THE EXPERIENCES OF FAMILY MEMBERS WHO PROVIDE SUPPORT TO THEIR RELATIVE WITH RHEUMATOID ARTHRITIS

by

Fatmah Fallatah

A thesis submitted to the School of Nursing
In conformity with the requirements for
the degree of Master of Science

Queen’s University
Kingston, Ontario, Canada
(December, 2012)

Copyright © Fatmah Fallatah, 2012
Abstract

Introduction

Rheumatoid arthritis (RA) is characterized by slow progression, functional limitations and poor quality of life. As a chronic disabling disease RA influence not only individuals but also their families. The impact of RA on family members includes providing the required care to the ill relative, postponing family plans, or altering family priorities and decisions due to the illness process.

Purpose of the Study

The psychosocial changes that family members experience may possible compromise their health, family function and relationships with each other. The purpose of the current study was to describe the experience of family members who provide social support to their relative with RA. This study was set to explore the forms of support that are needed by family members to provide adequate support to their relative with RA.

Method

The exploratory purpose of the study leads the researcher to conduct a descriptive qualitative study within the naturalistic inquiry. Naturalistic inquiry is consistent with the aims of this study in which the social support needs of family members of individuals with RA were explored and described.

Findings

Five themes emerged from the data analysis, including: 1) effect of the disease; 2) reshaping the relationship; 3) providing support; 4) social support needs; and, 5) finding balance and coping.
Conclusion

The impacts of RA on the lives of family members resulted from the chronicity of RA. Participants in this study described the effects of RA on themselves, the changes in the relationship with their relative with RA and their effort to maintain the relationship by providing support to their relative with RA. Additionally, they described the social support that they received from family members, friends and healthcare providers. They continuously identified the support they lacked. Nearly all participants were able to achieve balance between providing support and care to their relative with RA and engaging in their own life activities. They also utilized several coping strategies to achieve balance while providing support to their relative, carrying on their duty toward the family, work and their own personal needs.
Acknowledgments

First and foremost, I thank Allah (the God) for enabling me to complete the Master program. All praise is to Allah the Almighty. Peace and blessings be upon our prophet Mohammed. Then, I would like to acknowledge and thank those, to whom I am most grateful for their inspiration, encouragement and support throughout the completion of my thesis study. I would like to express my gratitude to my thesis supervisor Dr. Dana Edge for her help, insight, and mentorship that has made my learning journey an enjoyable and most valuable experience. The knowledge and skills that I have learned from her will benefit me in my future endeavours. Throughout this experience she contributed to my academic and personal development, and for that I thank her. I also wish to thank my committee members Dr. Diane Buchanan and Dr. Marianne Lamb. Their feedback, guidance and critique enhanced the thesis and encouraged me to strive for perfection.

I would like to thank the amazing people who agreed to take part in this study. Their stories and personal experiences enriched my thesis. Without their time, perspectives and insight this project would not have been possible.

I would like to acknowledge and thank the King Abdullah's Scholarship Program and the Saudi Arabia Cultural Bureau in Canada for investing in my education. Throughout my stay in Canada, they not only provided me with academic and financial support, but also presented me with incredible opportunities to explore, learn, and expand my horizon.

I wish to express my deepest gratitude to my parents, Abdulsamad and Nasime, for their unconditional love, continuous support and sincere prayers. They both pushed me to
work hard and achieve my goals. To my sisters for inspiring me to pursue my dream and
aim for higher education away from home and believing in me during the toughest
moments of my project. Furthermore, I would like to thank my brother, Mousa, for his
motivation and patience throughout my educational journey. Finally, I would like to
thank the rest of my family and friends in Canada and Saudi Arabia for their endless
support and ongoing encouragement.
# Table of Contents

Abstract......................................................................................................................... ii

Acknowledgements......................................................................................................... iv

Table of Contents ........................................................................................................... vi

List of Tables ................................................................................................................... x

List of Figures ................................................................................................................ xi

Chapter 1 Introduction ................................................................................................. 1

Rheumatoid Arthritis ...................................................................................................... 3

  Description of RA......................................................................................................... 3

  Etiology......................................................................................................................... 4

  Incidence Rate and Prevalence..................................................................................... 4

  Symptoms...................................................................................................................... 5

  Outcomes and Complications....................................................................................... 6

  Treatment...................................................................................................................... 6

  Purpose of the Study.................................................................................................... 7

Chapter 2 Literature Review ......................................................................................... 9

Social Support ................................................................................................................ 9

  Emotional Support........................................................................................................ 9

  Instrumental or Physical Support................................................................................ 11

  Informational Support................................................................................................. 12

  Availability of Social Support...................................................................................... 12

Research on Social Support and Chronic Illness......................................................... 14

  Search Strategy.......................................................................................................... 14

Chronic Illness in Children........................................................................................... 15
Siblings of children with chronic illness ............................................................... 15
Parents of children with chronic illness .............................................................. 17
Gender differences ............................................................................................... 19
Helpful & unhelpful .............................................................................................. 20
Chronic Illness in Adults ....................................................................................... 21
Spouses of chronically ill individuals ................................................................. 21
Family of chronically ill individual ...................................................................... 22
Cultural influences ............................................................................................... 23
The positive impact of illness on family members .............................................. 24
The Informational Need of Family Members ...................................................... 25
Coping and Social Support ................................................................................ 27
The Research Gap ............................................................................................... 28
Research question ................................................................................................ 28
Chapter 3 Method ............................................................................................... 29
Research Design .................................................................................................. 29
Participants ........................................................................................................... 30
Inclusion criteria ................................................................................................. 30
Recruitment and Sampling .................................................................................. 31
Ethical Consideration ......................................................................................... 33
Data Collection .................................................................................................... 34
The interview ......................................................................................................... 34
Data Analysis ........................................................................................................ 35
Declaration of Personal Interest ......................................................................... 36
Trustworthiness .................................................................................................................. 36

Chapter 4 Findings ......................................................................................................... 39

Key Characteristics of participants .............................................................................. 40

Themes .............................................................................................................................. 41

Research Question 1. What are the experiences of family members who provide 
social support to their relative with RA? ........................................................................ 42

Effects of the disease ...................................................................................................... 42

Emotional impact ............................................................................................................. 42

Lifestyle changes ........................................................................................................... 44

Concerns and worries .................................................................................................... 47

Positive impact of RA .................................................................................................. 48

Reshaping the relationship ............................................................................................ 49

Providing support ........................................................................................................... 51

Providing emotional support ......................................................................................... 51

Providing instrumental assistance ................................................................................... 53

Providing financial support ............................................................................................ 54

Research Question 2. What forms of social support are needed by family members 
provide adequate support to their relative with RA? .................................................. 55

The social support needs ................................................................................................. 56

Emotional support .......................................................................................................... 56

Instrumental assistance ................................................................................................. 58

Informational support .................................................................................................... 59

Availability of support .................................................................................................... 61

Finding balance and coping ........................................................................................... 62

Chapter 5 Discussion and Implication ............................................................................. 66

Discussion of the Context and the Emergent Needs for Support .................................. 66

The Context ....................................................................................................................... 66
Emergent needs for social support................................................................. 68
Finding Balance and Coping........................................................................ 71
Strength and limitations............................................................................... 73
Implications for Social Support Theory..................................................... 74
Implications for Nursing Research............................................................ 75
Implication for Healthcare Practice............................................................ 76
Conclusion.................................................................................................. 78
References................................................................................................... 80
Appendix I Recruitment Poster..................................................................... 95
Appendix II Social Work Services............................................................... 96
Appendix III Consent Form.......................................................................... 98
Appendix IV Participant Information Sheet................................................ 101
Appendix V Demographic Data..................................................................... 103
Appendix VI Genogram interview & Example............................................ 105
Appendix VII Interview Questions............................................................... 107
List of Tables

Table 1. Overview of participant demographics.................................................. 39
Table 2. List of themes.................................................................................. 41
List of Figures

*Figure 1.* Conceptual Drawing of the Element of Social Support Based on the Literature……… 13

*Figure 2.* The Experience of Family Members who Provide Support to Their Relative with RA. 65
Chapter 1
Introduction

Worldwide, chronic illnesses affect people of all age groups. Chronic illnesses are characterized by slow progression, functional limitations and poor quality of life. One of the chronic illnesses that lead to disability, mortality and morbidity is rheumatoid arthritis (RA). RA is a chronic disease that is differentiated by continual inflammation of joints, causing progressive joint destruction, deformities and different degrees of incapacitation (Riemsma, Taal, Kirwan & Rasker, 2001). The most significant challenge faced within the health care system in Canada is to provide quality health care to patients with chronic illness such as RA. Family members of individuals with RA influence the wellbeing and reduce the psychosocial demands of the illness on the chronically ill relative (Lim & Zebrack, 2004).

RA influences not only individuals but also their families; this chronic illness directly affects their lives in various ways, which includes: providing required care to the chronically ill relative, postponing family plans, or altering family priorities and decisions due to the illness process or treatment plan. Craft and Willadsen (1992) defined family as “a social context consisting of at least two persons characterized by caring, mutual attachment, long term commitment and responsibility to provide individual growth, supportive relationships, the health of members and of the unit, and the maintenance of the organization and the system during constant individual, family and societal change” (p, 519). In the previous definition, the context of family support system identified the importance of supportive behaviors among family members to
reduced stress when living with a person having a chronic illness (Coty & Wallston, 2010).

Providing care for a family member with chronic illness can be a physical and psychological challenge. A recent study reported that families manage the illness of their members differently; this depends on the individual personalities of the family members, the type of illness and to what extent the illness affects the function of the family (Ahlstrom, Skarsater & Danielson, 2007).

Living with chronically ill individuals puts family members at risk for enduring physical and psychological challenges, and also affects the functioning of the family. During chronic illness, family members experience transformation; they begin to recognize what happens and develop strategies to protect themselves. Additionally they invent new methods for relating to the chronically ill individual (Badger, 1996). Caplan and Killilea (1976) define social support as "attachments among individuals, or between individuals and groups that serve to promote competence in dealing with short-term crises and life transition, as well as long-term stress" (p. 41). Lin and colleagues (1986) confirmed that emotional and instrumental support from family members or friends significantly decreased depression following a stressful life event. Another study has demonstrated that social support acts as a buffer during a negative life event (Kiecolt-Glaser & Greenberg, 1984). Additionally, other studies show the relationship between stress and psychiatric disorders, such as depression (Brown & Harris, 1989; Paykel et al., 1969; Thoits, 1983) and anxiety (Tennant, Bebbington & Hurry, 1982). The majority of research about RA focuses on the social support needs of patients and formal caregivers. Studies have neglected the perspective of family members as they strive to maintain a
Rheumatoid Arthritis

In this section, I will present a description of RA, including etiology, prevalence, symptoms and complications. This will be followed by a discussion of various methods of treatment. A review of current research on the outcomes and prognosis of RA will also be explored. I will conclude this chapter with an overview of the purpose of the study.

Description of RA

RA starts as an inflammation in the synovium that becomes thick and edematous. This inflammation causes swelling, tenderness and stiffness of the joint (Chen & Wang, 2007). RA can affect lungs, pleura, pericardium, sclera and subcutaneous tissue. The autoimmune system serves as a defense mechanism of the body against diseases. Autoimmune cells identify the existence of protein of a foreign tissue, which triggers protection in opposition to an attack. Normally the autoimmune system does not attack the body. In RA, autoimmune cells attack the synovial membranes. Underlying the synovium lining is articular cartilage, which functions as shock-absorption to protect the underlying bones. The inflammation of the synovium causes synovium hyperplasia, an increase in synovial fluid, and pannus development (Smith, Smith & Seidner, 2011)

RA is differentiated from other types of arthritis by several criteria that are agreed upon by the American College of Rheumatology (ACR) and the European League against Rheumatism (EULAR) for the chronic erosive disease (Aletaha et al., 2010). The 2010 criteria set classified an individual as definitively having RA based on synovitis that is
not caused by other disease. Other criteria are joint involvement, serology, acute-phase reactants, and duration of symptoms (Carlone, 2010). Moreover, the diagnosis of definitive RA requires a score of six or more on the classification system (Nelson, 2011).

**Etiology**

The etiology of RA has not been determined yet. However, genetic, hormonal and environmental factors play main roles in developing RA (Nelson, 2011). The influence of genetic factors is reported to contribute 50% of the risk of developing RA (Scott, Wolfe & Huizinga, 2010). Hormones in pregnant women are reported to reduce RA symptoms, yet the symptoms are reported to be worse during postpartum (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2011). Smoking has been as a risk factor in these studies (Carlens et al., 2010; Hutchinson & Moots, 2001; Stolt et al., 2003) and others include alcohol, coffee, vitamin D, oral contraceptives and low socioeconomic status (Liao, Alfredsson & Karlson, 2009). However, for these risk factors the supporting evidence is weak.

**Incidence Rate and Prevalence**

The incidence and prevalence of RA differs significantly over time and between continents. The incidence rate of RA varies between 0.02 and 0.05% (20 to 50 cases per 100,000 adults) in North America (Doran, Pond, Crowson, O’Fallon & Gabriel, 2002; Gabriel, Crowson & O’Fallon, 1999) as well as Northern Europe (Aho, Kaipiainen-Seppanen, Heliovaara & Klaukka, 1998; Riise Jacobsen, Gran, Haga & Arnesen, 2000; Soderlin, Borjesson, Kautiainen, Skogh & Leirisalo-Repo, 2002; Symmons, Barrett, Bankhead, Scott & Silman., 1994). Countries of Southern Europe have reported a
comparatively lower incidence range between 0.01% and 0.02% (Drosos et al., 1997; Guillemín, Briancon, Klein, Sauleau & Pourel, 1994). There are no reports indicating the RA incidence rates in developing countries (Ndosi et al., 2011).

