times more women than men are affected (Arthur, 1998).

Little is known about the day-to-day experiences of those who live with rheumatoid arthritis because, to date, the main emphasis of research has been on the physical manifestations of the disease and how people cope with these. Still less is known about the experiences of family members despite recognition that “the handicap of chronic illness may fall as heavily on the family as on the patient, in terms of problems created for daily living and family life” (Anderson & Bury, 1988, pp.7-8). The study I describe in this thesis addresses these gaps through an exploration of the phenomenon of ‘living with rheumatoid arthritis’ from the perspectives of partners and adult children of people with rheumatoid arthritis and those who have the disease. The study utilises a hermeneutic phenomenological methodology informed by the writings of Heidegger (1889-1976) and Gadamer (1900-) to provide an understanding of the meaning the phenomenon has for the participants and illustrates the impact it has had on their lives.

This chapter outlines the purpose of the study and offers a description of my initial involvement and ongoing interest in the experience of living with rheumatoid arthritis. Providing such a description illustrates the beginning of my journey and an “orientation to the phenomenon” (Leonard, 1994, p. 57), an essential element of a hermeneutic phenomenological study. Following this description the context of the study is discussed. This discussion includes an explication of some of the assumptions I bring to the study and justification of the research method. The chapter concludes with a brief overview of the thesis.

Purpose of the study

The overall aim of this research is to explore the phenomenon of ‘living with rheumatoid arthritis’. Based on the premise that it is not only the person with the disease

who experiences the phenomenon, this study seeks to understand the phenomenon as experienced by partners and adult children of people who have rheumatoid arthritis as well as by the people themselves.

I provide an interpretation of the phenomenon that extends the insights of current literature of the impact rheumatoid arthritis has on the everyday lives of those who experience it. The findings are presented in this thesis with the aim of making the interpretation available to nurses and other health professionals so that they might better appreciate the experience of living with rheumatoid arthritis. It is my hope that this thesis will challenge readers to reflect on their practice and possibly enhance the quality of their care. A strength of a hermeneutic phenomenological study such as this is that it is aimed at making a difference to the practice of individual nurses (Gasquoine, 1996, p. 16).

Background context

My interest in rheumatoid arthritis began about fifteen years ago when I became a Charge Nurse of an acute medical ward in a large urban hospital. One of the physicians working on the ward practised in both general medicine and rheumatology and as a consequence there were a number of clients with rheumatoid arthritis admitted to the ward. Coming from a recent clinical background of cardiothoracic nursing I faced a rapid learning curve in relation to rheumatoid arthritis and the needs of clients with the disease.

Two women with rheumatoid arthritis, one an inpatient, one an outpatient, made a particular impression on me, to the point that I can still recall many aspects of their lives. Both women valued their independence and showed great fortitude and humour despite profound physical limitations resulting from their disease. One woman was widowed; the other received much support from her husband. Both were mothers to children who were in their early teens. Although rheumatoid arthritis greatly affected their mothering role, both women valued their contribution to the children's upbringing. It was through my involvement with these women that I first began to understand some of the complexities and extreme difficulties that are everyday realities for those living with rheumatoid arthritis. Following my encounters with these women I was left pondering many questions, such as: What does rheumatoid arthritis mean in their lives?

How do they manage in their everyday lives when away from the hospital? How do they remain so cheerful and strong in the face of such physical limitations? What are the effects on the family?

In the early 1980s in New Zealand there was an impetus to develop education programmes, in conjunction with the Arthritis Foundation, for clients and their families and I became involved in this at a local level. These programmes were underpinned by the work of American nurse Kate Lorig and are still used extensively throughout New Zealand and internationally (see Lorig, 1994; 1996). Additionally I am a foundation member of the New Zealand Health Professionals in Rheumatology, a professional group for those working with people who have rheumatological conditions. Although now employed in nursing education I have maintained my interest and have attempted to keep abreast with knowledge developments in the area of rheumatoid arthritis through reading and attending and presenting at conferences. I also provide professional supervision for three field officers from the local Arthritis Foundation.

At a number of conferences I have listened with interest to many research papers related to different aspects of the management of rheumatoid arthritis. Most of these studies have utilised quantitative methods and while they provided valuable information and have expanded my understanding, it has become apparent to me that the experience of the clients beyond the immediate clinical response is virtually invisible. I am also aware from my understanding of the literature that there is a dearth of qualitative studies related to the rheumatoid arthritis. Having developed an interest in, and knowledge of, research during my university studies, I am aware of the advantages that studies from within the interpretive tradition have in describing and valuing illness experiences. Consequently, I recognise the need for qualitative research that describes the experiences of those people actually living with the disease and increases the understanding of the professionals involved in their care. I know of the important contribution such studies could make to nursing knowledge and nursing practice.

The past twenty years has seen the emergence of interpretive inquiry in nursing research, with the work of Patricia Benner being particularly influential throughout this time. The publication of her seminal work 'From Novice to Expert' (1984) marked the beginning of a new era in nursing scholarship. This work highlighted for many nurses, myself included, the advantages of interpretive inquiry in answering many questions of

importance to nurses. In nursing education the work of Nancy Diekelmann (1988) provided a similar turning point. In the New Zealand context and for me personally, the works of Judith Christensen (1990), Irena Madjar (1991), Jo Ann Walton (1995) and latterly Liz Smythe (1998) have been particularly influential.

In 1995 the need to complete a dissertation as part of my university studies provided the opportunity to undertake a single-participant case study using phenomenological analysis that explored one woman's experience of living with rheumatoid arthritis (Roy, 1995). The study developed from my ongoing interest in rheumatology nursing and my interest in women's health that emerged during my university studies. While the study reported in the dissertation was a stand-alone piece of research it subsequently came to be considered the pilot for the present study.

Findings from the 1995 study broadened my understanding of the experience of living with rheumatoid arthritis and confirmed my belief that the effects of chronic illness are experienced not only by the person who has the disease but also by their families and others in close relationship to them. For example, the participant in the 1995 study spoke of the 'embarrassment' experienced by her children because she 'looked different' to other mothers. She also spoke of her family's reluctance to have anything in the house, such as raised blocks for the sofa, which drew attention to the fact that she had rheumatoid arthritis. As she talked about these and other issues related to her family I was thinking, 'It would be good to talk to them too, to hear of their experience of living with rheumatoid arthritis.' Although I recognised this 'ripple effect of chronic illness' (Dunsmore, 1998) I could not address this within the boundaries of the 1995 study.

As I began my doctoral studies I participated in a number of collaborative conversations in my attempts to develop and refine the questions for this study. I spoke with client groups and the participant from my previous study as well as nurses who had expertise in working with those who live with rheumatoid arthritis. The latter group included nurses from Auckland Public and Middlemore hospitals in Auckland and Queen Elizabeth Hospital in Rotorua, New Zealand's only hospital specialising specifically in rheumatological conditions. These conversations confirmed for me the need and value of undertaking research that focused on the everyday experiences of those living with rheumatoid arthritis, whether as partners, adult children or people with the disease.

It is within this context that I developed the questions for this study: What does it mean to live with rheumatoid arthritis? What is the experience of partners and children of those who have the disease? What impact does rheumatoid arthritis have on the everyday lives of those who experience the phenomenon?

Context of the study

Since the 1980s there has been a trend in New Zealand healthcare services to shift many services from hospital to community care settings. For the person living with rheumatoid arthritis this has meant easier access to many outpatient and community-based services. It has also meant that the availability of specialised in-patient care for people with rheumatoid arthritis has declined significantly and there appears to be regional variation in access to in-patient services. The decrease in specialised in-patient care is of particular significance for many of those who live with rheumatoid arthritis, be they people with the disease or family members. For many families a hospital admission for review and intensive treatment afforded 'time out' for the person with rheumatoid arthritis and for their family. It offered a time and space for reflection and, as a number of people have told me, a chance to 're-charge' the batteries. It is these benefits, often hidden, that have been lost in the restructuring process. Additionally, a number of wards with facilities designed specifically for those with rheumatoid arthritis and other rheumatological conditions and staffed by nurses with particular expertise have been closed or redesignated. Consequently, if the person with rheumatoid arthritis is admitted to hospital it is often to a ward environment that is less than suitable for their physical needs and they are cared for by nurses who may have little experience or understanding of their specific needs.

The move to increased community based care for people with rheumatoid arthritis has contributed to a devolution of nursing knowledge and expertise. There remain a few pockets of expertise within hospital settings, for example Queen Elizabeth Hospital in Rotorua, Hutt Valley Health, and Middlemore Hospital in Auckland, and within specialised outpatient clinics. However, nurses seem to be increasingly required to care for people with rheumatoid arthritis and their families without the knowledge, understanding and expertise to maximise their care of these people.

The past ten years has seen an increased availability in, and options for, surgical intervention for people with rheumatoid arthritis. Surgical intervention would now be the main reason for hospital admission for the person with rheumatoid arthritis. Surgery is available within the public health system, but waiting lists are often long with some people waiting more than a year for their surgery. Surgery in a private hospital is an option used by a number of people with rheumatoid arthritis to avoid the public hospital waiting lists. The cost of private surgery is often prohibitive unless private medical insurance is available. Insurance coverage is often difficult if not impossible for the person with rheumatoid arthritis to obtain under many health insurance schemes. All participants (or the partner/parent of participants) in the current study have had at least one surgical procedure, three participants have had more than ten. Planning for and recuperating from surgery is often a significant part of the experience of those currently living with rheumatoid arthritis.

Consumer demand for particular drug therapies has increased in New Zealand over the past two or three years. This trend has been influenced by direct drug-company advertising on television, in the print media (including the popular press) and through sponsorship of patient education programmes. For example, extensive advertising for Celebrex™ (see Appendix I) saw many people with rheumatoid arthritis specifically asking to be prescribed the drug upon its release in New Zealand. This despite the fact that, to date, the drug carries no government subsidy and costs the consumer approximately NZ\$55 for 30 tablets (a month's supply).

Although specific figures are not available, it appears that the majority of people with rheumatoid arthritis in New Zealand consult their general practitioner in the management of their disease. This consultation usually occurs in conjunction with a rheumatologist on a shared-care basis. Consultation with a rheumatologist in the public health system may involve a waiting period for an appointment of one to two months, although there is regional variation to this. People with severe disease, such as the participants in this study, are more likely to attend a rheumatology clinic or to consult privately with a rheumatologist on a regular basis.

The Arthritis Foundation of New Zealand through its 18 regional divisions and field officer network offers support, advice and education to people with rheumatoid arthritis and their families. This voluntary non-profit organisation, formed in 1966, works

closely with health professionals and funds research programmes. A number of nurses and other health professionals are employed as field officers by the Arthritis Foundation. Most participants in this study were members of the Foundation.

Assumptions and pre-understandings

Van Manen (1990) suggests that in phenomenological inquiry it is important to “make explicit our understandings, beliefs, biases, assumptions, presuppositions and theories” (p. 47). To do so is to recognise and acknowledge the influence these may have on the research process and, in particular, the analysis of data and final interpretation. So what are the assumptions and pre-understandings brought to this study that have shaped and influenced it?

Fundamental to my research is the premise that understanding the experience of illness as it is lived is a vital part of the knowledge from which expert nursing derives (Walton, 1995, p. 239). I make the assumption that nurses and other health professionals have significant knowledge about rheumatoid arthritis but they tend to take for granted the experiential values of pain, fatigue, deformity, fear, anxiety, and uncertainty inherent in the everyday experience of living with rheumatoid arthritis.

At the beginning of my earlier study I recorded the following assumptions relating to women who live with rheumatoid arthritis:

Women with rheumatoid arthritis often demonstrate personality traits of stoicism, independence (on their terms), fortitude and courage.

Most women with rheumatoid arthritis seem to have cheerful personalities and live full and rewarding lives despite a disease which leaves them with varying degrees of functional impairment which is often accompanied by pain and fatigue.

Although the literature discusses depression in women with rheumatoid arthritis this is not something I have seen.

Life for women with rheumatoid arthritis must be difficult at times, or in some cases all the time (Roy, 1995, p. 19-20).

While my assumptions were not “turned around” (Benner, 1994, p. 101) during the course of the 1995 study they were challenged and extended and I came to view them within the context of the participant’s experience. These new understandings came with me to the current study and were recorded as such:

Independence, fortitude and courage underpin an approach to life with rheumatoid arthritis. This is tempered by a vulnerability experienced at times when faced with conflicting emotions and the physical implications of a disease process that is variable and progressive.

Living with rheumatoid arthritis can be overwhelming, yet people can lead full and rewarding lives. The reality is that it is not the life they would necessarily have chosen. Life past, present, and future is affected by rheumatoid arthritis as are the lives of those to whom they are close.

Rheumatoid arthritis is not necessarily the main focus of life for those who live with the disease. For most of the time it is part of the taken-for-granted way of being-in-the-world.

Self-management and professional support are important in living with rheumatoid arthritis. They contribute to successful, ongoing adjustment to living with the disease to the extent that it becomes part of the taken-for-granted existence for those living with rheumatoid arthritis.

The ripple effect of chronic illness is such that family members too experience the phenomenon of 'living with rheumatoid arthritis' albeit in different ways (Journal entry, April 1996).

These pre-understandings, recorded in my journal early in the research process, have shaped and influenced my approach to this study. They, along with the other assumptions and pre-understandings I have brought to the study, have been reflected on and questioned as my understanding of the complex phenomenon of 'living with rheumatoid arthritis' has expanded during the course of this study.

Finally, it must be noted that I would not have understood and interpreted the participants' experiences in the way I have had I not had the experience of nursing and working with people who live with rheumatoid arthritis over a period of many years. There are also limits to my understanding in that I have not lived with rheumatoid arthritis as a person with the disease or as a partner or child. Readers of this thesis will also bring with them assumptions and pre-understandings of the phenomenon of 'living with rheumatoid arthritis' based on their experiences. As a reader, I invite you to reflect on these while remaining open to new understandings of the phenomenon.

Selecting and justifying the method

During the past decade a number of nurse scholars have called on the development of nursing knowledge which acknowledges, values and focuses on personal experience

(Brown & Williams, 1995). Indeed Benner and Wrubel (1989) see understanding the subjective illness experiences of people as being essential to nursing practice:

Understanding the meaning of the illness can facilitate treatment and cure. Even when no treatment is available and no cure is possible, understanding the meaning of the illness for the person and that person's life is a form of healing, in that such an understanding can overcome the sense of alienation, loss of self-understanding, and loss of social integration that accompany illness (p. 9).

Having completed a pilot study using a methodology informed by Heideggerian philosophy I was confident that some form of interpretive inquiry was appropriate for the current research. I wanted to go beyond just describing the phenomenon of 'living with rheumatoid arthritis'. While a fully emic view of something I have not experienced is impossible, what was possible was for me to develop an understanding and interpretation from the experiences of those who encounter the phenomenon in their everyday lives. I hoped to understand the phenomenon of 'living with rheumatoid arthritis' in a way that took into account contextual aspects as well as my experience and influence as a researcher in shaping the final research product. A method informed by my understandings of aspects of the philosophical hermeneutics of Gadamer (1900-) seemed particularly appealing. With its ontological focus on understanding and the role language and interpretation play in this, Gadamer's work seemed an appropriate foundation on which to build my research, and as such has guided the processes involved in the study. When I began the process of data analysis I came to realise that the writings of Heidegger (1889-1976) had much to offer in my quest for understanding of the phenomenon 'living with rheumatoid arthritis'. It was at this point that Heidegger's work began to strongly inform my study. It is primarily the writings of Heidegger that have been brought to the interpretations presented in the data chapters (Chapters 5-8) to help me 'shed light' on the phenomenon of 'living with rheumatoid arthritis'.

The biopsychosocial model is the often-espoused approach to the care of the person with rheumatoid arthritis. In principle, this is a sound framework on which to base the care of those living with rheumatoid arthritis. However, in practice, biological aspects often dominate over an integrated approach to care (Perry, 1991). Perhaps this is because of the dominance of biomedical and behavioural science research that underpins the practice of the health professionals involved in the care. Much of research

related to rheumatoid arthritis has developed from a biomedical perspective with its philosophical origins within the positivist tradition. Inherent in this tradition is the objectification of the phenomenon of interest with subjective data seen as either invalid or less valuable. The experiences of the client are seen as subjective and therefore undervalued. Kleinman (1988, p. 28), among others, calls for research methods that “enable us to grasp, behind the simple sounds of bodily pain and psychiatric symptoms, the complex inner language of hurt, desperation, and moral pain (and also triumph) of living an illness”. Hermeneutic phenomenology is one such method.

Hermeneutic phenomenology is seen as congruent with the humanistic philosophy that underpins nursing. It also recognises the contextualised nature of all human experience. This means that in hermeneutic phenomenology inquiry is directed at a phenomenon within its real life context, just as nursing practice is always situated in a real life context. Hermeneutic phenomenology recognises that people are “fundamentally self-interpreting beings for whom things have significance” (Leonard, 1994, p. 55). Furthermore because of this, “understanding human action always involves an interpretation, by the researcher, of the interpretations being made by those persons being studied” (ibid.). The philosophical underpinnings of the approach to this research are discussed further in Chapter Three.

There are a number of other research methodologies within the interpretive tradition that could have been used to explore the experiences of those who live with rheumatoid arthritis. Different methodologies offer alternative perspectives of understanding a phenomenon, all of which have the potential to increase nursing knowledge and inform nursing practice. For example, the use of grounded theory methodology would have identified the basic social process underpinning the experience and provided a theoretical framework of understanding. Alternatively, a critical approach may have focused on the effect changes in the structures and delivery of health services have had on the lives of those who live with rheumatoid arthritis. Although these other methodologies were considered as possible approaches to the phenomenon under study, I remained drawn to hermeneutic phenomenology. My earlier study had afforded me the opportunity to glimpse the potential of hermeneutic phenomenology to uncover and show the everyday realities of living with rheumatoid arthritis, to reveal the taken-for-granted nature of the experience, and to offer an interpretation with the potential to raise new understandings of the complex phenomenon of ‘living with rheumatoid arthritis’.

Overview of the thesis

This thesis is presented in nine chapters. Chapter Two explores “**Rheumatoid Arthritis and the Literature**” in an attempt to explicate the pre-understandings and assumptions that dominate the literature related to rheumatoid arthritis. Additionally, as part of the literature review, the chapter provides contextual information about rheumatoid arthritis as a background for understanding the participants’ experiences presented in the data chapters (Chapters 5-8).

In Chapter Three, “**Philosophy to Methodology**”, the philosophical underpinnings of the study are articulated. My understandings of the Heideggerian and Gadamerian notions that have informed the research are reviewed and their influence on the processes and outcomes of the study discussed.

Chapter Four, “**Methodology to Method**”, moves the research from the philosophical and methodological issues discussed in the previous chapter to consideration of the methods used in undertaking the study. The chapter addresses the issue of rigour and signposts the research journey in describing the research process. This is followed by a description of the interpretive processes utilised in the study.

An interpretation of the phenomenon of ‘living with rheumatoid arthritis’ is presented in the four data chapters, Chapters Five, Six, Seven and Eight. Chapter Five, “**The Hands**”, serves as an introduction to the interpretation and as such is presented somewhat differently from the other data chapters. It introduces some of the ideas that are carried forward and built on in the data chapters that follow. The focus of Chapter Five is the participants’ stories about ‘the hands’ of those who have rheumatoid arthritis and the role that they have in announcing the disease.

Chapter Six, “**The Everydayness of Living with a Disease Ravaged Body**”, begins to uncover the hiddenness of the everyday practical world of those who live with rheumatoid arthritis and explores the impact of living with a disease-ravaged body. Because of the emphasis on the physical aspects of the disease, the experiences of those participants who have rheumatoid arthritis take primacy in this chapter.

Chapter Seven, “**The Always-Thereness of Living with Rheumatoid Arthritis**”, explores the impact on the lives of those who experience the phenomenon of ‘living

with rheumatoid arthritis', whether as partners, as adult children, or as people with the disease. I suggest that the always-thereness of living with rheumatoid arthritis influences, to varying degrees, almost every aspect of their lives.

Chapter Eight, the final data chapter, is entitled "**Fear, Dread, Hope and Possibility**". This chapter explores the fears and anguish that the participants spoke of as they live with rheumatoid arthritis. It also shows the possibilities and strengths that may emerge as they live toward the future.

The final chapter of the thesis, "**The Meaning of Living with Rheumatoid Arthritis**", integrates and summarises the findings of the study as a way of synthesising the understandings that have emerged. The findings are explored alongside relevant literature and limitations of the study discussed. The chapter concludes with a discussion on the implications of the study for nursing practice and education and recommendations are made for further research.

CHAPTER TWO: Rheumatoid Arthritis and the Literature

The more ways in which we can analyse any phenomenon, the more potential there is for seeing different images and details that are not readily apparent when only viewed from one perspective.... It is like seeing the image of a garden in a mirror, with many flowers, many colours, and many beds, then moving the mirror closer to a bed of Californian poppies and seeing the rich yellow cups swaying in the fine breeze, then keeping the mirror in position and stepping back a few feet to get another look, to discover different shades of colour blending with the green of the stems. Each of the images depends on where the mirror is in relation to the garden and where the viewer is in relation to the mirror and the garden (Meleis, 1991, p. 249).

The literature review in hermeneutic phenomenology attempts to explicate the pre-suppositions and assumptions that dominate the literature in relation to the phenomenon under study (van Manen, 1990). There has been very little written specifically about the experience of living with rheumatoid arthritis, but there is a wide range of literature on the broader topics related to rheumatoid arthritis. This chapter reviews three particular views of rheumatoid arthritis that feature strongly in the literature. Firstly, the view of rheumatoid arthritis as a disease process which incorporates epidemiology and theories of aetiology. Secondly, the view which relates to the management and the consequences of the disease for the person. Both these views, which are described primarily by health professionals, are considered together as the biomedical view. The third view reflects on what rheumatoid arthritis means from a psychosocial perspective. Two additional views are included in this review, not because they are particularly dominant in the literature but because of their specific importance to this study. These views are: the nursing view, included here because it is part of my historical horizon and as such influences my perspective of the phenomenon; and the client/family view of the experience of living with rheumatoid arthritis.

The biomedical and the psychosocial views dominate the literature related to living with rheumatoid arthritis. The divisions are not absolute and there is considerable overlap in some instances. The biomedical literature is dominated by research which seeks to identify the cause of rheumatoid arthritis (particularly the role of genetics), predict the severity (particularly exploration of multi-factorial indices), and identify and evaluate management strategies (particularly drug regimens and surgery). Literature pertaining to the psychosocial view of rheumatoid arthritis is dominated by research that attempts to

explicate how people 'cope' when living with rheumatoid arthritis. Much of the research attempts to identify indices of coping, for example, sense of coherence, helplessness and stress appraisal. Many of the research studies reflective of both the biomedical and psychosocial views acknowledge the multi-dimensional effects of rheumatoid arthritis on an individual, but most use questionnaires and scales in an attempt to quantify data, providing a decontextualised approach that classifies or abstracts the experience of living with rheumatoid arthritis. However, each study makes its own contribution to expanding our understanding of the phenomenon of 'living with rheumatoid arthritis'.

The body of knowledge encompassing rheumatoid arthritis is extensive and it is beyond the scope of this chapter to provide anything more than a few 'snapshots' of this literature within the views outlined above. For this reason the main source for this review is the nursing literature along with some key articles from related disciplines such as medicine and psychology that provide an overview of the subject. In addition to outlining the views, this chapter provides contextual information as a background for understanding the participants' experiences presented in the data chapters (Chapters 5-8). The review first considers literature pertaining to the biomedical and psychosocial views before addressing the interface of nursing and the person with rheumatoid arthritis. The final sections of the chapter discuss the very small amount of literature relating to families living with rheumatoid arthritis and the day-to-day experience of living with the disease.

The biomedical view

Literature reflecting the biomedical view of rheumatoid arthritis is the area in which the majority of the research and writing associated with rheumatoid arthritis occurs. Most of the research is quantitative and is dominated by four particular themes: identifying the cause, predicting severity, optimal therapeutic regimens and testing the efficacy and safety of new chemotherapeutic agents. Nursing literature associated specifically with the biomedical view tends to be in the form of research-substantiated review or opinion articles (for example, see Arthur, 1995; 1998; le Gallez, 1994; Waterflow, 1992).

Epidemiology

In 1987 the American College of Rheumatology (ACR) published revised criteria for the classification of rheumatoid arthritis (Arnett, 1990). The seven criteria are: morning stiffness of at least one hour duration, soft-tissue swelling of three or more joint areas, soft-tissue swelling of hand joints, symmetric arthritis, rheumatoid nodules, positive serum rheumatoid factor, and typical radiological changes of the hand and wrist. A person is said to have rheumatoid arthritis when at least four of the seven criteria are present, the first four for at least six weeks (Arnett, 1990). It is the ACR classification that is most commonly used in epidemiological and clinical studies of rheumatoid arthritis.

The incidence of rheumatoid arthritis is most frequently cited as 1-2% of the adult population (see for example, Alarcon, 1995; Hannan, 1996; Pincus & Callahan, 1990). Rheumatoid arthritis has been described globally although it appears to be less prevalent among some Asian and African populations (Alarcon, 1995; Arthur, 1998). It would seem that being a woman is the primary risk factor for rheumatoid arthritis with 2-3 times more women than men affected by rheumatoid arthritis (Alarcon, 1995; Hannan, 1996). The age at onset of rheumatoid arthritis is most commonly between 30-50 years.

There is a noticeable lack of published epidemiological data related to arthritis in general, and rheumatoid arthritis in particular, for the New Zealand population. A 1995 (unpublished) Colmar-Brunton survey commissioned by the Auckland Branch of the Arthritis Foundation indicates that 11% of Aucklanders have arthritis. The results were based on a self-report telephone questionnaire and did not differentiate between the types of arthritis. KEMP (1996) cites his unpublished study in concluding that the incidence of rheumatoid arthritis in New Zealand mirrors the 1-2% of other published studies. Lennane, Rose, and Isdale (1960) reported a lower prevalence of rheumatoid arthritis in Maori¹ from Te Arawa². The low prevalence (ratio 1:4, Maori: Caucasian) was confirmed in a subsequent study of 458 inhabitants of the Maori rural community

¹ Aboriginal people of New Zealand.

² Confederation of eight Maori tribes found in the central area of New Zealand's North Island (Burchfield, 1986).

of Ruatahuna³ (Rose & Prior, 1963). The lower incidence of rheumatoid arthritis in Maori is thought to be due to a favourable genotype (Tan, Farmiloe, Roberts, Geursen, & Skinner, 1993). More recent New Zealand rheumatoid arthritis specific epidemiological data does not appear to be available.

Aetiology

The cause of rheumatoid arthritis has been a focus of rheumatology research for many years and although a number of theories have been explored and advances made in understanding the pathogenesis of the disease, the cause remains unknown. Current theories suggest that rheumatoid arthritis may be triggered by infectious agents (viral or microbial) or by other environmental agents (e.g. toxic chemicals) that lead to synovitis and chronic inflammatory disease. A genetic susceptibility is thought to account for 20-30% of the cases of rheumatoid arthritis, while 70-80% of cases are linked to environmental factors or other non-genetic personal attributes (e.g. fecundity) (Alarcon, 1995). Cellular level studies are the current focus of much biomedical research in the quest to identify the cause of rheumatoid arthritis. For example, Tan and his associates (Tan, 1995; Tan, Skinner, & Grinlinton, 1992) have conducted a number of studies in an attempt to identify and explore the role of cytokines⁴ in rheumatoid arthritis and to explore genetic factors associated with the incidence of rheumatoid arthritis (Tan, 1990; 1995; Tan et al., 1993). Predicting the severity of the disease is a further focus of current biomedical research (for example and discussion see McQueen & Tan, 1994; van Zeben, Hazes, Zwinderman, Vandenbroucke, & Breedveld, 1993). The significantly increased incidence of rheumatoid arthritis in women has led to numerous studies into the role of sex hormones in disease susceptibility and/or modulation, but as yet the exact relationship remains unclear (Alarcon, 1995).

³ Small rural town in the central North Island of New Zealand.

⁴ Cytokines are glycoproteins involved in inflammation. Defined over the past 10-15 years, their biologic activity reveals previously unknown complexities of the inflammatory response. In rheumatoid arthritis therapeutic interventions aimed at modifying the effects of cytokines are being trialed (Tan et al., 1992, p. 447).

Patients' theories

In addition to, and intertwined with, the biomedical theories about the cause of rheumatoid arthritis, are the theories and explanations offered by those who have the disease. Ailinger and Schweitzer (1993), in an ethnographic study explored patient explanations of rheumatoid arthritis. Participants (59) who suggested a cause of their disease identified causative factors of stress (31%), illness or physical trauma (31%) including infection prior to the onset (14%), heredity (12%), and climate (7%).

The apparent differences in biomedical and lay conceptions of arthritis have been identified in respect to aetiology (Elder, 1973), and treatment (Price et al., 1983 cited by Rice, 1994). Rice (1994) in a more recent qualitative study investigated an explanatory model of arthritis informed by Kleinman's (1988) work. In respect to aetiology, Rice identified marked differences between biomedical and lay explanations. Rice's study included 50 participants over the age of 60 years, 34 of whom indicated they had arthritis. Four participants identified themselves as having rheumatoid arthritis. Climate, diet and injury were the most commonly mentioned cause of arthritis.

Mortality in rheumatoid arthritis

Mortality is seldom discussed in relation to rheumatoid arthritis. However, there is increasing evidence to suggest that the presence of rheumatoid arthritis shortens the lifespan. Difficulty in gathering mortality statistics for rheumatoid arthritis can cloud evidence of increased mortality. For example, it is often only the primary and not secondary cause of death that is recorded on death certificates, which may render invisible the influence of rheumatoid arthritis. In an attempt to overcome such limitations, Pincus and Callahan (1990) reviewed ten published studies of actuarial survival rates over five years or longer in people with rheumatoid arthritis. Their review indicated "that rheumatoid arthritis patients die earlier than would be expected for persons of the same age and sex in the general population" (p. 27). The increased mortality rates in people with rheumatoid arthritis apply particularly to those people with more progressive disease, who rarely have long-term remission, have functional decline, increased radiographic damage, and work disability (Pincus & Callahan, 1990). It would be expected that an individual with a rheumatoid arthritis profile such as this would die five to ten years earlier than people of the same age and sex in the general

population (Corbett, Dalton, Young, Silman, & Shipley, 1993; Coste & Jouglu, 1994; Halverson, 1995; Pincus & Callahan, 1990). Cause of death may be directly associated with rheumatoid arthritis, for example, specific organ failure (e.g. lung), or to drug toxicity, renal, or gastrointestinal disease. For those with severe rheumatoid arthritis the 5-year survival rate is similar to survival rates for people with triple vessel coronary artery disease or Stage IV Hodgkin's disease (Halverson, 1995; Pincus & Callahan, 1990).

Treatment options and management

The literature reveals four main aims in the management and treatment of rheumatoid arthritis: relief of symptoms, prevention of joint damage, maintenance of joint function, and preservation of quality of life. Of significant contribution to these aims are chemotherapy and surgical intervention. Recent developments in both chemotherapeutic and surgical intervention are prevalent in the literature.

Chemotherapy

Nurses have an important role in the administration and monitoring of prescribed drugs as well as providing support and education for the client using them. The nursing literature pertaining to chemotherapy primarily consists of research-substantiated review or opinion articles. Current trends in chemotherapy used in the management of rheumatoid arthritis, as discussed in the literature, are briefly outlined and reviewed in this section to provide background for understanding the experiences of participants presented in the data chapters (Chapters 5-8). Arthur (1995) and Byrne (1998) outline the key groups of drugs used in the treatment of rheumatoid arthritis and the associated implications for nursing care. Drugs used in the treatment of rheumatoid arthritis can be categorised in three groups - analgesics, non-steroidal anti-inflammatories, and disease-modifying drugs. Analgesics, as first-line drugs, reduce joint pain but not stiffness and may be all that is required by the person with mild disease, or they may be used in combination with drugs from the other two groups to provide additional pain relief for those with more severe disease. Non-steroidal anti-inflammatory drugs (NSAIDs), also considered first-line drugs, are prescribed to relieve joint pain, swelling and stiffness (Arthur, 1995). Recent developments in NSAID therapy include the introduction of a

new group of NSAIDs known the COXIBs⁵ that are as effective in providing pain relief as earlier NSAIDs but with significant reduction in gastrointestinal side-effects (Byrne, 1998; Jones, 1999).

Second-line drugs are referred to variously as disease-modifying antirheumatic drugs (DMARDs) or slow-acting antirheumatic drugs (SMARDs) and are prescribed in an attempt to induce disease remission (see glossary, Appendix I, for examples). As data from several studies show a reduction in life expectancy in people with rheumatoid arthritis, these second-line drugs are now introduced much earlier in the course of the disease, often before joint damage has occurred (Arthur, 1995; Byrne, 1998; Sew-Hoy, 1994). Recently released DMARDs including leflunomide and etanercept are rheumatoid arthritis-specific medications that are showing promise in symptom relief and in slowing disease progression. However, these drugs are expensive in comparison with other DMARDs. For example, methotrexate costs approximately NZ\$25 per patient per year compared with NZ\$2500 for leflunomide or NZ\$20,000 for etanercept (Jones, 2000).

First and second-line medications all have potential side-effects. For example, the chemotherapeutic agent methotrexate may cause nausea, vomiting, mouth ulcers, rashes, headaches, alopecia, pneumonitis, renal disorders, bone marrow suppression and hepatic toxicity (see glossary, Appendix I). Awareness of, and monitoring for, these side-effects is essential for both nurses and clients. Nurses also play a pivotal role in providing the client with adequate information about medications (Ryan, 1997).

Both Arthur (1995) and Byrne (1998) briefly mention some of the non-physiological implications for the person taking these drugs - for example, the difficulty some people have in accepting the need to take such toxic drugs. However, there is little written from the client's perspective relating to chemotherapy.

⁵ COXIBs inhibit cyclooxygenase 2 (COX2) while leaving cyclooxygenase 1 (COX1) alone. COX1 is involved in the production of prostaglandins that are protective of tissue such as the gastric mucosa while COX2 are responsible for the production of prostaglandins that are actively involved in the inflammatory process (Byrne, 1998). COXIBs therefore have anti-inflammatory properties similar to other NSAIDs but with reduced risk to the integrity of the gastric mucosa (Jones, 2000).

Surgical intervention

The options for surgical intervention for people with rheumatoid arthritis have developed significantly over the last decade. Surgical options include: hip, knee, shoulder, elbow, ankle and wrist replacement; tendon transplants to thumbs; silastic implants⁶ to knuckles; fixing/arthrodesis of joints, for example, thumb, great toe, wrists (Sturdy, 1998; Waterflow, 1992). Many procedures have moved from being experimental to being accepted and frequently used interventions for people with moderate and severe rheumatoid arthritis. In some areas of New Zealand public hospital waiting lists for this type of surgery are long. Surgery in a private hospital can reduce the waiting time significantly but is expensive, especially for those without medical insurance. Major and minor surgical procedures have been shown to make significant improvement in quality of life by maintaining mobility, dexterity and independence, reducing pain and improving appearance (Sturdy, 1998).

Symptoms of rheumatoid arthritis

The symptoms of rheumatoid arthritis as an indicator of disease activity feature strongly in research reflective of the meeting place between the biomedical and psychosocial views. Symptom reporting is important because physicians and other health professionals rely heavily on symptom reports from those with the disease in making treatment decisions and in planning care. Symptom reporting is also used as a measure in numerous research studies (for example, see Eberhardt, Larsson, & Nived, 1993; McNamara, 1992). Symptom scales and behavioural checklists are used by researchers in an attempt to predict such aspects as functional disability and disease severity or to show a correlation between severity of symptoms, coping indices, and psychosocial aspects of living with rheumatoid arthritis such as marital satisfaction.

Katz and Criswell (1996), in a study aimed at determining if differences exist in symptom reports between men and women with rheumatoid arthritis, found in unadjusted analyses from 664 participants (76.4% women) that women were more

⁶Made of silicone rubber these implants act as flexible hinges. They are often successful in reducing pain and providing a degree of useful joint motion. Implants are most common in the metacarpal-phalangeal joints but may also be used in the proximal-interphalangeal joints (Tan & Tregonning, 1993).

likely to evaluate their symptoms as severe. However, after adjusting for disease severity there was no significant difference between the symptom reports of men and women for 8 of the 9 symptoms (overall pain rating, severe pain in past two weeks, pain worse in last year than in previous year, severe swelling in past two weeks, swelling worse in last year than in previous year, weakness, fatigue in past two weeks, rheumatoid arthritis worse than in previous year). The exception was for the overall pain rating: “women’s pain ratings were significantly *lower* than men’s” (p. 445). These findings raise the question whether health professionals respond differently to complaints or prescribe treatment differently for men and women with rheumatoid arthritis. There is little evidence within rheumatology of differential treatment between men and women but anecdotal evidence suggests that men seem to receive total knee and hip joint arthroplasty at an earlier stage in the disease process than women do (H. Blackley, personal communication, 28.10.2000).

Holm, Rogers and Kwoh (1998) used symptom reports in addition to measures of psychosocial impairment to explore the relationship between these variables and future functional disability. Eighty-five adults (82% women) hospitalised for exacerbation of their rheumatoid arthritis participated in structured interviews. Chart reviews, and follow-up telephone interviews and a mail survey one year after discharge were also included as data. Findings suggest that physical and psychological impairments contributed differently to disability during concurrent and future time periods. While participants were in hospital, restricted joint mobility contributed to concurrent functional disability while one psychological impairment variable (low perceived self-efficacy for function) along with being older were the most significant factors in predicting future disability.

Symptom reports and behavioural measures were used in a study by Crosby (1988) which asked whether the presence of daily stress factors and emotional stress is associated with disease activity in rheumatoid arthritis. Data were collected from 101 participants (67% women) by means of a series of validated instruments such as the daily hassles scale (DHS), state trait anxiety inventory (STAI) and the rheumatoid arthritis disease activity scale (RADA). Findings demonstrated a significant relationship between emotional stress and disease activity, with a positive correlation between the number and severity of stress factors and emotional stress level, and between emotional stress level and rheumatoid arthritis disease activity. Interestingly, in her discussion on

the implications for nursing practice, Crosby discusses “other important findings discovered when individual items or clusters of items were assessed” (p. 459). These findings, such as participants’ lack of energy, difficulty in relaxing, and psychological suffering (as evidenced by comments such as ‘I feel like crying’), which seem qualitative in nature, were identified by Crosby as being particularly amenable to nursing intervention. However, Crosby does not discuss the qualitative nature of these responses or the possibility of studying the topic using qualitative research methods.

In a more recent study which explored the relationship between stress and disease activity, Zautra et al. (1998) used validated psychosocial measures to assess interpersonal stress (stressful life events and assessment of spouse relationships) and measures of disease activity (clinicians’ ratings and haematological assessment) in 20 women with rheumatoid arthritis over a twelve-week period. Zautra et al. found that disease activity increases following increases in interpersonal stress and that women with stronger marital relationships were less vulnerable to those stressors. As the researchers suggest, these findings are consistent with Engel’s (1977) biopsychosocial model of illness in that they show that “fluctuations in disease activity appear to be influenced by both biologic and psychosocial processes” (p. 278). The biopsychosocial model described by Engel is discussed further on page 29.

Two New Zealand studies that explore the biopsychosocial aspects of living with rheumatoid arthritis have been identified, both from within the discipline of psychology. In the first study Haddon (1995) investigated the relation between a set of illness cognitions (an individual’s cognitive responses) and the course their disease takes. Eighty-two respondents (response rate of 64%) returned a self-reported, self-administered questionnaire which measured disease course (changes over six months in performing activities of daily living, changes in symptoms, remission, fluctuations over the life of the disease and in the previous two years, and speed of change) and illness cognitions. Illness cognitions included knowledge and understanding of one’s rheumatoid arthritis, appraisal of present condition, expectations for the future, thinking style, and locus of control. Measures of disease activity and illness cognitions were measured using a variety of validated measures including the Modified Stanford Health Assessment Questionnaire (MHAQ) for assessment of activities of daily living and the Multidimensional Arthritis Locus of Control Scale (MALC) to measure locus of control. Results showed that after controlling for non-cognitive and demographic

factors, the illness cognitions, as a set, had no influence on the course of the disease. However, results did demonstrate a meaningful association between appraisal of present condition and expectation for the future. Following a comprehensive discussion of the results and measures used, Haddon concludes that his study “demonstrates the need for further examination of the role psychological, and especially cognitive factors, may play in the course of rheumatoid arthritis” (p. 90).

In the second study, Faull (2000b) proposed spirituality as the core dimension of self for coping with disability, and that this core determines characteristics of the social, physical and cognitive dimensions. The study was designed to test the reliability of a spirituality measure in people with musculoskeletal disabilities. Four-hundred and forty-four people (18%, like Faull himself, had rheumatoid arthritis) completed a self-report questionnaire package that measured perceptions of pain, disability, cognitive wellbeing, manageability, social support, and physical functioning. Results supported the reliability of the spirituality measure. Analysis of the relationships between the spiritual factors and other measures identified significant relationships. Faull suggests that spirituality appears to be related to the ability of the individual to positively cope with physical disability and obtain good cognitive and social health. Faull identifies the need for further research both quantitative and qualitative to explore the relationship between spirituality and coping with disability such as that experienced by people living with rheumatoid arthritis.

Qualitative research does not feature significantly in the literature pertaining to the biomedical view. However, one such study was undertaken by Tack (1990a). Tack explored the concept and meaning of fatigue in rheumatoid arthritis from the clients' perspective in semi-structured interviews with twenty people (17 women, 3 men). Thematic analysis revealed four main codes: descriptors, conditions, strategies and consequences which begin to reveal the significance of fatigue as experienced by people with rheumatoid arthritis. Fatigue was described as an overall sense of tiredness and heaviness that was associated with a desire to sleep. It was frequently related to, but differentiated from, pain. Participants said that the fatigue “is that which one never recuperates from; one stays tired all the time” (p. 68). Active disease process, dealing with environmental barriers, disturbed sleep, emotional stress and household activities were among the factors that contributed to fatigue. Strategies for managing fatigue included the use of ‘energy enhancers’, constant comparisons with others (often with

those perceived as 'worse off'), energy audits, and re-normalising (p. 69). Fatigue was found to increase irritability with self and others, increase frustration, helplessness, and hopelessness, impair performance at work and home, and intensify the experience of pain (p. 69). Tack used quantitative data collection and analysis methods in a second part of the research project to explore the same phenomenon (Tack, 1990b). The results of this triangulated study are significant in describing the severity and distress of fatigue. However, as the author notes, there is a need for further studies to investigate such things as the effects of age, gender, culture, and length of illness on perceptions of fatigue and to explore the relationship between fatigue, pain and depression.

The psychosocial view

The psychosocial aspects of rheumatoid arthritis are the major focus of non-biomedical research. As previously indicated, the psychosocial view is dominated by research that attempts to explicate how people 'cope' when living with rheumatoid arthritis. The Lazarus and Folkman model of coping (1984) provides the theoretical foundation for much of this research. This model considers coping to be a set of cognitive and behavioural responses to events perceived as stressful and has two domains: problem focused or instrumental coping and emotion-focused coping (Newbold, 1996). Limited mobility, pain, restricted life-style, self-care difficulties, threats to self-esteem, and worries about the future have been identified as major stressors in rheumatoid arthritis (Newbold, 1996). Cognitive and behavioural responses to these stressors have been the focus of numerous studies (see for example, Bendtsen & Hornquist, 1994; Brown, Nicassio, & Wallston, 1989; Burckhardt, 1987; Giorgino et al., 1994; Gunther, Mur, Kurz, & Meise, 1994; Lambert & Lambert, 1987; Pfeiffer, 1986; Revenson & Felton, 1989; Spitzer & Bar-Tal, 1995).

Social support

Social support has been shown to influence coping behaviours in people with rheumatoid arthritis (Abraido-Lanza, Guier, & Revenson, 1996; Roberts, Matecnyck, & Anthony, 1996) and is consequently the focus of a number of studies. In an article which is reflective of the literature related to social support Krol, Sanderman, and Suurmeijer (1993) highlight the importance of social networks and social support on the quality of life for the person with rheumatoid arthritis. Their literature review confirmed

the positive correlation between social support and quality of life (see also Brown & Wallston, 1989; Cronan, Groessl, & Kaplan, 1997; Fitzpatrick, Newman, Archer, & Shipley, 1991; Roberts et al., 1996).

A study by Revenson, Schiaffino, Majerovitz, and Gibofsky (1991) provides a cautious note in the area of social support. In their study they considered social network interactions as a potential source of both support and stress. The sample consisted of 101 people recently diagnosed with rheumatoid arthritis. A positive correlation was found between positive support and lower depression, while problematic support correlated to increased depression. These findings emphasise the importance of recognising that social support may be a source of both support and stress among people with rheumatoid arthritis.

Spousal relationships

Spouses are one of the prime sources of social support for the person with rheumatoid arthritis. Relationships between people with arthritis and their healthy spouse are the focus of a number of studies. For example, Manne and Zautra (1989), in a frequently cited study, examined whether the psychological adjustment of women with rheumatoid arthritis was related to the support and criticism received from their partners. Husbands of 103 women with rheumatoid arthritis were interviewed. These interviews were content coded for critical remarks. The men also completed rating scales that assessed their perceived vulnerability to illness and the degree of burden they experienced in assisting their wives. Wives completed rating scales of their coping and their perceived supportiveness of their spouse. Path analysis revealed that women with a highly critical spouse engaged in more maladaptive coping behaviours and reported poorer psychological adjustment. Independent of spousal criticism, women who perceived their spouse as supportive engaged in more adaptive coping.

In contrast, Revenson and Majerovitz (1991) in another frequently cited study explored the effects of rheumatoid arthritis on the well spouses of forty-two people with rheumatoid arthritis. Participants completed a mailed questionnaire that assessed marital adjustment, social support received from the person with rheumatoid arthritis and from the close social network, and depressive symptoms. It is not clear what the female:male ratio of spouses was. However, as there is an increased prevalence of rheumatoid

arthritis in women, more males would feature in the group of healthy spouses responsible for increased responsibility within the home. Revenson and Majerovitz (1991) acknowledge that for many men this responsibility may be outside the traditional male gender role. Results indicated that social resources were valuable for spouses of people with rheumatoid arthritis. Neither disease severity nor clients' psychological depression was a strong predictor of spouses' depression, in contrast to similar studies involving more acute life-threatening diseases. Revenson and Majerovitz hint at the limitations of their data collection methods, specifically the lack of open-ended questions, which prevented them from capturing fully "the chronic strains of living with an ill spouse" (p. 69). Their comments support my reservations about the ability of quantitative data alone to capture the essence of such complex phenomena.

In a more recent study, Bermas, Tucker, Winkelman and Katz (2000) surveyed 79 people with rheumatoid arthritis (76% of them women) and 78 spouses to examine independent associations of demographic characteristics, disease characteristics, and coping style with marital satisfaction. Results showed that participants were generally satisfied with their marriages. Lower marital satisfaction in people with rheumatoid arthritis was associated with higher education level, greater use of escape into fantasy (fantasising that things would be different), and greater use of finding blame. Lower marital satisfaction in spouses was associated with passive acceptance of the situation and less likelihood of finding blame. Female spouses were less likely to be satisfied with their marriage than male spouses were.

Women with rheumatoid arthritis

Few studies focus exclusively on women yet women comprise a significant percentage of the client group. As has already been stated, two to three times more women than men are affected by rheumatoid arthritis (Arthur, 1994). Research related specifically to women with rheumatoid arthritis appears to be conducted mainly within the quantitative paradigm by physicians, psychologists and physiotherapists. Research by nurses is scarce and much of what is available appears to be carried out by nurses working either from within another discipline (mainly psychology) or in collaboration with physicians (see for example, Allaire, Meenan, & Anderson, 1991; Bailey & Nielsen, 1993; Burckhardt, Clark, & Bennett, 1992; Ostensen & Rugelsjoen, 1992).

Women's unpaid work and their role as homemaker has been the subject of a number of studies related to women with rheumatoid arthritis (see for example, Allaire, Anderson, & Meenan, 1996; Allaire, Partridge, Andrews, & Liang, 1993; Fifield, Reisine, & Grady, 1991). Reisine, Goodenow, and Grady (1987) developed a measure of homemaker functioning based on conceptualising the homemaker role on two dimensions: instrumental functions and the nurturant dimension. This measure was used in a study of 142 women with rheumatoid arthritis currently living with their spouses and/or children. Participants rated both their ability to complete, and their level of satisfaction in their ability to complete, five household tasks: shopping, cleaning, cooking, laundry, and managing finances. These tasks represented instrumental functions. Participants also rated the five tasks included in the nurturant dimension of the homemaker role. These tasks were listening and comforting, making arrangements for others and taking them places, maintaining ties with others, teaching and guiding, and visiting or taking care of sick people. Results showed that the disease severely limited both nurturant and instrumental functions. The researchers were surprised by the high and previously undocumented limitations in functioning within the nurturant dimension. This result is particularly significant given that most of the women with limitations in nurturant dimension reported greater dissatisfaction in their functioning within this dimension than with instrumental functioning. What was also apparent was that irrespective of the degree of disability, women with rheumatoid arthritis continued to assume major responsibility for homemaking.

Psychological well-being in women with rheumatoid arthritis was the focus of a study by Lambert (1985). The study examined the relationship between social support, severity of illness, and demographic characteristics and the level of psychological well-being. Results showed that decreased psychological well-being resulted from the inability to carry out daily tasks with ease and limitations in social support. However, it was the experience of pain that emerged as the primary predictor of psychological well-being. As joint pain and difficulty in carrying out tasks increase, psychological well-being decreases.

Brown and Williams (1995) explored women's experiences of living with rheumatoid arthritis in one of the few qualitative studies reported in the literature. Their study is discussed further on Page 37.

