

**Exploring the perceptions of women with Rheumatoid Arthritis of how their
illness impacts their relationship with their intimate life partner.**

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ABSTRACT

This study explores women's perceptions of how their illness (Rheumatoid Arthritis-RA) affects their relationship with their intimate life partner. RA is a chronic, inflammatory, auto-immune illness, which mainly affects the synovial membranes of multiple joints. This highly inflammatory poly-arthritis may lead to joint destruction, chronic pain, deformity and loss of functioning as unfortunate outcomes of the established illness. RA affects key life domains such as psychological well-being, social well-being, family and couple relationships, employment, loss of independence and restrictions in daily functioning.

This is a qualitative study and grounded theory methods were used to analyze the data. Eight women from the "care and share" circles of the Arthritis Foundation in the greater Cape Town area participated in the study. Participants, meeting the criteria set out for this study, were purposively selected and appointments for interviews were made at their place of residence. Participation was informed, voluntary and confidentiality guaranteed. Participants were informed about the nature and purpose of the study, as well as to the method of data-collection to be used. They were informed of their right to withdraw from the process at any time. The ethics board of the University of the Western Cape approved the ethical standard of the proposal. They were interviewed in English, individually and in depth by using a semi-structured interview schedule. The interviews were audio-tape recorded and the data was transcribed, followed by analysis using the constant comparison method of grounded theory.

The findings suggested that communication, role definition and division of labour as well as intimacy and/or sexual functioning emerged as the areas in a relationship that are most affected by RA. The participants found that chronic pain, loss of functionality and/or mobility, deformity and the unpredictability of symptoms were the most salient features of RA, which affected their relationships with a spouse or partner. This study has elicited data that has potential value for those interested in the area of women's illness experiences, especially in their perceptions of adapting to a chronic illness.

A proposal for the conduction of the study was submitted to the University of the Western Cape and the ethics board of the university approved of the ethical conduct proposed for the study.

October 2006



DECLARATION

I declare that *Exploring the perceptions of women with Rheumatoid Arthritis of how their illness impacts their relationship with their intimate life partner* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full name: Roné Gerber

Date: 31 October 2006

Signed: _____



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CHAPTER 1

INTRODUCTION

1.1. Statement of the problem

This study focuses on women's perceptions of how their illness (Rheumatoid Arthritis-RA) affects their spousal and or partner (couple) relationship. The maintenance of healthy, functional couple relationships is regarded as an important protective factor against the myriad of challenges and stressors facing an individual diagnosed with the illness. Besides having to deal with the various chronic physical symptoms of RA, a person has to adjust to and cope with emotional aspects resulting from living with RA. If adjustment to and coping with RA is not effective, the individual may experience negative disease outcomes such as increased disease activity, depression and a general overall decrease in quality of life. These negative outcomes affect the individual, the couple, the family and the broader context of the persons' social networks. Lyons (1993, p. 186), mentioned that a chronic illness that is not managed effectively might have a negative impact on a person's lifestyle. Such an illness may often lead to reduced social contact with valued others, a termination of "activity-based contacts (work, sport)", resulting in "dysfunctional relationships in which there is little meaningful companionate activity, support, communication or intimacy". Janssen, Philipsen and Halfens (1990) highlighted the possible reduction in social networks as a result of an unmanaged illness and Sullivan, Mikail and Weinshenker (1992) found that chronic illness might increase marital difficulties. In addition, it also has an effect on the health and economic systems of the person, their family and even the country they live in, as these individuals become more dependent on these systems.

Understanding the effects of RA on the couple relationship from the perspective of the person with RA will therefore provide added insight and understanding into the adjustment and coping processes of people living with RA. This understanding will help to inform possible interventions aimed at ensuring the maintenance of healthy and functional relationships between couples as such relationships serve as a crucial protective factor in coping more efficiently with RA and ensuring optimal quality of life for such individuals and their families.

This study also focuses on the perceptions of women with RA, as more women than men are affected by the illness. Women may have different perceptions as to the effect of their RA on their couple relationship, as their experiences of illness are often different to that of men, due to the different social, economic and psychological roles that women have in intimate relationships (Crooks, 2001).

Historically, women have been generally excluded from health related research, as the majority of the focus was on men, and then mostly on the biomedical aspects of illness (Naidoo, 2004). In addition “Women’s health is moving from a focus on gynaecology and reproductive issues, to Gyn-ecology... which is concerned within her dis-eases and not her diseases” (McBride, 2001, p. 316). Dis-eases implies more than mere physiological factors. According to McBride (1993) as cited in Crooks (2001), a biomedical researched based conception of women’s health excludes important contextual factors related to and influencing health by only focusing on normative data, which does not represent the full range of a women’s illness experience. It is stated that: “...biomedical research has made important contributions to our understanding of the health of populations, but has added little to our

knowledge of the unique and individual health experience of women” (Crooks, 2001, p. 317).

According to Naidoo (2004), attitudes have since changed and women’s health-related issues are given priority in research. Gender differences in health are addressed regularly in literature and it has been found that men die earlier than women do in industrialized societies, but women have poorer health than men in general (Naidoo, 2004). In addition, MacIntyre and Hunt (1997) found that women have lower mortality rates, but higher morbidity rates, with women suffering from more non-fatal chronic illnesses such as hypertension, kidney disease and auto-immune diseases, of which RA forms part (cited in Naidoo, 2004).

Given the factors involving women and their health related issues, this study will be contributing to the growing body of literature, which focuses on the unique experiences of women in relation to their health and/or illness experiences. According to the Arthritis Foundation (2000), RA also affects more women than men, at an average of between 2:1 and 3:1 worldwide (including South Africa) and therefore this study will focus on the unique and individual experiences of women relating to their perceptions of the effects of RA on their relationship with a significant other.

1.2. RA: A chronic illness

Rheumatoid Arthritis (RA) is an inflammatory, systemic and chronic illness, which mainly affects the synovial membranes of multiple joints (Arthritis Foundation, 2003). This highly inflammatory poly-arthritis may often lead to varying degrees of

joint destruction, deformity and loss of functioning, as the most common outcomes in the established disease (Matsumoto, 2004).

Matsumoto (2004), mentions that chronic pain, disability and excess mortality are possible unfortunate outcomes of the disease. RA is an autoimmune disorder of unknown etiology and may also affect other systems in the body such as the renal-, cardiovascular- and pulmonary-systems (Arthritis Foundation, 2003). Because of the unknown etiology of RA, it has been described as “one of modern medicine’s major enigmas” (Buchanan, 2001 as cited in Naidoo, Lindegger & Mody, 2004).

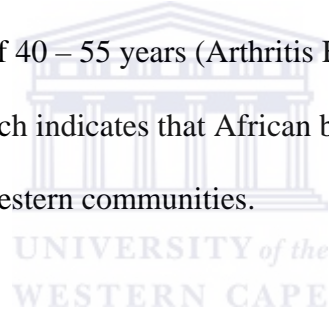
RA forms part of the muscular-skeletal group of diseases, which is regarded as the single most important reason for loss of ability to work or impairment of ability to work in the world (Arthritis Foundation, 2003). The effects of these diseases on the world economy and its related psychosocial effects have caused the World Health Organization to declare this decade (2000 to 2010) as the “Bone and Joint Decade” (Mody, 2004). On September 16, 2002, the Minister of health of South Africa, Dr. Manto Tshabalala-Msimang, signed the declaration of the Bone and Joint Decade, committing South Africa to the ongoing research, management and support of muscular-skeletal diseases.

1.2.1. Epidemiology

The prevalence and incidence of RA is relatively constant in many populations, at about 1% of the total population worldwide, according to Silman and Pearson (2002). However, a high prevalence of RA has been reported in the Pima Indians (5.3%) and in the Chippowa Indians (6.8%) (Silman & Pearson, 2002). The general impression is

that RA has a lower prevalence and a milder course in developing countries. Epidemiological studies from different regions show that varying prevalence is possibly related to urbanization. The data suggests that where severe disability does occur, it presents a significant health challenge because of scarce medical and social resources in these developing countries such as South Africa (Kalla & Tikly, 2003).

According to Mody (1995), RA is reported in large numbers from many parts of Africa, whereas it used to be considered as a rarity in Africa. Prevalence in rural areas is less common, but in urban populations it is similar to western communities (Woolf & Pflieger, 2003). More women than men are affected (ratios of between 2:1 to 5:1 have been reported) and RA affects any age group, including children, but is mostly diagnosed between the ages of 40 – 55 years (Arthritis Foundation, 2003). According to Mody (1995), recent research indicates that African blacks may have a younger age of onset than is the norm in western communities.



From the available statistics, the prevalence of RA in South Africa correlates with the one percent of the worldwide statistic. Furthermore, the gender profile of people diagnosed and living with RA in South Africa is approximately 2:1 (female to male ratio), as in the rest of the world. Given South Africa's third-world status in terms of economical and healthcare resources, such a prevalence of RA places a burden on these systems, due to the illnesses' chronicity and high cost of management. Effective management of a chronic illness, such as RA, will lessen the reliance on the healthcare system and allow people living with RA to be more independent and self-sufficient instead of relying on the state's resources, to ensure their optimal functioning.

1.2.2. Impact of RA

According to Naidoo (2001), RA is a very costly disease to the individual, workplace and healthcare system. In a developing country such as South Africa, with a healthcare system already under strain due to lack of funding and other demanding health issues, such as HIV/AIDS, the cost of caring for RA patients is very high.

“Despite investigations into ways of improving the quality of life of individuals with RA, it is difficult to contain the overall cost of this debilitating disease. Attempts to prevent the disease from manifesting have been futile thus far” (Naidoo, Lindegger & Mody, 2004, p. 20).

Bishop (2005, p. 219) regards the onset of RA as a “life-changing event”, implying the start of a lifelong process of “adaptation to significant physical, psychological, social and environmental changes”. Bury (1991, p. 451), described the onset of a chronic illness as a “biographical disruption”, emphasizing the impact that such a disease has on a person’s life course. RA impacts on various levels of a person’s functioning. Besides the obvious physical symptoms, psychological and social domains are adversely affected. Key life domains affected by RA include psychological well-being (Anderson, Bradley & Young, 1985); social well-being (Revenson, Schiaffino, Majerowitz & Gibofsky, 1991; Fitzpatrick, Newman, Archer & Shipley, 1991); family relationships (Barlow, Turner & Wright, 1993); employment (Lubeck, 1995) and restrictions in daily functioning and loss of independence (Taal, Erwin & Weigman, 1993). Chronic pain, which is often present with RA, is also associated with a multitude of secondary stressors such as sleep disruption, under-employment, interpersonal tensions and difficulties with basic tasks of daily living (Taal *et al*, 1993). A range of negative emotions, including depression,

anger, and anxiety are frequently experienced by people coping with a variety of chronic pain conditions according to Craig (1999), as well as Robinson and Riley (1999).

Chronic pain, physical deformity, loss of functionality and /or impaired mobility and unpredictability of symptoms have emerged from the data as the most commonly experienced symptoms or outcomes of RA by all eight participants in varying degrees. Therefore, this study focuses on these common, but not exclusive, symptoms of RA and their effect on women's couple relationships, specifically each symptom and its effect on communication, role definitions and/or division of labour, as well as intimacy, as important affected areas of the relationship as identified by the participants.

For the purpose of this study, the focus will mainly be on the life domain of family relationships, and more specifically on the close, intimate interpersonal relationship with a significant other, being a spouse or partner (couple).

1.3. Description of “close, intimate relationship with a significant other”

In defining “close intimate relationship with a significant other”, this description allows for heterosexual as well as homosexual couples, whether they are married (legally according to South African law or in any of the other culturally-sanctioned unions) or co-habiting. For the purpose of this study, participants are required to have been considered a couple, according to the above mentioned description, for a

minimum period of two years prior to the onset of the illness and at least an additional five years after the onset of RA.

1.4. Aim and objectives

Aim

The aim of this study is to explore women's perceptions of how their illness (RA) affects their relationship with their significant other, being a spouse or partner.

Objectives

The first objective of this study is to explore the perceived effect of specific symptomatic features of RA on the women's relationships with their significant other (spouse or partner).

The second objective is to explore the perceived effect of the most salient challenges related to RA. The following challenges of RA emerged from the data as the most prominent: chronic pain, deformity, loss of functionality and/or mobility and the unpredictability of symptoms. The perceived effect of these challenges of RA on specific aspects (communication, role-definition and/or division of labour, and intimacy and/or sexual functioning) of close, intimate relationships with a significant other is then explored.

The study will attempt to gain a better understanding of the underlying processes that affect close, intimate relationships of women with RA and how they perceive these factors to impact on their relationships with a spouse and/or partner by the exploration and analysis of these women's perceptions.

Exploration of women's illness experiences is crucial in developing a theoretical understanding of the myriad of variables involved in this process, thereby expanding the existing body of knowledge to ensure a broader, contextual lens with which diseases and the illness-experience may be studied.

1.5. Organization of the thesis

Chapter two is the theoretical overview and review of the literature and explores the various theoretical concepts relevant to this study. Existing research pertaining to this study is also examined. Studies relating to coping and adjustment to chronic illnesses such as RA are focussed on.

The methods used in the study are discussed in chapter three. Grounded theory as a qualitative method is discussed, and a description of participants and method of data collection and analysis is provided. Finally, self-reflexive issues are discussed and ethical issues are considered.

Chapter four presents the findings and discussion. Themes that emerged as a result of grounded theory analysis are presented and these themes are discussed in the context of the literature.

The key findings of the study are presented in Chapter five, together with concluding comments. Finally, limitations of the study are considered and future research opportunities are discussed.