The prevalence estimates of RA in Northern Europe and North America range from 0.5 to 1.1% (MacGregor & Silman, 2003; Riise, Jacobsen & Gran, 2000; Silman & Hochberg, 2001), while in Southern Europe it varies between 0.3 and 0.7% (Andrianakos et al., 2003; Carmona et al., 2002; Cimmino, Moggiana, Mela & Accardo, 1998; Stojanovic, Vlachinac, Palic-Obradovic, Janosevic & Adanja 1998). The prevalence in developing countries ranges between 0.1 and 0.5% (Akar et al., 2004; Darmawan, Muirden, Valkenburg & Wigley, 1993; Pountain, 1991; Silman & Hochberg, 2001; Spindler et al., 2002), and in some African countries, 0–0.3% (Silman & Hochberg, 2001; Silman et al., 1993).

In Canada, only one research study was found that reported RA prevalence. This study investigated rheumatic diseases in the North West Territories (Oen et al., 1986). From reviewed medical records of a sample of Keewatin Inuit and computerized data from the Manitoba Health Services Commission for out-of-province patients, 0.6% were diagnosed and lived with RA between 1972 to 1982 (Oen et al., 1986). Badley and DesMeules (2003) reported that RA strikes about 1% of the Canadian population and affects women twice as frequently as men.

**Symptoms**

Patients with RA experience the symptoms once the disease flares up. When the illness flares up, the joints become swollen, red, stiff, tender or/and painful. Gradually,
joint destruction and physical impairment occur. The joint pain and synovitis are in general, but not always, symmetrical and involve the small joints of the hands, wrists, elbows, and shoulders. However, the larger joints of the feet, ankles and knees can also be affected. Other symptoms may be presented such as fatigue, appetite loss, low fever, and reduced range of motion. As a result of RA, other vital organs of the body such as the heart and lung can be affected (Goodson et al., 2004; Stoll & Bendszus, 2006).

**Outcomes and Complications**

The main outcomes in rheumatoid arthritis are constant joint inflammation, permanent damage, and impaired function (Scott & Steer, 2007). Other significant outcomes are disease-associated comorbidities such as cardiac diseases (Scott & Steer, 2007) and extra-articular manifestations as in interstitial lung disease (Young & Koduri, 2007). The outcomes and complications of RA are associated with early mortality and declined quality of life. According to Scott and colleagues (2010), the main goals of RA treatment are remission and maintaining joints without inflammation or erosion.

**Treatment**

The treatment of RA includes medications, surgery, lifestyle adjustments, and supportive treatment. Pharmacological treatment has two main goals: (a) to enhance and maintain quality of life; and, (b) to prevent disease progression. For decades, RA was treated when the symptoms became extreme and damage became permanent (Bensen, Bensen, Adachi & Tugwell, 1990). Now, the concept behind treating RA is similar to oncology treatment. In order to prevent deformities and flare ups, the treatment should be aggressive and strong. Nonsteroidal anti-inflammatory drugs (NSAIDs) are used to
alleviate pain. With three months of diagnosis, ACR recommends administering disease modifying anti-rheumatic drugs (DMARDs) to avoid disease progression and deformities. A combination of DMARDs and anti-tumor necrosis factor (anti-TNF) are used when DMARDs fail to prevent disease progression.

Supportive treatments are delivered by a multidisciplinary team, which includes rheumatologists, nurses, physiotherapists, occupational therapists and podiatrists. Supportive treatments include but are not limited to joint protection, exercise, and psychological counseling. Many patients may turn to herbal and alternative treatments such as acupuncture. Surgical joint replacement is highly successful procedure to restore joint function and reduce pain (Callahan, Drake, Heck & Dittus, 1994; Hawker et al., 1998). The ongoing monitoring and treatment of comorbidities associated with RA is vital. Comorbidities that are caused by RA include: atherosclerosis, Sjogren syndrome, nodules, vasculitis, pulmonary fibrosis, iritis, renal disease, osteoporosis, pericarditis, pleuritis, and anemia (Scott, Wolfe & Huizinga, 2010). The characteristics of RA during both flare up and remission periods, and have sizeable effects on everyday activities as well as on the relationship with family members and social ties. Patients with RA are affected in different stages of life by reduced and restricted ability to maintain work and activities (Benka et al., 2012).

**Purpose of the Study**

In health and illness, family nursing links knowledge about family and health with nursing practices that combine individual, family and larger systems (Wright, Watson & Bell, 1996). According to Wright and colleagues (1996), the nursing aspects of family
health requires combining family structure, functioning in health and illness, psychosocial and contextual aspects of nursing while considering the family as a unit and viewing the health issues of individual in the treatment of the family. The objective of the current study was to describe the experience of family members who provide social support to their relative with RA. This study was also set to explore the forms of support that are needed by family members to provide adequate support to their relative with RA.

Chapter two begins with an overview of social support theory. Next, I provide an exploration of the literature on the social support needs of family members of people with chronic disease. Examples of research on chronic illness and social support required by family members are addressed. Chapter three describes the research method, including the research question, design, setting, recruitment of participants and ethical approval. Next, chapter four presents the findings from the research with a description of participant characteristics and emergent themes. In chapter five, I present a discussion of the association between previous literature findings and the findings of the current study. Moreover, chapter five includes the limitations of the study and the implications for social support theory, nursing research and healthcare practice that have been identified, ending with a summary of the study and conclusions.
Chapter 2
Literature Review

This chapter will begin with an overview of social support as a concept and discussion of the four components of social support, as described in the literature. Next, is presented a literature review that includes descriptive and explanatory articles for families experiencing the chronic illness of adult or pediatric family members. Due to the absence of literature examining the social support needs of family members of people with RA, literature pertaining to chronic illnesses is also included.

Social Support

People integrate into a society through their relationships with others; these relationships create the personal network of a person. Agneessens and colleagues (2006) explained that the personal network consists of all others with whom a person has various connections, and the most significant connection is providing social support. A personal network includes intimate relationships, friendships, and neighborhood or community contacts. Many studies showed the importance of an individual’s social support network on stress, psychological, physical wellbeing and health (House, Umberson & Landis, 1988; Lin & Ensel, 1989; Sarason & Sarason, 1985; Veiel & Baumann, 1992a). Sarason et al. (1983) describe social support as “the existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us” (Sarason, Levine, Basham, & Sarason, 1983, p.127). Social support is the function performed for the individual by family members, friends and others, who provide instrumental, informational or/and emotional support (House & Kahn, 1985). Social support, as a
concept, was first introduced in studies by Caplan (1974, 1976), Cassel (1976), and Cobb (1976). Since the introduction of the social support concept there have been extensive studies on the link of social support to physical and mental wellbeing (Cohen & Wills, 1985; Gottlieb, 1983; Kessler & McLeod, 1985; Kessler, Price, & Wortman, 1985). Social support has been studied among individuals living in the context of depression, cancer, mental disorders, and other health conditions.

The concept of social support has been found to influence the coping of family members of patients with chronic disease. Weiss (1974) defines social support concept as interpersonal interaction with others that may produce positive feelings such as being loved, attachment, and security, belonging to a group, availability of emotional, physical and informational help. Another aspect of support is the availability of social support (Muhlbauer, 2002) that indicates the availability and willingness of another person to provide support.

**Emotional Support**

Cobe (1976) defined emotional support as an exchange through communication, which conveys the information that one is loved and cared for, respected and valued, and a member of a network of mutual obligation. Moreover, social support was defined by Moss as feeling of belonging, accepted and being loved and needed not for what this individual can accomplish (1973). Emotional support involves providing care, empathy, love and trust (Bowsher, 1994). Emotional support includes gestures of comforting, such as demonstrating that an individual is available when needed (Coffman & Ray, 2002) and physical attendance is not always needed (Finfgeld-Connett, 2005). Emotional support
can include sending cards or flowers (Gurowka & Lightman, 1995) or prayers from others (Hupc ery, 2001). Other methods also include the use of Internet (Tichon & Shapiro, 2003) and telephone (Chien-Huey Chang & Schaller, 2000) to provide emotional support.

**Instrumental or Physical Support**

The provision of tangible goods or services to others is instrumental and physical support (House, 1981, Tilden & Weinert, 1987). It is the most direct type of social support and is comprised of assistance in many forms such as providing financial aid, time, assisting in assigned tasks, and other obvious activities on behalf of the individual (Hinson Langford et al., 1996). Instrumental support involves providing physical care (Makabe & Hull, 2000), and assistance with household tasks (Gurowka & Lightman, 1995). A study reported that instrumental support could be noted to have emotional meaning as well (Brown, Nesse, Vinokur, & Smith, 2003) as it provides social interaction. However, instrumental support is distinguished from emotional support. Instrumental support can provide social interaction activities, as when preparing meals, giving medication, or participating in physical activities (Hinson Langford et al., 1996).

Although anyone could provide instrumental support, it is most effective when it is anticipated and viewed appropriate by the recipient of the support. Instrumental support from other people is viewed as inappropriate when the recipient loses freedom, and feels inadequate and uncomfortable (Gross, Wallston & Pilliav, 1979). Receiving inappropriate support has a negative impact on the recipient that causes stress and prevents adjustment to the challenging event (Cohen & McKay, 1984).
Informational Support

Providing a person with information that can be applied to personal and environmental problems is defined as informational support (House, 1981; Krause, 1986). Cronenwett (1985) reported that informational support aided individuals in problem-solving. Informational support includes “advice, guidance, suggestions, directives and information” (Nelson & Brice, 2008, p 72). The relevancy of the source and character of support is depends on the individuals involved and the type of support needed by them (Nelson & Brice, 2008).

Availability of Social Support

Support availability refers to the perception perceived by the individual as specific availability of another individual for help (Barrera, 1986; Tardy, 1985). Various factors influence the availability of support such as the personality traits of the recipient, the characteristics of the personal network, coping skills and styles; this may determine whether or not social support interaction will take place (Ueno, 2005). Individuals may acquire support availability from different aspects of a social relationship; in addition, researchers have claimed that being a member of social networks or having many social obligations increases the amount of support received (Ueno, 2005). For example, a person who lost his job may seek financial support from his family members or friends who are willing and able to provide him financial assistance or help to find a job.

A conceptual representation of social support has been developed from the literature review (Figure 1). The conceptual model was developed in an attempt to determine the common elements of social support as identified in the literature.
Figure 1. Conceptual Drawing of the Elements of Social Support Based on the Literature
Research on Social Support and Chronic Illness

Search Strategy

To obtain studies for the literature review, several steps were conducted. Step one was a broad search of literature using electronic databases such as MEDLINE, CINAHL, and PsycINFO. The following search terms were used as key words to search the literature: rheumatoid arthritis AND family AND social support, and chronic disease AND family AND social support. In order to capture accurate meaning from each database, the keywords varied slightly. Articles in the English language from 1970 through to 2012 have been included to ensure adequate retrieval of relevant literature.

Three hundred and sixty-one articles were found. Studies were screened with a goal for finding articles that focused specifically on rheumatoid arthritis or a chronic disease and the social support needed by the family members of a chronically ill individual. Only articles published in English were considered. Articles were excluded if they did not focus on rheumatoid arthritis or a chronic disease and also if the articles did not focus on the social support needed by the family members of a chronically ill individual. If the study design was ambiguous, or methods adopted for the research were not clearly mentioned, or if the arguments posed were not well reasoned, such articles have not been included.

The screening process was conducted through three steps to obtain articles for review. The first step was a broad search of articles to find abstracts that met the inclusion criteria. Titles and abstracts of each article was printed and reviewed. Sixty-five articles were duplicates. The remaining articles were examined carefully to determine if
they met the inclusion/exclusion criteria. References of each article were searched to find additional articles of interest. Only fifty-nine articles were included. The initial search omitted articles focused on: caregiver burden, family resilience, coping strategy, quality of life, social support for chronically ill person. No studies were found that examined the social support need of family members of people with RA. Due to limited articles on social support needs of family members of adults with chronic illnesses, articles examining the social support needs of family members of children with chronic illness were included. Articles investigating the effects of chronic illness of a child on siblings (3) and parents (33) were reviewed. Articles investigating the effect of chronic illness of spouse (14) and family members (9) were reviewed. Forty-two articles were quantitative articles and seventeen articles were qualitative. Following data analysis, a second literature search was conducted, as the concept of coping and the influence of culture emerged from the interviews. The following search terms were used as key words to search the literature: coping AND social support with 2997 articles found. Only ten articles were included.

**Chronic Illness in Children**

**Siblings of children with chronic illness.** The chronic illness of a sibling is one of the most significant challenging experiences for children to encounter. Numerous researchers have documented the impact of chronic illness of a child on siblings. Frankel and Wamboldt (1998) found that siblings of chronically ill children had difficulty in sibling relations and sibling adjustment, as well as difficulty in maintaining social relationships outside the family. A study reported that adolescent siblings of cancer
survivors experienced symptoms of post-traumatic distress (PTD) (Alderfer, Labay & Kazak, 2003). Approximately a third of the sample (total=78) expressed moderate to severe post-traumatic symptoms on the Posttraumatic Stress Disorder Reaction Index (PTSD-RI) (Alderfer, Labay, Kazak, 2003). In addition, some of them were experiencing negative emotions such as jealousy due to all the attention being given to the ill sibling (Prchal & Landolt, 2012). The researchers also found that the psychological distress of parents, exhibited being sensitive, irritable, burdened or weak, was difficult on siblings and in some families resulted in role change (Prchal & Landolt, 2012).