The nursing view

Nurses are called on to care for people with rheumatoid arthritis in a variety of settings, within the hospital and within the community. People with rheumatoid arthritis require the expertise of nurses on numerous occasions during the course of their illness. Many times the need for nursing care will be directly associated with their rheumatoid arthritis, however, there are also times when these people require nursing care for reasons of co-morbidity. While acknowledging the diverse nature of potential relationships between nurses and people with rheumatoid arthritis, this section focuses on nursing knowledge specific to the person with rheumatoid arthritis and the care given by nurses with specialised knowledge of rheumatology nursing.

A biopsychosocial model is the often-espoused approach to care and management of the person living with rheumatoid arthritis. The biopsychosocial model of chronic illness was described by Engel (1977) and is based on the premise that in chronic illness biological, psychological, and social aspects co-determine the illness trajectory. Schoenfeld-Smith et al. (1996), following a study that examined longitudinal relationships among biopsychosocial variables to predict future psychological and physical disability in people with rheumatoid arthritis, “argue strongly for the importance of a biopsychosocial perspective in its management” (p. 374).

Alongside the biopsychosocial approach to care and management is the multidisciplinary team approach. Multi-disciplinary teams providing care for people with rheumatoid arthritis have been reported since the 1960s. The contribution of nurses to these teams was often taken-for-granted to the extent that nurses were not recorded in writings of the day as having been involved, although their role has subsequently been acknowledged (Pigg, 1990). The implicit nature of nursing’s contribution to the care of the person with rheumatoid arthritis continues to permeate much of the rheumatology literature with a small number of exceptions (see for example, Hill, 1992; 1998b; le Gallez, 1998; Pigg, Driscoll, & Caniff, 1985; Ryan, 1996a).

The multidisciplinary team approach values the input from a range of health professionals in the management and care of those who have rheumatoid arthritis and may include for example, the nurse, physiotherapist, occupational therapist, rheumatologist, social worker, and general practitioner. Although perceived as having a

level structure, the multidisciplinary team is often dominated or led by the physician, despite growing evidence that shows quantitative and qualitative benefits to the client when other health professionals assume the lead carer role. For example, Pigg (1990) cites a 1968 study (Katz et al.) that revealed the wide scope and positive impact on client outcomes of rheumatology nursing within an outpatient clinic. More recent studies have highlighted the efficacy (Hill, 1991a; Hill, Bird, Harmer, Wright, & Lawton, 1994) and client satisfaction (Hill, 1997) of nurse-led outpatient clinics for people with rheumatoid arthritis. Confirming the results of North American research, these studies showed the nurse-led clinic to be equally as effective as the rheumatologist-led clinic in the “management of the disease process and significantly more effective in reducing symptoms and improving psychological status in clients” (Hill, 1991a, p. 31). Ryan, (1995) reports on the success of similar approach that sees a nurse and occupational therapist combine as lead carers in an outpatient clinic for people with rheumatoid arthritis. A comprehensive approach to care that enables people to have an active part in their care and feel in control of their situation underpins the success of such clinics.

In an opinion article that supports the approach to client care described by Hill (1991a) and Ryan (1995), Anderson (1995) argues for the use of a patient empowerment model in the management of chronic illnesses. The primary focus of Anderson’s work has been the management of diabetes. However, this model would seem equally applicable in the management of rheumatoid arthritis. The patient empowerment model focuses primarily on the nature of the relationship between the client and health professionals. It recognises that people with chronic illnesses are in charge of their own care on a daily basis and as such can be considered their own health-care providers. Anderson recommends that health professionals acknowledge that in daily treatment the locus of control and decision-making rests with the client, and provide ongoing expertise and support so that clients can make informed choices about living with and caring for their illness.

Nursing knowledge and care in rheumatoid arthritis historically

Little has changed, yet much has changed in nursing the client with rheumatoid arthritis. The aims of nursing care remain remarkably similar across the decades, yet advances in nursing knowledge and the corresponding advances in medical science, along with

socio-political changes to structures of health care delivery, have altered the detailed aspects of nursing care delivery to the person with rheumatoid arthritis. Pearce (1939) in a textbook of nursing described the aims of treatment in rheumatoid arthritis as “to effect arrest of the disease at the earliest possible moment, to relieve pain, and to prevent deformity” (p. 812). These aims mirror those described today, although the invisibility of psychosocial aspects must be noted. Reflecting what one would expect to be the knowledge at the time, Pearce identifies the dominant theories of causation as infection, endocrine deficiency, and “some inherent familial tendency that given suitable circumstances the disease will develop” (p. 810). She identifies predisposing factors as “anything which lowers the resistance of the body, such as anxiety and worry, mental strain, sustained fatigue, and exposure to damp and cold” (p. 810). These theories of causation have distinct similarities to contemporary theories (as outlined on page 17). Treatment to be offered to the patients included bed-rest during a ‘flare’, application of splints, heat, massage and passive movement of affected joints, active movement as soon as acute pain is relieved. These aspects of care remain fundamental to contemporary nursing practice. Discussion of drug therapy is limited in Pearce’s writing, although mention is made of the use of salicylate for joint and muscle pain (p. 812) and the administration of gold injections, recently introduced in the treatment of rheumatoid arthritis (p. 813). Discussion of any psychosocial aspects of nursing care is limited to a cautionary note in regard to the disappointment a patient may feel if gold does not induce the hoped-for remission (p. 815).

In a less-comprehensive discussion of rheumatoid arthritis, Hitch (1952) outlines similar theories of causation and aims of treatment. However, in addition to the use of splints, heat, bed-rest, massage and active and passive movement Hitch offers some treatments “which have been tried with varying results” (p. 394). These treatments include painting the joints with iodine, iodine orally, protein-induced shock, administration of some intestinal antiseptic, electrical treatment by diathermy, injections of gold, and electro-pyrexia (body wrapped and temperature raised to 104°F (40°C) and maintained at that level for eight hours). Of these treatments gold is still used (although with the availability of other chemotherapeutic agents the use of gold is now less common) and forms of electro-pyrexia may be available. For example, Queen Elizabeth Hospital (QEH) in Rotorua offers clients pyretic (steam) baths which are described as being “similar to a sauna, patients lie on an enclosed bed, receiving treatment from thermally

heated steam” (QEH Information booklet). Hitch (1952) mentions briefly the availability of surgical treatment “to render joints more useful” and says “much is hoped from the recent discovery of ... cortisone” (p. 395). No mention is made by Hitch of psychosocial aspects of nursing care.

Contemporary nursing knowledge and care in rheumatoid arthritis

Over the past two decades, internationally and in New Zealand, there has been a number of developments that have contributed to an increased body of nursing knowledge of rheumatology conditions. In the United Kingdom the Rheumatology Nursing Forum (RNF) was established in 1981. Under the auspices of the Royal College of Nursing, this group is now recognised worldwide as a body of expert nursing knowledge. RNF members have contributed significantly to research and dissemination of nursing knowledge (see for example, Arthur, 1995; Brown & Williams, 1995; Hewlett, 1994; Hill, 1985; 1991b; 1992; 1998b; le Gallez, 1984; 1998; Pigg et al., 1985; Ryan, 1996a). In the United States nurses participated in planning for the inception of the Arthritis Health Professionals Association (AHPA) in 1965 and continue to maintain a high profile within this group (Pigg, 1990). Nurses have played a similar role in the inception and ongoing function of the New Zealand Health Professionals in Rheumatology (NZHPR). This group is affiliated to the International Health Professionals in Rheumatology along with the RNF, AHPA and similar groups from a number of other countries including Australia. The NZHPR held its inaugural meeting in 1984 and holds a biennial conference as a forum to share research and update knowledge. Every second NZHPR conference is held in conjunction with the Australian Rheumatology Health Professionals Association and the Australian and New Zealand Rheumatology Associations.

Arthur (1994) provides a clinical review of nursing care of clients with rheumatoid arthritis. She advocates a “problem-solving, holistic model of nursing care” (p. 331) that incorporates a multidisciplinary biopsychosocial model. Arthur suggests that the philosophy of care when nursing people with rheumatoid arthritis should be to encourage clients to cope within their own capabilities. Moreover, nurses have a unique role in facilitating the care of clients with rheumatoid arthritis.

Waterflow (1992) provides a similarly comprehensive approach to the pathophysiological aspects of the disease and like Arthur (1994) uses a biopsychosocial approach. Waterflow is a nurse educator who has had rheumatoid arthritis for more than twenty years. Her article is not a personal account but she acknowledges the comments and opinions expressed are influenced by her personal experience. As with many other articles using a biopsychosocial approach, psychosocial aspects are not dealt with in the same depth as pathophysiological ones. Waterflow (1992) suggests that nurse-led management teams can provide a comprehensive and sensitive approach to client care. She sees support and encouragement from nurses as vital in instilling a positive attitude in people with arthritis.

Education about the disease and strategies for living with it have been shown to have positive benefits. Client education for people with rheumatoid arthritis has been shown to increase knowledge (Hill et al., 1994; Lindroth et al., 1997), change behaviour (Lorig, Konkol, & Gonzalez, 1987), increase physical function and increase psychosocial health (Mullen, Laville, Biddle, & Lorig, 1987). A number of education programmes have been developed and are used extensively as a complement to medical treatment of people with rheumatoid arthritis (for example, see Lindroth et al., 1997; Lorig & Gonzalez, 1992). The primary principle underpinning many of these programmes is that of self-care. Self-care in chronic illness determines outcome as much as professional care (Callahan & Pincus, 1997). An improvement of 15-30% in reported symptoms is attainable through client education interventions (Hirano, Laurent, & Lorig, 1994; Superio-Cabuslay, Ward, & Lorig, 1996). Client education has been extensively researched especially in the United States. Hirano, Laurent, and Lorig (1994) in a literature review identified 45 studies focusing on intervention or evaluation of client education programmes published between 1987-1991. Client education is an ongoing process which, like so many aspects in the management of rheumatoid arthritis, relies on the combined efforts of the client, their partner/family, and the multi-disciplinary team (Hill, 1998a).

The client and family view

The impact of chronic illness on family functioning has received increasing recognition (Anderson & Bury, 1988). However, there is a paucity of research on the specific impact of rheumatoid arthritis on family life with the exception of the literature,

previously discussed, which explores social support and spousal relationships. Rheumatoid arthritis has also been shown to impact on sexuality (Kraaimaat, Bakker, Janssen, & Bijlsma, 1996), on role functioning (Reisine et al., 1987), and on household work performance (Allaire et al., 1991). The main focus of these studies has been the experience of the person with rheumatoid arthritis and/or their healthy spouse.

Few researchers have studied the effects on the family unit and its members when a parent has rheumatoid arthritis. However, le Gallez (1993) provides one such study, which she suggests is the first known study in which the “impressions, fears and hopes of each individual family member have been recorded” (p. 31). Le Gallez undertook a qualitative study involving 22 families in which one parent (13 women, 9 men) had severe or very severe rheumatoid arthritis. The study aimed to assess the disease’s impact on aspects of family life. The specific aspects considered were: the marriage, sexual activity and satisfaction, client’s work, the partner’s working pattern, and the children. Participants, who included clients, spouses, and 40 children aged 11-33 years, were interviewed separately in their own homes. Interviews lasted between four and six hours. Le Gallez does not discuss analysis of data. Results show that the impact of rheumatoid arthritis on the family is intense with repercussions experienced by all members. The depth of the impact seems to depend not on degree of disability but on how well the person with rheumatoid arthritis is “able to adjust to the disease and accept the physical limitations it imposed” (p. 31). For most of the children the effect of living with a parent suffering from a painful, chronic illness was not detrimental, but a minority did suffer verbal and physical abuse. Half the children considered the experience strengthened family relationships and most expressed “deep concern and displayed a nurturing attitude towards the ill parent” (p. 33). Le Gallez notes the efforts made by both parents to minimise the impact on their children by striving to retain a “normal family atmosphere” (p. 33). The disease had wide-ranging effects on sexual and working relationships, but marriage to a partner with rheumatoid arthritis did not result in a threat to the relationship for the majority. Le Gallez’s (1993) study is one of the few that attempts to explore the issue of sexual relationships for people with rheumatoid arthritis.

Living with rheumatoid arthritis as a day-to-day experience

There is a dearth of literature associated with everyday aspects of living with rheumatoid arthritis and only a few studies focus on the individual experiences of those living with the disease. However there appears to be a growing interest in this aspect of the experience. Strauss (1975) in a landmark volume that explored the experience of chronic illness through focusing on the ill person and his/her family at home, “revolutionised how chronic illness could be researched” (Gullickson, 1993, p. 1387). The grounded theory methodology, which underpins the studies described in Strauss’ book, emphasises the contextualised experience of the individual living with a chronic illness. The work of Strauss and his associate Glaser has been influential in researching the experience of chronic illness in general (for example see, Baker & Stern, 1993; Charmaz, 1983; Cohen, 1993; Robinson, 1993) and rheumatoid arthritis in particular (for example see, Dildy, 1992; Shaul, 1995; Wiener, 1975b). A small number of studies using qualitative methods to explore the everyday experiences of living with rheumatoid arthritis have been located, some of which were published before my doctoral work began while others have been published concurrent to my research. Six of these studies are outlined in this section.

The studies by Wiener (1975b), Dildy (1992) and Shaul (1995) use grounded theory methodology in a way that results in the abstraction of particular notions in describing the experience of living with rheumatoid arthritis. Wiener (1975b) in an often-cited article outlines her study that involved twenty-one participants with rheumatoid arthritis (16 women, 5 men). Drawing further on the study, Wiener (1975a) has authored a chapter in Strauss’ (1975) book and in the subsequent edition (Wiener, 1984). Data analysis in Wiener’s study identified a core category of ‘tolerating the uncertainty’. While all living requires some tolerance of uncertainty, Wiener’s study shows that the uncertainty in living with rheumatoid arthritis is exaggerated beyond the usual level of toleration. Wiener found that people with rheumatoid arthritis develop strategies to deal with this uncertainty. The strategies identified were: juxtaposing hope of relief and/or remission against the dread of progression, normalising through covering-up, keeping-up, and pacing, and of re-normalising through adjusting to reduced activities.

Dildy (1992), in a doctoral study, used grounded theory methodology to explore the nature, meaning and impact of suffering from the perspective of people with rheumatoid

arthritis. Dildy sought also to identify causes of suffering and what nursing interventions the participants identified as being effective in the alleviation of suffering. Fourteen people (9 women, 5 men) participated in semi-structured interviews. Suffering was found to be “a process of significant, multidimensional personal change, a process of regaining normalcy or striving to be ‘okay’” (Dildy, 1996, p. 178). Suffering was resolved through a three-phase process: disintegration of self, the shattered self, and the reconstruction of self. Dildy notes that “two of the informants were unable to progress through the final phase and their suffering remained unresolved” (p. 159). The cyclical nature of the process was also acknowledged. Suffering resulted in constant struggling, lost dreams, restricted future orientation and withdrawal from others especially when feeling unwell. Factors potentiating suffering were identified as stress, emotional upset and physical exertion, while social encouragement was a mitigating factor. Participants in Dildy’s study identified empathy, attitude, and comfort measures as being the nursing interventions most effective in alleviating their suffering.

In a further study, Shaul (1995) used grounded theory methodology to explore and describe the impact of rheumatoid arthritis on the life roles of women between the ages of 30 and 75 years. Thirty women participated in semi-structured interviews that “encouraged them to tell their story of living with rheumatoid arthritis from the first symptom to the present” (p. 290). Analysis revealed a three-stage transitional process: becoming aware, learning to live with it, and mastery. Mastery did not imply control over the disease but mastery in living with rheumatoid arthritis and a redefinition of what constitutes quality of life. Shaul acknowledges that this transitional process would be re-experienced over the course of the illness experience.

Bury (1982), a medical sociologist, drew on semi-structured interviews with thirty people (25 women, 5 men) newly diagnosed with rheumatoid arthritis to explore “the problems of recognition and changes in life situations and relationships occasioned by the development of the illness” (p. 167). Bury suggests that the development of a chronic illness like rheumatoid arthritis is “most usefully regarded as a form of biographical disruption” (p. 169). He identifies three aspects of disruption: disruption of taken-for-granted assumptions and behaviours, disruption to normal explanatory systems, and response to disruption involving the mobilisation of resources. Bury draws on this study in much of his subsequent writing (see for example Bury, 1988; 1991; 1997). In uncovering the everyday ongoing experience of living with rheumatoid

arthritis this study seems limited because of its focus on the initial experience of living with the disease.

Perry (1991), a retired nurse educator who has had rheumatoid arthritis for more than 15 years, provides a personal account of her experience of living with the disease. She describes the impact the disease has had on her life, describing the disease as an abstraction; “the only reality is the individual’s response to that abstraction” (p. 58). Perry considers that the rheumatologist’s principal focus is her body’s response to the disease, while the specialist nurses and physiotherapists show a greater understanding of her total experience. She mentions that the greatest deficit in assessment is the underestimation of the exhaustion caused by the illness.

In a study aimed at exploring women’s experiences of rheumatoid arthritis, Brown and Williams (1995) interviewed seven women in non-directive conversational interviews. The authors acknowledge a feminist perspective underpinning their attempt to enable the women to reflect on matters of concern to them. From narrative analysis three themes emerged: seeking help, searching for meaning, and uncertainty about symptoms. This article provides illuminating and thought-provoking insights into women’s experiences with rheumatoid arthritis. The authors suggest the challenge for nurses is to consider how to “develop imaginative ways of both facilitating patients’ accounts of personal experience and, importantly, of incorporating the insights provided through these accounts into clinical practice” (p. 700). They also argue that by explicitly and visibly attaching importance to clients’ perspectives, and by making them the focus of research, the traditional view of the passive roles assigned to clients is challenged.

Ryan (1996b), in the only phenomenological study located, explored the experience of living with rheumatoid arthritis “from the patient’s frame of reference to understand the global impact that this chronic illness has on social, psychological and physical well-being” (p. 45). Seven people participated in in-depth interviews, the transcriptions of which were used for analysis. Colaizzi’s procedural steps (1978, cited by Ryan, 1996b) guided data collection and analysis. Five themes were identified which “highlighted the enormous impact that rheumatoid arthritis has on a patient’s life” (p. 45). The themes were: alteration in self esteem/role, relationships within the family network, frustration at perceived limitations, negative perceptions regarding the future, and dissatisfaction with the doctor/patient relationship. The brevity of the article in which the findings are

reported perhaps contributes to the difficulty in capturing the meaning of these themes beyond a brief description. It is also possible that the structured approach to data analysis inherent in Colaizzi's method contributes to this. As a result of her findings, Ryan advocates nurse-led clinics where nurse and patient may engage in meaningful dialogue. She suggests that it is within such an environment that nurses with adequate education and experience can address problems in a holistic manner and encourage patient empowerment.

When viewed in combination, these studies present a coherent 'big picture' of the experience of living with rheumatoid arthritis, showing that when the disease strikes it disrupts lives and nothing is the same. Life becomes full of uncertainty. The process of coming to live with rheumatoid arthritis is exhausting and frustrating and is relived over and over again with each flare of the disease. My study seeks to reveal and unfold more of this 'big picture' of living with rheumatoid arthritis.

Conclusion

This chapter, in providing an overview of the literature related to rheumatoid arthritis, has situated the present study within the context of an extensive body of knowledge. It is important to note that most of the "viewers" (Meleis, 1991, p. 249) who have built the body of knowledge reflected in this literature review have been health professionals. Two views, the biomedical and psychosocial, have been shown to dominate the literature. Within the biomedical view there is a proliferation of cellular-level studies, while the psychosocial view focuses primarily on psychological aspects of coping and adjustment. It would seem that many studies pathologise or psychologise the experience of living with rheumatoid arthritis.

Much of the research explores the experience of living with rheumatoid arthritis at times of breakdown, for example, during acute exacerbation or increased pain, with little consideration given to the ongoing totality of the experience of those who live with the disease. Most rheumatoid arthritis research is grounded in empirical analytic research methodology, which means the phenomenon is often decontextualised and the response of the individual lost. Few studies focus on the possible positive outcomes that may come from the experience of living with rheumatoid arthritis. While many studies acknowledge the multidimensional effects of rheumatoid arthritis there are few studies

that focus specifically on the daily lives of those who experience it. Furthermore, the experiences of family members beyond those of the spouse are all but invisible.

This chapter has also identified the important contribution of nurses in the care of those who live with rheumatoid arthritis, highlighting the pivotal role the nurse may have in the multi-disciplinary team. Nurses are at the forefront of research that seeks to understand the experience and meaning of living with the disease, although, as yet, this body of knowledge is not extensive.

The literature review presented in this chapter has shown that there is much of the deep meaning of 'living with rheumatoid arthritis' yet to be uncovered. There is a need for more research that identifies the perspectives, and makes visible the realities, of those who experience the phenomenon of 'living with rheumatoid arthritis'. The research presented in this thesis addresses this need as it uncovers further layers of meaning of this complex illness experience. The philosophical underpinnings of this research and their methodological influences are discussed in the next chapter, Chapter Three.

CHAPTER THREE: Philosophy to Methodology

This chapter explores the philosophical underpinnings of this research which, Koch suggests, is “the necessary starting point of [an] inquiry” (1994b, p. 827). The approach taken in this study is informed by the work of Martin Heidegger, particularly “Being in Time” (1927/1962), and by the work of Hans-Georg Gadamer, principally “Truth and Method” (1960/1989). My understandings of the Heideggerian and Gadamerian notions that have informed this research are reviewed and their influence on the processes and outcomes of the study discussed.

The hermeneutic turn

Derived from the Greek word *hermeneuein* (to interpret), hermeneutics has its academic origins in the tradition of biblical exegesis, the interpretation of biblical texts, and was prevalent in disciplines such as theology and law. Contemporary hermeneutic philosophy, which emphasises the human experience of understanding and interpretation, has its historical roots in European philosophies (Thompson, 1990).

Phenomenology as a school of thought has more recent origins and is usually attributed to the work of Edmund Husserl (1859-1938), under whose influence phenomenology “came to mean the study of phenomena, as-phenomena-appear-through-consciousness” (Thompson, 1990, p. 232). Husserlian phenomenology emphasises epistemological questions of knowing. Husserl argued that analysing consciousness and its objects in direct experience through phenomenology could identify the foundations of knowledge. Husserl’s work has come to be seen as the “culmination of the Descartes-Hume-Kant tradition of philosophy, which sees the fundamental human situation as that of a subject in a world of objects” (Magee & Dreyfus, 1987, p. 257).

Heidegger, a student of Husserl, questioned the subject-object relation of the human situation. He contended that as humans we are not subjects or spectators detached from some external reality, trying to gain knowledge of it as something different from ourselves, and trying to relate to it. Instead we are part and parcel of it (Magee & Dreyfus, 1987). This led Heidegger (1927/1962) to raise anew the question of the meaning of Being, “What is the Being of beings?”, the fundamental question of the ancient Greeks. This shift from the epistemological questions and the dichotomy

between subjectivity and objectivity of Husserlian phenomenology to the ontological foundations of Heidegger's work has been called the "hermeneutic turn" (Hoy, 1993, p. 170). Heidegger, drawing on the works of Husserl and Dilthey (1833-1911), suggested that "the questions they were pursuing about how people *know* were only secondary to a consideration of how people *are* in their everyday endeavours" (MacLeod, 1996, p. 139). Heidegger showed how the question of Being took primacy over concerns about knowledge. This philosophical 'turn' with its emphasis on the ontological questions of being rather than the epistemological questions of knowing has required a re-visioning of what it means to be a person (Leonard, 1989). Heidegger's hermeneutic turn has influenced contemporary approaches to hermeneutic phenomenology. What then are the Heideggerian notions that have informed this study?

Phenomenon

A phenomenon is "that which shows itself in itself" (Heidegger, 1927/1962, p. 28). It is an entity that lies in the light of day or can be brought to the light. A phenomenon "can show itself from itself in many ways depending on the kind of access we have to it" (ibid.). It is possible that the phenomenon can show itself as something which in itself it is not (a semblance) or indeed for something to show itself as an indication of something that does not show itself (an appearance) (Heidegger, 1927/1962, p. 29). A phenomenon can be covered up in a number of ways; it may be still "undiscovered", "disguised", or having once been discovered it becomes "buried over" (Heidegger, 1927/1962, p. 35-36).

How can a phenomenon be brought to the light of day? Heidegger suggests that phenomena can be illuminated through language (discourse, conversation, from the Greek '*logos*'). Logos "lets something be seen that is" (1927/1962, p. 32). 'Phenomenology', therefore, as an expression of the relationship between 'phenomenon' and 'logos' means, "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (p. 34). In reply to his own question "what is it that phenomenology is to 'let us see'?", Heidegger says, "it is something that proximally and for the most part does not show itself at all: it is something that lies hidden ... the Being of entities." (p. 35). Phenomenology then is a way of access to the Being of entities.

What does this mean for my study? It means that I expect the phenomenon 'living with rheumatoid arthritis' to be hidden, but that it is possible to bring it to the light of day; it is possible to uncover something of the meaning of 'living with rheumatoid arthritis'. However, I must be mindful in bringing it to light that what I uncover is the phenomenon itself and not a semblance. I seek the appearance that is as near to the phenomenon itself as it is possible to be, without my having a personal experience of living with rheumatoid arthritis.

Being

The question of the meaning of Being (existence) is the foundation of Heidegger's philosophy. In his 'Letter on Humanism' Heidegger offers this insight on Being, "Yet Being – what is Being? It is It itself.... Being is farther than all beings and yet is nearer to man than every being, be it a rock, a beast, a work of art, a machine, be it an angel or God. Being is the nearest. Yet it remains the farthest from man" (1947/1993, p. 234). Heidegger gives a sense of the elusiveness of the meaning of Being, it is here, there, and all around us and yet in its closeness it is intangible, hidden from us. It can only be approached indirectly and grasped intuitively (Kohl, 1965). Being just 'is'.

Being is a phenomenon and as such may remain hidden, or covered up so extensively that it becomes forgotten (Heidegger, 1927/1962, p. 35). Heidegger suggests, however, that light can be shed on Being through exploration of human existence in its everydayness. Heidegger, then, in his quest for Being analyses the conditions for being-in-the-world as a human being (Kohl, 1965).

Being-in-the-world

Dasein is the term given by Heidegger to denote human existence. Dasein is distinguished from other forms of beings or entities (for example, trees and animals) by the fact that "in its very Being, that Being is an issue for it" (Heidegger, 1927/1962, p. 12). Differently phrased, "to be human is just to *care* about what it is to be human" (Guignon, 1983, p. 86), to care about who we 'are' and who we can 'be'.

Dasein translates as 'being-there', but is widely accepted in English writing in its non-translated form. Before anything else we exist, we are 'there'. The 'there' of Dasein is:

the world: the concrete, literal, actual, daily world. To be human is to be immersed, implanted, rooted in the earth, in the [everyday] matter-of-factness of the world ... it is here and now and everywhere around us. We are in it. Totally. (How could we be anywhere else?) (Steiner, 1978, p. 83).

Heidegger uses the term 'being-in-the-world' to express the situatedness of Dasein and world. The hyphens suggest the inseparability of our 'world' and ourselves. In this sense we are always in the world. We are as much a part of it as it is a part of us. We constitute and are constituted by our 'world'. Depending on the particular 'world' or 'worlds' one is involved in, certain things matter more or less. For example, the safety of a pedestrian crossing outside a school is probably of greater concern, matters more, to a mother (in the world of motherhood) than it does to a young single stockbroker (in the world of business). The inseparability of people from their worlds underpins the processes inherent in this study.

What does this mean for my study? It gives me confidence that the phenomenon of 'living with rheumatoid arthritis' can be uncovered through the experiences of people, of Dasein. To understand what it means to live with rheumatoid arthritis I needed to seek understanding through the everyday lives of those who experience the phenomenon because, as Heidegger reminds us, it is through the everyday world of Dasein that meaning is found (1927/1962, p. 66).

Thrownness

Heidegger tells us that one of the basic characteristics of Dasein is "that it is" (1927/1962, p. 174). That we 'are' is a basic fact of our existence, the how and why of our lives are open to our influence, our interpretation and to possibility. That our life just 'is' is not open to negotiation. Heidegger suggests we are 'thrown' into existence, that our being-in-the-world is a thrownness (1927/1962, p. 276). Steiner offers an interpretation of the notion 'thrownness' when he says:

We certainly do not know whence we came into being, except in the most trivial physiological regard. No biology of parentage answers the real question. We do not know toward what end we have been projected into existence, except in reference to death.... Yet it is just this twofold unknowing which makes the "thrown" condition of human existence the more emphatic and palpable. We are "delivered over"... to an actuality, to a "there" to a complete, enveloping presentness. Dasein must take up this presentness, it must assume it into its own existence. It cannot do otherwise and continue to be (1978, p. 87-88).

In thrownness we are delivered over to a 'there' that is historically, culturally, and socially bounded. We are 'thrown' into a world that is "not of our making but with which we are nonetheless stuck" (Hall, 1993, p. 137). We have no control over our thrownness and yet our thrownness determines our possibilities in life. For example, being born in New Zealand in the 1990s affords certain possibilities in life, possibilities that are different than if one was born in Africa, or in 19th Century New Zealand. We take up our thrownness and do with it what we will, but always within the limits of the world into which we have been thrown. However, as Walton suggests,

Heidegger's view is not a fatalistic or deterministic one. Rather it posits that each of us is an individual, who must come up against history and the future in such a way that we make our own life according to our choices within certain limits which constrain us (1995, p. 14).

Heidegger's notion of thrownness extends beyond the thrownness of our initial coming into existence. Once thrown into existence we remain forever in the throw. Throughout our lives things happen to us and we are thrown into situations of which we have no experience. However, once something happens or we are thrown into certain situations it becomes part of our Being. Yet, the Being of Dasein can be fully ascertained only when it has run the course between birth and death. The paradox of this did not escape Heidegger, as Guignon describes:

In order to conceptualise life as a happening [Heidegger] interprets Dasein as an ongoing process pointing toward its realisation and completion. Dasein's Being-a-whole is to be understood as a Being-*toward*-the end: its Being-toward-death (Guignon, 1983, p. 88).

Heidegger's notion of thrownness is central to our understanding of the phenomenon of 'living with rheumatoid arthritis'. Participants in this study have been thrown into the world of living with rheumatoid arthritis. There is a thrownness to having the disease just as there is a thrownness to living with it as a partner or child of someone who has the disease. Living with rheumatoid arthritis is their way of being-in-the-world. The thrownness of the experience means 'learning' to live, to 'be', in this world, a world in which there are many possibilities.

Once thrown, these people remain in the throw of living with rheumatoid arthritis. To not be in the world with rheumatoid arthritis is no longer possible. It is only in death that the possibility of not being-in-the-world with rheumatoid arthritis, and of not being,

exists. On the journey between being thrown into the world with rheumatoid arthritis and death, they remain in the throw, never knowing how rheumatoid arthritis will disclose itself. In addition, these people are in the throw of whatever else may occur in their lives. The world of rheumatoid arthritis is but one world in which these people exist. For example, they are also in the world as mothers, fathers, friends, and colleagues. Their being-in-the-world with rheumatoid arthritis influences and is influenced by all these other worlds. The notion of 'thrownness' is drawn on throughout the data chapters.

Time

Heidegger (1927/1962, p. 17) tells us that "time must be brought to light – and genuinely conceived – as the horizon for all understanding of Being and for any way of interpreting it". Being cannot be grasped without taking time into consideration. The sense of time that Heidegger describes has a tripartite structure consisting of past, present, and future (Young, 1997). The past (Dasein's thrownness), influences the present (being-in), both of which influence and are influenced by the future (projection of possibilities). Krell's (1993, p. 22) explanation provides clarity, "I pursue various possibilities for my future, bear the weight of my own past, and act or drift in the present. Of course at any given moment of my life all three structures are in play."

The temporal aspect of Being is particularly significant in this study. For example, in facing the future the person with rheumatoid arthritis may bring with them memories of a mother or grandmother who had rheumatoid arthritis. These memories, which are part of their Being, will influence the decisions they make in the present (perhaps around treatment options) as well as the way they view their future possibilities. The fusion of past, present, and future dimensions of time are particularly significant in Chapter Eight.

Being-with-others

We are always in the world with others; the world of Dasein is a with-world. Like the inseparability of Dasein and world, so too is the inseparability of Dasein and 'others'. Heidegger tells us that 'others' does not mean 'everyone else but me'. Rather 'others' are "those from whom, for the most part, one does *not* distinguish oneself – those among whom one is too" (Heidegger, 1927/1962, p. 118). King (1964) provides clarity to the notion of being-with:

Just as man is never a worldless subject ... so he is never an isolated, otherless, "I", but in advance understands himself as I-myself-with (possible other selves). The "with" already refers him to the other as a self, i.e. as one who exists in the same way as he himself and yet is the "other" *with* whom he can be together in the same world (p. 105).

Being-with others in-the-world is fundamental to our Being. We are always alongside others. There are those close to us in our world, those with whom we have relationships, those for whom we care and who matter to us. There are many further 'others' in the world, 'others' with whom we do not have a relationship as such, who none the less influence the way we are in the world. Who are these somewhat anonymous 'others'?

Heidegger suggests "the 'who' is not this one, not that one, not oneself, not some people, and not the sum of them all. The 'who' is the neuter, *the 'they' [das Man]*" (Heidegger, 1927/1962, p. 126). Furthermore, the 'they' is a necessary part of our being, "it belongs to Dasein's positive constitution" (Heidegger, 1927/1962, p. 129). Our cultural values and traditions as well as public opinion underpin the 'they'. What one does or does not do in particular situations is determined by these values, traditions, and opinions, and of course our thrownness. It is the 'they' that dictates our average everyday way of being-in-the-world.

'Being-with others' is particularly relevant in understanding the phenomenon of 'living with rheumatoid arthritis' and as such underpins the interpretations presented in this thesis, especially those in Chapter Seven.

Being-for: care and solicitude

Alongside Being-in the world and Being-with others, one of the fundamental aspects of Dasein described by Heidegger is Being-for. The Being-for of Dasein's existence is 'care' (*Sorge*). Care signifies " 'care-for,' [and] 'concern for and with'" (Steiner, 1978, p. 100). Care has many forms, such as the concern for things in the practical world and the concern with, and caring for, Being itself. It is because of this fundamental way of being-in-the-world, care, that things, people and our own Being, matter to us in our lives.

Heidegger names the care and concern we have for others as 'solicitude'. Solicitude describes how we 'are' with one another. There are different modes or possibilities of solicitude. There are the indifferent and deficient modes of solicitude such as "being for,

against, or without another, passing another by, [or] not ‘mattering’ to one another” (Heidegger, 1927/1962, p. 121). It is these modes of solicitude that tend to characterise our everyday being-with others, especially those with whom we have no immediate relationship. The positive mode of solicitude has two extreme possibilities, ‘leaping in’ and ‘leaping ahead’. The caring for which ‘leaps in’ is characterised by taking care away from the other, usually by taking care of things for them. In contrast care that ‘leaps ahead’ is characterised not by the taking away of care but the giving back of care. Care and its derivative solicitude are important notions in this study and are discussed further, particularly in Chapter Seven.

The influence of Gadamer

Hans-Georg Gadamer (1900-) was a student of Martin Heidegger (1889-1976) and as such it is difficult, if not impossible, to see where Heidegger’s work ends and Gadamer’s begins. Gadamer has used Heidegger’s work as his point of departure in his exploration of hermeneutic philosophy. The work of Gadamer is described by some as being “central to the evolution of contemporary hermeneutic philosophy” (Thompson, 1990). Like Heidegger, Gadamer focuses on the ontological question of Being as opposed to the epistemological question of knowing. The problematic of Gadamer’s work is the phenomenon of ‘understanding’ and is based on the premise of the universality of understanding that, Gadamer argues, “pervades all human relations to the world” (1960/1989, p. xxii). In other words, understanding is our way of being-in-the-world.

Understanding, interpretation, and prejudice

Heidegger contends that understanding of the world rests in interpretation. It is through interpretation that we understand, and conversely it is through understanding that we interpret. “In interpretation, understanding does not become something different. It becomes itself” (Heidegger, 1927/1962, p. 148). Interpretation, in the ontological sense, describes the primary understanding that runs through our various ways of existing in and interpreting the world and involves working through the possibilities projected by the understanding (Hoy, 1993). Heidegger construes that when we look at something we do not perceive its physical properties, instead we see it as an already interpreted ‘something’ (for example, *as a door, or as a table*) (Heidegger, 1927/1962, p. 149). In

seeing something *as* something we understand it for what it is and what it means to us. We grasp the meaning of something *as* something through its web of relations with other entities.

It is the context of understanding that makes it possible to understand something *as* something. This context is not explicit but makes up the background of understanding (Hoy, 1993), or in Heidegger's term 'fore-structure'. Three interwoven 'pieces' constitute the fore-structure of understanding; fore-having (something we have in advance), fore-sight (something we see in advance), and fore-conception (something we grasp in advance) (Heidegger, 1927/1962, p. 159). Understanding then relies on our prior understandings, our assumptions, and our grasp of something. In this sense there can be no understanding or interpretation that is free of this fore-structure, "an interpretation is never a pre-suppositionless apprehending of something presented to us" (Heidegger, 1927/1962, p. 150).

Extending Heidegger's notion of the fore-structure of understanding, Gadamer introduces the notion of prejudice. Contrary to the negative connotation the word usually carries today, 'prejudices' may be positive or negative (Gadamer, 1960/1989, p. 270). In this sense prejudice means "a judgement that is rendered before all the elements that determine a situation have been finally examined" (ibid.). Prejudices can affect the way we approach, interact with, and question the 'other' of the situation we are trying to understand. Therefore, it is essential that we recognise, foreground, our prejudices, keeping open the possibility that these might be discarded or extended as we come to a new understanding of the situation. Gadamer tells us that a person cannot be free of prejudices and therefore cannot claim objectivity in a situation; to do so is to "misunderstand". Furthermore, "(a) person who does not admit that he is dominated by prejudices will fail to see what manifests itself by their light" (1960/1989, p. 360).

Gadamer reminds us that "interpretation must be on guard against arbitrary fancies and the limits imposed by imperceptible habits of thought" (1960/1989, p. 266). The challenge Gadamer offers the interpretive researcher is to examine the "habits of thought" that dwell within us all. Unexamined pre-understandings or prejudices may distract us in our interpretation of the phenomenon. It is therefore necessary to explicate one's pre-understandings in relation to the phenomenon under study (Geanellos, 1998). The aim is not to 'bracket' or hold at bay these pre-understandings but to articulate

them, remain conscious of them, and explore them in light of new understandings that emerge as we dwell with the data. In examining our pre-understandings we are remaining open to the meanings of the text (Gadamer, 1960/1989, p. 268). What has this meant for this study?

To understand the experience of living with rheumatoid arthritis I needed to consider the context or background of understanding (the fore-structure) of the phenomenon and to examine the prejudices that I brought to the study, and maintain an openness to them. To do this I needed to look at what has gone before, the historical context of 'living with rheumatoid arthritis'. I needed to explore the assumptions that I brought to the study, and to try to uncover the taken-for-granted understandings of the phenomenon. The context of the study and the assumptions I brought to it have been discussed in Chapters One and Two. The data chapters (Chapters 5-8) provide an uncovering of the taken-for-granted understandings of 'living with rheumatoid arthritis' through interpretations which offer new understandings of the phenomenon.

The hermeneutic circle

Fundamental to the work of both Heidegger and Gadamer is the circularity of understanding, the hermeneutic circle. Originally an insight of Schleiermacher (1768-1834) and carried through into the work of Dilthey (1833-1911), the 'hermeneutic circle' refers to the notion that understanding involves moving constantly between the whole and the part and back to the whole (Annells, 1996, p. 707). With each movement of the circle, understanding is expanding and new understandings revealed, as we integrate to the whole what we have come to understand as we looked at, questioned, and interpreted the parts. The new expanded understanding in turn influences how we understand and interpret the parts. Understanding "is always a movement in this kind of circle, which is why the repeated return from the whole to the parts, and vice versa is essential" (Gadamer, 1960/1989, p. 190). The hermeneutic circle has no beginning and no end, there is constant movement, as parts inform whole, whole informs parts ad infinitum. Moreover, it is within the hermeneutic circle that meaning is found.

The notion of the hermeneutic circle is significant in this study. For example, it has informed the approach to data analysis and interpretation and the recognition that there is no one understanding of the phenomenon of 'living with rheumatoid arthritis'. The

interpretation of the phenomenon I present is fixed within the pages of this thesis, and as such is an understanding of the phenomenon. It sheds new light on the phenomenon but it, like all understanding, is open to growth and change as it is read and shared beyond the bindings of the thesis.

Language and dialogue

Like Heidegger, Gadamer considers “language is the universal medium in which understanding occurs” (1960/1989, p. 389). Gadamer’s notion of language is ontological, at the core of our being-in-the-world and it reveals how we are in the world. “In language, things and the meaning of things in our world become present to us” (Thompson, 1990, p. 262). Language is not just a tool that we put to use like some object such as a hammer. When we use language, the words we use are always related to or directed at a particular thought. We cannot think about anything without words forming in our mind. What language does is allow something that already exists to emerge, to show itself. Gadamer terms this the “coming-into-language of the thing itself” (1960/1989, p. 378). Just as we cannot think about anything without words forming, we cannot understand or interpret anything without words, even if the words are not the exact words to express our understanding. For example, participants in this study found it difficult at times to find the ‘right’ words to describe their worst pain. They still understood their pain as their worst pain; it was just that the words that formed in their minds were not always able to describe its complexity to someone who has not experienced the pain of rheumatoid arthritis.

Gadamer uses an analogy with dialogue or conversation to help illuminate the role of the language in the act of understanding. In conversation there is a reciprocal relationship between both parties who come to new understandings through “question and answer, giving and taking, talking at cross-purposes, and seeing each other’s point of view” (Gadamer, 1960/1989, p. 368). They may not agree with each other but through the conversation the understandings of both have changed.

When the analogy is applied to the interpretation of text, it can be seen that there is also a reciprocal relationship between interpreter and text. Certainly the text does not speak to us in the same way as a person in a conversation; however, it becomes the challenge of the interpreter to ‘make the text speak’. Making the text speak comes through

questioning, not just arbitrary questions but questions that relate to an answer that is expected in the text (Gadamer, 1960/1989, p. 377). How do we know to ask a question, the answer to which is anticipated in the text? We know because as the interpreter, we are already situated in what we are attempting to interpret, to understand. Making the text speak also assumes an openness to the question, a wanting to know on the part of the interpreter, and conversely a recognition that one does not know. “Questioning opens up possibilities of meaning” (Gadamer, 1960/1989, p. 375). We must always be open to the possibilities of new understanding through the dialogue.

What has this meant for my study? The question and answer of dialogue has informed the study in a number of ways. The primary dialogue has been between myself as the interpreter and the data as text and as such underpins the analysis and interpretation of data. The notion is also reflected in the data collection methods used, in particular the conversational-style interviews that were the main method of data collection. Furthermore, in the writing of this thesis I have attempted to use a style that reflects the dialogical ‘to’ and ‘fro’ of question and answer. This is done in the expectation that you, the reader, will in turn dialogue with this text and perhaps come to a new understanding of the phenomenon of ‘living with rheumatoid arthritis’.

Fusion of horizons

We come to any understanding with particular horizons, horizons of the past, present and future (Heidegger, 1927/1962, p. 407). Extending Heidegger’s notion, Gadamer defines horizon as “the range of vision that includes everything that can be seen from a particular vantage point” (1960/1989, p. 302). In this sense we can speak of ‘narrowing horizons’ and ‘opening new horizons’. Horizons are never fixed, but something “into which we move and which moves with us” (Gadamer, 1960/1989, p. 304). Gadamer uses the notion of ‘fusion of horizons’ as a metaphor of understanding. ‘Fusion’ describes the coming together of the horizons of the past and present in completion of the act of understanding. In other words, there is a fusion of horizons that occurs between our historical horizon (our vision of the past) and our horizon of the present. This leads to both horizons being superseded as we come to a new understanding of the situation (Gadamer, 1960/1989, p. 307).

In hermeneutic phenomenology, understanding occurs when the horizons of the researcher 'fuse' with the horizon, context, or standpoint of the phenomenon of interest (Thompson, 1990). In this study there is a fusion of many horizons. As the researcher and interpreter, my horizon of understanding has constantly expanded throughout the study. I began the study with particular prejudices and a particular horizon. As I became more familiar with the literature related to rheumatoid arthritis, as my philosophical journey progressed, as I conversed with the participants, supervisors and colleagues, as I dwelt with the data, and as I wrote and rewrote, my horizon of understanding constantly expanded.

Alongside this is the recognition that there is also fusion between my horizon and those of the participants. Just as I came to the interviews with a particular horizon so too did the participants. In creating the data for this study, through dialogue, there was a fusion of horizons between the participants and myself.

The political challenge

Heidegger's writing, and by implication the work of Gadamer and many others, has been challenged because of his involvement in the National Socialist (Nazi) party of 1933 and his subsequent silence on the issue. Young (1997) speaks of the "noise surrounding the political question" of Heidegger's work, however, within nursing scholarship this 'noise' is not very loud. With the exception of Holmes (1992; 1996) the nursing literature is almost silent on the debate. It is beyond the scope of this thesis to present and debate the case but it is necessary to acknowledge its existence.

As with any debate, there are primarily two sides, the critics and the apologists (to use Holmes' terms, 1996). Neither side denies Heidegger's involvement in the National Socialist (Nazi) party and the politics of pre-war Germany. The debate, instead, centres on the relationship between Heidegger's politics and his philosophy. The problematic question at the centre of the debate is whether Heidegger's fascist views are inherent in his philosophy. Following a comprehensive review of Heidegger's writings and political involvement, Young (1997) argues that Heidegger's philosophy is "free from the taint of Nazism" (p. 5) while acknowledging that there is "something fundamentally unacceptable in the character of Heidegger's political commitment" (p. 52).

Furthermore, says Young, “one may accept some, or all, of his philosophy without fear of being committed to, or moved into proximity with, fascism” (p. 5).

Where does this leave a study that is informed by Heideggerian notions? Nancy Diekelmann (1996), whose work in nursing scholarship is underpinned by Heideggerian philosophy, suggests that in remaining silent about his political involvement Heidegger has left us a gift, the gift of ‘lest we forget’. Heidegger’s silence means that his work now remains always open and problematic and challenges us to ask, “Where is the fascism in my own work?” (ibid.). My response to this question is, “It does not appear to be inherent in my study.” Heidegger’s work has informed the method and interpretations of this study in a way that has encouraged me to remain open to different possibilities of meaning, to reflect on the situatedness of my understandings and to be respectful of the understandings that others have brought to the study. I have also been cautioned and encouraged to look for the ‘they’ and to become aware of their effect on my understanding. In keeping open and questioning the possibility of fascism in our work we are keeping alive the memories of a time many would rather forget, a time when perhaps the “whole world had gone mad” (Diekelmann & Diekelmann, 1996). Moreover, we are keeping concern alive, a questioning concern that should accompany any new understandings.

Conclusion

This chapter has briefly outlined a number of notions drawn from the works of Martin Heidegger and Hans-Georg Gadamer that have informed this research. Further reference is made to these notions at relevant stages throughout this thesis as they inform and enrich this study; such is the inseparability of philosophy, methodology and method.

The next chapter moves from methodology to method as I describe and discuss the research processes involved in this study.

CHAPTER FOUR: Methodology to Method

This chapter moves the research from the philosophical and methodological issues discussed in Chapter Three to consideration of the research method. The issue of rigour in hermeneutic phenomenological research is addressed and I describe and discuss the method involved in undertaking the research. Although my journey is presented here in a linear form, in reality the decision-making and activities described often occurred in a somewhat circuitous way as reading, discussion, reflection, and context exerted their influence on the research method and procedures. Throughout the study I attempted to maintain an open attitude to the processes involved. I made some initial decisions about such things as types of data, data sources and approaches to data analysis. However, these decisions were always open to question and modification as the study progressed.

The question of rigour

The issue of rigour in qualitative research has fuelled much debate in the academic literature (see for example, Angen, 2000; Cutcliffe & McKenna, 1999; Emden & Sandelowski, 1999; Koch, 1994a; Koch & Harrington, 1998; Lincoln & Guba, 1985; Nolan, 1995; Sandelowski, 1993). Much of the debate centres on the identification of what constitutes “goodness” in qualitative research (Emden & Sandelowski, 1999). Following a critical review of this debate, Koch and Harrington (1998) appealed to researchers “to incorporate a reflexive account into their research product [thesis] by signposting to readers ‘what is going on’ while researching” (p. 882). A reflexive account that describes ‘what has gone on’ during the research process is grounded in a reflexive approach to research that is characterised by ongoing self-critique and self-appraisal. A reflexive account allows the reader to decide if the research product is believable or plausible, Koch and Harrington’s terms for rigour (p. 889). Koch and Harrington’s (1994) view is informed by the philosophical works of Gadamer (1976) and offers a position on the question of rigour that is congruent with the philosophical underpinnings of this study.

How have I maintained a reflexive approach to my research? My research journal has been a valuable tool in this process. The mind-maps that I have drawn at various stages of the journey have also helped to clarify my thoughts and the direction and ‘whole’ of the interpretation. Presenting at conferences, locally and internationally, and discussion

with my supervisors, fellow doctoral students, colleagues and friends, has provided opportunity for articulation of numerous aspects of the research such as philosophical underpinnings, ethical considerations, and analysis. These presentations and discussions have sometimes been difficult, at times challenging my understandings, and on most occasions they have been rewarding. At all times they have provided opportunities for ongoing self-critique and appraisal.

Often I would note comments made by my supervisors during our meetings. At the time of writing, these comments were sometimes puzzling or the time was not available to think about them. Yet on many occasions, I would return to, or 'happen upon', these comments at a later stage and dialogue with them. It was as if they were waiting their moment to question or guide my direction.

I enjoyed many solitary walks along coastal beaches and busy city streets where my research went with me, the current issue of the research to the forefront of my mind. These walks afforded the space for reflection, for clarification of thinking, and of understanding. Often I carried home new insights that had to be committed to paper the moment I returned.

Writing and rewriting have been an essential aspect of analysis and interpretation in this study. This process has provided the opportunity for reflection, for dialogue with the text, and for questioning assumptions as the interpretation evolved.