CHAPTER 2

THEORETICAL OVERVIEW AND REVIEW OF LITERATURE

2.1. Introduction

This study focuses on the perceptions of women with RA. Grounded theory as a method of study will be used because it lends itself well to the study of women and their illness experiences. McBride (1993) as cited in Crooks (2001, p. 12) mentions that: “women’s health issues have been considered from a biomedical, positivistic research perspective, formed from normative data. This does not represent the full range of women’s health or illness experiences, and seldom accounts for the extent of contextual factors operating to break down or maintain health”. Crooks (2001) emphasized the need for researchers to pay closer attention to women’s experiences and their understanding of situations, including health related experiences in order to provide meaningful evidence-based care to women. An important context of this understanding of women’s experiences is the social interactions within which meaning and insight is formed.

A method of study is required for women’s health that attends to the variety of contextual variables, including women’s perceptions, attributions of meaning, relationships, caring responsibilities and preferences for interaction in the health-care field. Symbolic interactionism and grounded theory together provide the broad lens for meaningful research into women’s health issues (Crooks, 2001). Symbolic interactionism is described as “the study of the intersections of interaction, biography, and social structure in a particular historic moment” (Denzin, 1992, p. 21). The basic

elements and the dynamic interaction between them in these intersections need to be understood, and making sense of self and life experiences need to be the focus.

There is also a link between feminist and grounded theories, which has developed over the years. Feminist grounded theories emerged in nursing literature as an established research methodology in the Health and Social Sciences. The researchers examining the compatibility between feminist and grounded theory traditions in scientific knowledge-generation have concluded that the two traditions “are congruent with each other, although not entirely without epistemological, methodological and normative tensions” (Kushner & Morrow, 2003, p. 30). One of the most important differences between grounded theory and feminist theory is that grounded theory is considered to be a primarily methodological strategy, whereas feminist theory in contrast originated as a broad theoretical perspective or paradigm. Kushner and Morrow (2003), suggest that interplay between both theories can bring out strengths and deal with limitations of each perspective.

2.2. The etiology of RA

2.2.1. The biomedical model of RA

There is an abundance of bio-medical research on RA describing the disease, it's possible etiology and a myriad of treatment options to try and reduce disease activity. In spite of extensive research worldwide, the etiology of RA remains unknown and treatment options are limited to reducing disease activity versus curing RA. This biomedical research refers to RA as a disease, focusing on the physiological aspects, rather than attempting to understand RA as an illness, which alludes to more than mere biological factors.

RA is therefore described as an autoimmune illness of unknown etiology, affecting multiple joints in the body with inflammation. It is a chronic, degenerative disease, which could lead to joint destruction, culminating in chronic pain, swelling, stiffness, deformity, loss of functioning and mobility (Arthritis Foundation, 2001; Matsumoto, 2004).

Treatment modalities normally include disease modifying medication to be taken chronically and may result in several negative side effects, ranging from ulceration and bleeding, to osteopenia (loss of bone density) and renal complications (Conn, 2001). Chronic use of glucocorticoids, such as prednisone, may also affect appearance by inducing bloatedness, especially to the face (Conn, 2001). Further medical treatment focuses on pain-management and reduction of inflammation.

2.2.2. The biopsychosocial model of RA

From a biopsychosocial theoretical perspective, RA is not only described in biological terms, but the social and psychological aspects of the illness have also been considered in the etiology of RA. Psychosocial and socio-demographic factors are crucially important in disease outcome, and international trends in research are focussing on these factors, according to Naidoo (2004). In a South African based study done by Naidoo, Lindegger and Mody (2004), in which they investigated the way in which psychosocial factors are associated with socio-demographic factors, disease factors, and health related quality of health, it was found that more women than men are affected by RA, that participants in this study had a decreased chance of being in a marriage or co-habitation and that these patients might be at risk for depression and other mood disorders indicative of psychological well-being.

Furthermore, the study found that paid employment was negatively affected by RA and that lower socio-economic status was linked to worse disease outcome compared to people living in higher socio-economic conditions. Developed countries offered better healthcare options than developing countries such as South Africa, also resulting in worse RA disease outcomes in these developing countries.

2.2.3. The psychological aspects of RA

Psychosomatic medicine acknowledged psychological factors in the etiology of disease from the time of Freud (1955) and Cannon (1932) to Kaplan (1984). Freud and later on Kaplan found that unconscious psychological factors could contribute to the development of physical symptoms, and Cannon showed that emotion may cause physiological changes and could thus cause disease. Other theoretical concepts flowing from the field of psychosomatic medicine highlighted an association between personality and disease in general (Dunbar, 1943), and the link between personal conflict and the development of specific diseases (Alexander, 1950) as cited in Marks, Murray, Evans, and Willig (2000). These two researchers developed specific personality profiles of those prone to various diseases, including RA. Proving causality remained challenging, but research by Friedman and Booth-Kewley (1987) as well as Matthews (1988), suggest a strong connection between psychological states and the etiology of certain illnesses, including arthritis. It is suggested by some of these researchers that a negative emotional state (depression, anxiety, hostility) and repression as a coping style may produce pathogenic physiological changes. Negative mood states could also lead to practicing of faulty health behaviours, which in turn may result in the development of diseases. In addition, stressful life events such as bereavement, being depressed and events involving the loss or lack of perceived

control has been associated with immunocompromises (Kiecolt-Glaser, McGuire, Robles & Glaser, 2002). Research is continuing to establish the relevant links between psychological factors and the development, course, management and outcome of illness, but that psychological factors contribute to the development of certain illnesses is generally accepted as relevant.

2.3. Adaptation to RA

The process of adapting to chronic illness is complex and research is conducted continuously to expand the existing knowledge base. Adaptation to RA is often the focus of such studies due to the unique nature of this illness. Adaptation to RA is not normally a once of experience, but due to the degenerative nature of RA, as well as the characteristic unpredictability of the symptomology, a process of repeated adaptation and adjustment takes place. Coping theory is widely used to understand the adaptation processes to various disruptive life events, including chronic illness. Knowledge is constantly sought to improve this theory in order to facilitate a better understanding of the processes involved in adapting to a chronic illness, such as RA.

2.3.1. Coping

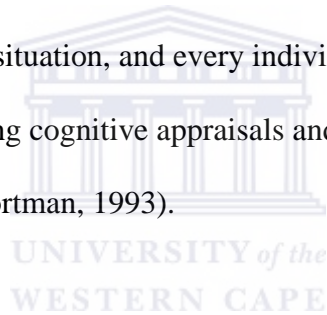
Coping consists of “cognitive and behavioural efforts to manage specific external or internal demands (and conflict between them) that are appraised as taxing or exceeding the resources of the person” (Lazarus, 1991, p. 125). According to Spitzer, Bar-tal and Golanter (1995), the moderating effect of coping on the relationship between stress and adaptation has been established previously in the literature by (Pearlin & Schooler, 1978; Billings & Moos, 1981; Kasl, 1984; Lazarus & Folkman, 1984; Folkman & Lazarus, 1985; Laux & Weber, 1987; Lazarus, 1991). In essence,

coping theory suggests that each person-environment encounter is appraised to determine the degree of harm, threat or benefit it poses, as well as to consider the possible resources available to manage the interaction (Lazarus & Folkman, 1984). As a result of this appraisal process, emotions arise and coping strategies are then used to manage both the emotional responses as well as the actual problem, if possible (Dewar, 2001).

Coping strategies are broadly categorized as problem-focused strategies (which address circumstances that can be changed) and emotion-focused strategies, which may limit distress in circumstances where change cannot happen, such as a chronic illness like RA (Lazarus & Folkman, 1984).

RA is recognized as a chronic illness, with no known etiology or cure, with debilitating, degenerative sequelae and a typical unpredictable waxing and waning of symptoms. These unique aspects related to RA make it a highly stressful and unpredictable illness, qualifying it as an experience of “continuous suffering”, as described by Dewar (2001). According to Cassel (1991, p. 24), suffering is “distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person”, which includes physical as well as emotional dimensions. Suffering accompanies many of the symptoms, treatments and circumstances of ill health and is therefore considered to be a distressing experience (Dewar, 2001). Coping is also the process by which an individual manages this suffering, attempts to minimize its effects and tries to make meaning of the experience.

Every individual has their own coping style, which in turn informs their actual coping response, whether it is positive or negative (Folkman, 1997). A wide range of behavioural, personal and environmental factors such as social support, personality and individual coping styles influences coping. Personality characteristics such as hardiness, optimism and a sense of control may contribute positively to an individual's coping efforts. Negative, pessimistic and introverted personality types tend to have poorer coping outcomes (Adler, 1994). An individual's coping styles, cognitive appraisals and general functioning before the onset of a chronic illness will often influence the way in which such an individual copes with the illness (Affleck, 1996). Pre-existing personal or relational difficulties will play a role in the adaptation to a chronic illness (Folkman, 1997). An important adaptational factor is a person's ability to make meaning out of their situation, and every individual will make their own meaning based on their existing cognitive appraisals and emotional and behavioural responses to the situation (Wortman, 1993).



For the purposes of this study the focus will not be on individual coping, but rather on social support and dyadic coping as additional coping strategies.

2.3.1.1. Dyadic coping

In research concerning coping, an interactive approach has been described, focusing specifically on the married couple as a unit. With regard to coping in marriages, this enlarged perspective has been suggested by a number of theorists and researchers proposing to define coping in dyads as an interpersonal process involving both partners yielding to different conceptualizations of dyadic coping as:

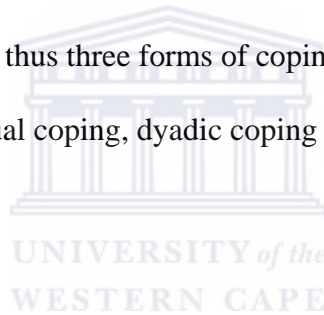
- (a) “an effort to establish and maintain close relationships” (e.g. Coyne & Smith, 1991; DeLongis & O’Brien, 1990; O’Brien & DeLongis, 1997)
- (b) “the congruence of individual coping efforts with both partners” (Barbarin, Hughes & Chesler, 1985; Revenson, 1994; Terry 1989) and
- (c) “ an interpersonal coping process by involving both partners in order to reduce problem- and emotion- focused stress” (Bodenmann, 1995; 1997)” as cited in Pakenham (1998, p. 269).

The terms “dyadic stress” and “dyadic coping” are both defined as “parts of an interpersonal process involving both marital partners. Dyadic stress is defined as a specific stressful encounter that affects both partners either directly or indirectly and triggers the coping efforts of both partners (dyadic coping) within a defined time frame and a defined geographical location” (Revenson, Kayser & Bodenmann, 2005). Three elements may stimulate a joint problem-solving process and common emotion-focused coping activities if one supports the assumption that married individuals are invested within a shared social context. These elements include the interdependence of the spouses, their common concerns and their mutual goals. Individual coping efforts are also used during the dyadic coping process, and can not be excluded from the overall coping process at all.

Assuming that both partners are committed and willing to invest in the relationship, dyadic coping will have two primary objectives: to reduce stress for each partner and the enhancement of relationship quality (Revenson, Kayser & Bodenmann, 2005). Both these objectives will therefore lead to a better adjustment to a chronic illness such as RA, where an optimal interpersonal relationship with a significant other has

been proven to serve as a protective factor. Good adjustment is defined as “either a return to pre-stressor functioning or personal and dyadic growth” (Revenson, Kayser & Bodenmann, 2005).

Several assumptions underlie the theory of dyadic coping. Firstly, it must be conceptualized from a systems perspective; secondly, it is regarded as only one way to manage a stressor (other ways include individual coping efforts and supportive transactions between one partner and his or her social network, or between the couple and their social network), thirdly, dyadic coping is most often used after individual coping efforts have been made and did not succeed; and lastly, dyadic coping may involve both positive and negative modes of coping (Revenson, Kayser & Bodenmann, 2005). There are thus three forms of coping with stress in close relationships, namely individual coping, dyadic coping and seeking support from others.



According to Bodenmann (2001), three different forms of dyadic coping can be identified according to the situation and both the individual and dyadic appraisals and goals. These are common, supportive and delegated dyadic coping. These forms of dyadic coping can be either positive or negative in nature, and it may be problem- or emotion- centered. In common dyadic coping, both partners take part in the coping process more or less symmetrically, to handle a problem-focused or an emotion-focused issue relevant to them, such as joint problem solving, equal division of tasks or common religious activities. Supportive dyadic coping is provided by one partner to assist the other partner, who is generally or at that time not equipped with effective coping resources, to achieve the maintenance or restoration of an adaptive state by

helping with daily tasks, practical advice or helping the partner to reframe the situation. In delegated dyadic coping, one partner will take over certain tasks and duties of the other in an effort to reduce stress experienced by that partner, such as one partner taking over the shopping duties to relieve the other from that added stress (Bodenmann, 2001).

An important factor to be taken into consideration in the process of dyadic coping is the issue of reciprocity in emotional support between the care-giving and care-receiving partners. Reciprocity plays a vital role in terms of marital adjustment and perceived burden, according to Wright and Aquilino (1998) as cited in Bodenmann (2001).

A number of studies have focused on stress and dyadic coping in physical illness, especially RA, such as Manne and Zautra (1990) and Revenson (2003). According to Pakenham (1998) as well as Revenson (1994), researchers utilizing the congruence concept of dyadic coping reported a positive association with marital adjustment, fewer burdens for the spouse and better general functioning. Theorists referring to the coping congruence or discrepancy of partners, argue that the compatibility of problem- and emotion-focused coping strategies within both partners may be predictive of marital adjustment. This implies an optimal outcome if both partners apply similar or complimentary coping strategies while facing a common stress event, according to Revenson (1994). Other researchers such as Barbarin, Hughes, and Chesler (1985) found that couples who were similar in emotion-focused and dissimilar in problem-focused coping tended to have a better outcome.

In summary, Bodenmann (2001) mentions that there is significant empirical evidence to support the importance of the role that dyadic coping plays in the framework of physical illness. Several studies have revealed that partner support may even outweigh personal characteristics in determining coping efficacy (Bodenmann, 2001; Revenson, 2003; Danoff-Burg, 2000).