Read and colleagues’ (2010) study examined the impact and coping associated with Duchenne Muscular Dystrophy (DMD) of a sibling. They interviewed 35 healthy siblings (18 girls, 17 boys from 29 families) and their parents to validate the siblings’ findings. The interview included questions about what the siblings first noticed about the affected sibling, what it is like having a sibling with DMD, and what makes it better if things are difficult. The parents were interviewed to explore their own experiences and views on having a son with DMD. Read and colleagues (2010) identified six themes from the siblings’ interviews. Knowledge regarding the nature of DMD was obtained sequentially and differed in breadth. While siblings were assisting in everyday routines and caring responsibilities, they were able to maintain activities and interests that they desired. The positive impact of the illness on family involved improved family cohesion and increased sense of maturity. However, negative impacts included the changed nature of the relationship with their affected sibling, feeling excluded and lacking attention from parents. Coping mechanisms included participating in providing care for the sibling,
although ‘avoidance’ or ‘distraction’ techniques were also evident by being involved in
different activities and interests. They were supported by extended family members,
friends, and teachers. Additionally, the siblings limited negative emotions by engaging in
activities outside the family.

Prchal and Landolt (2012) studied children (n= 7) aged 11 to 18 years, who were
siblings of cancer patients. The siblings experienced a decisive change in family life,
which was illustrated by physical detachment of family members and by emotionally
strained parents. In the interview, the siblings discussed the effects of parents’ absences
on them especially for the first month of diagnosis and also during hospitalization of the
sibling. Parents were not approachable when the siblings needed their help and support
with homework, or knowing about their day, or sharing meals. In addition, the siblings
shared the household duties such as cooking, cleaning, and doing laundry. However, for
some siblings sharing duties was considered as an opportunity to help the family in time
of need. Three siblings mentioned that illness of their siblings affected holiday planning,
either by canceling vacations or by the siblings staying with other relatives or at home for
the holidays (Prchal & Landolt 2012).

Parents of children with chronic illness. The parents of a chronically ill child
struggle to meet the demands of parenting. They are required constantly to change their
roles and lifestyle. The nature of the disease, the need to manage the symptoms and the
complexity of the treatment all cause emotional strain for family members. It begins with
uncertainty of the health condition of the child (Baron-Cohen, 1994). They also discover
the possibility of separation from their children due to hospitalization, change in their
parenting responsibilities and role strain (Hopia et al., 2004; Mu & Tomlinson, 1997). One study reported that parents of chronically ill children often become emotionally strained not knowing what they should do for their child and not being able to participate in taking care of the hospitalized child (Hopia et al., 2004). When a child is diagnosed with chronic illness, the family as a unit, experiences a range of emotions such as shock, sadness, fear, nervousness, frustration, anger and sorrow (Austin, 1990; Hallberg & Sallfors, 2003). Additionally their response includes feeling guilty and a decline in self-worthiness (Stevens, 1990). In some instances, knowing the diagnosis was perceived as a relief by parents of chronically ill children (Nuutila & Salanter, 2006). Another study reported that fathers of children with asthma were relieved in knowing the diagnosis of their children, and relieved to know that the manifestations were not caused by some other potentially fatal disease (Cashin, Small & Solberg, 2008).

Chronic illness of the child has extreme effects on family function and relationships among the members of the family. Parents in one study experienced guilt due to having a child with an illness, and that resulted in difficulties in caring for the child (Hamlett, Pellegrini & Katz, 1992). Their behavior towards the ill child and toward the healthy sibling differed (Hamlett, Pellegrini & Katz, 1992; Hentinen & Kyngas, 1997). Diehl and colleagues (1991) reported that parents of a chronically ill child had difficulties being together as a couple. Also they reported that siblings were jealous of the constant attention toward the ill sibling and embarrassed to invite friends to the home due to illness of the sibling (Diehl, Moffitt & Wade, 1991). However, chronic illness of a child has various positive impacts on family members. Two studies highlighted the

18
positive impacts of the presence of chronically ill child on mothers and their family members, which included improvement in their parenting skills, family members’ level of care for each other, and an increase in their awareness, sensitivity and tolerance for each other (Chernoff, List, DeVet & Ireys, 2001; Nisell, Öjmyr-Joelsson, Frenckner, Rydelius & Christensson, 2003). Gannoni and Shute (2009) examined the parents’ experiences with chronic illness of their child. They reported positive emotions such as growing parental confidence, notably once the treatment of the children made satisfactory progress, and pride in the child’s ability to learn self-management. Parents also described personal growth in their children, including emotional maturity and disciplined behaviors (Gannoni & Shute, 2009).

**Gender differences.** Throughout history, caring of ill family members was a part of the role of women. However, it is common now for men as husbands and fathers to become caregivers (Kramer & Thompson, 2002). Despite the effort to provide equality between men and women, the social support services for fathers do not attempt to accommodate the cultural attitude and tradition of men (Johansson, Anderzen-Carlsson, Ahlin & Andershed, 2012; Ware & Ravall, 2007). The fathers in the previous two studies identified the gender differences in adjusting and coping with their children’s illness. Several fathers from both studies reported difficulties expressing their emotions. They had to maintain a face of being strong and coping, although in private they were in significant emotional distress (Johansson et al., 2012; Ware & Ravall, 2007).

In another study exploring how parents from opposite genders cope with their autistic child, Gray (2003) conducted in-depth semi structured interview of 32 mothers
and 21 fathers. Additionally, Gray interviewed 21 couples. The interview questions covered these areas: the effects of autism on the family, the role of family members, the effects of the disease on the family members, and parents coping mechanisms. He found that the first most common coping strategy utilized by both mothers and fathers was anticipating the difficult situations and planning accordingly to deal with it. The second strategy was “taking life one day at a time” (p.638). The disability of children affected the mothers in everyday life, which caused psychological distress and career interruption. Mothers also used various strategies to cope with living with an autistic child and appreciated the support and help from family and friends. On the other hand, the most utilized strategies by the fathers at home were to keep the autistic children engaged in activities, and to maintain their career (Gray, 2003).

**Helpful & unhelpful support.** Since previous studies highlighted the negative effects of lack of support, various studies have also indicated that some social support can be viewed as negative interaction rather than supportive interaction. Two studies examined the helpful and unhelpful support in parents of children and preadolescents with chronic illness (Brewer et al., 2007; Garwick, Patterson, Bennett & Blum, 1998). In the UK, Brewer and colleagues (2007) interviewed parents of children with Juvenile-onset Huntington’s disease (JHD) (n=12), and used qualitative interpretative phenomenology to analyze the data. They examined the support that was provided by family members and healthcare providers. Garwick and colleagues (1998) conducted a multi-method cohort study with one-year follow up in the United States. They identified
the perceptions of support received by parents of chronically ill preadolescents (n=124) from extended family members, community members, healthcare and school providers.

The participants in both studies identified helpful support that was received from family members, extended family, friends, and healthcare professionals. These helpful supports included: listening, being open, and providing flexible care and appropriate support. However, participants also reported unsupportive interactions. The unsupportive interaction involved inadequate contact with the affected child and the family, lack of understanding in relation to illness and treatment of the child, inadequate emotional and instrumental support, making insensitive comments and blaming the parents for the condition of the child (Brewer et al., 2007; Garwick, Patterson, Bennett & Blum, 1998).

**Chronic Illness in Adults**

**Spouses of chronically ill individuals.** When the spouse is diagnosed with chronic illness, the healthy spouse, in particular, is faced with threatening demands not only on the chronically ill spouse’s life but also on his/her own life (Kuyper & Wester, 1998). Spouses are burdened with responsibilities, such as providing care and support to their spouse (Rees, O’Boyle & MacDonagh, 2001). Rees and colleagues (2001) reported that many spouses were reluctant to expose the true burden of living with a chronically ill person as it may be viewed being unfaithful to their spouse. Kuyper and colleague (1998) reported that healthy spouses identified painful loss in shared activities such as going for walks, having dinner together, going for holidays and making love. Many spouses feel guilty in enjoying activities that their ill spouse is excluded from (Northouse, 1984). Spouses who participated in Baanders and Heijmans’ study (2007) reported the negative
effects of the illness on their lives but also highlighted the positive effects. The negative effects of living with a chronically ill spouse represent strain in personal life and loss of social interaction; however, the positive effect was highlighted by intrinsic fulfillment. The financial burden in younger couples was reported to be higher than retired couples due to the dependence on income of one spouse and loss of savings (Baanders & Heijmans, 2007). The experience of spouses living with chronically ill individuals exhibited the everyday struggle of the spouses to maintain balance between their caring duties and sustaining a normal lifestyle (Eriksson & Svedlund, 2005). Spouses in the study reported that their lives were no longer as planned and the future was unpredictable; they also were required to adjust and adapt to their spouse’s health condition (Eriksson & Svedlund, 2005). Other studies also identified the positive effects of chronic illness on the relationship between chronically ill individuals and their spouses. Spouses described an increase in their self-esteem, feelings of satisfaction, gratification and becoming closer to their spouse (Folkman, Chesney, Collette, Boccellari & Cooke, 1996; Kramer, 1997). In many studies, female spouses reported higher burden in the physical, social, and financial aspects of their lives when compared to male spouses as male spouses seek support from others when caring for their chronically ill spouse (Baanders & Heijmans, 2007; Hagedoorn et al., 2001). In Berg’s study (2002), women reported neglecting their physical needs in the shadow of their spouse’s illness.

**Families of chronically ill individuals.** Family members of chronically individuals typically provide support to their chronically ill relative. The support depends on the needs of the relative and on his or her health condition. The support can range
from providing emotional support as in listening and advising, or instrumental support as in shopping, transportation, cooking and cleaning (Gaugler, Newcomer, Kane & Kane, 2005). Family members also experience unhelpful interactions from other family members, friends and healthcare providers. Unhelpful interactions such as blaming, declining the request for support, and disrespect have been reported (Neufeld et al., 2007). Participants in several studies pointed out the lack of support from some of their own family members and the increased need for help in providing care to the chronically ill individual (Magliano et al., 2004a, 2005b; Merrell et al., 2004; Neufeld et al., 2007). In addition, family members abandoned their own health needs to support the chronically ill individual. Other family members reported that it is difficult to cope with the chronic illness and provide support to the parents of a chronically ill child if they themselves had to take care of other family members with chronic illness or are living with chronic illness themselves (Brewer et al., 2007).

**Cultural influences.** Merrell and colleagues (2004) examined the impact of chronic illness of individuals in Bangladeshi families and reported that family members viewed providing care and support to the chronically ill relative and each other as a positive experience and as a characteristic of ethnical identity. They reported feeling privileged, lucky and satisfied to take care of their relative (Merrell et al., 2004). On the other hand, South Korean families reported that there was a taboo towards expressing emotional distress linked to chronic illness. In other words, serious chronic diseases are viewed as a source of shame, and a consequence of terrible things done in a previous life (White et al., 2002). Magliano and colleagues (2005) reported that Italian families’
continuous adaptation to the relative’s unpredictable pain and illness affected the everyday lives of family members. Chronic illness of family members affected the social activities of several families, including Sunday outings, holidays, and travelling (Magliano et al., 2005).

Guarnaccia and Parra (1996) conducted a comparative investigation of Hispanic-American, African-American and European-American families with a view to understanding the family's experience of living with a relative with severe mental illness and how their culture influenced recognizing symptoms, classifying the illness and responding to the relative's behavior. Family members in the Guarnaccia and Parra (1996) study did not consider providing emotional and instrumental support a burden rather, they viewed cooking meals, shopping for grocery, talking to their relative and listening to his/her concerns as what you do for family members.

The positive impact of illness on family members. Several coping strategies that family members utilized to approach the illness of their relative were reported in the literature. They maintained close and strong relationships among themselves and with the chronically ill individual (Rehm & Franck, 2000; Hallberg & Sallfors, 2003). In addition, siblings of chronically ill child reported increased cohesion and closeness between family members (Prchal & Landolt, 2012). Family members shared their experience with other families in similar situations by talking to them and sharing information and providing support (Magliano et al., 2005; Ware & Raval, 2007). Participants also identified a sense of personal growth (Gannoni & Shute, 2009; Ware & Raval, 2007). Support from other
family members and friends could be as simple as a phone call or a visit (Tommis et al., 2010).

A study investigated the form of contribution that individuals who has mental illness make to their families, from the perspective of those individuals with mental illness and their family members (Greenberg, Greenley & Benedict, 1994). Greenberg and colleagues (1994) recruited 725 individuals suffering from severe mental illness and 725 family members living in rural counties in Wisconsin; the mentally ill participants reported providing help and companionship to their family members, and 59 percent of family members reported receiving such a help. According to Greenberg and colleagues (1994) the relative with mental illness provided help to their family members by doing household chores, shopping, being a good listener and providing companionship.

**The Informational Needs of Family Members**

Family members of chronically ill individuals require general information about the disease such as the risk factors associated with the disease (Eames, McKenna, Worrall & Read, 2003), how the disease is diagnosed (Garrett & Cowdell, 2005; Wackerbarth & Johnson, 2002) and the outcomes of the disease (Beaver & Witham, 2007; Eames et al., 2003; Hoffmann, McKenna, Worrall & Read, 2004). They also need to know the treatment options and the anticipated benefits and risks of each treatment (Chio et al., 2008). Another key area of required information is the availability of services for the patients (Eames et al., 2003). Family members of chronically ill individuals reported the need for general information of the disease paired with tailored information suitable for their delicate and unique situation and educational needs.
(Washington, Meadows, Elliott & Koopman, 2011). The studies emphasized that participants needed health care providers to provide adequate information regarding the chronically ill individual (Hallberg & Sallfors, 2003; Hopia et al., 2004; Ware & Raval, 2007).

Parents of chronically ill children consider themselves to be strongly connected to the child, and providing care to the child is vital for the recovery and wellbeing of the child (Shields, 2001). Parents expressed the need to participate in the care of the child (Bragadottir, 1999; Hallström, Runeson & Elander, 2002; Lindstrand, Brodin & Lind, 2002), and in planning the care and engaging in making decisions regarding the care and treatments of the child (Lindstrand, Brodin & Lind, 2002; Shields, 2001). The need to receive adequate information about the child’s diagnosis, prognosis, the side effects and risks of the medical treatment is essential (Rosenthal et al., 2001). They also need to know how to manage and cope with the child’s pain and illness (Pyke-Grimm et al., 1999).