Does this thesis incorporate a 'reflexive account'? The answer to that question lies ultimately with the reader. However, I believe there are 'signposts' inherent in this thesis that describe to the reader 'what has gone on'. For example, there is explication of the understandings that I have brought to the research and the historical horizons of both the participants and myself, discussion of ethical considerations, and excerpts from my journal. I endeavour throughout the thesis to lay open to inspection the decision-making and processes that have guided both the method and interpretation. I have conversed with a range of literature, positioning this literature in the context of this study. I have included participants' stories in my data chapters along with my interpretation so others can decide for themselves whether the interpretations are warranted.

Is this research believable? That is a decision that rests with the reader. As the reader, you will approach this thesis with your own horizon of understanding. You may not share my interpretation but I hope you will be able to follow the way in which I came to it. I invite you to ponder the question of rigour as you journey through this thesis, following the signposts that I put before you, reaching your own decision as to its believability or plausibility.

Signposting the journey - the audit trail

The method used in this study involved the gathering of various forms of data that provided text for analysis and interpretation of the phenomenon 'living with rheumatoid arthritis'. The primary source of data was the text of transcribed interviews. Other data, including journal notes, literature, informal observations and conversations, and participant-generated writing, also contributed. The processes involved in the study, including those related to data collection, data management and analysis, along with ethical considerations, are described and discussed in the remaining sections of this chapter.

Selecting the participants

Following ethical approval for the study, recruitment of participants began in January 1997. Participants were accessed in one of five ways: word of mouth through colleagues; through fieldworkers of a local arthritis foundation; by the researcher speaking about the proposed research to interested groups; through a local rheumatologist; and by snowball effect with participants recruited early in the study approaching people they knew. I made the decision to spread the accessing of participants for two main reasons. Firstly, I considered that by restricting recruitment to one area, for example the local arthritis foundation fieldworkers, I might unduly limit the group of potential participants as I hoped the group of participants recruited might reflect some of the range of people who experience the phenomenon. Secondly, I considered that by accessing participants in a variety of ways I was decreasing the likelihood of participants being identified, either directly or by guesswork, in the thesis.

In all cases the potential participant was approached by an intermediary and given an appropriate information sheet (Appendix A, B, & C). The potential participant was then asked to either contact me directly should she/he wish to participate, or provide the

intermediary with a phone number and permission for me to contact them a week later. Intermediaries were asked to sign a non-disclosure form (Appendix G) requiring them to keep participants' identities confidential. Twelve people acted as intermediaries during the recruitment phase which lasted from January 1997 to December 1997.

In addition to the recruitment procedures described above, with approval from the ethics committees, the participant from my previous study (Roy, 1995) was approached for permission to include the transcripts from her interviews as data for the current study. Permission was granted and an addendum to the original consent form was signed (Appendix F).

Informed Consent was obtained after potential participants had read and discussed the information sheet. They had the opportunity to ask questions, and to discuss their potential involvement with anyone else they may have wished to, such as family members or a health advocacy service. Written consent was obtained prior to the first interview, and a copy of the form provided for the participant (Appendix A, B, & C). However, because I view consent as an ongoing process, consent was obtained again verbally prior to any subsequent interviews.

Criteria for participation

Interview data were gathered from three groups of people whom I considered best able to help in furthering my understanding of the phenomenon 'living with rheumatoid arthritis'. These people experience the phenomenon as they live their everyday lives and were therefore regarded as experts whose stories could contribute to my understanding of the phenomenon. Consistent with Gadamer's notion of 'fusion of horizons,' the role of both researcher and participant (as co-researcher) in generating the data is acknowledged (Hekman, 1984).

The first group consisted of men and women aged thirty years or more who have chronic rheumatoid arthritis. Thirty years of age was used as a lower age limit to exclude people who may have been given a diagnosis of Still's disease or juvenile

rheumatoid arthritis⁷ while at the same time ensuring that the potential participant had an established disease pattern that would indicate the 'chronic' nature of their disease. Verification of diagnosis from a medical practitioner was considered unnecessary. My previous experience of working with people with rheumatoid arthritis led me to believe that potential participants, when approached by an intermediary, would be able to decide for themselves if they met the inclusion criteria of having 'chronic rheumatoid arthritis'.

This proved to be the case, with one exception. I discovered, within the first few minutes of beginning the interview with one participant, that the correct diagnosis for this person was 'psoriatic arthritis⁸'. By this stage the participant had read and discussed the Information Sheet and signed a Consent Form (Appendix A). Both documents were headed "living with chronic rheumatoid arthritis" and included statements such as "as you are a person who has chronic rheumatoid arthritis..." (Information Sheet 1, Appendix A). The interview was already under way, should I stop the interview? As with many such dilemmas, I had to make an immediate decision. I decided, in fairness to the participant whose story I had come to hear, that I would continue with the interview and then discuss the issue later with my supervisors. As the interview continued, I became aware that when this participant talked about 'arthritis' and its day-to-day effects, the story had parallels with what I had been hearing from other participants. The story varied because of the psoriasis, but there were also variations amongst the stories from other participants. Following discussion with my supervisors, I decided to include the transcript from this interview as data. Specific references to the participant's experiences with psoriasis were not included.

⁷There is current debate related to the nomenclature given to rheumatic diseases of childhood. Historically they have been referred to by a variety of labels, for example, Still's disease, juvenile chronic arthritis, or juvenile rheumatoid arthritis. There is a move to use the uniform term "idiopathic arthritis of childhood" (IAC) as proposed by the International League Against Rheumatism (ILAR) Standing Committee for Paediatric Rheumatology, Chile (1994), South Africa (1997) (Manners, 1997).

⁸ Psoriatic arthritis is a chronic peripheral, polyarthritis similar to rheumatoid arthritis and is associated with a previous, ongoing psoriasis (a skin disorder characterised by circumscribed red patches covered by thick, dry, silvery, adherent scales that are the result of excessive development of epithelial cells). People with psoriatic arthritis experience similar problems to those with rheumatoid arthritis (Hill, 1998b).

Partners of people who have chronic rheumatoid arthritis constituted the second group of participants. However, they were not the partners of the participants from group one. I was aware from my previous study (Roy, 1995) that there is a potential for strained relationships and conflict within families who live with rheumatoid arthritis. The opportunity to talk about the experience of living with rheumatoid arthritis may have strengthened relationships within the families but there was also the real risk that it may have exacerbated the tensions. Therefore, for the safety of participants and their families, and for me as the researcher, none of the participants are related.

The third group consisted of adult birth children (over 18 years) of a parent with chronic rheumatoid arthritis. Relatives of those participants in either of the previous groups were not included in this group. The genetic contribution to the onset of rheumatoid arthritis (Chapter Two) guided the decision to include birth children of people with rheumatoid arthritis. The term ‘adult birth child’ appears on the information sheets and consent forms (Appendix C & E). However, throughout the thesis these people are referred to by the simpler term ‘adult child’.

Because of the reflective nature of the interview process used in this study a further inclusion criteria was the potential participants’ ability to communicate fluently in English, the only language I speak. However, this did not imply that participants must be Pakeha⁹ or speak only English.

The study participants

In all, twenty-five people were interviewed: eleven people who have rheumatoid arthritis (eight women and three men); six partners of people who have rheumatoid arthritis (two women and four men); and eight adult children of people with rheumatoid arthritis (six daughters and two sons). Of the adult children, five had mothers and three had fathers with rheumatoid arthritis.

Participants had a diverse range of experience of the phenomenon. Participants with rheumatoid arthritis were aged from twenty-five to fifty years of age at the onset of the disease. The time since diagnosis of participants, participants’ partner, or participants’

⁹ A New Zealander of non-Maori descent, usually Caucasian.

parent ranged from eighteen months to thirty-five years. Some of the adult children had lived with the phenomenon all their lives while others were in their teens when their parent was diagnosed with rheumatoid arthritis. Partners were all in established relationships before rheumatoid arthritis intervened in their lives.

Although I was not seeking a sample from which to generalise findings, it seemed important that the profile of the participants as a group reflected the incidence of the disease (recall Chapters 1-2). It made sense to talk to more women than men in the first group, those who have rheumatoid arthritis; and vice versa for partners of those with rheumatoid arthritis. When recruiting adult children I was keen to talk to sons and daughters of men and women who had rheumatoid arthritis. Achieving this profile of participants meant asking intermediaries to specifically approach particular groups of people to discuss the possibility of their participation. It was more difficult to recruit the sons of people with rheumatoid arthritis and men who have the disease than it was to recruit the other participants.

Of the eleven people with rheumatoid arthritis nine were living with a spouse, three with children still at home and five with adult children no longer at home. One of the participants was living alone, having never married and with a close supportive family living nearby. Another participant was divorced with children still at home.

Of the six partners of people with rheumatoid arthritis all were married, three with children still at home and two with children no longer at home. One participant had no children.

Of the eight adult children of people with rheumatoid arthritis only one still lived at home. Three were partnered with children.

Although specific data were not collected, it appeared that participants reflected a wide range of socio-economic status. One participant was dependent on state-funded welfare payments as the sole form of income while, at the other extreme, another participant lived in what could be described by New Zealand standards as significant affluence. Throughout the research process I wondered about these extremes and the effect of socioeconomics on the phenomenon. It is beyond the scope of this study to specifically explore this. However, the understanding that I have come to, given the conversations I have had, is that while affluence may temper some of the problems, for example buying

in help for domestic tasks, it does not affect the underlying always-thereness of living with rheumatoid arthritis.

Twenty-one participants were Pakeha, while three participants were born in Europe and have lived in New Zealand for more than twenty years. One participant was born in New Zealand to parents who belong to an ethnic minority group (which for reasons of anonymity is not disclosed). No participants identified as Maori.

Although in some way at odds with the Gadamerian perspective of the situatedness of experience, I consider it impossible to provide further detail of the participants for fear of further compromising their anonymity. In a hermeneutic phenomenological study it is extremely difficult, if not impossible, to guarantee anonymity because of the nature of data generated. The data are extremely personal and even if some of the biographical and demographic details are changed it is probably not difficult for an acquaintance of the participant to identify the person. In a country like New Zealand, with its comparatively small population, the likelihood of identification is further increased (Roy & Eichblatt, 1996).

Ethical considerations

The study received approval from two ethics committees, the Massey University Human Ethics Committee and the local Regional Health Authority Ethics Committee. The latter committee requires annual reapproval, which has been granted throughout this study.

The complexity of the consent process in this study resulted in the development of five different information sheets and consent forms (Appendix A, B, C, D, & E). Perhaps the most vulnerable group were the people I have called the 'non-participating person with rheumatoid arthritis', the partners and parents of participants. Although the intention was to focus on the partner/child's experiences of 'living with rheumatoid arthritis' it seemed inevitable that certain details about the life of the non-participating person with rheumatoid arthritis would be revealed during the interviews. Consequently, intermediaries approached these people and their permission was sought to invite their partner or son/daughter to participate (see Appendix D & E).

As described above, given the small number of participants and the depth of disclosure in interview data, providing anonymity in a study such as this is problematic (Holloway

& Wheeler, 1995; Roy & Eichblatt, 1996). This was outlined in the information sheets (Appendices A-E) and discussed with potential participants at the time of initial consent. Efforts have been made to provide anonymity through the use of pseudonyms and changing some identifiers, for example the age or number of children of a participant, where these were not considered essential to the overall interpretation. However, there are many such identifiers that were necessarily retained to maintain the integrity of the interpretation. I grappled with the decision of whether to attribute each quotation to a particular participant; Morse (1998) cautions against this. Finally, I decided that to exclude the pseudonym from the quotations would detract from the understanding of the phenomenon in its interweaving complexity.

During some of the interviews participants spoke, knowingly or unknowingly, of other participants in the study. My journal notes recall an incident when one participant asked me directly “*My friend [Maria], do you know her?*” I had to tread a fine line between not lying and maintaining the confidentiality of the participant (Maria). Some participants also disclosed the names of their practitioners (or partners’/parents’ practitioner), speaking of aspects of their care that I now carry with me, but will not disclose because of the confidentiality inherent in the research process.

Three participants have died during the course of this study, two of complications associated with their rheumatoid arthritis. These participants had all received copies of their interview transcripts some months before their deaths and had the opportunity to amend or withdraw any or all of their data. Two deaths occurred after the data analysis phase, the time until which the participants had the opportunity to withdraw data. One death occurred after the transcripts had been reviewed by the participant, but before data analysis. The issue was discussed with my supervisor and the participant’s next of kin. The decision was made to honour the participant’s memory and commitment to the study by retaining the transcripts as data for the study.

Data gathering

The interview in data collection

Interviews took place in a variety of settings over an eleven-month period from February 1997 to January 1998. In total I interviewed twenty-four people, the resulting transcriptions generating 933 pages of text. There was an additional 107 pages of text

from the transcribed interviews with the participant from my previous study (Roy, 1995). The taped interviews ranged in length from 45 minutes to over two hours. On average an interview lasted 90 minutes. The interviews took place in two phases. Phase one involved interviewing the participants who have rheumatoid arthritis. During phase two the partners and the adult children were interviewed, the order depending on an individual's availability at a particular time.

Initially I had anticipated interviewing all participants at least twice. This occurred with seven participants in phase one, the people with rheumatoid arthritis. However, I soon discovered that the depth of disclosure in the first interview was such that during the second interview participants began repeating their stories. In some instances, the second interview was useful for clarification of points made in the first interview. Clarification became less of an issue as data collection continued and I found myself more able to pick up on points for clarification at the time that they occurred. Although I kept open the possibility of scheduling additional interviews if participants wanted them or if I thought they were necessary, this was not needed. However, on three occasions participants contacted me after reading the transcripts of their interviews to offer further details of a particular experience or to clarify a particular point. A further four participants contacted me after significant events occurred in their lives, for example, a hospital admission. This additional material was noted as an addendum to the original transcripts.

Interviews were preceded by phone calls to make arrangements and answer any immediate queries potential participants may have had. The potential participant or I, depending on the arrangement made with the intermediary, initiated the call. The interviews were scheduled at mutually agreeable times and at a location chosen by the participant. I was very aware that for the participants with rheumatoid arthritis physical comfort during the interviews was an important consideration. I was also aware that for a number of these participants transport could be difficult. Therefore, I was willing to travel to meet them in their own homes if that was what suited them best. Across both phases all but three interviews took place in the participant's home. At the request of particular participants, one interview occurred at the participant's office, one at my university, and the other at my home. In addition to the taped interview sessions, I also met with participants to discuss the study and obtain written consent. Again, most of these meetings were in the participants' homes. During these visits I was more likely to

meet other family members, often because the signing of the consent form had to be witnessed (a requirement of one of the ethics committees). Meeting family members in this way provided further insights to my understanding of the phenomenon as we shared informal conversations.

For phase two, the interviews with partners and children, I had to meet the partner/parent with rheumatoid arthritis to obtain their consent (recall the discussion on page 61). In some instances this meeting was combined with my initial meeting with the potential participant where we discussed the research, their potential involvement and, if appropriate, signed the consents. On other occasions I met the non-participating person with rheumatoid arthritis first, obtaining their consent to invite their partner or child to participate in the research. This latter situation occurred with all but two of the adult children and was primarily due to either work commitments of the adult child and/or because they were no longer living with the parent. As occurred when meeting family members of participants in phase one, the non-participating partners/parents were keen to discuss their experiences with the phenomenon. Although these conversations were not recorded in any form they did add to my understanding of the phenomenon.

There were two instances where people with rheumatoid arthritis agreed to their partner/child being invited to participate but the partner/child declined the invitation.

How did I know that twenty-five participants were enough? I did not know really, although after thirty-three interviews the volume of data was overwhelming. I sensed that I had 'enough'. Recalling a conversation with David Allen (personal communication, 20.11.97) where he spoke of the 'data stop' gave me the confidence to say 'enough is enough'. Data collection in hermeneutic phenomenology is never finished, understanding is never complete, and there is always room for more data, and new understanding. However, on a pragmatic level a research study needs to be finished at some point, decisions have to be made. After thirty-three interviews I was able to recognise the depth and complexity of the data and to accept that the data collection was, in David's term (*ibid.*), 'done'.

The Interview - Conversation

The 'interviews', conversation-like in nature, were essentially unstructured and framed around the question 'Can you please tell me about your experience of 'living with

rheumatoid arthritis’?’ An assumption I carried with me to each interview was that the participant and I were co-creators of the data (text). The participant and I came to the interviews with our own horizons that would shape, and in turn be shaped by, the dialogue in which we engaged.

Usually I suggested to participants that they might like to start by giving me some background information such as their age and how long they had experienced the phenomenon. Beginning with relatively ‘safe’ information such as this was often an ‘ice-breaker’ and seemed to help the participants feel at ease. A number of participants, particularly those people who have rheumatoid arthritis, began by telling me what I considered to be ‘sanitised accounts’. Information, such as their medical histories, was given in a way that they had probably told to health professionals many times before. The use by many of medical terminology illustrated an in-depth scientific knowledge of their disease. While this may have also been an ‘ice-breaker’ for these participants I consider that it may relate to what Strauss et al. (1984) describe as the different types of ‘biographies’ that people with chronic illness have. What I was hearing was perhaps the “disease biography” (p. 186); the information most commonly sought by the health professionals these participants usually have contact with. However, it usually required only a slight probing question from me for the participants to begin sharing their other ‘biographies’, the stories of ‘living with rheumatoid arthritis’. At times I was humbled and almost overwhelmed by the depth of the disclosures. I felt privileged to be sharing their stories in this way.

Although the interviews were essentially conversations I did have a general list of topic areas I wished to cover. This list, which was carried in my head, included such things as social, occupational and family life, relationships, and daily activities. These areas were refined where participants were interviewed more than once, although in most cases the second interview was used for clarification and the sharing of tentative interpretations. Where there was only one interview, during the later part of the interview I asked questions related to tentative interpretations that were emerging from interviews with previous participants. These questions were prefaced by a comment such as ‘I’ve been told that...’ or ‘some people experience...’

Participants in both phases of interviews expressed surprise at some of the questions asked or aspects of their story that I picked up on, making comments such as “*I haven’t*

thought about it that way before” or “No one’s asked me about that before”. Many participants had used the time between their initial agreement to participate and the time of the interview to reflect somewhat on their experience. For example, Pat commented, *“One of the things that I’ve thought about since I discussed (the research) with you is...”* (Pat, 1:1).

A number of participants spoke of the benefit to them in telling their stories. Although not the exclusive domain of hermeneutic phenomenology, it is important to note the potential benefit to participants of this type of interview. As well as providing an opportunity to reflect on their experiences and perhaps look at them in a different way, for many participants the interview was the first time they had ever had the opportunity to tell their story. This seemed particularly so for the partners and adult children. One partner thanked me profusely for inviting him to participate; adding that in the thirty years his wife has had rheumatoid arthritis this was the first time anyone had asked him specifically about what it has meant to him (Journal entry, 21.8.97). Jan, whose mother has rheumatoid arthritis, had this to say:

This is the first chance I’ve had to tell my story. I was really excited to be able to tell my story I guess, because it’s the first time that there’s been a recognition that there is even a story to tell from any other perspective than Mum’s. It’s really important to be able to put it out there somehow. I think it’s amazing that there are people, like you, who are looking at and acknowledging the reality of being a patient, and the effects that that has on all the people around them (Jan, 1:30).

In the literature there are numerous references to the benefits of participating in qualitative research. The process is described as cathartic, providing an opportunity for self-acknowledgement, self-awareness, empowerment and healing (Hutchinson, Wilson, & Wilson, 1994; Sorrell & Redmond, 1995). I certainly consider this one of the positive benefits of participation. As human beings we like to be acknowledged and to be listened to.

During a number of interviews participants became distressed as they spoke of particular aspects of their lives. Sometimes the distress disclosed itself in tears, at other times by silence or by changing the subject. On these occasions I offered to turn off the tape, or made that decision myself. I sat through silences, letting them ‘be’, or respected the participant’s need to move on from the subject. A journal entry records one such situation:

We ended the taping when [the participant] became upset... I just let her talk off-tape and then checked how she was feeling (she said she was ok). She was keen to show me her garden ... so we debriefed further as we walked (Journal entry, 27.2.97).

Participants occasionally asked me questions about specific aspects of the disease or sought my advice, calling on my knowledge and experience as a nurse. I answered these as they occurred, considering it part of the "blurring of roles" (Roy & Eichblatt, 1996) of 'nurse' and 'researcher' that frequently occurs in this type of research. Being a nurse is part of my way of being-in the world as is my being a researcher. It is not possible for me to 'be' anything but a nurse and a researcher in situations such as this.

Some interviews were easier than others were. In any social relationship there are some people it is easier to establish a rapport with than others, so too in interviews such as these. There were two interviews that I considered difficult in terms of conversation flow and rapport with the participants. My journal notes made directly after the interviews contain comments such as '*much less 'open' than other participants*' (Journal entry, 13.5.97) and '*interview felt quite stilted at times*' (Journal entry, 10.9.97). Although these interviews were more difficult and I had some initial concern that the data would be of limited use, this proved not to be the case. Once the interviews were transcribed I was able to gain insights which have been valuable contributions to the overall interpretation.

There were other interviews where rapport was easily established with the participants but the interviews were far from easy. In these cases the difficulty for me, as the researcher, came from the content of the participants' stories. Two interviews were particularly challenging as I listened to the participants telling of traumatic events in their lives. On these occasions, on completion of the interview I had the need to escape, usually to the sanctuary of my garden. Revisiting the particular transcripts and tapes during data analysis sometimes generated similar feelings, although not as acute as the first time. This aspect also had repercussions for my relationship with the transcribing typist. When I passed on the tapes to her I would advise her of aspects of the stories that I had found difficult to hear and we often spent time discussing the content, as a form of debriefing, after she had completed the transcribing.

Terminating the relationship with participants

Termination of the relationship with participants in research such as this requires special attention. The relationship with participants has been intense with significant personal disclosure on their part. Although the intensity of the relationship was only for a brief period, the duration of the study has meant that the relationship with some participants has stretched over more than four years, five years in the case of the participant from my previous study. For this reason termination of the relationship was considered at the planning stage of this study. As part of the process of Informed Consent the participants' role in the research was outlined. This included discussing the proposed time frame of the research. Participants knew in advance that I would maintain contact with them to provide progress reports throughout the study. As well as providing the participants with reports on progress these letters, sent every six to twelve months, enabled the relationship to terminate at a pace acceptable to individual participants. Letters included an invitation to contact me if they wished. Most participants have not contacted me since receiving the transcripts of their interviews while others have contacted me for a variety of reasons. One participant contacts me regularly to discuss her ongoing experience of living with rheumatoid arthritis and also to discuss my progress with the thesis. Van Manen (1990, p. 98) notes that "Participants often invest more than a passing interest in the research project in which they have willingly involved themselves."

Other data

The interview transcripts have provided the primary data for this study. However, numerous other data have contributed to the overall 'text' from which the interpretation has been made. Inclusion of multiple sources of data in hermeneutic phenomenological studies such as this are of value (Munhall, 1994). Other forms of data include the journal notes, literature (for example: autobiographical accounts of living with rheumatoid arthritis, magazine and newspaper articles, as well as academic literature), informal observation, informal conversations, and participant-generated writings. The latter consisted of five pieces of writing by participants that told of aspects of their experience of living with rheumatoid arthritis. These writings were all spontaneously offered to me during the interviews.

Discussion with colleagues and friends, while not constituting data as such, sometimes led me in a new or different direction. This occurred particularly during the analysis phase of the study. Sometimes the path I went down came quickly to an end, at other times the path was long, involved and joined with other paths on which I was travelling. However, all these paths influenced my horizon in some way and thus contributed to my growing understanding of the phenomenon of 'living with rheumatoid arthritis'.

Data management

All interview data were transcribed verbatim by a transcribing typist, with the exception of one interview, which I transcribed myself. The transcriber, who was paid, provided the transcriptions on computer disk and hard copy. The original hard copy and disks were stored separately from the subsequent copies.

On receipt of the transcripts I reviewed them while listening to the tapes of the interviews. During this review I corrected mistakes as well as adding notes about pauses, silences, tone, laughter, tears and other such contextual nuances. The reviewed transcription was then sent to the particular participant for their interest and to give them the opportunity to add or delete anything that they might wish. In returning the transcripts to the participants I was maintaining their right, as indicated on the information sheets (Appendix A-C), to verify, alter or withdraw all or part of their transcription up until the time data analysis had been completed. It was an ethical imperative, informed from my experience in a previous study (Roy, 1995), that drove this decision given the depth of disclosure that may occur during interviews in hermeneutic phenomenological research. Seven participants did contact me with additional information, which was added to the transcript. No participant withdrew any of the interview material. One participant requested that a copy of the transcription not be sent, as he did not want such a document 'lying around'. When the particular transcript was available I sent the participant a letter advising him of this with the offer to send a copy if at any time in the future he wished to have one. Participants were offered a copy of the audiotape of their interview, although no one accepted this offer.

The first few transcripts were sent out corrected but still in the verbatim form which included 'umms', 'ahhs', pauses and other nuances of speech. I modified this practice after feedback from the early participants about how 'embarrassed' they were to have

spoken this way. One participant spent a number of hours grammatically correcting the transcript before returning it to me. To avoid this situation following subsequent interviews, I deleted these 'spacers' before sending out copies of the transcripts. However, I continued to use the unedited transcripts for data analysis, having realised that in editing out such 'spacers' I may have eliminated meaningful and analytically useful information (Blauner, 1987; DeVault, 1990; cited by Sandelowski, 1994).

Transcript data presented in this thesis have been recrafted to enhance the presentation and flow of the stories and to enable the meaning to be made "more explicit, more apparent and more revealing" (Smythe, 1998, p. 110). Editing out spacers, unless they were considered essential in drawing meaning from a particular story, is one strategy used. During the interviews, stories were sometimes shared in a way that found parts of a story intertwined with other stories or revisited more than once. In these cases I have drawn these parts together, recrafting them as one story. The process of recrafting has the potential to simultaneously pull the reader in and prompt reflection on the meaning of the story (van Manen, 1990). For a key to abbreviations and conventions used in the transcript data see Appendix J.

Data security

All transcripts, audiotapes and other information pertaining to participants were stored in a locked filing cabinet. In the transcripts used for analysis all names were replaced by a pseudonym or by denoting their relationship to the participant, for example [husband].

Computer files containing information that might lead to identification of participants, such as names and addresses, were protected by an access password.

In accordance with Massey University requirements, all data including audiotapes will be securely kept for ten years following completion of the study. After this time the transcripts will be shredded, computer files deleted, and audiotapes destroyed.

The interpretive process

In the process of hermeneutic interpretation the researcher enters into dialogue with the text. The process, which is not linear, is characterised by the interplay of the parts and the whole that is central to the hermeneutic circle. It involves a "synthesis of the horizons of both the text and the interpreter" (MacLeod, 1996, p. 150).

Pre-understandings

Gadamer reminds us that “interpretation must be on guard against arbitrary fancies and the limits imposed by imperceptible habits of thought” (1960/1989, p. 266). Unexamined pre-understandings or prejudices (to use Gadamer’s term) may distract us in our interpretation of the phenomenon. It is therefore necessary to explicate one’s pre-understandings in relation to the phenomenon under study (Geanellos, 1998). My pre-understandings, my background and situation, have been brought to the interpretation, influencing, for example, my dialogue with the text and with the literature, and my decisions about which stories to bring forward, and which to leave behind. Recall the pre-understandings and context that were discussed in Chapters One and Two.

The pre-understandings of the participants have also influenced the interpretation presented in this thesis. The participants, as self-interpreting individuals, brought to the interviews their own pre-understandings, which shaped the stories they shared. The text was in this way co-determined by the historical situation of both myself, as the researcher, and the participants. Hekman (1984, p. 348), in discussing the methodological implications of Gadamer’s philosophy, suggests that the researcher must seek to define the historical and cultural horizons of the participants, recognising that these horizons will also influence the construction of the text (the interview transcription) used for interpretation. While it has not been possible to attend to this on an individual basis, participant by participant, a general definition of the historical and cultural horizons of the participants has been articulated, primarily in Chapter One.

How have I worked with the pre-understandings? At the beginning of my previous study (Roy, 1995) I recorded my assumptions and pre-understandings of what it was like to live with rheumatoid arthritis. These pre-understandings were re-visited on completion of that study. I noted, “my assumptions have been challenged and extended in the course of this study.... While my assumptions have not been “turned around” (Benner, 1994, p. 101), I now view them within the context of what I have come to understand from [the participant’s] experience” (Roy, 1995, p. 64). Again, when beginning this journey I considered my pre-understandings, now broadened with the knowledge of the original study and further reading of academic and biographical literature. Conversations, both formal and informal, had furthered extended my horizon of understanding. Recall the explication of these in Chapter One.

Exploration of pre-understandings has been ongoing throughout the research process. I found writing a journal a useful way to document this. It was not always evident to me at the time that what I was writing about were my changing understandings. However, as I reflected on my writing, particularly during data analysis and the process of writing the thesis, the journal provided evidence of new understandings, of broadened horizons. It also provided opportunity to reflect on whether my pre-understandings were driving the interpretation or whether I was allowing the text to “assert its own truth” (Gadamer, 1960/1989). For example, in a journal entry in December 1997 I note:

There is danger in romanticising and danger in catastrophying (sic) [the experience of living with rheumatoid arthritis]; this is a conversation I need to have.

This statement was made after I read an interpretation of living with rheumatoid arthritis that I considered ‘romanticised’ the experience. Reflecting on my reaction to the interpretation, I became aware of the tension that these positions brought to my research. Throughout the study, especially during analysis and interpretation I worked with this tension, often asking of myself ‘Am I romanticising?’, ‘Am I catastrophying’ the experience of living with rheumatoid arthritis.

Reflecting on my understandings and holding open the possibility that these may change and that new understandings might evolve which would challenge, shape and extend my understandings was fundamental to my being a researcher in this study.

Analysing the data

One of the most paralysing moments in conducting qualitative research is beginning analysis (Sandelowski, 1995, p. 371).

How true the words of Sandelowski seem as I reflect on my experience of data analysis in this study. There was an almost panicked sense of ‘What do I do now, how do I do it?’ I read many books and articles in an effort to find guidance for my analysis; the work of Sandelowski (1995) and van Manen (1990) have been particularly useful. I was also guided by my conversations with others who had walked the path before. However, I came to realise that the process of data analysis, like the research process itself, was a journey that I had to make alone, albeit with some help along the way. Throughout the process I endeavoured to maintain congruency with the philosophies which informed this research. The process was circuitous, with blind allies and meandering paths, which

makes it difficult to describe in a sequential way. It involved a dynamic interplay of turning to the phenomenon, investigating it, reflecting on the themes, describing the phenomenon, remaining orientated, and always considering parts and whole (van Manen, 1990, p. 30).

At the completion of each interview I wrote a profile of each participant that included such details as how long they had lived with the phenomenon and the constitution of their family, along with some of the aspects of their stories that initially 'grabbed' me during the interview. These profiles were useful reference points as I worked with the data, sometimes needing to recall contextual details of their experiences that were not recorded in the transcripts.

I then reviewed each transcript, getting a sense of the whole. During subsequent readings (and sometimes during the first) I began flagging stories or turns of phrase that 'leapt out' at me as I read. I wrote notes in the margins and sometimes in my journal. I then wrote a summary of each transcript attempting to capture 'what seemed to matter'. The work with the early transcripts influenced subsequent interviews as they affected my horizon of understanding, often nudging the conversation in directions it might not otherwise have taken.

When all the interviews were complete and the individual transcripts handled as described above, I began working with the 'groups' of transcripts. I spent time with the partners' transcripts, the adult children's, and those of the people with rheumatoid arthritis, all the time looking for insights to guide my analysis, my understanding. I tried at all times to keep the research question before me, asking, "What is this telling me of 'living with rheumatoid arthritis'?"

As I had insights from one transcript (or group of transcripts) I read the others to see what they told me of this insight. I worked through and across all the transcripts and all the 'insights' in this way. I wrote copious notes and drew mind-maps in an attempt to capture my emerging understandings. From these early insights came the identification of what I called 'bits' (others would probably refer to them as themes). In total there were ten of these themes that were, over a period eighteen months, written about in draft chapters.

I wrote these chapters knowing that in all probability they were only a part of the journey, a tentative attempt at uncovering something of the phenomenon of 'living with rheumatoid arthritis'. As I wrote I carried with me memories of the journey of a fellow PhD student. As I shared the first of my ten chapters with our PhD support group she read it and said, as I recall, "It is good. It reminds me of the thirteen chapters I wrote early in my writing." I knew then that my writing had only just begun. I knew that the ten chapters were only a beginning, that there was more writing to do. However, with those ten chapters written I considered the first level of analysis had ended. What lay ahead was to take my analysis to a deeper level, the level of interpretation.

Writing and rewriting

Writing and rewriting were an essential aspect of analysis and interpretation in this study. Writing is a way of sustaining discourse with the phenomenon, it fixes thoughts on paper, and enables the dialectical to and fro between interpreter and text (van Manen, 1990). It was through writing and rewriting that the meanings from the participants' stories emerged. It was through writing and rewriting that I was able to move beyond the ten 'themes' to the notions that I present to you in Chapters Five, Six, Seven, and Eight.

How did I move from the ten 'themes' to the deeper level of analysis? At a meeting with my supervisors I was asked, "What are the three things that matter most?" Reflecting on all that had gone before in my dwelling with the data and my deepening insights from the writing of Heidegger, I eventually offered a reply to this question. I identified three 'things which seemed to matter most'. I then produced another mind-map, a rather large one this time, which plotted the interrelationship of these three notions.

I then went back to the 'theme' chapters to find the stories that seemed to encapsulate aspects of the three overarching notions. This process I liken to shuffling and re-dealing a pack of cards. It was as if I shuffled the ten themes and re-dealt the stories into three piles. The stories from one theme did not all end up in the same pile. Some stories came forward while others were left behind. I returned to the transcripts to see if there were other stories that I had prematurely left behind.

Next I identified the stories I considered best able to illuminate my understandings of the three overarching notions. I worked with each of these stories producing an interpretation that involved three sections; the story in the participant's words, what I understood the story to be saying, and then the meaning of the story. It was to the latter section that I brought the writings of others (primarily Heidegger) to help me 'shed light' on the meaning of the story and on the phenomenon of 'living with rheumatoid arthritis'.

Finally, the data chapters were written (and rewritten) incorporating the stories and the interpretations that are presented in this thesis as a means of sharing the new understandings I have come to of the phenomenon of 'living with rheumatoid arthritis'.

Are the interpretations warranted?

With this question we return to the issue of rigour. Once again it remains for you, as the reader, to make that decision. Throughout the study I have endeavoured to involve others in the decisions and the interpretations I have made recognising that "it is always important that other eyes, and other minds, share my journey" (Smythe, 1998, p. 112). Involving others guards against unwarranted interpretations informed by unrecognised or unquestioned assumptions or prejudices.

There were numerous 'others' who have shared my journey or parts of it. My supervisors have read some of the transcripts, the theme chapters, and the data chapters. They have questioned and guided, enabling me to see when things were unclear. My fellow PhD students provided their responses to the tentative interpretations shared and discussed with them in the safe environment of our support group.

I have shared my work in various ways with practitioners and students, both formally and informally. Sharing the emerging notions in this way has elicited the 'phenomenological nod'. The 'nod', attributed by van Manen to Buytendijk, is described as "a way of indicating that a good phenomenological description is something that we can nod to, recognising it as an experience that we have had or could have" (1990, p. 27). The 'nod' has also been evoked when I have discussed my work with people whose experience of the phenomenon mirrors that of the participants in the study.

Conclusion

This chapter signposts the journey and describes the interpretive processes involved in this study. In doing so I have attempted to provide evidence on which the reader may make an informed decision as to believability or plausibility of my work. However, this decision remains to be made and cannot be made until the journey's end.

Koch and Harrington (1998, p. 889) liken the final research product to a “thoughtfully constructed tapestry [the appreciation of which] will rely upon each needlepoint and the craft of its maker”. At this point in the thesis only the outline of the tapestry has been sewn. In the following four data chapters the intricate stitches are placed in the interwoven tapestry that comes to reveal a picture of the phenomenon of ‘living with rheumatoid arthritis’.

CHAPTER FIVE: The Hands

His hands were completely deformed, like the claws of a bird, and a gauze bandage had to be used to prevent his fingernails from growing into the flesh. He was no longer able to pick up his paintbrush, and it had to be wedged between his rigid fingers. And so, day after day, he continued to paint... (Feist, 1993, p. 75).

Feist is describing the hands of Pierre-Auguste Renoir (1841-1919). Renoir lived with rheumatoid arthritis at a time when treatment was limited to bathing in warm thermal waters and to finding a place in the sun to avoid the chilling temperatures of winter. Renoir suffered the debilitating effects of rheumatoid arthritis for more than twenty years yet, like many people with rheumatoid arthritis, he continued with his work. Although his paintbrush had to “be wedged between his rigid fingers” or “tied to his crippled hand with pieces of string” (Feist, 1993, p. 95) he continued to paint, producing some of his finest works. At times he resorted to moving his arm in short, sudden jerks as a way of thrusting the paintbrush forward. Renoir’s comment on this technique was “You see, you don’t even need a hand for painting!” (cited by Feist, 1993, p. 78). During this period he also took up sculpture. Like many others with rheumatoid arthritis, Renoir adapted his way of doing things to accommodate the functional limitations of his hands. Unable to mould the clay physically, Renoir used another’s hands to create his works of art. A young art student, Richard Guino, became Renoir’s hands. Guino followed precise instructions to create sculptures “which had never been touched by Renoir’s hands but which are nevertheless works that come from his own mind ... made according to Renoir’s ideas of what is beautiful in a human being” (Feist, 1993, p. 78).

Renoir’s hands were a significant part of his life and made a major contribution to his ability to create his works of art. Like most people who live with rheumatoid arthritis, Renoir’s hands suffered the ravages of the disease leaving them visibly deformed and severely limited in function. A photograph of Renoir taken about 1890 shows swollen metacarpophalangeal joints (MCPs)¹⁰ and, in a photo from 1901, ulnar deviation¹¹ is

¹⁰ Metacarpophalangeal joints (MCPs) are at the junction of the long slender bones of the hand (the metacarpals) and the long bone of the fingers (the proximal phalanges). These joints are commonly referred to as the knuckles.

visible. By 1911 photographs of Renoir show him seated in a wheelchair. However, the most powerful imagery of these photos continues to be his hands. One is left in wonderment at his ability to create such fine works of art.

The hands of people who have rheumatoid arthritis are a powerful symbol of the disease. They are often used to illustrate articles about rheumatoid arthritis in both the popular press and academic publications. A hand featured in advertising the 1998 fund-raising campaign for the Arthritis Foundation of New Zealand and is incorporated in the group's logo. For the participants in this study the hands invoked a myriad of emotions and formed the basis of numerous stories. As I read these stories and thought about the people who had shared them with me I came to see the hands as being symbolic of the phenomenon of 'living with rheumatoid arthritis'.

In our society the hands play a significant role in who we are and how we behave as human beings. For example, we greet people with the shaking of hands, we use our hands to reach out and touch people to convey such feelings as love and concern and to offer comfort. In prayer the hands are joined palm to palm, removing them from everyday use thus encouraging religious reflection. Women in particular decorate and adorn their hands with nail polish and jewellery and in doing so announce themselves in particular ways. The hands and the way we use them are also what set us apart as a species. The elongated human thumb can rotate freely and is fully opposable to the other fingers allowing the hands to be used for precise manipulation and grasping. However, as Heidegger suggests, the hand is this and much more.

The hand's essence can never be determined, or explained, by its being an organ that can be grasped. Apes, too, have organs that can grasp, but they do not have hands. The hand is infinitely different from all the grasping organs – paws, claws, or fangs – different by an abyss of essence (Heidegger, 1951/1993, p. 380).

What is the essence of the hands in 'living with rheumatoid arthritis'? What happens when the effects of rheumatoid arthritis ravage the hands? This chapter begins to

¹¹ Ulnar deviation is a deformity characteristic of rheumatoid arthritis. The fingers (the proximal phalanges) shift in position drifting in the direction of the ulnar bone (the arm bone on the little finger or medial side of the arm). It results from the swelling of the MCPs and the stretching of tendons, which pull the fingers to the ulnar side with the ulnar bone being displaced.

uncover the essence of the hands within the experience of living with rheumatoid arthritis and how the hands can be seen to be symbolic of 'living with rheumatoid arthritis'. This chapter also introduces some of the ideas that are carried forward and built on in the other data chapters.

For most people who have rheumatoid arthritis the disease manifests itself in the hands. Indeed all participants (or participants' partner or parent) suffered the effects of the disease in their hands. Furthermore, all but two had marked deformity of the hands, and all experienced varying degrees of decreased function of the hands. The pharmacological and surgical interventions available today mean few people with rheumatoid arthritis experience deformity of the hands as extensive as that experienced by Renoir. However, for most people the pain and the decreasing functionality of the hands are always there. With the physical changes of the hands ravaged by rheumatoid arthritis comes the change in appearance, "*the visible bit*" (Margaret, 1:12). The hands now announce the disease.

Announcing the disease

The hands may announce the disease to the person suffering from rheumatoid arthritis. Changes in the hands may alert the person to the fact that something is wrong that can no longer be ignored. Consider Max's story.

I blamed [the joint pains] on the camping. I thought 'Oh well, it was wet'. It was always raining that particular week and we were sleeping on stretchers. That's always uncomfortable. I just blamed it on that actually. Then I saw my hands on the steering wheel, all swollen up, no knuckles to be seen. I thought, 'No. It's something else' (Max, 1:2).

Max tells us it was the visible changes in his hands that convinced him that there was more to the joint pains he was experiencing than the after-effects of a week camping in extremely inclement conditions. It was seeing the swelling of his hands in front of him as he drove the car that drew Max to the possibility that 'something' was wrong. It was the appearance of his hands that 'announced' the possibility that the joint pains he had been experiencing were due to something more than the discomfort of camping in the rain.

Heidegger suggests that a phenomenon or entity can show itself in a number of ways. One such possibility is that it can 'announce' itself through something that does show

itself, but is not the thing in itself. Heidegger refers to this as an 'appearance' (1927/1962, p. 29). In Max's story the swelling of the hands is an appearance of rheumatoid arthritis. The swelling of the hands shows itself, it is visible. Initially it is an appearance of 'something'. Max does not know exactly what. It is only after consultation with his doctor that rheumatoid arthritis is diagnosed. The swelling of the hands as an appearance of something is now understood to be an appearance of rheumatoid arthritis and as such announces the disease.

Announcing the disease to others

As well as announcing the disease to the person suffering from rheumatoid arthritis the hands may also announce the disease to others. Jan, whose mother has rheumatoid arthritis, provides an example.

When you look at her hands she has got classic rheumatoid arthritis, she's got these deformities that you can label. But when it's something so new and she was so healthy and so fit and so young that until those signs start showing themselves it's difficult to accept. Probably a lot of it is not wanting to believe it (Jan, 1:2).

Jan found it hard to believe that her mother had rheumatoid arthritis until the hands showed signs of deformity. For Jan the visible changes in her mother's hands meant she could no longer deny the existence of the disease. The visible changes were an appearance of the disease. There were other appearances of the disease that Jan's mother experienced, such as pain and fatigue, but because these were less visible Jan was, to some extent, able to ignore them. It is as if there was still hope that her mother did not really have rheumatoid arthritis. Hope that the pain and fatigue were due to something other than rheumatoid arthritis. However, with the appearance of physical deformities in her mother's hands hope fled, Jan could no longer not believe her mother had rheumatoid arthritis.

Announcing the difference

As well as announcing the disease, the hands announce the difference between people with rheumatoid arthritis and those who do not have the disease. To some people the difference in the hands of a person with rheumatoid arthritis may not be apparent until

the disease is quite advanced when subluxation of the joints¹² and ulnar deviation are visible. Others may notice the subtle changes of swollen MCPs or a facial expression indicating the experience of pain as the hands are used. Whether the changes are subtle or extensive, the hands of the person with rheumatoid arthritis are expressive of the disease. They differentiate or categorise the person as having a disease. Ian notices this categorisation when people first meet his wife:

It's amazing when you talk to people, they all look at Jane's hands, the size and things like that, and say, "Oh you've got arthritis" (Ian, 1:12).

The shape and size of Jane's hands as an appearance of rheumatoid arthritis announce to others, be they family, friends or strangers, that she has arthritis. The hands look different and their difference is recognised as arthritis. The casual observer may not be able to differentiate between the hands of someone with rheumatoid arthritis and the hands of someone with another form of arthritis, such as osteoarthritis. Nonetheless, the appearance of the hands announces the difference. In their difference the hands of a person who has rheumatoid arthritis stand out from the hands of others.

The hidden hands

The hands announce the difference in a very public way. It is virtually impossible for the hands to be anything but visible in the daily activities of everyday life. The announcement of difference can be difficult to accept especially for those who, like Primrose, treasure their privacy.

I don't like the rheumatoid arthritis to be noticeable so I usually try to keep my hands covered. I don't want people to know that I've got a problem. It's just that I want to keep my problems to myself (Primrose, 2:21).

Primrose is aware that her hands indicate to others that she has "a problem". As a very private person she would rather not let others know. In an effort to maintain her privacy she attempts to hide that which announces her "problem", her hands. How does she hide her hands, keep them covered? She covers or hides them in a very open way. During our conversations I noticed that Primrose constantly held one hand in the other. As she held them, she gently pulled them into 'normal' alignment. When held in this way her hands

¹² Subluxation – partial dislocation of a joint.

no longer had the look of hands ravaged by rheumatoid arthritis. They covered over the announcement of the disease. Heidegger tells us “an entity [may] show itself as something which in itself it is *not*.... This kind of showing itself is what we call ‘*seeming*’ or ‘*semblance*’”(1927/1962, p. 29). Primrose’s hands now took on a semblance of normality, they seemed to be normal. They no longer announced difference. What happens to the semblance of normality when Primrose wants to use her hands?

Keeping the hands covered, so as not to announce the difference, is an option in some situations but quite impracticable in others. Ian highlights this when he talks of his admiration for Jane, his wife, who has rheumatoid arthritis, as she struggles to maintain social contacts.

Jane struggles quite often to go out and meet other people, as she is very conscious of her hands. When she goes out socially to dinner or something like that she doesn’t like people to know about her rheumatoid arthritis so she will hide her hands as much as she can. It’s all right until she has to put things up to her mouth and then she’s got these hands that won’t hold the knife (Ian, 1:18).

Ian tells us how his wife’s hands identify her as being different. When she can, Jane will hide her hands as much as possible. At dinner she will keep them under the table. In their hiddenness the difference is covered over. But hands are so vital to our being-in-the-world that they cannot remain hidden for long. Jane’s hands cannot remain hidden for long. At dinner they are needed to transfer food from the plate to her mouth. When the hands are taken out of hiding they announce their difference, they announce the disease.

Averting the gaze

In addition to hiding the hands, there are other strategies people use in an attempt to avert the focus of the public gaze from the hands. Consider Primrose’s story.

I wouldn’t say [my hands] were as bad as to call them deformed, but they are definitely malformed, and the one thing I’ve found since they’ve been like this is that I don’t like wearing jewellery. I’m very conscious that arthritis is pretty ugly and I don’t really want to draw attention to my hands. I stopped wearing my watch because it was uncomfortable, but a ring wouldn’t be uncomfortable. I’ve got one or two big rings, they are nice but I wouldn’t want to put them on (Primrose, 1:25).

Primrose no longer wears rings, not because of discomfort or difficulty in putting the rings on her “*malformed*” fingers but because she does not want to draw attention to her hands. She does not want to draw attention to her rheumatoid arthritis. Similarly, Ivy no longer uses nail polish for fear of drawing attention to her hands. As she says, “*I used to have pretty hands. I used to wear pretty nail polish. I couldn’t bear to do that now. It just makes them stick out [and] look worse*” (Ivy, 1:29). Primrose and Ivy no longer adorn their hands in an effort to not attract the gaze of others to the hands that announce the rheumatoid arthritis. The attempts of both these women to shift the focus of public gaze from the hands are tinged with a degree of sadness and loss. Before their hands were ravaged by rheumatoid arthritis both women enjoyed decorating and adorning their hands, it was part of their identities as women. Now their hands are a symbol of the disease, a symbol that accentuates their difference and distance from others and from the women they once were.

Surgical intervention is another means of avoiding attention being drawn to the hands.¹³ Although the surgery is performed primarily in the hope of decreasing pain and improving function, the cosmetic result is also an important factor for many people. As Margaret says, “*One of the reasons I wanted to have my right knuckles done, my hand straightened, was that I didn’t like the visible bit*” (Margaret, 1:6). The potential of surgery to improve the look of the hands seems to be of particular importance to women with rheumatoid arthritis. Surgery offers the possibility of realigning the joints and straightening the fingers and in so doing removes some of the deformities characteristic of the hand ravaged by rheumatoid arthritis. It is as if surgery, like Primrose’s action in hiding her hands (recall p. 81), provides a semblance of normality. Following surgery the hands seem like ‘normal’ hands, they seem like the hands of a person who does not have rheumatoid arthritis. The hands do not announce the difference as loudly as they once did or draw as strongly the gaze of others.

¹³ Options for surgical interventions include replacement of the MCPs, arthrodesis (fusion) of the interphalangeal joints, and synovectomy (removal of the synovium or lining of the joint) of the finger joints.

In changing the look of the hands through surgical intervention are the hands no longer an appearance of the disease? In the next story Jill reflects on the look of her hands following a number of surgical procedures.

Even after the surgery I am still not comfortable with my hands. Some people say they don't notice, but I am very aware. They are deformed and I'm really aware that these lumps are sticking up. They're really horrible. Actually the one on that hand you can hardly see, the same with the ones underneath. Most people wouldn't see them but I'm aware of them all the time. It's like if you've got a zit [pimple] on your face. To somebody else it's just a little mark, they don't even notice it, but you know it's there, it's a beacon (Jill, 1:24).

After a number of operations on her hands Jill is still very conscious of the differences in her hands. Surgery is perhaps successful in averting the gaze of others, but to Jill the subtle differences that remain seem like beacons signalling to all around. Surgery may avert the gaze of others, veiling the hands in a semblance of normality. However, for the person with rheumatoid arthritis the hands are still an appearance of the disease. At their essence the hands remain beacons that shine the light on difference, and on the disease.