This study will touch on all three areas of coping, i.e. the individual level, the dyadic level as well as the broader social levels. In the process of adjusting to a chronic illness such as RA, the continuous nature of the stressor will definitely involve coping at all levels, but the focus will be mostly on the dyad as a system. The focus of this study is the perceptions of women with RA on the effect that their illness has on their couple relationship. This implies an attempt to add understanding to the broader processes of adjustment to and coping with RA (specifically dyadic coping), by looking at the effects of this illness on couple relationships from the perspective of the women living with RA.

2.3.1.2. Social support as a coping strategy

One of the most significant and widely researched coping strategies is social support. Social support can be defined as “the provision of resources to an individual by another person or persons” (Okun & Lockwood, 2003, p. 15). There are three components to social support which are generally recognized: (1) social embeddedness (which captures the extensiveness and structure of one’s social ties), (2) enacted support (which is often quantified by the frequency with which one receives a variety of supportive social provisions) and (3) perceived quality of support

which refers to an individual's cognitive appraisal of the availability of support (Schwarzer & Leppin, 1991) as cited in Okun and Lockwood (2003).

Social support (whether positive or negative) has been extensively researched in the literature as an important coping resource in managing illness (Corbin & Strauss, 1988; Northouse, 1988; Revenson, 1990; Miller, 2000; and Dewar, 2001). Social support has been hypothesized to provide a buffer between the individual and the sources of stress as well as providing tangible assistance in meeting needs (Miller, 2000). According to Silver, Wortman and Crofton (1990), one of the most challenging aspects in managing illness is to maintain social support and preserve interpersonal relationships as valued coping resources.

Social ties and relationships have extensive effects upon individuals' health and well being, according to Fitzpatrick, Newman, Lamb and Shipley (1988). These social ties and relationships may indirectly mediate the stresses of ill health and the individuals' responses to illness in terms of adjustment and coping, as well as having a "buffering effect", which may reduce the adverse effects of stressors such as life events or the varied demands of a chronic illness.

In examining social support from the perspective of the recipients' beliefs about the amount and quality of support that is available from their social networks (i.e. perceived support), the relational context of social support theory has not been fully explored. Reis, Collins and Berscheid (2000) as cited in Frasier, Tix and Barnett (2003) argued that the meaning of a particular behaviour might change dramatically depending on the relational context. Several investigators have stressed the need to

better understand enacted support processes within close relationships; particularly marital relationships (eg. Abby, Andrews & Halman, 1995; Acitelli & Antonycci, 1994; Carels & Beaucom. 1999; Pasch, Revenson & Sullivan, 1997). According to Griffen, Friend, Kaell and Bennett (2001), patients with RA tend to rely heavily on a partner or primary support provider for daily assistance and regular social support. According to Griffen, Friend, Kaell and Bennett (2001), patients living with a partner have been found to report more social support, less depression and anxiety and greater psychological well being compared to people without partners.

Close interpersonal relationships can therefore be considered as supportive and caring, but when these relationships are characterized by conflict, misunderstanding and criticism, it may have a negative impact on the psychosocial functioning of the person with RA, as described by Manne and Zautra, (1989); Revenson, Schiaffino, Majerowitz & Gibofsky (1993). Problematic interactions between people with RA and their significant others may occur more frequently when “patients are more severely ill or are more distressed by their illness” (Griffen, Friend, Kaell & Bennett, 2001, p. 133). Revenson and Majerowitz (1990), found that spouses of patients with RA could provide support that is more problematic to patients with more severe RA (such as unhelpful or unsolicited suggestions and/or advice and becoming annoyed when their advice was not taken).

It is clear from the literature that close, intimate relationships with a significant other play an important role in the psychosocial well being of people with RA. In the context of social support theory, the perception of received support as experienced or appraised by the individual with RA is crucial to the understanding of the process.

2.3.1.3. Negative Social Support

It is also important to note that not all social support is necessarily regarded as positive. The term “negative support” has been used to describe the provision of support that does not meet the recipient’s needs or is perceived by the recipient as non-supportive. “Negative support” implies help, information or concern that is positive in its giving, but negative in its receipt. The intent is therefore good and without malice (Revenson, 1990). The complete absence of social support can also be experienced as negative and constitutes another negative aspect of social support. Therefore, as the cognitive approaches suggest, the supportiveness of an interaction is perceived in the eyes of the beholder (Coyne & DeLongis, 1986). Negative support can therefore be described as the “perceived meaning of the interpersonal interaction” (Revenson, 1990, p. 95).

2.4. Adult attachment theory and the process of adaptation to RA

Adaptation to chronic illness requires an alteration of life and self “to accommodate bodily losses and limit and resolve the lost unity between body and self” (Charmaz, 1995, p. 657). Adapting seldom occurs only once, but is rather an ongoing process where chronically ill people are forced to adapt repeatedly as more losses occur over time. According to Charmaz (1995, p. 657), “adapting shades into acceptance”, where other ways of living with a chronic illness include “ignoring it, minimizing it, struggling against it, reconciling self to it, and embracing it”.

Adult attachment theory and cognitive-behavioural theories are just some of the psychological theories used to try to understand the processes involved in adapting to and living with a chronic illness, such as RA. These theories are used to try and

explain the individual and relational psychological processes involved when a person, couple, or family is challenged by the onset of a chronic illness, such as RA.

The assumption underlying adult attachment theory is that individuals of all ages have an attachment behavioural system, which is activated in response to stressful or threatening events; with the function of promoting survival and security (Bowlby, 1982; Bretherton, 1985). The way in which individuals cope with distress and regulate feelings differ and these differences are thought to be as a result (or partially as a result) of such an individual's attachment history. This attachment history relates to regulations of distress in relation to attachment figures, such as caretakers during childhood and adolescence (Ainsworth, Blehar, Waters & Woll, 1978; Bowlby, 1973; Bretherton, 1985; Kobak & Sceery, 1988) as cited in Collins and Freeney (2004). Based on the experiences with attachment figures, the individual will develop generalized representations about whether close others will be supportive and responsive in times of need, and also whether the self is worthy of care and support (Collins & Feeney, 2004). Attachment theorists refer to these mental representations as internal working models of attachment (Bowlby, 1982; Bretherton, 1985). These internal working models of attachment are cognitive-affective-motivational schemas that contain, besides attachment-related knowledge, episodic memories, goal structures and action tendencies, according to Collins and Allard (2001); Collins and Reed (1994). Once developed, these working models are thought to operate largely outside of awareness and play an important role in shaping cognition, affect and behaviour in attachment relevant contexts (Collins & Allard, 2001; Collins & Reed, 1994).

There are two underlying dimensions commonly associated with attachment styles, namely anxiety and avoidance; resulting ultimately in the defining of four prototypical attachment styles, according to Collins and Feeney (2004). The anxiety dimension refers to the degree to which an individual may worry about being rejected, abandoned or unloved by significant others. Avoidance assesses the degree to which individuals limit intimacy and inter-dependence on others. Therefore, secure individuals are low in anxiety and avoidance, allowing them to feel valued and worthy of affection, perceiving attachment figures as generally caring, responsive and reliable. These secure individuals will form close relationships and will depend on others when needed.

Pre-occupied individuals have high anxiety, but they are low in avoidance. As a result, they would normally desire closeness and intimacy with others, but may lack the confidence in others' availability and likely responses to their needs. They have concerns about being abandoned or rejected, but depend on the approval of others for a sense of personal well-being (Collins & Feeney, 2004).

Fearful-avoidant individuals possess high levels of anxiety and avoidance. They experience high levels of fear of rejection and abandonment by others, as well as a strong sense of distrust in others. A discomfort with intimacy and the avoidance of close relationships are the result of this style (Collins & Feeney, 2004).

Dismissing-avoidant individuals are low in anxiety, but high in avoidance. They tend to feel confident and view themselves as invulnerable to negative feelings. They perceive attachment figures as unreliable and unresponsive. They will try to maintain

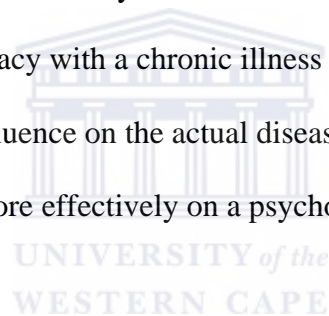
a positive self-image in the face of potential rejection by denying attachment needs, distancing themselves from others and restricting expressions of emotionality (Collins & Feeney, 2004).

Attachment theory is relevant to social support not only because the attachment behavioural system will be automatically activated in response to stressful or threatening events, but also because working models of attachment contain both implicit and explicit expectations about the likelihood that significant others will be emotionally available in response to need (Collins & Feeney, 2004). Attachment styles will therefore play a significant role in determining how an individual will perceive social support from a significant other. The relevance of attachment theory to the study of social support and coping is crucial and although this particular study will not have the scope to investigate the participants' various attachment styles, in looking at their perceptions of the effects of their illness on their relationships with a significant other, it remains an important theoretical context to consider in this type of research. Perceptions of women with RA on the effect of their illness on their couple relationships would have been influenced by their particular attachment styles, prior to onset of illness.

In reviewing the literature for this study, quantitative research about RA and its effects on the individual dominated. Qualitative research on RA focuses on coping and adjustment to the illness, often highlighting one of the typical symptoms of the illness and its effect on the individuals' ability to cope and adjust. Qualitative studies focusing on women's perceptions of the effects of the illness on their couple

relationships specifically, is limited to studies done by Revenson, Kayser and Bodenmann (1995); Coyne and Smith (1991); and DeLongis and O'Brien (1990). Maintaining and managing a healthy, functional relationship with a spouse and /or partner is an important aspect in coping effectively with RA. It is suggested in the literature that the maintenance of an effective intimate relationship may serve as a significant buffering effect in coping with a chronic illness such as RA.

These dyadic relationships are considered to be crucial in the social support theory to serve either as a buffering effect or in the case of dysfunctional or ineffective relationships as an additional stressor on the coping process. Therefore, the importance of maintaining functional dyadic relationships are clear in order to assist in an individual's coping efficacy with a chronic illness such as RA. Dyadic relationships may have an influence on the actual disease outcome, as well as the individual's ability to cope more effectively on a psychosocial level.



Social support literature in terms of coping with chronic illness is vast, with the most recent focus being on the relational context in which human behaviour takes place (Reis, 2000). Researchers such as Reis, Collins and Berscheid (2000), are insisting that any science of human behaviour that neglects the influence of relationships “ is destined to be inaccurate and incomplete” (Reis *et al.*, 2000, p. 844). Several researchers have highlighted the need to understand the processes of enacted support within close relationships, and in particular within marital relationships, such as Carels and Beaucom (1999); Pasch, Bradbury, and Sullivan (1997); and Frazier, Tix and Barnett (2003). Furthermore, Coyne and Anderson (1999); Coyne and DeLongis (1986); Pistrang and Barker (1995), are just some of the researchers who have stated

that support from other relatives and friends can't compensate for a lack of support from one's spouse. Mostly the reception of supportive behaviour by one's spouse (or the perception of such behaviour as supportive), should lead to lower levels of distress for the individual with the illness as stated by Manne and Zautra (1989); and Vinokur, Price and Caplan (1996), to name but a couple. On the other hand, so called "unsupportive behaviour" by a spouse (whether "real or perceived"); is linked with even greater distress than that of any other source, according to Coyne and Anderson (1999); Major, Zubek, Cooper, Gozzarelli and Richards (1997); and Revenson and Majerowitz, (1990).

2.5. Summary of chapter

This is a qualitative study and grounded theory is used as a method. Relevant theoretical concepts underpinning this study is discussed, including a review of the literature pertaining to these concepts. The most relevant theoretical concepts pertaining to this study falls within the biopsychosocial approach, taking the individual, the couple and the system into consideration in the etiology of and adaptation to chronic illness, such as RA. Main theoretical concepts discussed in this chapter focused on coping and social support in the management and adaptation to chronic illness, such as RA. Different coping approaches were highlighted such as individual, dyadic and social methods of coping. Two psychological theories relevant to adaptation to chronic illness were described, namely adult attachment theory and a cognitive- behavioral theory, which underpins coping theory in general.

CHAPTER 3

METHODS

3.1. Introduction

Recent trends in chronic illness research have gradually moved towards the use of qualitative methods. This is because it presents unique opportunities for understanding RA from the perspective of those affected by the condition, as well as for critically evaluating many of the associations of traditional psychological variables that have emerged from decades of quantitative research (Arcury & Quandt, 1998). “It is recognised that the subtleties and personal meanings inherent in chronic illness, are best investigated using qualitative methods” (Turner, Williams & Barlow, 2002, p. 97).

Furthermore, grounded theory methods will be used in this study as it falls within a qualitative framework and lends itself well to the study of interpersonal and person-environment interactions. Grounded theory is a qualitative research method based on the Symbolic Interaction perspective. The founders, Barney Glaser and Anselm Strauss (1967), called the method “grounded” because a theory was systematically obtained from a broad array of data through a “rigorous process of constant comparison” (Glaser, 1992; Glaser & Strauss, 1967; Stern, 1980). A human problem and the social psychological or social-structural processes arising from it, is ideally suited for grounded theory research (Crooks, 2001). One of the strengths of grounded theory is that it explains what is actually happening in practical life at a particular time, rather than describing what should be going on (McCallin, 2003).

Strauss and Corbin's approach to grounded theory draws on "social constructionist anthology and the post-structuralist paradigm" where reality cannot be known, but can be interpreted (McCann & Clark 2003, p. 19). This post-modern perspective disagrees with the idea of epistemological absolutes, but focuses on the ambiguity in the social world. A post-modern perspective poses a need for multiple positions whilst recognising the various contradictions inherent in these positions. Established truths and beliefs are challenged by a post-structural worldview (McCann & Clark, 2003).