The studies identified negative interactions with health care providers, for example, refusal to provide requested support, and disrespect toward the family (Neufeld et al., 2007; Ware & Raval, 2007). Many participants identified ways health care services could be improved to accommodate patients and their families’ needs. These included the need to discuss the diagnosis and treatment with the physician, and to be given the opportunity to acknowledge their fear and struggle (Gannoni & Shute, 2009; Raval & Ware, 2007).
Participants were either not aware of the support services that were available to assist them in providing care to the chronically ill individual, or services were not appropriate culturally (Hsiao & Riper, 2009; Merrell et al., 2004). Some families had received support from family members, friends and the healthcare professionals. Helpful interactions were reported in one study such as being a good listener, being honest with the family members, being open and flexible to work according to suggested methods (Brewer et al., 2007).

**Coping and Social Support**

Social support has been shown to mediate and moderate the negative impact of stressful events and continuous challenges (Folkman & Moskowitz, 2004; Ptacek & Pierce, 2003). The potential of social support to reduce stress and assist in coping has been broadly discussed in previous studies (Eckenrode, 1991; Hobfoll, 2002). In a seminal paper, Thoits (1986) recommended linking social support with coping, and suggested the benefits of reconceptualizing social support as coping assistance. Thoits argued that social support and coping have similar functions. These consist of: (a) instrumental function, which in terms of coping, incorporates behavioral problem-focused coping and in terms of social support is known as instrumental assistance; (b) emotional function, which in terms of coping, incorporates emotional-coping function, and in terms of social support is known as emotional support; (c) perceived support, which in terms of coping, incorporates cognitive appraisal, and in terms of social support is known as informational support (Thoits, 1986).
The Research Gap

In the existing literature, the impact of chronic illness on family members can be presented as feeling powerless, depressed and being emotionally strained. It can also affect their social life, and restrict their social activities. The psychological effects and social life changes that family members experience with their relative’s illness can pose a considerable problem for them and their relatives as it compromises their health, family function and relationships with each other. The review highlighted the importance of social support to the family members of individuals with chronic illness, cancer and life threatening illnesses, but it did not focus on chronic illnesses that cause disabilities such as RA. Surprisingly, social support needs of family members of people with RA have not received much attention from researchers. So far, understanding of social support has been primarily limited to research on coping strategies that are used by people with RA and family members in dealing with their relative’s chronic illness. Therefore, it is increasingly vital to identify the social support that is required by family members of individuals with RA so that the appropriate policies and interventions can be established to assist them.

Research Questions

The current study is set to answer two questions:

1) What are the experiences of family members who provide social support to their relative with RA?

2) What forms of social support are needed by family members to provide adequate support to their relative with RA?
Chapter 3

Method

This chapter provides an understanding of the research methodology and the reasons for specific research decisions made during the course of research. This section presents a comprehensive discussion addressing the following areas: research design, sampling and recruitment process, ethical consideration, collection and analysis of the data. In this section, I will also outline how the rigour of the data was addressed in the current study.

Research Design

The exploratory purpose of the study led the researcher to conduct a descriptive qualitative study within the naturalistic inquiry approach. Naturalistic inquiry involves subjectivity, individuality and interpretation as a method to expand our understanding (Awty, Welch, & Kuhn, 2010). In addition, it is an exploration-oriented process that discovers the absolute reality in its “natural” surrounding (Patton, 2002). Within naturalistic inquiry, the concept of reality is a subjective, varied, and dynamic phenomenon (Patton, 2002). From this perspective, the world is perceived as a combination of thought, analysis, and perception of an individual (Oliver, 2004). Reality is formulated in the mind of individuals (Lincoln & Guba, 1985), which is experienced differently by individuals due to their understanding, perspective, beliefs, traditions, and relationships (Awty et al., 2010). Naturalistic inquiry is congruent with the aims of this study in which the experience of providing support to relative and social support needs of
family members were explored and described. Therefore, it was considered the most suitable method to explore the perspectives and expectations of family members for the social support, as the meaning given by them is in essence, their reality. It is the perspective of the family members that is required.

A qualitative descriptive approach is a method of inquiry that describes the participant’s unique perception and experience of the world and its phenomena (Neergaard, Olesen, Andersen & Sondergaard, 2009). A qualitative descriptive approach provides rich and direct description of an experience or event in a language that is easily understood. Whereas other qualitative approaches aim to offer thick description as in an ethnographic, or interpret the meaning of an experience as in phenomenology, or develop a theory as in grounded theory (Sandelowski, 2000; Sullivan-Bolyai, Bova & Harper, 2005) a qualitative descriptive approach provides an extensive summary of an experience through the lens of the participants using simple language (Sandelowski, 2000). Qualitative description aims to focus on participants’ descriptions of an experience in their own words that propose methods to modify behaviors, promote better outcomes, or alleviate unfavorable health effects (Sullivan-Bolyai, Bova & Harper, 2005).

Participants

**Inclusion criteria.** The population of interest for this study was family members of individuals with rheumatoid arthritis. The sampling frame was limited to family members of individuals with rheumatoid arthritis who were willing to talk about their experience with relatives being affected with RA in Kingston, Picton and Toronto, Ontario. The inclusion criteria were as follows:
1. A family member of an individual with rheumatoid arthritis (family member is related by blood, marriage or certain traditions and beliefs);

2. Able to speak English; and

3. Eighteen years or older.

**Recruitment and Sampling**

In May 2011, the researcher and the supervisor, Dr. Edge, met the Directors of The Arthritis Society in Kingston, Ontario in order to obtain suggestions on ways to recruit participants. The research project and inclusion criteria were discussed. The director of The Arthritis Society in Kingston, Ontario suggested presenting the study to the rheumatologists practicing in Kingston, Ontario. He also introduced the researcher and the study to the rheumatologists. A PowerPoint presentation was created to describe the research project, and at the presentation, the researcher handed out a hard copy of the research summary to the ten rheumatologists who attended the presentation. The rheumatologists’ feedback and suggestions were considered. At this time, the researcher contacted the director of The Arthritis Society in Toronto, Ontario. In fall 2011, following ethical approval, the researcher displayed the research posters (see Appendix I) and mini versions of the poster were left for participants at The Arthritis Society. By March 2012, ethical approval was obtained to publish information and provide a link to the poster on The Arthritis Society website. The aim was to recruit ten family members of people with RA. As of March 2012, only three participants were recruited.

The researcher explored different areas for recruiting participants through using personal and professional contacts, due to significant difficulties in recruiting
participants. In February 2012, the researcher and the supervisor, Dr. Edge, met with several staff members from the Family Health Team (FHT) in Picton to informally present information about the research project and handed out an overview of the study, which contained the researcher contact information. An overview of the study and poster were sent electronically to nursing managers at the Family Health Teams in Kingston, in order to obtain best suggestions on methods to recruit participants from these clinics. Subsequently in March 2012, posters and mini posters were mailed to the Family Health Teams at Kingston and Picton. It was expected that the recruitment process would take no more than three months to complete. However, the research project was extended four months exceeding the completion date. Therefore, the researcher posted a recruitment advertisement on Kijiji and Craigslist, but only recruited one participant through social media avenues.

Recruitment was a two-level process. Posters describing the study were posted with the researcher’s contact information, and mini versions of the posters were left for potential participants to take home from The Arthritis Society or the FHTs. In addition, word-of-mouth recruitment was used to recruit participants through a neutral contact in Toronto. Snowball sampling involves asking volunteer participants to identify other potential participants who contacted the researcher by e-mail or telephone expressing their interest to participate in the study. The researcher tried to promote snowball sampling by providing recruited participants with mini posters and asking if they were willing to give the mini posters to other potential participants. It was hoped that The Arthritis Society and the Family Health Team clinics would provide most of the required
sample, however, word-of-mouth transmission proved to be the most effective method for recruitment as it provided six of the seven participants. For the study, the researcher aimed to recruit 10 family members of individuals with RA. While recruiting, the researcher and the supervisor, Dr. Edge, were analyzing the data. The recruitment was terminated because the researcher was not obtaining any new information and also due to time constraints. According to Sandelowski, the sample size should not be too small to achieve data saturation, and also should not be too large to facilitate deep analysis (1995).

**Ethical Consideration**

Ethical approval was obtained from Queen’s University Health Science Research Ethics Board (HSREB). In addition, the study was reviewed and approved by The Arthritis Society, and The Family Health Team in Kingston and Picton, Ontario.

The consent form and elements of the study were discussed in person by the researcher and the participants. There are no identified benefits or risks related to the participants volunteering in this research. However, in an unusual situation, family members might be at risk emotionally. If required, the researcher was prepared to offer the participants a pamphlet of the social work services provided by The Arthritis Society, which advised the participants to call Ottawa or Toronto numbers for help (see Appendix II).

To maintain confidentiality, each participant was required to select an alias that would be used in interview transcriptions, documentation and all other research documentation. Each participant was assigned a code that was used for consents and the digitally recorded interview. The transcribed interviews and the assigned codes were
stored separately from the consent forms in a password protected laptop and encrypted USB. The data were encrypted and stored in one computer device that is protected with a password. The transcript hardcopies, consent forms, encrypted USB and researcher personal notes were stored in a locked cabinet.

**Data Collection**

The data were collected through in-depth, semi-structured interviews that were audio-recorded. Prior to conducting interviews with participants, the researcher conducted practiced interviews on friends and family members. Then, the digital-recorded interviews were reviewed and required changes were implemented before interviewing family members of individuals with RA. These practice interviews were exclusively used to improve the interview skills of the researcher prior to conducting interview with the research participants (Miles & Huberman, 1994).

**The interview.** The interviews were conducted in the homes of participants, or in a public location that was convenient for the participants. When the potential participant was interested in participating in the research, informed, written consent (see Appendix III) was obtained after the purpose of the study and the study process was explained to the participants (see Appendix IV). Each participant was interviewed for one hour to one and a half hours. Demographic and genogram data were collected to determine the characteristics of participants and their family members (see Appendix V&VI) and used in data analysis. A digital recorder was used to record the interviews, and a manual tape-recorder was kept as a back up, for circumstances when there were technical difficulties with the digital-recorder during interviews. To initiate the interview,
the participants were asked to talk about their experience with relatives being affected with RA. An interview guide with questions and probes was used to engage the participants in telling their stories (see Appendix VII). The participants were informed that after the first interview the researcher might require one or two follow up interviews to clarify or elaborate on parts of the first interview.

Field notes were used to keep an account of thoughts, reaction, feelings, biases, challenges, ideas, and impressions the researcher had prior to, during, or after each interview. Later the field notes were used to examine their influence on the data and to determine the consequences of personal experience on the data collection and analysis. The key trends and themes that emerged were documented to guide in later analyzing of the data (Strauss & Corbin, 1998).

Data Analysis

To validate or extend social support theory conceptually, qualitative direct content analysis was used to analyze the data. Each interview was transcribed shortly after the completion of the interview, or within a few days of the interview date. Then the transcripts were reviewed a number of times by the researcher and supervisor to detect the need for clarification or elaboration.

Both the researcher and supervisor individually read the transcripts and used a highlighting approach to abstract passages that the researcher and supervisor deemed to reflect the experience of family members with their relative’s illness and their social support needs. Then all highlighted passages were coded. The codes were themes that emerged from the interview with family members of people with RA that described their
experience in providing support to their relatives. Also predetermined codes were used from social support theory, which includes the availability of emotional support, instrumental support, and informational support. In addition, any statements that were not categorized with the initial coding scheme were given a new code. Following individual coding, the researcher and supervisor discussed their individual coding schemes and discussed any discrepancies prior to the subsequent coding of all the interviews. The codes and the categories were organized into tables to help in identifying the social support needs of family members of individuals with RA and to assist discussion during collaborative analysis with the supervisor. Additionally, the committee members, Drs. Buchanan and Lamb, reviewed the transcribed interviews and the analysis individually and confirmed that the emerged themes were resulted from the data and not from the researcher’s bias.

Declaration of personal interest

I am a registered nurse from Saudi Arabia; I decided to conduct this study, as at the age of forty-five, my father was diagnosed with Rheumatoid Arthritis (RA). The agonizing pain, the deformities and loss of function played a considerable role in shaping the lives of my family. My intent was to provide a glimpse of the experience of family members of people with RA and their needs.

Trustworthiness

In qualitative research, the trustworthiness is described through concepts of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985; Patton, 1987; Polit & Hungler, 1999). Credibility in naturalistic inquiry is the ‘truth’ of
the findings of the inquiry that will be achieved by providing a rich, solid description of a phenomenon (Lincoln & Guba, 1985). To establish credibility the researcher used open ended interviewing techniques and used a question guide to aid the researcher in the interviews. Further, the credibility of the research was enhanced as participants with diverse experiences, and potentially with different perspectives, responded to the questions (Adler & Adler, 1988; Patton, 1987). In addition, the researcher used reflexive journal and audit trail to confirm that data is accurately documented (Graneheim & Lundman, 2003).

Trustworthiness also includes transferability. According to Polit and Hungler (1999, p. 717) transferability is “the extent to which the findings can be transferred to other settings or groups”. Therefore, a thorough description of the background and selection and distinctiveness of participants, methods, settings, data collection and analyzing process was described in this chapter and the following chapters to assist the reader in determining the potentiality to apply the current research findings to another context.

In confirmability, the researcher confirmed that the research and its findings emerged from the focus of the research and not the result of the researcher’s bias (Erlandson et al., 1993) (described later). By reflecting on preconceptions of the researcher, the researcher set aside or eliminated all biases about the phenomenon; this allowed her to understand the phenomenon from the view of the participants (Creswell, 1998). The motivation and reasons for pursuing this area of research was clarified through presenting the researcher’s personal experiences, beliefs, preconceptions, and
assumptions about the research topic. Self-reflection and external review was achieved once these descriptions are disclosed in writing.
Chapter 4
Findings

In this chapter, I present an overview of the characteristics and experiences of the seven family members of people with RA who participated in this study. The findings of the study consist of five themes. The themes are effects of the disease, reshaping of the relationship, providing support, the social support needs and finding balance and coping.