Noticing and not-noticing

For the partners and the adult children of those who have rheumatoid arthritis the physical changes in the hands of their loved ones often become part of the taken-for-granted nature of their experience of living with rheumatoid arthritis. Although they recognise the changes in the hands they have come to accept them as normal. It is only on reflection or when a particular incident occurs that draws their attention to the hands that the difference is noticed. Ian provides an interesting analogy in his description of how the changes in his wife's hands seldom now announce to him their difference.

Her hands have really changed. I don't really notice it although I suppose I did initially. It doesn't worry me. As I hold her hand her grip's quite strong and the actual deviation in her hand doesn't worry me all that much. I suppose I've got used to it. It's a bit like brakes in your car, when they are starting to go off and you are driving the car all the time, you don't necessarily feel them. It's only when somebody else gets in and drives your car, they say, "You want to get those brakes attended to", that you actually notice them. Well I suppose this arthritis thing has been a little bit like that really. You just don't notice (Ian, 1:18).

Ian draws an analogy between not noticing the difference in his wife's hands and the gradual deterioration of the brakes on a car. When one is constantly driving the same car

the gradual deterioration is not noticed. However, someone else driving the car can draw one's attention to the deterioration. When something is part of everyday life it becomes taken-for-granted. In everyday familiarity the thing (deteriorating car brakes) is covered over (Hall, 1993, p. 126). The changes in his wife's hands have similarly become part of the taken-for-granted nature of Ian's experience of living with rheumatoid arthritis, and are no longer noticed by him to be different. Their difference is covered over in the everydayness of living with rheumatoid arthritis.

Although those close to the person with rheumatoid arthritis may not, in the everydayness of living with the disease, notice the hands as being different there are occasions when the differences are announced anew. In the next story Pat, whose wife has rheumatoid arthritis, provides a graphic illustration of this.

I don't notice her hands all the time. I've got used to them now and most of the time I don't notice the difference. But recently it was my birthday and we were in a restaurant, a regular haunt of ours, which is run by a young couple. The woman is very attractive with long beautiful hands. She has her birthday on the same day as mine and as usual I gave her a bottle of wine to celebrate. When she came over [to say thanks], she put her arms around my neck and her hands down on my chest and I took her hands. I wanted to comment about what lovely hands she has and I felt, I didn't feel embarrassed because she had her arms around my neck, I felt embarrassed for my wife. Here was this woman with these really beautiful hands, they were exceptionally beautiful hands, and here was this comparison with poor Wendy with her beaten up hands. I didn't quite know how to handle it. I found it hard to handle because I'm so used to Wendy's hands. I just like to hold her hands. But all of the sudden the fact that those very beautiful ones were there really drew attention to the fact that Wendy's are so different. Those beautiful hands were on me and I happened to be holding them at that particular time. We even had a few laughs about it, but I didn't actually talk to Wendy about it. But I wondered if she was thinking about the comparison at that particular time. Because she will hide her hands from photographs, she notices the difference (Pat, 1:28).

Pat tells us that for the most part he takes-for-granted his wife's "beaten up" hands. He likes to hold his wife's hands and does not notice their difference, he has "got used to them now". However, there are times when he is drawn to the difference. In this story the difference was announced anew when Pat found himself holding a pair of "exceptionally beautiful" hands. Heidegger tells us that "the hand's gestures run everywhere through language ... when man speaks by being silent" (1951/1993, p. 381). Of what were these "exceptionally beautiful" hands speaking? In the gesture of extending themselves in thanks these "exceptionally beautiful" hands spoke of

difference. In the beauty of these hands the difference in the hands of Pat's wife was uncovered, announced anew. Perhaps with that moment came an understanding of why the "beaten up" hands are hidden. It is as if there was a reaching out to the 'other' as Pat 'spoke' his concern, his care, for his wife across the abyss of the "exceptionally beautiful" hands.

The touch

Visible changes in the hands announce the difference in a very public way. However, the hands of a person with rheumatoid arthritis also announce difference in other ways, some public, some more private. When it comes to announcing the difference both the appearance and the function of the hands are significant. Initially it is the physical appearance that announces the difference but when the hands are used the difference may be announced through altered function and performance. Perhaps a different way of using the hands, a different way of performing a task, an inability to perform a task, or even an expression of pain when attempting to use the hands. Mary, whose father has rheumatoid arthritis, describes one such announcement of difference.

The earliest memory I have of my Dad is when he used to pull jellybeans out of the sky for us. He'd have them hidden up his sleeve. We'd say, "there's one" and point them out and he would pluck them out of the sky with his hand. I guess I'm really aware of how different his hands are now. Sometimes when I'm sitting with my feet on the couch he will tickle my feet. Because he doesn't have any movement it's a different feeling to what you would get with full movement, also when he touches me on the arm, it's different, it's not a normal sort of touch. It's hard to describe really. It's almost like somebody with a fake hand or something, it's kind of different (Mary, 1:24).

Mary describes the difference in the feel of her father's touch as he tickles her feet or touches her arm. The feel of being touched by the hand ravaged by rheumatoid arthritis has changed, it feels different "almost like a fake hand". The stillness of the touch accentuates the difference. What is it like to touch with hands like these? Mary poignantly contrasts the hands of her father today with her early memories of the 'magic' those hands once performed. Touch is an important function of the hands but in the always-thereness of living with rheumatoid arthritis the experience of touching and being touched is changed.

The handshake

Just as the experience of the touch of her father's hands announces their difference to Mary, difference can be announced for people with rheumatoid arthritis when others touch them on their hands.

Heidegger reminds us that “the hand extends itself, and receives its own welcome in the hands of others” (1951/1993, p. 381). Using the hands in greeting, in welcome, is an integral part of New Zealand society. There is some variation amongst different cultural groups but in most instances an accepted manner of greeting between people involves some form of grasping of the hands. For example, most Pakeha¹⁴, especially men, greet each other by grasping each other by the right hand and shaking them. For Maori the grasping of both hands often occurs in conjunction with a hongī¹⁵. What if the hand extending itself in welcome is the hand of someone with rheumatoid arthritis? What welcome does it receive? Consider the following story from Jim, whose hands are affected by rheumatoid arthritis but the visible changes are, as yet, only subtle.

I hate handshakes. Hate them, absolutely hate them. Because people squeeze you too tight and it hurts. In my line of work it is hard to avoid them, but I try not to shake hands. When I do I'm just careful, I brace my hand and then I try and pull my hand away quite quickly. Some people, men obviously, have horrendous handshakes and they seem to think that the harder they squeeze you, the more friendly it is. We have got one friend, an older bloke, who just about breaks a normal person's hand and I just refuse to shake his hand. But I sometimes worry that people might think I'm a bit funny giving a wee limp handshake. Close friends might quite often just give me a tap on the back or something like that or if they do shake my hand it's just a nice soft one (Jim, 1:20).

Jim finds handshakes extremely painful but difficult to avoid because of his gender and his work situation where the shaking of hands is the accepted norm. He experiences the robust squeeze of the hand that is considered “*more friendly*” as anything but friendly. We do not normally expect something offered in friendship to “*send [us] through the roof*” in pain. In living with rheumatoid arthritis the meaning of a handshake is transformed from a widely accepted form of greeting, which often carries little

¹⁴ A New Zealander of non-Maori descent, usually Caucasian.

¹⁵ The pressing of noses together as a greeting.

significance in what it communicates. In its transformation it becomes something to be endured, something to be avoided, or even something to be feared. When the hand of a person with rheumatoid arthritis “extends itself, and receives its own welcome in the hands of others” (Heidegger, 1951/1993, p. 381) the welcome it receives is often a welcome clothed in pain.

What of the other person faced with welcoming the hand ravaged by rheumatoid arthritis into their hand? How might they experience the difference and distance that the meeting of two hands may announce? Danni, whose mother has rheumatoid arthritis, has witnessed numerous episodes where her mother is expected to shake hands:

I think sometimes she finds it hard when someone offers their hand for shaking, she gets a little bit embarrassed. Sometimes she will shake it but other times she will say something like “My hands aren’t really shakeable”, she will make a joke. I think she is not actually embarrassed for herself, she is embarrassed for them, for their reaction when they suddenly realise that her hands aren’t normal. It’s as if they’re thinking ‘How am I going to shake that?’ ‘What do I do?’ ‘Am I going to hurt her?’ They are a bit scared. People are scared to touch her, because they might hurt her (Danni, 1:24).

Danni suggests that her mother, whose hands are visibly ravaged by rheumatoid arthritis gets a “*little embarrassed*” when faced with extending her hand in greeting. Embarrassed not so much for herself but for the discomfort of those confronted with the difference her hands disclose. Perhaps in her embarrassment, Danni’s mother is showing concern for others just as they are perhaps showing concern for her. Concern for others, Heidegger suggests, is fundamental to human existence (1927/1962, p. 57). Danni continues:

I remember one man who went to shake her hand and handled it really well. He went to say, “Oh pleased to meet you” and she put her hand up and said “Oh well you can’t really shake my hand.” He said, “Oh that’s all right” and just took her hand with both of his hands and said, “I’ll just go like this.” He gently held her hand and kissed it. It was a really warm gesture; it was really neat. I think she must have felt like she was a queen, it was so well done. I remember the look on her face (Danni, 1:25).

Danni recalls a time when the difference in her mother’s hands was met with gentleness and sincerity when one man, faced with the ‘unshakeable’ hand, gently received it into his own two hands and touched it with a kiss. Of what did this gesture speak? There is a sense of solicitous concern, of bridging the abyss of difference, of leaving both people

feeling good about their 'self'. Could it be that in the difference announced by the hands there is the possibility of creating a new language of greeting through new actions?

The calling hands

The characteristic changes in the hands of a person with rheumatoid arthritis are widely recognised. Although the changes may not always be attributed to the effects of the disease the fact that the hands are different and that there is 'something wrong' could be ignored by few. People with rheumatoid arthritis, who do not for the most part like drawing attention to their hands, find somewhat paradoxically that there are times when recognition or announcement of the difference is useful. In the next story Jill provides an example.

Sometimes it's an advantage having a deformity. You don't like having deformities, but now and again it is an advantage. If I'm flying alone I know I can't pull a suitcase off the luggage carousel so I try and position myself next to a nice strong looking gentleman. I position myself so I can see in advance that my bag is coming up and I just have to show my hands and say "I've got arthritis could you please lift my case" (Jill, 2:32).

Although Jill does not like having a visible "deformity", there are times when the difference announced by her hands can be an advantage, especially when seeking assistance to do something that she herself can no longer do. In not hiding her hands, Jill is showing her rheumatoid arthritis. She is showing herself as being-in-the-world with rheumatoid arthritis. In showing herself in this way Jill is facing the limited possibilities of the situation. She knows she cannot remove the suitcase from the carousel, she knows her hands cannot perform this task, she knows that the suitcase will continue to go round and round unless she seeks help. In showing her hands Jill is finding advantage in the visible deformity of the hands. In showing her hands, the hands are calling forth help, they are calling forth care.

Conclusion

The characteristic changes in the hands of those who have rheumatoid arthritis announce the disease in numerous ways, both personal and public. The announcement of difference portrayed by the hands means the disease is constantly 'on show'. The hands that announce the disease draw attention to the differences and distance between those who do and those who do not have rheumatoid arthritis.

The hands engage us in our everyday living, and for the most part the use of our hands is taken-for-granted. Much of our contact with things and with others in our world is through our hands. As Heidegger suggests, “the hand does not only grasp and catch, or push and pull. The hand reaches and extends, receives and welcomes The hand holds. The hand carries. The hand designs and signs...” (1951/1993, p. 381). It is as if the hands are the meeting place of ‘self’ and ‘world’, and ‘self’ and ‘other’. The hand engages us in our everyday way of being-in-the-world and enables the crafting of our lives. Perhaps the essence of being human is in the hands.

In the presence of rheumatoid arthritis the hands are altered, their appearance announcing difference and their use no longer taken-for-granted. It is as if in the presence of rheumatoid arthritis the ‘handiness’ of the hand is taken away. To take away the handiness of the hand is perhaps to take away from the taken-for-grantedness of being human. The hands remain the meeting place of self and world, and self and other but the nature of the meeting is changed forever in the always-thereness of living with rheumatoid arthritis.

As an introduction to the interpretation of the phenomenon of ‘living with rheumatoid arthritis’, this chapter has focused on the stories about ‘the hands’ of those who have rheumatoid arthritis and the role that they have in announcing the disease to the person with rheumatoid arthritis and to others. It has also introduced some of the ideas that are carried forward and built on in the following three data chapters. The next chapter begins to uncover the hiddenness of the everyday practical world of those who live with rheumatoid arthritis and explores the impact of living with a disease-ravaged body.

CHAPTER SIX: The Everydayness of Living with a Disease-ravaged Body

The body is the vehicle of being in the world, and having a body is, for a living creature, to be involved [involved] in a definite environment, to identify oneself with certain projects and be continually committed to them (Merleau-Ponty, 1966, p. 82).

If the body is the vehicle of being-in-the-world what happens when the body changes, when it no longer functions as it once did? Just as the hand of a person with rheumatoid arthritis needs to find a new way of being-in-the-world, so to does the whole dynamic interconnected body. One's involvement with the environment does not cease with disability but it is possibly forever changed especially when the disability is as irrevocable as is the disability of rheumatoid arthritis.

For the person who has the disease, rheumatoid arthritis provides a constant challenge to everyday activities. Living with pain, with fatigue, and with joints that no longer function as they once did alters the person's involvement with their environment, with their world. Everyday tasks, taken-for-granted by most people, challenge the person with rheumatoid arthritis. For example, showering can be energy sapping and pain producing, requiring ingenuity and increased time to complete the task, while dressing requires planning and forethought as to how to put on different items of clothing as well as to what one wears. Many of these everyday activities may on their own seem unimportant. Yet, the cumulative picture is somewhat different. Many little things add up. When every small task requires more energy, more pain, more striving and more time, then simply getting through the day can sometimes take more than the person has to give. Consider Tony's description of his wife's everyday challenge of living with rheumatoid arthritis.

Most of us go through life; most well people go through life and very occasionally we might utilise 80% or 90% of our capability. But I look at my wife and to get through a day, day in day out, she doesn't do much, but it actually takes 99% of her capability, or even 101% of it often, and she has done that for so long. If you were dishing out awards or gold medals, it's people like my wife who, much more so than most of us who are well people, truly deserve the prizes. I'm totally in awe of the effort that she has to put in to living (Tony, 1:5).

Tony tells us he is "in awe" of his wife's ability to get through the day. He compares her efforts with those of 'well' people and recognises that for her to achieve a few of the

everyday tasks taken-for-granted by most of us requires an almost Herculean effort. For her to attend to the everyday tasks of bathing, dressing, toileting and a little food preparation takes much of the energy and time that she has to give. Often there is insufficient time or energy to do more than that.

Merleau-Ponty reminds us of the “I” within us all that is “committed to a certain physical or inter-human world, who continues to tend towards his [sic] world despite handicaps...” (1966, p. 81). How does a person like Tony’s wife, whose body is ravaged by rheumatoid arthritis, continue to tend towards their world? How is the achievement of everyday tasks affected by the presence of rheumatoid arthritis? What does it mean to live with a disease-ravaged body?

The focus of this chapter is to begin to uncover the hiddenness of the everyday practical world of living with rheumatoid arthritis. It explores the impact of living with a disease-ravaged body. Because of the emphasis on physicality, the experiences of those who have rheumatoid arthritis take primacy in this chapter. However, the experiences of other participants, the partners and the adult children, are at times interwoven to provide further insights and understandings. The everydayness shows the taken-for-granted differences that are announced when something happens. Something could be exacerbation of the disease, a ‘bad’ day, leaving home, experiencing pain, or trying to do all the things one wants or needs to do. In the everydayness we see how those who live with rheumatoid arthritis remain “committed to a certain physical or inter-human world” and “continue to tend toward [that] world despite [the handicap of rheumatoid arthritis]” (Merleau-Ponty, 1966, p. 81).

Practical world

What is the world of the everydayness? Heidegger would suggest that the world of the everydayness is the practical world. The practical world is the world of everyday activity in which, proximally and for the most part, Dasein dwells (1927/1962, p. 370). It is the world that is most often covered over and taken-for-granted. In the practical world we use things, are concerned with things, insofar as they help us achieve our goals or the purposes of our activities. It is the instrumental functioning of the thing, and not its perceptual properties, which are of concern in the practical world. Perceptual properties are the concern of the theoretical world. Often we do not specifically notice

the object or thing we are using as a 'thing' in itself, because our concern is with the purpose of an activity. Heidegger's example of a hammer is useful in illustrating this point. In hammering a nail, we do not notice the specific perceptual characteristics of the hammer we are using. Our attention, our concern, is focused on getting the nail into the wood, the work we require of the hammer. In familiar everyday surroundings an object, such as the hammer, "withdraws from view and serves its instrumental function invisibly" (Hall, 1993, p. 128), it is taken-for-granted. This withdrawal from view and the invisibility of objects in the practical world is encapsulated in Heidegger's notion of "ready-to-hand" which is discussed further on pages 94-101.

Heidegger suggests that the practical world, in which we proximally and for the most part find ourselves, provides the fundamental basis from which the theoretical world can be encountered (1927/1962, p. 87). In the breakdown of the practical world, we see the network of relations in which the instrumental functioning is embedded. In breakdown, the network of relations comes into view (Hall, 1993, p. 127). For example, if the hammer breaks or is lost the hammer is experienced as unready-to-hand (Heidegger, 1927/1962, p. 55), and we 'look around' for something else that can be used for the purpose. The focus of the looking around in this instance remains the purpose, or the "for the sake of which" (Heidegger, 1927/1962, p. 87), that we want to use the hammer, not the hammer itself. We are looking around for something or somehow to get the nail into the wood. Heidegger refers to looking around in this way as "circumspection"(p. 73). Circumspection is contrasted to the objective 'just looking' that occurs in the theoretical world as for example, in the practice of science. In the practice of science, a theoretical standpoint is often required for the achievement of its purpose.

How can this notion of the practical world help in uncovering the phenomenon of 'living with rheumatoid arthritis'? Exploration of the practical world of those who live with rheumatoid arthritis, in particular the breakdown of that world uncovers more of the phenomenon. What does the data show of the practical world, of the everydayness? What is shown in the breakdown of the practical world? What is shown in the breakdown of the disease-ravaged body?

Everydayness and the ready-to-hand

In the following story, Rosie, who has had rheumatoid arthritis for more than thirty years, shares with us a little of what it is like for her to live with the everydayness of a disease ravaged body.

I just relax as much as I can and try to forget [the pain]. I try to put something in my mind that will take me away from the pain. I go over my adventures, just something that will keep me busy and take me away from the pain, take me away from my body, my scaffolding as I call it. I see my scaffolding as being different from me. I always say [my body] is my scaffolding. It's not me. It's just my bits and pieces, the things that hold me together. I haven't always had this sort of picture. I think it's come since I've adjusted more to the RA. I suppose in the last 20 years (Rosie, 1:19).

This story begins with an insight into a strategy that this woman uses in living with the pain of her rheumatoid arthritis. In telling the story, Rosie describes using visualisation to draw her focus away from her body, her “scaffold”. In using the analogy between her body and a “scaffold” she seems to separate her painful body from the ‘real’ her. She continues:

My scaffold, that's my outside. Well that's not really me all those aches. My arms and my legs are not me... this is me, this part here [pointing to her heart]. I always feel that my brain and my heart are the essential me, and these [indicating arms and legs] are the things I have to walk around on or do things with, they are just my scaffold. When I want to walk, I have to use the legs that don't want to walk very well. I have it in my brain that I am going to get out of bed and walk down the hallway, and then I get up and realise I can't do it. Or I think, 'Right I'll do this' and find I can't do it. The real me can do it. But the things I've got to do it with won't do it. Sometimes I am lying in bed thinking I will be able to get out of bed and walk down the hallway. But then I can't even get up off the bed and I come down to earth with a big plonk when I realise that I can't do it. I have a mental picture of being able to do something. It is only a mental picture because I can't remember really what it's like. I can't remember what it's like to run. My body can't remember what it's like. I'm a free spirit in my brain. I'm going to do all these wonderful things. My scaffold is the bits that prop me up really. The essential part is here on the inside. Unfortunately, the scaffolding has to be around the building, doesn't it? The building is my essential part. So really one can't manage without the other. But my scaffolding is not very good (Rosie, 2:25-26).

It would seem that Rosie no longer experiences her body in a taken-for-granted way. With every movement Rosie is reminded of the changes in her body, the effects the disease has had on its appearance and its function. Yet, there is a part of her that does

not acknowledge that change, the free spirit that sees her running or effortlessly getting up in the morning. For Rosie, the 'real' her, the 'essential part', the 'I' of Merleau-Ponty, is free of the confines of her disease-ravaged body. There is an interrelatedness between the "*scaffold*" and the "*essential part*" as "*one can't manage without the other*". The "*scaffold*" cannot be managed without even though it no longer functions as it once did, or as Rosie would like it to. As she says, "*When I want to walk I have to use the legs that don't want to walk very well*". Sometimes Rosie develops a mental picture of being able to do something free from the constraints of the "*scaffold*". However, she also tells us that she cannot really remember what it is like to run, to have a body free from her scaffold. There seems to be a difference between a 'mental picture' and 'remembering'.

The Collins dictionary states that a scaffold is a "temporary metal or wooden framework that is used to support workmen and materials during the erection, repair, etc. of a building or construction" (1998, p. 1372). Rosie draws an analogy between her "*essential part*" as a building being supported by her arms and legs (the things she has to walk around on or do things with), her scaffold. The body, the arms and legs in particular, seems to be objectified; it feels foreign, like a thing. Sadly for Rosie, her scaffold is not a temporary structure; she lives with her scaffold constantly as she attends to her everyday activities in the practical world. Living with joints that no longer function as they once did presents challenges to the everyday way of doing things for this woman. Heidegger's notion of the 'ready-to-hand' provides a useful lens with which to interpret this story.

The smooth functioning of our body is, for most people, taken-for-granted, it goes unnoticed, it is something that occurs almost automatically. "In ordinary practical activity we make use of things but do not typically notice or attend to them" (Hall, 1993, p. 126), our attention being directed to the work we want to achieve (for example, walking down the hallway). In the process of completing the task our attention is drawn, not to the 'things' involved in the activity but to the 'doing' of the activity. As Heidegger says:

That with which our everyday dealings proximally dwell is not the tools themselves. On the contrary, that with which we concern ourselves primarily is the work (1927/1962, p. 69).

To return to Heidegger's example of a hammer, when we use a hammer our attention is drawn not to the hammer itself but to the task we want to complete, the hammering in of a nail. The hammer is ready-to-hand and as such is not really noticed.

The peculiarity of what is proximally ready-to-hand is that, in its readiness to hand, it must as it were, withdraw in order to be ready-to-hand quite authentically (Heidegger, 1927/1962, p. 69).

What if the handle on the hammer breaks? It is no longer suitable for its intended activity (nail driving) and our attention is drawn to it, it shows itself to us and is no longer taken-for-granted. It is now 'unready-to-hand' (Heidegger, 1927/1962, p. 73). To complete the nail driving we must find a substitute for the hammer.

Heidegger applies the notion of ready-to-hand to 'things', equipment (such as the hammer), that we use 'in order to' complete particular tasks (Heidegger, 1927/1962, p. 69). Is the body a tool, a thing? The body is not usually considered a 'thing' but could it be that when it cannot be used in the usual way attention is drawn to it as if it were a 'thing'? Rosie speaks of her "*scaffold*", of the "*bits and pieces*" that "*hold [her] together*". Other participants when referring to their bodies spoke of "*the shoulder*", "*the feet*", "*the knee*" and not "*my shoulder*", "*my feet*", "*my knee*". There is a sense that the body when ravaged by rheumatoid arthritis is objectified and can at times be experienced as if it were a 'thing'. Extending Heidegger's notion of ready-to-hand can help in interpreting Rosie's story and in further understanding the phenomenon of 'living with rheumatoid arthritis'.

In Rosie's story, her limbs become 'things', her "*scaffold, just [her] bits and pieces, the things that hold [her] together*". They are no longer experienced as ready-to-hand, they become unready-to-hand. As Rosie's joints have succumbed to ravages of rheumatoid arthritis they have become less able to do what she wants or expects them to do. They have become unready-to-hand, conspicuous, their functioning no longer taken-for-granted. The previously almost-automatic act of getting out of bed and walking down the hallway is no longer inconspicuous. Rosie's concern is no longer primarily with the work for which she wants to use her body. Rosie's body no longer "withdraws in order to be ready-to-hand" (Heidegger, 1927/1962, p. 69). Her body itself is now a concern alongside the concern for the work for which she wants to use her body. Rosie's whole body is experienced as unready-to-hand with the realisation that she cannot leap out of

bed and run down the corridor, that her joints will not work as they once did no matter how willing the mind might be. In living with rheumatoid arthritis the smooth functioning of the body can no longer be assumed or taken-for-granted.

Circumspective looking

Not only is the body no longer experienced as ready-to-hand by those who live with rheumatoid arthritis, there is a myriad of ‘things’ that are also no longer experienced as ready-to-hand. There are little things such as toothbrushes, car keys, and kitchen utensils. There are larger things such as clothes, shoes, cars, and public transport. When something is experienced as unready-to-hand, the person may adapt the way they do something by using other joints. For example, Sue, who has had rheumatoid arthritis for more than fifteen years, uses her forearm instead of her hands to squeeze such things as shampoo, toothpaste and dishwashing liquid out of their containers. Sometimes everyday things designed for one purpose are used in a different way, as Sue outlines:

I can't reach right down for washing my feet. I use a small towel as a flannel so that I can actually hold it, and pull it up between my toes. I drop the soap down onto the flannel, and then I put my feet over it and scrub them like that [indicates rubbing her foot on the floor]. Most things I do differently. I pick up things differently or do things a little bit different to what you would normally. I have a toy broom that I can reach up to dust with and those kinds of things (Sue, 2:35).

Sue describes using a towel as flannel and a toy broom for a duster. She does this in response to experiencing as unready-to-hand the equipment ‘normally’ used for the tasks of washing feet and dusting. A flannel is too small and a cloth duster requires too much bending or stretching, Sue experiences both as unready-to-hand. Circumspection is required to draw back from the unready-to-hand to the ready-to-hand. As Sue circumspectively ‘looks around’ she focuses not on the things themselves (the face flannel and the cloth duster) but on the purpose for which, the “for sake of which” (Heidegger, 1927/1962, p. 87), she needs these things (washing her feet, dusting). In circumspectively ‘looking around’ she may ask ‘how can I wash my feet?’ and ‘how can I manage the dusting?’

People living with rheumatoid arthritis become very skilled at circumspective looking around as they live with the unreadiness-to-hand of their everyday world. Liz, whose husband has had rheumatoid arthritis for more than twenty years, has become very adept

at finding solutions to the numerous problems her husband experiences in his everyday activities. As she tells us:

Whatever happens we find a solution. You just have to do it as it comes up, because you can't think ahead, you just have to do it as it gets there. [For example], my husband wears shin pads in the summer when he's wearing shorts. I've made them from a piece of thick upholstery vinyl with a piece of very thin foam plastic, because everything he drops, he drops it on to his shins and his skin is so thin from all the Prednisone he's had. Even the cat climbs up his legs and puts its claws in, not that it means to. His legs always have little sores all over them. So he puts the pads in his long socks and he has worn those two summers now and we have kept his shins from being so damaged (Liz, 1:15).

Liz speaks of always finding a solution to problems as they arise. Some things can be planned for. However, the inherent invisibility of things experienced as ready-to-hand means that more often than not “*you can't think ahead*”. It is only when things have disclosed themselves as unready-to-hand that circumspective looking begins. Liz tells of making shin pads for her husband to provide protection for his shins while he “*potters in the garage and garden*”. In this instance the unreadiness-to-hand does not disclose itself through something that does not work, as with the flannel which is too small or the broken hammer. Instead the unreadiness-to-hand is disclosed when something is recognised to be missing. Liz recognised that ‘some thing’ was missing, something to provide protection for her husband’s shins. Liz, in circumspectively looking around, identified, and made, something for the purpose of providing protection for her husband’s shins.

Heidegger suggests there are three ways in which what “is ready-to-hand loses its readiness-to-hand” (1927/1962, p. 74), conspicuousness, obtrusiveness, and obstinacy. For Liz something with which to protect her husband’s shins was missing, it was noticed as missing. Similarly, if we have no implement with which to hammer we notice the hammer as missing. When we miss something in this way it amounts to coming across it as obtrusively unready-to-hand, “the ready-to-hand enters the mode of obtrusiveness” (Heidegger, 1927/1962, p. 73). This contrasts to the conspicuousness of the unready-to-hand when things (joints, face-flannels) no longer work for the purpose we expect of them.

In drawing back from the unready-to-hand to the ready-to-hand circumspection leads to new or different ways of doing something. With time, this new way of doing something

may in itself become taken-for-granted by those who live with rheumatoid arthritis. This transition is illustrated in the next story that tells of an intimate aspect of everyday life for Primrose, a woman who has lived with rheumatoid arthritis for more than thirty years.

From the unready-to-hand to ready-to-hand

Primrose describes what is an everyday activity for most of us and something about which we do not usually even stop to think. That is wiping her bottom after using the toilet. As she describes it:

Because of my wrists and shoulders, I have trouble with my toileting. To wipe myself I manage by making a sort of rope out of toilet paper. I pull a lot [of toilet paper] off the roll, you need a lot. I get about four thicknesses, and then I fold it over a few times, so that I can get front and back. I pull, to and fro. According to what my bowel movement has been like, say for instance I had a loose motion then I'll do it twice to make sure. But a lot of times I don't need to do it twice. It's not 100% efficient, so from time to time I get a bit of a sore bottom. It's not so much not being able to reach because once I have got the bit of rope, I do my best to go up and down both sides, but I can't see. I just don't know whether I'm right or wrong. One of the things I have to be careful with is that to [use the rope] I have to stand away from the toilet in order to get the rope between my legs. At the same time, I have to bend forward and I'm pretty careful about bending forward. So I stand near the wall and I can rest my head against the door if I need to. I suppose I'm used to it now (Primrose, 2:10).

In this story Primrose describes how she has adapted her way of doing a particular task (wiping her bottom) to accommodate the changes in her body. Her neck, shoulders, wrists, and hands have all been ravaged by rheumatoid arthritis, their strength and function altered. Performing the intimate task of body hygiene becomes problematic and a different way of doing things is required. A rope is made from the toilet paper, an act in itself not without difficulty for this woman with limited function in her hands. She then stands, moves away from the toilet and bends forward, resting her head on the door for support if needed. She passes the rope between her legs pulling it to and fro, front and back, all the time using joints that no longer work as well as they once did. What previously took a few seconds to perform now takes several minutes. This is a story that tells of private ingenuity and determination. It offers an insight to the difficulties faced by this woman in maintaining independence in the everyday activity of toileting. It also suggests that to a certain extent this new way of doing things, albeit difficult, becomes

taken-for-granted by this woman (“*I suppose I’m used to it now*”) in the everydayness of living with rheumatoid arthritis.

Living with joints that no longer function as they once did presents challenges to the everyday way of doing things for this woman. Primrose reveals her new way of doing things, of accommodating joints that no longer function as they once did. Heidegger’s notions of ready-to-hand and unready-to-hand again provide a useful lens with which to interpret this story (1927/1962). There are numerous things involved in wiping the bottom, such as toilet paper, the layout of the toilet, and the joints involved in preparing for and performing the activity. Over time, Primrose’s joints have become less able to do what she wants them to do. They have become unready-to-hand. The previously simple act of tearing off some toilet paper and attending to her hygiene is no longer possible. Consequently, as in Heidegger’s example of hammering, an alternative is required.

Once joints are damaged by rheumatoid arthritis, their functionality is forever altered. Joint replacement may return some degree of functionality but it is unlikely to restore full function. Unlike Heidegger’s example of hammering, it is not possible for Primrose to seek out a new thing (new joints) to do the task; the alternative is a different way of doing things. We can only guess at the probable gradual process that was involved in the transition from the old way of doing things to the new, at the circumspection required as new possibilities were explored. The new way of doing things involves using things in a different way. The joints are used differently; in fact, the whole body position is altered. The toilet paper becomes a rope, the walls and door used to support the body during the process of wiping. Although this different approach may be difficult, torturous, and time consuming, it in itself has become taken-for-granted, part of the everydayness of being-in-the-world with rheumatoid arthritis. The ‘tools’ (joints, paper, and bathroom) are ready-to-hand and the concern is with the ‘work’ required (wiping the bottom). The process, although “*not 100% efficient*” means that something which in our society is considered private and independently accomplished can remain so for the person who lives with rheumatoid arthritis.

In Primrose’s story we learn of the adapted technique she uses when she is in her own home, in her own bathroom, where she has some control over her environment, where things are for the most part experienced as ready-to-hand. What happens when she is

out of her usual environment? What happens if she is in a toilet where the paper is not easily accessible or toilet area not large enough to accommodate the different body positioning? What if the paper is tissue squares or the roll the type that allows only a small length to be removed at one time? How then can the rope be made? While many of the changes people with rheumatoid arthritis make to the way they do things work well in their home environment being away from home can be problematic.

Everydayness and dwelling

The next story provides an example of the problems that people who have rheumatoid arthritis can encounter on leaving home. Sue, who has had rheumatoid arthritis for more than fifteen years, describes her battles with public toilets.

The way my toilet roll is set up in my bathroom is all right, but if I'm out it can be a problem. Especially if it's one of those toilet rolls, the big industrial ones, that are funnel-shaped and they have a very narrow gap where the paper comes out. Often the end of the paper rolls up, it's not out, and I have a real problem getting to the paper. One time it was particularly bad. I was staying at this motel and the units didn't have toilets in them. In the toilet block, you had to push this knob on the wall, which gave you two minutes in the toilet. The holder was on the left-hand side and the end of the toilet roll had gone up. Because of my fingers I couldn't get my left hand up, to pull the paper down, so I had to use this hand, my right hand. I had my hand stuck up this stupid little funnel thing trying to get the toilet roll down when the lights went out. So my right hand was stuck and I was trying so hard to pull it down, that I actually fell off the toilet. I had half my bottom on the toilet, my knee on the ground. My left hand was useless, and I am trying to get myself up, to get back up on the toilet and it's dark. I had great visions of finding myself stuck in there for the night, but I finally managed to get up.

I also have problems with the little boxes of toilet tissue, especially if someone has left the empty box in there, and I have to try and pull that out before I can get to the next one. Well that is just awful. I am in there for such a long time. I'm sure people must wonder what I'm up to because I'm pulling and shoving at it. Usually I yell out to someone "Is there anybody there?" and I say to them, "Look the box is stuck, can you please pass me some toilet paper under the door". I feel like a right ninny too. Another problem I have is that when my hips are very sore, I have that drop on to the toilet. You hear this thud when I'm in there. I can't get down to the seat and so I drop. At home, I have quite a high toilet with an extra strong seat and if I'm really bad I'll get the raised toilet seat out from under the house. But if I'm out somewhere and the toilet is any lower than my one is at home I am really in trouble. Some places have really quite low toilets and I actually drop to the seat, that last little distance. It's just the same as a low settee, I drop down and then getting off is also a problem. I have to rock backwards and forwards about six times and then on the last rock I lunge myself

forward and get off. I have a rail at home to pull myself up but you don't usually see them when you're out. I broke a toilet seat once. We were staying in a motel and by the end of the fourth day it cracked from me just dropping on it, that final little drop (Sue, 2:32-33, 35-37).

In this story, Sue describes her experiences of using public toilets. The toilet paper is experienced as unready-to-hand, some times because the end of the roll is held tight by its funnel-shaped container that is impervious to Sue's rheumatoid arthritis-ravaged hands. On other occasions those same hands are confronted with an empty tissue box which is often resistant to Sue's attempts to access the new box which awaits the removal of the empty one before it drops into position. If Sue seeks help by asking someone to pass her some toilet paper, she feels "*like a right ninny*". There is perhaps humiliation in seeking help from a stranger for such a private task. Along with the unreadiness-to-hand of the toilet paper, Sue often finds the height of the toilet and the strength of toilet seats to be unsuitable in accommodating her painful stiffened joints. They too are unready-to-hand. Sue contrasts the use of public toilets with her experience at home, where she, like Primrose, is able to manipulate the environment to accommodate her specific needs. Her toilet is higher than standard and it has a reinforced seat to accommodate "*the drop*". The toilet roll is easily accessible and a handrail fitted that Sue uses to pull herself up from the toilet. If Sue is experiencing a 'bad patch' when her knees and hips are particularly painful, she reduces "*the drop*" further by temporarily adding a raised toilet seat. In manipulating the environment, Sue is able to make ready-to-hand what she needs to perform the task of toileting. In her own home, Sue experiences the things (toilet, toilet paper) required to perform the task of toileting in a ready-to-hand way. As Heidegger reminds us, when things are ready-to-hand, they withdraw from our notice, our focus or concern is instead on the task being completed (1927/1962, p. 69).

The experiences of Sue and Primrose are not isolated examples. Many other participants who have rheumatoid arthritis spoke of the difficulties they face in completing many of the everyday tasks taken-for-granted by most people, of which toileting is but one example. Toileting is a basic function necessarily performed a number of times each day. In the familiar environment of their own home where things are experienced as ready-to-hand some of the difficulties faced by the person with rheumatoid arthritis may themselves become to some extent taken-for-granted. However, the difficulties are often

announced anew when these people are away from home. As Rosie also tells us *“Toilets control a lot of my life when I’m not at home. I’m always thinking about where a suitable toilet might be. When I’m out I’d rather come home than try public toilets”* (Rosie, 1:15).

Heidegger tells us “dwelling is the essence of “being-in-the-world”” (1947/1993, p. 260). Dwelling in this sense is more than a spatial relation and refers to the “manner in which mortals are on the earth” (1954/1993, p. 350). Heidegger speaks of the “domain of our dwelling” (1954/1993, p. 347) which includes ‘dwelling places’, such as buildings, as well as other places and situations in which we feel ‘at home’. Heidegger provides an example, “The truck driver is at home on the highway, but he does not have his lodgings there” (1954/1993, p. 147). Dwelling, the sense of feeling at-home, is dependent on our way of being-in-the-world. For the person who lives with rheumatoid arthritis, who is in-the-world with rheumatoid arthritis, ‘dwelling’ is particularly significant. Many participants, like Primrose and Sue, are able to manipulate many aspects of the environment in their own homes to the extent that they feel at-home. Many of the everyday difficulties faced by those living with rheumatoid arthritis are covered over in the familiarity of home where things are set up ready-to-hand. In the familiarity of their own home the difficulties may become taken-for-granted. However, on leaving home they experience a feeling of not-at-homeness. It is a not-at-homeness that goes beyond the spatial relation of being in their own home. On leaving home, they are no longer in-the-world in a familiar way. Away from home the unreadiness-to-hand of their world is accentuated, it shows itself, as such things as public toilets are experienced as unready-to-hand. It is as if being-in-the-world with rheumatoid arthritis matters less when at home.

Experiencing the body as unready-to-hand, of coming to experience the difficulties of doing things in a new ready-to-hand way, and of dwelling in a world that often swings between the ready-to-hand and the unready-to-hand are constitutive of the everydayness of living with rheumatoid arthritis. However, there is a further experience that constitutes and is constituted by all these and more. That is the experience of pain.

The everydayness of pain

There is the remarkable protected state in which we feel ourselves safely enfolded so that we are able, lightly and effortlessly, to embrace our desire

for active participation in life. But ... we [also] know the oppressive weight of things which bear down on us, dragging us downwards ... (Gadamer, 1993/1996, p 75).

Gadamer discusses the play between health and illness. He contrasts our ability as humans, when healthy and full of confidence, to “lightly and effortlessly embrace our desire for active participation in life” with the “oppressive weight” that can come with the experience of illness, “things that bear down on us” (ibid.). Gadamer seems to offer a way of thinking about the experience of living with rheumatoid arthritis in terms of what it is in the everyday lives of those who have the disease that reduces their ability to “lightly and effortlessly ... embrace [a] desire for active participation in life” (ibid.). It seems that many of the well-documented signs and symptoms of rheumatoid arthritis, such as stiffness, fatigue, joint damage and the associated decrease in function, contribute to reducing the ability of those who have the disease to actively participate in life. Yet, for people who live with a diagnosis of rheumatoid arthritis one of the most talked of “things” that bear down on them as part of the illness experience is pain. Pain is something constantly experienced in the everydayness of living with rheumatoid arthritis by those who have the disease. Pain influences and is influenced by their participation in the world, by their “involvement in a definite environment” and their identification with and commitment to certain projects (Merleau-Ponty, 1966, p. 82). How do these people experience pain? How does the pain experience influence the everydayness of their lives? What is the pain like?

What is the pain like? ... How would I describe the pain? ... Painful, every move that you make, everything you do ... How do you describe pain? ... [long pause] ... How do you describe pain? I don't know ... It is painful, I know that much (Max, 1:15).

The language of pain

Participants used a range of words to describe their pain. Some of these words are presented:

Pain
Nagging, throbbing bruised
Sharp, sore and ripping.
A deep heavy draggingness
Of aches, stinging and screaming.
Of broken glass, or not,
Hard punches, fracture like
And extreme.

*An orchestration, thumping and continuous,
 Sharp, softer, achy
 Fiery, horrendous, busy and not fleeting
 Taking over, deep inside.
 Dull heavy, toothache-like, nagging, dragging
 Weighing you down
 Deep
 Deep inside
 Screaming, like being
 S-t-r-e-t-c-h-e-d until you've torn*

These words come from participants' stories. Stories shared by those who have rheumatoid arthritis and experience first hand the pain of the disease. These people struggle to find the words to describe their pain. They search for words that speak of what the pain is like, and sometimes what it is not like. Gadamer reminds us of the "coming-into-language of the thing itself" (1960/1989, p. 378), that we cannot think about any thing without words forming in our minds. What if the words that come to mind are inadequate in showing the thing (the pain) itself? The language of pain seems to be more than the words used, or not used, in speaking of pain. When the participants struggle to find the words to describe their pain it is not so much that the pain has no language, it is that the difficulty comes in the 'wording' of the pain. The difficulty in finding words to express the experience of pain does not diminish their knowing of pain. The difficulty comes in expressing that knowing. Heidegger (1959/1993) reminds us that language is more than speaking and hearing, wording and listening. Language speaks by saying, by showing, that which is there to be said. However, "saying and speaking are not identical. One can speak, speak endlessly, and it may say nothing at all. As opposed to that, one can be silent, not speak at all, and in not speaking say a great deal" (1959/1993, p. 408). The wording of the participants' pain shows us something of their pain (and an appearance of the phenomenon of 'living with rheumatoid arthritis'), but we also need to look beyond the words to see what the silences and the 'non-wording' are showing. Perhaps we can consider the words as signs pointing us in the direction of an understanding of pain yet not showing us all the possibilities. What is it that remains hidden? Perhaps some of what is hidden is beyond the verbalisation of the experience but the showing is there in the tears, the frustration and the actions of the pain (for example, reaching for the pill bottle or nurturing the joint).

Living-with-pain

What does the data show of this pain? Consider Margaret's story.

I do have pain all the time; it certainly isn't the pain which I am aware of all the time. If I sit down and somebody said "Are you in pain?" I might say "No" and then I'll think 'Well actually yes those bits do hurt', but it is all relative. I will always be aware of the bit that is hurting the most and if somebody really makes me think I will realise that other bits aren't too good either (Margaret, 3:18).

Margaret, who has lived with rheumatoid arthritis for more than fifteen years, tells us she has pain constantly, although it is often pain of which for the most part she is unaware. It is only when her attention is drawn to it that she becomes aware of the pain. It is as if this pain has become taken-for-granted, something that is just 'there' and a reality of being-in-the-world with rheumatoid arthritis. It is this experience of pain which is encapsulated in the notion of living-with-pain (Roy, 1995). Living-with-pain is the embodied experience of pain, the pain that is part of the taken-for-granted existence for people who have rheumatoid arthritis.

Living-with-pain means the pain is in the background. The person with rheumatoid arthritis is able to actively participate in life, even though this participation may be limited by other factors associated with the disease. There is an acceptance of a certain level of pain and, as Lily tells us, "*You learn to put pain aside when you've got it all the time. Because if you don't it can stop you doing what you need to do and what you want to do*" (1:22). When the pain is backgrounded other things matter more than the pain matters, other aspects of life are the main concern of the person living-with the pain of rheumatoid arthritis. Gadamer suggests that as "human beings we possess this awesome capacity to give ourselves over to something completely and to allow what is 'other' to be there in its own right" (Gadamer, 1993/1996, p. 74). It would seem that when the pain is backgrounded it is possible to be concerned with or focus on other things. The pain is still there (the 'other' in its own right) but it is not the primary focus of attention at that time, it is just there. In living-with-pain it is possible for the people who have rheumatoid arthritis to 'give themselves over' to something else.

In Sue's description of her 'everyday pain', which follows, we glimpse an example of the type of pain encapsulated in the notion of living-with-pain.

I wake up in the morning and sometimes I think I've had no sleep at all, because I have had this interrupted sleep all night. I toss and turn because different joints start aching in the night. It's either a knee or a shoulder or something. Then when I first put my feet on the floor, it's hard to describe to people. I suppose it's a bit like that advert on TV where they say it's like having glass in your joints, there is this excruciating pain that I get in my feet before I get them moving. It really is like walking on eggshells or glass; I just sort of go 'ooh, ooh, ooh' all the way to the shower. Then it's a matter of getting my fingers moving and they feel like they have been tied up for hours on end. That's the only way I can think of explaining it. Or if you have been on a long journey, you know what it's like when you have been on a long journey and you haven't had a rest stop and you get out and you have to uncrinkle yourself. That's what I have to do, uncrinkle myself. Then I get on with my normal business, then I go to reach up and I can't reach up, or I go to pick up something and I can't pick it up and then I know that I am having a pretty troublesome day. But they are the normal sort of things that I experience. [The pain] is always there, I am never ever totally pain free. But I do things because I've got to. I've got used to the pain always being there. But it hurts. I just get used to the dull ache; it's part of life for me now anyway. I can't give in to it. It's very easy to think 'Oh I'm not feeling well' and then lay down, but I have to get up and get going, because otherwise I would seize up (Sue, 2:22-23).

Sue describes a pain that disturbs her sleep as it creeps around her body, affecting one joint after another. She endures the pain that comes with stiffness as she “*uncrinkles*” herself each morning. She endures but does not give in to the pain during the day because she does not want to “*seize up*”, possibly adding further to her pain. In contrast to Margaret’s experience of ‘unawareness’, it would seem that Sue is for the most part aware of her pain. However, the presence of pain, the fact that she has pain and will have pain, is taken-for-granted, it is always there, and part of the everydayness of Sue’s life. Alongside this taken-for-grantedness is the tension of needing to push through the pain, to get past it, and to take strategies to stop getting oneself ‘crinkled’ and stiff. It is as if there is a fight against pain, a fight that is part of the everydayness of living-with-the-pain of rheumatoid arthritis. Perhaps in living-with-the-pain the fight itself becomes taken-for-granted.

Working-to-the-pain and working-into-the-pain

Other participants also spoke of strategies they used in living-with-pain. Lily describes one such strategy.

Because of the lessening amount of pressure it takes to produce pain, I can only go to where the pain makes me think 'Oh, I might drop that.' The

number of cups and mugs and plates that have just landed with a clatter on the floor as a result, I just get used to that. It's no use swearing. I do get a bit uptight, if I drop a good crystal bowl. I try to monitor things. When pain is down, the monitor that I have always used is to work to the pain. I can work to the pain for quite a while, but if I work into the pain, I will suffer later (Lily, 1:3-4).

Lily uses the notions of 'working-to-the-pain' and 'working-into-the-pain' as a strategy for monitoring the level of pain and recognising when it is time to listen to the pain, at times moderating her activities. There is a sense that working-to-the-pain and working-into-the-pain are taken-for-granted in the everydayness of Lily's life. There seems to be a fine balance between working-to-the-pain and working-into-the-pain. Living-with-pain means working with this balance. When working-to-the-pain it is as if the pain is an ally going along for the ride. Working-into-the-pain is perhaps moving into enemy territory. Activities are planned in anticipation of the pain that may occur as a consequence of the activities. At times, the benefits of a particular activity might be considered to merit the incursion into enemy territory, to merit the payback of increased pain. In this way, working-into-the-pain, moving into enemy territory, is sometimes a conscious decision. Lily continues:

Sometimes I choose to work into the pain, knowing I will pay the consequences later. For example, on Thursday I chose to go out and clean the windows. It took me most of the day and I knew my arms were going to be grotty at the end of that time, because I had been working into the pain. And even though I took [an anti-inflammatory medication] beforehand I knew I was still going to be sore. But I achieved something on my list; I got the damn job done. There will come a time when I won't be cleaning windows. So I do what I can, while I can, without hopefully being too stupid about it and doing a permanent injury. I've got to weigh up the consequences and weigh up what the results will be and if they are going to be acceptable, then I go ahead and do it. I only work into the pain for a short length of time, a few hours, and I wouldn't do it every day. If it suddenly became an activity that I had to do every day and it was giving me hell, then that is the time I would have to stop and think, no this is not good enough, how can I change this, or who do I get to do it instead (Lily, 2:28).

Lily provides an example of when she would choose to work-into-the-pain. She chose to spend all day cleaning the windows knowing that she would experience the payback of pain. However, in completing the job she experienced the satisfaction of crossing something off the list. Heidegger reminds us of the obstinacy of that which is unready-to-hand (1927/1962, p. 74). Perhaps the dirty windows in their obstinacy called out to

Lily, demanding her attention. She chose to heed the call knowing that the answer involved working-into-the-pain. Making the decision to work-into-the-pain involves weighing up the consequences and results. When weighing up favours the results, then working-into-the pain occurs.

Working-into-the-pain may be the choice of action when the obstinacy of the unready-to-hand discloses itself, as in the example Lily gave us. There are also other reasons as to why someone would choose to work-into-the-pain. Consider Sue's story.