3.2. The philosophical assumptions of grounded theory

According to Annelis (1997), the following philosophical assumptions underlie grounded theory:

Theoretical sensitivity

Theoretical sensitivity is gained by a preliminary review of the literature whilst remaining mindful about the risk of tainting your view of the field and hindering the development of categories (themes) according to Schreiber (2001).

Theoretical sampling

Theoretical sampling involves a "purposive sampling" or sampling using certain pre-arranged criteria (Patton, 1990). Once the early data is collected and analysed, further sampling could be based on the categories and developing theory (Glaser, 1978).

Constant comparative analysis

Constant comparative analysis is a cyclical process, shifting from open to axial and then selective coding, and, at times simultaneously coding at several levels (McCann, 2003).

3.3. Coding and categorising of data

The coding process begins with open coding, which entails fragmenting or breaking down the data with the intent of conceptualising the data and identifying patterns or events in the data (McCann, 2003). Coded data gets inserted into a coding template whereafter concepts are elevated to provisional categories. The third step in conceptualising is to identify a core category. Once the core category is identified, the categories are modified and the theory integrated with the categories and sub-categories (Carpenter, 1995).

This study is focussing on the perceptions of women with RA, and a woman conducts the research. This also places the study within a feminist framework, which lends itself to the study of women and their illness experiences.

There is a link between feminist and grounded theories, which has developed over the years. Feminist grounded theories emerged in nursing literature as an established research methodology in the Health and Social Sciences. The researchers examining the compatibility between feminist and grounded theory traditions in scientific knowledge-generation have concluded that the two traditions are congruent with each other, although not entirely without epistemological, methodological and normative tensions (Kushner & Morrow, 2003).

Crooks (2001) states that: "To provide meaningful, evidence-based care to women as researchers, we need to attend to women's experiences, their own understanding of health-related issues, and the social interactions within which they gain meaning and insight into their situation". Women's emotional reaction to their illness experience is often ignored or becomes problematic and, at times, diagnosable in the bio-medical

model. The illness experience represents the personal and socially constructed meanings surrounding a disease event or sequence of events. “Illness is larger than disease and represents the personal, cultural and interpersonal interpretations of disease, including reactions to disease, changes in state of being and impact on social functioning” (Crooks, 2001, p. 14).

A method of study is required for women’s health that attends to the variety of contextual variables, including women’s perceptions, attributions of meaning, relationships, caring responsibilities and preferences for interaction in the health-care field. Symbolic interaction and grounded theory together provide the broad lens for meaningful research into women’s health issues (Crooks, 2001).

The current study uses a qualitative research approach, which is considered appropriate for this type of study, because qualitative research lends itself well to the study of lived experiences. The grounded theory method is chosen to conduct the study, as this method has been proven to address the relevant issues to this study particularly well, such as focussing on the personal and socially constructed meanings of the illness experience. Although grounded theory in its original form generates theory, it is not uncommon that small studies with tight timeframes may use grounded theory as an analytical framework, incorporating constant comparative analysis as a method of qualitative analysis. Therefore, the size of the project will determine whether the researcher uses the methodology to generate theory or draws on the method as a strategy for qualitative analysis. In a small-scale project, such as this study, it is acceptable to describe and explain some underlying social processes

shaping interaction and behaviour, instead of developing a substantive theory (McCallin, 2003).

3.4. Research setting

Participants selected for this study were all members of the Western Cape branch of the Arthritis “care and share” circles. Members of these circles normally meet once a month at various locations in and around Cape Town. Every “care and share” circle has a group leader who is trained by the Arthritis Foundation of South Africa to facilitate these monthly gatherings by presenting and discussing a prescribed arthritis self help course with the members. The focus of this self- help course is mainly about the physical challenges and ways to deal with these physical challenges of RA. These “care and share” circles are not regarded as support groups, but rather as educational groups aiming at empowering RA and other arthritis patients with as much knowledge as possible about their illness in order to ensure independent living.

The participants for this study were all contacted telephonically and appointments were made for the interviews at their homes at times that they found to be convenient. Every participant was individually interviewed and disturbances at home were kept to the minimum as arranged beforehand. One participant was lying down in bed during the interview as she was unable to walk or sit up at the time, and the other participants were interviewed sitting in the most comfortable position for them. Interviews were kept short (on average forty-five minutes) with breaks to allow for participants’ optimal comfort.

3.5. Participants

A purposive sampling strategy was used to select the participants for this study. This is often the sampling strategy of grounded theory research and is also called ‘theoretical sampling’ to indicate that, although participants are not randomly selected, their selection is guided by emergent theory (Arcury & Quandt, 1998). For the purposes of this study, participants were carefully selected according to specific inclusion and exclusion criteria in order to assure adherence to the specific focus and scope of this study.

Participants were selected from a group of people (adults, male and female) who are members of the Arthritis Foundation of South Africa and who are attending the various monthly “care and share” circles at various venues in and around Cape Town.

I approached the leaders of the “care and share” circles, which are held in different geographical locations in and around Cape Town and then requested that they speak to their respective group members to identify potential participants who meet the study criteria. The leaders of the following branches were contacted: Simonstown, Tokai, Mitchells Plain, Claremont, Sea Point, Milnerton, Bellville and Khayelitsha.

The inclusion and exclusion criteria were as follows:

Inclusion criteria

All participants had to be women and they had to be diagnosed with RA by a medical practitioner and had to be living with the illness for at least five years or longer. A five year period after the onset of RA usually means that the afflicted individual is in his or her established phase of the disease course. Acute and chronic phases of RA require different adjustment and coping efforts. RA is often characterized by an acute onset, followed by the more established phase of the illness, which may be interspersed with acute “flare-ups” followed by relative disease inactivity. During this established (chronic) phase, the symptoms are often waxing and waning, making the illness highly unpredictable.

All participants had to be in a relationship with a spouse and/or partner in the form of a marriage or co-habitation during this five-year period (or longer) after being diagnosed with the illness. The perceptions of women of the effect of their illness on their couple relationships demands for the purposes of this study, that the couple had to be together throughout the first five years of RA in order to account for the acute and chronic phases of the illness.

All participants needed to be in these relationships at least two years prior to the onset of RA and remained in the same relationship at least five years after the onset of the illness. A relative time period of two years prior to onset of RA will allow the participants to perceive the effect of the illness after onset, having been living as a couple without RA before. A minimum period of two years prior to onset should

allow the couple to establish relational patterns as a couple- unit without the additional stressor of dealing with RA from the outset.

Exclusion criteria:

Those suffering from any additional major illnesses, not related to RA, were excluded to prevent overlapping of illness symptoms and hence ambiguity concerning the data.

Although people with RA often experience other illnesses or forms of ill health related to RA (such as osteoporosis, heart disease, pulmonary and renal disease), people with other major illnesses unrelated to RA were excluded, such as any form of cancer or HIV/AIDS.

Once identified, I phoned these potential participants and confirmed that they met all the criteria and that they were willing to participate in the study, before setting up individual appointments with each of them at a place and time of their convenience for the purpose of interviewing them.

An overview of the demographic profile of the participants is presented in table 3.1.

Table 3.1. Demographic Profile

Demographics	Participants							
	1	2	3	4	5	6	7	8
Age								
20 – 29 years								
30 – 39 years	X							
40 – 49 years		X			X		X	
50 – 59 years						X		
60 – 69 years			X					X
70 + years				X				
Home Language								
English		X	X	X	X	X		X
Afrikaans	X						X	
Marital Status								
Single								
Divorced		X						X
Married			X		X	X	X	
Widowed				X				
Co-habiting	X							
Dependants								
Yes		X (2)	X (2)		X (2)	X (2)	X (2)	
No	X			X				X
Educational Level								
Tertiary				X			X	X
Matric	X		X					
Std 8-9		X			X	X		
Std 6-8								
Lower than Std 6								
Employment Status								
Employed		X						X
Retired								
Unemployed							X	
Boarded	X		X	X	X	X		
Religion								
Muslim						X		
Christian	X		X	X	X		X	X
Other		X						
Duration of RA in years	6	15	10	10	12	22	7	30

All the participants resided in the greater Cape Metropole. Participants two, four, seven and eight live in the Northern Suburbs (Century City, Edgemean, Bellville and Bothasig), participant six lives in Mitchells Plain (Lentegeur) and participant three in Steenberg. Participants one and five reside in the Southern Suburbs (Wynberg and Plumstead respectively).

The ages of the participants ranged from between 30-39 to over 70 years of age, with the average age being between 50-59 years.

Six participants stated English as a home language and two stated Afrikaans as so, but they consider themselves as bilingual.

In terms of marital status, four participants are married and one is co-habiting in a same-sex relationship. Two participants are divorced and one is widowed. Five participants have dependants (two each) and three have no dependants.

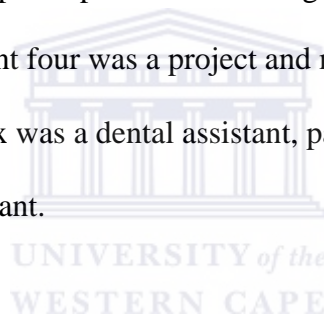
Three participants' highest educational qualification was Std 8, two completed Matric and three had obtained a tertiary qualification.

Five participants had been medically boarded and two were employed. One participant is unemployed due to the illness, but not officially medically boarded as she chose to resign instead of being declared medically unfit to work by the state or company she worked for.

Six participants were of the Christian faith; one was Muslim and another Jewish.

All but one of the participants who had been formally employed on a full-time basis, were either medically boarded or had to drastically reduce their working hours because of their illness. Only one participant (participant 8) managed to sustain full-time employment after the onset of RA. Of the remaining seven participants, two managed to find part-time employment (for a small stipend) with the Arthritis Foundation in a “patient-partner” programme, aimed at educating medical students at Grootte Schuur Hospital, on the physical manifestation of symptoms of RA. The remaining five participants are unemployed and medically boarded.

Participant one worked in IT, participant two was a legal secretary, participant three was a nursing sister, participant four was a project and marketing manager, participant five a secretary, participant six was a dental assistant, participant seven a teacher and participant eight is an accountant.



3.6. Procedure

Once the leaders of the “care and share circles” identified potential participants, they were contacted telephonically so the aim and objectives of the study could be explained to them. If they met the criteria of the study and were willing to participate in the study, an appointment was made with them at their places of residence. Those potential participants who did not meet the required criteria for this particular study were thanked for their willingness to participate, and the reason for their exclusion was explained to them. Two potential participants were excluded because they had been diagnosed with RA prior to getting married, and another because she was only married for two years after the onset of RA.

On meeting, participants were informed about the nature and purpose of the study, the proposed method of data collection (individual, audio-recorded interviews), as well as the confidentiality aspects related to the study. Participants were informed of their right to withdraw from the study at any time. A consent form detailing their agreement to participate in the study, and assuring them of confidentiality and the right to withdraw at any point during the project was given to participants to sign after they have been informed and were given the opportunity to ask questions or raise concerns. (See Appendix C for a copy of the consent form given to participants to sign). The participants were then asked to complete the biographical questionnaire. Some participants who struggled to write due to deformity of their hands, associated with RA, verbally recited their details in order for them to be collected.

3.7. Ethical comments

A proposal for the conduction of the study was submitted to the University of the Western Cape and the ethics board of the university approved of the ethical conduct proposed for the study.

Participation was informed, voluntary and confidentiality guaranteed. Informed consent involved assuring that participants were informed about the nature and purpose of the study, as well as to the method of data collection to be used.

Participants were informed of their right to withdraw from the study at any time and participation was voluntary. Participants were informed that a summary of the findings would be made available to the participants as well as the Arthritis Foundation of South Africa, without compromising their confidentiality.

3.8. Data Collection

In depth, semi-structured interviews were conducted using an interview guide. (See appendix A for a copy of the interview guide used). The interviews were audio-recorded with the permission of the participants. Brief notes were taken during the interviews to capture non-verbal behaviour and communication. Interviews lasted between 40 minutes to an hour. The limited time-span was partly due to the fact that participants were all physically unable to participate for longer periods of time, due to pain and exhaustion, as all but two of the participants in this study were experiencing active-phase flare-ups at the time of the interview. Participants were all interviewed within the comfort of their own homes. One participant was lying down in bed during her interview, and the others were seated in their most comfortable chairs. Participants were given the opportunity to stop the interviews at any stage when they needed to move around a bit or were feeling tired. Interviews were then resumed after these breaks. The scope of the study did not allow for elaboration on issues outside of the proposed objectives and saturation of data was reached after eight interviews.

3.9. Data analysis

The interviews were audio-recorded and transcribed. These transcripts were then subjected to a process of coding, to assist the researcher in breaking down the original data, conceptualise it and re-arrange it in new ways. The three coding stages in grounded theory are termed open coding, axial coding and selective coding (Strauss & Corbin, 1998). Coding in these three stages does not necessarily follow in sequence, but one may move in and out of the different forms of coding throughout any coding session.

Open coding assists in the fragmentation or breaking down of the data. The intent of coding is to conceptualise the data by analysing it and identifying patterns or events in the data. The aim of this stage of analysis is to identify discreet concepts, which are the basic units of analysis in grounded theory (Strauss & Corbin, 1998). By looking for similarities and asking questions, concepts that are in essence very similar can eventually be labelled with the same name. Each concept is then defined in terms of a set of discreet properties and dimensions to add clarity and understanding. Then a list of concepts generated has to be sorted into groups of similar or related phenomena, which in turn become categories. According to Strauss and Corbin (1998), categories have conceptual power because they can pull together other groups of concepts or sub-categories. It is this feature that moves open coding to axial coding (Priest, Roberts & Woods, 2002). During the analysis of the data in this study, the transcribed data was analysed by firstly reading carefully through the first transcription, and then to code the data line by line into discreet concepts. These concepts were then sorted into similar groups or sub-categories according to grounded theory methods. In this way various physical symptoms of RA started to emerge as having different types of effects on the relationships of the participants. Important areas of the relationships that were perceived as being affected were also emerging from the data. Once the first transcript was analysed, it allowed me to recognise similar “categories” in other transcripts. It also allowed me to ask more in-depth questions about these similar aspects to ensure rich data.