Participant Characteristics

Seven participants were recruited in this study. Four were males and three were females. Three participants were Asians, three were Europeans, and one was from the Caribbean. English is a second language for four participants. Two participants were daughters of women with RA, one participant was a wife and the rest were male spouses of women afflicted with RA. Three of the participants were employed and the rest were retired. Two participants are currently healthcare providers. Participant demographics are presented in Table 1.

Table 1. Overview of participant demographics

<table>
<thead>
<tr>
<th>Pseudonym for Participants</th>
<th>Age Category</th>
<th>Relative with RA &amp; Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christy</td>
<td>Male (70-74)</td>
<td>Wife (65-69)</td>
</tr>
<tr>
<td>Gordon</td>
<td>Male (45-49)</td>
<td>Wife (45-49)</td>
</tr>
<tr>
<td>Richard</td>
<td>Male (70-74)</td>
<td>Wife (65-69)</td>
</tr>
<tr>
<td>Mary</td>
<td>Female (70-74)</td>
<td>Husband (75-79)</td>
</tr>
<tr>
<td>Paul</td>
<td>Male (70-74)</td>
<td>Wife (65-69)</td>
</tr>
<tr>
<td>Katiana</td>
<td>Female (25-29)</td>
<td>Mother (45-49)</td>
</tr>
<tr>
<td>Caroline</td>
<td>Female (50-54)</td>
<td>Mother (70-74)</td>
</tr>
</tbody>
</table>
Key Characteristics of Participants

Christy is a retired man; his wife was diagnosed with RA in 2009. He lives with his wife, daughter and her family. Emotional support is mutual between him and his wife. Gordon is a healthcare professional; his wife was diagnosed with RA after initially being misdiagnosed. He shares outdoor activities with his 10-year-old daughter. Richard is retired; he carries a big load of household duties, and providing emotional support and instrumental assistance to his wife, daughter and her family. He receives emotional support from his wife and daughter. Mary, a housewife, provides support to her husband by being strong and accepting the illness. Her husband was diagnosed with RA 20 years ago. She receives emotional and informational support from her daughters, and lacks instrumental assistance when her husband’s RA flares up. Paul is first generation Canadian and he is retired; his wife has undergone total knee replacement of both knees due to progressive RA. He is satisfied with the emotional support he receives from his friends, sons and from the community he belongs to. He maintains his routine and shares household responsibilities with his wife. English is his second language.

Katiana is a young professional; her mother was diagnosed with RA when Katiana was a child. Her early exposure to RA helped her in accepting and adjusting to the illness. She receives and provides social support to her mother and other siblings. Caroline, a healthcare professional, uses her expertise to enforce boundaries and find a balance between providing social support to her mother, work, study and meeting needs of her extended family. Her mother was diagnosed with RA after falling in the bathroom. Caroline’s husband, adult children and friends are her source of social support.
Themes

Five main themes were identified as findings of this study. All themes are supported by quotations from the interviews of participants. The themes are organized to answer the questions of the study. Three themes were identified that answer the first question: what are the experiences of family members who provide social support to their relative with RA? Two themes were identified that answer the second question of the current study: what forms of social support are needed by family members to provide adequate support to their relative with RA? The themes are organized in Table 2. Additionally, each theme is supported with quotations that are embedded within the descriptions of each theme and/or standalone quotations.

Table 2. List of themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Q1 What are the experiences of family members who provide social support to their relative with RA?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Effect of the disease</td>
</tr>
<tr>
<td></td>
<td>• Lifestyle change</td>
</tr>
<tr>
<td></td>
<td>• Positive effect of RA</td>
</tr>
<tr>
<td></td>
<td>Reshaping the relationship</td>
</tr>
<tr>
<td></td>
<td>Providing support</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q2 What forms of social support are needed by family members to provide adequate support to their relative with RA?

- Social support needs
  - Emotional support
    - The talk
  - Instrumental assistance
  - Informational support
  - Availability of support

- Finding balance and coping

Research Question 1. What are the experiences of family members who provide social support to their relative with RA?

Three themes emerged that answered this question. Two of the themes emerged with subcategories. The themes are effect of the disease, reshaping the relationship and providing support.

Effects of the disease. This theme emerged strongly from narratives of the participants and it reflects the impact of RA on them and on their family. The impact varied due to the severity of the disease. It included emotional impact, lifestyle changes, concerns and worries and positive effects of RA.

Emotional impact. The family members in the study experienced a range of emotional responses. All talked about the event leading to RA diagnosis and described their initial and ongoing emotional responses. Participants talked about feeling sad, shocked, frustrated and helpless. Mary was shocked and sad knowing the diagnosis, even though her husband was engaged in numerous physical activities before being diagnosed with RA:
We [the family] never expected the disease, but when the doctor told us we were a little sad… He [husband’s activities before being diagnosed with RA] walked a lot, cycled and chopped firewood [at home of origin]. *(Mary)*

Katiana also described her feelings when she learnt at a young age about the chronicity of her mother’s condition:

I was upset and I was sad. As a child there are not many things you can do to help her. It was a tough thing for me to watch. *(Katiana)*

Another participant described his emotional response to his wife’s constant complaint of pain:

I feel sad for her, because she is a person who normally is able to bear the pain. She rarely complains and after a long married life, this is the first time. She sometimes complains that her pain is unbearable. *(Christy)*

Frustration was another emotional response that was noted by two participants. Gordon expressed his frustration due to the rapid progression of his wife’s condition and its impact on the everyday routine of his family:

On one level it is frustrating [because] when we were in [another province], my daughter and I continued to ride our bicycle back and forth to work and school, and doing all other stuff, when we went to town riding our bicycles, my wife could not come with us to do that. *(Gordon)*
Additionally, Caroline described her ongoing frustration since RA is the main topic that highlighted her conversations with her mother, sister, husband and friends:

I mean it progressed for few years to the point I hear about it all the time, and daily. All the conversations are around it. *(Caroline)*

**Lifestyle changes.** Many participants spoke about the lifestyle changes that occurred within their own life and their family. Lifestyle changes took many forms, which were described by the participants as excluding the family member with RA from activities that the family enjoyed, limiting the physical activities, lack of shared activities between the family member with RA and the participants, seeking alternatives and added responsibilities.

Family plans were altered and changed radically to accommodate the health condition of the family member with RA. One participant talked about the type of vacation that his family enjoyed previously; they used to go for hikes and camp for weeks in different parts of the world. The entire family appreciated outdoor activities. However, the vacation plans changed to planning a vacation that is not physically demanding such as going on cruises:

… [Now] we do not do holidays that takes a lot of travel, [we did] activities that were not [strenuous]. Cruises actually worked up well, because you actually have a travel day, then a day of activity and then another cruise day. *(Gordon)*

The family excluded the member with RA from activities that are physically exhausting such as “riding bicycle” “going for walks” “making apple sauce and maple syrup”:
Yeah she cannot do other stuff. So I would say planning a cruise and events like that it worked out to be good. *(Gordon)*

Additionally, when Gordon was asked about the type of activities that he engages in to reduce his frustrations, he talked about the difficulties in participating in physical activities when his wife cannot share the same activities with him and their daughter:

> It is only difficult to get my wife out and to do all of that she is unable (sigh) to go out with our daughter. She [the daughter] started doing cross-country running; last summer she was training 3 to 4 times a week, but again my wife cannot come. She cannot ride her bicycle to go to the store. So she is again excluded from that. *(Gordon)*

Another participant also talked about a situation when he asks his wife “to come” with him for a walk “but she said no” *(Paul)*, due to the pain and discomfort. Similarly, Richard described a situation when he asked his wife to walk for longer distance during their regular walks:

> She does not want to walk for long time, because sometimes I ask if we could walk more, she will say no. She knows it has a limit. If she walks longer she will have pain. *(Richard)*

As a child Katiana recalled experiencing changes in the behavior of her mother due to RA flare ups. She was used to her mother being active with her children, however due to RA her mother’s activity reduced:

> I am used to her to be active and being with us, she used to greet us when we arrived home, but when we came home she was in
bed. It was a little bit of an awakening for me to understand.

(Katiana)

All participants talked about the necessity to change the family lifestyle and seek alternatives to adjust to the needs of the relative with RA. Lifestyle changes were either major as in moving from a two-story house to an apartment, or minor as in providing assistance in carrying the shopping bags. Paul described the difficulties that his wife faces with living in a big, two-story house. Her difficulties are mainly caused by frequently using the stairs, which aggravates her pain and discomfort. Paul finds it difficult to leave the house, where they started their family and raised their children:

We moved here in the ‘70s I tried to move couple of times but my boys liked it here. Now she complains about the house, and asks to move to an apartment…. if worse comes to worse we will move. (Paul)

Another participant also discussed with her mother the existing options to live comfortably and manage her household responsibilities by moving to an apartment:

At the moment I have been encouraging her, and we’ve discussed it a few times, to maybe consider moving into something a bit more manageable for her. If she didn’t have anybody’s help, no homecare, nothing, how would she cope? (Katiana)

Husbands of women with RA had to take over household tasks that were previously part of the wives’ responsibilities to alleviate the pain and maintain comfort:

Her activities are less when compared to before. She [wife before being diagnosed with RA] used to do a lot of activities and a lot of work at home, but now I am taking care of most of the work..... (Richard)
The added responsibilities affected the physical abilities of a husband who described the negative effects of taking up more household responsibilities:

I need to go for check up; my back hurts, this [neck] hurts, because I am working all the time at home. (Paul)

*Concerns and worries.* All seven participants expressed their concerns and worries about their loved ones with RA. The concerns and worries varied by age and by the severity of the illness. Husbands of women with RA were more concerned about their wives emotional wellbeing. Christy was worried about his wife’s emotions and her prognosis to RA as a chronic illness; he expressed his wife’s view of RA as punishment from God:

My concern was for her, her feelings, because she is very religious person and she, to some extent, is sad when it comes to her sickness. She feels why God should give her this type of illness. (Christy)

Gordon, as well, talked about his concerns and worries about his wife’s health condition:

My greatest challenge would be that my wife gets some relief from the whole process. (Gordon)

He questioned his wife’s ability to maintain a positive attitude regardless of her progressing health condition and failure of treatments regimes:

I do not know how she will be able to maintain positive outlook through all of this. (Gordon)
Mary described a situation when the RA of her husband flared up after coming home from a long flight. He was bed ridden and she had difficulties in managing his depression, pain and fatigue. Her struggle in maintaining the daily routine was due to lack of support. She struggled in taking care of her husband and household duties:

My children are not with me. I had to do the grocery by myself and feed him. I had a hard time. (Mary)

Another participant talked about her concerns and worries about her mother’s health condition. She was concerned about the financial status and its impact on the mother’s lifestyle:

There’s a financial concern, to make sure she’s able to eat and pay her bills and everything else. There’s also just the lifestyle concern of being able to maintain the space that she’s living in. Whether it’s a big house or an apartment, are you comfortable doing it or do you need help? (Katiana)

However, one participant expressed no significant worries considering his wife’s health condition, which he compares to other people who are affected with RA:

Her condition is not so bad. I heard about many people who cannot… I know people who cannot walk, so the husband is not in a position to come to any social function. By God’s grace I do not have that problem. She is not a burden to me because of this; I do not worry about it. (Richard)

**Positive impact of RA.** Some of participants expressed the positive impact of RA on them and their relationship with their relative who is affected with RA. Husbands described the positive impact of the illness, which was illuminated by becoming closer
and their increased understanding of each other as a result of knowing that wives were suffering from RA:

    Our relationship has not changed; I think it has become closer, because I know she is suffering of pain. (Christy)

    I do not feel it as a burden, or she is a burden to me. Whatever we do it is for both of us. So certain things she does it for example, she cooks not for herself only, but for both of us. (Richard)

Katiana also pointed out the positive influence of RA on her personality and life. She described the personal growth that was influenced by the mother’s illness. She described the changes in her relationship with her mother and how that helped her to adjust with RA. She was able to communicate her concerns and fears about RA. She said:

    It made a huge difference in just my outlook and my ability to handle the situation better. (Katiana)

**Reshaping the relationship.** Participants in this study described how RA shaped their relationship with the relative affected with RA and other family members. For the spouses of people with RA, the relationship was described as being “a very happy married life” and “we have better understanding.” (Mary). Most spouses were sharing several activities together such as “going for walks” “visiting friends” “going for coffee” “going for day trips with group of friends.” However, one participant had a difficult time in maintaining relationship with his wife due to her fatigue and his long working hours:

    Part of that it is trying to figure out how I can spend time with my wife when she is having troubles. (Gordon)
He described his effort to maintain the relationship with his wife; he wakes up in the early morning and prepares her tea and sits and talks to her for couple of minutes, and then he resumes his daily routine. His relationship with his wife is maintained by the presence of their daughter who acts as a focus of their relationship. The relationship between his wife and daughter was considered as being strong; they shared activities such as dancing, as the mother accompanies her daughter to every dance practice:

She [the daughter] is a pretty good dancer; she and my wife do a good job with the extra work they do with the dance that is part of my daughter’s success. (Gordon)

Gordon also pointed out that his wife is excluded from physical activities, and most of the social activities due to her medications, which did not help her feel better.

Two participants described their relationship with their respective mothers, which were built on “respect”. They both acknowledge their responsibilities toward their mothers and appreciated their mothers’ “sacrifices”:

…out of respect for her, and for all her sacrifices I do not want her to feel that she has no one to lean on. (Katiana)

Both participants negotiated care, gave choices and facilitated decision-making of their mothers:

I felt I have been a little cautious; I do not want to take her choices off her because I know how important it is...taking it from her. You know she raised us and we respect her, but still give her choices. With her any information even about RA we have to say it many times, before it sinks
in and registers. And then she is kind “okay I will try it” alright, good it means less pain on your feet [wearing orthopedic shoes]. She does not want to know all the detail [regarding the illness and treatment].