I had a busy day on Saturday. First of all, I had gone with the children to swimming at 6.00 o'clock in the morning and then at half past eight I went and helped with a sausage sizzle as fund-raising for the swimming club. I was there until 2 o'clock and then I helped back at the pool at the stroke clinic. I did the afternoon tea and all that, so it was rather a big day for me. I knew it was going to be tough so I had taken a couple of painkillers in the mid-afternoon to help me through. We didn't get home until after 8 o'clock and then my chest became really painful. I started feeling like when I had broken ribs and I couldn't breathe. It just got slowly worse and worse so I headed to the Emergency Clinic (Sue, 2:2).

Sue recounts the sequence of events that led to a visit to the Emergency Department for treatment following the acute exacerbation of a respiratory condition related to her rheumatoid arthritis. It would seem that Sue made a conscious decision to do what she did on that day. She knew it was going to be busy and she knew it was going to be 'tough'. She even took some analgesics to help her through the day. Sue seems to have made a conscious decision to work-into-the-pain. At the point she made the decision, she could not anticipate fully the implications of that decision. However, she was aware of the possibility of a cost for working-into-the-pain. Sue continues:

You have got to know your limitations. You've got to get the balance right. Nine times out of ten I get it right. But sometimes I miscalculate and overdo it and find myself flat on my back the next day. Sometimes I do more than what I should, and those days I do miscalculate and I have a bad couple of days afterwards. And then sometimes I take a calculated risk (Sue, 2:17).

Sue knows her limitations and strives to find the balance between doing too much and doing what she wants and needs to do. She strives to find the balance between working-to-the-pain and working-into-the-pain. She mostly "gets it right", and occasionally gets it wrong, miscalculates. Then there are other times when she takes a "calculated risk" working-into-the-pain despite knowing that the possibility of "paying for it" is high. Why would Sue choose to work-into-the-pain in this way? As a mother, she cares for

her children, her involvement in the world means being involved with and caring for her children. Perhaps Sue has a need to show other people that she can still do things, such as supporting her children and involving herself in community activities. Perhaps sometimes other things (mothering) matter more than the pain of rheumatoid arthritis.

The notions of working-to-the-pain and working-into-the-pain provide a useful lens in coming to understand something of the everydayness of pain, as well as providing a strategy for those who live-with the pain of rheumatoid arthritis. Listening to and for the pain is part of living-with-pain. Although the taken-for-grantedness of the pain in this sense means that it is in the background, there is the ever-present possibility of the pain disclosing itself further. There is a fine line between living-with-pain (the backgrounding of pain) and the foregrounding of the pain. Recognising when that line is being crossed is something that people seem to come to know as part of living with rheumatoid arthritis. For example, Primrose speaks of “*getting on with what [she] wants to do*”, of ignoring the pain until the line is reached.

I think I cope with [the pain] quite well in that I know it's there, accept it's there, and get on with what I want to do. Obviously, I can't do that when the pain gets up to beyond that level where I can ignore it (Primrose, 1:27).

What happens when the line is crossed, when the pain announces itself anew, when it screams its presence? This foregrounding of the pain is illustrated in a second dimension of the pain experience, being-in-pain (Roy, 1995).

Being-in-pain

Being-in-pain is the dimension of pain when, for a variety of reasons, the pain becomes overwhelming and “*you lose that control of it*” (Margaret, 3:18). Being-in-pain reflects the times when the pain becomes relentless, when it becomes the ‘worst pain’. Being-in-pain reflects the times when the pain may not be the worst pain but contextual influences are such that it is foregrounded and experienced as if it were the worst pain. Being-in-pain is when the person with rheumatoid arthritis again, and again, and again comes to experience “the oppressive weight of [pain] which bears down on [them]” (Gadamer, 1993/1996, p. 75).

What is the worst pain? How is it experienced? Consider Lily's description.

It is like, it's a fiery ripping pain, it's just like a fracture of a bone, like a very bad sprain, it's an extreme pain. At its worst. It really is. It feels as

though you've been stretched until you've torn, until everything is just screaming (Lily, 2:36).

From Lily's story we have a picture of a very acute pain (*fiery, screaming, extreme*) which Lily likens to a bone fracture. Anyone who has suffered a bone fracture can begin to identify with this. However, "*being stretched until you've torn*" is something most of us can only begin to imagine. The phrase suggests a form of torture, of being laid out on a hard platform. Arms and legs then tied individually at the four corners of the platform to winders which are turned, tightening in a vice-like way and tearing at the joints and sinews of the body. As Lily tells us, this intense pain is one part of the overall experience, perhaps the part that is often rather simply labelled 'acute pain'. Lily continues:

Fortunately everything isn't doing that all at once, the rest of your body will be an orchestration of bad aches and swelling and soreness and thumping pain, it can be really quite horrible. When it's like that I take something fairly solid and I go quietly off to bed. (Lily, 2:36)

Lily uses the metaphor of an orchestra to convey the movement of the pain around the various joints in her body. A movement that announces itself in a variety of ways; as an aching pain, a swelling pain, a thumping pain that may be overpowering in its 'horribleness'. One can almost imagine the orchestra's conductor pointing the baton, indicating the turn of a particular joint to 'lead' in the symphony of pain. Meanwhile other joints wait their turn to lead, while softly playing the melody, still contributing their pain to the symphony. When experiencing her worst pain Lily *takes "something fairly solid"* (an analgesic) and goes "*quietly off to bed*".

Other participants also spoke of days when the pain is so bad that they will just go back to bed or withdraw in some way from everyday activities, in effect isolating themselves from others. At times of intense pain, the person with rheumatoid arthritis may find it difficult or even impossible to communicate verbally with others. Sue tells us that there are days when she "*just expects [her family] to know*" when the pain is "*really bad*" (2:13). There are signals for the family to read, as she says, "*If I'm running for the painkillers they know that I'm in trouble, that I can't stand it any more*" (2:13).

Gadamer reminds us of the power of pain to cause us to "withdraw from all external experience of the world and turn us back on ourselves" (1993/1996, p. 75). Could it be

that the effort required to cope with being-in-pain contributes to the withdrawal from others and an inwards focus on the self? Perhaps there is a need to 'be' with the pain, to acknowledge its presence, to face it. To verbalise how bad things are is perhaps just too difficult when being-in-pain dominates one's world.

Sometimes the domination of being-in-pain can be overwhelming. We can glimpse something of the overwhelming domination of being-in-pain in the next story.

RA patients get on with their lives or they top¹⁶ themselves. There is very little in between. It's the desolation. When you get that constant pain all the time and you are not getting the release of rest, because your rest is so interrupted and not just your rest, but your sleep, you do become very unbalanced emotionally and the lack of balance can be critical. I think it starts out as a form of grieving that you are not able to do what you can do and it can get worse and worse. If you haven't got support, either from your family or from your friends and associates, then yes, it can get very close to that wanting to top yourself (Lily, 2:24).

Lily suggests two possibilities of being-in-the-world with rheumatoid arthritis. The first possibility is to 'get on with life', the second to end that life. There is she posits, "very little in between". In the story, we hear of a concoction of things that might inform a decision about which possibility to pursue. There is "that constant pain" (being-in-pain), the unrestful rest, the unsleepful sleep, and the grief of not being able to do things that you feel you should be able to do, all of which contribute to a loss of emotional balance. It would seem that balance is important. When the balance becomes unbalanced there is potential for a downward spiral which, without the safety net of supporting family and friends, may bring one desolately to the brink of the possibility of death. There is a sense that being-in-pain may be the factor that contributes the most to the unbalancing. In its presence the pain influences, and is influenced by, all the other factors.

Lily's story shows the interrelatedness of such things as pain, rest, sleep, and lack of support. It shows how in the face of pain the mattering of things, of life itself, is altered. Perhaps in the face of such pain, the only escape is seen to be in death. Is the possibility of death in the face of pain actualised in the lives of those who live with rheumatoid

¹⁶ Slang expression meaning to kill (Treffry, 1998, p. 1612).

arthritis? This is not a question that I can answer anecdotally or empirically, nor is it a question that requires an answer in the context of this study. What is of particular significance in Lily's story is not so much whether people do or do not "*top themselves*" but that the desolating presence of pain can be such that one might even consider the possibility. Death as a possibility of being-in-pain discloses much for us to add to our understanding of 'living with rheumatoid arthritis'.

The everydayness and time

The everydayness of pain and the unreadiness-to-hand of the body experienced by many of those who live with rheumatoid arthritis means that everyday tasks require more time to complete. For example, Sue takes two hours to get up, shower and get dressed in the mornings. Or as she speaks of it, "*It takes a while in the morning to get going, to have a hot shower and get everything moving, to just sort of iron everything out*" (2:2). Ivy's story offers a further example. Ivy, who has had rheumatoid arthritis for more than twenty years, describes descending the stairs of her home each morning as she left for work.

The stairs were quite steep and each step I took was agony so I had to take one foot down and then bring the other one down and have a rest. I had to go sideways when my legs were sore, and I just had to rest. There was about 14 stairs. There were rails on either side, but it was just the agony of going down, going down is more difficult than going up. It was just so painful; it took about twenty minutes to get down. It didn't matter how long it took coming up, but I had to be at work at 8.30 am. We had to leave here at 7.45 am for me to be there at 8.30 am so I had to get up at 5.45 am to be ready to go - two hours it took me. I had to allow that amount of time (Ivy, 1:33).

Ivy tells us of a journey, a journey she made almost daily for about twelve years until alterations to the house removed the need to descend the stairs to get to the car. Ivy knows descending the stairs will be painful, she also knows that it is necessary if she is going to make it to work. Going to work is the purpose for which she is descending the stairs but in the unreadiness-to-hand of her body, Ivy's concern is with the task of getting down the stairs, not on getting to work. Her concern is with the agony of going down one foot after another, with having a brief rest before the next torturous step, with repeating it fourteen times over. The agony takes away the taken-for-grantedness of putting one step in front of the other. There is a sense that time almost stands still as we picture her moving ever so slowly down toward the car. Perhaps for Ivy it does feel as if

it takes forever to get down the stairs. Ivy knows from previous journeys down the stairs that it will take “*about twenty minutes to get down*”. She knows that to get to work on time she needs to be in the car by 7.45 am. It does not matter how long it takes coming up the stairs at the end of the day, but it does matter going down, she has to be at work by 8.30 am. Does the ‘mattering’ of time when descending the stairs increase the agony of the descent? Perhaps knowing she has to be in the car by 7.45 am. intensifies the agony of going down. Time does not matter as much at the end of the day for Ivy. At the end of the day, the pressure on time has reduced.

In living with rheumatoid arthritis, time is experienced differently. The experience of time, lived time, shapes and is shaped by the experience of living with rheumatoid arthritis. When we speak of time in this sense we are not talking of the linear time that is marked by the ticking of a clock. Instead, we are speaking in Heidegger’s terms of “primordial time” (1927/1962, p. 333). Primordial time relates to the way we ‘reckon with time’. Heidegger provides an example of this ‘reckoning with time’:

Any particular Dasein either ‘has the time’ or ‘does not have it’. It either ‘takes time’ for something or ‘cannot allow any time for it’” (Heidegger, 1927/1962, p. 404).

Primordial time, as reckoning with time, is fundamental to everyday being-in-the-world. It is from primordial time that the “ordinary conception of time” (clock time) has its origins (p. 405). Clock time is the public reckoning of time. In modern times, in the everydayness of our lives, both primordial time and clock time are of significance, we reckon with both. How can this help in interpreting Ivy’s story? How is time experienced in Ivy’s story?

Ivy ‘needs time’ to get down the stairs because she ‘takes time’, a long time, to get down the stairs. To ‘make time’ for getting down the stairs she gets up at 5.45 am. By getting up at this time she ‘has time’ to get down the stairs. There seems to be a tension in Ivy’s story between primordial time and clock time. Clock time imposes its ‘mattering’ in the morning more than it does in the evening. In the morning, it matters that Ivy ‘needs’ and ‘takes’ twenty minutes to get down the stairs. In the evening when she does not have to be anywhere by a certain time it does not matter how much time Ivy ‘takes’ to ascend the stairs. In the evening, the tension between clock time and primordial time is less tense.

As with so much of our everyday lives, the experience of time is often covered over in the taken-for-grantedness of our lives. To understand more of the phenomenon of 'living with rheumatoid arthritis' it is important to uncover something of the taken-for-grantedness of time. Let us consider an example. When I spoke to Primrose about her everyday activities of showering and dressing, she said that she "*deliberately spreads things out a long way*". In doing this she takes time and makes time to do what she needs to do within her physical limits. It was only in response to a question from me that she put a clock time on how long it took her to shower and get dressed. Her response was:

It's hard to say how long isn't it? But in the actual time I spend, it's only the ordinary time it takes anyone, but I like to space it out with rests in between. But to go and have a shower and get dressed, I'm pushing myself, but I can do it in about half an hour (Primrose, 1:19).

Primrose found it difficult to relate her everyday experience of time with clock time. She knows that showering and dressing takes time, she allows that time, she spends that time every morning. When asked to reckon that time in clock time she tells us it takes the "*ordinary time it takes anyone ... about half an hour*".

When undertaking many of our everyday activities, whether as a person with rheumatoid arthritis or not, we do not in the taken-for-grantedness of these activities reckon with clock time. In our everyday lives we, for the most part, experience time, are concerned with time, in the more primordial sense, of having time, making time, needing time, taking time. We use time. When asked to put a time (clock time) on how long it takes to shower, to brush our teeth, to eat our dinner, most of us would find it difficult to be accurate in terms of clock time. These activities just take the time they do. Often it is only when our attention is drawn to the time it takes that we notice the time it takes. Such was the experience of Primrose. A week after our conversation Primrose phoned to say that showering and dressing "*takes at least an hour*", she was "*astounded that it takes that long*" (Journal entry, 15 May 1997).

In the everydayness of living with rheumatoid arthritis it takes time to do things, just as it takes time for those not living with rheumatoid arthritis to do things. However, the person who has the disease for the most part takes more time, needs more time, uses more time to do things. In the taken-for-grantedness of their lives they are often unaware of just how much time (clock time) they use. In the everydayness of living with

rheumatoid arthritis, time (available time) may be ‘used up’ before even the most basic ‘activities of daily living’ are attended to. Remember at the beginning of this Chapter Tony told us that *“to get through a day, day in day out, [my wife] doesn’t do much, but it actually takes 99% of her capability, or even 101% of it often”* (1:5). Could it be that in taking 99% or even 101% of her ‘capability’, ‘not doing much’ is also taking 99% or even 101% of her time? Time, in the everyday sense, is not infinite and the tension between clock time and primordial time is always there. It is always there whether or not one lives with rheumatoid arthritis. However, in the everydayness of living with rheumatoid arthritis the tension is intensified. How is this tension lived with?

For the person with rheumatoid arthritis the tension between primordial time and clock time can be extreme. The tension is announced when they try to do the things they want to do, the things they need to do, and the things that they are expected to do, while living with a body that always needs more time. Margaret tells us, *“As a person with RA you have to put in more time because everything takes you longer”* (3:19). How can the person who has rheumatoid arthritis reckon with the demands of time? How can they *“put in more time”*? There are a number of possibilities, two of which are particularly relevant to our present exploration.

Pushing the limits of time

Firstly, there is ‘pushing-the-limits-of-time’. In pushing-the-limits-of-time, the person who has rheumatoid arthritis recognises that it takes more time to do things. In coming to recognise that they need more time they push the boundaries of ‘daytime’ to accommodate the extra time needed to do what has to be done. For example, Sue (p. 113) and Ivy (p. 113) have both told us of getting up two hours before they have to be somewhere even if that means getting up at 4 am. Margaret provides a further example as she describes her involvement as an organiser of a recent conference.

Most mornings I was starting at 4 am. I was getting up at the crack of dawn so I could get through a fairly normal workload, it is the only way I could manage it. It was the only way I could keep tabs on what was happening. Then I went through until about 10 or 11 at night so I was at full stretch, but you see by this time I was on Prednisone and that was what was getting me through. I knew I was taking a hell of a risk with my health, I hope I don’t pay for it (Margaret, 3:9).

Margaret tells us that she was at “*full stretch*” during this time. She made time to do what had to be done (“*a fairly normal workload*”) by starting her day at 4 am and going through until late into the evening, she stretched time, she pushed-the-limits-of-time. She tells us that the Prednisone she was taking during the period of the conference ‘got her through’. It is as if the Prednisone gave her more time. Margaret then tells us that she knew she was risking her health. It would seem that pushing-the-limits-of-time, like working-into-the-pain, sometimes involves a calculated risk. In pushing-the-limits-of-time, the body may also be pushed to its limits, often at a cost to a person’s health. Recall the earlier story (p. 109) of Sue’s visit to the emergency department at the end of a day when she seems to have pushed-the-limits-of-time. Could it be that using time through pushing-the-limits-of-time can be done in the short term to achieve a particular project but is not viable in the long term? ‘Living with rheumatoid arthritis’ means choosing carefully when to push-the-limits-of-time.

Letting go

The second possibility of reckoning with time, of living with the tension of primordial time and clock time that is relevant to our present exploration involves coming to accept that ‘something’ has to go. That not ‘everything’ can have time found for it or made for it, that it is sometimes necessary to ‘let go’ of something. Consider Margaret’s story.

Living with RA means learning to live within your capabilities and [to] accept that things are going to take you longer to do. You definitely have to reassess your priorities and for me if I have energy I want to spend it with some amount of enjoyment, particularly with my family. I don’t want to wear myself out doing housework. I might have a squeaky clean house but I’d have no energy or patience or time to spend with them and that is no good. I’d rather, if it can be afforded, get someone in to do some of the hard physical jobs so that I’ve got some energy to go out and enjoy life. That’s important because you don’t have your family for very long, not your children anyway. It is all part of reassessing where you are at and how you are going to manage your life (Margaret, 2:24).

Margaret suggests that living with rheumatoid arthritis means “*learning to live within your capabilities and [to] accept that things are going to take longer to do*”. Having done this, she tells us, it is then necessary to reassess priorities, to decide on the best way to spend the available energy, the best way to spend the available time. For Margaret the family takes priority over a “*squeaky clean house*”. The family matters more than the housework, so she will ‘save’ her time and energy to ‘spend’ with them.

In an effort to save her time Margaret “*get[s] someone in to do some of the hard physical jobs*” within the constraints of the family budget. Buying-in help is a way of letting go of the physical jobs. In letting go of these jobs, there is more time for other things, the family in particular.

Letting go, saves time, makes time, and allows time for what matters to the person with rheumatoid arthritis. Different things matter to different people so what is let go of and what is made time for varies in the everydayness of living with rheumatoid arthritis. What is let go of will for the most part depend on what matters most or least to a person. This may be for example, paid work, a hobby, community involvement, or housework. Sometimes letting go is welcomed, other times it is tinged with sadness and grief, some things are easier to let go of than others. Time might not be the only reason for letting go of these things. Like every aspect of living with rheumatoid arthritis, letting go involves an intertwining of many things. However, when reckoning with the tension of time, letting go is always a possibility. For most people, letting go is inevitable in reckoning with the tension of time within the everydayness of living with rheumatoid arthritis. In reckoning with time when so many things take more time, decisions are made about what there is time for, what there has to be time for, and what there is not time for. Decisions are made as to what can be let go of to make time for the things that need time.

In the everydayness of living with rheumatoid arthritis, it seems that most people work with both the possibilities of pushing-the-limits-of-time and of letting go. Sometimes they will choose to soldier on, to extend the boundaries of daytime, to push their bodies to the limit, to take the calculated risk, and to push-the-limits-of-time, in an effort to find time to do what they want to do and what they have to do. There will be times when they will not find time in this way. Instead time will be found, or made, by letting go of something that is taking up the time that needs to spent elsewhere, that needs to spent on something that in the everydayness of living with rheumatoid arthritis matters more.

Conclusion

Living with rheumatoid arthritis means living with joints that no longer work as they once did, it means living with a disease-ravaged body. It means experiencing the world,

and at times the body, as unready-to-hand. It means living in a world that is not always a dwelling place, that one is not always at-home in. Living with rheumatoid arthritis means living-with and being-in pain. It means experiencing time differently, of pushing-the-limits-of-time and of letting go in order to make time and take time to attend to the things that matter.

People who live with rheumatoid arthritis constantly strive to feel at-home in their worlds, they strive towards independence, they strive to find meaning in their lives. In striving they constantly live with the tension between the ready-to-hand and the unready-to-hand, and between the self that wants to be involved and the self that cannot be involved. Fundamental to the striving is the attempts to halt or at least temper the progression of the disease through submission to a myriad of treatments. It is as if the body is offered up to a range of treatments in the hope of making it more ready-to-hand. In making their bodies more ready-to-hand people with rheumatoid arthritis are more able to function in the everyday practical world, more able to “tend towards [their] world despite the handicap [of rheumatoid arthritis]” (Merleau-Ponty, 1966, p. 81). When the body is experienced as more ready-to-hand the person with rheumatoid arthritis is more able to concern themselves with other aspects of their lives, with what matters most in their lives. They are able to concern themselves with being parents, partners, colleagues, and friends, to be involved in their communities, their environments.

This chapter has begun to uncover the hiddenness of the everyday practical world of those who live with rheumatoid arthritis. It has also explored the impact of living with a disease-ravaged body, an experience that in itself, at times, may become taken-for-granted. The focus of the next chapter is the impact on the lives of those who experience the phenomenon of ‘living with rheumatoid arthritis’, whether as partners, as adult children, or as people with the disease. I suggest that in the always-thereness of living with rheumatoid arthritis, almost every aspect of their lives is, to varying degrees, affected.

CHAPTER SEVEN: The Always-Thereness

'Living with rheumatoid arthritis' pervades all aspects of the lives of people who experience the phenomenon. It goes before them and penetrates all other ways of their being-in-the-world; it is always there. Sometimes the intensity of the pervasion is greater than at other times, some 'worlds' are affected more than others are. However, the underlying 'thereness' of living with rheumatoid arthritis remains, if not centre stage then waiting in the wings. It is as if life is taken over by rheumatoid arthritis. As discussed in Chapter Three (p. 43), these people are always in the throw of rheumatoid arthritis. The always-thereness of living with rheumatoid arthritis is not necessarily, or always, the most important aspect of their being, other things may 'matter' more, but rheumatoid arthritis alters the 'mattering'.

Being-in-the-world with rheumatoid arthritis is but one of the many ways participants are in the world. Being-in-the-world with rheumatoid arthritis occurs in the context of a myriad of other ways of being-in-the-world, other experiences of thrownness. People who live with rheumatoid arthritis, whether as partners, as adult children, or as people who have the disease, are for example, also in the world as parents, workers, students, and friends. They form and maintain relationships, they give birth, they make career choices, and they seek an active participation in life. They are always already in these other worlds and their involvement in these worlds does not cease in the thrownness of rheumatoid arthritis but it is forever altered, forever different. As Tony, a partner, tells us:

I can't think of a part of my life that's not affected. It's not that I've not been able to actually do things in my life, but I've done them in a different way, and I've done different things (Tony, 1:14).

Whether one is a person who has rheumatoid arthritis or a partner or an adult child of someone who has the disease, living with rheumatoid arthritis is alongside and part of all the other ways of being-in-the-world. While closely linked to the everydayness of the practical world discussed in the previous chapter, this chapter explores the impact on the lives of those who experience the phenomenon of 'living with rheumatoid arthritis' from a broader perspective. I suggest that the always-thereness of living with rheumatoid arthritis influences to varying degrees almost every aspect of the lives of those who, like Tony, live in the throw of rheumatoid arthritis.

Heideggerian underpinnings

Heidegger speaks of worldhood. Worldhood refers to the background world that underpins our being. It is primordial and more fundamental than the practical world of the ready-to-hand that was explored in the previous chapter. It is the *a priori* world in which we 'dwell', in which we feel 'at home'. It is the world into which we are thrown. As humans we constitute and are constituted by this world (1927/1962, p. 63).

Worldhood provides the background familiarity from which we make sense of our practical everyday world, and from which we can take a theoretical stance on the world. For example, as a nurse the background familiarity with the worldhood of 'nursing' means that the sphygmomanometer is experienced as ready-to-hand. For someone without this background familiarity the sphygmomanometer is at best a present-at-hand object, something to be thought about, to be puzzled about. Although this background familiarity is perhaps best understood in relation to practical activities, this is just a particular case of what Heidegger describes as "our general familiarity and ways of coping that constitute our way of being in the broadest sense" (Hall, 1993, p. 132).

We acquire this background familiarity through socialisation or acculturation and as such we are for the most part unaware of the acquisition, it just 'is'. The influence of acculturation on the background familiarity of worldhood means that the way we encounter things and others is often influenced by societal or cultural norms, what one does or does not do in a particular situation.

It is against the background familiarity of worldhood that things show up for us or are encountered as what they are. It is the differences in the background familiarities of worldhood that make different things relevant or irrelevant, matter or not matter to different people. As Hall summarises:

We just *are* our most general and fundamental way of "comporting" ourselves towards things and human beings, and these same manners of "comportment" are the background without which things and others could not be encountered (1993, p. 133).

How can this notion of worldhood help in uncovering the phenomenon of 'living with rheumatoid arthritis'? Worldhood is the background familiarity from which we encounter things and others, from where we understand what it is to be. Could it be that in living with rheumatoid arthritis people develop a certain background familiarity that

effects and affects their encountering of things and others? Perhaps accommodating rheumatoid arthritis in their lives involves backgrounding the perspectives and practices of the world of rheumatoid arthritis. It is the notion of worldhood that underpins the always-thereness of living with rheumatoid arthritis.

In the always-thereness, living with rheumatoid arthritis becomes part of the background familiarity of these peoples' lives. It is in the always-thereness that things show up for them and are encountered in certain ways, that things matter or do not matter, are relevant or irrelevant. Furthermore, it is in the always-thereness of being-in-the-world with rheumatoid arthritis that the possibilities for a person's world are disclosed. As King (1964, p. 87), drawing on Heidegger's writings, suggests it is in and from these possibilities that people understand themselves and their relation to others; and, conversely, it is by reference to their world that people understand other beings in relevance to and bearing upon their own existence.

How do we show this worldhood, this background familiarity? Heidegger would suggest we cannot because there is no more fundamental background to fall back on, from which to attend to or grasp it (Hall, 1993). However, from my understanding of worldhood I would suggest that while it is not possible to show worldhood as such, it is possible to show, or at least glimpse, the influence of this background familiarity on aspects of the various worlds that people inhabit. By exploring the always-thereness of rheumatoid arthritis, we can perhaps begin to understand how the fundamental being of these people is forever altered through living with rheumatoid arthritis. We can begin to grasp how living with rheumatoid arthritis alters the way these people encounter things and others in their world. How the 'comportment' of their lives alters as the always-thereness of rheumatoid arthritis affects the background familiarity of their lives.

Before we move on it is important to consider briefly two particular aspects of always-thereness which are very much part of the background familiarity, the worldhood, of those who live with rheumatoid arthritis. These are uncertainty and relentlessness.

Uncertainty

Uncertainty is part of the always-thereness of living with rheumatoid arthritis and as such is part of the background familiarity, the worldhood. Everyone lives with uncertainty in life. We can never be sure that the projections we have for our lives

will eventuate this way or that, possibilities are just that until they are in the past. It is only in retrospect that they are certain. However, uncertainty has increased significance for those living with rheumatoid arthritis. Jan, whose mother has rheumatoid arthritis, lives constantly with uncertainty. Consider her story.

What does it mean to live with RA? Gosh it means so much. I think it demands a lot of self-denial and constant compassion. It means constantly re-evaluating the roles that people have to play. I have found myself constantly re-evaluating my role, what am I expected to do in this situation, what should I do? It is an omnipresent kind of pressure and sadness I guess. It's really sad and lonely a lot of the time. There's always the helplessness and everything is out of your control so you have to just accept what comes and then never knowing what's next. You are constantly holding your breath, you never quite know what's next. It's like a waiting game in a way but you are not sure what you are waiting for. Well that's what I find. It's almost like holding your breath. The uncertainty of it all, and no end to it. There's an ever-present feeling and it's like living with another entity. An entity that you don't know particularly well and it seems kind of black most of the time, but you are constantly trying to get to know it and see the end of it, but it's never quite there, you can't quite see it. Sort of menacing but I would like to get to know it better (Jan, 1:23).

Jan likens living with the uncertainty of rheumatoid arthritis to a waiting game in which you are always holding your breath. There is a sense of helplessness and loss of control in never knowing what the rheumatoid arthritis will next disclose of itself. There is no end to the uncertainty that is as ever-present as the disease.

The nature of the rheumatoid arthritis is such that living with the disease means living with the constancy of not knowing how it is going to disclose itself, on a daily basis, a yearly basis, over a lifetime. Will these joints work today? Is today going to be a good day? Can I control the pain today or is it going to control me? Which joint will be the next to go? I am feeling great at the moment, am I in remission? Children wonder, is Dad going to be able to come to the school sports? Does Mum need help today? What should I do? Partners wonder, is it OK to touch her? Can she look after the children today? What do I need to do?

Uncertainty calls forth vigilance in those who live with rheumatoid arthritis. There is an almost constant, but not always conscious, monitoring of 'how things are'. Of how the pain is today, of which joint is the most troublesome, of what is going to be possible today, of what must be left undone. The person with the disease is the focus of the vigilance, but it is not only they who are vigilant. Partners and adult children too

monitor 'how things are'. For example, Liz (a partner) "*watch[es] practically everything*" her husband does. The 'watching' involves listening to him in the bathroom taking his analgesics. Liz "*can tell how many pills he is taking by how many times he puts the glass down on the cabinet.*" She knows "*He's really in trouble if the glass goes down a third time*" (1:12). Vigilance, the watching, the monitoring is part of living with the uncertainty. There is certainty in the uncertainty, the certainty that the uncertainty is always there and as such affects the way things and others are encountered in the world.

Relentlessness

Intertwined with the uncertainty of living with rheumatoid arthritis is relentlessness. Relentlessness may not be part of the experience of all those who live with rheumatoid arthritis, particularly for those with a less-severe appearance of the disease. However, for all the participants in this study relentlessness is part of their experience. There is relentlessness of disease progression, the relentlessness of treatment, the relentlessness of pain, the relentlessness of the everydayness of living with rheumatoid arthritis. As Sue, who has rheumatoid arthritis, tells us "*It's always a constant circle of something*" (1:7), while Tony speaks of the "*incessantness*" of his wife's disease (1:7). Consider Rosie's story.

I don't know about the next surgery, this is the worry because that knee and my hip are going and I've got that elbow and my shoulder going and that wrist is painful and so this is the thing I like to put at the back of my mind. What else is going to go? And how am I going to cope with surgery, which I really don't like. I really feel as if I have had enough and each time I go in, I worry about the anaesthetic, I get so frightened of the anaesthetic. I hate being away from home, and just the mere fact of going in to surgery, again, and again, and again, it's that monotonous. When is this going to stop? I don't suppose it ever will. That's the anger, anger I suppose, anger. I suppose I have a lot of grief about it still, after all these years, grief about it, that these things are happening and what do you do about it. There is nothing you can really do about it, as I said before you just have to get on living and get as much out of life as you can. That's the thing that's important (Rosie, 1:28).

It seems that for Rosie, who has had rheumatoid arthritis for more than thirty years, the relentlessness of disease progression is mirrored in the relentlessness of surgery. There is the knee, the hip, the elbow, the shoulder and the wrist that have been taken over by the disease. There seems a certainty that something else is 'going to go,' uncertainty

about which joint and when. It is a relentlessness that she likes to put at the back of her mind, but it is always there. How am I going to cope with the surgery, she wonders? Surgery that is relentlessly monotonous, that takes her away from home again, and again, and again. There is anger at the relentlessness and a grudging acceptance of the thrownness of the situation. Amidst the relentlessness of the disease and the treatment, and the anger and grief, the thing that remains most important to Rosie, what concerns her most, is that she gets as much out of life as possible. In this instance, the relentlessness of rheumatoid arthritis has not altered what matters (getting the most out of life) but it has altered how it matters, the possibilities for that life. As joint after joint is taken over by the disease, the range of possibilities for that life changes, often in a gradually diminishing circle of possibility.

Uncertainty and relentlessness, as constitutive of the always-thereness of living with rheumatoid arthritis, are parts of the background familiarity, the worldhood of those who experience the phenomenon. Uncertainty and relentlessness are with them in all their worlds, in their being-with others. Uncertainty and relentlessness, as constitutive of the always-thereness of living with rheumatoid arthritis, underpin the ‘mattering’ of people’s lives.

How does the always-thereness of rheumatoid arthritis affect what shows up as important or not important to these people?

Always-thereness and being-with others

Heidegger reminds us that we are always in the world with others. ‘Others’ being “those from whom, for the most part, one does *not* distinguish oneself – those among whom one is too” (1927/1962, p. 118). The person living with rheumatoid arthritis is in the world with others and as such is involved in relationships with others. There are, for example, relationships with family, with friends, with colleagues, and with health professionals. Relationships, being-with others, are always in terms of oneself and one’s world. We speak of ‘my partner’, ‘my child’, and ‘my friend’. The relating of these relationships is to our own being and to our own world. Smythe (1998, p. 163) provides clarity when she says, “relationships begin with self, and happen to self, yet by their very nature they are about being with others”.

What does the data show of relationships? How is the always-thereness of rheumatoid arthritis disclosed in the data? How is the ‘mattering’ shown in relationships? The always-thereness of rheumatoid arthritis influences relationships in a myriad of ways. It changes the dynamics of relationships. Lily, who has rheumatoid arthritis, speaks of her husband not “*getting past this invalid thing [which] causes some grief between [them] as she tends not to be consulted the same*” (1:17). While Pam, whose mother has rheumatoid arthritis, tells of the role reversal that occurs when her mother “*is having a bad patch*”. At these times Pam tends “*to be like the parent and tries to make her feel better*” (Pam, 1:12). Sometimes the always-thereness of living with rheumatoid arthritis is said to contribute to the death of a relationship, at other times to strengthening a relationship. Jan’s relationship with her mother has strengthened in the presence of her mother’s rheumatoid arthritis, but even in its strength it seems tossed in uncertainty and relentlessness.

I think it’s made us much closer. I know her much better than I think I ever would have had it not been for the RA. At times it’s made it really crappy too because I’d like to be able to actually spend some quality time with her, but a lot of the time that’s impossible, because it’s made her a very tired, very angry, very difficult person to be around. A very difficult person to love a lot of the time. It’s made me admire her in a way that I don’t think I would have otherwise, so it’s made me just intensely aware of all of those sorts of good and bad qualities that she has. We never have bad communication, we never yell at each other, but I swing between love and hate with her in the way that her disease affects our relationship. At times it’s just so bloody difficult to have a relationship with her because all that there is is her RA when it’s bad. And when it’s good she’s just Mum and that’s great (Jan, 1:23).

This story was told with deep emotion and through tears, such is the importance of this relationship to Jan. Jan finds the relationship with her mother changed in the always-thereness of rheumatoid arthritis. The relationship oscillates to the dictatorship of the physical manifestations of the disease. It is as if the relationship is at the beck and call of the always-thereness of the disease. When the disease is quiescent the relationship blossoms, when Jan’s mother is tired and in pain the relationship is strained. Perhaps at times when the rheumatoid arthritis is bad, when her mother is taken over by the rheumatoid arthritis (“*is her RA*”) then the being-with of the relationship is just too hard. Gadamer reminds us of the “profound inwardization” that can occur with the experience

of pain (1993/1996, p. 75), and Heidegger speaks of “closing oneself off” and “hiding oneself away” as possible ways of being-with others (1927/1962, p. 124). It seems as if Jan’s mother closes herself off to the relationship with her daughter through her pain and her anger. For Jan it is hard to love the mother who “*is her RA*”. Is it her mother she hates at these times, is it the disease, or is it what the disease does to their relationship? Rheumatoid arthritis in its always-thereness often gets in the way of the relationship yet, paradoxically, it also strengthens the relationship (“*it’s made us closer*”).

In the always-thereness of living with rheumatoid arthritis, close relationships remain important, relationships matter to people. It is the being of relationships that are affected by the always-thereness. Consider Rosie’s story.

Shoes are always a problem. One day a friend of mine came along and said, “Why don’t you wear running shoes?” I thought ‘I can’t wear running shoes, really me, me in running shoes, no way’. But I considered it very carefully and I went and tried some and I discovered that running shoes were the answer because they are soft, they are very light and they support my feet. So ever since then, I’ve worn running shoes. I’ve also worn trousers because I thought I don’t want people to see my feet. I think if I’ve got something nice on my top, it doesn’t matter about my feet, people don’t look at my silly nerdy white socks and my running shoes. I must admit that I don’t like them, but then what else can I do? It’s like so many of my other clothes, I really find it difficult to go and buy clothes. I’m not the smart cookie that I used to be but then I’m comfortable and my family love me and so what does it matter (Rosie, 1:22).

Rosie’s story seems to be about what matters. She tells us that dressing nicely in smart clothes used to matter, but as her body has been ravaged by rheumatoid arthritis it is no longer possible to dress for style. She somewhat grudgingly accepts this situation, aware that being a ‘smart cookie’ is no longer possible and what matters now is to dress for comfort. Yet how she presents herself to others, within the limits of these possibilities, remains a concern. She wears something that will draw attention from her lower body, something that will draw others to her as herself, and not her as her rheumatoid arthritis. Above and beyond the mattering of comfort and how she presents herself to others is the mattering of her relationship with her family. As long as her family loves her, nothing else matters. To be loved and to be accepted by her family is what matters most to Rosie.

It would seem that loving and acceptance as fundamental needs of relationships remain strong in the always-thereness of living with rheumatoid arthritis. Whilst this

fundamental need does not change, there are strains to being loved and accepted within relationships taken over by rheumatoid arthritis.

What are the strains?

The strains are in the always-thereness of living with rheumatoid arthritis, of living with pain, fatigue, and joints that no longer work as well, of living with a disease-ravaged body, of living with a person who experiences all of these. We can glimpse these strains by considering intimate aspects of relationship, in particular the sexual relationship couples share. It seems that it is within these relationships that the strains of being loved and accepted are often disclosed. It is these stories that are not often heard. These stories seem to show the always-thereness of rheumatoid arthritis in relationships, although much still remains in the dark. We begin with the story from a woman who has had rheumatoid arthritis for more than fifteen years.

There are problems with pain and very often pain can totally take over and I find that I just cannot relax and achieve a climax and so it all becomes rather one-sided. We have got to think about other positions that will make it easier for me. It can be a tremendous physical and emotional relief to actually reach a climax to know my body is still working. It may actually bring tears because it is a relief, I can still get there, and it is brilliant, despite the fact that there is a certain amount of pain and some modification. I am still OK. I am still together. It is terribly important (Margaret, 3:37-38).

Margaret is speaking of one of the most intimate ways one can be with an ‘other’, sexual intercourse. It is a time when the ‘we’ of the relationship can consume ‘self’ and ‘other’, and yet at this most intimate moment ‘self’ remains paramount. The ‘we’ of this relationship is considerate of Margaret’s painful joints, altering positions in an attempt to provide comfort. Margaret tells us that at times the pain can “*totally take over*” making the relationship “*rather one-sided*”, limiting her pleasure of the relationship. However, when the pain is less and she is able achieve an orgasm there is relief in knowing her body “*is still working*”, a relief that is both physical and emotional.

It would seem that sexual expression through intercourse is important in the relationship between Margaret and her husband, even though intercourse may sometimes be taken over by the always-thereness of rheumatoid arthritis. Intercourse is also important to Margaret as an individual, achievement of an orgasm is important to who she is as a woman, it provides a cohesiveness to who she is (“*I am still together*”). Non-

achievement of orgasm perhaps brings her face to face yet again with her disease-ravaged body, it draws her away from the 'we' of the relationship. In the always-thereness, intercourse matters in the being-with 'other'. For other people living with rheumatoid arthritis intercourse as an act of sexual expression is not so important. Consider Rosie's situation.

We haven't been very sexually active since I broke my hip. I just couldn't cope. It's sad but my husband says he doesn't mind. He worries about me more than he worries about that. I think being together is probably as good, but then I do regret that I just can't cope with sex. But it's not a big thing. Neither of us has considered it a big thing. And he realises that it does hurt, with all the joints it did hurt me, he is very considerate and says, "No, if it hurts you, there's no pleasure in it" (Rosie, 1:11).

For Rosie and her husband the ravages of rheumatoid arthritis on her body have meant a foreclosing of sexual expression through intercourse. There is no pleasure in an activity that causes great pain. Intimacy, "being together", is still important for this couple but is expressed in a different way, through touch and the caring way her husband meets her many other physical needs. As Heidegger reminds us, it is the background familiarity of worldhood that discloses things that matter to us. For this relationship, it is not so much that intercourse does not matter any more, it is just that other things (not wanting to cause pain) matter more. It is in the mattering.

Uncertainty may influence the mattering of the relationship. As Ian tells us:

The physical side of our relationship hasn't really been affected. There are times when we've just got to be careful I suppose. It's not always that easy. I might want to go to bed and make love and she's asleep and she's already told me about ten times how sore she is, so I think 'Oh well that's a write off tonight, might as well read my book' (Ian, 1:28).

Fluctuations in levels of pain and fatigue can influence the being of relationship. For Ian the always-thereness of rheumatoid arthritis means that he often puts his wife's needs ahead of his own needs. Intercourse remains important to the relationship, and for the most part has been unaffected by his wife's rheumatoid arthritis. Yet, there are times when in the always-thereness of living with rheumatoid arthritis other things matter more than having intercourse matters. Ian seems to have developed an understanding and acceptance of the changing situation, sometimes at the expense of his own needs. Perhaps the ever-present uncertainty of living with rheumatoid arthritis calls forth understanding. Self retreats for the benefit of the other of the relationship. What matters

in the relationship, at this moment, is not self (Ian) but other (his wife). In the face of pain, self withdraws.

Sadly for some participants, the relationship has not survived the preclusion of intercourse; the strain has become fatal. The partner of one woman blamed the breakdown of their marriage on the changes in her appearance and the fact that it was *too painful for [her] to have sex* (Sue, 2:14). It seems that when relationships are strong, not sharing certain activities (sexual intercourse) does not matter much, for the self still feels good about self. When the relationship is more tentative, more strained (e.g. does he still find me attractive?) then not sharing certain activities (intercourse) matters. The 'not-sharing' is a loss to the relationship, a loss that can be fatal to the relationship. Is it at times like this that the fundamental need to be loved and accepted is lost and forgotten in the always-thereness of living with rheumatoid arthritis?

For some people changes in the mattering of the relationship, while not fatal, remain an ongoing tension to the relationship as Jo's story demonstrates. Jo's husband has had rheumatoid arthritis for more than fifteen years.

The physical side of our relationship has taken a huge change. I was unprepared for that. In some ways I think that sex to Neil has become kind of like proving his manhood. Like it's become incredibly over-important to him. It is something he can still do when all his other manly things are going by the board. It frustrates me and some nights I feel, he needs this. I don't but he does. Isn't that awful? I shouldn't say that, but yes, I do think 'he needs this, I don't'. So it's become something that I just accept as being something he needs (Jo, 1:28).

For Jo's husband sex matters more, is more important in the always-thereness of living with rheumatoid arthritis. In being-with his wife in this way he perhaps feels like the husband he wants to be, the husband he once was before rheumatoid arthritis intervened. There is tension in the relationship, as Jo does not have the same need for sex as her husband. It is a tension that expresses itself in frustration and guilt as she reflects on the 'awfulness' of her feelings about their different needs. Yet it would seem that the frustration and guilt of the situation in which she often finds herself also calls forth a loving care in which she puts the needs of another ahead of her own. In not putting herself first, she is taking care of someone else's needs. This is perhaps a loving care that is called forth by the always-thereness of rheumatoid arthritis.

Always-thereness and the call to care

The loving care called forth in the previous story is a further aspect of relationships, of being-with others, that is enmeshed in the always-thereness of rheumatoid arthritis. It is an aspect of relationship that requires further exploration. Consider now a story from Jan, the daughter of a woman with rheumatoid arthritis.

I think it has definitely affected the choices that I have made. There are courses that I would really like to have done that are out of [the city] but I think that for long periods of time I couldn't handle being that far away from her. So I guess that geographically it's restricted my education commitments. Where other people my age would be thinking completely about themselves I find myself far more family orientated, I feel I need to just not think of myself, I guess that all those decisions are affected by Mum (Jan, 1:13).

The need to be close to her mother limits Jan's career choice. Educational opportunities are restricted to those that keep her in close proximity to her mother. What is the pull that keeps Jan close to her mother, which draws her to think not just of herself when making choices? Perhaps it is the pull of rheumatoid arthritis, the pull of the always-thereness, the pull as a call to care.

Care and Solitude

Alongside Being-in the world and Being-with others one of the fundamental aspects of Dasein described by Heidegger is Being-for. The Being-for of Dasein's existence is 'care' (*Sorge*). Care signifies "'care-for,' [and] 'concern for and with'" (Steiner, 1978, p. 100). In the way that background familiarity, worldhood, accounts for *how* we are in the world, care accounts for *why*.

Care has many forms, such as the concern for things and the ready-to-hand of the practical world and the concern with and caring for being itself. In this latter sense care relates to the way things matter to us, it constitutes all our involvement in the world (Frede, 1993). Hoffman (1993, p. 200) helps in understanding this aspect of care:

Dasein is care, for Dasein is always concerned about its being. My life ... is not something indifferent to me, something that leaves me cold, as it were; on the contrary, it is something that *matters* to me. Now my life matters to me - indeed *must* matter to me - only because I am aware that I don't have it "forever" and "once for all"; life matters only because I am aware that it can be snatched away from me by the power of death.

It is because of this fundamental way of being-in-the-world, care, that things and people matter to us in our lives.

A further form of care is the care and concern we have for others, which Heidegger names as 'solicitude'. Solicitude describes how we are with one another. There are different modes or possibilities of solicitude. There are the indifferent and deficient modes of solicitude such as "being for, against, or without another, passing another by, [or] not 'mattering' to one another" (Heidegger, 1927/1962, p. 121). It is these modes of solicitude that tend to characterise our everyday being-with others, especially the anonymous others with whom we have no immediate relationship. The positive mode of solicitude has two extreme possibilities, 'leaping in' and 'leaping ahead'. The differences between the two possibilities are subtle, and both have their place.

The caring-for which leaps in is characterised by taking care away from the other, usually by taking care of things for them. For example, a husband may take care of cooking meals when his wife with rheumatoid arthritis is having a 'bad day'. In this situation the other, the wife, steps back (is thrown out of her position, Heidegger suggests). Later, when she is feeling more able, the wife can choose to take back the task of cooking or to let go, disburden herself, of it completely. Heidegger cautions that care which leaps in can lead to domination of, and dependency in, the person from whom care is taken away, even if this domination is tacit and of which the person may be unaware (1927/1962, p. 122). Despite the possibility of dependency, there are times when leaping in is necessary and desirable.

In contrast to care that leaps in, care that leaps ahead is characterised not by the taking away of care but by the giving back of care. King helps in the understanding of this notion when she says, "Such caring-for is not primarily concerned with what the other does but with his existence as a self" (1964, p. 108). In this mode of care the husband may discuss how he can best help his wife in preparing a meal and on her suggestion may assist with certain tasks, or together they may decide to have takeaways. Heidegger contends that our everyday being-with those close to us maintains itself between these two extremes of positive solicitude (1927/1962, p. 159). How is care experienced in the data?

Thrownness and the call to care

In the always-thereness of living with rheumatoid arthritis, people are thrown into the call to care in ways they could never have imagined. The call can be strong, it can be weak, it can be answered, it can be ignored, it can vary in intensity as the disease and its symptoms vary in intensity, but it is a call that is always there. Just as these people are always in the throw of living with rheumatoid arthritis so too are they always in the throw of the call to care. Always being in the throw is illustrated in the next story from Ian, whose wife has had rheumatoid arthritis for more than twenty years.

How she is is always in the back of my mind. I am very conscious of the fact that she is on her own at home and I'm always wondering how she is coping and things. If she's not too well I don't even like going out of the gate in the morning, but not being a person of independent means I can't not work, that tends to be a frustration, but we are not well off so I can't just give up work (Ian, 1:11).

Ian speaks of the frustration he feels at not being able, for financial reasons, to give up work and answer the call to care for his wife. To be available if, and when, she needs him, to be there to see for himself that she is all right. He tells of finding it difficult leaving her (“going out the gate”) when he goes to work, especially when she is “not too well”. The gate is a barrier he must constantly traverse. Could it be that the gate is the barrier from which the call to care cannot be heard once it is passed through? Perhaps he is afraid of not being able to heed the call. Perhaps the call to care is so strong he has trouble passing through the gate, knowing that the call is stronger to stay than to go. Yet, earning money is also important for him, for them. There is a tension between the call of multiple concerns. In always-thereness of living with rheumatoid arthritis, it would seem that the call to care cannot be shut off completely. Ian, and many like him, takes the call with him into his other worlds.

Pain as a call to care

What are the calls to care? There would seem to be innumerable calls inherent in the always-thereness of living with rheumatoid arthritis. For example, there are the calls that stem from joints that no longer work as they once did. There are the calls that fatigue and increasing disability bring. Then there is the call that shouts perhaps the loudest, the call of pain. The next story from Ian, a partner, provides an example of the call of pain.

I find it really frustrating when my wife's in pain. Part of the frustration is not being able to do anything about the pain. It's very difficult, sometimes I give her a bit of a hug and of course she just goes, 'Ooh' ... and you think 'Oh shit, I've done that wrong.' I don't intend to do it wrong. But I can't do anything about the pain. I tend to lighten the load, I'll do the washing, hang out the washing, and I'll make the bed. I do as much as I can I suppose to actually lighten the load of the everyday chore type stuff (Ian, 1:20).

Ian, whose wife has rheumatoid arthritis, speaks of the frustration he feels when she is in pain. There is the frustration at not being able to do anything about the pain. There is the frustration of trying to ease the pain, instead adding to it as his wife recoils from his touch. The frustration is somewhat relieved by lightening the load for his wife, by doing some of the everyday tasks she might normally do.