Axial coding is the process whereby connections are made between categories and sub-categories. To clarify the point of axial coding, Strauss and Corbin (1998) described an organisational scheme they call a “paradigm”, in which a phenomenon is

analysed in terms of its context, conditions and consequences. What caused the phenomenon, what is the context in which the phenomenon occurred, what interviewing conditions were present, what actions and consequences arose as a result? (Priest, Roberts & Woods, 2002). During this stage of analysis, the context of “phase of illness” (either acute or chronic phase) emerged as an important context, affecting perceptions of women on the effect of their RA on their couple relationships.

The final phase of coding is called selective coding. This stage involves identifying one or two core categories to which all other sub-categories relate and building a conceptual framework from which to develop a grounded theory (Priest, Roberts & Woods, 2002). Core categories or main themes were identified as symptoms or outcomes of RA and the effect (biopsychosocial) of these symptoms or outcomes on the relationship and how couples managed these illness symptoms in their relationships. Most commonly experienced symptoms or outcomes and those perceived as having the most effect on the relationship with spouse and/or partner emerged as the following sub-categories: chronic pain, loss of functionality and/or mobility, deformity and the unpredictability of symptoms. Specific core areas of the relationship with a spouse and/or partner that are affected emerged from the data. These areas of the relationship were mentioned by all the participants and emerged as the most significant sub-categories, namely communication, intimacy, and role definition and/or division of labour.

3.10. Reflexivity

I chose to conduct this study because I am living with a partner who has been diagnosed with RA six years ago. I have lived through the experience of being a partner to a chronically ill person, and I have noticed the myriad of effects that the illness has had on our relationship. I wanted to find out how this illness experience impacts on intimate relationships from the perspective of the ill person.

Over the last six years I have also attended some of the monthly “care and share” meetings of the Arthritis Foundation in Tokai, Western Cape. I have listened to many people (mainly women) sharing their illness experience. I noticed that the emphasis of support offered was informational and focussed mainly on the physical well being of the RA patients, with a lesser focus on psychological factors such as depression as a result of illness. Psychosocial effects of RA were hardly being addressed, especially the possible effects of the illness on spousal/partner relationships.

Some of the participants have met me previously at the “care and share” circles. Some expressed concerns regarding confidentiality due to the personal nature of the interviews. Confidentiality was guaranteed and all participants were happy to participate after the procedure was explained to them. The fact that I was living with a partner who suffers from RA may have influenced some of the participants who knew me beforehand. They would more often than other participants say to me: “Oh, you know how it is....”, whereas other participants who didn’t know me proceeded to explain their experiences in more detail. My response to the “oh, you know how it is” answers were always: “No, I don’t know exactly how it is for you, please tell me...?”.

Another variable, which might have impacted on the interview process, is race. Participants were not asked to identify themselves according to race, but if broad political terms may be used such as black and white, then five participants were white and three were black. I am white, and therefore the difference in race might have influenced the power-balance in the interviews, due to the inherent historical realities of South Africa.

Cultural differences based on religious affiliations may also have impacted on the interviewing process. Six of the participants were of the Christian faith, one Muslim and another Jewish. My perspectives would be drawn from a Christian framework and this could have influenced the relationship during the interview process.

Age is another variable that needs to be considered, as I am much younger than most of the participants are. During the interviews I noticed that some older women were uncomfortable at times in sharing experiences around intimacy in their relationships – especially sexual intimacy.

Finally, it is important to consider the fact that I am currently an Intern Counselling Psychologist, which means that I have been studying Psychology for six years. This fact would require from me to resist organising data in terms of psychological concepts and constructs, but rather to allow participants' experiences to unfold according to their own perspectives and not my own, which is informed by psychological thinking and a feminist belief system.

CHAPTER 4

FINDINGS AND DISCUSSION

4.1. Introduction

The findings are presented and discussed in this chapter. The discussion considers participants' perceptions regarding the effects of RA on their relationships with their significant other, being a spouse or partner.

In analysing the data for this study two core categories (main themes) emerged, namely the challenges of RA, and coping with the perceived effect of the challenges of RA in the context of a close, intimate relationship with a spouse or partner. During this chronic phase of RA, participants described periods of relative illness “inactivity” interspersed with unexpected, sudden “flare-ups” of illness activity. The duration and intensity of these flare-ups (acute stages) are unpredictable and variable, and differs from individual to individual. Perceptions of the effects of RA on close intimate relationships with a significant other differed during these distinct phases of the illness as described above.

Sub-categories (sub-themes) related to the challenges of RA emerged as chronic pain, deformity, loss of functioning and/or mobility and the unpredictability of symptoms. The sub-categories (sub-themes) related to coping with the perceived effect of these challenges in a relationship with a spouse or partner emerged as communication, intimacy and sexual functioning, role-definitions and division of labour or responsibilities as the areas perceived to be most affected by the various symptoms of RA by all the participants.

Furthermore, the areas of the relationship with a spouse or partner that emerged as most commonly affected by the RA symptoms are also not the only areas within such a relationship that are affected by the illness, but for the purposes of this study these aspects were the most salient. The areas of the relationship most affected by abovementioned RA symptoms emerged from the data as the following:

communication, role definition and/or division of labour and intimacy and/or sexual functioning.

4.2. The challenges of RA

The challenges of RA that emerged from the data as most significant in its perceived effect on spousal or partner relationships, were chronic pain, loss of functionality and or mobility, unpredictability of symptoms and deformity. Each of these challenges of RA and its individual perceived effect on the specific areas of the relationship (communication, role definition and/or division of labour and intimacy and/or sexual functioning) with a spouse or partner is discussed.

4.2.1. Chronic pain

All eight of the participants described the experience of chronic pain as one of the most challenging symptoms of RA. The experience of chronic pain, as a typical symptom of RA, is reflected in the following quotation:

P5: “ The disease is extremely painful and yes, I do experience a tremendous amount of pain. And that would be chronic pain and uhm....there are times that I have to just basically take myself off to bed.....Chronic pain is a constant reminder of what this disease is twenty four seven.”

P1: “The most overwhelming aspect (of RA) must be the chronic pain. It drives me insane...”

Chronic pain and the experience of it are considered to be one of the most challenging aspects of living with RA. Chronic pain is defined by Bonica (1990) as “pain which persists a month beyond the usual course of an acute disease or a reasonable time for an injury to heal” as cited by Smith and Friedemann (1999, p. 544). Chronic pain is described as unique and real to every individual and is defined by the person who feels it (Smith & Friedemann, 1999).

Living with chronic pain impacts on a person’s physical, psychological and social well-being. “Chronic pain is typically associated with a multitude of secondary stressors such as sleep disruptions, under employment, interpersonal tensions and difficulties with basic tasks of daily living (Taal et al., 1993) as cited in Newth and DeLonghis (2004, p. 283). In addition, chronic pain is associated with a range of negative emotions such as depression, anger and anxiety. The perceived effect of chronic pain on the four specific areas of a relationship, namely communication, role definition and/or division of labour and intimacy and/or sexual functioning emerged from the data as follows:

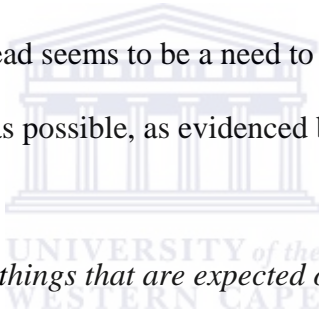
4.2.1.1. Chronic pain and its effect on communication

Most participants (P1, P2, P3, P5, P6, and P7) felt that they needed to shield their significant others from knowing the extent of chronic pain that they were experiencing. Two of the participants described their chronic pain as follows:

P1: "I can't be open with her about my pain, because it would really upset her. At first it was very difficult for me to talk about it, because I had to come to terms with it myself first."

P2: "Uhm I would just say that I was in a bit of pain sometimes and he actually would just ignore it. I didn't want to push the issue and rather tried to cope with the pain myself. I don't think he ever realised how much pain I was experiencing."

Reasons for not communicating about the chronic pain differed from participant to participant, but a common thread seems to be a need to try and maintain as much of the status quo, prior to onset, as possible, as evidenced by the following quotation:



P6: "I can't do all the things that are expected of a Muslim wife anymore, mostly because of the pain. I didn't know how to talk to him about this. I didn't know how we could stay in the marriage like before, so in a way I wanted to free him from me, so that he could find someone else who was able to be a wife to him."

Another reason for not communicating about the pain was a need to try and protect the spouse/partner of knowing the extent of their suffering as mentioned by the following participant:

P7: “I know that my illness has placed such an extra burden on him, so I try not to complain or let him know how sore I am. I don’t think he needs to handle that as well.”

One of the participants was afraid of her spouse’s reaction from her constant “complaining”.

P4: “ My husband would come home and say ‘Hi sweetheart, how’re you doing? Is the tea on? How was your day?’ and you are anxious to tell him that you haven’t been okay today and supper wasn’t ready because your hands were sore and you haven’t been able to peel the vegetables. You are so fed-up of hearing yourself complain that you tend not to say anything, just something like ‘Okay’ or ‘Fine’ and then blaming your husband in your head for not knowing that you lying; for not saying I can see you’re not feeling well, what can I do to help?”

In withholding the extent to which the chronic pain was being experienced, emotional difficulties were encountered by some participants (P1, P2, P3, P6), such as anger and resentment at times towards spouse or partner for not understanding how the pain feels at all times. Changes in communication patterns affected both individuals in the relationship and often led to misunderstandings or inadequate support being provided by the partner or spouse without RA as illustrated by the following quotation:

P2 “...a lot of frustration and a lot of anger, but I think also anger directed towards my ex-husband for not understanding what I was going through with

the pain and all...he was not acknowledging me at all, he ignored me when I told him I was in pain..."

Open and direct communication within spousal or partner relationships is considered crucial to facilitating optimal functioning in these relationships. Researchers in marital counselling, such as Miller, Corrales and Wackman (1975) laid the foundation for the focus and importance of communication in the context of marriage. All participants perceived chronic pain as a difficult topic to communicate about openly and honestly with their spouse or partner initially. Most participants felt that they needed to shield their significant others from knowing the extent of chronic pain that they were experiencing, either to protect their spouse or partner or to protect the relationship and their position within it from the harsh realities of RA.

4.2.1.2. Chronic pain and its effect on role definition and/or division of labour

All the participants perceived chronic pain as affecting their ability to remain in paid employment. Chronic pain also affected daily functioning in terms of chores and responsibilities. All but one of the participants had to resign or was medically boarded from their full-time employment. The person who was able to maintain her employment status is one of the participants who has described her RA as being very mild throughout the 30 year duration, as illustrated by the following quotation:

P8: "I think that I have been very lucky with my RA. Even though I've had it for thirty years, there was never a time that I felt I couldn't work anymore. My pain has always been very mild; in the beginning as well as later on. I have

experienced flare-ups, but it was completely manageable. I consider myself very lucky in comparison to other people with RA that I know of.”

The remainder of the participants experienced chronic pain as overwhelming and debilitating, especially during the initial phase and the active phases of flare-ups. Each individual experienced variable degrees and durations of chronic pain. These participants all perceive chronic pain as having had a significant effect on their ability to work both in- and outside of the house as reflected in the following quotation:

P7: “In the beginning the pain was completely overwhelming and constant. I wasn’t able to teach any longer, yet I tried to keep working as long as possible. Eventually I had to resign, after four years. Although it got better at times, it was short lived and attacks of pain were frequent and intolerable. A person has only so much sick-leave you know?”

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Chronic pain, as a symptom of RA, caused seven out of eight participants to involuntarily withdraw from paid employment or forced them into partial, instead of full-time, employment as evidenced by the following quotation:

P3: “I lost interest in my work, because I was in pain most of the time....I would go to lunch and the pain would subside, but as soon as I got up to go back to work, I would have pain all over my body. I had to actually give up being in charge of a ward and eventually I had to stop working all together.”

P1: “Slowly but surely I had to give up my career. I couldn’t cope with the chronic pain anymore.”

The reduction of monthly household income forces changes in the relationship as evidenced by the following quotation:

P3: “We don’t get as much money as we were used to anymore. I have to live off my grant that they gave me and that is all. My husband has not been working for a while and now he can’t get a pension either, because he didn’t get pension from his work. So we are basically living on my pension.”

Allocation of responsibilities has to be re-examined and the individual with the illness also has to deal with the emotional consequences of such a changed role and responsibility. In essence such changes may have a direct effect on the person’s sense of identity as stated in the following quotation:

P2: “The most difficult thing for me, was that I was not able to work, earn money and do the things I used to do in and around the house. I just can’t get through a job like I used to be able to: I used to be able to type, but now I can’t type anymore. If I want to pack out vegetables, I can’t pack it out, because of the pain. Everything seems to be just so much more difficult.”

Seven out the eight women perceived their roles in the family as being that of primary caregiver and being responsible for daily chores such as shopping, cooking, cleaning, washing and ironing. A great sense of frustration was expressed by most of the

participants in coping with the chronic pain in relation to these roles and responsibilities as illustrated by the following quotations:

P6: “After my diagnosis I left my husband and went to stay with my mother, because I felt that I couldn’t be a wife to him anymore. The pain stopped me from being able to cook properly, clean the house or do any of those things a wife should do. I stayed with my mother for two years until my husband could convince me that he didn’t care about those things as much as I did.”