*(Caroline)*

One daughter described her obligations toward her mother as “it takes time and energy, and knowledge” to provide the care and attention she requires. Sometimes it is difficult to call and talk several times a day, because “I work, what I am supposed to do, right?” *(Caroline)*. Additionally, the participant previously experienced caregiving burden for not being able to resume daily activities such as going to the gym, seeing friends, watch TV, and to have the personal time and space that she desired to be “productive” with her mother, husband, friends and work.

**Providing support.** All participants in this study reported providing emotional support and instrumental assistance to their relatives with RA. For participants, providing support was viewed as a responsibility or an obligation due to the type of relationship and the progress of the illness.

**Providing emotional support.** Providing emotional support is part of the participants’ responsibility and obligation towards the family member with RA. The emotional support took many forms, which could be as simple as accompanying the family member with RA to a medical appointment and providing support during minor procedures. Being present, either with the relative in the doctor’s clinic or waiting outside in the waiting area, were commonly expressed examples of emotional support. One
participant talked about accompanying her husband when he had to go through a procedure after immigrating to Canada:

“...I was with him when the doctor took fluid out of his knee. Whenever he goes to the doctor I go with him...[and] the doctor told him to take the medication and he will be alright ” (Mary)

Another participant also described her experience of being with her mother during an invasive procedure. She indicated that she understood that her mother sometimes requires this type of medical attention, because it makes her feel better. This made her realize the physical limitations of her mother.

Christy also talked about his wife’s condition and explained how his wife seeks emotional support from him:

If ever she speaks about it, she speaks about it to me or to our family doctor.... She is not a complaining type, she feels by [constant] complaining, she may irritate others. She doesn’t really complain. She does only in a rare occasion and even when she complains, she only complains to me. She will not complain to anybody else. (Christy)

A participant explained that to maintain their marriage she has to motivate her husband and positively influence her husband and “make him feel strong.” She also explained how her husband’s illness affected her emotionally:

I feel sad but I do not show it to him. I keep it for myself, and think about it and pray to God. (Mary)

However, she does not surrender to negative emotions:
I do not give in to [depression]. If we both will go in that mood and we are both weak, everything will finish. (Mary)

Katiana also described the time she spent with her mother and how she considered it as “the most important thing” for her mother:

Just to sit and talk to her and have a cup of tea or make her breakfast and we share that time together. I’ve realized as I’ve gotten older that time is the most important thing for her, if we give her that time, it is the best thing. She doesn’t care if we’re doing anything or not, paint her nails, that kind of stuff, she appreciates those things. (Katiana)

**Providing instrumental assistance.** Nearly all of the participants described their instrumental assistance to their relative with RA. The instrumental support varied due to the type of relationship to the RA relative, the stage of the illness and family structure.

Instrumental assistance involved: pitching in, accommodating the relative with RA and providing financial aid.

**Pitching in.** Several participants described their assistance in household tasks and changes in the role of the family. Katiana described her role when she was child in assisting her mother during her illness:

There was a lot of role changing; we were taking care more of the household chores, cooking meals for the family. Even doing the groceries, we were pitching in more and more because the disease was debilitating her. (Katiana)

Similarly many husbands in the study were happy to provide instrumental assistance to their wives with RA. They “cleaned”, “vacuumed”, did “gardening” and “laundry”. They
all were happy to help and assist. Additionally, many participants drove the relative with RA to doctor’s appointment or to other places when they needed transportation.

*Accommodating.* The daughters of women with RA described two situations when they have to “accommodate” their respective mothers. These situations rise from RA flare ups, or being overwhelmed with medical information. Katiana described her reaction to her mother’s flare up “I do try to accommodate her as much as I can” by providing food and drinks, help her to sleep and rest while Katiana took care of mother’s duties toward herself and her sisters. That also included “accomplishing some of the [household] tasks”. Similarly, Caroline provided food and drinks to her mother. She claimed to be “food on wheels” for her mother. She cooked food that her mother liked such as BBQ “hotdogs”:

I am her meals on wheels. I know she only cooks certain food. So when I have barbeque, I will have her over and cook enough so she can take several meals with her. Or if I cook something I make sure to make extra; just to make sure that she is eating. (*Caroline*)

Also Caroline described how she accommodated her mother when she was overwhelmed with the information about her medical condition that healthcare professionals provided her with. Caroline was involved in the educational process with her mother and during the medical visits she assessed her mother’s understanding of her health condition. She also explained to her mother the process of treatment and discussed the outcomes of each treatment option. She also talked about searching for alternatives to help ease the pain and discomfort such as using walker and orthopedic shoes.
Providing financial support. One participant provided financial support and shared accommodation with her family member with RA, given her kin’s limited resources that resulted from early retirement due to joint damage and disability. Amongst participants, financial support was often provided to pay bills and maintain the house:

I’ll help with finances and that kind of stuff and then I could help you take care of the house as well. (Katina).

All male spouses of women with RA talked about providing support to their wives who were either housewives or retired early due to the severity of RA. The financial support took many forms such as buying over-the-counter medications, paying for transportation to and from medical appointments, hiring a helper to maintain the house, and supporting early retirement decision.

Research Question 2. What forms of social support are needed by family members provide adequate support to their relative with RA?

To answer this question, two themes were identified from the narratives of family members of people with RA who participated in this study. The social support needs present a description of what family members required providing adequate support to their relative with RA. Another theme that emerged from the findings is finding balance and coping; this was possible only when social support needs of family members of people with RA were fulfilled.
The social support needs. Social support concept guided the analysis and participants’ responses were representative of the four components of social support theory.

Emotional support. Almost all participants in this study described the mutual emotional support that highlighted their relationship with their family member with RA. Mutual emotional support was described as depending on each other when one is sick, being available to show love and provide care and attention. Spending quality time by sharing activities such as going for walks, cooking together, playing board games, going for coffee, to movies, and to church. Several participants received emotional support from other family members, friends and healthcare professionals. Several participants received emotional support from other family members, friends and healthcare professionals. Other family members expressed understanding the responsibilities and obligations of the participants toward the family members with RA. They listened to their stories and concerns; they provided emotional support by calling and inquiring about the family member with RA when being present physically was unachievable:

Yes mentally my daughters supported me...They kept calling me, and inquired about their father’s health. My daughter, who is in the USA, comes to visit whenever it is possible for her. Being a doctor, it is hard for her to get time off. (Mary)

Another participant stated that she and her husband supported each other:

My husband and I have our parents, so we have to take care of both and emotionally support [each other]. (Caroline)
The talk. Two participants had to talk to their children and siblings to explain the condition of the family member with RA. Gordon had to explain his wife’s condition to his ten-year-old daughter when she asked about the exclusion of the mother from the physical activities. Caroline also had the talk with her siblings to share the care of her mother with them. She asked them “you know it is our responsibility to honor our mom, be there and do what we have to do, so what are you prepared and committed to do?” Extended family members also provided emotional support by taking part in the care of family member with RA. The talk also included providing advice when other family members needed advice or support in dealing with the stress of having a family member with RA.

Healthcare providers also provided emotional support to some of the participants in this study. Several participants talked about their family doctor who provided various treatment options to the family member with RA, and respected the family decision regarding the appropriate treatment and comfort measures. Several participants noted that the family doctor offered referral to other specialists or other medical professionals also to relieve pain and discomfort. They talked about the good qualities of their doctor, which included respecting religious beliefs regarding the treatment options, taking the complaints seriously, and working in partnership with family members of people with RA to discover methods to help the relative with RA:

My family physician is very good; she is excellent I should say. You don’t have to ask her to send you to a specialist. She will treat you and whenever she needs, she immediately refers you to specialist. (Christy)
On the other hand, one participant expressed his frustration with the lack of understanding by the rheumatologist to his wife’s condition. In this situation, the specialist misdiagnosed her; the symptoms of physical and psychological exhaustion of his wife were possibly resulted from being “depressed and overworked.” His frustration was due to the rheumatologist neglecting all signs and symptoms of RA and not taking her complaints seriously.

**Instrumental assistance.** In the study, family members of people with RA received instrumental assistance from other family members and relatives. The instrumental assistance included: transportation, grocery shopping, and sharing the care of the family member with RA during the flare up. For Christy, living with his daughter’s family provided him with financial support, as he did not have to worry about financial requirements of his wife’s illness with RA. Some participants also turned to paid assistance such as in transporting the family members with RA to and from the doctor, cutting wood and housekeeping. Additionally, some participants also received support from their work place by having flexible working hours, and being able to take time off work: “If I needed to be off work, they were supportive” (Caroline). Similarly Katiana described the support she received from her employer:

I do not care if I am late for work, if I have to do something for her [mother]; I just call or send a message to a co-worker that I will be late. I do not tell them why and they do not care. If it is something to do with her; they will understand. (Katiana)
Nearly all participants described the financial burden of RA on their family member and its consequences. Paying for over the counter medications such as *glucosamine* was considered to be a burden for retired or unemployed family members. Also the provider in the family may be under pressure to double the salary to maintain financial obligations. Participants struggled to maintain a decent living depending on one income or an inadequate income. Their struggle was primarily due to medication costs, change in lifestyle, and requirements of the family member with RA. Additionally that affected their ability to seek paid help as often as they need:

Right now, if we could get the housekeeper more often, it would be great.
(Gordon)

*Informational support.* The information required regarding RA and its chronicity varied for each participant. Experience with the disease was one participant’s source of information. Another participant sought information from the family doctor and she considered it to be adequate and satisfactory. Also many participants searched the Internet for information about RA, its complications and treatments. They also search for assistive devices that could assist the family member with RA in everyday activities. One participant used several sources to obtain information about RA; she turns to the family member with RA for her experience and knowledge about the disease, The Arthritis Society, medical books, and the Internet. Moreover, participants often considered a second opinion for diagnosis and treatment. Another participant also obtained information by asking relatives who are healthcare professionals. One
participant pointed out the poor quality of information that is accessible through the Internet:

I mean it is surprising what is technically available, but the problem is being in isolation. A lot of information does not necessarily make any sense to people…. surprising, but some of the sites of medication I understand what that means, I understand the implication, but for other people it is a vague term that they do not understand. (*Gordon*)

Many participants reported the lack of informational support from healthcare providers. One participant compared between the informational support that he received as a diabetic patient in the form of seminars and workshop, with the lack of information his wife received regarding RA. Additionally, Paul also talked about the lack of proper explanation for his wife’s constant knee pain, post knee replacement:

When we asked the doctor he asked in return are all your children similar?! It is the same thing where your knees are concerned... He said it was the same procedure, and the x-ray looks good. (*Paul*)

Participants required informational support that is tailored according to the cultural differences and the various educational backgrounds. Many questions needed to be acknowledged:

So far there have not been any seminars or any form of instructions to let us know what rheumatic arthritis is, the type of arthritis that people can get and especially rheumatic arthritis, the ill effects of rheumatic arthritis, why a person gets rheumatic arthritis and whether it can be cured permanently or whether it’s going to be lifelong illness. If it is life long you have to be
taking Tylenol and if you are taking Tylenol lifelong what are the ill effect it has on your liver or your system. (Christy)

Another participant described her situation when her mother with RA was hospitalized due to medication toxicity. She talked about being emotionally strained not knowing the reason for the admission of her mother to the intensive care unit. She said that no one was explaining to her and her siblings the health condition of the mother. She said they used medical terminology to explain briefly, without respecting their non-medical background. She had to search for a couple of the medical terms on the Internet, and she found misleading information that added to her stress and fear. However, one night she called the intensive care unit and spoke to a nurse who was taking care of her mother that night. She asked him to explain to her the mother’s condition; the nurse explained in detail the mother’s condition using less medical terminology. She said that she appreciated his attitude toward her limited knowledge about the mother’s condition and giving her the opportunity to ask questions and thoroughly understand the mother’s condition. She said that after talking to the nurse, she was reassured.

**Availability of support.** Many participants utilized various resources of support in an attempt to seek emotional, instrumental and informational support. Emotional support was available to many participants through their interaction with others in their social network. Two participants belonged to community groups, which facilitated interaction between the members with respect to their culture, religion and age. Both participants described their sense of belonging to these communities, and the various activities that they share with other members in the community. Other participants talked about the
availability of services that were provided by organizations such as information regarding RA, social events, and visitation. Additionally, participants described their interaction with other family members, friends and healthcare providers that offered them emotional support. Caroline spoke about her husband’s understanding and persistent support to accommodate her obligation toward her mother. Richard also talked about the availability of mutual support between him and his daughter.