In Ian's story, it is as if pain is a call to care. A call heard very loudly by Ian, yet a call that is difficult to answer. Ian cannot take the pain away and that is part of the frustration for him. In the face of pain there is a sense of helplessness, but not of carelessness. Although Ian cannot take the pain away he can take away some of the things that add to the pain. He can attend to the washing and make the bed; he can "lighten the load". By taking care of the "chores", he is perhaps giving his wife space to be with her pain and to deal with it in the way she finds best. The call to care of pain is for the most part ever-present in living with rheumatoid arthritis, it is always there.

Answering the call – leaping ahead

Once heard, how might the call to care be answered? Pam often answers the call to care for her mother who has rheumatoid arthritis. Consider Pam's story.

Mum will very seldom ask for help, so usually you do it subtly, like if she has a hospital appointment, I know what it's like if she has got to park the car. She often can't get a disabled parking space so if I can I will take her to the hospital and drop her at the door. I will go up and wait and then I bring the car up to the door when she's finished, just little things like that. Or if she is doing her shopping I will try and do mine on the same day. She can shop alone but it takes a toll by the time she has lifted it all into the car and then gets home and has to unpack it all. If I go with her, at least I can pop it into the car and it just makes it a bit easier. Even reaching tins down off the shelf is hard for her as well, so yeah; I do little things like that (Pam, 1:4).

Pam speaks of doing a lot of "little things" in helping her mother, driving her to the hospital, being there to help with the grocery shopping. Doing these "little things" requires forethought for Pam as she has to arrange time off work for a hospital

appointment and to schedule her shopping at a time convenient to her mother, yet she does them willingly. Pam is solicitous in her concern for her mother. She leaps ahead in her concern, not taking over things for her mother but providing the supportive care that relieves some of her mother's burden. The "little things" that Pam does are done in a subtle, supportive way, an enabling way that leaves her mother feeling good about herself.

Answering the call – leaping in

How else might the call be answered? The next story provides an example as Jan describes the care she provides when her mother's rheumatoid arthritis is particularly active.

When Mum has her bad patches... because she goes through long periods where she is fine, but when her bloods are up and she is sore and tired, a lot of the time she can't actually do those sorts of things, doing up buttons and that sort of thing. So when she is sick I generally go and stay with her and at those times there is a lot of... helping her go to the toilet and just basic things like that.... really physically demanding. It's like having a child in a way (Jan, 1:9).

Jan speaks of the help she gives her mother during "bad patches". This help involves moving into her mother's home and attending to many of her physical requirements such as toileting and dressing. Fluctuations in the disease process alter the call to care. When the person with rheumatoid arthritis is experiencing increased pain and fatigue, when joints are even more inflamed the call changes from one of leaping ahead to one that calls forth leaping in. When her mother is experiencing a "bad patch" Jan leaps in, taking care of many things for her mother. In leaping in the being of their relationship alters, "It's like having a child". The mother/child relationship is turned upside-down. Leaping in is none the less essential as without Jan's care her mother would be unable to attend adequately to many of her basic needs.

Answering the call – indifferent and deficient modes

In the always-thereness of living with rheumatoid arthritis the call to care can be answered in a way that Heidegger would call 'indifferent' or 'deficient' (1927/1962, p. 121). Consider Lily's story:

Sometimes I think my husband sees me as something almost to be ashamed of. Just the fact that all our friends know that I am no longer able to go out and do things the way we used to. I think it's sometimes a case of 'I wish I could discard her'. If I ignore her, she doesn't exist sort of thing. When I'm really sick, I don't care. The last thing I feel like is being traipsed off somewhere to go visiting, because the chairs won't be comfortable. And people wonder what the hell you are doing if after you have only been sitting ten minutes you have to struggle to your feet and move yourself around because you are hurting. You don't really want to draw attention to yourself like that anyway. So I find it is better not to be bothered (Lily, 2:19).

Lily thinks that there are times when her husband is ashamed of her, ashamed of the way she is as a woman with rheumatoid arthritis. She is the woman who can no longer join in activities or socialise with friends the way she once did. Perhaps she is not the wife he thinks she should be or the wife he has come to expect. She feels ignored in the relationship, discarded almost. It is as if she is a chattel, something that can be put aside and forgotten until it is next required.

What is the care of this story? There is a sense in this story that both Lily and her husband have, in Heidegger's terms, 'closed off' to the possibility of relationship. In the always-thereness of living with rheumatoid arthritis, especially when there is an exacerbation of symptoms, care can flourish in its indifferent or deficient mode. It is as if Lily and her husband are ships passing in the night, barely seeing each other, unable to reach out through the darkness. There is a sense that Lily does not always matter in her husband's life, that in his day-to-day activities he would rather be without her. She is left feeling shamed and ignored by his indifference. Lily's response to her husband's indifferent way of care is to respond in a similar way, "to not be bothered". In caring this way, she perhaps cocoons herself away from the hurt she might otherwise feel. Lily continues:

My husband can't get past this, this invalid, and that tends to cause some grief between us. I tend to not be consulted the same. He took over, for quite a long time, and I've just twigged him up about it. For example, he was always the one who would decide when we would entertain and who would come and all of this, and I didn't like that. So I recently said to him "Look I think we will have so and so around". "Oh I don't know about that", he said. I was quite blunt, and I said, "Whose shoulders does the work fall on?" "Oh yes, I suppose so" he said. I did a whole lot of food preparation in 10 minutes down at the supermarket and came back and did the rest here at home. Then I had a lie down and a sleep then got up and had a shower

and got pretty and laid the table out and all my visitors arrived and I was bright eyed and bushy tailed. It was good (Lily, 1:18).

Lily speaks of her husband “*taking over*” many aspects of her life, of not consulting her, as she would like to be consulted. This she considers relates to him seeing her as an “*invalid*”. Having lived with rheumatoid arthritis for more than fifteen years, Lily has recently drawn his attention to the issue, “*twigged him up about it*”. It would seem that in the face of living with rheumatoid arthritis Lily’s husband has leapt in, taking over for himself many of the decisions that they would previously have made as a couple. Leaping in in this way may be well intentioned and have initially been welcomed by Lily. However, over time it has become the cause of tension in the relationship, “*caused some grief between*” them. Heidegger reminds us that care which leaps in can sometimes lead to domination of one person over another (1927/1962, p. 122). This seems to be what has happened between Lily and her husband. Perhaps Lily has only just become aware of this domination, or perhaps until now she has given tacit approval to it. For whatever reason, Lily has now reached the point where she can no longer live with this domination in a situation in which she is very capable of sharing decisions and has taken back the care.

Knowing when to leap in or to leap ahead

Knowing how to answer the call to care, knowing whether to leap in or to leap ahead, can be fraught with difficulty and frustration as those answering the call strive to get it right, but occasionally get it wrong. Consider Fran’s story.

It is really really frustrating. I try and do things to help her ... it’s so frustrating ...when you are trying to do things for her that are going to help her quality of life, I just don’t understand why she can’t accept the help. Sometimes she will ask us to take lids off something. If I’m in the kitchen and I see her pouring a hot water bottle, I will offer to help but you have to second guess, she doesn’t ask, you have to work it out. You have to be constantly aware of what she is doing and whether or not she can or can’t do it, she won’t say, “Look this is hard for me. Please do it.” I mean there is usually someone around when she pours her hot water bottle for the night, but she won’t ask for help, you have to guess. It is hard trying to second guess the whole time but she won’t tell you what’s hard for her either, you have to work it out. It’s frustrating. I have to think, okay what is going to be hurting her and if she complains you have to make sure you take note of it (Fran, 1:9-10).

Knowing when to leap in and help her mother and knowing when to stand back is very difficult for Fran. Fran's mother has had rheumatoid arthritis for four years and her functionality has rapidly declined, especially in the last two years. Fran has not had the time or experience that many other participants have had of answering the call to care. She tells us of the frustration she feels when her mother does not accept her offers of, or attempts to, help. There are times when her mother will ask directly for help, other times when Fran somewhat frantically tries to guess when help is required.

This story suggests the need to find the balance between leaping in and leaping ahead. Knowing how to care is no easy task for Fran. She seems to want constantly to leap in, taking care of things for her mother, when perhaps it might be better to stand back and await the invitation. Knowing how to answer the call to care involves concern and vigilance ("*second guessing*"), concern and vigilance in waiting and watching for the leaping-in moment. Perhaps in watching and waiting one is in fact leaping ahead.

In contrast to Fran, Sam has lived almost all her life in the always-thereness of rheumatoid arthritis. She was three years old when her mother was diagnosed with rheumatoid arthritis. In the next story, she speaks of learning how to answer the call to care.

When I was a teenager I'd get impatient, I used to rush in and say 'Here I'll do that'. Mum used to get so upset. I learned from that, I suppose it took me a while to learn from that, that you don't just rush in and do it, you wait until she actually needs help, because she can do things, it just takes her longer, and if I rush in there and grab something out of her hands then she will feel silly in front of everybody, and I don't want her to do that, because she will feel worse (Sam, 1:23).

Sam tells of how, as a teenager, she would impatiently rush in (leap in) to do things for her mother. With time she learnt that leaping in in this way was inappropriate as it left her mother upset and feeling "*silly*" in front of others. By standing back and letting her mother do for herself the things that she can do, Sam is indeed caring for her mother. She is caring for the 'self' of her mother. She is caring for her mother's autonomy, as a mother, as a woman, as a hostess. In standing back, Sam is letting her mother 'be'. Young, interpreting Heidegger, suggests that the meaning Heidegger gives to 'letting it be' is one of "authentic solicitude" (1997, p. 105), one of leaping ahead.

The being of self that letting be allows in this story can be the very thing that gets in the way of care at other times. For example, Mary says of her father, who has rheumatoid arthritis, “*He expects me to do things sometimes that I don’t really want to do. I wouldn’t mind if I was doing nothing, but often I’m halfway through something or about to go out*” (1:16). In this example the being of self (Mary’s self) is more important than helping the other. The call to care wants to be ignored.

Finding the balance

Is it possible to find the balance, to answer the call to care in a way that everyone feels cared for in a positively solicitous way? It is hard to get it right all the time. Many participants, like Pat, tell of “*still making mistakes even after more than thirty years*” of living with rheumatoid arthritis (1:15). However, most of those living with the always-thereness of rheumatoid arthritis seem to get it right most of the time. The next story illustrates finding the balance. It shows the presence of care that leaps in and care that leaps ahead. It also shows the reciprocity of care that is also called forth in the always-thereness of living with rheumatoid arthritis.

I think that I am closer to my husband than I would be if I didn’t have rheumatoid arthritis because of him dressing me and pushing me around. I suppose if I took the time I could do many of the things, but I get so tired doing it and he does it for me. It means that in some ways it makes us closer. I think it’s because he helps me getting dressed and we can talk about things, and he even knows how to get my bra on properly (Laughter). He always has to come with me when we go out which has meant that we have a very strong relationship which is so, so important. I have got a lot of friends, because people aren’t sorry for me, they see that I have got difficulties but it’s me they talk to not the difficulty. Everybody tries. Take the toilets that we have in the Church hall. They consulted me about them and made sure that I can use them, and every time I use them they say, “Did it work all right, are you happy with it?” I can say that there are other people coming along who are going to find it just as useful and just as convenient (Rosie, 1:14).

Rosie, who has had rheumatoid arthritis for more than thirty years, is now in a wheelchair. In this story, she describes the feeling of being ‘closer’ to her husband. The closeness has developed as he necessarily leaps in to care for her many physical needs. It is a caring that arises in part from such acts as dressing her and always being together. In leaping in, Rosie’s husband is taking care of the things that she needs him to take care of. Heidegger cautions of the danger of domination and dependency that can arise

from the mode of care which leaps in (1927/1962, p. 122). Yet, there is no sense of domination in the relationship between Rosie and her husband. There is dependency in the relationship as she requires his almost constant care, but it is not a dependency that could be considered in any way to be negative.

Rosie also describes the caring she feels from her church community, who recently sought her opinion when designing a new toilet facility. This is the care that leaps ahead in its solicitude. Ensuring the toilets were suitable for her use meant the toilet had to be a unisex one in which her husband would feel comfortable in attending to her care. It is the care that leapt ahead, enabling a degree of independence and comfort that Rosie, and to some extent her husband, would otherwise not have had.

Reciprocity of caring also resonates in Rosie's story. In describing using the newly designed toilet that has involved her input, Rosie looks to the future. She hopes "*Other people coming along are going to find it just as useful and just as convenient*". To both care and be cared for is constitutive of being human. The nursing literature resonates with the need to 'allow' the person who has rheumatoid arthritis to be as independent as possible and to participate in as much 'self-care' as is reasonable. Yet perhaps it is not only self-care but also caring for others that matters. In severe disability it is easy to leap in and take away caring. In the always-thereness of living with rheumatoid arthritis, even in the face of severe disability, caring for others matters.

There is also laughter in Rosie's life. She shares with her husband a love and intimacy that is perhaps greater than that shared by many couples. Perhaps this love and care was always there, but it could also be that the rheumatoid arthritis in its always-thereness has called out this care in new ways.

Always-thereness and the dictatorship of they

As has already been discussed, we are always in the world with others. There are the others, described above, who are close to us in our world, those with whom we have relationships, those for whom we care and who matter to us. There are many others in the world, others with whom we do not have a relationship as such, who none the less influence the way we are in the world. Who are these others? Heidegger suggests "The 'who' is not this one, not that one, not oneself, not some people, and not the sum of them all. The 'who' is the neuter, *the 'they' [das Man]*" (1927/1962, p. 126).

Furthermore, 'they' are a necessary part of our being, "[they] belong to Dasein's positive constitution" (p. 129). Our cultural values and traditions as well as public opinion underpin the 'they'. These values, traditions, and opinions determine what one does or does not do in particular situations. It is they who dictate our average everyday way of being-in-the-world. As Heidegger describes it:

We take pleasure and enjoy ourselves as *they* take pleasure; we read, see, and judge about literature and art as *they* see and judge; likewise we shrink back from the 'great mass' as *they* shrink back; we find shocking what *they* find shocking. The 'they' which is nothing definite, and which all are, though not as the sum, prescribes the Being of everydayness (1927/1962, p. 127).

In other words, in our everyday being, we are for the most part the 'they-self'. Our actions and our interpretations, or understandings, of the world are guided by what 'they' say is right, or is wrong, is possible or not possible, should be done or should not be done. The 'they-self' is neither good nor bad, it just 'is'. Without recourse to the they-self, much of the mundane actions of our everyday lives would not occur in the taken-for-granted way that they do.

Because the 'they' guides the behaviours and actions of our everyday lives, it is important in the exploration of any phenomenon to consider the 'they'. Who are the 'they' of this study? Who are the 'they' inherent in the always-thereness of living with rheumatoid arthritis?

The 'they' of this study are both implicit and explicit in the experiences of those living with rheumatoid arthritis. The 'they' of our focus are the 'they' that prescribe or dictate the average everyday being of those who live with rheumatoid arthritis. Those who live in close relation, partners and adult children in particular, can voice the 'they' to the person who has the disease. The media that surrounds everyday life speaks as 'they', as do health professionals, friends, shopkeepers, and many others encountered in everyday life. Partners and adult children too are in the web of the 'they', living their lives as 'one does', and as one should. Let us consider the experiences of 'they' from the data.

In the following story Sue, who has rheumatoid arthritis, describes the frustration of not being able to do what she should be able to do, of what 'they' say she should be able to do.

It can be annoying when your mind is willing and your body's not, your mind is willing to do things and in your mind, like in my mind I can still do everything that I used to be able to do and I get up to do it and I get angry, really angry at myself when I can't do it. Then my mother will come along and do it for me, and I get cross, not really at her, but at the thought of her doing it. It's the same with my children. Sometimes I get cross because someone has to do it for me and it makes me really angry because I'm only 45 and I'm quite capable in my mind. I'm still active enough, I still feel I can do it and I get really frustrated with myself when I can't (Sue, 1:3).

In the story Sue speaks of the anger and frustration she experiences when she cannot do things that her mind is willing to do but her body is unable to do. There is the frustration of not being able to do what she wants to do, what 'one' should be able to do, what 'they' can do, and the anger and frustration of having to watch someone else do these things for her. What adds to the anger and frustration is that some days she is able to do some things, on other days she cannot. As Sue continues:

I have bad days and not so bad days. On a bad day there is no way that I can just pull a small packet of chips apart for my daughter. We have to get out scissors or a knife and we have to cut it open. It is just simple, silly little things like that that are so frustrating. And I sit here and think how useless can I be that I can't even open a packet of chips for a child (Sue, 2:12).

Sue's frustration seems twofold. Firstly, she does not have the strength in her fingers to open the bag of chips, resorting instead to using scissors. Secondly, there are constant fluctuations in her ability to complete a 'simple' task such as this. On a 'good' day, she can do it, on a 'bad' day she cannot; such is the uncertainty of her life. What is the 'they' of this story? 'They' tell Sue that at forty-five years of age, she should be able to do things for herself, however, in the always-thereness of living with rheumatoid arthritis, she cannot. The frustration and anger is perhaps not so much that she needs help (from her mother, the scissors) but knowing that she should not need help. Knowing that 'they' (other mothers, other 45-year-olds) do not need help.

Knowing what 'one' should and should not be able to do, how we 'measure up' against others, against 'they', is something we all do, it is constitutive of our being-in-the world. As King, interpreting Heidegger, says, "[we] understand [ourselves] in [our] difference from the others by the *distance* which separates [our] own possibilities from theirs" (1964, p. 112). In other words, for those living with rheumatoid arthritis 'they' are always there to announce the difference, to accentuate the difference, the difference inherent in the always-thereness. Consider Jim's story.

I just try and get on and do what I can do. Like I say with the pain really, I just about block it out and I just do things. Until I stop, like now, sit down and think about how I do things, and I realise that it is different. That I do do things differently and that there's a lot I can no longer do. Being with other people, like when we are camping at Christmas, I feel inferior sometimes because I can't do a lot of the things that everyone else is doing. I try and restrict myself and if they are going to be doing something that I can't do, I will try to plan something else or stay away. Say it might be a walk, it might be a game. I remember going to a camp, a men's camp from Church once. We were having a game kicking the football back and forwards to each other and then it became competitive, it always ends up like that with guys, you know. And in the end we actually split into two teams. There was a line on the ground and you had to kick the ball and then where it stopped, or where you caught it, you then had to kick it back to the other person and try and keep them moving back. And I couldn't kick it, I couldn't even kick it to the line, let alone get it past, to get the guy to go back further. I could actually throw it further than I could kick it but that was two years ago, but I couldn't throw it now either. I felt really bad.

I don't like going to the camps any more, and that's one of the reasons I don't go because before I was into everything sporty. I can't do it now so I don't try, and so they think I'm sort of a wuss or something like that. So it hurts me to be there watching them and to know that I used to be able to do these things and probably better than all of them, and to now not be able to do it. So I would rather not be there. To stand and watch is just too hard. So I'd rather just make an excuse that I can't go.

It's the same with the kids with their soccer. I've really wanted to coach them, like all Dads want to coach their boys, but I can't, so I just try and keep away from the practices. It's hard because I played 'rep' soccer, and feel I've got a lot to offer, but I would rather not try knowing that I couldn't do it. I want to do it, but I just can't do it. I try and go to all their games but even that's hard. One parent normally gets to be a linesman. When I see the coach with the flag looking for someone to do the job I try and just keep away until he has given it to someone else because I couldn't run the sideline. So with things like that I suppose I'm aware of what I can't do, and so I keep back so I don't get asked. But I mean that's how it is (Jim, 1:34-36).

What is the they-self of this story? Jim speaks primarily of being a man and being a father. Jim measures himself up against other men and other fathers and finds that there are many things that 'everyone' else is doing that he is unable to do. He cannot walk the way others walk, as 'they' walk. He cannot kick or throw a ball the way others can kick or throw a ball, the way 'they' can. He cannot run the sideline like others run the sideline. When Jim measures himself up against others, he recognises the distance between what he can do and what others can do, what 'they' can do. In being-with others he often "*feels inferior*". It hurts him to feel inferior when he does not measure

up to others, when the distance and difference is too great. It also hurts him that others might judge him as inferior (“*a wuss or something*”) if he does not try to do as others do, as ‘they’ do. If he can, Jim will plan to do other things, or to exclude himself from events, rather than show the difference and distance. If he cannot exclude himself, such as from the sideline of soccer games, he will withdraw (“*keep out of the way*”) rather than face the ‘they-self’ in which difference is accentuated. To stand by and face the difference can be “*too hard*”. It is in the ‘dictatorship of they’ that difference is announced again, and again, and again.

There is a sense of anger, frustration and sadness for Jim in not being able to do the things ‘one’ should be able to do as a man and as a father. He misses out on being the father he would like to be and finds it hard to be the father he is. The father he is cannot coach soccer, yet “*all Dads want to coach*”. ‘Other’ Dads can coach; ‘they’ can coach. It is not that Jim does not want to do what other Dads do, what ‘they’ do, it is that he cannot. Unlike other fathers, Jim does not have the choice whether or not to coach the soccer team. Jim’s only choice is not to coach. He does not have the choice to be the father he wants to be. In the always-thereness of living with rheumatoid arthritis, he is the father he is, not the father he would like to be; the father ‘they’ say he should be. There is a grudging acceptance of “*how it is*”, of the thrownness of his situation.

The ‘dictatorship of they’, of what one should and should not do, permeates this story as Jim recognises the difference between himself and others. The difference is measured in the distance between what he can and cannot do as a man and as a father and what other men and other fathers do, the distance between himself and ‘normal’ men, ‘normal’ fathers, and what ‘they’ can do. There is, however, another ‘other’, another ‘they’, to whom Jim measures himself, that is the ‘other’ of his past, the ‘self’ he was before he was thrown into the world with rheumatoid arthritis (“*a ‘rep’ soccer player, into everything sporty*”). We all live with the ‘they’ of our past. Few of us can do at forty what we were able to do at twenty years of age. However, the difference and distance is accentuated in the always-thereness of living with rheumatoid arthritis.

We cannot forget our past. As Heidegger reminds us, our past goes with us, alongside the present and into the future (1927/1962, p. 20). Jim’s past, his being the father, the man, he once was goes with him. Against the past of his being-in the world Jim is also able to understand the distance and difference between the father/man he once was and

the father/man he is. The ‘they’ of the past that comes with him lingers as a constant challenge to his being-in-the-world with rheumatoid arthritis. Living with rheumatoid arthritis means learning to live with this tension of ‘they’.

We have so far glimpsed the tension of the ‘they’ in two ways. Firstly, the tension of the ‘normal’ ‘they’, of everyday doing what ‘one’ does when one is not in the world with rheumatoid arthritis. Secondly, the tension of the past, of what ‘one’ did before being thrown into the world with rheumatoid arthritis. There is a third dimension to this tension. The ‘they’ of what ‘one’ should do and what ‘one’ should not do when one has rheumatoid arthritis also dictates to people with the disease. As Sue tells us:

My main problem has been not doing too much. For years my rheumatologist has been saying, “You are still doing too much. You’ve got to learn to pace yourself”, which is darned annoying at times (Sue, 1:3).

Sue finds ‘not doing too much’ and ‘pacing herself’ annoying at times. Although these things are prescribed as what ‘one’ should do in living with rheumatoid arthritis it is very difficult to fit this in with the reality of her life as a mother of three. Sue lives with the constant tension of doing what she should do as a person with rheumatoid arthritis, and doing what she should do as a mother. This tension is further illustrated in Margaret’s story.

I’ve started having trouble with my wrists and I have probably done too much. I was very very stupid when there was a water shortage. There was a very hefty campaign to save water and the thought of the water having to be turned off and going to stand-pipes for water was very threatening to someone like me. So obviously, I was doing my bit, and I was bucketing the water and I did tremendous damage to my wrists. When I told my rheumatologist what I did he was furious at me he said, “Look, we have got a water shortage now for possibly six months, you have got arthritis for the rest of your life and what are you going to do if your hands and wrists are useless to you?” But you see I am a conscientious person and I sort of fell into the trap of doing my bit. I have an aunt, an 80-year-old aunt, who was bucketing water, her bath water, and then tipping it into the cistern. Maybe it is the mould I come from (Margaret, 1:8).

Margaret incurred the wrath of her rheumatologist and accelerated the destruction of her wrists, already damaged by fifteen years of disease, through carrying bucket loads of water. In hindsight, she considers her actions to have been “*stupid*” and that carrying the buckets amounted to “*doing too much*”. The ‘they-self’ knows that as a woman with rheumatoid arthritis ‘one’ does not “*do too much*”, ‘one’ paces oneself, and ‘one’ is

always concerned about the principles of joint preservation. Yet, what of the woman, who as a wife and mother, has strong community values, always willing to do ‘her bit’? ‘They’ told Margaret of the need to conserve water or suffer the consequences, consequences that were “*threatening*” in their severity to her as a wife and mother, and as a woman with rheumatoid arthritis. Margaret knew that she, the person with rheumatoid arthritis, should not carry the water, ‘they’ said she should not, but as a woman with a social conscience, she ‘knew’ she should do it, ‘they’ said she should. She was caught between conflicting ‘they’; the ‘self’ was entrapped by the ‘dictatorship of they’. ‘They’ were giving her discordant messages; she seems to have heard the loudest one. Next time, aware of the consequences, she may choose to listen to a different voice, or she may not.

Living with this tension between the ‘they’ of being-in-the-world with rheumatoid arthritis and other ‘they’ is always there for people like Margaret. The ‘they’ of living with rheumatoid arthritis are often health professionals who prescribe what ‘one’ should and should not do as a person with rheumatoid arthritis. These prescriptions are often at odds with the everyday realities of life for these people as they strive to be parents, lovers, friends, and colleagues. It is the tension of conflicting ‘they’ that underpins the ‘*soldiering on*’ (Lilly, 2:29) that occurs in the lives of many people who live with rheumatoid arthritis. Soldiering on enables them to do what ‘one’ should do, what ‘one’ needs to do, as a parent, as a partner, as a worker. Soldiering on is always in the face of what ‘one’ should do as a person with rheumatoid arthritis.

Working with the tensions of ‘they’

The next story illustrates how one woman works with the tension of the ‘they’ as she lives in the always-thereness of living with rheumatoid arthritis.

I found it very hard in the beginning to admit that I couldn't do things any more. I now know that there are days where I've got to rest, like today. It used to worry me, I would be worried because everything was a mess and I would try and do it and because I'd try and force myself that little bit extra, then I would be out for a week or two weeks. Now I know that there are days I have to rest and it doesn't worry me if things don't get done. They will still be there tomorrow and the next day and then I'll do it. Before I used to go into a panic and do it and then absolutely annihilate myself for a couple of weeks. But over the years now I've just got to the stage where I just think 'To hell with it, it will have to wait.' I don't worry about it any more (Sue, 1:2).

Sue speaks of adjusting to the fact that some days she needs to rest, days when her rheumatoid arthritis is particularly active and the pain is particularly intense. She used to find it impossible to rest in the presence of ‘mess’, when the house needed tidying, the clothes needed washing, and the bathroom needed cleaning. She would soldier on with these tasks, ignoring the need to rest and as a consequence putting herself in the situation where, instead of needing to rest for one day, she would need to rest for two weeks. Over time she has developed a *laissez-faire* approach, ignoring the mess and resting, as she needs.

It seems that in the early days it was the ‘they’ of how to be a ‘normal’ woman that spoke louder than the ‘they’ of how to be-in-the-world-with-rheumatoid-arthritis spoke. Sue did what ‘one’ was expected to do as a woman and mother (have a tidy house) and ignoring what ‘one’ should do as a person with rheumatoid arthritis (rest when needed, not wipe yourself out for two weeks). What happened, what brought about this change?

Sometimes we are drawn from our average everydayness to face the dictatorship of they and in so doing recognise that there are other ways of being-in-the-world, ways that are acceptable for the individual, even if they are different from what ‘one’ does. We come to recognise that other possibilities of being-in, being-with, and being-for are acceptable. Gelven interpreting Heidegger says:

When Dasein gets into a certain mood, however, in which this involvement with the they-self is no longer an easy, “natural” kind of thing, Dasein seems forced to stand back and reflect upon its role. The feeling at-home with the thoughtless milieu of the “they” is lost. In the midst of such alienation Dasein turns to itself (1970, p. 120).

In other words, there are times (perhaps for Sue it is during those times when she is forced to rest after “*annihilating*” her self) when we stop and reflect about ourselves as individuals. Instead of ‘going with the flow’ and doing what ‘one’ does we stop and think about what ‘I’ do, what ‘I’ want to do with ‘my’ life, what is important to ‘me’. Reflecting on herself, Sue was able to recognise that her well-being through rest was more important than the tidy house dictated by ‘they’.

Reflecting on ‘self’, turning to ‘self’, is not always easy such is the power of the ‘they’. It is rendered even more problematic by the tension between the ‘they’ of ‘normal’ being-in-the-world, the ‘they’ of past (pre-rheumatoid arthritis) being-in-the-world, and

the 'they' of being-in-the-world with rheumatoid arthritis. Facing the 'they' involves working with the tension of multiple 'they'. Moreover, as facing the 'they' is not how we comport ourselves most of the time, turning to 'self' is often transient. We are often, and usually, drawn back to doing what 'one' does, what 'they' do. For example, although Sue is now comfortable in resting when she needs to despite the 'mess', there are other times when she ignores the call to rest. She will often soldier on with other things, supporting her children's sporting endeavours, perhaps because her children matter more than the tidy house matters. Perhaps facing the 'they' (resting as 'they' say she should rest) when she chooses to, means that choosing not to rest remains a possibility when something matters more.

The tensions between the 'dictatorships of they' underpin the always-thereness of living with rheumatoid arthritis, whether as a partner, an adult child or a person with the disease. Can this tension be resolved? I have come to understand that the conflicting tensions between the 'they' of the past, the 'they' of 'normal' everyday life, and the 'they' of being-in-the-world with rheumatoid arthritis can never be resolved, they are always there. Living with the tension is fundamental to being-in-the-world with rheumatoid arthritis. For the most part this tension is covered over in the being of everydayness where the 'they-self' resides. However, at times it is disclosed in the anger, the frustration, and the sadness of living with rheumatoid arthritis. Yet, this tension also discloses the strength, the tenacity, and the loving care of living with rheumatoid arthritis.

Conclusion - the play of the always-thereness

'Play' is a Gadamerian notion brought to this interpretation because of its usefulness in helping to disclose some of the tensions that exist in the lives of those who live with rheumatoid arthritis. The Gadamerian notion of play is complex, however one aspect of this notion is particularly useful here. Gadamer speaks of the metaphorical use of the word 'play' (which he considers meaningless to distinguish from the literal usage) such as the play of light and the play of the waves. In this usage what is intended is "to-and-fro movement that is not tied to any goal that would bring it to an end" (Gadamer, 1960/1989, p. 103). Gadamer suggests that it is the movement of the play that is central and it makes no difference who or what performs the movement. Furthermore, play is

not to be understood as something a person does but something that happens, as it were, by itself (1960/1989, p. 104-105).

It is worth considering the play of the always-thereness. Those living with rheumatoid arthritis, whether as partners, as adult children, or as people with the disease, live with the play, with the tension, between rheumatoid arthritis mattering and not mattering in their lives, in the 'worlds' in which they dwell on a daily basis. Gadamer suggests that it is the movement of the play, not the players, which takes central stage. Perhaps it is the play of the always-thereness that takes central stage in the lives of those who live with rheumatoid arthritis. It is in the play of the always-thereness that rheumatoid arthritis becomes part of the background familiarity for encountering anything at all. In the play of the always-thereness the mattering alters. Hall draws us back to Heidegger when he says:

The different background practices and perspectives lead to equally different styles of encountering and dealing with things involved, and they make different features of things relevant or irrelevant, important or unimportant. (1993, p. 134)

The background practices and perspectives, the worldhood of those who live with rheumatoid arthritis remain always in the play of the always-thereness. Being human means inhabiting a number of worlds, and worldhood is the structure that underpins them all. As the always-thereness of living with rheumatoid arthritis is part of this structure, so too does it underpin all aspects of those worlds. It is always there.

This chapter has explored the impact on the lives of those who experience the phenomenon of 'living with rheumatoid arthritis', whether as partners, as adult children, or as people with the disease. I suggest that the always-thereness of living with rheumatoid arthritis becomes part of the background familiarity in their lives and as such it influences, to varying degrees, almost every aspect of their lives. In the next chapter the fears and anguish that the participants spoke of as they live with rheumatoid arthritis are explored along with the possibilities and strengths that may emerge as they live in the always-thereness of living with rheumatoid arthritis.

CHAPTER EIGHT: Fear, Dread, Hope and Possibility

I sometimes think about where I am going to be in ten years' time, or 20 years' time, what will I be able to do, what will I not be able to do and if I am going to be in a wheelchair or not. I think about that. But I try not to. But every now and again I might see someone in a wheelchair and I quickly think 'Oh that could be me' (Jim, 1:31).

The future is at some time a concern for most people. As a person with rheumatoid arthritis Jim seems to think of his future in terms of what he may or may not be able to do physically. The sight of someone in a wheelchair often calls him to think of his future although it is something about which he would rather not think. In Jim's story there seems to be a sense of anxiety or fear as to what the future may hold, "*where [he is] going to be*".

Many participants speak of the future and of what it might mean for themselves and their families. This is the case whether they are people with rheumatoid arthritis, or partners or adult children of someone with the disease. Sometimes participants speak in terms of fear of and for the future. Other times they speak of hope for the future in terms of new treatments that might be available or the possibility of the always-awaited remission. The future is spoken of with a sense of anticipation, perhaps even of inevitability; anticipation and inevitability in relation to how things might progress in terms of the rheumatoid arthritis. Alongside this sense of anticipation and inevitability is the desire to plan, in practical terms, for the future. People plan for the possibility of declining functionality in the person with rheumatoid arthritis, of how that might be accommodated, through such things as alterations to the house, or the type of car purchased. For some, a change in employment is made or career decisions altered in anticipation of what the future might bring. Although these decisions are made on a practical level there remains an underlying sense of anguish and fear associated with the stories of the future. Anguish of what? Fear of what?

This chapter explores the fears and anguish that the participants spoke of as they live in the always-thereness rheumatoid arthritis. It explores the fears, anguish, and hope they experience as they face the future in the throw of rheumatoid arthritis. It shows the possibilities and strengths that may emerge as they live toward the future.

Heideggerian Notions

Heidegger offers some thoughts that might help in uncovering this aspect of 'living with rheumatoid arthritis'. Heidegger speaks of 'fear' and of 'angst', acknowledging their interconnectedness while at the same time clearly differentiating between them (1927/1962, p. 342). I too need to make this differentiation. I begin with 'angst', or 'dread' as it is often translated.

Dread

'Angst' has been translated as 'anxiety' (Frede, 1993; Heidegger, 1927/1962) or 'dread' (Gelven, 1970; King, 1964). I will use the term 'dread'. Heidegger identifies 'dread' as one of the basic moods of Dasein. "Dasein always has some mood" (Heidegger, 1927/1962, p. 134). We may have good moods and bad moods, our mood may change, but we are never without some mood. Although we always have a mood, the being of that mood can change. Mood is something that just happens, it is just 'there'. In our everyday living, we do not always recognise our mood. However, there are times when mood discloses itself, we become aware of being in a happy mood, a contemplative mood, or a bad mood. With the disclosure of mood, we can choose to turn towards or turn away from that mood. "When we master a mood, we do so by way of a counter-mood" (Heidegger, 1927/1962, p. 136). Having a mood makes it possible to direct oneself toward (or to turn away from) something that matters. The fact that one thing or another matters to us is grounded in our state-of-mind or mood (Heidegger, 1927/1962, p. 134). What is it that matters to us when we are in a mood of dread?

Heidegger suggests that during times of dread we are forced to confront our own finitude, our own being-toward-death. In so doing we recognise the finiteness of the possibilities of our life instead of seeing life as an "endless multiplicity of possibilities" (1927/1962, p. 384). Dread like any mood discloses itself only intermittently but it is always 'there'. Gelven, in discussing Heidegger's notion, describes dread as the "weird and uncanny feeling, in which the whole familiar world seems to lose its normal significance" (1970, p. 115). When we are face to face with our own mortality the things that matter to us in our everyday lives are overshadowed by the realisation of the finiteness of our being. That which dread turns towards or away from comes from within our being, and the enormity of what it brings us face to face with (our being-

toward-death) is such that “few of us recognise it as fully and explicitly experienced by us” (King, 1964, p. 128). The thing that matters to us (our being-toward-death) when the mood of dread is disclosed, that which we turn towards or turn from, is something about which we can do nothing (King, 1964, p. 130). It just ‘is’. Moreover, in dread the things we can do something about shrink into insignificance or irrelevance. How does dread differ from fear?

Fear

In contrast to dread, fear is always fear of something. In our experience of fear we can discover some ‘thing’ that we are fearful of. Furthermore, fear is always fear for ourselves as individual beings. King helps us to grasp by explaining this notion:

Fear is always “fear for...” In being afraid, man is afraid for himself. Man is capable of fear, because in his being it is this being itself which is at stake.... Even when fear is not directly and immediately for his own being, but for property and possession, man still fears for himself, because his access to things, his “being near to things” essentially belong to his being-in-the-world (King, 1964, p. 80).

In other words, we fear some ‘thing’, for example an impending appointment with the dentist. We fear what it will mean for us, pain at the hands of the dentist perhaps; it is our being that is at stake. With fear, we also know what will take the fear away, cancellation of the dental appointment for example. We may fear for our property or possessions. For example, we might fear for the safety of our home while we are away on holiday. Our home is very much part of our being-in-the-world and if it were burgled or burnt down while we were away it would affect us greatly. Again there is something we can do to remove (or at least diminish) the fear. We could install a burglar alarm and ensure electrical appliances are switched off to minimise fire risk. King continues:

Similarly, when man is afraid for someone else, he still fears also for himself, being threatened in the most fundamental relational possibility of his existence, his being with others like himself” (1964, p. 81).

Fearing for others, even if they do not fear for themselves, is constitutive of our being-in-the-world with others. However, in fearing for others it is our being that we fear for. Heidegger tells us, in fearing for others “what one is apprehensive about is one’s Being-with with the Other, who might be torn away from one” (1927/1962, p. 142). In other words in fearing for others, we are fearful of what it might mean to us in our

relationship to others. Furthermore, it is because we are already in the world, intimately connected to the world, that something can be fearsome to us.

How can these notions of fear and dread help us in our understanding of ‘living with rheumatoid arthritis’?

Fear and dread in living with rheumatoid arthritis

Heidegger in his exploration of dread tells us that dread brings us face to face with our being-toward-death. What if we consider this in regard to being-in-the-world with rheumatoid arthritis? Being-toward-death is a reality for everybody from the moment they are born. Being-in-the-world with rheumatoid arthritis has a similar inevitability. The nature of the disease is such that once a person has the disease it is with them for the rest of their lives, they remain in the throw. Some people may have only one or two exacerbations when the disease discloses itself and then retreats to the dark. Yet, it is always already there. Not being-in-the-world with rheumatoid arthritis is no longer a possibility. As being-toward-death discloses to us the finiteness of our being, being-in-the-world with rheumatoid arthritis discloses a finiteness of possibilities for those who live with the disease. For partners and adult children too, once thrown into the world of living with rheumatoid arthritis the thrownness remains with them for the rest of their lives. Even if they no longer live with rheumatoid arthritis in a practical sense through separation from or death of the person who has the disease, they carry with them the experience of living with rheumatoid arthritis. It will always go ahead of them, influencing their worlds.

How are fear and dread revealed in the data? Consider this story from Tony, whose wife has had rheumatoid arthritis for more than thirty years.

While most folks say things like “I’m going to retire at 60 and I can’t wait for a big European trip” or “Next year I’m going to buy this art work” or something, my wife’s goals are quite different. Her goal is to get through the day or the week; the next year she can hardly bear to think about.

The deterioration continues so insidiously that it can hardly be thought of, so we don’t plan like other people plan. In a sense now, I contradict myself, because we are here in a new house and we have planned for it, but generally my wife doesn’t like to think too much about times that are out there. I think that part of her way of coping is to get by one day at a time. I cajoled her into shifting house; it has been very stressful for us. All through the house, everything is just as easy as we can ever get it but that all took

decisions. It all took thinking about, consulting about, but it is a bit of planning for the future. But I know my wife gets by by actually trying not to think of when she's 60 or 65, the relative horribleness of that.

When I look upon the future, it's hard to see the blue sky if the truth's to be told. I talked to my GP recently, asked him about the future and he has no inspiration other than to say eventually it may affect Shona's longevity, and that's not something I like to think about but it's likely to shorten her life. I suspect that privately she would be happy not to lead a normal life span. I think in her circumstances I would probably feel the same. I can empathise with that (Tony, 1:21-23).

In this story Tony is speaking of the future, and of making plans for the future. For Tony the future and his future plans are intertwined with those of his wife whose physical “*deterioration continues so insidiously*”. Tony sees his friends planning ahead for a perceived bright future of a healthy retirement and overseas travel, however for him the future does not seem so bright. He sees a future marked by continual deterioration in his wife's strength and functionality and possibly premature death, something about which he does not like to think. Living toward the future involves a tension for Tony between planning and not planning for the future. He recognises that his wife “*doesn't like to think too much about times that are out there*” preferring to “*get by one day at a time*”. However, planning does occur in their lives but it is different, they plan in a different way and for different things, for a different future in the world with rheumatoid arthritis. For example, they recently moved to a new home designed specifically for them with his wife's deteriorating functionality a prime consideration. Although not required at present, doorways and bathrooms have been designed for wheelchair access. There is a sense in this story that Tony shares his wife's reluctance to consider the “*relative horribleness*” of the future but it is something he does consider having recently discussed his wife's prognosis with his doctor. He does not like to think about rheumatoid arthritis shortening his wife's life span while at the same time empathising with his wife being “*happy not to lead a normal life span*”.

Living with rheumatoid arthritis interpenetrates all aspects of life, past, present and future. Anticipation of the future reveals possibilities, possibilities that are constituted by the past and present. There is an awareness, an anticipation, in Tony's story that the possibilities for his life and that of his wife are very much affected by the thrownness of rheumatoid arthritis. Although the future, and his wife's increasing physical limitations, “*can hardly be thought of*” by Tony, it is thought of. The knowing Tony brings with

him from the past and the present influences his anticipation of the future. It is a knowing that knows of the relentlessness of rheumatoid arthritis in its attack on his wife's functionality. A knowing that has come to know of the effect the disease may have on his wife's longevity and on her thinking about death. A knowing that recognises the possibilities of what might happen and what might not happen, of what can be planned and what cannot be planned.

What is it in Tony's story that "*can hardly be thought of*"? Is it the future in itself or is it what the future might bring? There is perhaps an underlying sense of dread of the future in Tony's story, a dread of the "*horribleness*" that the future might hold.

There is a sense of dread at the possibility that his wife's life may be shortened by her having rheumatoid arthritis. King, interpreting Heidegger, reminds us dread is always dread of something about which we can do nothing (1964, p. 130). The dread is something Tony can do nothing about; not having rheumatoid arthritis is not a possibility. Turning towards the dread is not something he likes to do, but at times the mood does disclose itself and he finds himself face to face with it. Tony, as a partner, has lived with rheumatoid arthritis for more than thirty years. He knows of the insidiousness of his wife's disease and recognises the finiteness of possibilities for the future, for example, a retirement different from that of his friends and perhaps becoming a widower earlier than expected. Turning away from the dread brings Tony into the everydayness of being-in-the-world with rheumatoid arthritis. This is the familiar world, the practical world, where 'things' matter. In the everydayness, there are things that can be changed, plans that can be made, that will influence the everydayness of his being-in-the-world with rheumatoid arthritis. However, no amount of planning for the future can change that which is disclosed in dread.

Like Tony, Jan, whose mother has rheumatoid arthritis, speaks in the next story of looking forward to the future.

It's really hard because I am also looking forward to the future. There is the looking forward and the anticipation of the wheelchair and all those sorts of things, which I can't help but imagine, are to come. The inevitability of that kind of helplessness is really scary. I can't help but wonder, what does that mean for everybody? I imagine that I will be looking after her and that affects the way that I look at my future as well because I guess there is always going to be a need for me to take that into consideration (Jan, 1:15-16).

Jan tell us how difficult it is for her to consider the future, to look forward to the future. 'Looking forward to' is usually associated with anticipation of something pleasurable, but for Jan the looking-forward-to is "scary" as she anticipates further deterioration in her mother's functionality and the possibility of the use of a wheelchair. The effect of these changes on Jan's own future is part of the anticipation. She anticipates a future role in helping care for her mother and considers this as she plans her own future. Jan's story seems to be full of dread and of fear. In dread, Jan sees the finiteness of possibilities for her life. Jan dreads the physical changes in her mother's body and what she sees as the inevitable helplessness that comes with them. There is nothing she can do about this; what will be, will be. The rheumatoid arthritis 'is' already. Jan fears for 'everybody', her mother with rheumatoid arthritis, and those close to her, "*What does that mean for everybody*" she wonders? She fears for herself, for what her mother's deteriorating physical condition might mean for her future. Heidegger reminds us fear is always fear for ourselves, for our own sake (1927/1962, p. 142). Jan faces the fear by planning a future with the consideration of looking after her mother. Recall in the previous chapter that Jan tells us of making career choices with this consideration in mind (p. 131).

Turning away or fleeing from fear is always a possibility of being-in-the-world. The next story provides an example. In fleeing from fear, Margaret, like many other participants, avoided joining an arthritis support group for many years following her diagnosis with rheumatoid arthritis. She tells us:

It took me a long time to go to a support group meeting. I think that there is the fear thing because you know you are going to see people whose arthritis is more advanced than yours and it can be a bit scary. But since I have been involved I have had a tremendous amount of help and support (Margaret, 1:32).

Margaret feared joining an arthritis support group because she would meet people whose rheumatoid arthritis was more advanced than hers, which "*can be a bit scary*". Perhaps she feared for herself, for her future, in what she was to see in others. Seeing people whose arthritis is more advanced than her own would bring her face to face with that which she feared, there is no turning away from it. Understood in the Heideggerian sense, the fear described by Margaret is something about which she could do something. She could turn away from the fear and not go to the support group, or she could face her fear and attend. Heidegger reminds us, our fear is always in relation to our own being

(1927/1962, p. 142). In seeing people who are different from us, “*whose arthritis is more advanced*” for example, we see them in relation to how we are or how we might be. Over time, Margaret faced her fear. Perhaps the advent of physical deformity, especially in her hands, helped her face the fear and get involved in a support group. In joining the group the fear is confronted, met face on, and it is no longer that which is feared but a source of support and care.

Fear seems to be always there, part of the background familiarity, for many of those living with rheumatoid arthritis. It is always hovering in the background and occasionally in the foreground. As Margaret tells us fear can be “*one of the hardest things*” to live with when you have rheumatoid arthritis.

One of the hardest things for me is a bit of fear. There is always the fear of whether I am still going to be accepted by the rest of the family. Because I know quite a few people who have got bad arthritis and the family by and large has to get on without that person. I like to feel needed and useful (Margaret, 1:6).

Margaret speaks of fear of not being accepted by her family, of not being needed, of not being useful. There is a sense, based on her experience with others, that Margaret relates progression of the disease and decreasing functionality to increasing isolation from the family. Margaret fears for herself as a useful and needed person within the family. It is perhaps this fear that underpins the need to ‘soldier on’ as Margaret and others like her try to maintain a sense of normality in their lives. This fear, although only disclosing itself intermittently, is always with Margaret; it is always there in living with rheumatoid arthritis.

Fear as dread

In everyday usage the words ‘dread’ and ‘fear’ are often used interchangeably, a thesaurus showing each as a synonym of the other (Landau, 1985). Indeed Heidegger denotes this:

These are kindred phenomena.... For the most part they have not been distinguished from each other: that which is fear, gets designated as [“dread”], while that which has the character of [dread], gets called “fear” (1927/1962, p. 185).

‘Fear’ is perhaps more commonly used than ‘dread’ in the everyday language of most New Zealanders, and this would seem to be the case of participants in this study. The

challenge in this analysis is to differentiate the use of the word 'fear' as fear or as dread, in Heidegger's sense of the notions. In the next story, the 'fear' spoken of is analysed as dread, that is 'fear as dread'.

My greatest fear about my RA is becoming helpless. That would be my greatest fear. Being unable to do things for myself. Being unable to bath without help, to dress without help, to feed myself, to go to the toilet, to clean myself up. Those things, I mean it's the total loss of dignity, of not being able to do those things. I would not like that at all, and that would be my greatest fear (Lily, 2:34).

Lily speaks of the fear of "becoming helpless", of being unable to do things for herself, to dress, to eat, to bath, to toilet. She fears the indignity of helplessness. Lily speaks of fear about something, helplessness. However, the 'thing' in this context is her own being, she fears being helpless. The fear in this story is fear as dread because there is not really anything Lily can do about it. She will either become helpless or she will not, such is the thrownness of rheumatoid arthritis. She may take medications and have surgery, which may delay the onset of helplessness, but the possibility remains open. In dread, the possibility of helplessness is revealed. Being-in-the-world with rheumatoid arthritis means living with the dread of possible dependency.

Fear as dread is evident in many other stories and is often, as with Lily, related to the physical progression of the disease, "how it might end up" (Margaret, 1:6). The dreadness of dread in these stories seems to be the possibility of severe disability, seldom is the possibility of not being severely disabled spoken about. The dreadness will always be part of being-in-the-world with rheumatoid arthritis for these people while they wait for the throw of the disease to show itself of itself in its entirety. However, it will never show itself completely until it is no more. The disease is such that it will only be in death that it is fully known, that it will be no more.

Temporality and thrownness in fear and dread

Temporality and thrownness are significant in the experience of fear and dread in living with rheumatoid arthritis. Lily's story provides an example.

When I first got the news that it was RA I thought back to my grandmother who got RA and in eight years she was dead. She was in a wheelchair in two years, almost totally immobile, and then she got heart complications. She got it later than me; she was about 56 I think. It came on suddenly like it did with me and she was really really ill, and it just never went away, because

in those days I don't think they had anything much at all, it was Aspirin or Aspirin. I don't think now that I might end up like my grandmother, but in the early days, it was a real fear. It could happen, but medical science has advanced so much that it is highly unlikely (Lily, 2:29).

Lily talks of the time when she was first told she had rheumatoid arthritis. On hearing the diagnosis, Lily's thoughts were of her grandmother who was struck down with rheumatoid arthritis. With little available treatment and what would seem to be a fulminant disease course, Lily's grandmother died within eight years from cardiac complications associated with her rheumatoid arthritis. In the early days of Lily's own illness journey she often feared that she might "*end up like [her] grandmother*". Lily attributes advances in medical sciences in influencing the course of her illness. She has also now lived with the disease for fifteen years, seven years longer than her grandmother did. Although Lily does not "*think now that [she] might end up like her grandmother*" the memory of her grandmother will always be with her.

In this story, we again see the word 'fear' used in the sense that we have come to understand as dread. We hear of the influence of the past on what is disclosed in dread. The dread relates to the past that goes before Lily, her memories of her grandmother. Heidegger reminds us that our past is something that goes ahead of us in our present and our future. As he says:

Its own past – and this always means the past of its 'generation' – is not something which *follows along after* Dasein, but something which already goes ahead of it (1927/1962, p. 20).

Lily and other participants who speak of relatives who had rheumatoid arthritis carry memories of these people with them. The memory of the grandmother dying within eight years of diagnosis with rheumatoid arthritis is always with Lily, it is part of her being, and it goes before any thoughts she may have of what the future might hold. The memory of her grandmother is perhaps a measure, a comparison, for Lily of how she is faring on her journey.

There seems to be recognition of the historicity of the grandmother's experience, what was not available to her is available to Lily. The thrownness of Lily's being is such that possibilities are open to her that were not open to her grandmother. Possibilities, such as the availability of medications like Methotrexate and of joint replacement surgery, that influence Lily's way of being-in-the-world with rheumatoid arthritis.

Like Lily, Margaret had a grandmother with rheumatoid arthritis. In Margaret's story there is a sense of an appreciation of the throw of thrownness.

There are some days, particularly if I am having a bad day, when I think 'What would I be like if I didn't have modern medication?' I really wonder if I might have been as bad as my grandmother, it wouldn't surprise me. I tend to count my blessings. I believe I have been very lucky to be born at a time when there is a lot of medication available (Margaret, 2:10).

Margaret "counts [her] blessings" that due to the time of her birth, the throw of thrownness; she has had the benefit of modern medications. Yet there are times when dread discloses itself that she "wonders if [she] might have been as bad as [her] grandmother". Perhaps in dread advantages of historicity are revealed.

Worry as dread

Having come to understand how fear could be interpreted as dread I came to see in the data other experiences that seemed to be expressions of dread, although that was not the word the participants used. It became apparent that like fear, 'worry' could be interpreted as dread. Pam, whose mother has had rheumatoid arthritis for nearly twenty years, shared a story that speaks of 'worry'.

I don't very often tell Mum if I've got aches and pains, because I know that that will get her worrying. She doesn't dwell on it but I know it worries her that I might get RA. She said that I could go and have this blood test to see if I've got the gene for it. But I won't have it done. I've said to Mum "If I've got the gene, well if it's going to happen it's going to happen, I don't want to be worrying about it between now and then." I mean I could adjust my lifestyle left right and centre, and then I could get a virus and that could be what sets it off anyway. I don't feel it's something I need to worry about at the moment. If it was really bothering me and in my day-to-day living it was affecting me, worrying about it, then I would go and have the test done. But to be honest I don't ever really think about me having RA from one day to the next, unless I get like a sore shoulder or something. Then there's usually a good reason why I'm aching so I have to be a wee bit careful I don't get too paranoid. I would have the test if it is going to help in research but for my own sake I don't really need to know, I don't have a need to know at the moment (Pam, 1:22-23).

In this story both Pam and her mother are concerned about the possibility that Pam might get rheumatoid arthritis. Pam withholds information from her mother because in telling her mother of any aches or pains she might have she worries her mother. Pam does not want to know whether she has the gene which predisposes to rheumatoid

arthritis because she does not want to worry about something which may not happen. Pam would have the test done, seek the knowing, if the worrying was affecting her “*day-to-day living*”, or if it helped in medical research. However, in not knowing she worries, especially if she gets “*a sore shoulder or something*”, she worries that the pain might be an announcement of rheumatoid arthritis.

What would knowing she had the gene disclose to Pam? If she has the gene she is more likely to get rheumatoid arthritis, although, an environmental trigger is thought to be required to activate the gene. There is an increased possibility of her getting rheumatoid arthritis, although there remains the possibility she would not. Would knowing alleviate the worrying?

What would knowing she did not have the gene disclose to her? Although the likelihood of Pam getting rheumatoid arthritis is significantly reduced if the gene is not identified, there remains the possibility that she will get rheumatoid arthritis, and the possibility that she will not. Would knowing she did not have the gene alleviate the worrying?

Perhaps in this story dread is manifest as worry. Pam tells us her mother worries that she (Pam) might get rheumatoid arthritis. The worry in this context is, as in dread, something about which nothing can be done. Whether Pam gets rheumatoid arthritis is something which neither Pam nor her mother can do any thing about, other than worry, such is the thrownness of rheumatoid arthritis. Perhaps for Pam’s mother there is dread in being a mother who may have passed the gene, and the disease, on to her daughter.

Pam has the opportunity, due to modern technology, to prise open ever so slightly the window of possibilities for the future. She can find out whether or not she has the gene that predisposes one to rheumatoid arthritis. However, having the gene does not mean she will get rheumatoid arthritis, just as not having the gene does not mean she will not get rheumatoid arthritis. It still remains a lottery but with altered odds. Either way Pam remains, as always, in the throw. Pam tells us she does not want to know whether she has the gene because she does not “*want to be worrying*”, it is not “*something [she] needs to worry about at the moment*”. Would knowing confront the dread? By not knowing is she turning away from the dread? The knowing may bring her face to face with dread, with the finiteness of possibilities for the future. There is dread in knowing, and dread in not knowing.

Although Pam does not want to worry and feels she does not have a need to worry, there is a sense that the worrying is always there although only fleetingly disclosed. When Pam experiences a “*sore shoulder or something*”, rheumatoid arthritis as a possibility discloses itself. The pain could be an appearance of the disease, although it is most likely only a semblance, “*There’s usually a good reason why I’m aching*”. Perhaps there is the fleeting feeling of dread, that uncanny not-at-homeness before Pam thinks about other possible causes for the pain. Heidegger reminds us our past always goes before us. The knowing that goes before, the knowing that knows of her mother’s rheumatoid arthritis contributes to that which is disclosed in dread.

Dread and possibility

In the mood of dread we face our own being-toward-death, we experience the feeling of “uncanny not-at-homeness”. It is in the mood of dread that we face the finiteness of possibilities of our lives (Heidegger, 1927/1962, p. 384). What possibilities are disclosed in the dread of living with rheumatoid arthritis? Consider Jill’s story.

I remember how it affected me when I first had the pain and stiffness of RA and before it was under control, wondering what the future was going to hold. I can remember one Mother’s Day thinking, ‘Well even if the children bring me a cup of tea in bed I’m so uncomfortable that I can’t even sit up in bed to enjoy it.’ I wondered ‘Am I going to be like this for the rest of my life?’

Within about a year of me having arthritis, we had a friend who was dying of leukaemia. I can remember driving down the motorway, going towards the hospital to visit her. It was a horrible winter’s night. Sitting in the car I was just so uncomfortable and in so much pain that I thought to myself, ‘In some ways I envy Rachel. At least she is going to die and her suffering will be over, whereas I could have years of this.’

With hindsight, it seems ridiculous, because although I’ve had a few off years in between, overall now I’ve got a really good lifestyle. But that’s how it gets to you in those early days, when you are still trying to come to terms with it and wondering to what extent it is going to affect your lifestyle. You feel you are never going to have a normal life again, and never be able to enjoy things again. But then you find later on well, yes, there are things that you can do. I still have fears about how it might end up but certainly not to the same extent (Jill, 1:15).

Jill tells us that throughout her illness experience “*wondering what the future is going to hold*” and “*fears of how it might end up*” have been with her. In this story, as in previous stories, the fear that Jill speaks of seems to be fear as dread. There have been

times, especially when the disease has been particularly active and the pain particularly severe, when Jill sees the possibilities for her life as particularly full of dread. On one such occasion, early death from a disease such as cancer seemed preferable to living with the suffering of rheumatoid arthritis. With time, “*wondering*” and “*fearing*” have abated somewhat as living with rheumatoid arthritis has become part of the everydayness of Jill’s life and the intensity of the earlier feelings now seem “*ridiculous*”. Alongside the “*wondering*” and “*fearing*” is the recognition that a “*good lifestyle*” and a “*normal life*” are still possible. However, what constitutes the good lifestyle and normal life are changed in the thrownness of rheumatoid arthritis.

In Jill’s story we glimpse the influence of mood on being. When the mood of dread discloses itself it is often in the face of not knowing, of being-in-pain, and of fear. Jill was experiencing severe pain and discomfort on the journey to see a dying friend. The dreadfulness of living with rheumatoid arthritis disclosed itself. In the dread of that night death seemed preferable to years of suffering in the presence of rheumatoid arthritis, in the dread of that night death as a possibility called loudly. With hindsight, and coming to know what the future of that night held, the thoughts of that night now “*seem ridiculous*”. Heidegger reminds us “when [dread] has subsided, then in our everyday way of talking we are accustomed to say that ‘it was really nothing’” (Heidegger, 1927/1962, p. 187). In the context of this story, could it be that the words “*it seems ridiculous*” are another way of saying ‘it was really nothing’? Yet this ‘nothing’, this ‘no-thing’, that “*seems ridiculous*” can, more than fifteen years on, be recounted with vivid clarity. The dread of that night will always go ahead of Jill; it is part of her being-in-the-world with rheumatoid arthritis.

In dread one is face to face with one’s thrownness and one’s being-in-the-world with rheumatoid arthritis. Recognising the finiteness of possibilities for being-in-the-world with rheumatoid arthritis does not occur in just one experience of dread. The uncanny not-at-homeness of dread is disclosed over and over. Furthermore, the possibilities disclosed in dread vary at different stages of the illness experience and with the ebb and flow of the disease process. What seemed not possible to Jill in the early days of her disease (a good lifestyle and ‘normal’ life) is now possible. Over the years her rheumatoid arthritis has shown more of itself and Jill has come to know ways of managing the disease and of living with it, “*to come to terms with it*”. Perhaps in “*coming to terms with it*” Jill recognises the finiteness of possibilities, which takes into

account the fluctuating nature of the disease process and the corresponding uncertainty. It seems important to remain open to these fluctuating possibilities.

As Jill tells us, “*fearing*” and “*wondering*” abate somewhat as one comes to terms with living with rheumatoid arthritis, yet it is always there waiting to show itself anew. How the rheumatoid arthritis may finally show itself remains a dread. Additionally, new fears may be disclosed as the illness journey progresses. One such fear for Jill and a number of other participants relates to the medications used to manage rheumatoid arthritis. Stories of medication use reveal the fear, dread, and hope in living with rheumatoid arthritis.

Fear, dread, and hope

Next to fear of the future, the fear most often spoken of by participants was fear related to the medications used in the management of rheumatoid arthritis. Medications keep open future possibilities for the person with rheumatoid arthritis and by association the partners and adult children. For partners and adult children, much of what is or is not possible in their lives is contingent on the possibilities open to the person with rheumatoid arthritis.

Many of the medications used in the management of rheumatoid arthritis are effective for some people, but not so effective for others. Some drugs are effective in the short-term but not the long-term as a tolerance to them grows; some drugs offer effective management of rheumatoid arthritis but the side-effects are intolerable. Again, the uncertainty of living with rheumatoid arthritis emerges. In the next story, Jill tells of the fear of running out of medication.

I think one fear is that I'll run out of medication. When I have to come off one drug and then the next one doesn't work for me I begin to get a bit panicky and start thinking, 'Are they going to be able to find something else that will work?' Like Salazopyrin, first of all it seemed to work and then it began to wear off so the dosage was increased. Then that's not any good and then it's Chloroquine time, then Methotrexate. I'm just hoping that I don't run out of new medications to try. I think it's always a fear that I become immune to the effect of the medication I'm on. And there is always that fear in the back of my mind, 'Is there going to be something else that works?' (Jill, 1:15).

Jill fears running out of medication as she develops a tolerance to drug after drug. What was effective to begin with becomes ineffective despite an increased dosage. There is

the fear that the pharmaceutical industry will not be able to keep up with the ability of her body to develop a tolerance to the various drugs available in the management of rheumatoid arthritis. In fearing that she might run out of medication she fears for her own being-in-the-world with rheumatoid arthritis. It is a fear that brings her face to face with the dread of rheumatoid arthritis. Without medication the rheumatoid arthritis will show itself of itself much sooner. Like that of the grandmothers, spoken of earlier, who did not have the benefit of modern medications, Jill's rheumatoid arthritis would most probably have followed a very different course without medication. In this sense medications cover-up the 'is' of rheumatoid arthritis. It is the 'is' of rheumatoid arthritis that is so often dreaded.

Paul also fears running out of medication, not through developing a tolerance but through developing an intolerance or side-effect to the medication which is keeping his rheumatoid arthritis in abeyance.

In terms of coping with my RA I think that short of the Methotrexate not killing my liver, I will just carry on like this forever. And short of Methotrexate not getting made I guess; I just wouldn't want to countenance that day. It would be like losing my lifeline if you like (Paul, 20-21).

For Paul, Methotrexate is a lifeline and, as long as it does not "kill [his] liver¹⁷" or is no longer manufactured, he considers life will carry on much as it is. Paradoxically, as well as being a lifeline, Methotrexate also makes Paul ill.

The major concern I have is what I call the Methotrexate blues, within four or five hours of taking the tablets I feel yuk. I feel like I want to throw up but I don't. Just general listlessness, it's hard to describe really, lethargic, it's just the sort of feeling that wells up from the stomach to my throat and into my head. Methotrexate is also making my hair fall out and I just don't like taking the drugs (Paul, 1:11).

As Paul's story suggests, living with the side-effects of medications is part of living with rheumatoid arthritis, and so too is living with the possibility of side-effects. For many participants there is a fine balance between the benefits and possible side-effects

¹⁷ Hepatic toxicity is a documented side-effect of Methotrexate (see Appendix I). Liver function tests are routinely performed on those taking Methotrexate.

of particular medications and it is something that is always with them. In the next story Tony, a partner, talks of thirty years of drug-taking by his wife.

My wife's RA fluxes but it's always fluxing on a trend line of being able to do less, less functionality, less strength and needing stronger drugs. As Shona builds up her tolerance, the drugs seem to be getting harsher. She's getting in to drugs that are tougher on the system and she's been taking strong drugs for 30 years, which says a lot for her constitution. She's taking Methotrexate and she's on Prednisone and things like that. It's like being hooked on hard drugs I think. Once you're on them you plan to get off them, but I can only see the dose is getting stronger and stronger. There are a whole lot of side-effects just waiting to cause a major problem (Tony, 1:7).

Tony speaks of the tolerance to medications that develops over time, necessitating higher dosages, and harsher drugs. He likens his wife's medication regime to being hooked on hard (illicit) drugs. The dread in Tony's story that lies waiting in the darkness, about which he can do nothing, seems to be a dread of the inevitable progression of his wife's rheumatoid arthritis and her need for stronger drugs and larger dosages. A dread of the associated side-effects that are "*just waiting to cause a major problem*". The side-effects are waiting to be disclosed, but there is always the possibility that they may never be disclosed.

In the drugs used to treat rheumatoid arthritis lies the paradox of fear, dread, and hope. There is the fear of the unavailability of certain drugs or that medical science might not keep up with need of the body for a new drug. There is the dread of developing tolerance or intolerance to drugs and a dread of possible side-effects. However, drugs also offer hope, in drugs there is the hope for the future. There is always the hope that the drugs, like surgery, might open, or keep open, possibilities for being-in-the-world with rheumatoid arthritis.

Balancing fear, dread, and hope

Hope, like fear, is a mode of being-toward possibilities. Hope, like fear, is 'hoping for' and is in terms of what we hope for ourselves. For example, Jill tells us, "*I am always hopeful of course that I might go into remission*" (2:16). Heidegger reminds us "he who hopes takes himself *with* him into his hope, as it were, and brings himself up against what he hopes for" (1927/1962, p. 345). Furthermore, hope is "related to our burdens" (ibid.). The burden to which the hoping relates in these stories is the burden of living with rheumatoid arthritis. The hope is for a pain-free future for the person with

rheumatoid arthritis, for the drug that will trigger remission of the disease, for an end to the relentless progression of the disease, for a 'normal' life. Hopelessness and fearlessness are also modes of being-towards these possibilities. However, hopelessness and fearlessness do not seem to feature in the stories. A realistic degree of hope seems to be maintained. Hope balances fear and dread, they are in constant tension, a tension that enables living with rheumatoid arthritis. In the tension of hope, fear, and dread, people face the relentlessness of the disease and the uncertainty of the future.

Hope can perhaps be thought of as holding ajar the door of future possibility. In dread that door seems to be closing; in hope the finiteness of possibilities is not so finite. In the next story it is perhaps hope that makes the everydayness of living with rheumatoid arthritis bearable. Jo, whose husband has had rheumatoid arthritis for more than fifteen years, shares this story.

I think it's quite sad. Neil isn't the person I married and it's not how I ever envisaged our life and if I look ahead to the future, I get really emotional because I think, 'Well, it's not going to be what we dreamed of'. And it's not what we dreamed of now. I don't dwell on the future very much because it's just a big question mark. What's ahead of us? It's hard. The unknown. I joke to him, I say, "You never know, with the technology and the medicine you never know what's going to happen." So when he says "Well I won't be here, you will be lucky if I see 50", I tend to say "You don't know what's around the corner, none of us do". I still have hope that something will happen, something that can help him. I know that the damage that's been done can't be undone, but if the pain wasn't there, that it would be different and I mean the Prednisone has absolutely destroyed him, but there's nothing else that seems to have any effect. I keep thinking well there might be something, there might be something one day. I've got that hope (Jo, 1:28-29).

Jo laments that the life she and her husband live is not what they dreamed it would be. Their future too looms very differently from the future they had anticipated when they married twenty years ago, or even fifteen years ago when Neil was first diagnosed with rheumatoid arthritis. Anticipation of the future, which is fundamental to our being-in-the-world, is now tinged with dread for Jo as she anticipates a future in the world with rheumatoid arthritis. Yet alongside the dread is hope, hope of what medical science may offer in the future, hope that "*there might be something one day*".

Jo's story feels very sad. The past, present, and future are intertwined in the dread of the future. The possibilities for the future seem bleak to Jo, the now is not what she had

ever dreamed it would be and the possibilities that once seemed open are now not possible. Perhaps in Jo's story we glimpse the dreadfulness of dread. The dreadfulness of the dread for Jo means that the possibilities for the future are blanketed by a "big question mark, the unknown". Yet in dread the "unknown" is only unknown in the sense that we can never know for sure what the future holds. In dread the finiteness of possibilities is recognised, the unknown becomes known. Jo knows the future is "not going to be what [they] dreamed of". As she told me, she knows there will not be the active, outdoor-orientated family life, or the grand European tour they had promised themselves once the children left home, or the fulfilment of career aspirations. Perhaps it is the disclosure of the finiteness of possibilities that saddens Jo. It is as if there is dreadness in being a partner who cannot do a thing to help.

Amidst the dread there is a ray of light, hope. Jo talks of hope. In speaking of hope she is holding open the possibility, not of miracle cures but for something, a new treatment or drug, that would help her husband. Jo knows that the damage already done to her husband's body cannot be undone, that the disease and the drugs used to treat it have irreparably ravaged his body. What she hopes for is her husband's freedom from pain. Perhaps freedom from pain will reopen possibilities for Jo and her family.

Balancing of hope, fear and dread, living with the tension of the three, continues even when what is disclosed in dread is not as dreadful as first imagined. Ian's wife has had rheumatoid arthritis for more than twenty years. Consider his story.

It hasn't been all that easy, but it hasn't been all bad once you get into a routine. I think that the worst part was way back when she first got RA and nobody really knew what the future was going to be. We know now that it's never going to go away, but we didn't know in 1978 that it was going to hang around for another 20 years or whatever. It is never going to go away and I suppose we have learned to adapt our lifestyle to some degree to live with it. I don't think Jane is going to get any better. If anything, she is going to get progressively worse. She's on hormone replacement therapy, she's on steroids, she's on Methotrexate, she's on the non-steroidal anti-inflammatories, she has an ulcer, and she has whatever else goes along with it. All these other little side-effects that are connected to the whole scene. I don't think it's going to get any easier in the future. I would like to think that we can carry on on the plane that it is at the moment, it's probably not too bad. I want to keep myself fit so that if things don't go right for her then at least I'm here to help. I can't afford to let myself get all slack and totally go to seed. I want to be fit so I can be here. I may have to be her legs as well as my own, and her arms (Ian, 1:29).

It would seem that for Ian the unknownness of the future is often worse than the retrospective reality. Ian found living with rheumatoid arthritis was worse at the beginning of the illness journey because he did not know what the future would bring, but then again neither did he realise it would still be around in twenty years' time. Ian seems fairly resigned to the future, is planning for it by keeping himself fit, but he does not seem to be dreading the future the way some are. Ian considers the possibility that he may have to help his wife much more than he already does, become her arms and legs, but at the same time is open to the possibility that his wife's condition might stabilise. Perhaps Ian has faced the dread. In facing the dread, he has become aware of the finiteness of possibilities for his life as the husband of someone with rheumatoid arthritis. Ian is making the most of the possibilities, accepting what he cannot change, the thrownness of his wife's rheumatoid arthritis, the thrownness of his life, while at the same time he is hoping that her condition remains as it is at present. Yet, he is also holding open the possibility that his wife's rheumatoid arthritis might not "*carry on on the plane it is at the moment*" and is working at keeping himself fit so that he will be better able to help her.

In living with rheumatoid arthritis there is the need to balance the hope of remission, of surgery, of a new treatment, of freedom from pain, with the fear of running out of medications, of the next surgery and the dread of disease progression, of the next painful joint, of dependency, of the future.

The strength of dread

Is there strength in dread? Perhaps the strength is in recognising the finiteness of possibilities and making the most of what is possible and in focusing on what can be done, not on what cannot be done. Perhaps the strength is in facing the dread, acknowledging its disclosure, and reflecting on life's possibilities. What does the data reveal of the strength of dread?

Strength as advantage

For the person who has rheumatoid arthritis, recognising the finiteness of possibilities for one's life can provide motivation to make the most of opportunities while living with the limitations of a disease-ravaged body. Consider Rosie's story.

I think there are a lot of advantages with rheumatoid arthritis really. I have turned disadvantages into advantages. I think that I am closer to my husband than I would be because of him dressing me and pushing me around.... He always has to come with me so it has meant that we have a very strong relationship which is so, so important (Rosie, 1:14).

Rosie speaks of the advantages of living with rheumatoid arthritis, of turning disadvantages into advantages. It is perhaps difficult for those not living with an illness such as rheumatoid arthritis to consider any advantage in living with such a disease. Yet, Rosie describes the feeling of being closer to her husband that has emerged from the care he provides through such acts as dressing her, pushing her in the wheelchair and always being with her. In recognising and valuing the strength of their relationship, Rosie has turned some of disadvantages of living with rheumatoid arthritis, such as loss of mobility and independence, into advantages. In doing so, she is perhaps seeing the possibilities in her increasing physical limitations.

What of other participants, of partners and adult children, do they too experience advantages in living with rheumatoid arthritis? Consider the next three stories, one from Sam, an adult child, one from Jo, a partner, and one from Margaret, who has had rheumatoid arthritis for more than fifteen years. The three stories provide further examples of the advantages of living with rheumatoid arthritis.

Mum has always been very positive and strong and even when she doesn't feel strong she always, to me, seems strong. I think that has rubbed off on me as far as being positive and having a good outlook on life. I know that if something happens it happens and that's life, whereas there are a lot of people who can't accept even the littlest things that happen to them (Sam, 1:50).

Sam, who was three when her mother was diagnosed with rheumatoid arthritis, attributes her positive outlook on life to living with rheumatoid arthritis. Throughout her life Sam has seen and experienced her mother's strength and positive attitude to living with rheumatoid arthritis, a strength and attitude now manifest in Sam's own being. Sam has also come to recognise the thrownness of life, "*I know that if something happens it happens*". Sam's strength of character has been nurtured in the always-thereness of living with rheumatoid arthritis. Jo also identifies the emergence of an inner strength in the years since her husband was diagnosed with rheumatoid arthritis.

I cope better with a lot of different things. There are people who really need me and who would really struggle if I fell apart, there's that feeling of 'I've

got to do it'. Who is going to do it if I don't do it? So there is that extra kind of responsibility that makes you pull yourself up. Put your shoulders back, grit your teeth, and get on with it. I have to be strong. It's just something you develop, something I've had to do. I think I always leant on [my husband] and depended on him. It's been a kind of reversal of roles. Although he still makes decisions I feel strong, I feel able to cope with things, that I probably wouldn't have, even ten years ago (Jo. 1:17).

What are the advantages spoken of in this story? Jo speaks of feeling strong, of being needed, of being able to cope with things now with which she previously may have struggled. Jo's strength has emerged from necessity, from the difficulties thrown at her in living with rheumatoid arthritis. She may have developed this strength, this resoluteness, anyway. However, there is a sense that living with rheumatoid arthritis has called forth this resoluteness. In the next story, Margaret, like Rosie in the earlier story, tells us of advantages that have arisen from her increased physical limitations.

Because I haven't had a job all these years, I have been available to my children. I have nearly always been home when they have come home from school. I have been a very supportive parent and I have made myself available if they want to talk to me. Before I got RA I was an extremely busy person, I was always on the go. I think I might have put a few people off because I appeared to be frightfully efficient and very capable. I was always dashing around doing things. Since I have had to slow down and accept my limitations I have had more time for people and I don't think that it has harmed me at all. I think it has made me more patient with myself and certainly more understanding of people with problems. I have tried to instil into the children an understanding that anybody with a problem, please don't look at just the outside problem do look to see what is inside that person. I think they have picked up on that. They certainly have learnt to do things, to look around and see what needs to be done and to be aware and to be supportive. I don't think it has done them any harm at all to be perfectly honest (Margaret, 2:20).

Margaret tells us that in accepting her limitations she has more time. More time for her children, for other people, for herself. The physical limitations she experiences in living with rheumatoid arthritis mean that she has not been able to pursue paid employment, that she has had to “*slow down*”. Although she regrets this, she has also come to see the advantage in it, the advantage of more time. There is a sense in this story that living with rheumatoid arthritis allows for the possibility of having more time for others and for ‘self’. A possibility that occurs because the physical limitations of the disease can limit the possibility of participating in activities such as paid employment.

It is somewhat paradoxical to think of rheumatoid arthritis allowing more time. Recall in Chapter Five that the everydayness of time was discussed, when we saw how day-to-day living takes up so much time for the person who has rheumatoid arthritis. Living with rheumatoid arthritis means needing more time to do the ordinary everyday things such as washing and dressing. Recall also that 'letting go' was suggested as a means of finding time in the presence of rheumatoid arthritis. In having to let go of things (paid employment), the advantage of more time is disclosed. It is as if in taking more time the physical limitations of living with rheumatoid arthritis also give more time.

There are advantages to living with rheumatoid arthritis, advantages that may emerge from the disadvantages of living with rheumatoid arthritis. The advantages show the positive possibilities of being-in-the-world with rheumatoid arthritis. In facing the dread of living with rheumatoid arthritis, the positive possibilities in life are seen. Heidegger reminds us "Pain gives of its healing power where we least expect it" (1971/1975, p. 7). Perhaps facing the dread gives of its healing the power that discloses itself in the advantages of living with rheumatoid arthritis.

Hope as strength

Steiner, interpreting Heidegger, says, "hope is the reaching forward of care" (1978, p. 101). In hope, there is concern (care) for the future, a concern for oneself and for others. Hope perhaps offers strength in facing the burden of living with rheumatoid arthritis. Jan, whose mother has rheumatoid arthritis, speaks of hope.

I think for a while we went through that whole thing of, 'She will get better', 'It might be really good', 'She might get better', 'She might go into remission'. As you go along you take the next bit of hope and you think 'We'll go for that now'. Then when that's out of the question 'We'll go for that now' but I guess you reach a point where the only way to deal with it is by accepting it in a way. While I still hope that it will be as comfortable as it can be, I don't see Mum getting better any more. I hope she does go into remission at some time but I think that the way that things have gone I don't expect that to be the case. She has good times and bad times, but it's rumbling along pretty steadily (Jan, 1:17).

This story tells of a changing dimension of hope. Initially Jan's hope was for her mother's complete recovery. As the rheumatoid arthritis disclosed more of itself Jan came to realise that a complete recovery was not possible. However, she still maintains hope, but what is hoped for has changed. Jan now hopes for a remission of the disease

and she hopes for her mother's comfort. Hope changes in the face of relentless disease progression, but hope remains a constant. It is what is hoped for that changes, is forever altered. There is a sense that hope offers strength. The strength of hope is in its potential to keep open possibilities in the face of the uncertainty and relentlessness of living with rheumatoid arthritis.

Accentuating the positive

The strength of dread for those who live with rheumatoid arthritis is in the freedom to appreciate life as it is now and into the future. Recognising the finiteness of possibilities for one's life and appreciating the positive possibilities is perhaps linked to the philosophy of 'taking one day at a time' adopted by many participants such as Margaret. As she says:

I don't particularly like looking into the future and wondering where I am going to end up. I just think it is better that I more or less take each day at a time and make the most of opportunities now. I don't really find it is terribly helpful to look too far into the future. None of us really know (Margaret, 2:10).

Margaret tells us she does not "like" looking to the future. Perhaps in looking to the future she experiences that 'uncanny not-at-homeness' of dread. Perhaps in facing the dread, she sees a gradually diminishing circle of possibilities for her life; from which she appreciates the possibilities, the opportunities, available now. The freedom to appreciate life now can be enabling. As Lily says:

I make the most of life. I mean at the moment this may be as good as I get, and it's not as good as I was, but I still do plenty (Lily, 1:13).

Appreciating life as it is now perhaps helps those who live with rheumatoid arthritis to cope with the uncertainty of the disease. The uncertainty, the not-knowingness of living with a disease which can vary year by year, week by week, day by day, hour by hour. What is possible one day may not be possible the next. What was not possible today may be possible tomorrow. Under these circumstances "living for the day is a good idea" (Lily, 2:8). It is as if 'living for the day' is a strength of dread disclosed in the everydayness of living with rheumatoid arthritis.

In living for today, taking one day at a time, Margaret and Lily are authentically being with the uncertainty and fluctuating nature of the disease. Perhaps in facing the dread

they have recognised that ‘taking one day at a time’ is an authentic way to ‘be’ with rheumatoid arthritis. They are accepting the thrownness of their situations and living with the balance of what is possible today and what is not possible.

The strength in dread is in accentuating the positive possibilities of now, of appreciating what can be done and not dwelling on those things that cannot be done. This is not the ‘going with the flow’ of the ‘dictatorship of they’ but a purposeful decision about being-with rheumatoid arthritis. The strength in dread is in the turning toward the freedom for being one’s own self as a possibility.

Resoluteness and possibility

The strength of dread is that it calls forth resoluteness in those who live with rheumatoid arthritis, be they partners, adult children or people with the disease. Resoluteness, Heidegger tells us, “is to be authentically oneself” (1927/1962, p. 301), to be “authentically self-focusing” (Guignon, 1993, p. 229). To be authentically self-focusing, to be resolute, is not to close oneself off from others because, as Heidegger reminds us, we are always ‘with’ others ‘in’ the world. Authentic self-focusing provides an opportunity to define or redefine life in the thrownness of rheumatoid arthritis, to recognise perhaps that ‘self’ is ‘self’ in spite of, or because of, the adversity of rheumatoid arthritis. Furthermore, “authentic self-focusing, understood as a resolute reaching forward into a finite range of possibilities, gives coherence, cohesiveness, and integrity to a life course” (Guignon, 1993, p. 229).

In facing the dread of living with rheumatoid arthritis, in recognising the finiteness of possibilities, people come to live their lives resolutely. Resoluteness underpins hope, pushing the limits of time and letting go. It underpins living-with and being-in pain, and living with the unreadiness-to-hand of the practical world of the everyday. It underpins living with a disease-ravaged body. Resoluteness underpins living with the uncertainty and relentlessness of rheumatoid arthritis, of being a partner or adult child of someone who has the disease.

Resoluteness as a possibility of being-in-the-world with rheumatoid arthritis is not something that happens instantaneously, a person does not suddenly become resolute. It is not something that happens to all people who live with rheumatoid arthritis, but it does happen to many. Resoluteness may wax and wane and is constantly challenged in

the everydayness of living with rheumatoid arthritis. There may be times, such as during an acute exacerbation of the disease or when there is stress in the family or at work, when resoluteness breaks down. Resoluteness emerges from facing the dread of living with rheumatoid arthritis again, and again, and again. It comes from recognising and living with the finite possibilities disclosed in dread, of coming to know what matters in life and what does not matter so much. Resoluteness as a possibility of being-in-the-world with rheumatoid arthritis may become part of the background familiarity of living with rheumatoid arthritis.

In the everydayness and always-thereness of living with rheumatoid arthritis, people are drawn to face the dread. In facing the dread they may find a strength, a strength that is enmeshed in authenticity, a strength of self that calls forth resoluteness, a strength that constitutes and is constituted by being-in-the-world with rheumatoid arthritis. Perhaps it is in living resolutely that those who live well with rheumatoid arthritis, be they partners, adult children, or people with the disease, stand out against those who do not live so well in the face of rheumatoid arthritis.

Conclusion

Reflect on the following poem that seems to capture the spirit of this chapter and of 'living with rheumatoid arthritis'.

*Oh, who will unsnarl my body
into gestures of love?
Who will give my heart room
to fly free in its rickety cage? ...
Who will nudge the dreams back into my head,
back into my bones, where rhyming with one
another like wind chimes,
They will make music wherever I move?*
(Millar, 1988, p. 45).

Who will give, who will nudge, asks the poet? Perhaps it is the 'self'. The 'self', the resolute self, that finds strength in the fear, the dread, the hope, and the possibility of living with rheumatoid arthritis.

In the final chapter, which follows, the findings presented in this and the previous three data chapters are summarised and discussed in relation to the substantive nursing literature and recommendations made for practice, education and research.

CHAPTER NINE: The Meaning of 'Living with Rheumatoid Arthritis'

The aim of this thesis has been to explore the phenomenon of 'living with rheumatoid arthritis'. The phenomenon has been shown by the data to be multifaceted, in constant flux and to be constantly evolving. Data in the form of interview transcripts were gathered from partners and adult children of people who have rheumatoid arthritis and from those who themselves have the disease.

Living with rheumatoid arthritis means living with the uncertainty and relentlessness of a disease that is always there. In its always-thereness it becomes part of the background familiarity of the lives of those who experience the phenomenon. People who live with rheumatoid arthritis take the experience with them as it permeates every aspect of their lives. At times the effect is small, at other times it is enormous, but it is always there. Other worlds are experienced differently in the always-thereness of living with rheumatoid arthritis. In the presence of rheumatoid arthritis different things matter and things matter differently.

This chapter synthesises the understandings that have emerged from the study and explores these understandings alongside the relevant literature. Limitations of this study are discussed and recommendations are made for nursing practice and for further research.

Striving to live with rheumatoid arthritis

The diagnosis of rheumatoid arthritis brings with it new experiences and new meanings. When rheumatoid arthritis first announces itself people are thrown out of their usual everyday way of being-in-the-world. Usual ways of doing things, of using the body, of relating to others are no longer experienced in a taken-for-granted way. In the thrownness of rheumatoid arthritis it becomes necessary to find a new way of being-in-the-world. This is achieved through the use of such strategies as using the body in different ways, using things differently and learning to give and receive care.

With a damaged body and damaged appearance the person with rheumatoid arthritis experiences their body and their environment as unready-to-hand. Living with rheumatoid arthritis means setting oneself up to experience one's body and the environment as more ready-to-hand. It becomes necessary to work out new ways to do

things. Partners and children contribute to working out new ways to do things as they too strive to live with rheumatoid arthritis and come to be-in-the-world in a new way.

In striving to live with rheumatoid arthritis people come to live with the call to care. It is a call that is enmeshed in the pain, the decreased functionality, and the always-thereness of living with rheumatoid arthritis. Sometimes it is easy to answer the call; sometimes it is not. Sometimes it requires 'just little things' to answer the call, at other times a more consuming care is required. It takes time to come to know when to leap in or to leap ahead in one's care and despite many years of living with rheumatoid arthritis it is not always possible to find the right balance between leaping in and leaping ahead. Recognition of the reciprocity of caring is important in striving to live with rheumatoid arthritis; even in the face of severe disability caring for others matters.

With time the new way of doing things, of using the body and things in different ways, of giving and receiving care in different ways, becomes part of the taken-for-granted everydayness of living with rheumatoid arthritis. However, the taken-for-grantedness that emerges from these new ways of doing things is always tenuous. It does not take much to tip the balance and for the unreadiness-to-hand of the body or the environment to be disclosed again. For example, homes can be set up to accommodate the unreadiness-to-hand of a disease-ravaged body; however, going out brings ongoing challenges. In striving to live with rheumatoid arthritis the unreadiness-to-hand of the body and the environment is revealed again and again.

Coming to live with pain is a large part of striving to live in the world with rheumatoid arthritis. Living with a certain degree of pain becomes taken-for-granted. When living with the pain of rheumatoid arthritis in this taken-for-granted way other things matter more than the pain matters, other things in life become the main concern. Working-to and working-into the pain are strategies for living with the pain of rheumatoid arthritis. However, despite all efforts to keep it at bay, there are times when the pain breaks through. The pain becomes the focus; nothing matters as much as the pain. Strategies used at times like this include withdrawing from the world, when the person with rheumatoid arthritis may internalise their pain. Partners and children also strive to live with the pain of rheumatoid arthritis. There is frustration and helplessness in knowing a loved one is in pain, of wanting to take away that pain yet not being able to do so, and

of sometimes unintentionally adding to the pain. Learning to live with and be with the pain is part of the everyday experience of living with rheumatoid arthritis.

Striving to live with rheumatoid arthritis means coming to live with the uncertainty and unknownness of the disease and its manifestations, of waking up and not knowing if it is going to be a good day or a bad day, of the variability of the experience, of the unknown future, and of always living with the uncertainty. There is a sense of helplessness in never knowing what the rheumatoid arthritis will next disclose of itself. Living with the uncertainty of rheumatoid arthritis calls forth vigilance in those who experience the phenomenon whether as partners, adult children, or people with the disease. It is a vigilance that monitors 'how things are'; a vigilance that guides the help and care that is offered and received in the everydayness of living with rheumatoid arthritis. Paradoxically, the uncertainty also helps maintain and keep hope alive. There is hope that this time the disease might go into remission, or that a new drug or surgery will take away the pain. Hope is an essential element of living with the fear and dread of rheumatoid arthritis.

Living resolutely with rheumatoid arthritis

Over time as enabling strategies are developed, those living with rheumatoid arthritis come once again to experience the world in an everyday way that is, for the most part, taken-for-granted. In striving to live with rheumatoid arthritis they have come to be-in-the-world in a new way, a way that calls forth resoluteness in the face of the always-thereness of living with rheumatoid arthritis. Achieving resoluteness comes through accommodating rheumatoid arthritis into one's everyday life, of living with the tension of multiple 'they', through facing the fear and dread of living with rheumatoid arthritis while recognising the possibilities for one's life, and in maintaining hope.

Living resolutely in the everydayness of rheumatoid arthritis means learning to live with the 'they' that are inherent in everyday life. Underpinned by cultural values, traditions and public opinion of what one should or should not do in a particular situation, 'they' dictate our everyday way of being-in-the-world. The person who has rheumatoid arthritis lives constantly with the tension of multiple 'they'. There is the 'they' of how they were before being thrown into the world with rheumatoid arthritis and the 'they' of what they should or should not do as a person with rheumatoid arthritis. There is also

the 'they' of the imagined self; that is how they should be as mothers, lovers, friends, colleagues, and of how they thought they might be at this stage in their life had rheumatoid arthritis not intervened. Living with the tension of multiple 'they' is part of recognising and juggling what matters most at any one time. Partners and adult children also live with the tension of multiple 'they', of what they should do as a partner or adult child of someone with rheumatoid arthritis, and what they should and need to do in the other worlds they also inhabit.

Facing the fear and the dread is an integral part of living with rheumatoid arthritis. In the always-thereness of living with rheumatoid arthritis there are many fears and many dreads to be faced. There is, for example, the fear of meeting others whose disease is more advanced or the fear that certain drugs may be unavailable. There is the dread of helplessness and the dread that manifests itself as worry. In facing the fear and the dread of living with rheumatoid arthritis possibilities for one's life are disclosed. In living resolutely with rheumatoid arthritis there is a need for fear and dread to be balanced with hope. There is hope for a pain-free future, for a new drug that will trigger remission, for an end to the relentless progression of the disease.

Living resolutely with rheumatoid arthritis discloses a strength that comes from facing the fear and dread of the future, of facing the changing possibilities, of recognising that there are things that can be done that still bring meaning to life even though these may be different things, different possibilities. Life is different. It is through living resolutely with rheumatoid arthritis that what matters most in life emerges, such as the mattering of relationships. Living with rheumatoid arthritis means accepting the challenge of 'what is', and of valuing the positive things that come from the experience. Examples of the 'gifts' of rheumatoid arthritis are strengthening relationships, of being 'better' people, of taking 'time' for people or gaining strength through caring and taking responsibility for one another.

Living resolutely becomes part of the everydayness of living with rheumatoid arthritis for many, but not necessarily all, of those who experience the phenomenon. Some people may constantly strive to live resolutely but never quite achieve it. Resoluteness as a possibility of being-in-the-world with rheumatoid arthritis may become part of the background familiarity in the lives of those who live with rheumatoid arthritis.

However, living resolutely with rheumatoid arthritis is always tenuous and at the beck and call of the disease and a myriad of other influences from other worlds.

The tenuousness of living resolutely

Although the nature of living resolutely with rheumatoid arthritis is to be-in-the-world in an everyday way that in itself becomes taken-for-granted, there is a tenuousness to the experience. It is a tenuousness that is grounded in the uncertainty of living with rheumatoid arthritis, a tenuousness that can break down at any moment. Resoluteness in the everydayness of living with rheumatoid arthritis is so uncertain that it can be lost at any time, in any way. Part of living resolutely is to live with the breakdown of resoluteness.

The things that take away the resolute everydayness include an exacerbation of the disease, increased pain, another joint 'going' leading to decreased functionality, or it could be facing surgery again and again. It may be the demands of other worlds, the call of careers and relationships, for example, that draw those living with rheumatoid arthritis as partners, adult children or those with the disease away from the taken-for-grantedness of their everyday world. It is the times when dread yet again discloses itself.

The pull of multiple 'they' may also contribute to a breakdown of resoluteness if the tensions are too strong. For example, the pull of being a mother may pull too strongly against what one should do as a person with rheumatoid arthritis or the pull of being a daughter and a friend may at times cause tensions in relationships with others.

Knowing that the everyday resoluteness can be so easily lost brings forth the uncertainty, fear and dread that is part of living with rheumatoid arthritis. A significant finding of this study is that even the person who appears the most resolute can be drawn to the despair and the dread at any time. Even the most resolute are called again and again to strive and work toward being-in-the-world with rheumatoid arthritis in an everyday taken-for-granted way.

The spiralling circle of living with rheumatoid arthritis

With the breakdown of resoluteness those living with rheumatoid arthritis return again to strive and work toward that place of resolute everydayness. They come again to pick up the strategies that are going to bring them back to a taken-for-granted everydayness.

It is a cyclic pattern of always working towards the everydayness of resolute coping, but knowing that this can be lost at any time. Living with rheumatoid arthritis means living with the spiralling cyclical nature of the disease and of living resolutely. Furthermore, the relentlessness of disease progression, which is the experience of many of those who live with rheumatoid arthritis, means that a decreased level of functionality must often be incorporated in the new way of being-in-the world that constitutes each turn of the cycle.

Some people with mild disease may not experience this cyclic pattern. However, even if a person has experienced only one exacerbation of the disease, if rheumatoid arthritis has announced itself on only one occasion, they still live with the ever-present possibility that it will announce itself anew. Rheumatoid arthritis, and the spiralling circle of living with it, as a possibility, is always there.

The spiralling cyclical nature of living resolutely in the face of rheumatoid arthritis is the same but different for family members, for partners and adult children. They too live with the cyclical nature of the experience. They too are at the beck and call of the uncertainty and the relentlessness of the disease.

The spiralling circle of living with rheumatoid arthritis becomes, over time, part of the background familiarity in the lives of those who experience the phenomenon. At different stages of the cycle rheumatoid arthritis matters more in their lives, dominates other worlds more, than at other stages. When living resolutely in the taken-for-granted everydayness, the rheumatoid arthritis seems to matter less than when one is coping with a breakdown of resoluteness or striving again to be-in-the-world in an everyday way. With a breakdown of resoluteness comes an opportunity to redefine oneself, to take stock of possibilities and to make choices as to the direction that may be taken, given the finiteness of possibilities. This taking stock, this redefining, provides the opportunity to consider what matters most, to focus on what can be done and not on what cannot be done. It provides a sense of purpose and direction, albeit perhaps an altered purpose in which the mattering of life is different. Each person, whether a partner, an adult child or person with the disease, comes in their own time to face the dread, to recognise the finiteness of possibilities of their lives, and to recognise that 'self' is 'self' despite, or because of, the adversity of rheumatoid arthritis.

The phenomenon and the substantive literature

This study shows that the complexities and tensions of living with rheumatoid arthritis cannot be focused to one concept or for the most part quantified. The findings complement those studies, outlined in Chapter Two, from within the interpretive paradigm while adding depth of meaning to many of the understandings identified in studies from within the positivist paradigm.

This study shows that living with rheumatoid arthritis is an experience that is veiled in uncertainty and often involves a relentless progression of disability in those who have the disease. Identifying uncertainty as fundamental to the experience of living with rheumatoid arthritis is consistent with the findings of a number of studies (see for example Brown & Williams, 1995; Bury, 1982; Shaul, 1995). Wiener (1975b), in a landmark grounded theory study, identifies 'tolerating uncertainty' as central to the experience of living with rheumatoid arthritis. She suggests that those who live with rheumatoid arthritis develop strategies for living with the uncertainty of the disease. One of these strategies is "juggling the hope of relief and/or remission against the dread of progression and dependency" (p. 99). This juggling of hope and dread is consistent with the use of these notions in my study. However, the interpretation offered in this thesis extends understanding of the notion of dread by suggesting that it is through facing the possibilities that are disclosed in the dread of progression that one may come to live resolutely with rheumatoid arthritis. Furthermore, it is not only the dread of progression and dependency that draws one to these possibilities, the experience of dread has been shown to be this and more. Additionally, this study shows that all those who live with rheumatoid arthritis, whether as partners, adult children or people with the disease, experience dread. My study takes the understanding of dread to a deeper level of meaning, reflecting the outcomes expected in a hermeneutic phenomenological study.

The cyclical nature of the experience is shown in this study to be vital to understanding the phenomenon of 'living with rheumatoid arthritis'. This supports the findings of a number of studies, for example Shaul (1995), Wiener (1975b) and Dildy (1992) that similarly identify the cyclical nature of the experience. However, in many studies the cyclical nature remains covered over. My study deepens understanding of this cycle, particularly in regard to the breakdown in resoluteness as an ever-present possibility for

those who live resolutely. This study shows that even when resoluteness becomes part of the everyday lives of those who live with rheumatoid arthritis there are times when the dread discloses itself again and again. The breakdown may be brief, almost transitory or it may be a more prolonged episode requiring a re-evaluation of possibilities, of what matters in life.

Dildy (1992; 1996), in a study which resonates with my work, identifies the nature of suffering in rheumatoid arthritis as “a process of significant multidimensional personal change, a process of regaining normalcy and striving to be ‘okay’” (p. 178). Dildy describes a three-phase process involved in resolving suffering: disintegration of personhood, the shattered self and reconstruction of self. As well as describing the process as cyclical, Dildy notes that not everyone is necessarily able to complete this process. Paralleling my findings that suggest not everyone necessarily comes to live resolutely with rheumatoid arthritis, Dildy notes that some participants in her study were unable to reach the point where they felt “okay” about themselves, their bodies and their limitations, which are necessary dimensions of the reconstructed self.

Resoluteness has been identified in my study as a strength of dread and, in facing the dread, advantages of living with rheumatoid arthritis may be disclosed. This is consistent with Dildy’s (1992) findings which suggest that participants found meaning through “the positive growth-producing changes associated with the suffering experience” (p. 180). Changes reported by Dildy include increased sensitivity and being more attuned to the feelings of others.

The notion of regaining normalcy (Dildy, 1992) or re-normalising (Wiener, 1975b) is congruent with the findings of this study. Although I consider the term ‘normal’ to be problematic (what is normal?), both Dildy and Wiener use the notion to describe a process of accommodating the disease. Re-normalising is described by Wiener (1975b) as “lowering expectations and developing a new set of norms for action, which is directly related to the frequency and duration of flare-ups [disease exacerbations]” (p. 101). Re-normalising can be likened to striving to live resolutely, which, as my study shows, means coming to be-in-the-world in new ways and re-evaluating the possibilities for one’s life. Wiener (1975b) suggests that over time what constitutes ‘normal’ changes, just as I suggest that what matters in life changes in the always-thereness of living with rheumatoid arthritis. My study extends the work of Dildy and Wiener in that

I show how over time this new way of being-in-the-world becomes taken-for-granted in the everyday lives of those who live with rheumatoid arthritis. Furthermore, this study shows the tenuous nature of the taken-for-granted everydayness.