P2: “I had my routine around the house, but suddenly I couldn’t do even the simplest of things – you can’t hold the duster cause your hand’s too sore, bending down to put the corners of the sheet over the mattress is suddenly a major obstacle; pushing a pillow into a pillowcase is too difficult when your hands are sore. You know that basically everything that you want to do is going to turn around and bite you every minute.”

P1: “The pain gets me down and that is something I have to fight on a minute to minute basis. Filling the kettle and making tea is now a mission, opening and closing taps; walking from my room to the bathroom is often very painful....Now my life gets dictated by something over which I have no control...It feels as if I’ve lost my bloody independence!”

Besides the effects of chronic pain on the woman’s ability to work in the paid environment, it also has an effect on her ability to cope with daily chores and responsibilities in the home. Women differ on the roles that they assume within a

marriage or relationship and in the family. In a qualitative study conducted by Brown and Williams (1995), involving women's experiences of RA, it was found that in spite of the so-called sexual-revolution of the last twenty years, many women still consider homemaking as integral to their sense of identity. Those participants with children added the role of being mother to their list of responsibilities. Most participants experienced difficulties in maintaining these roles and performing the daily tasks required of them prior to onset of RA.

Responsibilities and division of labour are functions of all spousal or partner relationships. How you divide the different responsibilities and the labour (both in and outside the home) contributes significantly to the role identity of each member in the dyad. Compas, Worsham, Epping-Jordan, Grant, Mireault, Howell and Malcarne (1994); as well as Pedersen and Revenson (2004), stated that tasks that the person with RA normally completed around the home before developing the illness, often could not be managed any longer and needed to be taken on by a spouse or other family member. Papadopoulos (1995), stated that chronic illness raises issues of permanence with the individual who has the illness. This can be translated into role re-assignment, responsibility sharing and attachments.

The way in which the family handles these issues will contribute to the social support that the person needs and will often have an effect on this person's health and functioning. Manne, Alfieri, Taylor and Dogherty (1999); Revenson and Majerovitz (1990), described how such patients might experience feelings of guilt and inadequacy as a result of their inability to assume their normal tasks, whilst spouses or other members of the family might feel extra pressure and resentment at the additional

responsibilities. This situation may lead to a sense of inequality in the relationship and the person with RA might experience the need to reciprocate. Although this is not the only factor that contributes to a person's role identity, it is definitely a significant part of such an identity. The loss and/or change of this role definition may have a myriad of consequences for the individual as well as the couple. Any change in the identity of one partner will inevitably have some kind of effect on the relationship as a dyad. An inability to pursue or maintain a career, if so desired, may have far-reaching economic, social and emotional effects on an individual but also on the dyad (couple) of which such an individual is a member.

In relationships where the woman was doing paid work, she was contributing to the economic welfare of the couple-unit and the family. The loss of or changes in this role has many different consequences to the person as an individual, to the dyad as a couple and if relevant, the family as a unit. Loss of employment may lead to loss of income, which may result in a compromised economic and social status. A lower or reduced income, coupled with a drop in social status, may affect a woman living with RA on a physical and emotional level, as well as have an influence on the functioning of the couple.

4.2.1.3. Chronic pain and its effect on intimacy and/or sexual functioning

All eight of the participants perceived chronic pain to have had a negative impact on their ability to be sexually intimate with their spouse or partner at first, as evidenced by the following quotations:

P1: “On a physical intimacy level the changes have been drastic...Pain is a terrible thing...”

P2: “Intimacy and sex became a big thing in our lives. After doing all my other duties I couldn’t really do what I did before in bed. It was just too sore. We never spoke about it or anything. He would just come to bed with a computer most of the time and when there was intercourse or whatever it wasn’t as nice as it used to be.”

Although chronic pain was perceived by all of the participants as having a negative effect on their levels of intimacy and sexual functioning; some participants made a clear distinction between the initial and chronic phases of the illness, and the flare-ups occurring within the chronic phase. All participants initially struggled to cope with the chronic pain, as it affected their intimacy levels with partners or spouses. Instead of communicating about the problem, this participant chose to avoid intimacy and sex (avoidance coping). She described her difficulties in communicating to her husband about sex and intimacy as follows:

P4: “I didn’t want him to feel he was being rejected. So, what I did was tending to stay downstairs and watching TV until I thought that he would be asleep. That is how I handled that, because it was too hard to communicate about the pain. After he died I realised how stupid it was, but then it was too late. But I think fear of losing someone after being with them for so many years and having something really special, prevents one from addressing the issues.”

However, some participants (P1, P3, P5, P6, P7) were able to negotiate certain changes and made adjustments together with their spouse or partners, which allowed them to cope more effectively with the effects of chronic pain in this sphere of their relationship as illustrated by the following quotation:

P5: "Surely the pain changed our levels of intimacy at times, but it also allowed us to explore more comfortable positions...It actually made me talk to him a lot more, saying what I wanted and adjusting to the pain. He was very understanding and patient and in a way I think we became closer than before."

The literature contained some studies that were conducted to explore the effects of chronic pain on intimacy/sexual functioning of spouses or partners. Osborne and Maruta (1980) as well as Sjogren and Fugel-Meyer (1981) confirmed an association between chronic pain and sexual dysfunction. Few studies exist that directly examine chronic pain and intimacy and/or sexuality, according to Smith and Grabois (1995). However, problems with sexual functioning have been reported in patients with RA (Lim, 1995). Monga, Tan, Ostermann, Monga and Grabpois (1998, p. 327), stated that "chronic pain, fatigue, and limited range of motion may distract from pleasurable sensations during sexual activity. Low self-esteem and deformity are common factors that may interfere with sexual desire in patients with chronic pain." Furthermore, many drugs used in the treatment of chronic pain, such as opiates, anti-depressants and muscle-relaxants could also impair sexual desire, arousal, and orgasm, according to Monga et al. (1998).

Intimacy and sexual functioning are important aspects in the maintenance of healthy relationships in couples. Difficulty in this area may lead to negative consequences for the couple as a unit, or for either spouse or partner as an individual. Women particularly tend to fear rejection if they are perceived as “unable to keep their man satisfied sexually” and the fear is that he will look for it elsewhere. This increased insecurity gets amplified in a situation where it may be physically impossible for the woman to have sex with her spouse/partner at certain periods of the illness, leading to a possible sense of dissatisfaction from the spouse/partner, leaving the women feeling “useless”, worthless as a woman, insecure, fearful and ultimately leading to behaviour such as withdrawal or avoidance. This may in turn lead to many misunderstandings which could ultimately result in the termination of the relationship as the worst case scenario, or a troubled relationship which fails to serve as a buffer against illness, but rather increases the stress on the individual with the illness and the couple as a unit.

4.2.2. Loss of functionality and/or mobility

All eight participants described a loss of mobility and functionality related to RA to varying degrees during the course of the illness. A common symptom of RA is morning stiffness and depending on the severity of the illness, it can last up to many hours into the day as described by the following participant:

P 7 “...some days I can hardly move to get out of bed. Everything is stiff and sore and it takes a long time to warm up and to be able to use my joints properly. Taking a shower or just brushing my hair becomes a mission when my hands won't move as I want them to.”

4.2.2.1. **Loss of functionality and/or mobility and its effect on communication**

Similar themes as to those discussed with chronic pain and communication was mentioned by all of the participants. Most participants tried not to let on how much their daily functioning and mobility was affected by RA. It was, however, more difficult to hide these obvious effects, than to conceal chronic pain. Loss of mobility and functioning is visible to the individual as well as the spouse/partner. This forces the person living with RA to talk about it, mostly by asking for help with physical tasks. Having to ask for assistance in performing daily tasks at times affected some participants emotionally. It affected their sense of independence and control over their own lives and often left them feeling angry and frustrated. When emotional reactions to this situation could not be mediated, by a functional relationship with a spouse/partner or other forms of social support, a sense of helplessness would develop which in turn could be a contributing factor to the experience of depression.

P2: "A lot of frustration and a lot of anger, because I could not function properly anymore. A lot of the anger was directed towards myself and finally I found myself being really depressed. My ex-husband left me when I probably needed him the most."

Other participants learnt with time and by educating themselves about their illness how to cope most effectively with the limitation of mobility and functioning. Those participants who invited their spouses/partners to support meetings, doctors visits and reading material concerning RA, managed to find creative ways of coping with the diminishing mobility and gradual loss of function.

P3: “My husband became quite ingenious in designing all sorts of tools and gadgets that I could use to make my life easier. In this way I could still manage to do things by myself and I didn’t have to ask him to do things for me all the time.”

Once again adjustment and coping seemed to be dependent upon participants’ ability to embrace a different identity to pre-onset of their illness. All participants perceived the initial phase of the first two to three years of onset as being the most challenging, in terms of adjustment. With time and intermediate periods of decreased disease activity, most participants were able to come to terms with the gradual loss of mobility and functioning. Due to the degenerative nature of RA participants were challenged during the chronic phases of the illness to continue their adjustment to new immobility and challenges to functioning. Communicating these gradual changes to their spouse/partner became easier over time, to most participants.

P1: “Loss of mobility and the fact that my body is losing its natural ability due to the disease is something that we have to cope with on a daily basis. Every now and again I discover yet another thing that I am not able to do anymore. Most of the practical things can be handled with proper planning and the use of assistive devices. Somehow it is easier to tell my partner that I need an electric can-opener than telling her that I can’t walk on the beach anymore, like before.”

4.2.2.2. Loss of functionality and/or mobility and its effect on role definition and division of labour.

Most of the participants (all but P8) perceived the effects of loss of functionality and mobility as affecting their own sense of self and identity to a large degree.

Participants often referred to themselves as being two different people: the one before RA and the one after RA. Loss of mobility limited previously enjoyable activities – from outdoor activities to social relationships as described by the following quotation:

P6: “In a way RA made my life much smaller. I couldn’t do half the things I was used to doing before and I found it difficult to accept this new way of being. I thought that my husband would not love me anymore and that I would be considered mostly as a burden.”

Most of the participants in this study (barring P2 and P8) indicated that after they initially struggled to keep up with daily physical expectations, they eventually re-negotiated roles and responsibilities in the marriage or relationship to adjust to and accommodate for the illness.

P3: “It was almost like becoming a child in the house because they had to do most of the things for me. My husband had to do all the heavy housework as well as things like chopping the vegetables. The children helped as well but he took over a lot of the work initially. Once the disease settled down a bit, I was able to chip in, and nowadays he will help even without me having to ask when he sees that I am struggling with something.”

P4: "I used to run everything in the house, from social director to plumber. It was somewhat natural and some people called it bossy. Then suddenly I couldn't meet my own demands that I set myself to do. It was so frustrating not to be able to do stupid little things that you were able to do without even thinking before."

Due to chronic inflammation of the synovium, damage is done to cartilage and connective tissues in all the affected joints (Woolf & Pfleger, 2003). Loss of mobility and functioning inevitably becomes one of the characteristics of RA. Besides impaired mobility, other physical abilities are affected, ranging from grip to walking. Most participants reported a gradual loss of functioning and mobility, with the initial phase being the most difficult to manage. Daily activities and routines are constantly challenged by this situation.

Frustration, irritation, anger and at times helplessness, are some of the emotional effects that are experienced by the participants due to this loss of mobility and functioning. Their sense of bodily control seems to be diminished, as the person with RA has to adjust constantly to accommodate deteriorating levels of physical functioning. Loss of independence and control are some of the unfortunate outcomes of living with a chronic degenerative illness such as RA. Lyons (1993) mentions that illness is a threat to self-efficacy, and loss of control is a threat to self-identity. Therefore, maintenance of identity and self-worth are tied to the perceived ability to control the illness and to minimise its intrusiveness.

Within the context of a spousal or partner relationship, these negative outcomes may either be amplified or diluted depending on the functionality of the relationship.

Healthy and functional relationships may serve as a buffering effect, as a form of social support in the process of coping with these difficulties for a person living with RA. Spousal or partner relationships that are not functioning optimally may result in an increased sense of helplessness, loss of control and ultimately loss of a sense of self. The identity of the couple as a unit is also adversely affected in this process, and adjustments need to be made to the whole identity of the couple to manage the effects of the illness (Lyons & Meade, 1993; Charmaz, 1995 and Kralik, 2003).

4.2.2.3. Loss of functionality and/or mobility and it's effect on intimacy and/or sexual functioning.

Seven of the eight participants experienced the loss of functionality and mobility as having an effect on their sexual functioning within their relationships. One participant described it as follows:

P4 “ This illness changed everything in my life...even my sex life...I just can't do what I used to do like I used to do it anymore... I always have to think if this will work or not... I guess it robs me from doing it on the spur of the moment sometimes...”

Adjustments had to be made to sexual positions to accommodate stiff and sore joints. Although pain had the biggest effect, the combination of stiffness of joints and pain led to avoidance of sexual intimacy, unless the issue was openly discussed and adjustments were made.

P6: “If you’ve spent the day struggling to brush your teeth and hair and barely managed to take a shower, because nothing moves as you want it to, an invitation to intimate time in bed seems completely overwhelming. You don’t want to disappoint your husband, but sometimes the thought of having sex fills me with dread.”

If however, the spouse or partner is made to understand the nature of the illness, communication about intimacy and sex become less threatening and may even lead to increased levels of intimacy after some adjustments have been negotiated, as described by one participant:

P1: “Our level of intimacy on an emotional level has increased. It took a lot of work from both of us and lots of talking, but we are now closer than ever before. I would say our intimacy is probably a lot more quality and less quantity.”

4.2.3. Unpredictability of the symptoms

Every one of the participants felt that the unpredictability of the RA symptoms was difficult to deal with continuously, and found it hard to explain this unpredictable process to their spouse or partner.

P1 “ I just felt that I could not speak to her about this thing all the time... I needed to make sense of it myself somehow...