For instrumental assistance, many participants obtained instrumental assistance from their spouse with RA. The instrumental assistance from spouse included cooking and cleaning. Two participants talked about hiring a helper to maintain the household, cut wood and transport the family member with RA to and from the doctor clinic. For informational support, many participants turned to their family doctor:

The first thing we do know naturally is to book an appointment with the family doctor and see the family doctor. (Christy)

We had the chance to go to the US and consult another doctor to get a second opinion. (Richard)

Moreover, many participants search for information on the Internet:

She will go on the website and look for it. When we have more complications, we go to see our doctor she will discuss it with him. (Richard)

From the Internet [I get the information], I Google everything. (Caroline)
Two participants are healthcare professionals who have the advantage of obtaining the most recent information from medical journals and publications:

We both have the advantage of being able to access any medical file we want to. In term of computer based literature search within subscriptions only or medical publication, yeah we had gone through it all. (Gordon)

**Finding balance and coping.** As a result of living with a family member with RA, participants in the study reported their method for achieving balance and coping with the illness and its consequences. The first method of finding balance and coping was accepting the illness. During their interviews Paul, Richard and Caroline talked about accepting the illness of their loved ones:

When you get old these things happen, you see old people with a lot of health problems and pain, you have to cope. (Paul)

Richard talked about comparing between his wife’s health condition and other people who were affected with RA and were disabled. Caroline reported accepting the illness of her mother due to her experience as healthcare professional and the age of her mother:

I was not really surprised, I guess because I worked in a hospital.... I am pretty aware of that side of it…. I was fine with it and my siblings we were all pretty good about it. You know it is part of getting older; the change does happen. So we are okay with it. (Caroline)

The second method of finding balance and coping with the RA of family member is by having “me time” and “alone time”. Two participants described the process of learning to achieve balance. One participant utilized her clinical knowledge to set the
boundaries between providing care and her personal life. She talked about the process of learning to cope with health care demands of her family member with RA. She lacked the support, time, and energy. She was not able to perform as a caregiver, a mother, a wife and a clinician. She started recognizing the impacts of providing care to her family member with RA, and established “me time”, which was scheduled to fit her situation. She talked about traveling to be “off duty”, going for walks with her family members, studying, baking, exercising, meeting friends and relatives. She reported being “productive” and being able to provide holistic care to her mother. Another participant also confirmed the need for “alone time” away from the family member with RA. She described her alone time to be spent interacting socially, volunteering and exercising. Many participants also reported seeking physical activities to relieve stress and frustration.

Participants in this study described the effects of RA on their family member and on their life; they described the changes in their relationship and their effort to maintain relationship by providing support to their relative with RA. Additionally, they described the social support that they received from family members, friends and healthcare providers. Also they identified the support they lacked. Nearly all participants were able to achieve balance between providing support and care to their relative with RA and their personal life. They also utilized several coping strategies to achieve balance among providing support to their relative, carrying on their duty toward the family, work and their own personal needs. In an attempt to capture all the findings of this study, a figure
was created to feature the experiences of family members providing support to their relative with RA.

Effects of The Disease
- Emotional impact
- Lifestyle changes
- Concerns & worries
- Positive effects

Relative with RA

Reshaped the relationship

Family member

Needs social support to

Provide emotional support & instrumental assistance

achieve coping

Figure 2. The Experience of Family Members Who Provide Support to Their Relative with RA
Chapter 5

Discussion and Implications

In this chapter, I present a discussion of the main findings of the study in relation to the existing evidence regarding the social support needs of family members of people with chronic illness. The discussion will be presented in two sections: a description of context and themes that emerged from the finding of the study.

Discussion of the Context and the Emergent Needs for Support

The Context. Living with a relative who has RA affected family members in a number of ways. The impact resulted from the chronicity of RA and its complications. Participants in this study described the effects of RA on their family members and their lives; they described the changes in their relationship with their relative who has RA and reported their effort to maintain the relationship by providing support to their relative. Family members of a person who has RA in this study reported experiencing a range of emotional consequences that resulted from the chronic pain experienced by their relative and the complications caused by the side effects of treatment. Several participants in the current study reported reactions to the illness of their relative with RA that are similar to those of a Swedish study that explored the experiences of female spouses whose husbands required dialysis due to impaired renal function or who were afflicted with neurological illness requiring long term care (Eriksson & Svedlund, 2005). The spouses, in both the current study and that of Eriksson and Svedlund (2005), reported altering their daily routine to provide support and accommodate the health condition of their spouse.
The findings in this study support the findings of previous studies that reported that family members of chronically ill individuals experienced a range of emotions when their relative was diagnosed with chronic illness such as shock, sadness, fear, nervousness, frustration, anger and sorrow (Austin, 1990; Hallberg & Sallfors, 2003). Many participants in the current study concealed their emotional distress from their relative in an attempt to strengthen and motivate their relative. Additionally, the participants in this study reported numerous changes that have occurred within their lives. According to two studies, family members of chronically ill persons experience financial burden, career, as well as role and relationship changes (Baanders & Heijmans, 2007; Rees, O’Boyle & MacDonagh, 2001). Kuyper and Wester (1998) concluded that healthy spouses experienced painful loss of shared activities with their ill spouse such as having dinner together, going for walks and holidays. Similarly, the spouses of people with RA in the current study experienced loss in shared activities and interest with the ill spouse. However, unlike what has been reported previously in the literature, most participants in the current study searched for activities that fit the health condition of their relatives; for one participant, cruise holidays worked better than camping, and other participants went for walks, cooked, shopped and visited friends together, providing evidence for adaptation and eventual coping by the family members in this study.

According to Ell (1996) families are characterized by sociocultural differences and various structures, also they are distinguished from each others by their own social support needs and coping strategies. Similarly participants in this study reported role changes that reshaped the relationship with their relative with RA. Role changes were
primarily noted in spouses’ relationships as most of the male spouses carried out various house chores that were not considered as apart of their duty in their own culture. Also, role changes were reported by a daughter of a woman with RA due to early exposure to the mother’s chronic illness; the participant and her siblings were “pitching in” and assisting the mother during her illness.

Nearly all participants in this study reported financial burden. Baanders and Heijmans (2007) found that younger couples experienced more financial burden than retired couples, as they depend on one income and lose their savings; however, nearly all spouses in the current study reported financial burden due to the loss of income, financial cost of over-the-counter medications, retirement or starting a new life as a new immigrant to Canada. Many participants in this study highlighted the positive effect of RA on them and their relationship with their relative afflicted with RA. The findings of this study are similar to studies that described an increase in self-esteem, satisfaction, gratification in healthy spouses and feeling closer to their chronically ill spouse (Folkman, Chesney, Collette, Boccellari & Cooke, 1996; Kramer, 1997). People with mental illness reported providing support and company to their families; their family members also reported receiving support from their relative who has mental illness in form of instrumental and emotional support. The support included helping in the house chores, doing shopping, being a good listener (Greenberg, Greenley & Benedict, 1994). Likewise, in the current study several participants reported receiving help and companionship from their relative with RA. Similar to Guarnaccia and Parra (1996) participants in the current study did not view providing support to their relative with RA as a burden.
Emergent needs for social support. The current study sought to identify the social support needs of family members of people with RA and is unique as being the first known study to do so. Emotional support was defined by Cobb (1976) as emotions exchanged through communication, which conveys the information that one is loved and cared for, respected and valued, and developed a sense of belonging to a network. Emotional support is essential for coping of family members with RA. The amount and characteristic of emotional support needed by family members is determined partially by the duration and severity of the illness. According to the participants in the current study, emotional support was received from the relative with RA, other family members, friends, and healthcare providers. The emotional support ranged from just being available to talk to, or listen to problems, or provide advice when needed, or show love and caring. Some family members searched for emotional support from healthcare providers as healthcare providers know the illness of the relative; however, the emotional support was often not provided or was inadequate. Many participants reported that the relative’s family physician was a reliable source of emotional support for them; yet, several voiced not being comfortable and confident that the rheumatologist understood their concerns and worries.

Examples of instrumental support, the second component of the social support, were provided in the interviews by participants. Similar to emotional support, several participants received instrumental support from the relative afflicted with RA, other family members, and friends. Some forms of instrumental support were lacking, such as financial aid, availability of free transportation and help in maintaining the household.
Nearly all participants reported the lack of financial aid that changed their priorities and altered their future plans. Many participants indicated that as a result of their limited financial circumstances, they ignored their own priorities and chose to channel any extra funds to their relative with RA. Also as a consequence of limited finances many participants were unable to hire outside help as required to maintain the house, or pay for a taxi when transporting relative with RA to and from a doctor’s appointment.

One of the most important findings of this study is that family members of individuals with RA rarely received comprehensive information from healthcare providers. The lack of information and knowledge in turn reduced their ability to provide informational support to the relative with RA. Participants in this study identified a broad variety of topics and issues that they required, including the need for basic knowledge about the disease, treatment options and availability of other services. Previous studies examining stroke have also identified a gap in the delivery of information to patients and their families by healthcare providers (Eames, McKenna & Worrall, 2003; Hoffmann, McKenna, Worrall & Read, 2004). Moreover, in the current study, participants emphasized that proposed informational and educational sessions need to be tailored to fit their unique situations and delivered in a form that could be understood by a layman. This also was reported in studies of the informal caregivers of chronically ill individuals who struggled in understanding medical jargon and information that was delivered without an extensive explanation (Hoffmann, McKenna, Worrall & Read, 2004; Nikoletti, Kristjanson, Tataryn, McPhee & Burt, 2003; O’Connell, Baker & Prosser, 2003). Two main sources of information and education were described as being accessed by the
family members in this study: Internet websites and family doctors. However, the lack of reliable medical websites that target people without medical backgrounds, as well as the lack of time allocated for the family members to discuss with their relative’s family physician the disease and their concerns regarding the health of their relative were two of the key barriers identified within the study.

**Finding balance and coping.** A central theme, finding balance and coping emerged from the study. Social support functioned as a coping strategy that was used by the participants to reduce stress, maintain psychological wellbeing and achieve balance between the demands of the illness and their personal life. The effect of RA on family members required the availability of social support from family, friends, community, and healthcare providers. In the current study, many participants described how social support facilitated them in coping with their relative’s illness. Negative feelings such as stress, depression, and anxiety were reduced when emotional support was received from intimates and confidants. Instrumental support facilitated taking breaks from the ongoing pressure of providing support to the relative with RA, maintaining the relationship with other family members and friends, having alone time to recharge, and maintaining a healthy lifestyle. On the other hand, lack of support delayed the process of coping and prolonged the negative impact of living with relative with RA.

As discussed in the literature review, Thoits (1986) viewed social support as stress-related interpersonal interaction where significant people provide support to reduce stress and solve problems. This concept is used in coping literature when investigating effective problem-solving methods. In the current study, family members described the
behavioral, emotional and perceived support that they received to facilitate and strengthen their coping with the illness of their relative. The support also assisted them in solving problem related to the relative’s illness by providing instrumental assistance, emotional support and informational support. The findings of the current study support Thiots’ suggestion to conceptualize social support as an aid to coping.

In an attempt to understand the experience of family members who participated in the current study, Figure 2 (presented at the end of the Findings Chapter) was developed to incorporate the components of social support concept with the situational, interpersonal, and intrapersonal factors that arose from the analysis. According to Pierce and colleagues (1996) social support has three aspects: personality, personal relationship and social structure. To understand the social support and coping of individuals the influence of the three aspects should be examined in other studies.

Family members of individuals with RA needed social support to achieve balance and cope with the chronicity and disability of RA. The source of social support and form varies according to their needs. The findings of this study support the findings of previous studies that examined the social support needs of family members and caregivers of chronically ill individuals. Similar to two previous studies that examined the social support needs of informal caregiver of people with COPD and cancer, the absence of appropriate informational support that is tailored to meet the needs of the family members in this study delayed them in coping with their loved one’s chronic, disabling rheumatoid arthritis (Bee, Barnes & Luker, 2009; Caress, Luker, Chalmers & Salmon, 2009).
**Strengths and limitations**

The strength of this study lies in being the first known study that was conducted to provide an understanding of the social support needs of family members of people afflicted with RA. The study targeted the neglected population of family members who are in constant contact with a relative with RA. In this study, the sources and forms of social support that were used by family members to live with their relative who has RA were identified. This study clearly illustrates that social support enables the family members to cope with their relative’s chronic illness, and affirms existing literature on the role of social support in coping (Thoits, 1986). A theoretical strength is that similar themes emerged despite the heterogeneity of the study sample. Participants in the study came from diverse backgrounds, including socioeconomic class, employment status, ethnicity and educational preparation. Some participants in the current study were dependent upon old age pensions for their daily expenses, or receiving a pension from their country of origin. Other participants were self-employed, or working for health or military institutes. Culturally, participants self-identified as being originally from Canada, Asia, Europe or the Caribbean. Participants’ educational backgrounds ranged from graduate degrees to high school diplomas. It is possible that those individuals who were not coping well with their relative’s rheumatoid arthritis condition perhaps chose not to participate in the study. There was no way to determine if this form of selection bias may have occurred; regardless, it is a limitation, along with the small sample size, that requires caution when interpreting the results. Furthermore, the study is limited as it does
not shed light on the experience and social support needs of female spouses and sons of people affected with RA.

**Implications for Social Support Theory**

The findings of the current study suggest the importance of linking social support theory with the concept of coping as an outcome of receiving appropriate support among study participants in a variety of social contexts and of different ages. As previously stated, RA not only affects the individuals alone, but also their family members, who experience physical and psychological challenges of living with relative with a chronic and disabling illness. To understand the social support and coping of individuals the role of the person’s characteristics and social environment should be examined (Pierce, Sarason & Sarason, 1996). Linking social support with coping provides an explanation to why some individuals handle the challenges of the chronic illness of their family member better than others (Mactavish & Iwasaki, 2005). Additionally, coping ought to be examined within the social context (Kosciulek, 2004).

**Implications for Nursing Research**

The current small, exploratory study is an initial step to identify the social support needs of family members, and many aspects of social support needs and coping of family members of people with RA require further investigation. People from different cultures experience and react differently to the illness of their relatives. They also have distinctive beliefs and values regarding illness and their relationship with others. The effect of culture on the social support and coping of family members of people with RA, differ within ethnic groups as they practice diverse cultures. To obtain a richer and deeper
account of the social support needs of diverse groups within Canada, future studies, could identify the needs based on specific ethnic groups. The second aspect to explore is an in-depth investigation of the social support needs and coping in female spouses, adult and young children of people afflicted with RA, as these aggregates were not part of the current investigation. The third area for future research is to examine what factors and situations allow family members to reframe their situation in a positive light. Exploring and evaluating these coping strategies will help in promoting physical and psychological wellbeing.