Living with the dictatorship of 'they', of living with the tensions of 'they' is uncovered in my study. While not specifically addressed in any of the studies I have located, the notion can be linked to findings reported in other studies. For example Shaul (1995) reports that the experience of depression was related to the person with rheumatoid arthritis observing others doing things that they could no longer do. Additionally, Wiener (1975b) identifies 'keeping up' as a strategy used by those with rheumatoid arthritis to maintain or attend to what they perceive to be normal activities. Living with the tension of 'they' extends understanding of notions such as Wiener's 'keeping up' as it sheds further light on why people may choose to keep up or why the often-reported role changes are viewed by participants as frustrating or depressing.

This thesis makes very visible the individual experiences of pain in living with rheumatoid arthritis. The experiences of participants in this study reveal two distinct dimensions to the pain experience, living-with-pain and being-in-pain. This is consistent with, but also expands, the findings of Shaul's (1995) study. She contrasts the pain that is often present even when the disease is quiescent with the debilitating pain experienced during an exacerbation of the disease. Dildy (1992) suggests that physical pain is a significant aspect of the suffering experience of those with rheumatoid arthritis and the descriptors used by participants in her study mirror those used by participants in my study to describe their pain. Significantly, my study extends understanding of pain in living with rheumatoid arthritis by considering not only the experiences of those who have the disease but also the experiences of those who vicariously experience the pain of rheumatoid arthritis, that is partners and adult children. It discloses the frustration, despair, and helplessness of watching a loved one in pain.

My study shows the interpenetrating effects of rheumatoid arthritis, how those living with rheumatoid arthritis take the experience with them to all their other worlds, as it becomes part of the background familiarity of their lives. It provides a lens through which the mattering of life is viewed. This notion has not been explicitly addressed in any of the studies located, although this finding is consistent with the work of Benner

and Wrubel (1989), who suggest that chronic illness becomes “woven into the fabric” (p. 136) of a person’s world and into a person’s meanings.

Making visible the experiences of partners and adult children who live with rheumatoid arthritis is a strength of my study. Many aspects of relationship within the participants’ families are similar to those described by le Gallez (1984) in one of the few qualitative studies found which explore the effects of rheumatoid arthritis on the family. As previously outlined (p. 34), le Gallez (1984) describes the impact of rheumatoid arthritis as “intense [with] repercussions ... experienced by the whole family” (p. 31). The wide-ranging effects uncovered in my study both extend and contrast the findings of le Gallez’s (1993) study.

Le Gallez found that in most cases “the males appear to have accepted the task of caring for their female partners without question” (p. 32). Extending this understanding, my study shows some of the complexities of caring in the face of rheumatoid arthritis, of balancing and coming to know when to leap in and when to leap ahead, of recognising and valuing the reciprocity of caring, and the tensions of the ‘indifferent’ modes of care. Caring is shown to be significant in the experiences of the adult children in my study. This is in contrast to le Gallez’s study. Le Gallez considers that because the well parent carries the burden of care for the ill parent instead of sharing it with the children, the children cannot be considered as carers. It would seem that le Gallez’s definition of ‘caring’ pertains primarily to the physical care required by the person with rheumatoid arthritis to attend to their activities of daily living and this may account for the difference in interpretation between the studies.

Half of the children in le Gallez’s study (age range 11-33 years at the time of the study) said living with a parent with rheumatoid arthritis had brought them closer together, most expressing deep concern and displaying a nurturing attitude towards the ill parent. This is similar to the advantages of which a number of participants in my study spoke. In my study, partners and those with the disease also spoke of the ‘gifts’ of rheumatoid arthritis.

Le Gallez (1993) found that in most families enormous effort went in to retaining a ‘normal’ family life, thus minimising the impact of the disease on the children, to the extent that most children “continued with their lives in much the same way as their

peers” (p. 33). A number of participants in my study (both partners and those with rheumatoid arthritis) spoke of trying not to burden their children or of hiding the worst effects of rheumatoid arthritis from them. Indeed a number of children recognise and acknowledge the attempts of their parents to protect them from much of the impact of rheumatoid arthritis. However, the impact of rheumatoid arthritis on the lives of the adult children in my study is significant and, in contrast to participants in le Gallez’s study, it could not be said that they “continued with their lives in much the same way as their peers” (p. 33). As my study shows, living with rheumatoid arthritis becomes part of the background familiarity of their lives, influencing to varying degrees every aspect of it.

A strength of my study is that it shows the everydayness of living with rheumatoid arthritis. It shows what it is like to live with a disease-ravaged body, of what it means to take time to do things. It gives a sense of what the pain, the decreased function, the fatigue, the uncertainty, and the relentlessness means in the everyday lives of those who experience the phenomenon. It shows the experience of living with rheumatoid arthritis to be multifaceted, complex and in constant flux, incorporating the taken-for-granted everyday aspects of the experience as well as the fears and dread enmeshed in the experience. It balances this by showing the possibility of resoluteness as a way of being-in-the-world with rheumatoid arthritis, and the tenuousness of this. In disclosing the multifaceted complexity of the experience in this way, my study incorporates images of the experience as both burdensome and transformative. Thorne (1998) in a meta-study of chronic illness research between 1980 and 1996 found that loss and burden characterised qualitative studies of chronic illness in the 1980s while studies from the 1990s present a more optimistic perspective. In presenting both burdensome and transformative images, my study has found the balance between “romanticising and catastrophying (sic)” (Journal entry, December 1997) the experience of living with rheumatoid arthritis, a balance between the perspectives predominant in the studies of the 1980s and the 1990s.

Implications and recommendations for practice and education

I believe that nurses have much to offer those who live with rheumatoid arthritis, whether they be partners, children, or people with the disease. Nurses work with those who live with rheumatoid arthritis in a wide variety of contexts within the community

and in hospital settings. They may be called on to provide care for the person with rheumatoid arthritis at times of acute exacerbation of the disease, during times of surgical intervention, or they may provide ongoing care within an outpatient or community setting. At other times nurses may provide care in the context of comorbidity, when rheumatoid arthritis is not the primary call to care but is alongside some other need. Nurses also work with others who experience the phenomenon of 'living with rheumatoid arthritis', such as the partners and adult children whose experiences are interpreted in this thesis. However, the experience of 'living with rheumatoid arthritis' is often covered over in the lives of these people and the experience, as a call to care, may not be heard by nurses. This study offers an interpretation of the experience of 'living with rheumatoid arthritis' that has the potential to reveal new understandings of the phenomenon to those who engage with the study and to enhance the quality of their care.

The study shows the cyclical nature of the experience of living with rheumatoid arthritis. Nurses work with people at all stages of the cycle. Sometimes they will care for people whose resoluteness is not so resolute, at other times the taken-for-granted everydayness of the experience may mean the rheumatoid arthritis does not matter as much as another need. It is important then that nurses recognise and understand this cycle when caring for those who live with rheumatoid arthritis. Nurses have an important role in helping clients recognise and live with the tenuous cycle of living resolutely with rheumatoid arthritis, of being aware of the cycle and in considering strategies that may be useful as they strive and work toward, or return to, the resolute everydayness.

My study identifies living with the tension of multiple 'they' as a reality of being-in-the-world with rheumatoid arthritis. For people with the disease one of the 'they' that speaks loudly is the 'they' of what one should or should not do in living with rheumatoid arthritis. Nurses, along with other health professionals, often prescribe and reinforce what one should or should not do in living with rheumatoid arthritis, for example, pacing, joint preservation, and rest. It is important then that nurses recognise that the techniques and strategies they are suggesting may be at odds with the everyday reality of the lives of those who live with the disease. As nurses, we need to recognise that there will be other pulls on the time and energy of these people. In coming to understand the tension of multiple 'they' it is possible for nurses to work with these

tensions and not against them. We need to talk to the person about how they might realistically and individually incorporate such notions as pacing and resting into their everyday lives. It is also necessary to discuss with the person and with their family 'what matters most' to them, to help them identify and develop strategies so that they can do what 'matters most' to them and to their families within the limits that the disease imposes on their lives. Developing such strategies may enable them to live well with the tension of multiple 'they' that are inherent in the always-thereness of living with rheumatoid arthritis.

The always-thereness of living with rheumatoid arthritis means that people experiencing the phenomenon take the experience with them to all their worlds, whether they are partners, adult children, or people with the disease. Nurses must remain mindful of this when caring for any person who lives with rheumatoid arthritis no matter what the context is. For example, if the wife of a person who has rheumatoid arthritis presents with hypertension then to suggest that she go home to rest in bed for a few days is unrealistic if she is providing constant care for her husband. A recommendation such as this is likely to increase the stress, and the blood pressure, of this woman as she finds herself caught in the tension of 'they'; of knowing what she should do for her own health and of what she needs to do as the wife of someone who has rheumatoid arthritis.

Nurses need to work with the often espoused, but sometimes not actualised, notion of 'individualised care', to listen to clients, to assess their individual needs. Does she need help with her meals? Can he turn on the shower? Perhaps she needs to use a towel instead of a flannel to wash herself. It is often 'the little things' that can draw what is experienced by the person living with rheumatoid arthritis as unready-to-hand back to the ready-to-hand. It is often these 'little things', which are imbued with nursing knowledge and skill, that are covered over and lost in the busy world of clinical practice (MacLeod, 1994). It is the 'little things', which are often taken-for-granted, that tip the balance between independence and dependence for the person with rheumatoid arthritis. Benner (1984) suggests that attending to the 'little things' of client care is fundamental to expert nursing care. In caring for those who live with rheumatoid arthritis attending to the 'little things' is essential.

It is often the 'little things' that make a difference for partners and adult children living with rheumatoid arthritis. It is important that nurses acknowledge their reality, listening

to their story, recognising that they too may require care. Caring for the partner or children, even by doing the little things, may be a form of leaping ahead in the care of the person with rheumatoid arthritis as it serves to strengthen relationships within the families.

I suggest in Chapter Eight (p. 174) the notion of 'resoluteness' to describe accommodation of the disease into the everyday way of being-in-the world in living with rheumatoid arthritis and the associated redefining of one's life. The 'how' of the process of redefining life is as individualised as the people themselves. There is no formulaic guide to 'becoming resolute'. As has been shown, it is an ongoing, dynamic, constantly evolving process. Nurses and other health professionals can foster this process by providing guidance and support to those living with rheumatoid arthritis. For example, the nurse may help the person to explore the possibilities in their lives, in their relationships with others, and to identify those things that matter most to them. The nurse may encourage the person to focus on what can be done rather than what cannot be done. The nurse can nurture hope in those who live with rheumatoid arthritis. Christensen (1990, p. 106) found that hope, when supported by the encouragement of nurses, sustains people through their present circumstances. As has been shown (p. 166), hope balances fear and dread in living with rheumatoid arthritis. In fostering the process of 'becoming resolute' the nurse is offering care that leaps ahead in its solicitude. It is care that enables the process while at the same time recognising that the journey is each individual's own. Faull (2000a) in using the analogy of 'the door of adversity' was speaking of the role of health professionals when he said (as my notes from the presentation record), "We can only show [those living with rheumatoid arthritis] how they might open the door, we cannot push them through."

As well as leaping ahead in our care for those who live with rheumatoid arthritis, we as nurses, whether working in hospital or community settings, must not lose sight of the times when it is necessary to leap in with our care for the client. For example, the person with rheumatoid arthritis recovering from joint replacement surgery will require increased help, help that leaps in in its solicitude, in attending to their basic hygiene needs when they may be experiencing their bodies as unready-to-hand. We must listen and look for the pain, working with the pain not against it, balancing care that leaps in with care that leaps ahead. Finding the balance between leaping in and leaping ahead may not be easy for nurses (as it is not for those who live constantly with rheumatoid

arthritis). There may be times when mistakes are made, when leaping in occurs at times when leaping ahead may be a better option. However, the skilled, knowledgeable practitioner will constantly “strive to get it right” (Spence, 1999, p. 159). “Striving successfully requires knowing and valuing the patients’ worlds and their different ways of being” (ibid.).

Time is experienced differently in the always-thereness of living with rheumatoid arthritis. People with rheumatoid arthritis take more time and need more time to attend to many of the basic activities of daily living, to sit up in bed, to get out of bed, to shower, to eat their meal. Moreover, they may require varying levels of assistance with these tasks and more. Nurses may experience frustration at the sheer time it takes to care for someone with rheumatoid arthritis. When caring for someone with rheumatoid arthritis it is important that nurses recognise, plan for, and allow for, time to care. Perhaps in recognising and understanding that time is experienced differently, and by planning and allowing for it, nurses will be more able to deal with any frustration that they may experience.

Chapter Six contrasts the experiences of people who have rheumatoid arthritis as they move between familiar and unfamiliar environments. In the familiar environment of their own home where things are experienced as ready-to-hand some of the difficulties in attending to everyday activities may themselves become taken-for-granted. However, the difficulties are announced anew when these people are away from home. On leaving home, people with rheumatoid arthritis often experience anew the unreadiness-to-hand of their world. At the out-patient clinic, the local health centre or in the hospital ward, they may find themselves no longer in-the-world in a familiar way. What might we as nurses do to minimise the experience of not-at-homeness of an unfamiliar world? Nurses need to work with the individual to ensure the environment can be experienced in the most ready-to-hand way that is possible given the structural and economic restraints that may be in play. For example, this may involve organising the bed-space to accommodate the individual’s needs, adjusting the height of the bed, ensuring a raised toilet seat is constantly ready-to-hand. It may also involve advocating for more suitable resources within the clinical area for people with rheumatoid arthritis, such as door handles or taps that are easier for the hands ravaged with rheumatoid arthritis to manipulate. As nurses we must not lose sight of the fact that we often create and

maintain environments that are experienced as unready-to-hand by the person with rheumatoid arthritis and their families.

Being in hospital may be restorative of self for those living with rheumatoid arthritis. It may provide time out from the stresses of everyday life, whether the person is a partner, child or person with rheumatoid arthritis. Participants in my study, particularly those who have the disease, spoke of the opportunities for reflection and reappraisal of their lives afforded by an admission to hospital. Partners and adult children also valued the opportunity for reflection and reappraisal that may emerge when their loved one is in hospital. Nurses can enhance the restorative nature of the experience by providing care within an environment that enables this.

This study has much to offer those practitioners involved specifically in client education. I acknowledge that it is the role of every nurse to be involved in client education, however, for those living with rheumatoid arthritis there are often specialised programmes aimed at providing education and support. It is to nurses involved with such programmes that I offer the following recommendations.

It is important that the experience of all those who live with rheumatoid arthritis is recognised and acknowledged within education programmes. It is often easy to lose sight of those whose needs do not call out as loudly; in particular partners and adult children. I would suggest that education programmes seek to provide opportunities to involve all family members, to acknowledge the impact on their lives as well as offering practical suggestions. For example, family members may find it valuable to discuss their experiences of watching their loved one in pain. Practical suggestions related to the notions of leaping in and leaping ahead in their care may help family members to develop strategies they can use when their parent/partner is in pain. This may lessen the sense of helplessness often experienced by family members when watching a loved one in pain.

Education programmes have the potential to enable the process of 'becoming resolute' by providing opportunities for those who live with rheumatoid arthritis to explore and reflect on what matters most in their lives, perhaps enabling them, for example, to 'let go' of those things that matter less and thus allowing more time to focus on what matters more. Programmes should provide opportunities for those living with

rheumatoid arthritis to acknowledge and reflect on the fear and dread with which they live and to explore possibilities. This may enable them to focus their time and energy on the things that they can do something about while still acknowledging the dread of those things about which they have no control.

Couples living with rheumatoid arthritis may benefit from the opportunity to discuss and reflect on issues of sexuality, that go beyond suggestions of altered positions for intercourse. The opportunity to reflect on such issues of what matters most to them as individuals and as a couple may strengthen a relationship strained by the presence of rheumatoid arthritis.

In caring for people who live with a chronic illness such as rheumatoid arthritis, nurses have much to offer. To fully realise this potential for care, it is vital the education curricula equip nurses at undergraduate and graduate levels with the necessary knowledge and skills for practice (Nolan & Nolan, 1999). My study contributes to the development of such knowledge and it has the potential to make an important contribution to nursing education at all levels. The study shows the everyday complexity of living with rheumatoid arthritis and provides valuable understandings of the situated illness experience that can, and should, be incorporated into education programmes and nursing practice. It shows the importance of engaging in meaningful dialogue with clients in understanding their situation and of recognising their expertise as people who live with rheumatoid arthritis. My study emphasises the importance of listening to clients' stories and valuing the contribution such stories can make to education and practice. Knowledge and understanding derived from this study extends and adds layers of situated meaning to the scientific knowledge of pathophysiology and aetiology of rheumatoid arthritis that students at all levels of nursing education take with them into practice. The inclusion in education curricula of knowledge underpinned by research from studies such as mine will provide insights to the experience of illness that are essential components of quality nursing care.

Study limitations and suggestions for further research

There are no limitations, and there is every limitation. There are no limitations because this study never presumed to be anything more than it is. There is every limitation because of what it did not do (Smythe, 1998, p. 246).

This study provides an insight into the experience of twenty-five people who live with rheumatoid arthritis. The findings relate specifically to their experiences and as such it is not possible to generalise these findings to other people living with rheumatoid arthritis. However, there may be commonalities and shared meanings with others who experience the phenomenon of 'living with rheumatoid arthritis'. It is also possible that the interpretations offered in this thesis may extend understanding of the experience of living with other chronic illnesses, especially those characterised by exacerbations and the potential for relentless progression, such as multiple sclerosis.

It is possible that those who volunteered to participate in this study did so because they had the self-confidence and are, in the most part, living resolutely with rheumatoid arthritis. Absent perhaps are the voices of those who are struggling to live with rheumatoid arthritis.

There is the need to hear the voices of those whose cultural background differs from the predominantly Pakeha perspective offered in this thesis. The experience of living with rheumatoid arthritis within the Maori community in particular remains hidden, awaiting its moment of disclosure in future studies.

Family structure may have a significant impact on the experience of living with rheumatoid arthritis. Participants in the current study lived in family groups that aligned with the Western notion of a 'nuclear family' where parents and children reside together, with extended family living elsewhere. Furthermore, participants in my study were not related to each other. Although careful consideration of ethical issues would be required, studies that explore the experience of living with rheumatoid arthritis within families, in a variety of family structures and across cultural groups would further enhance understanding of the phenomenon of 'living with rheumatoid arthritis'.

There are numerous aspects of the experience of living with rheumatoid arthritis that would benefit from research that incorporates the perspectives of other people who live with rheumatoid arthritis. For example, there is a need for research that focuses on younger women with rheumatoid arthritis who give birth to and mother young children. It appears that there are few resources available to these women in New Zealand and their specific needs have not been identified. Most participants in this study have lived with rheumatoid arthritis for at least ten years. There is the sense that the length of time

one lives with the illness influences how one experiences the phenomenon. For this reason, research which focuses on people who are new to the experience of living with rheumatoid arthritis would further increase our understanding of this complex phenomenon.

Different participants will offer different stories for interpretation. Some may be similar, some very different from the stories shared in this study, but all will add to our understanding of the phenomenon of living with rheumatoid arthritis. Another researcher who brings with her different experiences, different prejudices, a different interpretive lens may analyse the data in a new way, adding further to our understanding of living with rheumatoid arthritis. Use of alternative research methodologies, as outlined in Chapter One (p. 11), also has the potential to broaden understandings by capturing different aspects of what is a complex and ever-changing phenomenon.

A strength of this study is the presence of the stories in Chapter Seven which speak of the sexual relationships of some of the participants. These stories, offered in the context of the mattering of relationships, of being with others, provide some understanding of an aspect of the phenomenon of living with rheumatoid arthritis which is not often articulated in the literature. However, my study leaves much to be uncovered. There is the potential for research to further explore the complexities of this aspect of being-with others.

The notion of resoluteness as discussed in the context of fear, dread, hope and possibility warrants further investigation and development. It would seem that there might be similarities between the notion of living resolutely with rheumatoid arthritis and the spiritual dimension of self suggested by Faull (2000a; 2000b) as being a core determinant of health in those who live with disability.

Many participants identified the importance to them of being cared for in a specialist area with staff, especially nurses, *geared for your needs* (Margaret, 1:34). Although this has not been a focus of my study, there is the need for further research to corroborate this and identify the benefits, especially as many of these specialist areas have recently closed or are under threat of closure. There is also a need for research that explores the interpersonal relationship between health professionals and people living with a chronic illness such as rheumatoid arthritis.

International studies (see Hill, 1991b; 1994; Ryan, 1995) indicate benefits to the client of nurse-led rheumatology clinics. In the restructured health service in New Zealand there is the potential for the development of such clinics here. Research is needed to ascertain the need for, and viability of, such clinics within the New Zealand context.

Throughout the process of planning and implementing this study I have become increasingly aware of the paucity of nursing research related to rheumatoid arthritis. It is essential that this situation change. Nurses have much to offer people living with rheumatoid arthritis both in the hospital and in the community, but it is essential that our practice is research based.

Concluding Statement

“Human worlds, being historical, contextual, and multifaceted, are only grasped under finite, situated aspects” (Benner, 1994, p. 100). Within the limits suggested by Benner, this study provides a hermeneutic analysis of the phenomenon of ‘living with rheumatoid arthritis’. It begins to uncover the meaning of ‘living with rheumatoid arthritis’ as shared in stories from twenty-five people who experience the phenomenon. The interpretation presented in this thesis offers the potential to challenge the assumptions and increase the understandings of nurses and other health professionals as they seek to understand an illness experience from the client’s perspective.

Rheumatoid arthritis has had a significant impact on most aspects of the participants’ lives. It is always there as part of the fundamental background from which they find meaning in their lives. Living with rheumatoid arthritis is incorporated into a new way of being-in-the-world for these people, a way of life that is altered in the thrownness of rheumatoid arthritis. Their way of being-in-the-world is such that rheumatoid arthritis is very much a reality yet, in its taken-for-grantedness, it does not always dominate as they, for the most part, continue to live very full and rewarding lives despite the disease. However, it is not the life they would necessarily have chosen. Their lives past, present, and future are affected by the everyday always-thereness of rheumatoid arthritis.

So the darkness shall be light, and the stillness the
dancing.
(T.S. Eliot, East Coker, The Four Quartets).

Even in adversity there is ‘light’, even in a body ravaged by rheumatoid arthritis the soul can ‘dance’.

APPENDIX A

Information sheet and consent form for participants in phase one, people with rheumatoid arthritis.¹⁸

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS**INFORMATION SHEET**

My name is DIANNE ROY. I am a Registered Nurse currently enrolled as a graduate student at Massey University in the Department of Nursing and Midwifery. I can be contacted on (number supplied).

My supervisor is Dr Judith Christensen. Dr Christensen is an Associate Professor in the Department of Nursing and Midwifery. She can be contacted on (number supplied).

I am carrying out this study to develop a better understanding of the impact rheumatoid arthritis has on the lives of partners and adult birth children (over 18 years) of men and women who have the disease, as well as on the lives of the people themselves. The study has grown out of my long held interest in, and experience of working with, people with rheumatoid arthritis.

As you are a person who has chronic rheumatoid arthritis I am inviting you to participate in this study.

If you agree to take part in this study you will:

- be asked to tell about your experience of living with rheumatoid arthritis in four to five taped interviews. You will be free to choose how much or how little you wish to tell about your experiences. While many people find it helpful to tell of their experiences, others may find themselves thinking and talking about things that could be stressful. If you were to become distressed the interview would be discontinued and assistance offered. The interviews will take 1-2 hours and will occur over 3-6 months. During the interviews we can stop and start the tape as many times as you might need. We will arrange a mutually agreeable time and place for the interviews.

¹⁸ All information sheets, consent forms and non-disclosure of information forms (Appendix A-G) were printed on Massey University letterhead for distribution to recipients.

- have the right to refuse to answer any particular questions and to discontinue an interview at any time.
- be free to ask any further questions about the study that occur during your participation
- be given a copy of the tape transcripts for verification or alteration, as well as a summary of the findings from the study. You will be free to withdraw all or part of your transcriptions up until the time that data analysis has been completed.
- have the right to withdraw from the study at any time without prejudice.

Because of the method of data analysis to be used in this research it is essential that the interviews are taped. Only those people who consent to the interviews being taped can be included as participants in the study. You will be given the option to receive a copy of the tapes.

The taped interviews will be heard only by me as the researcher, my supervisor, and the transcribing typist. The typist will be asked to sign a confidentiality agreement. During the interviews, in all transcripts and writings, and all discussions with my supervisor you will be referred to by pseudonym or code number. Your identity will be kept confidential to me as the researcher. Every attempt will be made to avoid identification of you or any person or place, in any written work prepared from the study. The original tapes, transcripts, and research notes will be stored in a locked cabinet during the study and for a period of at least ten years after completion of the study, after which they will be destroyed.

Please feel free to discuss this research and your possible participation in it with another person if you wish. If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone (number supplied).

If you decide to participate would you please ring me (number supplied) or, if you have given your permission for me to do so, you will be contacted in a weeks time to see if you have reached a decision. More time is available for you to consider the invitation should you require it.

APPENDIX A continued

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS

CONSENT FORM

RESEARCHER: Dianne Roy

PARTICIPANT: _____

I have heard and understood an explanation of the research project I have been invited to take part in. I have been given, and I have read, a written explanation of what is asked of me, and I have had the opportunity to ask questions and to have them answered. I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions. I understand that my consent to take part does not alter my legal rights.

I agree/do not agree to the interviews being audiotaped. I understand that I have the right to ask for the audiotape to be turned off at any time during the interview. I agree to provide information to the researcher on the understanding that my identity will remain confidential.

I understand the information may be used for the purpose of writing an academic research report and for any other papers that may result from this work.

I consent to take part as a participant in this research under the conditions set out in the Information Sheet.

Signed: _____ Participant

In my opinion consent was given freely and with understanding.

_____ Witness name (please print)

_____ Witness signature

Date: _____

Consent obtained by _____

Name

Signature

APPENDIX B

Information sheet and consent form for partners of people with rheumatoid arthritis.

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS

INFORMATION SHEET

My name is DIANNE ROY. I am a Registered Nurse currently enrolled as a graduate student at Massey University in the Department of Nursing and Midwifery. I can be contacted on (number supplied).

My supervisor is Dr Judith Christensen. Dr Christensen is an Associate Professor in the Department of Nursing and Midwifery. She can be contacted on (number supplied).

I am carrying out this study to develop a better understanding of the impact rheumatoid arthritis has on the lives of partners and adult birth children (over 18 years) of men and women who have the disease, as well as on the lives of the people themselves. The study has grown out of my long held interest in, and experience of working with, people with rheumatoid arthritis.

I am inviting you, the partner of a person who has chronic rheumatoid arthritis, to participate in this study.

If you agree to take part in this study you will:

- be asked in four to five taped interviews, to tell about your experiences as the partner of a person who has rheumatoid arthritis. You will be free to choose how much or how little you wish to tell about your experiences. While many people find it helpful to tell of their experiences, others may find themselves thinking and talking about things that could be stressful. If you were to become distressed the interview would be discontinued and assistance offered. The interviews will take 1-2 hours and will occur over 3-6 months. During the interviews we can stop and start the tape as many times as you might need. We will arrange a mutually agreeable time and place for the interviews.
- have the right to refuse to answer any particular questions and to discontinue an interview at any time.
- be free to ask any further questions about the study that occur during your participation.
- be given a copy of the tape transcripts for verification or alteration, as well as a summary of the findings from the study. You will be free to withdraw all or part of your transcriptions up until the time that data analysis has been completed.

- have the right to withdraw from the study at any time without prejudice.

Because of the method of data analysis to be used in this research it is essential that the interviews are taped. Only those people who consent to the interviews being taped can be included as participants in the study. You will be given the option to receive a copy of the tapes.

The taped interviews will be heard only by me as the researcher, my supervisor, and the transcribing typist. The typist will be asked to sign a confidentiality agreement. During the interviews, in all transcripts and writings, and all discussions with my supervisor you will be referred to by pseudonym or code number. Your identity will be kept confidential to me as the researcher. Every attempt will be made to avoid identification of you or any person or place, in any written work prepared from the study. The original tapes, transcripts, and research notes will be stored in a locked cabinet during the study and for a period of at least ten years after completion of the study, after which they will be destroyed.

Your partner has already consented to your being invited to participate in this study and, if you agree to participate, your discussing her/his disease in relation to your experiences of living with someone who has rheumatoid arthritis. Your partner has the right to withdraw this consent at any time, just as you do if you choose to participate. If one of you should wish to withdraw then, in the interests of your family I would choose not to continue the other's involvement in the study.

Please feel free to discuss this research and your possible participation in it with another person if you wish. If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone (number supplied).

If you decide to participate would you please ring me (number supplied) or, if you have given your permission for me to do so, you will be contacted in a weeks time to see if you have reached a decision. More time is available for you to consider the invitation should you require it.

APPENDIX B continued

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS

CONSENT FORM

RESEARCHER: Dianne Roy

PARTICIPANT: _____

I have heard and understood an explanation of the research project I have been invited to take part in. I have been given, and I have read, a written explanation of what is asked of me, and I have had the opportunity to ask questions and to have them answered. I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions in the study. I understand that my partner has also signed a consent and has the right to withdraw. If either one of us wishes to withdraw our consent the researcher will not continue the other's involvement in the study. I understand that my consent to take part does not alter my legal rights.

I agree/do not agree to the interviews being audiotaped. I understand that I have the right to ask for the audiotape to be turned off at any time during the interview. I agree to provide information to the researcher on the understanding that my identity will remain confidential.

I understand the information may be used for the purpose of writing an academic research report and for any other papers that may result from this work.

I consent to take part as a participant in this research under the conditions set out in the Information Sheet.

Signed: _____ Participant

In my opinion consent was given freely and with understanding.

_____ Witness name (please print)

_____ Witness signature

Date: _____

Consent obtained by _____

Name

Signature

APPENDIX C

Information sheet and consent for adult birth child of person with rheumatoid arthritis.

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS**INFORMATION SHEET**

My name is DIANNE ROY. I am a Registered Nurse currently enrolled as a graduate student at Massey University in the Department of Nursing and Midwifery. I can be contacted on (number supplied).

My supervisor is Dr Judith Christensen. Dr Christensen is an Associate Professor in the Department of Nursing and Midwifery. She can be contacted on (number supplied).

I am carrying out this study to develop a better understanding of the impact rheumatoid arthritis has on the lives of partners and adult birth children (over 18 years) of men and women who have the disease, as well as on the lives of the people themselves. The study has grown out of my long held interest in, and experience of working with, people with rheumatoid arthritis.

I am inviting you, the adult birth child of a parent who has chronic rheumatoid arthritis, to participate in this study.

If you agree to take part in this study you will:

- be asked in four to five taped interviews, to tell about your experiences of living with a parent who has rheumatoid arthritis. You will be free to choose how much or how little you wish to tell about your experiences. While many people find it helpful to tell of their experiences, others may find themselves thinking and talking about things that could be stressful. If you were to become distressed the interview would be discontinued and assistance offered. The interviews will take 1-2 hours and will occur over 3-6 months. During the interviews we can stop and start the tape as many times as you might need. We will arrange a mutually agreeable time and place for the interviews.
- have the right to refuse to answer any particular questions and to discontinue an interview at any time.
- be free to ask any further questions about the study that occur during your participation.

- be given a copy of the tape transcripts for verification or alteration, as well as a summary of the findings from the study. You will be free to withdraw all or part of your transcriptions up until the time that data analysis has been completed.
- have the right to withdraw from the study at any time without prejudice.

Because of the method of data analysis to be used in this research it is essential that the interviews are taped. Only those people who consent to the interviews being taped can be included as participants in the study. You will be given the option to receive a copy of the tapes.

The taped interviews will be heard only by me as the researcher, my supervisor, and the transcribing typist. The typist will be asked to sign a confidentiality agreement. During the interviews, in all transcripts and writings, and all discussions with my supervisor you will be referred to by pseudonym or code number. Your identity will be kept confidential to me as the researcher. Every attempt will be made to avoid identification of you or any person or place, in any reports prepared from the study. The original tapes, transcripts, and research notes will be stored in a locked cabinet during the study and for a period of at least ten years after completion of the study, after which they will be destroyed.

Your mother/father has already consented to your being invited to participate in this study and, if you agree to participate, your discussing her/his disease in relation to your experiences of living with someone who has rheumatoid arthritis. Your mother/father has the right to withdraw this consent at any time, just as you do if you choose to participate. If one of you should wish to withdraw then, in the interests of your family I would choose not to continue the other's involvement in the study.

Please feel free to discuss this research and your possible participation in it with another person if you wish. If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone (number supplied).

If you decide to participate would you please ring me (number supplied) or, if you have given your permission for me to do so, you will be contacted in a weeks time to see if you have reached a decision. More time is available for you to consider the invitation should you require it.

APPENDIX C continued

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS

CONSENT FORM

RESEARCHER: Dianne Roy

PARTICIPANT: _____

I have heard and understood an explanation of the research project I have been invited to take part in. I have been given, and I have read, a written explanation of what is asked of me, and I have had the opportunity to ask questions and to have them answered. I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions in the study. I understand that my mother/father has also signed a consent and has the right to withdraw. If either one of us wishes to withdraw our consent the researcher will not continue the other's involvement in the study. I understand that my consent to take part does not alter my legal rights.

I agree/do not agree to the interviews being audiotaped. I understand that I have the right to ask for the audiotape to be turned off at any time during the interview. I agree to provide information to the researcher on the understanding that my identity will remain confidential.

I understand the information may be used for the purpose of writing an academic research report and for any other papers that may result from this work.

I consent to take part as a participant in this research under the conditions set out in the Information Sheet.

Signed: _____ Participant

In my opinion consent was given freely and with understanding.

_____ Witness name (please print)

_____ Witness signature

Date: _____

Consent obtained by _____

Name

Signature

APPENDIX D

Information sheet and consent form for non-participating partner with rheumatoid arthritis.

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS**INFORMATION SHEET**

My name is DIANNE ROY. I am a Registered Nurse currently enrolled as a graduate student at Massey University in the Department of Nursing and Midwifery. I can be contacted on (number supplied).

My supervisor is Dr Judith Christensen. Dr Christensen is an Associate Professor in the Department of Nursing and Midwifery. She can be contacted on (number supplied).

I am carrying out this study to develop a better understanding of the impact rheumatoid arthritis has on the lives of partners and adult birth children (over 18 years) of men and women who have the disease, as well as on the lives of the people themselves. The study has grown out of my long held interest in, and experience of working with, people with rheumatoid arthritis.

This study is being carried out in three stages. Stage one involved interviewing people with rheumatoid arthritis and has been completed. I am now beginning stage two, which involves interviewing partners of people with rheumatoid arthritis.

In interviewing partners of people with rheumatoid arthritis I am interested in hearing their stories and the effect on their lives of living with someone who has rheumatoid arthritis. Inevitably in the telling of these stories reference will no doubt be made to the person and her/his disease.

For this reason I am inviting you, as a person who has rheumatoid arthritis, to consent to:

- your partner being invited to participate in this study.

(and if s/he agrees to participate):

- my obtaining information from her/him related to your disease and her/his experiences of living with someone who has rheumatoid arthritis.

- the use of the information provided by your partner for the purpose of writing an academic research report and for any other papers that result from this work.

If your consent is given you retain the right to withdraw this consent at any time without prejudice.

Your partner will also be asked to sign a consent and will also have the right to withdraw from the study. If one of you should wish to withdraw your consent then, in the interests of your family, I would choose not to continue the other's involvement in the study.

Your partner will receive transcriptions of the interviews s/he participates in and will have the option to receive a copy of the tapes. It is her/his decision as to whether or not the transcriptions or tapes will be shared.

Your family's involvement in the study will be kept confidential to me as the researcher. The person who has approached you about this study has signed a confidentiality agreement. During all stages of the research you and any other person named will be referred to by pseudonym or code number. Every attempt will be made to avoid identification of any person or place in any reports prepared from the study. The original tapes, transcriptions, and research notes will be stored in a locked cabinet during the study and for a period of at least ten years after completion of the study, after which they will be destroyed.

If your consent is given you will be asked to give an information sheet to your partner, which will inform them about the research and invite them to participate. The decision to participate will be her/his to make.

Please feel free to discuss this research with another person if you wish. If you have any queries or concerns regarding your rights in relation to this research you may contact the Health Advocates Trust, phone (number supplied).

If you decide to give your consent, as outlined above, would you please ring me (number supplied) or, if you have given your permission for me to do so, you will be contacted in a weeks time to see if you have reached a decision. More time is available for you to consider the invitation should you require it.

APPENDIX D continued

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS

CONSENT FORM

RESEARCHER: Dianne Roy

PERSON WITH RHEUMATOID ARTHRITIS: _____

I have heard and understood an explanation of the research project my partner will be invited to take part in. I have been given, and I have read, a written explanation of the research and my involvement in it. I have had the opportunity to ask questions and to have them answered.

I understand that I have the right withdraw my consent at any time. I understand that my partner will also sign a consent if s/he chooses to participate and will also have the right to withdraw. If either one of us wishes to withdraw our consent the researcher will not continue the other's involvement in the study. I understand that my consent to does not alter my legal rights.

I consent to my partner being invited to participate in this study.

If my partner accepts the invitation to participate in this study, I consent to the researcher obtaining information from her/him related to my disease and her/his experience of living with someone who has chronic rheumatoid arthritis on the understanding that my identity will remain confidential.

I understand the information may be used for the purpose of writing an academic research report and for any other papers that may result from this work.

Signed: _____

In my opinion consent was given freely and with understanding.

_____ Witness name (please print)

_____ Witness signature

Date: _____

Consent obtained by _____

Name

Signature

APPENDIX E

Information sheet and consent form for non-participating parent with rheumatoid arthritis.

LIVING WITH CHRONIC RHEUMATOID ARTHRITIS**INFORMATION SHEET**

My name is DIANNE ROY. I am a Registered Nurse currently enrolled as a graduate student at Massey University in the Department of Nursing and Midwifery. I can be contacted on (number supplied).

My supervisor is Dr Judith Christensen. Dr Christensen is an Associate Professor in the Department of Nursing and Midwifery. She can be contacted on (number supplied).

I am carrying out this study to develop a better understanding of the impact rheumatoid arthritis has on the lives of partners and adult birth children (over 18 years) of men and women who have the disease, as well as on the lives of the people themselves. The study has grown out of my long held interest in, and experience of working with, people with rheumatoid arthritis.

This study is being carried out in three stages. Stages one and two involved interviewing people with rheumatoid arthritis and the partners of people with rheumatoid arthritis and have been completed. I am now beginning stage three, which involves interviewing adult birth children of people with rheumatoid arthritis.

In interviewing the sons and daughters of people with rheumatoid arthritis I am interested in hearing their stories and the effect on their lives of living with someone who has rheumatoid arthritis. Inevitably in the telling of these stories reference will no doubt be made to the person and his/her disease.

For this reason I am inviting you, as a person who has rheumatoid arthritis, to consent to:

- your son/daughter being invited to participate in this study.

(and if he/she agrees to participate):

- my obtaining information from him/her related to your disease and his/her experiences of living with someone who has rheumatoid arthritis.

- the use of the information provided by your son/daughter for the purpose of writing an academic research report and for any other papers that result from this work.

If your consent is given you retain the right to withdraw this consent at any time without prejudice.

Your son/daughter will also be asked to sign a consent and will also have the right to withdraw from the study. If one of you should wish to withdraw your consent then, in the interests of your family, I would choose not to continue the other's involvement in the study.

Your son/daughter will receive transcriptions of the interviews they participate in and will have the option to receive a copy of the tapes. It is his/her decision as to whether or not the transcriptions or tapes will be shared.

Your family's involvement in the study will be kept confidential to me as the researcher. The person who has approached you about this study has signed a confidentiality agreement. During all stages of the research you and any other person named will be referred to by pseudonym or code number. Every attempt will be made to avoid identification of any person or place in any reports prepared from the study. The original tapes, transcriptions, and research notes will be stored in a locked cabinet during the study and for a period of at least ten years after completion of the study, after which they will be destroyed.

If your consent is given you will be asked to give an information sheet to your son/daughter that will inform them about the research and invite them to participate. The decision to participate will be his/her to make.

Please feel free to discuss this research with another person if you wish. If you have any queries or concerns regarding your rights in relation to this research you may contact the Health Advocates Trust, phone (number supplied).

If you decide to give your consent, as outlined above, would you please ring me (number supplied) or, if you have given your permission for me to do so, you will be contacted in a weeks time to see if you have reached a decision. More time is available for you to consider the invitation should you require it.

APPENDIX E continued

**LIVING WITH CHRONIC RHEUMATOID ARTHRITIS
CONSENT FORM**

RESEARCHER: Dianne Roy

PERSON WITH RHEUMATOID ARTHRITIS: _____

I have heard and understood an explanation of the research project my adult birth child will be invited to take part in. I have been given, and I have read, a written explanation of the research and my involvement in it. I have had the opportunity to ask questions and to have them answered.

I understand that I have the right to withdraw my consent at any time. I understand that my daughter/son will also sign a consent if s/he chooses to participate and will also have the right to withdraw. If either one of us wishes to withdraw our consent the researcher will not continue the other's involvement in the study. I understand that my consent to does not alter my legal rights.

I consent to my daughter/son being invited to participate in this study.

If my daughter/son accepts the invitation to participate in this study, I consent to the researcher obtaining information from her/him related to my disease and her/his experience of living with someone who has chronic rheumatoid arthritis on the understanding that my identity will remain confidential.

I understand the information may be used for the purpose of writing an academic research report and for any other papers that may result from this work.

Signed: _____

In my opinion consent was given freely and with understanding.

_____ Witness name (please print)

_____ Witness signature

Date: _____

Consent obtained by _____

Name

Signature

APPENDIX F

Consent form with addendum for participant from previous study.

CONSENT FORM

CASE STUDY OF A WOMAN WITH RHEUMATOID ARTHRITIS

RESEARCHER: Dianne Roy

PARTICIPANT: _____

I have heard and understood an explanation of the research project I have been invited to take part in. I have been given, and I have read, a written explanation of what is asked of me, and I have had the opportunity to ask questions and have them answered. I understand that I may withdraw from the study at any time and to decline to answer any particular questions in the study. I understand that my consent to take part does not alter my legal rights.

I agree to the interviews being taped. I agree to provide information to the researcher on the understanding that my identity will remain confidential.

I understand the information may be used for the purpose of writing an academic research report and for any other papers that may result from this work.

I consent to take part as a participant in this research.

Signed: _____ Participant

In my opinion consent was given freely and with understanding.

_____ Witness name (please print)

_____ Witness signature

Date: _____

Consent obtained by _____

Name

Signature

In addendum to the consent dated 20.6.95

I hereby give my permission for the transcripts to be included as data in the Doctoral research study being undertaken by Dianne Roy. I understand that the data may be used in writing a thesis and other associated writings or presentations.

Signed: _____

Date: _____

APPENDIX G

Non-disclosure forms for transcribing typist and intermediaries.

NON-DISCLOSURE OF INFORMATION**Typist**

I _____ agree not to disclose the name of, or any information that would lead to the identification of, the participants in the research study being undertaken by Dianne Roy.

The audiotapes, transcriptions, and computer disks will not be made available to anyone but the researcher or her supervisor and will be kept securely while in my possession.

I will not retain any copies of the audiotapes, computer disks, or transcriptions.

Signed: _____

Name: _____

Date: _____

APPENDIX G continued

NON-DISCLOSURE OF INFORMATION**Intermediary**

I _____ agree not to disclose the name of, or any information that would lead to the identification of, the participants in the research study being undertaken by Dianne Roy.

Signed: _____

Name: _____

Date: _____

APPENDIX H

Information for intermediaries.

Living with Chronic Rheumatoid Arthritis

Researcher: Dianne Roy RGON, BA (Hons)

Contact: (number given), Email: (address given)

Information for Intermediaries

Thank you for agreeing to assist in the recruitment of participants for my research study.

Please find enclosed verification of ethical approval for this study and a supply of Information Sheets. These are to be given to potential participants who meet the criteria for one of the two groups outlined below. There is a separate sheet for each group.

The study is to be conducted in three stages. The first stage involves in-depth interviews with up to ten people with chronic rheumatoid arthritis. The criteria for inclusion in this group are outlined below (group A). Stages two and three involve in-depth interviews with partners and adult birth children (over 18 years) of people with rheumatoid arthritis. Access to participants for stages two and three will be through people with chronic rheumatoid arthritis. These people with chronic rheumatoid arthritis constitute the second group of people I would ask you to approach. Criteria for inclusion are described below (group B). I intend to complete the stages sequentially and will contact you again when I am ready to recruit participants for stages two and three.

When you give the information sheets to potential participants could you please ask them if they would like to either contact me directly if they decide to participate, or whether they would prefer if I contacted them about a week after they have received the Information Sheet. If they prefer the latter option could you please obtain their contact phone number and pass it on to me.

To meet the requirements of the ethical approvals given for this study I need to ask you to sign a non-disclosure agreement to help protect participants' confidentiality. A copy

of this will be made available to you.

Criteria for inclusion in the study:

All participants need to be able to speak English fluently. This criterion does not exclude people who speak other languages but because of the reflective nature of the research process to be used in this study, participants' fluency in English is essential.

Group A:

Women and men, probably aged 30 years or older, who have chronic rheumatoid arthritis which developed after they reached adulthood (i.e. this excludes anyone with juvenile RA).

Group B:

Women and men who fit the criteria for group A but were not included in stage one of the study **and** have a partner **or** adult birth child (> 18 yr.).

NB. Only the partner **or** an adult birth child of the person would be invited to participate, as participants in this study will not be from the same family.

If you have any further queries, please do not hesitate to contact me.

Thank you.

Dianne Roy (February 1997).

26/06/97

Please give the person you are approaching the appropriate information sheet. There is one information sheet for those who think their partner might wish to participate and one for those who think their adult birth child might wish to participate.

The people with RA will be asked to consent to their partner/child being invited to participate. When consent has been given they will be asked to pass on the appropriate information sheet to their partner/child (i.e. they will be the intermediaries).

APPENDIX I

Glossary of Medications

COXIBs Abbreviation: Cyclooxygenase inhibitor. These are a new generation of non-steroidal anti-inflammatory drugs. COXIBs inhibit cyclooxygenase 2 (COX2) while leaving cyclooxygenase 1 (COX1) alone. COX1 is involved in the production of prostaglandins that are protective of tissue such as the gastric mucosa while COX2 are responsible for the production of prostaglandins that are actively involved in the inflammatory process. COXIBs therefore have anti-inflammatory properties similar to other NSAIDs but with reduced risk to the integrity of the gastric mucosa.

Celebrex™ Celecoxib. A COXIB recently released in New Zealand.

Chloroquine/hydroxychloroquine An antimalarial, the action of which is not clearly understood, this drug is used in the treatment of rheumatoid arthritis as a DMARD. Side-effects¹⁹: Ocular toxicity which may cause blindness, nausea and vomiting.

Digesic™ Dextropropoxyphene napsylate and paracetamol. An analgesic/antipyretic for the relief of mild to moderate pain. Side-effects: dizziness, nausea, vomiting and sedation.

DMARDs Abbreviation: Disease Modifying Antirheumatic Drugs. These drugs dampen disease activity and suppress synovitis.

Leflunomide A DMARD. Recently released, it is rheumatoid arthritis specific with immunosuppressive and anti-inflammatory properties. Side-effects: gastro-

¹⁹ Only most frequently reported side-effects are listed in this glossary

intestinal symptoms including anorexia, abdominal pain, diarrhoea, nausea and gastritis, hypertension, dizziness, alopecia with high dose, and hepatic toxicity.

Methotrexate Ledertrexate™. A DMARD (SMARD). A chemotherapeutic agent used in low doses in rheumatoid arthritis in an attempt to induce remission. Side-effects: nausea, vomiting, mouth ulcers, rashes, headaches, alopecia, pneumonitis, renal disorders, bone marrow suppression, and hepatic toxicity.

NSAIDs Abbreviation: Non-steroidal anti-inflammatory drugs. These drugs are prescribed to relieve joint pain, stiffness and swelling.

Paracetamol Panadol™. An analgesic/antipyretic agent. Side-effects: rare, allergic and haematological reactions reported.

Prednisone Delta Cortelan™. A corticosteroid used in rheumatoid arthritis for its anti-inflammatory properties. Side-effects: skin thinning, subcapsular cataracts, osteoporosis, and glaucoma.

SMARDs Abbreviation: Slow-acting antirheumatic drugs. Term often used interchangeably with DMARDs. Slow-acting refers to the variable time it takes for these drugs to be effective.

Salazopyrin™ Sulphasalazine. A DMARD, the exact action of which is unknown but is thought to inhibit the production and release of certain cytokines²⁰. Side-effects: blood dyscrasias including potentially fatal leucopenia, hepatic toxicity, skin rashes, nausea, vomiting, vertigo, tinnitus and a reversible reduction in sperm count.

Tagamet™ Cimetidine. An antiulcerant that inhibits gastric acid secretion and reduces pepsin output. Used in prevention of gastric ulceration, which is a risk in people taking NSAIDs. Side-effects: diarrhoea, tiredness, dizziness, and skin rashes.

²⁰ Cytokines are glycoproteins involved in inflammation. Defined over the past 10-15 years, their biologic activity reveals previously unknown complexities of the inflammatory response. In rheumatoid arthritis therapeutic interventions aimed at modifying the effects of cytokines are being trialed (Tan et al., 1992, p. 447).

Voltaren™ Diclofenac. A non-steroidal anti-inflammatory with antirheumatic, anti-inflammatory, antipyretic, and analgesic properties. Side-effects: epigastric pain, nausea, vomiting, diarrhoea, gastric ulceration/bleeding, headache, dizziness, and skin rashes.

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APPENDIX J

Key to Transcriptions

The abbreviations and conventions given below are used throughout this thesis, particularly when excerpts from the interview transcriptions are used.

<i>Italics</i>	the actual words of the participant are presented in italics
p. or pp.	page or pages
[]	comments made by the researcher to clarify or explain aspects of the transcription
RA	rheumatoid arthritis: this abbreviation was used by participants throughout the interviews to refer to the disease
...	indicates a pause within the original transcription or where material has been edited

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