P7 “ You feel so stupid sometimes... now you are okay and then the next thing you are not... maybe he thinks I am putting it on or something, so I keep quiet and try to pretend that I am fine...”

4.2.3.1. Unpredictability of symptoms and its effect on communication

Communicating to spouses or partners about the unpredictability of the illness was experienced as complicated by some of the participants, because they were unsure of whether their spouses/partners would believe them. Some participants described how difficult it was to explain this concept to their spouse/partner, when they did not fully comprehend it themselves.

P7: “One day I could get out of bed, shower and dry my hair, dress myself and cook breakfast and then maybe two days later, I had to ask my husband to help me take a shower. Let alone, wash my hair or make breakfast. I could see in his eyes that he was sceptical about the drastic changes and I wondered if he thought that I was perhaps putting it on.”

Once participants felt that they understood the waxing and waning of symptoms as part of the illness, they felt more confident and able to explain this to their spouses or partners. After the initial phase, most participants managed to educate themselves and their partners or spouses about all the symptoms related to RA. This knowledge proved to be invaluable to the effective coping and adjustment to RA by both parties, as described by the following quotation:

P3 “You must know as much about the disease as possible and the whole family must be involved and know what it is all about, because you don’t feel the same each day to see that you can be in control cause one day you are fine and the next day you can’t get up...so they must try and find out as much as possible about RA and understand why the person that have it ...why they feel like that certain days...”

Communicating about the illness facilitated better understanding between spouses or partners, which resulted in more functional relationships, which in turn facilitated more effective coping with the effects of the illness and in particular the waxing and waning characteristics associated with RA. Knowledge fostered understanding and in combination with open communication facilitated optimal coping, functional relationships and ultimately more positive disease-outcomes.

4.2.3.2. Unpredictability of symptoms and its effect on role definition and division of labour or responsibility

One of the most frustrating characteristics of RA is the so-called waxing and waning of symptoms, which makes it very difficult for a person to be able to predict functionality from day to day. As a result of this unpredictability, most participants expressed frustration at their inability to plan ahead. Tasks performed without difficulty the one day may become impossible to do the next or even within hours. Besides the obvious frustration it causes the individual living with RA, it also affects the relationship between the couple. When partners/spouses are not informed or educated about this aspect of RA, it may lead to conflict and misunderstanding regarding the roles and responsibilities required of the other person. Participants

described how they perceived their spouse/partner to becoming agitated and confused by the unpredictability of their functionality. Some participants often thought that their partners/spouses might think that they are shirking their responsibilities and arguments ensued, which affected the self-esteem of the person with RA tremendously.

P3: “As if it wasn’t hard enough, not to be able to do simple little household chores, I found myself struggling with the most ridiculous things one day just to be able to do the same task tomorrow – effortlessly. This confused me a lot, but I think my husband probably thought that I was looking for attention, until he realised how this thing works.”

In not being able to plan ahead, social functioning as a couple may also be affected. Invitations to functions, family gatherings and parties might have to be cancelled at the last minute due to a sudden onset of severe symptoms, resulting in disappointment and frustration for the couple as well as their social circle. The person with RA feels responsible for this situation, as most participants observed.

P1: “The unpredictable nature of this disease has probably cost me friendships. I often have to cancel or change appointments at the last minute and I sometimes think that my partner must be getting pretty sick of this. I’m getting sick of it myself”.

4.2.3.3. **Unpredictability of symptoms and its effect on intimacy/sexual functioning**

Some participants expressed frustration at the unpredictability of symptoms in relation to their intimacy and sexual functioning. Adjusting to pain, loss of mobility and function and deformity is already a big challenge in terms of maintaining intimacy and adequate sexual functioning in relationships. Not being able to predict when some of these symptoms will intensify or disappear adds another dimension of frustration and complication to the process of maintaining intimacy in a relationship. The majority of participants felt that they wanted to be intimate and have sex with their spouse or partner and that the unpredictability of some of the RA symptoms hindered their attempts of normalising their relationships. Some participants feared that their spouses/partners would not be able to understand how symptoms could come and go without rhyme or reason. One participant thought that her husband might have expected her to use the illness as an excuse to be intimate with him. This raised further fears with her that he might try and find sexual gratification elsewhere.

P4: "I was so scared that he would start looking for it elsewhere if I kept telling him that I wasn't feeling up to it. Or actually avoiding it all together. We were married for so many years and it was such a wonderful marriage and I uhm....I was just so scared that I was going to lose him...yet I couldn't get myself to talk about it."

4.2.4. **Deformity**

Deformity in RA, as a result of the degenerative qualities of the illness, usually only becomes visible years after the onset of the illness. Most of the participants in this

study have visible deformation of their hands and feet. Those without visible deformities dread the possibility of the most inevitable, long-term outcome of the illness, which is visible deformity. One participant described her feelings about her hands and feet as follows:

P 2 “ I don’t like to look at my hands and feet...they are so ugly...it looks like claws and I know other people stare at it...”

4.2.4.1. Deformity and its effect on communication

Even though the deformity associated with RA is visible, the emotional effect that it has on the individual is not. In not revealing the emotional effects of a physical deformity, it may cause the spouse or partner to believe that it has no effect on the person with RA. Alternatively, the spouse/partner might have strong feelings about the deformity, but is too nervous to share it with the other party, for fear of offending or hurting them. Most participants tended to avoid communication about the deformity with their spouse/partner.

P6: “Everyone can see what my hands look like and I’m walking really funny, because of the deformity of my feet. I don’t like seeing my body like this and I don’t know how my husband really feels about it. He tells me that he loves me, no matter what, but sometimes I can’t help to wonder if he is not repulsed by me.”

In not communicating with ones spouse/partner about the emotions evoked in both as a result of the deformity, misunderstanding and incorrect perceptions may lead to

conflict. In positive and functional relationships, open communication about feelings related to deformity is allowed to be expressed, and in this process it facilitates acceptance and adjustment to bodily changes for both parties.

P3: "I asked my husband how he felt about the way my hands have changed. He answered me by softly kissing each finger and telling me that he loved me just the same as always. At first I didn't believe him, but now I can see that he really meant it. It helps me to get used to it myself and to rather focus on making myself look as pretty as possible, in spite of the deformities... Old age would have changed my body in anyway, so I try and look after myself as well as possible and accept the things I cannot change... Wisdom seems to come with age, but it took a lot of time and talking to get us here."

The deformity of joints becomes more visible as the disease progresses and is hence not really visible during the initial phase. Most common and visible areas of deformity occur in the hands and feet. In addition to this, medication such as cortisone, which is often prescribed on a long-term basis for people with RA, may result in changes to the face and body, in the form of excessive swelling. These bodily changes have a significant effect on the role of the perception of women regarding their femininity and physical attractiveness. Body image forms an integral part of identity and has a direct effect on self-esteem and power in the world.

4.2.4.2. Deformity and its effect on role definition and/or division of labour

Seven of the eight participants mentioned deformity or fear of deformity as affecting their perceptions of their own bodies and their identity of being a woman.

P5: “Uhm I know we’ve spoken of physical aspects, but for me and maybe you can understand being a woman, it was(long silence {crying}) the realisation that my body was changing and the deformities for me was a big thing and still is at times. I like beautiful things and it was very difficult at times to look at myself and realise that this is what I was ending up looking like....It is a daily challenge, this having to meet the grief-cycle...being a woman it was quite something to realise that I could not wear the same clothes....and at the same time look at your fingers and your face, the way you walk...”

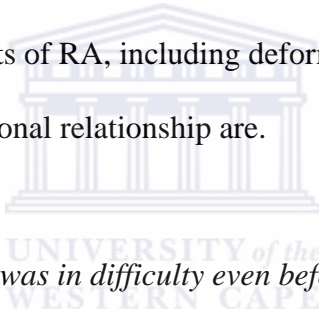
4.2.4.3. Deformity and its effect on intimacy and/or sexual functioning

Given the fact that the deformities affect body image one can assume that it would therefore also affect intimacy and sexual functioning. In the literature, body-image is strongly linked to intimacy and sexual functioning.

All participants have been experiencing varying degrees of deformity, since most of them have been living with RA for more than six years. Participants who have been living with RA for a longer period of time were visibly more deformed. Hiding the deformity was difficult as it involved mostly hands and feet.

P3: “I am so aware of the way my body looks now. Although my husband says that he loves me just the way I am, I do try and make myself look as pretty as possible everyday. I don’t want him to start looking around...”

Struggles with body-image as a result of deformity may contribute to loss of self-esteem and therefore complicate intimacy and sexual relations further. Besides having to negotiate around pain, mobility and loss of functioning, participants described an exasperation at having to contend with deformity and its effect on their already battered body-image in the process of trying to maintain healthy levels of intimacy and sexual functioning in their relationships. On the flipside, functional couple relationships provide a nurturing and facilitative environment for the person with RA, in which to cope with and adjust to the deformity more effectively. Once again this highlights the importance of maintaining positive and functional relationships to serve as a form of social support in the overall coping process of RA. Participants who are experiencing their spousal or partner relationships as mostly positive, seemed to be able to cope with all the aspects of RA, including deformity, much better than those having a negative or dysfunctional relationship are.



P2: "Our relationship was in difficulty even before I got ill. He worked away from home a lot and I found out that he was actually having an affair. After I got ill things just got worse. Before my illness sex was one of the things we actually used to enjoy together, but after I got ill it seemed as if he couldn't look at me anymore in that way. I felt so ugly and was in so much pain that I just didn't feel like having sex anymore. It wasn't long before I discovered that he was having another affair. Eventually he left me and we got divorced, against my will. I felt so betrayed."

P1: "I never thought that deformity would bother me so much. Luckily I have a partner who understands and our relationship has always been strong. At

times I am amazed that we are still happily involved. Nowadays we tend to take things as they come and we don't sweat the small stuff so much anymore. Both of us have discovered what is really important in life and in a strange way this illness has brought us closer. We look at my hands, see the changes and I can see she doesn't mind. The only way I could get past it, was to talk about it."

4.3. Chronicity of RA

Six of the eight participants (P1, P3, P4, P5, P6, and P7) managed to maintain their relationships with their spouse or partner after the onset of RA for a minimum period of five years. Two of the eight participants (P2, P8), however, were unable to sustain their relationships with their spouse, and these participants perceived the failure of their relationships to be linked to the illness.

Of the participants that managed to maintain their relationships, all of them perceived the first two to three years after onset of RA to be the most challenging time in negotiating all the necessary changes successfully, and in keeping their relationships functional. These participants felt that their relationships with a spouse or partner were an important factor in helping them to cope with their illness on a daily basis. Once the foundation for open communication was laid and both individuals and the couple as a unit were able to adjust to the required changes, the chronic phase of the illness was perceived as more manageable, by the individuals with RA. Not only does the individual members of the couple (dyad) require a change or amendment in their identity, but the couple as a unit needed to change their identity in order to adjust to the challenges and changes of a chronic illness. Once the initial adjustments were

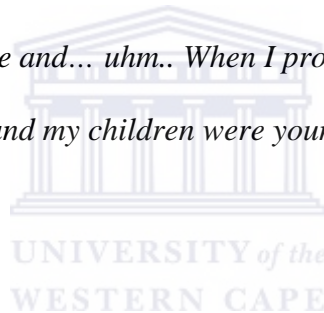
made on a physical and emotional level, the chronic phase seems to be characterised by a continuation of smaller and more gradual changes and adjustments. During periods of flare-ups, both individuals and the couple unit experience additional stresses; but it is usually negotiated successfully if a proper foundation was laid during the initial phase, according to the majority of the participants.

All participants emphasised the importance of information and education about their illness in order to understand and manage it optimally. Where spouses or partners were actively involved in this process, adjustments were negotiated more successfully. Those participants, who are experiencing their relationships with a spouse or partner as most supportive during the chronic phase of the illness, felt that the illness was perceived as a stressor affecting both individuals as well as the couple as a “team”. This “team” approach seemed to foster a perception of the illness as “our” challenge rather than an individual challenge. Most participants conceded, however, that the initial process until this stage of optimal functioning was reached, had been fraught with excessive physical and emotional difficulties that needed to be negotiated, adjusted to and coped with on a daily basis. The need for education about RA was stressed by all participants and is evidenced by the following quotation:

P4 “ ... the first thing one has to do once diagnosed, is to become educated about your disease. And ask how can I handle this at home?... What’s going to happen to me?...How am I going to feel?...Am I going to be able to live a normal married life?... so I know what to expect and I can warn my husband that there are going to be times that I will feel like this or that...”

Those participants (P2, P8) who got divorced a few years after the onset of RA, never seemed to succeed in adjusting to the new demands on them individually as well as in terms of a couple-unit. These participants were unable to cope with the demands of RA and were unable to enlist enough support from their spouse or partner in order to learn how to cope individually as well as together as a couple. Loss of their spousal or partner relationships was experienced as traumatic on many levels, but mainly because they blamed their illness for these losses, as well as the fact that they had to cope with their RA without the support and buffering effect of a close intimate relationship. This situation is evidenced by the following quotation:

P2: “ ...a lot of anger, but I think the anger is directed towards my ex-husband for leaving me and... uhm.. When I probably most needed him, especially at my age, and my children were young... and when I was so sick...”



In this study, all eight of the women who participated in the research, perceived RA to have a significant effect on their relationships with their spouse or partner. Most of the women were eventually able to maintain these important relationships and perceive them to be essential in the daily process of coping with RA. Two of the women in this study were unable to maintain their relationships with their spouse or partner and one of these women seemed to be unable to cope effectively on a daily basis; both physically and emotionally. She expressed regret about the loss of her relationship and bitterness towards the illness, which she believes, contributed to this loss.

None of the participants perceived the onset of RA to be a completely positive experience in their lives, but a majority of these women were able to reframe some of the difficulties into more positive life experiences. In the process it enriched their relationships with their spouse or partner. The road to adjustment, acceptance, coping and assuming a changed identity were described by some of these women as being long and difficult, with constant new challenges arising and new adjustments to be made, yet some of them were able to find some enrichment from the whole process, as evidenced by the following quotation:

P 1 "... RA made me weaker before it made me stronger."