**Implications for Healthcare Practice**

The current study reinforced previous work that family members need social support to achieve balance and cope with the illness of their relative. Healthcare providers are required to recognize and to be aware of the uniqueness and individuality of each family member in respect to their need for social support and the use of coping strategies. Nursing intervention must be geared to provide emotional support, informational support, and guidance to obtain instrumental assistance. There are numerous areas where nursing interventions are required. The diagnosis phase of RA is a critical time for patients and their family members, as they experience a range of emotions such as shock, anxiety, anger, fear and frustration. Healthcare providers need to assess the emotional impact of the diagnosis on the patients and their family and provide a chance to speak about these emotions. During this phase physicians are required to provide adequate and honest information regarding the illness, prognosis and treatment options and permit time for questioning and clarification (Stein & Wooley, 1990).
Throughout the diagnosis phase, healthcare providers should tailor the information to fit the educational and cultural backgrounds of the patients and their families. This includes providing information in clear and comprehensible language and without medical jargon (Eames, McKenna, Worrall & Read, 2003). Information should also be discussed with the patients and their families rather than handing it to them (Allison, Evans, Kilbride & Campbell, 2008).

Following the diagnosis, healthcare providers should schedule additional meetings to assess the comprehension of patients and their families and to determine their need for supplementary information. For example, in an outpatient clinic, nurses, including registered practical nurses, registered nurses, and nurse practitioners, assess the knowledge of patients and their family members regarding managing symptoms of RA in their everyday life, anti-rheumatic medication regimes, and blood tests. During this phase nurses not only provide informational support, but also emotional support by allowing the patients and their family members to express their feelings and concerns. Nurses also prescribe and educate patients and their family members on the use and benefits of joint splints and adaptive equipment. They refer patients to other healthcare professionals and to services, such as the Arthritis Self Management Program (ASMP).

Throughout the course of the illness, the informational needs of patients and their family members vary; an assessment of the informational and emotional needs in various settings and during flares and remission are required. Patients accompanied by their family members to an emergency room due to RA flare-ups are in need of emotional and informational support. Emergency room nurses have the opportunity to deliver social
support to alleviate physical and psychological challenges of patients and their family members. Nurses must assess patients’ self care and problem-solving abilities during remission and flares. Nurses should also provide information regarding the pharmacological and non-pharmacological approaches to manage RA pain and discomfort.

Patients receiving inpatient treatment and their families may experience a range of emotional distress due to unpredictable course of the illness, hospitalization and uncertainty of medical and surgical outcomes. Nurses are required to assess the emotional distress of admitted patients and their family members, and provide orientation to the inpatient unit, discuss the treatment plan, and hand out educational pamphlets regarding the medical treatment and surgical procedure, which is combined with oral and tailored educational sessions. Group informational sessions may benefit patients and their families through learning and sharing their experiences and knowledge with nurse educators and other patients and family members. Discharge plans should fit the informational needs, physical limitations and living arrangements of patients. Additionally, referral to other services should be arranged to facilitate self-care and quality of life of patients with RA and their family members.

**Conclusion**

The current qualitative study explores in depth the experience of seven family members providing support to their relative with RA. Throughout the study my intention was to answer the following questions: What are the experiences of family members who provide social support to their relative with RA? What forms of social support are needed
by family members to provide adequate support to their relative with RA? Five themes emerged from the data analysis, including: 1) effect of the disease; 2) reshaping the relationship; 3) providing support; 4) social support needs; and, 5) finding balance and coping. The emergent themes were discussed in relation to previous studies that examined social support of family members of people with chronic disease. Additionally, implications for social support theory, nursing research and healthcare practice were discussed. The social support needs of family members are influenced by their individual situation and social relationships with their relative with RA and others in the social network. The findings of the current study when linked with other related studies regarding the social support of family members of individuals with chronic illness have the potential to enhance nursing education, research and practice.
References


87


Neergaard, M. A., Olesen, F., Andersen, R.S., & Sondergaard, J. (2009). Qualitative description - the poor cousin of health research?. Medical Research Methodology, 9, 1-5.


Appendix I
Recruitment Poster

Family Members of People with
Rheumatoid Arthritis Wanted!

How do you express your own needs for social support?

This study will be examining the social support needs of family members of people with rheumatoid arthritis. The ultimate goal of the study is to identify the social support needs of family members living with a relative who has rheumatoid arthritis who are 18 years or older, to be able to provide valuable and useable information to health care professionals. This private interview will take approximately 1 – 1 ½ hours. You will have the opportunity to review the results.

Please contact: Fatmah Fallatah, BSN, MSc Nursing Student, Queen’s University

Phone: 416-951-7174
Email: 9ff8@queensu.ca
Learning to live with a chronic illness like arthritis can affect every aspect of your life and your lifestyle. The added challenges of increased stress and fatigue make things even more difficult, but you are not alone. The Arthritis Society's social workers are here to help.

Don't struggle by yourself

The Arthritis Society's social workers have advanced training in rheumatology and are a very important part of your health care team. Their expertise can help you — and your family — cope with the challenges of arthritis in many ways.

A social worker can help you:

- Access other social services and income and benefit programs.
- Identify government resources in your community.
- Discuss solutions to transportation or housing challenges.
- Cope with your emotions and manage stress.
- Talk with your family about how arthritis affects you.
- Meet other people with arthritis to share your experience.

Arthritis Rehabilitation and Education Program

Social workers are part of The Arthritis Society's Arthritis Rehabilitation & Education Program, which is designed to maximize your independence and improve your self-esteem and confidence. The Arthritis Rehabilitation & Education Program runs in communities throughout Ontario and serves people of all ages.

There is no cost to participate in this program. It has been funded by grants from the Ontario Ministry of Health and Long-Term Care, the educational materials have been provided by generous corporate and individual donors.

How do I get started?

If you have been diagnosed with arthritis, you can make an appointment to see a social worker by:

- Calling your local Arthritis Society office for our toll-free info line at 1.800.267.1433.
- Filling out a self-referral form on our website at www.arthritis.ca or emailing us.
- Asking your health care professional to do this for you.
In Ontario today, approximately 1.8 million people have arthritis – people of all ages and walks of life.

There are more than 100 different types of arthritis, generally classed as either degenerative or inflammatory arthritis. Some types attack the spine, wrists, knees or other joints, your internal organs, or your skin. Whatever your diagnosis, The Arthritis Society is here to help.

As a major funder of arthritis research in Canada, The Arthritis Society invests in finding the causes, and eventually a cure for this disease. Our goal? A world without arthritis.
Appendix III

Consent form

The Social Support Needs of Family Members of Individuals with Rheumatoid Arthritis

You are invited to participate in a research study directed by Fatmah Fallatah, a graduate student in the Queen’s School of Nursing, to find out the social support needs of family members of individuals with rheumatoid arthritis. Ms. Fallatah will read through this consent form with you and describe procedures in detail and answer any questions you may have. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Details of the study
The purpose of this study is to find out the social support needs of family members of individuals with rheumatoid arthritis. You will be considered for the study if you are 18 years or older, and are in contact with a family member with rheumatoid arthritis one or more times per week. If you agree to participate in this study, Ms. Fallatah will interview you. This interview will take approximately 1 – 1 ½ hours.

With your permission, Ms. Fallatah will audiotape the interview and will then type your interview. You will be identified by an alias of your choice. In addition, the researcher may ask for clarification of an issue you discussed. The researcher may ask for a second meeting, if the researcher needs to check information when the data are being analyzed. You are free not to answer any question. Tape recordings will only be available to Ms Fallatah and Dr. Edge. Data will be stored in a locked cabinet.

Potential Risks
There could be the potential risk of having a strong emotional reaction to discussing your past experiences. If you require ongoing emotional support after the interviews, you will
be referred to The Arthritis Society Social services for ongoing support/counseling service.

**Benefits**

You may benefit from being able to candidly speak about your experiences within a comfortable and non-judgmental environment. However, should you not directly benefit results from this study may improve the understanding of the social support needs of family members of people with rheumatoid arthritis and may benefit family members in the future.

**Confidentiality:**
All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. You will be identified an alias only. Data will be stored in locked files and will be available only to Fatmah Fallatah, and the Health Protection Branch in Canada. You will not be identified in any publication or reports.

**Freedom to Withdraw or Participate:**

Your participation in this study is voluntary. You may withdraw from this study at any time without any type of consequences.

**Liability:**

By signing this consent form, you do not waive your legal rights nor release the investigator(s) and sponsors from their legal and professional responsibilities.

**SUBJECT STATEMENT AND SIGNATURE SECTION:**

I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information.

If at any time I have further questions, problems or adverse events, I can contact
Fatmah Fallatah at 416-951-7174
Dr. Dana S. Edge at 613533-6000 ext. 74765

If I have questions regarding my rights as a research subject I can contact
Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching
Hospitals Research Ethics Board at 613533-6081

By signing this consent form, I am indicating that I agree to participate in this study.
______________________________________________
Signature of Patient Date

______________________________________________
Signature of Witness Date

STATEMENT OF INVESTIGATOR:
I have carefully explained to the subject the nature of the above research study. I certify
that, to the best of my knowledge, the subject understands clearly the nature of the study
and demands, benefits, and risks involved to participants in this study.

______________________________________________
Signature of Principal Investigator Date
Appendix IV

Participant Information Sheet

Project title:
The Social Support Needs of Family Members of Individuals with Rheumatoid Arthritis (RA)

You are invited to participate in a research study directed by Fatmah Fallatah, a graduate student in Queen’s University, School of Nursing, to find out the experience of family members of people who have rheumatoid arthritis and what the experience is like for them. Ms. Fallatah will read through this consent form with you and describe procedures in detail and answer any questions you may have. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Details of the study:
The purpose of this study is to find out the social support needs of family members of individuals with rheumatoid arthritis. You will be considered for the study if you are 18 years or older, and are in contact with a family member with rheumatoid arthritis one or more times per week. If you agree to participate in this study, Ms. Fallatah will interview you. This interview will take approximately 1 – 1 ½ hours. The interview will take place at Queen’s University, or your home, or a public location that will be convenient for you.

With your permission, Ms. Fallatah will audiotape the interview and will then type your interview. You will be identified by an alias of your choice. In addition, the researcher may ask for clarification of an issue you discussed. The researcher may ask for a second meeting, if the researcher needs to check information when the data are being analyzed. You are free not to answer any question. Tape recordings will only be available to Ms Fallatah and Dr. Edge. Data will be stored in a locked cabinet.
**Potential Risks:**
There could be the potential risk of having a strong emotional reaction to discussing your past experiences. If you require ongoing emotional support after the interviews, you will be referred to The Arthritis Society Social services for ongoing support/counseling service.

**Benefits:**
You may benefit from being able to candidly speak about your experiences within a comfortable and non-judgmental environment. However, should you not directly benefit results from this study may improve the understanding of the social support needs of family members of people with rheumatoid arthritis and may benefit family members in the future.

**Confidentiality:**
All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. You will be identified by a given name only. Data will be stored in locked files and will be available only to Fatmah Fallatah, and the Health Protection Branch in Canada. You will not be identified in any publication or reports.

**Freedom to Withdraw or Participate:**
Your participation in this study is voluntary. You may withdraw from this study at any time without any type of consequences. If at any time you have further questions, problems or adverse events, you can contact:

Fatmah Fallatah at 416- 951-7174
Appendix V
Demographical Data

❖ Age
What is your age? _________

❖ Sex
What is your sex? ____________

❖ Race/ethnicity
How do you describe your ethnical background? ______________

❖ Marital status
Are you:
(Circle the appropriate answer)

- Married
- Divorced
- Widowed
- Separated
- Never been married
- A member of an unmarried couple

❖ Employment status
Are you currently?
(Circle the appropriate answer)

- Employed for wages
- Self-employed
- Out of work for more than 1 year
• Out of work for less than 1 year
• A homemaker
• A student
• Retired
• Unable to work

❖ Education completed

What is the highest grad or year of school you completed?
(Circle the appropriate answer)
• Never attended school or only attended kindergarten
• Grades 1 through 8( Elementary)
• Grades 9 through 11 (Some high school)
• Grade 12 or GED (High school graduate)
• College 1 year to 3 years (Some college of technical school
• College 4 years (College graduate)
• Graduate School(Advance Degree)

❖ Family size
• How many adults live in your household? ____________
• How many children live in your household? ____________

❖ Spirituality

Are you affiliated with a religious organization? __________
Appendix VI
Genogram interview & example

RA and the Immediate Household

1. Who lives in the household? (Name, age, and gender)
2. How is each person related?
3. What is each person’s medical history?
Appendix VII

Interview Questions

The researcher will initiate the interview with open ended questions such as “As I mentioned previously, I am interested in the experience of family members of people who have rheumatoid arthritis and what the experience is like for them. I’d like to hear about your experiences…so let’s begin with you telling me about your relative’s illness and how the diagnosis affected you?” Other interview questions and probes will follow this general opening.

1. Tell me about your relative’s illness
   - When your relative was diagnosed with RA? what was your reaction?
   - How did you feel about your relative being diagnosed with RA?

2. Tell me what you know about RA
   - What treatment options were considered for your relative?
   - From where/whom you obtain information regarding your relative’s illness and treatment information?
   - Have you ever accompanied your relative to his/her doctor appointment? If so tell me about it
   - What has been your experience with doctors and other health care professionals or agencies?
   - What question would you most want answered by the clinician regarding your relative’s illness?

3. Tell me about your relationship with your relative who is affected by RA,

4. Your relative’s illness may have had an effect on your life
   - Could you talk about that and how it has affected you?
   - Has that changed since the diagnosis?

5. What kinds of relationships do you have with your other family members?
   - Is there someone in the family or another person who you talk about this illness and its effects on you?
   - In a difficult time, on whom can you depend on?
   - With whom can you share your happiness and sorrow?
   - To whom do you turn when in need of emotional, physical, financial and spiritual help?

6. Are there any concerns about your relative who has RA that worry you? When did the problem begin? Did you seek help for it? If so, when? What happened? What is the status of that problem now?
7. What are the greatest challenges you feel you are facing with your relative being affected with RA?

8. Do you have anything to add?