In conclusion, it would seem that close intimate relationships with a significant other are important sources of support for individuals living with RA. Besides physical support, a functional relationship with a spouse/partner will provide a safe environment for both individuals in which to learn to cope effectively with the illness. If the couple is unsuccessful in adjusting to the demands of RA, it will affect both individuals negatively; as well as leaving the person with RA without an important support system, which, in turn, may lead to negative disease outcome, depression and/or other coping difficulties.

CHAPTER 5

CONCLUSION

5.1. Integration of the findings of this study

The aim of this study was to explore the perceptions of women with rheumatoid arthritis on the effects of their illness on their spousal or partner relationships.

Two key categories emerged out of analysis, namely: the challenges (symptoms or outcomes) of RA and coping with the perceived effects of these challenges within the context of a relationship with a significant other. The four most salient challenges of RA that emerged from the data as having a perceived effect on a close intimate relationship with a significant other were chronic pain, loss of functionality and/or mobility, unpredictability of symptoms and deformity. All eight participants mentioned these four aspects of RA as having a significant effect on their relationships with their spouse or partner.

All eight participants described communication, role definition and/or division of labour and intimacy and sexual functioning as the most affected areas of their relationships with a significant other. The perceived specific effect of each of the four symptoms or outcomes of RA on each of the relationship areas mentioned by the participants were analyzed and interpreted.

Chronic pain as experienced by all eight participants, in varying degrees and stages of the illness, was perceived as having an effect on communication, intimacy and/or sexual functioning and role definition and/or division of labour in their relationships.

Participants found it difficult during the initial phase of the illness to communicate the extent and experience of their chronic pain to their spouses or partners. Chronic pain was perceived as overwhelming and debilitating at times. Participants perceived the first couple of years, after onset of RA, as more difficult to manage in terms of maintaining healthy, functional relationships with their spouse or partner, as the process of adaptation to a chronic illness normally requires an amount of time to adjust to the new challenges. Adjusting and adapting to the illness affected the couple as a unit, as well as each individual in this unit, in various ways. In the process of trying to cope with the chronic pain, participants all found it difficult to express their feelings about the pain honestly and openly to their spouse or partner. For most participants this was an attempt at maintaining the pre-morbid functioning and status quo of their relationships. In not communicating clearly, openly and honestly about their experiences of chronic pain, participants often felt misunderstood, which led to feelings of anger and resentment. If not managed, these feelings could easily contribute to the development of depression.

Chronic pain affected every domain of their functioning and often led to participants not being able to work in and outside the home as before. This led to some participants' involuntary termination of paid work as well as involuntary changes to pre-onset of RA roles and responsibilities in the family. This affected the sense of identity of all the participants to varying degrees, as well as the couples' identity. Charmaz (1995), states that a serious chronic illness undermines the unity between body and self, forcing identity changes. Adapting as a way of living with impairment explains how the body, self and identity intersect in illness. "Adapting means altering life and self to accommodate for bodily losses and limits and resolving the lost unity

between body and self...struggling with rather than against illness” (Charmaz, 1995, p. 657). Successful adjustment and adaptation to this illness takes place when the couple, as a unit, re-evaluate and embrace their “new identity” and learn to live with the illness; instead of fighting the illness.

A close intimate relationship with a spouse or partner is regarded in coping literature as the most important form of social support utilized by a person diagnosed with a chronic illness, such as RA (Griffen *et al.*, 2001). The importance of this relationship is highlighted in the theory of dyadic coping, emphasizing the possible negative as well as positive outcomes such relationships may regulate in the process of living with a chronic illness. Dyadic relationships may have an influence on the actual disease outcome, as well as on the individual’s ability to cope more effectively on a psychosocial level (Bodenmann, 2001). Researchers such as Manne and Zautra (1999) and Vinouker (1996), stated that the reception of supportive behaviour by a spouse (even the perception of such behaviour as supportive), leads to lower levels of distress for the individual with the illness. Unsupportive behaviour by a spouse or partner (whether real or perceived) is linked with even greater distress according to Coyne, Ellard and Smith (1990) as well as Revenson and Majerowitz (1990). Participants in this study experienced their relationships with their spouse or partner as important in the process of adapting to and coping with RA.

Loss of functioning and/ or mobility is a common outcome of RA, especially during the established phase of the illness where the destruction and inflammation of the joints due to disease activity have caused the loss of certain functional abilities, such as the optimal functioning of hands, shoulders, knees and feet to name but a few. This

may limit range of movement and mobility, as well as impact on a myriad of aspects related to daily functioning, depending on the stage and severity of the illness. All the women in this study experienced a degree of loss of functioning and/or mobility to during the various stages of their illness. The inability to pursue and maintain paid employment outside of the home, as well as the struggle to perform daily tasks of living as before the onset of RA, had a significant effect on the majority of the women in this study. Reduced financial resources due to the inability to work as before affected the relationships with spouse or partner of these women on many levels, especially in regards to their role definitions and the division of labour, as well as the family's socio-economic status. Communicating to their spouses or partners about the ongoing debilitating and degenerative nature of RA was perceived to be difficult and ineffective communication could lead to feelings of being misunderstood or not heard, eventually placing strain on the relationship.

Loss of functioning and/or mobility affected the sexual functioning and intimacy of all the women in this study in relation to their spouse or partner. Limited mobility inhibited sexual behaviour and adjustments had to be negotiated on a continuous basis. In combination with chronic pain and deformity, loss of functioning and mobility caused many difficulties in the sexual lives of the women participating in the study. A majority of these women had to adjust and continue adjusting to the many changes that RA caused in their lives, including their intimate and sexual relationships with their spouse or partner. Failure to adjust resulted in relational difficulties and even divorce, according to the participants 2 and 8. Effective communication, education about RA and the existence of a strong, healthy relationship prior to onset of RA are mentioned as protective factors in maintaining healthy relationships with

one's spouse or partner, according to participants 1, 3, 4, 5, 6, and 7. These women indicated initial adjustment and adaptational difficulties in terms of their relationships with their spouse or partner, but through effective communication, education and successful dyadic coping efforts they managed to maintain these relationships effectively.

Deformity of especially hands and feet are often an unfortunate result of RA in the longer term. Women in this study experienced the change in their bodies as “ugly” and as affecting their body image and sense of self adversely. Self-concept is composed of identity, body image, and role performance, and a positive self-concept gives a sense of meaning, wholeness, and consistency to a person (Potter, 2004). A physical change in the body (such as deformity caused by RA), can lead to an altered body image affecting identity and self-esteem. (Potter, 2004). An altered role performance as experienced by the majority of participants in this study, may also alter one's identity and self-esteem.

The unpredictability of symptoms affected all the women in the study. Symptoms “flared up” unexpectedly and lasted an undetermined amount of time and at a high level of severity. Planning in terms of daily functioning, work, social arrangements and leisure activity becomes impaired because of the unpredictability of RA. Spouses or partners were expected to adjust continuously according to the appearance and severity of the symptoms, often leading to confusion and misunderstandings if the communication is not clear and ongoing. Some of the women in the study felt that their spouse or partner were feeling angry and confused as to what they could or couldn't do on a daily basis, and that they preferred to try and “tough it out” rather

than say that they are not coping again on a specific day. This may lead to feelings of mutual resentment and anger, which negatively affects the relationship. This may then result in the demise of the relationship, which could be a buffer against the negative outcomes of the disease and as an effective coping mechanism.

Overall, this study indicated that women perceive the effects of RA on their relationships with their spouse or partner as significant and ongoing. During the initial phase after onset of RA, women have to deal with many challenges of RA, and in order to cope effectively with these challenges, they have to adjust and maintain their existing relationships and come to terms with a new identity as an individual and as a couple. This relationship remodeling takes place continuously as the individual and the couple learns to cope with the illness. Successful adaptation results in the maintaining of healthy relationships with spouse or partner, which serves as an important form of social support in the process of coping with RA. Failure to sustain a healthy relationship may take this important form of support away from the individual, resulting in possible negative disease outcome and lowered psychosocial functioning.

5.2. Limitations of this study

Limitations of this study should be considered in interpreting the findings, as a relatively small sample size (eight participants) was used. This will not allow any generalization to be made, as is often the case in qualitative research. A purposive sampling strategy was used to select participants for the study. This method of sampling may be considered as “convenient” and as limiting the population, rendering the sample as possible non-representative.

The use of English may have excluded other groupings from participating, which may have contributed to the exclusion of more different cultural perspectives. Only participants belonging to the “Care and Share” circles of the Arthritis Foundation in the greater Cape Town was used, which possibly excluded many other women with RA in other areas of Cape Town.

A qualitative research approach is not without its limitations. Findings from this qualitative study can not be generalized and have to be interpreted with care. Given the context and varied settings in which interviews were conducted, some of the information may not have been uniformly collected across all situations. Allowances were made for participants’ energy levels as well as accommodating for some participants’ pain and immobility.

Criticism of the Grounded Theory framework is that the epistemological assumptions have not been clearly explicated and that its links with existing social theory have been decreased (McCann & Clark, 2003). Tension exists between the researchers’ positions of objectivity in collecting data versus emerging in the data and getting close to participants in order to obtain rich data. Tension was experienced during this study between positions of objectivity and emergence in the data due to the researchers personal context (living with a partner who has RA).

5.3. Contributions of the study

This study contributes to the growing body of literature on the relational context of coping with a chronic illness. It also contributes to the body of knowledge concerning women’s health issues. The specific issues related to RA need to be addressed

separately from other chronic illnesses in research on adaptation to illness, because some RA related challenges are unique to the illness and may require different adaptational processes, especially in relation to relationships with a significant other.

5.4. Recommendations for future research

A number of studies have been conducted in the field of chronic illness. Coping with, adjustment and adaptation to RA have been described extensively in the literature, mostly focusing on the individual with the illness' efforts and processes. The concept of dyadic coping is relatively new in coping literature and emphasizes the importance of the relational context within the process of coping with a chronic illness such as RA. Bodenmann (1995) states that there are still many gaps in the research on dyadic coping to be addressed. It is suggested that future studies should make stronger attempts to distinguish among different types of stress that couples face, and how the nature of the stressor and the couples' appraisal of it shape dyadic coping. Little is known about the mutual influence of partners' appraisal processes.

Health psychology is a rapidly growing field in the context of quality of life.

Understanding the processes involved in coping with and adjusting to a chronic illness, such as RA, is crucial to the understanding of overall health functioning.

Future research should focus on people's health experiences, and especially on women's experiences of illness and health, as these meanings may differ according to gender and gender roles.

Following from this study, future research should explore women' illness experiences in depth, especially their perceptions as to the effect of their illness on their self-concept and how it affects coping as an individual and as a couple and a family.



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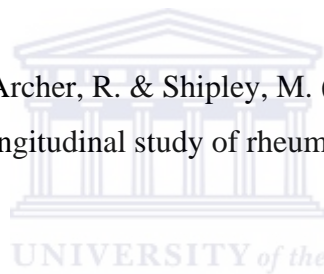
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APPENDIX 1



UNIVERSITY *of the*
WESTERN CAPE



UNIVERSITY *of the*
WESTERN CAPE



BACKGROUND INFORMATION QUESTIONNAIRE

Participant number: _____ (Please note that all information contained in this questionnaire will only be used for the purposes of this research project and will remain strictly confidential).

Please tick the box containing the correct information:

What is your current age?

20 – 29		30 – 39		40 – 49		50 – 59		60 – 69		70+	
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What is your home language?

English		Afrikaans		Xhosa		Other – Specify	
---------	--	-----------	--	-------	--	-----------------	--

In which residential area do you live?

Please specify:

What is your marital status?

Single		Divorced		Married		Co-habitation		Widowed	
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Do you have dependants?

Yes		No	
-----	--	----	--

If 'Yes', please specify how many dependants you have, what their ages are and to what extent they are dependent on you?

What is your highest education?

Please specify:

What is your current employment status?

Never worked			
Unemployed		How long?	
Employed		How long?	Occupation: _____
Other		Specify	

What is your religion?

Please specify:

Did you become more religious and/or change your religious affiliation because of the illness?

Yes		No	
-----	--	----	--

If Yes, please specify?

Do you have any major health problems other than Rheumatoid Arthritis?

If Yes, please specify:



SEMI-STRUCTURED INTERVIEW SCHEDULE

1. When were you diagnosed with Rheumatoid Arthritis? (Please specify the date if possible.)
2. How long have you been married/living with your current spouse/partner?
3. How long were you married/living with your spouse/partner prior to your diagnosis of RA?
4. How long have you been married/living with your spouse/partner after you were diagnosed with RA?
5. Which aspects of the illness do you experience most?
6. Which areas of your relationship do you think is most affected by RA?





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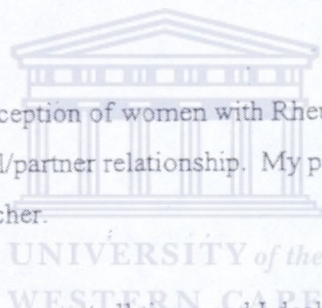
3 February 2005

TO WHOM IT MAY CONCERN

LETTER OF CONSENT

I, hereby consent to participate in the research project being undertaken by Roné Gerber as part of her M.Psych degree, which she is completing through the Department of Psychology, University of the Western Cape.

The research aims to explore the perception of women with Rheumatoid Arthritis of the effect of their illness on their spousal/partner relationship. My participation will be in the form of an interview with the researcher.



I understand that I will remain anonymous at all times and I declare my right to withdraw, at any stage, from the project. Furthermore, I assert that all my biographical details will be treated as confidential.

Date:

Place:

Signed: