

**THE MEANING OF SELF-CARE FOR WOMEN
WITH RHEUMATOID ARTHRITIS**

by

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Abstract

This study explored the self-care experiences of women with a medical diagnosis of rheumatoid arthritis for at least 2 years, but no more than 5 years at the time of enrollment in the study. The study participants were between the ages 35 years and 45 years, had completed high school and were English speaking. In-depth personal interviews were conducted with seven women. A follow-up conversation to confirm study findings was conducted in person or by telephone with all seven women. The audio taped interviews were transcribed and analyzed using content analysis. Study findings revealed five major themes: coming to terms with chronicity of rheumatoid arthritis, viewing themselves as experts, learning how to make changes, maintaining control of decisions, and building a network of support. Self-care was a complex, multidimensional experience that occurred in the context of everyday life. Self-care was understood by these women to be embedded in the whole experience of rheumatoid arthritis. It involved educating themselves and their health care providers, as well as seeking partnerships within the health care system. These themes were blended into a narrative that reflected the meanings and understandings of self-care as described by the women.

The implications of the findings from this study are discussed with recommendations made for practice, policy, and research. A key recommendation is for health care professionals to adopt a health promotion framework to guide their work with women with rheumatoid arthritis.

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Dedication

To Eric,

For your love, understanding, and encouragement
at every step on this journey.

CHAPTER I: INTRODUCTION AND OVERVIEW

Background to the Problem

Rheumatoid arthritis (RA) is a chronic illness associated with symptoms of pain, stiffness, and fatigue. It is an incurable illness and, if left untreated, can result in substantial or complete disability. RA is defined as a chronic systemic inflammatory disease of unknown cause that primarily affects the body's joints and related structures such as tendons and ligaments, but can also affect other parts of the body such as the heart, lungs, blood vessels, and eyes. Inflammation of the joints can cause stiffness, pain, swelling, and warmth. Generalized symptoms include feverishness, diminished energy, and lack of appetite. Persistence of the disease has debilitating effects on the musculoskeletal system and often leads to depression and other adverse psychosocial phenomena (Spiera & Oreskes, 1991). This chronic illness, affecting 300,000 (1 in 100) Canadians, can begin at any age, but most people develop RA between the ages of 25 and 50. Twice as many women as men develop RA.

The World Health Organization (1986) recognizes the rapidly growing needs of people suffering from chronic illnesses such as RA. It urges those involved in the planning and provision of health care services to critically assess the experience and knowledge available to address those needs. It also recommends that health care providers and planners suggest ways and means to strengthen the coping capacity of the chronically ill. Concurrently, there has been an increased public health emphasis on the betterment of people's quality of life and degree of independence through development of their coping and self-management capacities (Epp, 1986). Self-care

has been proposed as a central mechanism by which to achieve these objectives.

There are many published research studies which proclaim the importance of self-care in the management of a chronic illness such as RA (Boutaugh & Lorig, 1996; Brus, Taal, van de Laar, Rasker, & Eiegan, 1997; Daltroy & Liang, 1993; Edworthy, 2000; Hawley, 1995; Hill, 1997; Hirano, Laurent, & Lorig, 1994; Lindroth, Brattström, Bellman, Ekstaf, Olofsson, & Strömbeck, 1997; Lorig & Holman, 1993; Superio-Cabuslay, Ward, & Lorig, 1996). This published research evidence on self-care or self-management of RA covers a wide range of behaviors and attitudes which fall under the sphere of self-care.

Berman and Iris (1998) maintain that constructions of self-care are often grounded in the value systems of the health professionals who design and carry out research on education programs that promote self-care behaviors and strategies. Self-care is a value-laden concept. The beliefs and assumptions which inform a person's self-care practices are judged by society and health care professionals as appropriate or inappropriate without considering what may or may not be relevant for the person being judged. Those who design and research education programs which have not included the perspectives of those living with a chronic illness such as RA may have biased their program design and study findings with their own personal or professional values regarding self-care practices or experiences. An examination of the perspectives of those living with RA should be an essential component for developing relevant and meaningful health education programs or strategies which involve the teaching and learning of self-care practices.

The broader dimension of enhancing people's capacity to cope with chronic illness is often overlooked by the traditional biomedical model approach to illness (Kickbusch, 1992). The biomedical approach focuses on pathological and physical processes and emphasizes pragmatic therapeutic interventions and technology (Anderson & Bury, 1986; Gerhardt, 1990; Sacks, 1986). A patient's personal account of their illness experience is largely ignored within this perspective. Pincus & Callahan (1995) claim that the greatest challenge to the biomedical model in chronic illness is evidenced by the recognition that a person's health is determined more by their own actions than by the actions of health professionals and public officials. A person's health status may be determined as much by self-care as by professional health care. It is, however, important to acknowledge the limits of self-care while accepting its benefits. Self-care can offer significant advantages to some individuals, but can also be an idea used for "delegation of health work nobody else wants to do or that societies cannot afford to have professionals do anymore" (Kickbush, 1989, p.129).

There is an element, in the current discourses on the notion of self-care, which tends to imply an individual responsibility for health. These views an individual's behavior as being responsible for their health problems and those we face in our society (Minkler, 1999). The individual is often the target for interventions aimed at changing unhealthy behaviors through self-care strategies. These views, in relation to the term of self-care, hold the individual to be primarily accountable for their personal health. Yet little is known about personal experiences with self-care of chronic illnesses. Personal experiences of self-care or self management of chronic illnesses are poorly understood by health professionals involved in health care service provision and health

education program planning and evaluation.

Dean and Kickbusch (1995) call for an understanding of human responses to chronic illness from within the context of the life situation where they occur. An understanding of the perspectives of people living with chronic illnesses, such as RA, may provide opportunities for health care providers, educators and program planners to support self-care initiatives. In conducting this research study, I offer a different perspective to the health professional view. I offer richly detailed personal accounts of the self-care experiences of women living with RA.

Purpose of the Study

The purpose of this study is to explore the notion of self-care from the perspective of women with rheumatoid arthritis in order to inform policies and programs designed to support and enhance the self-care practices of women with RA.

The Researcher and the Setting

I am a registered nurse who graduated with a diploma in nursing from a hospital-based nursing program in a small prairie city. I worked in a variety of settings, but was employed primarily in acute care hospitals. I took several continuing education courses to keep up my knowledge and skills in critical care nursing. After several years of full-time work, an unhappy marriage and divorce, I left acute care hospital nursing and returned to formal schooling to complete a baccalaureate degree in nursing. During that university program, I deliberately challenged myself to seek clinical experiences outside of acute care hospital settings. I had started to question my participation in what seemed like "the revolving door syndrome" of acute health care.

The health care system was great at dealing with emergency or critical health care problems, but did very little in terms of disease prevention or health promotion. In one particular hospital, I tended to see the same patients over and over in the critical care unit where I worked. Providing health care for urgent problems was always handled efficiently, but it was becoming quite apparent that little was being done to prevent repeat admissions to an ever more costly system that demanded and usually got more and more sophisticated technology and equipment to diagnose and treat illness.

My experiences in health care have moved me out of acute care hospital settings into community based or ambulatory care settings. Acute care settings, in my view, have struggled with responding to changing patterns of disease prevalence from acute to chronic. As I attempted to provide nursing care for chronically ill people and their families in health care systems that emphasized philosophies consistent with the curing of illness, the use of excessive high technology, and the dominance and authority of biomedicine I became more and more frustrated and disillusioned. What was being done to assist those with chronic illness in a way that had relevance and meaning for them? I started to find out by working with chronically ill people in a community health setting.

I currently work in a community setting which provides direct health care treatment, counseling and education to persons with arthritis. There seems to be more emphasis and understanding of the broad range of health determinants that must be addressed when planning and providing health care with people with chronic arthritis. Yet, I continue to believe that good quality health care for those living with a chronic illness such as RA is lacking in several areas. Health care for the chronically

ill, including those with RA, continues to be fragmented and non-holistic. It doesn't address the areas of the illness experience that may be more important to the chronically ill person than physical or medical needs as determined by health care professionals. Biomedicine continues to dominate with an emphasis on pathology, disease and physical processes.

As a health care provider working with people with RA, my philosophy of people, health, and illness is holistic. I view illness as all the ways a sick person, their family and community perceive, live with, and respond to symptoms and suffering. My perception of health emphasizes wholeness and balance. I bring a biopsychosocial and spiritual approach to people with RA and their families by recognizing the interrelated physical, emotional, spiritual, social, and biological dimensions of people. I also believe that illness does not have to be present to be concerned with health. I attempt to carry out a holistic nursing practice by developing caring relationships with clients. This approach goes beyond mechanical treatment of disease and attends to the person's reports, perceptions, and experiences about their own body, spirit, and mind. I attempt to understand by entering through their world of meaning. The choices and decisions made regarding a particular client's health care are directed by and inclusive of that individual's preferences and goals.

I held several assumptions about the health care and self-care experiences of the women interviewed for this study. I believed these women all had experienced distressing clinical encounters within the health care system. They all had dealt with many uncomfortable and stressful symptoms and responses to the disease of RA. They had gone through several changes in their day to day lives as they struggled and

adapted to living with a chronic illness. I further believed that the term "self-care" had relevance and meaning to the women. Finally, I assumed that their personal understanding of self-care experiences could easily be talked about in a conversation that acknowledged their overall experiences of life with RA.

My approach to conducting a research study on self-care experiences in women with RA is related to my philosophy of nursing and what I believe about people, health, and illness. There is an abundance of published literature on self-care written by a whole range of people from a variety of academic and disciplinary traditions. I had great difficulty locating any specific self-care literature written by a person with RA that provided insight into their personal experiences. I wanted to find out about the self-care experience from the perspective of a person who is living with RA. Thus, I was interested in the emic or insider's view versus the etic or outsider's view (Merriam, 1998). While I conducted an investigation of personal perspectives and experiences with RA, I also sought to discover the social and environmental forces that possibly shaped a person's self-care experiences.

Research Questions

This study attempted to answer the following main research question:

What understandings and meanings do participants in this study, adult women with RA, have about self-care?

The subquestions were:

How do they describe their health care experiences generally and how do they talk about self-care specifically?

Does the notion of self-care have relevance and meaning for these participants?

How do their stories of self-care compare with the debates and ideas within the literature?

Research Design

The research questions I was interested in answering suggested the use of a qualitative design to provide the in-depth, richly detailed personal views of women with RA. A qualitative approach to sampling, data collection and analysis procedures provided me with an understanding of the meaning of self-care experiences from the perspectives of seven women who volunteered to be study participants. A qualitative approach is the design of choice when a researcher is interested in documenting an experience from the perspective of the person who has lived that experience (Brink & Wood, 1998). This research approach provided an account of how an experience was lived and how it felt. Personal interviews were carried out to explore the self-care experiences of seven women with rheumatoid arthritis.

A descriptive-exploratory approach, as described by Brink and Wood (1998) was utilized to carry out the study. While using descriptive and exploratory methods, this study was guided by the constructivist perspective of knowledge production and research. In this perspective, knowledge is socially constructed and multiple realities

exist (Guba & Lincoln, 1994).

There have been very few studies which examined the lives and experiences of women with RA. This study attempted to look for new knowledge, new understandings, and new meanings. A qualitative research design was, therefore, chosen to discover, with the participants, these new insights.

Significance of the Study

This study generated an understanding of how self-care is experienced by adult women with rheumatoid arthritis. Knowledge and understanding of these experiences can be used by health care providers and educators to adapt practices to the realities of the lives of the patients they see every day.

The clinical practice and research space has many unheard voices which are largely silenced by the reigning voice of biomedicine (Crabtree & Miller, 2000). By entering the voices of these women into conversations as evidence, the potential of clinical practice and research can be expanded and transformed. By offering a richly detailed description of everyday life, this study provides an additional perspective of self-care experiences that occur within and outside of clinical encounters. By understanding these experiences, the potential to examine current conceptualizations of self-care becomes possible. It is even possible that health care providers and educators may alter their clinical practices by offering services in a way that listens to and respects the everyday realities of those living with rheumatoid arthritis.

Outline of the Chapters

The subject area of self-care is broad and diverse in scope and ranges over many fields of study, disciplinary and professional practices, and scholarly writings. A review of the literature related to self-care as it relates to chronic illness and more specifically to RA is presented in Chapter Two. A detailed description of this study's research design is presented in Chapter Three. Chapter Four contains the stories of the study participants. These are presented as introductions to the individual women and then as a narrative to highlight the common themes that emerged from the study findings. A concluding discussion of self-care in the context of rheumatoid arthritis is presented in Chapter Five along with recommendations for health care practice, policy and future research.

CHAPTER II: SURVEY OF RELEVANT LITERATURE

The following literature was reviewed with the purpose of understanding the meaning of self-care from the perspective of persons living with rheumatoid arthritis. The chronic illness and self-care literature was spread out over a range of perspectives from broad health promotion positions to focused disciplinary traditions of inquiry. The literature review captured the main ideas and discussions regarding self-care, particularly as they related to chronic illness and rheumatoid arthritis.

The health promotion literature, and particularly Canadian literature, was explored for its explanation of self-care. The chronic illness experience has been well documented by Corbin and Strauss (1988), Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, and Wiener (1984), and Thorne (1993). These three publications are discussed for their contributions to current understandings of self-care. Six different disciplines (medicine, nursing, psychology, sociology, health education, and public health) are examined for their traditions of practice and research regarding self-care. Specific definitions of self-care that have been widely published are examined for their relevance to the purpose of this study. The research literature related to the Arthritis Self-Management Program is presented (Lorig & Holman, 1993; Edworthy, 2000). Qualitative research studies have explored and described the experience of living with rheumatoid arthritis and these have added to understanding self-care experiences (Brown & William, 1995; Ryan, 1996; Shaul, 1995). Finally, two personal accounts are presented for their contribution to this review of the literature.

The Health Promotion Approach

The Canadian approach to health promotion (Epp, 1986) reflects a balanced ecological perspective that includes personal responsibility for health behavior within the broader context of social responsibility. This perspective features a model which informs planning, practice, and policy making at the national level. It is within this approach that the notion of self-care takes the form of a specific strategy to aid people in achieving their health potential.

The guiding principles of this health promotion approach and its framework for strategic action have been articulated in a document published by Health and Welfare Canada (1986). This commitment to health promotion derived its vision from a common understanding of prerequisites for health. These were defined as peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity. Three major health challenges were identified in this document: reducing inequities, increasing prevention, and enhancing people's capacity to cope with chronic conditions and other health problems.

According to Minkler (1999), two elements of this approach were worth pointing out. First, reducing inequities between low and higher income groups was not framed in terms of personal responsibility, but referred to as a broader societal responsibility. Second, within the three levels concerned - health challenges, health promotion mechanisms, and implementation strategies- all had attention drawn to the role of broad institutional or societal change. Discussion of self-care was from within a framework that acknowledged and supported the creation of healthy environments where positive health behaviors could develop. Self-care was also recognized as an

important notion during health or illness.

The climate for strategic efforts that promote health has changed considerably in recent years. The promise of health reform which embraces a determinants of health perspective seems threatened by political and public debates over hospital beds and insured medical treatments. Well-meaning health ministry representatives continue to embrace a vision of health promotion while patients report on cuts to social programs (e.g. transportation programs, translation services, resources for family violence) that have direct benefits to their health. Deficit reduction is the current priority in the health system and those sectors outside of health, such as social, environmental, and educational services.

Despite all this, there is recognition in policy circles of the continued benefits of a health promotion approach to health policy (Edwards, 1997). The vision and potential of the meaningful benefits of health promotion have been demonstrated in the considerable body of literature built on studies utilizing participatory action research (Green, George, Daniel, Frankish, Herbert, Bowie, & O'Neill, 1995). Participatory action research (PAR) in health promotion attempts to find solutions to health problems and facilitate action or social change to achieve those solutions.

PAR has its roots in several social science disciplines and service fields. It is a research process rather than a specific methodology and "emphasizes the integration of three elements: research, education, and action" (Green et al., 1995, p. 3). Integral to PAR in health promotion is the active involvement of the people who would be the beneficiaries of the research. Involvement can include work and decisions at all phases of the research process and requires a continuous exchange of knowledge, skills, and

resources (Hall & Stock, 1985, cited in Green, et al, 1995). Health promotion and PAR differ from most biomedical approaches to research in the degree to which the affected population is actively engaged in assessing their own needs (McGowan & Green, 1995). It may also differ in that the process may not even start with a specific health problem.

Community development and adult education have historical traditions of "involving learners and communities in the assessment of their needs and in planning and evaluating programs for themselves." (Green, et al, 1995, p. 25). Seeking meaningful solutions to health problems with active involvement of participants has less of a tradition in the health sciences, but in today's communities many people seek active control over their health issues and health care. This may be particularly true for people living with chronic illnesses, for whom health problems may be multiple and irreversible, rather than focused and curable, and issues of day to day living or quality of life may take precedence over biomedical concerns. Green et al (1995) reviewed 400 published and unpublished papers on participatory research projects carried out in Canada. None of these projects or papers had rheumatoid arthritis as the identifiable health issue, but there were others that worked with participants with chronic illness such as diabetes (Daniel & Green, 1995; Brown, Calam, Grams, Grzybowski, Heffernan, Herbert & Wilson, 1994) and AIDS (Adrien & Godin, 1993).

In work published by McGowan and Green (1995) a PAR approach was utilized when four First Nations communities in B.C. approached The Arthritis Society to work with them in finding solutions to the health problem of arthritis, which they had identified themselves as a priority. Guided by a health promotion planning model, the

Arthritis Society researchers worked with the four communities as full partners and collaborated to determine methods that employed research processes that included quantitative and qualitative approaches. The communities defined their experiences with arthritis problems, specified their desired outcomes and determined the research questions. The communities adapted the existing Arthritis Self-Management Program to suit their conditions, trained the leaders, implemented and evaluated the program. Participants in this process demonstrated immediate reductions in behavioral risks and symptoms, as well as empowered themselves to engage meaningfully in their community's affairs. This project provided an example of where PAR created an opportunity for extending the benefits of research and health promotion to populations that had been deprived of new health knowledge and innovations available through self-care and mutual aid.

The Experience of Chronic Illness

Three publications are frequently cited in the chronic illness literature for their accounts of the chronic illness experience (Corbin & Strauss, 1988; Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener, 1984; Thorne, 1993). Although these authors are not specifically interested in self-care and have not aimed their research efforts towards exploration of this topic, the depth and breadth of their research with people with a variety of chronic illnesses frequently refers to aspects of self-care as part of the overall chronic illness experience. Their research also has included women with rheumatoid arthritis.

Thorne (1993) writes a very compelling account of her research with chronically

ill persons and their experiences within the health care system. She analyzed data collected over the course of several qualitative studies, each of which addressed some aspect of the chronic illness experience. Thorne understands the chronic illness experience to operate at three levels: the individual, the social and the structural. Each level is separate, but related. The findings of her analysis are thus presented in this manner, with the analysis extended to include interaction between these levels.

She presents her view of the chronic illness experience as a “complex social phenomenon emerging from factors inherent in a disease, in a society, and in a health care system” (p. 206). Serious flaws in the health care system, the people working within it and in the way it is organized are identified as major factors influencing the chronic illness experience. The stories of the people she interviewed are profiled throughout the book.

There were a total of 91 informants for the study analysis and of these 13 had a diagnosis of “arthritis”. The book did not include any accounting of the socio-economic circumstances or ethnic background of research participants. Thorne repeatedly draws attention to cultural influences on the chronic illness experience and I am surprised by this omission in her own publication. Some individual socioeconomic details are revealed in the detailed presentation of the findings, but these are scattered and not offered to the reader in a comprehensive way. There were 59 women and their ages were described as “middle adults”.

Thorne describes the self-care experience as a “movement “ of people who have recognized the flaws inherent in the traditional views of understanding health care. She writes that the self-care movement is the only hope for the dysfunctional health

care system as it exists today and proposes that the potential energy and wisdom in this collective movement may bring forward the discussion and action required to reorganize and restructure the current health care system.

The chronic illness experience has been extensively written about by Corbin and Strauss (Corbin & Strauss, 1988; Strauss et al, 1984). Their two publications focus on their years of research interviews with people with chronic illnesses, their families and their experiences with management of chronic illness at home. The emphasis is on the social and psychological (not the medical) aspects of living with a chronic illness. The authors continuously refer to the "work" of managing chronic illness at home. The perspectives of the people they interviewed was that it is "hard work" to stay alive, afloat, and functioning as physiological and social beings while living with a chronic illness. The work that was essential, unavoidable and central to managing chronic illness at home is presented in the richly detailed interviews conducted for this research.

Women with rheumatoid arthritis and their spouses were interviewed in both publications by Corbin and Strauss. Self-care is not specifically referred to in their analysis of the chronic illness experience, yet I could identify similarities in the experiences of the women in my study with those of the study participants in these two publications.

Disciplinary Contributions

Academic disciplines create and organize knowledge to answer questions considered to be important for that discipline (Gantz, 1990). For example, medical practitioners may ask "What is causing this disease?" and health educators may ask "What educational content and method of delivery will change behaviors in a desired

direction?" Each discipline tends to use language and research methods that is specific to its perspective. The following section includes a summary of the main ideas discussed among the disciplines of medicine, nursing, psychology, health education, sociology, and public health. These were the disciplines which had contributed substantially to mainstream, current, and government (such as B.C. Ministry of Health) publications of self-care that are publicly distributed or available to both health professionals and consumers of health care information.

The focus of self-care in medicine is the transfer of certain activities, such as assessment, monitoring, treatment, or compliance to patients. The self-care medical model is usually driven by symptoms and problems of the patient and the actions that must be undertaken to achieve therapeutic outcomes identified by the physician as consistent with current evidence-based medical knowledge. As Vickery (1986, p.23) explained, "medical self-care includes all those actions taken by an individual with respect to a medical problem". He considered medical problems to include major emergencies, care of chronic disease, and activities not necessarily related to current problems, such as screening tests. Kemper (1980) emphasized that self-care includes recognition of and action to deal with common problems, as well as knowing when to seek appropriate help. He furthers his definition to include "education as organized efforts to help generally healthy individuals develop skills, knowledge and motivation for preventing, recognizing, and managing common health problems which may affect themselves or their families" (p.64). Levin (1976) holds a broad view of self-care and he has detailed this perspective with Katz and Holst (1979) as:

a voluntary, self-limited, non-organized, universal, varying complex of behaviors... involving both continuous and episodic actions... and a decision-making process which involves self-observation, symptom perception and labeling, judgement of severity, and choice and assessment of treatment options. (p. 11).

Fry and Byrne (1976, p.27) describe self-care as activities that occur:

outside the established medical system... and encompassing four roles: (1) health promotion, (2) disease prevention, (3) self-diagnosis, self-medication, and self-treatment, and (4) participation in professional services. (p. 27) .

The usual emphasis of self-care from medicine's perspective is that patients are expected to change behaviors in order to carry out medical recommendations. The doctor's perspective takes precedence over the patient's perspective. Patients are expected to adapt or modify their behavior to deal with diseases or conditions, rather than modification of interventions by the doctor to accommodate the patient's circumstances. The individual remains the target for medical interventions. Medicine is usually not concerned with small or large group behavior and the clinical encounter very rarely includes assessment of environmental or social systems.

The discipline of nursing is concerned with the identification and assessment of self-care needs and abilities, planning nursing interventions to address those needs, evaluating the effectiveness of interventions, and understanding how patient needs determine nursing actions. Norris (1979) viewed self-care as a process that people and families initiate on their own to develop their potential for health. Other nurses saw self-care as directed by the patient and did not consider reliance on a professional assessment to determine needs and goals as authentic self-care (Kinlein, 1977).

Some authors expanded the nursing view of self-care to include a process that

develops a person's own health potential and permits making active choices about health care (Spradley, 1981; Hill & Smith, 1985). These authors promoted a perspective that self-care was more than participating in a routine set of activities that met daily needs, such as eating, dressing, or exercising. They proposed that self-care included the capacity to actively participate in decisions that affected one's health, not engaging in activities to meet needs determined by others and are completed without any health maintenance goal.

Orem (1991, 1995) is a nursing theorist who took the lead with defining self-care in a manner that differentiated it from "activities of daily living" which focused on environmental adaptation to improve physical and social functioning. She developed a theory of self-care between 1958 and 1965 which formed the basis of the Self-Care Deficit Theory of Nursing. The theory has informed nursing research, educational curricula and the organization of nursing departments within hospitals and community health settings across Canada. Orem created the conceptual framework or model to direct nurses in their thinking about the work of nursing and the relationship between nurses and patients. Orem (1991, 1995) defines self-care as:

activities that individuals personally initiate and perform on their own behalf in maintaining life, health, and well-being. Self-care is an adult's personal, continuous contribution to his/her own health and well-being (p.365).

The self-care deficit theory synthesizes knowledge about self-care and focuses on the limitations an individual might experience while performing self-care activities. The theory guides nurses towards three possible roles (Orem, 1991, 1995, cited in Health Canada, 1997):

1. to compensate for a person's inability to perform self-care by doing it for her or him.
2. to work together with the patient to meet his or her health needs.
3. to support and educate the patient who is learning to perform self-care in the face of illness or injury or medical procedure (p.13).

Orem's theory guides nurses towards task or intervention-oriented solutions as a means to address problems or manage "deficits". Nurses could also think about a person's strengths or assets as way of facilitating self-care. It also narrowly focuses on individuals and may not take into account the contextual factors, such as the setting of health care systems, which may significantly impact a person's experience of self-care.

Two research publications in the nursing literature specifically studied the self-care of persons with rheumatoid arthritis (Ailinger & Dear, 1993,1997). These authors used Orem's (1991, 1995) self-care deficit theory to guide their investigations and their findings were framed by Orem's "universal self-care requisites" (1995, p. 108). This nursing theory identifies three types of requisites for performing self-care: universal, developmental, and health deviation. These requisites are the "reasons for doing the action that constitute self-care" (1995, p.108). Universal self-care requisites include items associated with life processes, such as air, water, food, elimination, a balance between solitude and socialization, and several others which she claims are "common to all human beings at all stages of the life cycle" (Orem, 1995, p.109). Actions taken to meet these requisites become part of an individual's self-care system.

Ailinger and Dear (1993, 1997) studied the influence of RA on a person's ability to meet their universal self-care requisites. The authors used questionnaires and interviews to gather data from participants. A person's self-care agency was most

affected by difficulties associated with finding a balance between rest and activity, promotion of normalcy, and prevention of hazards. The last two issues are very broad and non-specific and may reflect limitations in the use of this theory to guide research intended to have direct application for clinical practice. The study concluded with the authors expressing a need for further research to explore and explain some aspects of the theory. They specifically refer to Orem's concept of the need to promote normalcy and call for further exploration of the apparent influence of the change from being normal and the impact of the awareness of "not being normal". These authors described the multidimensional nature of responses to rheumatoid arthritis and using Orem's theory to guide this research may have demonstrated its limitation for understanding the complexity of human experiences, including self-care. Ailinger and Dear include some interview quotes in their publications and these were richly detailed. They offered a view of the impact RA had made on participants' lives. By trying to fit participant responses into the self-care deficit theory, the overall tone and integrity of participants' responses was diluted. These publications noted the differences in age, gender, number of years of diagnosis, and education level of participants, but did not address any differences in ethnicity or cultural diversity.

Conceptual models or theories in nursing, as in other professions, provide an organized, systematic, and coherent view of complex human situations and events (Fitzpatrick & Whall, 1996). Each model or theory provides a unique perspective to observe and interpret phenomena, and then to formulate a response to the phenomena. Conceptual models may constrain a nurse's view of reality in a way that certain situations are perceived only in terms of the concepts and assertions made by

the model's author. Adopting Orem's theory as a means of understanding the self-care experiences of the chronically ill may limit the ability of nurses to recognize and respond to important phenomena that are not incorporated within the conceptual framework of the theory.

Psychologists are interested in self-care from the perspective of understanding human mental and emotional processes. Self-care, from the perspective of psychology, was typically examined from within the context of health belief, locus of control, values clarification, decision making and components of the "self" (e.g. self-control, self-management, self-confidence, self-efficacy, self-regulation, self-esteem, and self-concept).

Barofsky (1978) has written about self-care from the perspective of patient compliance and self-efficacy. Carl Rogers (1983) and Abraham Maslow (1970) proposed human beings innately care for the self. Maslow proposes an ordering of human needs that all people strive towards as they care for themselves. I recall learning about Maslow's "hierarchy of needs" in my nursing undergraduate program. The notion that one must have satisfied physiological needs before love or intimacy or respect of self does not represent my life experiences or explain those of patients I have known. The idea that human behavior can be explained by an ascending order of needs is far too simplistic, in my view, as a means of understanding human experience.

Bandura (1977, 1982, 1986) and Becker (1974) have studied the incongruity between human behavior and human knowledge, skill and motivation. They have written about health belief models and have contributed immensely to a growing body of literature on social learning, self-efficacy, and modeling. Self-efficacy theory, first

proposed by Bandura, is an outgrowth of social learning theory. Self-efficacy has been shown to be highly predictive of future health behaviors and the theory has been applied and studied in a range of health problems (Stretcher, McEvoy-DeVellis, Becker, & Rosenstock, 1986). Self-efficacy provides the theoretical underpinnings of the Arthritis Self-Management Program, a health education program, and is the basis for the detailed protocols to be followed by program instructors. The intent of the program is to change certain health behaviors by increasing the participants' confidence in trying out new skills (Lorig & Holman, 1993).

Health education can be considered a bridging discipline for those interested in individual human behavior (e.g. medicine, nursing, and psychology) and those interested in societies and organizations (e.g. sociology, anthropology, public health, and business) (Gantz, 1990). Health educators design and provide materials and programs to influence the ability of people to make healthy decisions and to behave accordingly. They are also interested in the improved health status of individuals as well as changing individual willingness to assume responsibility for being informed and acting responsibly. This perspective of health education is explained by Parcel, Bartlett, and Bruhn (1986) as being "any combination of learning experiences designed to facilitate voluntary adaptations of behavior conducive to health" (p.85). Green (1987) has written about self-care in a manner that reflects an approach to health education that stresses individual responsibility for health. More recent publications by Green and Kreuter (1991) describe a health education planning and evaluation model that utilizes a health promotion approach. The model acknowledges the multiple determinants of health and assists health educators in planning interventions that take into account the

social and environmental factors that influence health.

Sociology organizes its interests around the social, legal, political, and organizational supports and structures that enhance or impede self-care. The focus is not on individual actions. Two sociologists who have made large contributions to the literature on self-care are DeFrieze (1982, 1989) and Dean (1981, 1995). They advocate for an environment in which healthy behaviors can be chosen and maintained. DeFrieze (1982) argues for a view of self-care as:

a movement which seeks to build capacities of individuals to do for themselves what people have always done, even though in the last century some of these functions have been delegated to specialized occupations. (p. 29).

He broadens the scope of this definition to encompass initiatives undertaken on advice from health professionals, individual efforts through community actions, and management of acute or chronic illnesses through health promotion.

Public health is a discipline closely aligned with sociology by its mutual interest in the systems which support and guide actions that are taken on behalf of society and are beyond the scope of individual action. The emphasis is on delivering and evaluating programs and examples of this would be air pollution measures or immunization programs. Epp (1986) produced a document while he was Minister of Health for Canada. In this document he proposed self-care as one of three health promotion mechanisms to enable people to maximize their health potential. The other health promotion mechanisms are mutual aid and healthy environments. He writes that "factors such as beliefs, access to appropriate information, and being in surroundings that are manageable" (p.9) all play a role in self-care practices adopted by an

individual for the preservation of their health.

A review of the varied descriptions and explanations regarding self-care written by this assortment of disciplines has generated some commonalities within the various perspectives of self-care (Gantz, 1990):

- it is situation and culture specific;
- involves the capacity to act and make choices;
- is influenced by knowledge, skills, values, motivation, locus of control, and efficacy; and
- focuses on aspects of health care under individual control (as opposed to social policy or legislation) (p. 2).

Definitions of Self-Care

A mixture of descriptors and definitions of self-care, as well as related concepts, were found in the literature. No single definition prevailed or had widespread use in research studies. There were also notable differences in descriptions of the scope of self-care. The following discussion highlights the ideas and perspectives that were assembled within the literature that had a specific interest or emphasis on self-care.

Vickery and Iverson (1994) wrote about differences in medical self-care (actions concerning medical problems) and health self-care (actions aimed at improving or maintaining health). They viewed the individual as the central decision maker regarding both types of self-care because only the individual could attach a value to any of the risks or benefits associated with any of the actions being considered.

Self-care was conceptualized by Danaher and Williamson (1978) to be those activities which comprised health maintenance, and included disease prevention and care of self during illness. Levin, Katz, and Holst (1979) added to this view by broadening self-care activities to include the intentional behaviors of a lay person to

promote health or treat illness of oneself, family, friends, or community. These authors viewed self-care as being outside the framework of professional health care resources, but could be influenced by it. Other authors suggested that these behaviors could include the following specific self-care activities: consulting with other family members about symptoms; taking non-prescription medications, weight control, self-monitoring of chronic illness, participating in self-help groups such as Alcoholics Anonymous, and consumer political action on health issues (Fleming, 1984).

The perspective that self-care was interactive with the health care system and could not be viewed as behaviors independent of professional care was argued by Hickey, Dean, and Holstein (1986). Barofsky (1978) addressed the scope of self-care activities by dividing these into four types:

1. Regulatory self-care (for example, eating, sleeping, and bathing),
2. Preventative self-care (for example, exercising, dieting, and brushing one's teeth),
3. Reactive self-care (responding to symptoms of illness without a physician's intervention) and
4. Restorative self-care (which includes both behavior change and compliance with a professionally prescribed treatment regimen)(p. 373).

This typology included compliance as a self-care activity and some authors disagreed with the proposal of including compliance behavior as a type of self-care. Segall and Goldstein (1989) suggested that compliance behavior did not fit well conceptually as a form of self-care. Barofsky (1978) writes of the personal loss of control a patient will experience "as he [sic] participates in the health care process" (p. 372). He further explains that to address this loss of personal control over oneself in order to become a part of a system that is to restore health, in ways that are unfamiliar, health care providers have socialized patients to take responsibility for personal health.

He raises concerns about the lack of evidence to support such practices and has questions about how much of medically-initiated behaviors can be self-initiated and self-controlled. Barofsky argues that coercion or persuasion of patients to change behaviors, such as complying with a medication regime, can be considered self-care. It seems that Barofsky considers self-control to be a form of self-care.

Segall and Goldstein (1989) proposed that differentiating between primary and secondary self-care, as Dean (1986) had done, might address these conceptual concerns. Dean (1986) defined primary self-care as actions based on the individual's knowledge and secondary self-care as actions taken on information gained from consulting laypersons and professionals. The point of the primary and secondary designations appears to distinguish between two sources of knowledge. Dean also considered self-care to be activities that "includes decisions to do nothing, self-determined actions to promote health or treat illness, and decisions to seek advice in lay, professional, and alternative care networks, as well as evaluation of and decisions regarding action based on that advice" (p.62). The central element of Dean's perspective is that care is self-managed or within the control of the person.

The above discussion illustrates the diversity of opinions and perspectives found while searching the literature for definitions and descriptions of self-care. There was also overlap of terminology with self-help, self-management, self-support, self-control, and various other "selves" being interchanged with the term of self-care.

Self-Care and Rheumatoid Arthritis

A search of the literature addressing the specific area of self-care in rheumatoid arthritis produced a number of publications. These were primarily based on multiple research studies on the Arthritis Self-Management Program (Lorig & Holman, 1993). This program was developed at the Stanford Multipurpose Arthritis Centre starting in 1978 and has been widely disseminated in the United States, Canada, and Australia to thousands of people with arthritis. The program is taught by lay leaders who usually have arthritis themselves and have received training to teach the course. The program employs strategies aimed at improving self-efficacy for certain behaviors such as exercise, pain management, or communicating with physicians. The program has repeatedly demonstrated improvements in health status (i.e. decreased pain, disability, and depression) which is linked with enhancement of self-efficacy. The typical participant in these programs have been Caucasian women from middle to elderly-age, who have at least a grade 12 education and who have a diagnosis of rheumatoid arthritis, osteoarthritis, or fibromyalgia (Goeppinger & Lorig, 1997). It is unclear from this review why certain groups, such as those with a lesser education, of a different race, gender, or age did not attend these programs.

Edworthy (2000) reviewed the importance of self-management in arthritis care by looking specifically at the Arthritis Self-Management Program and Bone-Up on Arthritis Programs. The Bone-Up on Arthritis Program is American-based and is not offered in Canada. It is a home study program utilizing audio cassettes and print materials and is targeted at lower- literacy rural residents. Edworthy (2000) explains that these programs offer people with arthritis the opportunity to take control of decisions

related to their own health while developing meaningful relationships with their health care providers. He cautions though, that unless these programs can meet the standard of other "evidence-based" treatments familiar to those steeped in the tradition and science of medicine, then "harmful" side-effects may occur; such as patients becoming too self-determined and actually diagnosing their own medical conditions or adding alternative remedies to their medical management plan without consulting their health care providers.

These views reflect a rather paternalistic attitude common to traditional medical practitioners and have been a significant influence in the general public's dissatisfaction and general distrust of biomedicine and the health care system. While medical science has aligned itself so closely to the advances of technology, there remains no cure for rheumatoid arthritis and many other types of arthritis. In the meantime, faced with a life of chronic disease manifestations, people with arthritis have eagerly sought other sources of support.

A further examination of the literature related to self-care and RA uncovered a variety of publications based on organized health education programs to facilitate self-management of arthritis. The majority of these programs are designed, implemented, and evaluated by those with disciplinary roots in health education, psychology and psychotherapy (Daltroy & Liang, 1993). These programs have primarily been aimed at producing desirable changes in knowledge, behavior and health outcomes of people with arthritis. The most commonly reported programs are self-management education, cognitive-behavioral therapy, group exercise and education classes, telephone counseling, and mediated instruction (Boutaugh & Lorig, 1996). Studies have been

unevenly distributed over the many types of rheumatic and musculoskeletal diseases, however Lorig (1987) relates that 80% of those involved in reported studies have either rheumatoid arthritis or osteoarthritis.

The Experience of Rheumatoid Arthritis

There are few research publications offering insights into the experience of rheumatoid arthritis from the perspective of the person with the illness. Three qualitative research studies were found which presented this perspective (Brown & Williams, 1995; Ryan, 1996; Shaul, 1995).

Brown and Williams (1995) interviewed seven women with RA in order to explore their experience of RA and what it meant to live with it. Three inter-related themes emerged from the analysis of their interviews. These were seeking help, searching for meaning, and uncertainty about symptoms. The third theme, uncertainty of symptoms, was given greater emphasis in the report of findings as the experience of symptoms overshadowed many aspects of the women's lives, such as their family relationships, social interactions with friends, or physical capabilities.

The notion of self-care is not specifically referred to in this publication. Brown and Williams (1995) explicitly state their goal of making patient perspectives a visibly important contribution to clinical research and practice. It is their contention that people who experience illness can then make an active contribution to how their problems are conceived and resolved. The authors do not give any personal information on the background of these women.

A phenomenological exploration with seven people with RA was conducted by

Ryan (1996). No personal details regarding gender, ethnicity, socioeconomic, or cultural background of study participants was provided in this article. Five themes regarding self-esteem, relationship with the family, coping with frustration, the future, and the doctor-patient relationship were discussed in detail. Ryan (1996) makes several recommendations for nursing practice as she discusses each of these themes. A key finding was none of the participants felt they had control over events related to their rheumatoid arthritis. The thrust of her main recommendations were towards empowering individuals to participate and make choices in their illness management. The omission of details from this publication regarding the age, number of years living with RA, and the social context of where this study took place were drawbacks to fully understanding these patient's experiences.

Personal experiences of thirty women with RA were examined by Shaul (1995). The women in this study were between the ages of 30 and 75 years. Marital status, ethnic background and socioeconomic circumstances were all presented and discussed. The author was interested in the stories of women who have learned to live with the disease of RA , and how they managed the illness and the demands of their everyday lives.

The women described their experiences of living with RA as a transition process having three stages. Stage one was "becoming aware" (p.292), stage two was "learning to live with it" (p.293), and stage three was "mastery" (p.295). Each stage had it's own particular phases and these were discussed in detail. Shaul (1995) concluded that in order to achieve the level of mastery that allowed these women to live with RA and manage their roles and responsibilities, these women gained a sense of empowerment

over their situations and had developed a repertoire of strategies that they drew on to “cope with changes in the process and context of the illness” (p.296).

The approach by Shaul (1995) to explore the experience of RA over time gave a unique understanding of what physical, environmental, and social factors influenced their illness experience at different stages in their lives. It also provided insight into how the progressive, unpredictable nature of the illness affected the quality of their day to day lives.

These qualitative studies offered detailed findings of the experience of living with RA. They also gave some insight into self-care experiences, although the notion of self-care was not clearly quoted, nor was it explicitly explored by the researchers. Self-care was an implied experience which was a part of the day to day experience of living with RA.

Personal Accounts of Self-Care

Literature written by those living with RA about their personal experience is rare. One of the exceptions is Wanda James (2000), who wrote a detailed account of her life with RA. She was 41 years old when she wrote the book and has had RA for six years. She related “it has changed my life completely and irrevocably” (p. 5).

Her story focused mainly on her personal experiences with RA and not on self-care experiences. However, at the end of her book she had a section entitled “Survival Tips” (p. 139). These tips were what I would consider some strategies for self-care and encompass the physical, emotional, and social situations that present common day to day difficulties for those with RA. These strategies included very practical physical actions such as running warm water over stiff and sore fingers to loosen them up first

thing in the morning. She gave advice on how to take baths with the least amount of physical strain and how to dry off with large towels following a bath. She made several suggestions for using adaptive devices such as long handled reachers, built-up handles on eating utensils, button hooks, as well as how to organize a kitchen to minimize strain on inflamed joints during meal preparation. Wanda's advice also included instructions on pacing activities by dividing up tasks into smaller, manageable chunks.

She suggested not making firm commitments to plans that may not be manageable, thus avoiding the anxiety and stress related to canceling plans and disappointing friends, family or co-workers. She advocates for monitoring of symptoms, medication responses and side-effects, and communicating this to your doctor. She offered several tips for sleep involving the type of mattress, pillows, and bedding to use, as well as keeping the room dark and warm with all medications, food, and water close at hand. She suggested joining a support group, utilizing relaxation techniques as a way to manage pain and stress, learning more about the illness of RA, exercising, keeping socially active to avoid isolation, and asking for help when you need it. She also recommended talking to a professional or friend about feelings related to what it is like being ill.

Another publication was conceived and written by Cheryl Koehn, a woman with RA, and co-authored by a rheumatologist and a health and science writer (Koehn, Palmer, & Esdaile, 2002). It offered information assembled from "the scientific knowledge gained from thousands of research studies around the world" (p.3). The findings of these studies have been distilled into a "blueprint" called the "plan to win". The book's key message is taking control and minimizing or beating the potentially

devastating effects of RA in one's life. It contained easy to read information and offered practical advice on the disease of rheumatoid arthritis, the role of various health care professionals, medications, exercise, diet, nutrition and complimentary medicine. It also included information on the mind-body connection, relationships and sexuality, work, family, and leisure, surgery, pregnancy, childbirth and menopause. It also offered several further resources such as websites and news groups, where to buy specialized products, books, and journals, as well as "reliable" information on treatment therapies, RA research and clinical trials.

Sounding like a mini-medical textbook, Koehn et al. (2002) was clearly written through the lens of the scientific, biomedical perspective and offered very little insight into Cheryl's personal experiences, except the prologue which is one page and a half. It has, however, something to offer those with RA who seek very practical and concrete advice for the performance of daily physical tasks, such as gardening, shopping, traveling, cooking, and caring for children. It also makes some scientific research findings accessible for those that desire this information. Self-care was referred to as physical care and most specifically as those tasks related to personal hygiene and dressing.

Summary

A review of the relevant literature provided little understanding of the meaning of self-care from the perspective of those living with rheumatoid arthritis. The qualitative studies which explored the chronic illness experience in depth contributed some insight into what self-care might mean to those living with rheumatoid arthritis (Brown & Williams, 1995; Corbin & Strauss, 1988; Ryan, 1996; Shaul, 1995; Strauss et al., 1984,

Thorne, 1993).

The dominant world view of self-care has been described and determined by professionals from all disciplines, scholarly traditions, and academic interests. Writings and publications on the meaning of self-care by these various groups has resulted in a significant body of literature with no common language or way of linking terminology. The interest of professionals in self-care has been generally motivated by what it means to their particular area of practice, research, or policy development. In the area of health care, it continues to be health care professionals who have decided what the meaning and significance of self-care is for those living with rheumatoid arthritis. This is a surprising contradiction in view of repeated calls, in the literature, for the self-reported perspectives of those living with chronic illness to be included and respected by those involved in their health care.

To understand the self-care experiences of women with RA, more research is required which invites them to talk about their day to day lives. The relevance of self-care to women with RA and how self-care is understood could be explored in conversations which specifically talk about their personal experiences. Women with RA could actively contribute to shaping how health professionals understand self-care in the context of chronic illness.

CHAPTER III: RESEARCH DESIGN

A qualitative research design guided this study throughout all procedures. The rationale for all decisions made regarding the conduct of this research are detailed below. This chapter describes the procedures of sampling, recruitment, consent, data collection, confidentiality, reciprocity, and data analysis. Measures to assure the trustworthiness of this study are specified. The limitations and delimitations of the study findings are also presented.

Qualitative research is described by Creswell (1998) as:

an inquiry process of understanding based on distinct methodologies within traditions of inquiry that explores a social or human problem. The researcher build a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. (p. 15)

There are two main reasons for my choice of a qualitative approach to study the experience of self-care in women with RA. First, a review of the research literature indicated that more studies are needed from the perspective of persons living with RA. Second, as someone who does not have RA, I chose a qualitative design that would invite those with RA to tell their stories so that I could personally better understand what self-care really meant from their perspective.

In order to fully explore and describe the self-care experiences of a person with rheumatoid arthritis, I took myself, the researcher, on a journey of discovery. A descriptive-exploratory design was utilized to understand meaning from the participant's perspective (Brink & Wood, 1998). In qualitative inquiry, the researcher is the primary instrument of data collection and analysis. The data collected were mainly in the words of people living with RA and I sought to explore, understand, and express the meaning

of these words through the writing of a narrative understanding. My interpretation of these words were my reconstructions of the self-care experiences of these women. In keeping with the inductive process of qualitative research I built an understanding and determined some shared elements within the multiple stories of the self-care experiences of the study participants.

My choice of qualitative research methodology to guide this study was also reflective of the constructivist aim of developing a "consensus construction" by employing methods of "hermeneutics and dialectics" by continuously going back and forth between the data and study informants (Guba & Lincoln, 1994, p.111). By using methods of constant comparison, there was eventually the generation of a few constructions of which there was some consensus.

Sampling Procedures

Study informants were selected by a purposive sampling procedure, and more specifically by employing the use of homogenous sampling. Patton (1990) describes this procedure as one where the purpose is to describe some particular subgroup in depth. People with similar backgrounds and experiences were selected for the in-depth information they could provide.

I decided to speak to women aged 35 - 45 years. RA is twice as prevalent in women as men and it usually occurs between the ages of 25 and 50. Narrowing the age gap and recruiting only women accommodated a more homogenous sample. Another criterion was a diagnosis of RA for 2 to 5 years. The first year or two after diagnosis are usually very stressful. The typical issues and concerns I have heard from recently diagnosed people with RA are different from those who have lived with RA for

a few years. Time to experience the illness of RA often gives people the ability to reflect on and talk about the many aspects of the illness experience rather than their immediate distress over a new illness experience.

I recruited women who had graduated from high school to further reinforce the homogeneity of the sample. Choosing women who had thought about self-care and were willing to talk to someone about this idea provided the opportunity to interview a person who had thought about the idea and was interested in talking about the notion of self-care. English speaking women were sought because the researcher spoke and understood only English and I was interested in hearing richly detailed stories that could be easily talked about in a conversational manner.

For this study, the sample consisted of seven women informants who had RA and were attending the Mary Pack Arthritis Centre (a program of Vancouver Hospital & Health Sciences Centre) for treatment or education services. Given the purpose of the study, the choice of a sample size of seven informants was based on a number that was large enough to provide reasonable in-depth coverage of participants' perspectives of their self-care experiences with RA. The sample size was also small enough to provide in-depth information and rich detail to make the study findings useful, and to allow for realistic functioning within the researcher's available time and resources. Twelve people volunteered to participate in the study and seven women met the selection criteria.

Recruitment Process

The sample of seven women were chosen from volunteers who responded to a recruitment flyer that had been posted in a waiting room or handed out by staff of the Mary Pack Arthritis Program (a program of the Vancouver Hospital and Health Sciences Centre). I sought and received written permission to recruit the study sample from this site. Permission was granted by the Mary Pack Arthritis Program Research Committee (Appendix E). The program is located in a free standing building called the Mary Pack Arthritis Centre and also houses The Arthritis Society, and The Arthritis Research Centre of Canada. A recruitment flyer (Appendix B) was posted and handed out on the second floor of the building where treatment services were provided. A total of twelve people contacted me who were interested in participating in the study. Five people did not meet the recruitment criteria. Others contacted me, even though they knew they did not meet the recruitment criteria, because they were interested in what I was studying and wanted to know if they could participate in another way. One of these women was able to review the interview guide for the study and to give me her opinions and ideas about the suitability of the questions.

Recruitment of the women for this study included one participant who identified herself as Japanese, having been born in Japan and emigrated to Canada six years ago. Another woman stated she was born in India and moved with her parents to Tanzania, Africa when she was a young child. She identified her ethnicity as being South Asian. One woman identified herself as Chinese-Canadian. All other recruited women identified themselves as Caucasian.

The Mary Pack Arthritis Program was also my employer and I held a full time

nursing position in this program. I chose not to actively recruit any participants myself and I also did not want to select any volunteers who were receiving nursing care from me at the time of the study. I did not want to interfere with any nurse/client relationships that had been established by recruiting clients who would then be informants about their experiences in a health care system that also included me. The information I was seeking could possibly be influenced by their relationship with me as a health care provider. I also did not want to ask clients to participate who may have felt their health care could be jeopardized if they did not participate.

Consent

Each interested participant contacted me by telephone after they had seen the posted recruitment flyer or had been handed a flyer by staff at the Mary Pack Arthritis Centre. All selected informants were sent a letter of introduction outlining the purpose of the study and the expectations of participants (Appendix C). My phone number was included, as well as the phone number of my research supervisor, if any of the participants had any questions or chose not to participate in the study.

Each participant was contacted by telephone to review the content of the letter of introduction and to set up our first interview. Each participant read and signed a consent form giving me permission to conduct the interviews (Appendix D). At the beginning of the first interview, verbal permission was obtained to audiotape the interview.

Data Collection

Data were collected from selected participants by the use of personal focused interviews. In-depth interviewing was chosen as the means to explore a few general topics to uncover each participant's views and to value her preferences for framing and structuring her responses. The meaning attached to personal experiences are subject to a person's interpretation and perception of events (Schwandt, 1994). The interviews allowed participants to verbally convey their perspectives through their own language. This captured the participants' perspectives of their experiences as they viewed them and not as the researcher viewed them, an assumption fundamental to qualitative research (Marshall & Rossman, 1999).

Two interviews were conducted with each participant. The first interviews were conducted between December, 2000 and February, 2001. The second interviews were conducted between April, 2001 and August 2001.

The site of each interview was based on the preference of the participants. For the first interview, five were conducted in an office at the Mary Pack Arthritis Centre and two were at the homes of the women. The second interviews were conducted in an office at the Mary Pack Arthritis Centre, and one participant wanted to be interviewed by phone from home due to health related concerns.

To prepare for the first interview an interview guide with questions was provided to each participant prior to the interview (Appendix A). The guide was intended to familiarize the women with the content of some questions and allow them time to reflect on their personal experiences. The guide was also intended to provide some reassurance to the participants that they weren't being tested or evaluated in any way.

The guide was developed by myself, with the assistance of my research committee. I also sought the advice of other health care providers who work with clients with RA. In addition, I reviewed the guide and the questions with a person with RA, who did not meet the selection criteria for the study. She gave me valuable feedback on the appropriateness of the questions regarding sequencing, content, and overall understandability.

The first interview with each participant was audio-taped. Each audio taped interview lasted sixty to ninety minutes. After the tape recorder was shut off, all participants had further questions for me or had more to say regarding their experiences. These audio taped interviews and non-taped discussions were transcribed and provided to all the participants. I also wrote personal notes following each interview. These notes were my reflections on what I had observed during each interview and any ideas I had for further exploration or questions. It became clear as I reviewed my notes that each participant had provided rich, additional data beyond the audio taping. I suspected the tape recorder made some of the women uncomfortable or viewed it as a barrier to saying what was really on their mind. This suspicion was confirmed when I prepared for the second interview. Each participant declined the audio taping of the interview when they were presented with the choice of recording the conversation.

The second interviews were not audiotape recorded for the reasons outlined above and lasted from forty to sixty minutes each. The purpose of these second interviews was to clarify certain portions of data and to relate my interpretations of the data. During these interviews I took note of the women's responses to my

interpretations. We reviewed the transcripts of the first interviews together and I made notes on their clarifications and any additional reflections. We discussed our common understanding of my interpretation. I wrote brief notes during each second interview. Following these interviews I also wrote more notes on my personal reflections.

In addition to the two interviews with each participant I would occasionally have chance meetings with the women as they were attending the Mary Pack Arthritis Centre for doctor's visits, blood testing, or therapy appointments. We'd bump into each other in the waiting rooms or in the washroom, for example. We would have casual conversations about how the study was going and I would often share some of the emerging findings from my data analysis. The women would give me their feedback on whether they agreed and spoke more on their views regarding a particular topic or experience. These chance meetings provided additional data, as I would make notes of all these encounters. I advised all the women I met in this fashion that I would be writing down some of the information from our conversations.

Data collection ended when the second round of interviews were finished. It was evident that data were becoming saturated. No new information was being discovered and certain themes were being repeated.

Confidentiality

To ensure confidentiality for the participants, the women have not been identified. During data collection, participants were assigned a code number to identify tapes, computer software discs, and printed transcripts. Each participant was assigned a pseudonym for the purposes of the narrative and discussion of findings. The pseudonyms were alphabetized, starting with A, and reflect the order in which the

interviews were conducted.

All tapes, discs, printed transcripts, and written notes were stored in a locked file when not in use by the researcher. Data stored on a computer hard drive were password protected. Tapes, discs, printed transcripts, and notes will be kept in a locked cabinet for five years and will be destroyed after five years.

Reciprocity

All the women in this study were motivated to participate by their desire to help other people with RA and if they could, to spare them some of the negative experiences they had been through. They were explicit in their desire to have their voices heard by those possessors of power and knowledge in the world of biomedicine. One woman wanted to make sure my "report" would be available to all rheumatologists. All wanted their stories to be heard by those working in the health care system because they felt the patient's point of view was often disregarded or dismissed as an important element in clinical interactions.

The women in this study gave me their time, a genuine interest in my continued progress with the study, and their insightful and moving stories. I have offered to give them a copy of my completed thesis for their personal use. I will be contributing a copy of my thesis to the Mary Pack Arthritis Centre's medical library where doctors, allied health professionals, and students have access to texts, journals, and related materials. I will be presenting my research findings publicly to the staff and any interested patients of the Mary Pack Arthritis Centre. The women who participated in this study will be personally invited to attend. I will submit and present this research at conferences to disseminate the stories told to me by the women.

These women all benefited from an opportunity to air their views on the very personal subject of their experiences with health care and self-care. They all carried our conversations well beyond the boundaries of the formal semi-structured interviews and I had planned for the extra time. Some of the women had previous opportunities with counselors to speak of their distressing experiences or to work through problems. Some of the women had never spoken to anyone within the health care system of their experiences and therefore gained the additional benefit of developing some insight into unresolved issues by verbalizing with someone who just listened and occasionally reflected or reframed. All the women were invited to contact me at any time regarding questions they may have, providing assistance in access to resources, or if they wanted to set up appointments with me to spend time discussing or resolving more personal problems. All were invited to drop by my office anytime they were in the area and my door was open to just say "hi" or to update me on their busy lives.

One woman contacted me to assist her in obtaining information related to diet and arthritis. I did a literature search and produced a package of material for her. Another woman was interested in websites related to women's health and I compiled a list of these for her. One woman inquired about easy access to a particular rheumatologist and I facilitated that contact for her. I have seen and heard from all these women over the past few months as I have been writing this thesis.

Data analysis

Data collection and analysis occurred concurrently. The transcripts were typed by me within days of each interview. Data were transcribed by leaving a margin on the

left third of the page to write notes. Data organization followed the steps as suggested by Tesch (1990). As each typed transcript was completed, I reflected on a sense of the whole and noted ideas that came out.

Transcript content was repetitively reviewed for units of meaning or topics. A list of all topics was created on a large poster board and these were compared. Similar topics were connected with highlighted pen. Different topic clusters had different color lines. All the different topic clusters were then assigned a name that most creatively captured the substance of these major or unique topics. These topic descriptions were then used to review existing and any new transcripts as the interviewing and transcribing proceeded. I kept notes about any new ideas or reflections on data findings. Concepts eventually emerged from the continuous review of data. Concepts were then analyzed for themes or patterns. At the same time, commonalities, differences, anything unique and any gaps were noted. As themes emerged from the data, these were be taken back to the participants in the second interview in order to validate, clarify, and expand findings. Themes and patterns were analyzed and conclusions were drawn from this process.

Trustworthiness

Lincoln and Guba (1985) propose four constructs by which establish the “truth value” (p. 290) or trustworthiness of a qualitative study. These are credibility, transferability, dependability, and confirmability.

Credibility ensures the subject of inquiry or the phenomenon of interest has been accurately identified and described (Marshall & Rossman, 1999). I continually took data and tentative interpretations of data back to the participants in this study.

This occurred formally in the second interviews to clarify, expand, and confirm my interpretations of the initial interview. Typed transcripts of the first interview were given to the women and discussed with them at the second interview. Informal chance meetings occurred with all of the participants, at least once, and at these meetings we discussed and clarified emerging findings and confirmed the accuracy of my interpretations of the data. During initial data analysis, the topics or categories were generated from the data itself and not from a predetermined list of categories. In the narrative description of the personal experiences and the context of this research study, quotes from the women have been used to provide richly detailed information in their own voices.

Transferability refers to the demonstration that study findings will be useful to others in similar situations with similar research questions or questions of practice (Lincoln & Guba, 1985). The responsibility of generalizing one set of study findings to another setting rests with the researcher interested in the transfer rather than with the original researcher. To assist the reader or user of these research findings in comparing with their own situations I have provided a richly detailed description of the study's context using multiple quotes from the women's accounts of their experiences.

Dependability refers to the researcher's accounting for changing conditions in the phenomenon of interest and in the design related to development of insights into the setting (Marshall & Rossman, 1999). The qualitative, interpretivist assumption is that the social world is constantly changing and is not constant. In this study, this was apparent as the entire study took place over a period of nine months. Several events occurred within the lives of the women that reflected their day to day social realities.

These women were living with a chronic illness that changed and manifested itself in various ways on a daily basis; this was reflected in their stories. One woman became pregnant during the course of the study, another was planning a pregnancy with her partner. Two women became unemployed during the study. One woman married her partner. Notes were kept by the researcher which documented the course of decision making throughout the study. Notes were made on the original transcripts of the first interviews. Notes were made during the entire data analysis process, including the topic and category generation process. Reflective personal notes regarding my thoughts on the research process were kept and stored. Further notes were recorded during the second interviews and in the analysis of those conversations. All recorded data has been organized and stored in a manner that is easily retrievable.

Confirmability asks whether the findings of the study could be confirmed by another researcher (Guba & Lincoln, cited in Marshall & Rossman, 1999). Qualitative researchers demonstrate that the data help confirm the findings of the study and lead to the implications. Attempts to decrease bias in my interpretation were done by constantly bringing tentative study findings to the attention of colleagues in my work setting. These were health care providers who were familiar with qualitative research and had worked with women with RA. I would relate stories as told by the women and discuss my interpretations. The quotes used in the narrative represent much of the data in the interviews and have been used to maintain the context and perspectives of the participants.

Limitations and Delimitations of the Study

As a qualitative researcher, I am interested in the richly detailed information provided by the women in this study to understand their self-care experiences. I am also interested in the meanings these women have constructed to make sense of their self-care experiences. Some of these understandings may be transferable to other women with RA who have lived with the disease for 2 to 5 years.

These women all lived in a large city and had access to several health care providers and facilities. The experiences of rural women may be different.

All the women in the study had a high school education and all, with the exception of one woman, received a post-secondary education. Most had fairly stable economic circumstances, although this varied with their family composition and their ability to work. Perhaps women who have not graduated from high school or have less financial resources would have different experiences.

Four of the women in the study identified themselves as Caucasian. One stated she was Japanese. Another said she was born in India and lived from childhood until she was an adult in Tanzania, Africa. One woman said she was Chinese-Canadian, offering the information that she was born in Canada to parents who emigrated from China. The dominant perspectives in this study's findings are of Caucasian women.

To maintain some commonalities in the study findings, women between the ages of 35 and 45 years were selected for the study sample. It did not include men and the findings of the study may not be transferable to them. The perspectives of women aged younger or older may not be similar to those of the women in this study.

The women for this study were recruited from a busy health care centre where

the focus is medical treatment and most available services provide ideological and technical support for that view. The women were all engaged, to some degree, in supporting some aspect of medical management of their RA. Recruitment from this site may have predetermined a sample of women who valued and believed that traditional medical practices were a significant component of their health care and self-care experiences. Women recruited from sites other than those associated with traditional medical practices may have offered alternative perspectives.

The second interviews were not audiotape recorded and this may have limited my ability to capture the rich and detailed conversations that took place. I attempted to record most of what was said and then wrote down my impressions following each conversation. Some meaningful data may have been missed and therefore not included in the analysis and findings of the study.

Summary

This chapter has provided the rationale for my choice of a qualitative research design to study the self-care experiences of women with RA. Specific procedural steps regarding each aspect of the research process have been outlined. The following chapter details the analysis of the findings from the conversations with the women who participated in this study.

IV. THE MEANING OF SELF-CARE

The focus of this study was the understandings and meanings of the self-care experiences of seven women with RA. The findings of this study are presented in the form of a narrative, with the voices of the women woven throughout the account. Their voices are heard by using direct quotes from the interviews. These quotes assist the reader to develop an awareness and a first hand understanding of these personal experiences. Quotes were chosen for their representative character for illustrating or describing the particular phenomenon under discussion. Some quotes are representative of all the women's experiences.

All of the women in this study had unique stories of life with RA and of their self-care experiences as they grappled and dealt with the issues they faced every day. The following discussion begins with a brief introduction of each woman's demographic information, history of living with RA, and their personal understanding of self-care.

The introductions are followed by a discussion of the five major themes that emerged from the interview data during the analysis phase of the study. These themes were analyzed from the first and second interviews with each woman.

Introductions

Ann

Ann was 44 years old at the time of our first interview and had been diagnosed with RA for about 4 years. She had tried several different medications and had been through many surgical procedures, but her struggle with RA continued. She suffered daily pain, fatigue, and impaired physical functioning. Ann had suffered damage to her

wrists, hands, feet, hips, knees and shoulders and had difficulty walking at times. Her daughter at one time asked "Mom, why are you walking like Grandma?" , as she limped with severe hip pain from the car to the front door of her home. She frequently woke at night with shoulder pain and had many sleepless nights "in agony". She was married with two school aged children. She had enjoyed an active life with her family and worked full-time as a nurse. She left work two years ago because she could not keep up with the physical demands.

That was a really difficult decision - not to go to work - I thoroughly enjoyed what I did. So that was very, very...I guess like being robbed of something. You feel like being robbed of something that you enjoy. So I just felt that I had lost that and lost the control of being able to go back and not being able to make that decision because things just gradually got worse.

She sought out health care providers who would let her make decisions about her health care plan. Her life took on a round of ongoing medical appointments, trips to the pharmacy, and sessions with the physiotherapist or occupational therapist. She eventually built a team of health care providers who she trusted and she could rely on to give her the information and support she needed to make decisions. Ann believed that managing RA was not just controlling the disease, but looking at all aspects of the person with the disease.

I don't think the doctors see you as a whole person. They feel very focused on just the disease, on the physical part of what's wrong with you. They don't look at your emotional side or your mental side. They're just very focused on this one joint that's having pain and it's symptomatic treatment. They're not looking at the total picture of how you're feeling, how you're sleeping, is there any stress in your life, what all is causing your problem.

Ann fought to keep medical decisions within her control. She maintained a spirit

of confidence in herself as the person to decide what was in her best interests. She also relied on a network of supportive people, some health professionals and other people with RA, to assist her with RA management decisions. Her experience of self-care was a series of events learned through trial and error.

I think it's getting better as long as I space myself out. But those are the things I've had to learn because it wasn't something that came natural - to space out your chores.

Self-care, in Ann's view, was primarily the physical or functional tasks she had to attend to for day to day care, such as personal hygiene, exercise, or sleep management. She viewed being "*well rested, to use the bathroom... and keep up with the cooking and cleaning*" as a component of maintaining emotional or mental health. Embedded in this perspective were control issues and maintenance of independence because "*if you did it before and you can't do it now then you've lost something and that affects you mentally*".

Bonita

Bonita was a 38 year old married woman who had lived with RA for 3 years. She was employed in a management position that required a lot of traveling. She and her husband, Steven, lived in their own home, with an extended family who lived close by. Bonita described her RA as well controlled and "*I'm not back to normal, but I'm as close as I can be.*" She had been unable to work for the first nine months after diagnosis and was hospitalized for 6 weeks during that time. Her hospital experience was positive.

Everyone is very caring and helpful. They just care about what they're doing and it feels like they actually care about you as an individual, not just as a patient or a number.

Her ideas about self-care are related to the day to day basic activities that were required for normal functioning, such as showering in the morning or doing laundry. She strongly believed that self-care is not necessarily something that can be accomplished by oneself when living with RA.

I don't know if it has a different meaning for someone who is single as opposed to someone who is married or with family too... I would hear people with arthritis, in these different courses or groups, say they are single and I would just think - how do they manage?

During a one year period of time, she was unable to attend to her most basic personal needs, like toileting, brushing her hair, or bathing, due to pain and stiffness. At this time *"I could not do anything at all...I had so much pain and I was so stiff, all I could do was lie down"*.

Bonita talked about information seeking as being an important part of self-care. Finding information on your own *"in any of the arthritis publications or the Internet"* about aspects of RA management was her responsibility before looking to health professionals for material or direction to resources. Bonita maintained that despite her frequent use of the health care system *"I don't totally rely on them."*

Cathy

Cathy was a 35 year old woman with RA for the past three years. She was married to Tom and they lived in their own home with extended family living close by. Cathy's mother had been particularly supportive and had helped Cathy over many months of living with pain, no energy, and the emotional difficulty of giving up a

satisfying career and moving homes, all due to RA. Tom used to "*basically do this leverage thing to get me out of bed in the morning*" where he would pry her arms around his shoulders and pull her upright as "*we would do a 1-2-3 count*". They had learned to do this because Cathy "*felt absolutely horrible from terrible pain in the morning*". Cathy was a health professional working in a large urban hospital with an extremely busy and heavy job that challenged her in many ways. She had to give it up.

I finally couldn't take it anymore, the pain , the swelling, and just the overall fatigue... It was so difficult. It was taking me about two hours to get ready in the morning... I think I knew my body was just about ready to stage a coup if I didn't stop and rest.

She described her entry into the health care system as a patient with RA as "*an ongoing battle of one*". She felt her doctors saw her only as a disease and saw illness as "*black and white*". While her doctors were telling her she was getting better, Cathy felt she was getting worse. She decided to develop her own health care plan and launched herself into a program of self-care.

This wretched illness was probably going to be with me long term. I was going to have to deal with it. There wasn't going to be any miracle cure. I tried everything under the sun. I did your reflexology, your acupuncture, your accupressure, your Chinese herbs, your whatever of unpronounceable names of unpronounceable things to try.

To Cathy, self-care meant taking responsibility for her own care, rather than being a "*passive participant*". It meant asking questions about medications or treatments before accepting them. Seeking information was her responsibility rather than relying on her doctor to provide it. She saw herself being an active participant in her own care with a team of health care providers all providing a "*whole sort of care*".

She described this as consulting with her, as she would consult them, so she could manage her situation and her illness better.

Dagmar

Dagmar was a 45 year woman who has lived with RA for about 2½ years. In addition to RA, she has suffered from other chronic illnesses for many years. Dagmar was living on her own. When she first became ill with RA, she was hospitalized. Because of her pre-existing illnesses, health care staff focused on these other problems and the severe pain she was suffering from RA was ignored. On discharge from hospital, she became very socially isolated and was physically immobile. Her *"legs swelled up to here [points to mid-thigh] and I was in just unbelievable pain"*. She further described details of this experience: *"Just the gravity, taking my knee out of bed was too much, I couldn't manage the pain anymore"*.

It was a dreadful experience for Dagmar, but she survived. From that point on she decided to take her health care concerns into her own hands. She has devised a way of managing that suits her personal goals.

I do a lot for me. To me the physical and the mental are one. I'm willing and I'm going to deal with this without medicating because I can't go there. And I think I can do it now, I'm much stronger than I was mentally... I meditate, I do yoga, I go to the gym... I eat healthy.

Dagmar believes self-care is *"taking care of my health, my physical, mental, spiritual health"*. She has experienced RA as a *"life changing thing"* and part of self-care, for her, is seeking supportive health care providers to coach her and assist her in developing abilities in managing that does not include medications. She found a

specialist to support her approach while monitoring her disease. She had been referred to this specialist by another specialist for the primary purpose of medication management. Dagmar was able to negotiate a partnership based on her terms with this new specialist. She has become more creative in her strategies for self-care and has pushed forth into practicing mindfulness and self-awareness. She practices visualization as a means of relaxation and pain management and attends Buddhist retreats to strengthen her skills at mindfulness meditation.

Ellen

Ellen was a 41 year old single women who lived in an apartment close to her place of work. She was employed as a health care worker in a hospital. She has had RA for 5 years and was off work for three months when her RA was diagnosed. She felt that despite "*complaining bitterly*" about her wrist pain it was not addressed adequately. She made a lot of adjustments to her work hours and some of her duties when she returned to work. Viewing these "*concessions*" as part of self-care, Ellen describes these negotiations as knowing what her limits were, pointing out to her employer what would make her ill, and being aware of her body in the workplace. Despite all these adjustments, she continues to have "*days when my feet hurt and I have to be careful not to make my wrists bent from pain*". Ellen monitors her physical symptoms and describes RA as "*limiting on your lifestyle*".

The meaning of self-care, for Ellen, has been all about learning.

I think its taking the interest and the control over what's happening with you. I think knowing your medications and knowing how to take care of yourself is self-care. Knowing how to take care of yourself is learning, its a learned experience.

Ellen described many scenarios where she had to ask questions before she could make informed decisions. She spoke of the supportive relationship she has with her specialist, who presents her with “options” rather than prescribing solutions when problems arise. Ellen strongly believed that personal involvement in medical decision making is essential for her self-care of RA.

You just can't leave it all up to your doctor. To me, its really important especially when it comes to your arthritis, because to me it's a lifestyle, it's a lifestyle change that you have to undergo... If people don't get involved in it and get educated towards what they can and can't do and how they need to treat themselves and such and how they need to work with doctors, and physiotherapists, and occupational therapist, and the nursing staff... then they're not doing themselves any favours.

Fran

Fran has lived with RA for 5 years. She was 42 years old at the time of our first interview and living with her partner, with whom she was engaged to be married. None of her family lived in Canada. She was employed full time as an accountant in the business community. She had a lot of difficulty getting a diagnosis of RA and once she was diagnosed, she struggled to get answers to her questions. Most doctors did not want to spend the time to answer her queries regarding medications or to explain what was happening to her body. She finally found a doctor, a general practitioner (GP), who answered her questions satisfactorily and she felt she could trust. Prior to seeking out a more permanent relationship with this GP, Fran had sought help for medical problems from a walk-in clinic at her workplace where she encountered a different doctor each time she had a new problem. Developing trusting relationships with health care providers was very important to Fran.

The nurse knows a lot of patients, so that's why I was so relaxed when I talked to her. She saw a lot of real life, she's very close with patients. So just some tiny, tiny advice from her was very, very helpful for me... I told her I want to reduce my visits here for the treatment. She says "Some patients just skip. If you are very uncomfortable you can skip." She makes me feel easier.

She described her experience with RA as a "very, very terrible time" due to "serious pain". For a couple of years Fran struggled emotionally as she "could not do very tiny things. I could not reach to shower. I could not open the lid." She remains angry that this painful ordeal was not considered serious by her doctor .

For Fran, self-care meant following a good diet and developing an exercise program to keep her body mobile as "these two things are important for anybody". She also strongly believed in the role of preventative medicine in terms of health care providers providing information early in the disease process. She was worried about "bone damage, later on... knowing all the details of these things" and felt early information from her doctor was vital in order to adopt self-care practices that prevented future health problems.

Gloria

Gloria was a 36 year old single women, with RA for 4 years, who lived by herself. Her parents lived close by. She was a tutor in a private school and came to this career because she had to give up her previous job in the hospitality industry due to RA. She described days of suffering from pain "that nobody knew how to fix".

A typical day , for Gloria, consisted of waking in the morning with "stiffness ...usually a good hot bath will deal with that". She would go to work where she experienced "pain in my wrists and hands because I'm doing writing and typing and

stuff". Gloria explained, she usually had "end of the day issues". She went on to relate a story of persistent pain while she wrestled with preparing meals, doing housework, visiting friends, staying connected with her parents, and painting. She related that "by the end of the day I'm pretty toasted ... and then I flop into bed ... sometimes the pain is so bad, I worry that I can't function".

Her early experiences dealing with symptoms and searching for an explanation were extremely frustrating.

I found people either disbelieving or condescending or really not communicative. That's partially me because I was in the mind frame of "Well, the doctor knows everything". It really took for me to get really angry and start saying "You've got to do something about this". And slam my fist on the table and say "I'm not hallucinating. This is not a joke here." before I got any action.

Gloria thinks self-care is very important. Her understanding of self-care involves two components: the physical and the mental or emotional aspects of it. She believes you can't have one without the other, that they both need to be working in harmony for self-care to be a satisfactory experience.

I really found that when nobody was believing me, I was just so depressed because I just couldn't do anything... Once things started moving and I started getting some feedback and I started getting people talking to me about how I could help myself my whole attitude sort of mentally, spiritually, and emotionally - I think that's a part of it as well, the gold is great and that's obviously helping, but I think I have a better attitude about it and being able to have some control and knowing what I can do to help is a big part of being able to care for myself. Knowledge is power, right?

Gloria also needed time to pull her self-care strategies together. This required a lot of learning of how to apply some strategies to day to day living. She felt that health care providers often talked in terms of coping and pacing, but she had a hard time

translating that into practical terms. *"Issues like - slow down and pace yourself. Well, how do you do that" ?*

Themes

The understandings and meanings these women had about their self-care experiences revealed five major themes. Their experiences of self-care were framed and described from the perspective of their whole experience of RA. Each major theme is connected to several sub-themes. The major themes were closely tied to one another, but for the purposes of analyzing the complex nature of their self-care experiences, each theme was considered to be distinct, as well as interrelated. The five major themes were: coming to terms with the chronicity of RA, viewing themselves as experts, learning how to make changes, maintaining control of decisions, and building a network of support.

Coming to Terms with the Chronicity of RA

Living with Fears, Pain, and Unpredictability

None of the women recognized their earliest symptoms of joint pain, stiffness, and fatigue as being RA. They initially rationalized their symptom experiences as working too hard and not getting enough sleep or using the wrong body mechanics to perform physical tasks. Searching for an explanation for symptoms became a personal project when they did not resolve or became worse. Their descriptions of general health care experiences and initial contacts with the health care system were frustrating and in some cases frightening for them. Several of the women were not believed or told that their problems were minor and would go away.

Gloria: My initial experiences were really frustrating, really frustrating. I was diagnosed with tendinitis, and this and that and everything else. You know, "Go home and take two tylenol and call me next week" That kind of thing. I persisted in saying "Well you know it's not tendinitis because one day it's in my wrists and the next day it's in my hips...I don't think so. I've never heard of roving tendinitis, have you?" Then they kind of started going " Well maybe we better look at a few other things here".

In their quest for a medical explanation for their symptoms, most of these women knew there was more to what was going on in their bodies than what they were being told. When they were eventually diagnosed with RA, it became another round of searching for explanations of what was happening to their bodies. Actively seeking help and information was considered to be engaging in self-care.

A few of the women were given satisfactory information by empathetic doctors. The other women were astonished that their doctors either didn't want them to know, didn't know themselves or were too rushed to spend the time talking with them.

Cathy: I think it's very important to treat each patient as if they want to know the information instead of just saying "You don't need to bother yourself with that"...each patient could be different. In some cases, I'm sure, the patient won't want to know that information, but I got really frustrated because I wanted to know that information and I wasn't getting it...so they weren't listening to me.

Gloria: The doctors themselves, the rheumatologist and others, aren't really helpful in explaining what is going on sometimes. Information kind of trickles down to you afterwards. I know they're busy and all that kind of stuff. You go in to the appointment and you're in there for five minutes and they go "do, do, do, do..." And out you go and you don't really get much feedback.

The very professionals they had come to expect to rely on to provide reassurance and comfort were now treating them with disregard and sometimes blatant disrespect. Thorne (1993) speaks to this disconnection between the social logic

of health professionals being moral leaders in dignity and the actual potential they have to create havoc in the lives of people with illness by their interactions with patients in clinical encounters. In listening to the women's stories I heard a number of unsatisfying experiences with communication, primarily with doctors. This created confusion and distrust in the women. Lack of information and support fanned many fears.

Faced with not knowing what the future held, several women had fears of permanent disability or becoming completely dependant on family members or friends for physical needs. Many of the women had persistent pain, despite that being the initial reason for seeking medical care. They had fears of a lifetime of pain.

Ann: Being a nurse, I was very aware of pain. I thought I knew what pain was all about. I didn't. I had no idea what chronic pain is all about. To live with pain day in and day out...was an issue because it was never controlled...you were hoping one day you would wake up and have a day that was not... [that the] pain wasn't there, but that never happened.

One of the biggest fears for these women was the unpredictable nature of RA. One day they could be fine and the next day it was impossible to get out of bed. How were they ever going to cope with a life that was so up and down?

Fran: Sometimes if my friends ask me to go out to play tennis I get scared and I don't want to...it's better not to do it. Sometimes this disease gives me a kind of barrier, like a wall to step over.

This finding concurs with the findings of Brown and Williams (1995) who found in their study of women's experiences of rheumatoid arthritis that unpredictability of symptoms created a sense of uncertainty and sometimes dread in their day to day lives. Not knowing what each day would bring constrained future planning and narrowed their lives to just "getting by, day to day" (p. 699). The unpredictability of

symptoms, especially pain, made it difficult to plan for the future. Not knowing what the future might hold led to hesitation to make long-term plans. Ellen said *"I used to like to travel a lot...I haven't really taken any long trips since I was diagnosed with arthritis"*. This unpredictability and the fears related to it sometimes changed their planning orientation for the future to short-term and occasionally planning to just get by day to day.

Self-care to several of these women meant acknowledging these fears and trying to initiate and take measures to deal with them.

Fran: At the early stage of the disease, I want doctors to give patients information...Ignorance is bad because I cannot prepare for anything.

Dagmar: I don't want to resign myself to this. It's [self-care] also about learning to be with myself when I'm scared. I've been reading more about the mind and body, and to me it makes total sense, they are not separate things.

Dealing with Losses

There were many losses associated with a life with RA. These ranged from losing physical function and the ability to attend aerobic exercise classes to losing the ability to earn an income and generate their own livelihood. All these losses impacted these women's self-care experiences. What they once expected of themselves had to be recast in terms of life with RA. They compared their current abilities to past abilities and spoke of going through a process of mourning in order to weather these losses.

Ellen: I thought I was just working too hard. But it's a very insidious process, that things just gradually move up until you can't do them anymore... It's not until you can't do it, that you realize the disease

has taken that away from you.

Dagmar: Now I have it in my ankles. Anything I wear on my feet is a drag, so I can't do as much walking as I did before and I miss that because walking does help my energy.

Ann: It was just physically impossible to continue working in the environment that I was working because of all the joint pain and the heavy lifting that was involved.

An interesting note is that three of the women in this study were health professionals, in differing capacities. Two of the women were no longer able to work and directly related this to their RA. They both described chaotic workplaces in large urban hospitals.

It became obvious to Cathy and Ann they could not continue to perform as they wanted in their former work environments. Looking back at this significant event in their lives, they realized it was a sensible decision in terms of living with a chronic illness. Letting go of this important role in their life and coming to terms with the loss was regarded as self-care.

Ann: I knew all that stress wasn't good for me. It was aggravating my pain. I think from a psychological point of view it [leaving work] had a good effect on my coping...I was able to look after myself physically.

Constancy in work environments is a characteristic that can enable people with chronic illness and physical incapacities to remain employed in that work (Corbin & Strauss, 1988). A predictable work routine that enables people to respond in a habitual manner supports continued employment. Ellen talked about self-care as making workplace "concessions" to maintain a level of predictability and control over her environment. She had enjoyed the bustle of evening shift work, but gave that up to work

day shifts where she could sit more and spend less time *"running around"*.

Ellen: *When I went back to work, I said - this is what I can't do, this is what's going to make me ill - carrying heavy objects or moving things or standing on my feet for long periods of time...I'm not going to be able to function as well.*

The self-care undertaken by these women to cope with losses related to the onset of RA can be viewed more broadly as managing a process of grieving. Giving up a satisfying job, an activity or function often generated emotional responses. These emotional responses usually initiated analysis of new circumstances and then adaptation.

All of these women spoke of profound feelings of depression at some point in their illness experience. Cathy speaks to this time as *"when I was at my absolute worst. I was just plugging on and hanging on and I just felt useless."* The reflection and insight these women had was remarkable. They were able to work through these feelings of sadness and loss in a way that assisted them to accommodate the restrictions imposed on their lives by RA. In my conversations with these women, they spoke about self-care as reflecting on and attending to their emotions and this included dealing with losses. Gloria lived on her own and became depressed when *"I couldn't help myself and there was no one there to help me and I got into a real tailspin about it."* By examining her emotions and taking measures to talk to others about her depression, she believed that was *"a big part of being able to care for myself."*

Altered Identities

As the lives of these women took on a new meaning in terms of their abilities to care for themselves and others, they found their relationships changing within and

outside of their families. The women who had aligned themselves closely with their professional or workplace identity had adjustment problems when that large portion of their life changed or disappeared.

Ann: What I found really difficult for myself was I was a health care provider. I was a giver of health care. And now all I seem to be doing is receiving treatments after treatments after treatments from physiotherapy or surgery or whatever. So that was a difficult part for me...to learn to accept that I was not the giver, but I was the receiver. At the other end of the stick basically.

The women talked about changes in their ability to maintain habitual or traditional roles within their families, communities, and social networks. Some were concerned about the impact of these changes on those closest to them or those dependent on them. When Cathy and her husband moved into a new home, she expressed her feelings of inadequacy because *"I couldn't do any of the moving. I couldn't do any of the cleaning."* Yet, moving out of her family's home into her own home gave Cathy control over her situation. Her family had little understanding of her problems and they believed that she should keep busy and working and that was the best thing for her arthritis.

Cathy: Then, I really did take the rest that I needed and I did my own thing. My husband was very understanding and basically said "It's none of their business what I'm doing. I would just do whatever I have to do to get better." I think one of the reasons why I stopped working was that I could now be in my own home and pretty well rest without people judging me.

The women discussed the burden they felt their physical restrictions, limited financial contributions, and emotional upheavals may be placing on their families and friends. These altered or changed roles had an impact on how the women viewed

themselves as partners, friends, mothers, daughters, and employees.

Bonita dealt with these challenges as they came up and talked about how she relied on her family to assist with day to day activities when she could not do them. She described this reliance on family members as her understanding of self-care.

Bonita: There are daily things that you should do, like washing your hair or making lunch - those things you take for granted you should be able to do. That is what self-care is - it's just those basic things and getting help to do them.

According to Orem (1991, 1995) the provider of self-care is referred to as the self-care agent, regardless if the care giver is the patient or someone else. Orem's self-care theory operates on the assumption that every human has a need to care for themselves. Easton (1993), drawing on Orem's theory of self-care, explains that a person's attempts to gain control of situations must be considered a form of self-care. Control of the situation is the essential element of this perspective and this coincides with the way the women talked about the meaning of self-care for them.

There is No Cure

Strauss et al. (1984) write of the long-term and disproportionately intrusive qualities that chronic illness imposes on those who suffer from them. Fran spoke quite at length about this aspect of her RA. She could never forget that she had RA, even though she was free of symptoms at the time of our interview.

Fran: Even going to a party or talking to my friends, always that thing is somewhere in my brain. I never forget about my disease. I'll always have it, I have to remember. Even though I don't have pain, it's always in my mind. It's a part of my life. I'm living with a disease right now. It's a part of my life.

An integral aspect of coming to terms with knowing and living with the chronic

nature of RA was recognizing that a cure for RA was unlikely. This was often a pivotal event in the lives of these women as they were then able to move beyond seeking a cure and "getting on with their lives".

Cathy: I tried the whole thing...energy work, whatever, just everything under the sun I had tried because I was desperate to get rid of this or get any easing of the pain even. Later it was... never mind getting rid of it [RA] totally, but just getting some relief of the pain.

The shift from the "cure" perspective in their lives to a "care" perspective was often hinged to their interactions with others. All the social relationships within their lives had an impact on their ultimate acceptance of their illness as chronic.

Dagmar: It was really hard for me to also accept that I had it [RA] and that it did that to my body. It just affected me in such an all around way. I can't relate to people as well because I'm in pain and I'm trying to hold it all together...The people that didn't understand were people I see day to day and friends, and not so much health professionals. I mean if I didn't like Dr. X ... she knows I'd look for something better. I would continue to look for whoever will support me in whatever I have to do to manage this pain.

In a qualitative study of twelve people with a chronic illness, Baker and Stern (1993) found in their analysis of interviews that those who identified themselves as self-care agents no longer sought a cure for their illness. The process that seemed to underlie self-care readiness was accepting the reality of the illness and reframing its implications in their lives. This was no easy process and involved many complex and dynamic factors involving interactions with families, health providers, others with chronic illness and their communities.

The women I interviewed talked about the complexity of coming to terms with a life redefined as inclusive and accommodating of RA. Gloria felt that in order for her to

manage and care for herself on a daily basis she required “*feedback and help because you can’t pull it together yourself.*” She especially requested ongoing contact with health care providers to help her during the initial phases of figuring out which self-care strategies were going to allow her to live her life as independently as possible, but allow her access to assistance when she felt she was unable to manage.

Gloria: No one can keep trucking on by themselves all the time. I think self-care includes support. You need to be able to access support from other people, whether it’s physically or emotionally.

Recognition of chronicity seemed to occur in tandem with an expansion of ideas and abilities to develop self-care strategies that worked.

Viewing Themselves as Experts

Knowing Their Own Bodies

These women lived with daily pain, fatigue, weakness, swelling, and other symptoms. They became specialists in monitoring their responses to certain activities, treatments, emotional situations, and social events. These monitoring activities were understood to be self-care.

Ellen: You have these limitations and you know that if you push beyond your limit then you might start to experience some pain and some fatigue and then you have to stop and take a rest or move on to something different. So on a typical day you’re working within your limitations and if you’re going beyond, you’re aware of them.

The notion that they knew their bodies better than their doctors was frequently reinforced when their doctors directly contradicted their reports of physical symptoms or how they felt about their progress. The women in this study felt they innately knew whether a particular medication was working or not and did not need to rely on their

doctor to pronounce the treatment a success or failure. They felt they had expert knowledge about their own bodies. Self-care was determining, with their health care provider, their progress with a certain medically prescribed plan and evaluating whether it was appropriate for their circumstances or not. Shared expertise with their care providers represented a self-care strategy that developed as they became more familiar with treatments and their own progress.

Cathy: I guess to me knowing why I'm taking it [a medication], what I'm taking, what interaction it has on my body helps me know what I'm doing and why I'm doing it. I think it fosters greater compliance and just a greater motivation to say "Ok, I'm going to keep a record and find out whether this works or not". Instead of just waiting for the every three month visit to the rheumatologist and have him say "Well, you haven't changed one iota".

Dean and Kickbusch (1995) explain that "self-care is a term representing the range of health related decision-making and care undertaken by individuals on their own behalf" (p. 36). This broad view recognizes that it is the individual person that acts (or doesn't act) to preserve their health or to respond to symptoms. These authors refer to a continuum of caring for the self that, regardless of what level of professional services has been consulted, operates through the individual, who assimilates the influences and determines the care. The writing of these authors corresponds with what I heard in the conversations with all the women in this study. They decide when and where to initiate professional medical contacts and they decide whether professional advice or treatment will work for them. Self-care was monitoring the progress of their symptoms and response to treatments, consulting their care providers, and making decisions whether or not to seek further advice or treatment.

Self-care is an active social behavior occurring in the context of daily living

(Dean & Kickbusch, 1995). This thinking applies equally to the illness dimension of caring for the self and certainly with chronic illness it becomes even more apparent. The daily lives of these women were full of symptoms of illness and these were part of their normal routine, rather than infrequent or unusual occurrences. By examining and reflecting on the nature of these symptoms, such as what else was going on in their lives, the women came to understand their whole condition. Self-care was developing this expert understanding of their own situation and was fundamental to minimizing the impact of symptoms and their progression.

Pain was a symptom that required a range of strategies that was unique to each woman's circumstances. Dagmar chose to practice creative visualization and *"talked to my immune system"* as she preferred to avoid medications. Ann preferred physical measures, such as *"keeping my muscles and ligaments strong to support the joints"*, but augmented pain management with medications. Gloria felt her emotions intensified her pain experiences and developed techniques to *"quiet myself down, and keep things calm"* by using strategies for *"deep breathing and muscle relaxation"*. Bonita's way of dealing with pain was *"making sure I get my regular gold shots...it's important to keep the inflammation in remission"*.

Building a Knowledge Base

Once the women believed they had expertise in what was happening to their bodies, it then became important to collect and absorb current and accurate information about RA. Frequently, the medical "experts" who claimed to be the possessors of all knowledge about RA became the least responsive to the women's requests for information.

Fran: *Even Dr.X [rheumatologist] can't tell me what is the cause of this disease or the reason for this disease. And I wanted more of an explanation from him as a specialist, but he didn't give me enough information. He just gave me medication. He didn't give me information about what to do or what's going to happen, nothing.*

Cathy: *Before being under Dr. Z's care, it was pretty much like well "Don't you worry about it. You don't need to know the drug interactions. You don't need to know what it does to your liver". This sort of thing. Having taken so much of biochemistry, physiology, and anatomy in my undergrad, I really needed to know the drug interactions. I really wanted to know. How does this thing work and how is it helping my arthritis when it helps a whole slew of other things like cancer?*

Thorne's (1993) study of patients with chronic illness revealed consistency of findings with the women of this study with regard to the lack of information provided to them by their doctors. Realizing that doctors do not know everything contradicted their entry into the chronic illness experience when they had an attitude of reverence towards doctors. As the women became more and more reliant on their own expertise they began to realize the role their own beliefs about doctors had played in setting them up for disappointment. Ellen once believed doctors were the only legitimate expert in any matters to do with health: *"I believed in going to the doctors and asking because I don't have the answers."* Gloria once thought *"the doctor knows everything."* The women soon realized that most doctors had no idea what constituted daily life with RA. Thorne (1993) found that this shattering of confidence in the medical profession shifted the thinking of patients and families from "doctor knows best" to accepting the limitations of their own doctors.

All the women in this study identified the need for accurate and current information and very seldom was this information given to them by doctors.

Gloria: Knowledge is a big part of being able to care for myself. Knowledge is power, right? You need to count in those things I want to know when it comes to self-care... And I think that the doctors themselves aren't very helpful.

The women in this study found ways to obtain information they desired related to the disease of RA, medical treatments, support groups, and resources from sources other than their doctors. They sought out information from the Internet, The Arthritis Society, libraries, family and friends, community centres, and other health professionals such as nurses, physiotherapists, or pharmacists. One woman attended the Arthritis Self-Management Program and found it "depressing"

Bonita: I didn't find it to be very helpful. The book they give you is very good. But the facilitator wasn't very motivational ...He would come up and complain about being tired. Dealing with all these arthritis patients, it wasn't good.

All of the women in this study began their experience with RA with no doubt about the superiority of traditional medicine. As the months and years went on, it became harder to justify this thinking, particularly as traditional medicine revealed its impotence with understanding and assisting in the day to day realities of life with RA.

Ellen: Unless the people are trained and aware of the impact of arthritis and what's behind it and everything, they really aren't aware of it. They don't consider it, they don't know how to consider it. They don't know anything about it.

In pursuit of self-care strategies and information outside of the domain of medical expertise, these women often found more compassion and acceptance of their views from non-traditional, alternative, or complementary health care providers. This added to their arsenal of self-care strategies and widened their scope of options.

Dagmar: I've seen a person who is going to help me change my diet to help my rheumatoid arthritis. I've heard enough about people who change their diet and it really helps...I'm starting to see this therapist this week...So right now my rheumatoid arthritis is first and foremost because that is the biggest problem in my life right now. This therapist ...he's really neat. He's on a sliding scale [for payment]. He's going to go shopping with me and show me places where I can get what I need to get. The place where he goes all the time, he gets a 30% discount.

The women talked about becoming more aware of the complexity of their illness condition. They understood that their emotions, interactions with family, employment and financial situations, spiritual connections, and community contexts all intertwined with their disease state to influence their daily lives. Their stories reflected a growing sense that traditional medicine was ignoring relevant aspects of their chronic illness experience. As they became attentive to appreciating a more holistic framework for self-care, they eagerly sought practitioners, healers, and care providers who reflected these values in their approach to illness management. For example, Ann consulted a practitioner of Ayurvedic medicine as she explored alternatives to the shoulder surgery offered by an orthopedic surgeon. She explained that *"they [doctors] are not trained in this country to treat you like a whole person or to spend time with you."* Dagmar was interested in alternative approaches to RA management from the onset of her illness. She had tried a range of strategies for pain control from creative visualization, relaxation, and dietary therapy. Cathy had unsuccessfully tried reflexology, accupressure, and Chinese herbs to initially cope with symptoms.

The pursuit of non-traditional methods of symptom management or health promoting strategies offered comfort and relief for some of the women. It also

prompted them to question themselves about the superiority of traditional medicine and how they may have been socialized to depend on doctors as the sole authority on matters of the body and illness. It also raised issues of traditional medicine viewing diseases as single entities, while these women's stories illustrated the complexities and variations within their experiences in spite of their identical medical diagnoses.

Cathy: Different patients can have different levels of severity of rheumatoid arthritis. In any manner, it will affect an individual very differently. Depending on medications, their lifestyle and what not, they will control it in a very different way and they'll cope with it differently.

Educating Others

As these women became more confident in themselves as experts in RA in charge of their self-care, some saw opportunities to help others with RA who were struggling with a new diagnosis or were unable to access adequate information. Stepping outside of their own lives and own problems was therapeutic and empowering for them. It rewarded them to know they could make a positive difference in someone else's life and it created a sense that this was a part of caring for themselves.

Bonita: I travel a lot for my job and I often meet people who have RA who don't know anything about it. They don't know anything about their disease or medical treatments and I can see they have deformities in their hands or they're having a hard time doing things in their job. I feel like I have to tell them there is lots of information and treatment or programs for them out there.

Some reflected on the role models with RA who influenced them.

Ann: I filled the prescription and I brought it home and I was still scared to start taking methotrexate [a RA drug]. I went through ATIS [Arthritis Telephone Information Service] and they connected me with a person who was in a similar situation and who had been taking

methotrexate and was doing well. She was actually the one who talked me through it...Amazingly, I tolerated methotrexate very well.

A self-care strategy of making connections with others who have been through similar experiences was found in other studies of the chronically ill (Baker & Stern, 1993; Brown & Williams; 1995, Thorne, 1993). The accounts of the women in this study revealed that they connected with others with RA through organized support groups or conferences, informal meetings at medical appointments, and by volunteering at The Arthritis Society either as a telephone advisor or public speaker. These networks provided both information and support for the women. The exchange of ideas and sharing of information frequently helped them through a difficult problem, as it did for Ann. For some, it was reassuring that others knew what they were living through. A more important objective for some was establishing a source of support and insight into dealing with the health care system. Bonita preferred going to the Mary Pack Arthritis Centre for weekly medication injections because *"I meet and talk with other people in the waiting room and sometimes we can help someone out."*

Finding reassurance in their own efforts to educate themselves and others with RA, the women saw a great need to educate health professionals about the experience of RA. They saw this as part of the whole process of self-care. By being activists for change in the way health care providers dealt with people with RA, they were developing skills in themselves they saw as beneficial to their overall health.

Gloria: I haven't had to really deal with pharmacists other than getting some anti-inflammatories at one point. She was cool because she gave it to me in the hard lid to take off...and I explained my problem to her...and then she looked at the medication and went "Hold on"...and went and got me an easy

lid. She was pretty smart. She clued in right away.

Cathy: I got referred to a really good massage therapist and I ended up seeing the physiotherapist there. I think he was much more familiar with orthopedic injuries than with arthritis... So I feel that I really had to educate them and really help them know and understand what rheumatoid arthritis was all about. And how it doesn't just affect the joints, per se, and that it really affects many different areas...your emotions ,your work and your family life.

They felt that participating in this study was another opportunity to "get their message out there" to various health care providers, especially doctors. I could not find any comparable findings in the literature regarding chronically ill individuals educating health care professionals about their illness as a strategy for managing chronic illness. By educating health care providers to the disease of RA and the common problems associated with it seemed a very practical matter for ensuring reasonable health care provision in the short term. By further educating those health care providers the women had established longer term relationships with gave them the opportunity to enlighten them to the unique circumstances within their illness experience. This self-care strategy further ensured an individualized approach from their health care providers, in contrast to a standardized or textbook approach to their health care problems.

Learning How to Make Changes

An Evolution

These women saw the changes they had made to accommodate RA as an evolutionary process. Learning to do many day to day self-care activities differently or to think in a new way about handling problems was an educative process, usually by trial and error.

Ellen: Self-care as it is concerned with rheumatoid arthritis, to me is taking an interest and control over what's happening with you. I want to keep in control and know what my medications are and make sure I take them and know the side-effects and sort of be educated about what is going on and what I can do to change things in respect to what I'm doing and how I'm doing it so it will benefit me...Like someone else can go out and walk for two to three hours and another person may be able to do only thirty minutes walking. Knowing how to take care of yourself is learning, it's a learned experience... It's different for each person and I think that's where they have to take care of themselves... You have to know what you can and can't do.

Corbin and Strauss (1984) and Strauss et al (1988) have chronicled this aspect of chronic disease management in detail and refer to this as the "work" of chronic illness. According to these authors, learning how to handle this work effectively is a key component of acceptance of chronic illness by patients and their families. The work involved can be both extensive and burdensome.

The accounts of the women in this study indicated that changes resulting from chronic illness management tended to be cyclical and compounded the impact of previous changes. Their stories also indicated that they devoted a considerable amount of energy towards maintaining their health status and managing emotional stability.

Gloria: The job that I'm in - I can't take breaks - so I've had to learn how to slow down and pace myself. That was hard, because I couldn't take what I learned and apply it right away because when you're thrown back in the real world and you're going "Ok, I need to cope here, but I don't even have time to breathe."

Thorne (1993) refers to "health maintenance work" (p.42) as all the efforts that patients and their families give towards maintaining the best level of health one is able to achieve within the setting of a chronic illness. The work involved is directed toward

whatever symbolizes health for that person. The women in this study told stories of having to learn many new skills and ways of thinking about doing things since the onset of RA.

As their lives evolved with changes to family relationships, employment situations, or leisure activities, they adapted their self-care strategies within the contexts of day to day life. Learning to apply self-care during times of RA flares or emotional stress created new opportunities for mastery in management of RA and greater control over day to day life. Shaul (1995) explains, in her study of women with RA, that mastery and the achievement of a satisfying quality of life was obtained when individuals gained a sense of empowerment over their situation and had developed a repertoire of strategies on which to draw in order to cope with the changes in the process and context of RA. These findings coincide with the accounts provided by the women in my conversations with them. Bonita explained *"we often go out for dinner when I'm tired at the end of the day...or we'll order in, if I'm too tired to go out."* The women learned how to set and reset goals, to ask for help from others, to control pain, to pace and plan for energy depletion and restoration, to maintain connections with family and community, and to work with health care providers in managing their medical treatment plan. Self-care was managing all the day to day activities developed through trial and error learning, to adapt to the variable and unpredictable nature of RA within the context of daily living.

The women were all aware of the availability of the Arthritis Self-Management Program. Bonita was the only one who attended and found it didn't offer what it claims and, in fact, found it *"depressing."* The brochures and posters that promote this program

throughout the Mary Pack Arthritis Centre encourage those with arthritis to attend this program to understand arthritis and its treatments, learn to cope with pain, and take an active role in managing arthritis (The Arthritis Society, 1998). The program follows a standardized course outline that is strictly followed by the course leaders who usually have arthritis themselves.

Ellen decided not to attend because *"you have to go for six evenings and it's not free...it's not much, but I'd rather spend my money on other things."* Ann felt *"when you're so busy and tired all the time, the last thing I want to do is spend my time sitting in a class being told what to do."*

It's Personal

These women were very clear that their self-care experiences could not be talked about like it was some naturally occurring process that kicked in automatically with a diagnosis of RA. There were no recipes or script to follow. They had to figure out a new way of caring for themselves that was unique to them and made sense to them.

Developing personal modes of self-care also served as a way of controlling symptoms and minimizing the interactional friction experienced with visits to doctors. Personalizing their self-care also could have prevented minor annoyances from becoming bigger problems (Corbin & Strauss, 1988).

Dagmar: There's stiffness and that really saps your energy. So I was resting a lot and I was depressed and the arthritis and pain makes it worse...So much depends on whether I'm motivated or not. And when I'm depressed it's a whole different story...Self-care means taking care of my own health, my physical, mental, spiritual health. I do creative visualization and I talk to my immune system and I do this daily and sometimes several times during the day... And I also journal my pain. I've done that three times a day for

two months solid.

Gloria: For self-care you can give everybody the tools, but if you're sick and in pain, applying those tools cannot always be a simple or an easy matter. I guess that's the big thing I want to get across. It doesn't happen overnight. It's not an instant thing. It's not "Oh goody, you've learned all this stuff, so now magically you're going to be able to take care of yourself". It doesn't happen that way.

As Gloria felt, it was still hard work to make these changes. Sometimes the changes imposed by chronic illness are often more problematic than the disease itself (Thorne, 1993). A frequent problem encountered by the chronically ill is the energy and time that must be invested in organizing the hard work of illness management and this was talked about by the women in this study.

The process of "normalization" is referred to by Corbin and Strauss (1988) and Strauss et al (1984) as the efforts made by individuals and their families to integrate chronic illness and the illness-related management strategies into the fabric of everyday life. Eventually, they redefine what is normal and no longer see the illness as something temporary. Strauss and his colleagues also acknowledge that an emphasis on normalizing can disadvantage some individuals with chronic illness because it requires resourcefulness and hard work in the extreme.

The accounts of some of these women did refer to the process of normalizing. Bonita believed *"I'm not back to normal, but I'm as close as I can be."* Fran related *"For one year I could not do anything with my life. After that, I could return to normal life"*. Fran further described her experiences with RA as having evolved to her current view that it is *"like wearing glasses."* When the glasses are new, you are constantly aware of them. With the passage of time, they are *"no big deal."* Normal, in the sense that these

women talked about it, imparted a view that was tied to the capacity to engage in activities of everyday life.

The idea of “normal” was used as a reference point by some of the women to describe their general experiences of living with RA. Their ideas and thoughts about self-care were described as personal and individual, and different from others with RA to accommodate their particular circumstances. I found it a curious contradiction, that while these women described unique and personal understandings of their self-care experiences, they seemed to generalize what “normal” meant to them.

Explanations of the abstract notion of “normal” has been explored to some extent (Thorne, 1993; Wolfensberger, W, 1980a, 1980b; Wood-Dauphinee, S. & William, J.I., 1987). While the term “normal” in the statistical sense refers to a usual measure or tendency, its social meaning suggests such attributes as acceptability and desirability. When people redefine their own standard of normal on the basis of their own everyday life experience, they include a range of human experiences and modify the criteria by which social desirability is judged. This individualizes the standard for normal and makes it more personal.

Normalizing can be advantageous as a means to minimize the social effects of having a chronic disease. By attending to the normal aspects of day to day life, the significance of limitations can be minimized. A disadvantage may occur when trying to normalize causes a person to deny the implications of their illness. Cathy tried to carry on with commuting to work and maintaining “normal” social relationships and *“finally couldn’t take it any more and it got to the point where it was just useless trying to carry on.”* Cathy’s account related her feelings that striving to normalize interfered with

acceptance of her limitations. It revealed that "normal" was largely an artificial construct that had been socially accepted as valid. Assumptions about normalcy have shaped the women's adjustment to chronic illness. Rejecting the social value of normalcy allowed some of these women to develop unique and individualized strategies for self-care. Each woman's situation was different and they each had developed distinctive self-care strategies to suit their unique circumstances and this was clearly communicated in our conversations.

Maintaining Control

Expectations versus Realities

As the women began to understand the complex nature of their illness and its management, they increasingly took on responsibility for control of their health care. As they became more confident in their self-care experiences, they felt more confident about becoming consulted and involved in areas traditionally controlled by health care providers. Health care providers had their own way of conducting business and for some of the women, challenges to that domain was frequently a source of irritation. What the women expected from clinical interactions and what sometimes occurred during the clinical encounter was sometimes quite different.

Fran: I'm sometimes disappointed with doctors because they don't give me enough information...not enough to make me relaxed. And everybody says a different thing... Well, like the pharmacist I went to get my medicine. One pharmacist says "You better take this tablet in the morning". And another pharmacist said "You better take it at night before bedtime". And another one says "Once per day, it doesn't matter what time of day". They just want to show you their knowledge, like any professional. Everybody says different things and that just makes me confused. I just ignore it and take it anytime in the day and try not to forget.

Health care professionals often ignore, misinterpret, or deliberately insult patients when they became assertive in their requests to take on responsibility for health care (Thorne, 1993). Reinforcement of the power imbalance between patient and health care provider was a common experience for the women in this study. Cathy became quite distraught when she tried to relate her emotional instability to her doctor *"I would tell him about the emotional aspects of dealing with this and he would say "Oh, don't start crying on me."* She interpreted this message to mean *"Shut up and stop crying. What prescription can I write you this time."* Thorne (1993) has recounted incidents where patients had actually been told to "Shut up." or "Stop crying." by health care providers. In her study of women with RA, Shaul (1995) also found that health care providers were seldom cited as providing the support the women felt was needed in their lives. She explained that the women who took an active role in controlling the management of their RA had not only learned how to live with the illness, but could explain what they did and how it worked for them.

Some of the women told stories of very caring and understanding health care providers who provided support, information, or other assistance at their request.

Ellen: Dr. X has always been very straightforward in telling me what's going on. She gives me options and asks me if I'd prefer A,B,C, or D, and explains each option. I still need her judgment on certain things, though, and she will tell me what she thinks. So now I can really work with her and I can take on most of the responsibility. I think I'm a little more educated about making these decisions now.

Doctors who listened and consulted were eagerly sought out and some of the women had established beneficial relationships with doctors. The women understood self-care

to include seeking and establishing good communication and trust with health care providers. They especially sought out doctors who respected their desire to manage or direct their RA in a manner that suited the realities of their lives.

It's a Struggle

Control struggles are often played out between chronically ill patients and health professionals (Thorne, 1993). The chronically ill are frequently viewed as "troublesome" by some health care providers because of their desire to maintain control of their own health care. In addition, those living with a chronic illness also have a greater capacity to evaluate the quality of health care because of their range of experiences within the health care system.

Dagmar: I do like my specialist, however, I do want to know everything. I do understand that you're [the specialist] a professional and the whole nine yards, but this is my body and I want to know everything, so take the time to please talk to me. I was going to see someone else, but I went back to her and I had a list of questions and she answered them all for me and I saw her again this week and she's been pretty good.

Ann: When I first started seeing a specialist, within months I was having such a hard time with him that I just couldn't go on and see him. His attitude was "I'm the doctor, you are the patient. Do as I say. Don't ask any questions"... He didn't like the fact that I was questioning him on issues.

The issue of control was explained in Baker and Stern's (1993) study as being part of the participants' perception of viewing themselves as self-care agents. Those that saw themselves as being in control over the course of their illness had developed ways of adapting their lifestyle and managing their treatment regime. How they lived and looked after themselves was clearly seen as influential in determining their illness

course.

The women in this study acknowledged the limits of the health care system and the people within it.

Bonita: I was off work and contemplating I can't go back to my old job. I saw a social worker and it was a very general conversation. I thought it could have been more specific. If they're going to offer that service - that there could be career counseling.

The women recounted their personal discovery of understanding that they were really the best people to judge their circumstances. They became confident that their own understanding was just as valid as any clinical or technical expertise related to health care decisions. Ellen related that *"you should be involved in the decision making about your treatment and change it if you can't live with it"*. Being in control of their health care created a sense of order and logic in their lives whether or not the formal health care system was involved. Self-care was managing the day to day decisions and accessing formal health care when it was necessary, but maintaining control over when and how that was done.

Building a Network of Support

Seeking Partnerships

To access the types of resources these women wanted to keep control in their hands and to practice self-care the way they chose, it became necessary to seek out health care providers who were supportive and facilitative.

Bonita: I still like to come to the Arthritis Centre every week for my injection. I'm not interested in learning how to inject myself. I find the regular contact with the nurses at the centre very beneficial. I can discuss problems as they come up and they understand what

I'm talking about because they see people with arthritis all the time. They always take the time to help me with new problems that come up or answer any questions I have.

Ellen: The physiotherapists are really helpful. You can schedule visits as you need them. I still go for checkups with the physios. They measure your range of motion and they let you know. And I can ask them about exercises and things like that.

The women also desired mutually respectful relationships with their doctors.

They actively sought out and worked at maintaining good communication with doctors who were respectful of their choices for self-care and provided clinical care in a way these women thought was beneficial.

Ellen: I think I'm a little more educated about making these decisions now. ...Now I can really work with my specialist rather than have her take on most of the responsibility. I mean I still listen and I do defer to her judgement because I do think she knows better than I do ultimately. But she'll give me the option now and say ..."it's up to you, what do you think"?

The significance of health care relationships to the overall experience of living with RA was emphasized by the women in this study. More specifically they talked about self-care as seeking out relationships with health care providers who respected and supported their control of decisions related to RA management. They also talked about self-care as working at maintaining these relationships.

Thorne (1993) also writes of the important role health care providers played in the chronic illness experience of those she interviewed. In her studies she found these relationships became as significant as any others in their lives. The primary value of developing these connections was "having someone to talk to" (p.82) and having their experiences validated and understood by a health care provider.

Connecting with others who had RA was also an essential component of self-care. It helped emotionally to interact socially with others who understood what they were experiencing. The women sought advice from others with RA and found benefits from talking through similar problems and exchanging ideas with relation to care of RA.

Gloria: There are some days that I go "I can't take care of myself today. I can't cook myself dinner. I'm too tired." So sometimes I think you need to be able to talk to somebody about it that could perhaps say "Well have you heard about this service that so and so has that can maybe come in and cook your dinner once a week"... or whatever it is, just to start bouncing ideas, because I think you can get tunnel vision sometimes... I think that self-care includes support. To be able to care for yourself you need to be able to access support from other people [with RA]. Whether it is just emotionally, if you need to talk to somebody, or whether it is physically, learning to deal with whatever you're having to deal with on a physical level.

Thorne (1993) found in her study that the vast majority of people with chronic illness sought cooperative involvement with others for the purposes of information and support. The common motivation for seeking these formal and informal contacts was related to the difficulties inherent in obtaining health care for their chronic illness.

The idea of chronically ill people connecting with each other to deal with their health concerns has been articulated by Epp (1986) as a strategy for health promotion. The term coined for this activity is "mutual aid" (p.7) and has been aligned with self-care as a health promotion mechanism where people help each other through informal networks. The notion of interdependency within communities was described as the creation of connections which support people who want to live independently without relying on professional resources. This view was echoed by the women in this study. In our conversations, the idea of being understood and supported by others who lived

with RA really fostered confidence and skills to manage their illness.

Working the System

Negotiating their way through the health care system was often daunting and often discouraging. Learning the ins and outs of the system was central to understanding and making sense of their illness experience. In order to maintain their confidence in self-care these women became very skillful at mastering the organizational structures that stood in the way of accessing what they determined was necessary for their health care.

Cathy: My specialist took a position in another country and was going to have to transfer my care to another specialist. I knew that initially when I wanted to see Dr. X, there was a year's waiting list, so I got in the back door when she agreed to take me on.

Ann: There's always a waiting list to get in to see a physiotherapist at the Arthritis Centre. So they referred me to a physiotherapist at a local hospital ...who has worked with RA patients. She was the one that called me and once we got going it was great. I've been back and forth in outpatient physio at that hospital for three or four years now on and off and every time it gets worse we're back at the treatment. The other part that I thought was wonderful, was that financially it wasn't draining. Going through the hospital physiotherapy program I was not having to pay the user fee for twelve treatments, which just goes like this [snaps her fingers].... And I find, not only is she very good, she's very knowledgeable with arthritis patients. And the service is local, very close to home. And I used the OT [occupational therapy] department there initially for my splints.

According to Dean and Kickbusch (1995), who cite the World Health Organization's (1986) concept of health promotion, the daily life of individuals cannot be separated from social structures and options for caring in a given community. Self-care is an integral component of the wider social context. It is the basic form of health

care that determines health and well-being, as well as the use of "other forms and levels of care." (p.39) Self-care is influenced by professional beliefs and interactions with health care providers functioning within health care systems. This inevitably was the experience of the women in this study.

They, however, viewed self-care as a strategy for operating within the existing system. It was a way of manipulating the system to gain access to what they required on their terms. Thorne (1993) also writes of patients and their families having to learn the culture of health care delivery in order to develop ways of influencing its decision making on their behalf.

When Dagmar wasn't consulted about a schedule for timing her participation in a particular program, she had to negotiate with the bureaucracy for adjustments that accommodated her circumstances.

Dagmar: I was so busy with the woman's project I was involved in and I was exhausted. Then I was scheduled for this other program with occupational therapy and all that...and I just phoned them and said "I may be able to do that in the new year when I'm finished with all this other stuff. I couldn't possibly do it now." So they finally changed it.

The women in this study had many problems dealing with the bureaucracy and organization of the health care system. Fran felt her diagnosis of RA was unjustifiably delayed because "*Here in Canada, it takes too long to see a specialist.*" Some of the rules and policies did not make sense to them on the basis of clinical or social welfare interests. Particularly problematic was the referral system and access to health care providers.

Ann: Those are the issues - long waits to see a specialist, long waits to have surgery. So when you hear you have to wait eight

months minimum before your surgery it means you have live with this pain and this disability and I don't have a functional arm.

Ann's experience with waiting for shoulder surgery had a direct impact on her physical functioning, as well as her sense of productivity and contribution to her family and community. As a result of waiting so long for surgery, the physiotherapy has been arduous and will be long term because *"waiting so long and not using my arm caused a lot of contracture and scarring...and I may get only 50% function back."* Ann strongly felt that loss of productivity, the impact on family, and the toll of persistent pain should all be taken into account when waiting lists for surgery are prioritized. She concluded that the health care system has created these inefficient and damaging rules because *"They think their time is valuable, but yours isn't. Because you are a patient you have nothing else to do."* The system demanded compliant and passive recipients.

Some of the women talked about their frustration at waiting to see a second specialist in rheumatology. This occurred after they were diagnosed with RA, but were unsatisfied in their relationship with the rheumatologist. They had to obtain a second referral from their family doctor to see the specialist of their choice. They felt because they already had a diagnosis of RA, it was a waste of time and money. Cathy felt it was *"detrimental to wait so long...it's like a window of opportunity being closed on you"*. The person who controlled access to the services they wanted was the family doctor and they were only accessible by appointment and in person. This created another source of energy depletion for the women and more waiting. A person with RA does not have the authority to phone up a rheumatologist's office and make a first time appointment. That authority rests with the family doctor who acts as gatekeeper. Cathy questioned

the financial incentives for keeping such a system in place: *"I'm very opinionated about the whole system...it costs money every time you see a doctor."*

A source of irritation for Gloria was requiring a referral from her doctor to access some services at the Mary Pack Arthritis Centre. She felt that she should have been able to directly refer herself .

Gloria: Im going to have this [RA] for the rest of my life. It's not going away. Why should I need my doctor to decide when I need a physiotherapist when I can make that decision myself?

The impression by these women that their lives were hindered by processes that favoured remuneration of doctors has been echoed in the findings of Thorne (1993). Medical fee-for-service systems, as it exists in Canada, provides little incentive to change practices in a way that accommodates the chronically ill. Thus, doctors offices are crowded with people who know their own needs, but must have an authoritative confirmation before they can gain access to services.

The women talked about needing access to services in a timely manner when a specific problem surfaces. An emotional problem, financial issue, or fitting for shoe orthotics or hand splints should be attended to when the problem arises.

Ellen: You can't leave it up to the doctor. You have to get involved and make some decisions and get active in your treatment. Get to know your physiotherapist or whoever and know how you can get the treatment you need.

Waiting for services could exacerbate problems and lengthen the time for resolution of the problem or perhaps create a permanent problem. The women of this study were motivated to participate by their desire to help others with RA. Fran said "I

want this report to go to all rheumatologists, so they know what it is like." By telling their stories, they all had hoped to influence the health care system. The rules and procedures of an intensely bureaucratic health care system ought to be reconsidered for their applicability to chronic illness situations.

Summary

Self-care was an essential, relevant experience in the lives of these women. Their meanings and understandings of self-care were embedded within the overall experience of living with RA. Conversations with these seven women extracted and examined the meaning and relevance of self-care as it was lived by them. Self-care, in the context of RA, was a complex, multidimensional experience that occurred in the context of everyday life.

The next chapter will discuss the findings of this study and compare them with current understandings of self-care in the literature. Implications of this study's findings for policy, practice, and research will also be presented.

CHAPTER V: CONCLUSIONS AND RECOMMENDATIONS

Self-care of rheumatoid arthritis was a multi-faceted experience for the women in this study. It was a part of the whole chronic illness experience of RA. This study extracted and examined the meanings and understanding of the self-care experience in the context of the whole experience of living with RA.

The findings of this study will be summarized and compared with current understandings of self-care found in the literature. The implications for practice, policy, and research are presented.

Summary of Findings

The lives of the women in this study were changed the day they received a medical diagnosis of rheumatoid arthritis. Becoming a chronically ill person with RA involved a journey of many changes. The relentless pain and many fears that these women suffered continued to shape their self-care experiences at the time of the interviews. Their fears loomed large and took many forms. There were fears of permanent disability, of losing gainful employment, of suffering numerous serious side-effects from many different medications, and of a lifetime of pain. Their bodies seemed to be turning against them. All the women spoke of an overwhelming fear of not knowing what would happen next and the distress of coping with the unpredictability of RA. Fueling their fears was inadequate access to information, distressing communication with health care providers, and distrust of a health care system that was supposed to help. Self-care was getting through the day, acknowledging their fears, attending to personal physical care, seeking relief of symptoms, and trying to figure out what was happening to their bodies.

Alongside these fears and with the passage of time as their symptoms of RA flared and settled, several of the women experienced losses. They lost physical function, paid employment, time with families, and their former healthy selves. Self-care was mourning these losses in a manner that made it easier to handle these changes.

Relationships changed within families as roles were altered. Some women underwent uneventful workplace changes, some could no longer work at a job that was strongly tied to their identity. Self-care was negotiating workplace changes or adapting to new circumstances either in the home or workplace. In some cases it was intense grieving for a lost job and letting that process run its course.

The dawning of a new reality occurred with the gradual recognition that there is no cure for RA. The new reality became one infused with self-care. All the women spoke of this transition as a movement towards getting back to as normal as possible within the context of life with a chronic illness. For some, self-care became a focus on seeking alternative therapies to manage symptoms or to develop a new way of strengthening personal assets. A few of the women sought doctors who would support their blending of traditional medicine with alternative medicine. Some women chose the path of traditional medicine and actively sought doctors who were empathetic, answered their questions, and provided information. Self-care involved finding a trusted medical consultant.

Each of the women became familiar with their body's responses to RA and their treatments of RA. They developed skills at self-care which included symptom control, managing emotions, and dealing successfully with social situations. As they

became experts on their own bodies they began to see their relationships with health care providers, and the health care system differently. Learning that health care providers don't always care and they often don't give information easily, these women became more confident in their ability to collect, assess and apply information they felt was required for their situations. They described this process of building a knowledge base as consistent with their ideas about self-care. Two of the women continued to have trusting relationships with their specialists throughout their course of RA and up until the time of the interviews.

Educating those around them became a mission for one of the women and part of daily life for the others. The women felt educating others, particularly health care providers, was a means to help them understand what it was like to live with RA. Education of others was undertaken to influence their overall experiences within and outside of the health care system. Two of the women had very memorable experiences of talking to another person with RA when they were grappling with a particularly difficult issue. They saw themselves as able to educate and assist others with RA and this provided them with a sense of purpose and reward. Helping others to care for themselves was viewed as self-care. It nurtured a need for cooperative exchange of information and support between people with similar experiences. It also was a benefit for these women to educate health professionals about RA. It was very beneficial if they had the opportunity to educate a health care provider about their particular situation, especially if the women were interested in establishing a longer term relationship with that provider.

Much hard work and energy was devoted to making changes and adaptations

in their lives. It involved learning new ways of thinking and doing that was unique to their particular circumstances. This involved trial and error and all of the women referred to this in one way or another as a learning process. Self-care meant educating themselves to live their life in a new way. The changes brought to them by chronic illness created circumstances that challenged their more creative side. The continuous adapting and learning also refocused their evaluation of the health care system. They saw themselves as reluctant to rely on a system that was fairly unresponsive to their circumstances, yet also understood that it was necessary to access the formal system from time to time.

Seeing the health care system through a more critical eye, the women became adept at figuring out what they really wanted from the system. They came to terms with what they could and couldn't control. All the women understood self-care to be the control of any decisions related to health care management of their RA. They had learned to identify what they required from health care providers and they undertook measures to ensure decisions were in their favour. The women spoke of negotiating with doctors or other health care providers for information, time, medications, treatments, and a range of other items as part of self-care.

To access the health care system in a manner that suited their circumstances, the women aligned themselves with health care providers who facilitated this aspect of their self-care. As they broadened their support network to include others with RA, it became apparent that there were ways to work the system to get what they wanted. Some women also saw that accessing services outside the formal system was more relevant to their situation as they became more familiar with a

broader range of health care services.

Self-care in the context of rheumatoid arthritis was certainly a complex and multi-faceted personal and social experience. The above summary of findings illustrate that self-care is a dynamic, evolving, and personal experience, carried out in various ways within the multidimensional lives of these women. Self-care takes place within the changing and dynamic context of family lives, communities and also within a system of health care dominated by the cultural influences of biomedicine. Self-care was generally learned by a process of trial and error and it evolved over time to include a broad scope of activities that included managing, dealing with, and educating the health care system.

Discussion

The findings from this study of women with RA reflect similar findings from the studies done with the chronically ill by Corbin and Strauss (1988), Strauss et al. (1984) and Thorne (1993). These published studies investigated large numbers of chronically ill individuals over time, including women with RA and their families and obtained their perspectives on many aspects of their illness experience. These studies chronicled similar findings that reflected the meanings and understandings of self-care for the women in this study. Self-care was hard work, it was learned over time, it involved more than care of the physical self or participating in the routine aspects of daily activities, and it frequently consisted of partnering or negotiating relationships with health care providers.

The images that are evoked from this study are of complex lives filled with medical regimes, management of many physical and emotional problems, and

negotiating health services. The contrast is striking when compared to the usual social images of victimization and passivity as characteristic of the chronically ill.

Pain was a day to day reality for most of these women. All experienced unrelenting pain at the onset of their RA. For some it subsided as the disease came under control, for others it was a persistent invasion into many aspects of their lives. It affected sleep quality, energy level, mood, relationships within and outside of families, and work abilities. The most pressing problem for the overwhelming majority of arthritis patients is pain (Wright, 1992). The pain of arthritis is usually severe and either under-treated or mistreated. Uncontrolled chronic pain is destructive to a person's sense of self and quality of life, as well as being a predictor for loss of productive work and future disability (Burckhardt, 2001; Chapman & Gavrin, 1999). The idea that pain can pervade so many areas of one's life is documented in all studies from the perspective of those with RA (Brown & Williams, 1995; Corbin & Strauss, 1988, Ryan, 1996; Strauss et al., 1984, Thorne, 1993).

The experience of pain and their efforts to seek relief created fear and uncertainty in the lives of the women. It also was the beginning of experiencing conflictual relationships with health care providers and set the stage for developing strategies of maneuvering within the health care system. The accounts of these women detailed the strategies they developed for coping with the pain of RA. These involved some self-taught skills that were developed out of desperation for pain relief. The combination of strategies learned through clinical encounters and through their own methods is uniquely chronicled in this study.

The women had inconsistent or poor communication with health care providers

and frustrating encounters with doctors. Their relationships with health care providers became a significant component of self-care experiences, as these were the people whose actions and attitudes determined the level of distress the women would experience in the course of their illness. Health care providers also held the weight of authority in access to the health care system as well as determining the course of medical treatments. Negotiating partnerships with care providers they could trust became an aspect of self-care that determined the future course of their illness. The shift in unsuspecting reverence of doctors and other health care providers, to complete disillusionment, to a negotiated partnership is considered a major adaptive task for those living with chronic illness (Barnard, 1988; Duff, 1988; Kleinman, Eisenberg, & Good, 1978; Ryan, 1996, Shaul, 1995; & Thorne, 1993).

Education of health care providers was viewed as a solution to distressing clinical encounters. The women believed that if their care providers were enlightened about the disease of RA and as it personally affected them, it assured individualized attention to their particular problems. This management aspect of health care relationships was a form of reconstructed trust (Thorne, 1993). However, these women took this idea a step further with their intentional undertaking of a teaching and learning event. The intentional teaching of health professionals was accomplished after intense searching for a suitable candidate and from the stories of these women there were few. The deliberate attempts to engage in an education process where power relationships have shifted is not discussed to any degree in the literature. The women in this study were all well educated and three of them worked in the health care system, currently or in the past, and had confidence in their ability to influence their situation. Undertaking

these efforts to educate a trusted health care provider required knowledge, skill, energy, and time. It was also considered self-care.

Managing the emotional aspects of the chronic illness experience was a key component of self-care. The self-care work related to managing fear, depression, and grief was described in detail and suggested this feature of the overall experience of RA was significant for these women. This aspect of self-care required considerable analysis and modification of emotional responses to the course and prognosis of RA. Emotional work was just as time consuming and important as other health maintenance work. A notable feature of the self-care work related to dealing with emotions was that it occurred almost exclusively outside the health care system and in some accounts was made more difficult because of encounters with health care providers within the system. Dealing with emotions is a common thread throughout other qualitative studies examining the overall experience of RA (Brown & Williams, 1995; Ryan, 1996; Shaul, 1995) and other chronic illnesses (Corbin & Strauss, 1988; Strauss et al., 1984; Thorne, 1993).

The women recounted that the idea of self-care really had no significance or meaning for them before the onset of RA. Once RA became a part of their life, self-care became something to think about as a means to manage an intrusive new reality. In reviewing the literature for this study, the vast majority of the ideas and debates about the definitions of self-care, which activities constitute self-care, or how health care professionals have conceptualized self-care did not reflect the realities of the lives of these women. The predominant focus in most of the literature related to medical health care is on changing the behavior of the individual through self-care. The stories of these

women dispute the notion that self-care occurs in isolation of the world around them. The notion of self-care and how it fits into the biomedical frame of reference represents a false ideal that concentrates on getting individuals to change certain behavioral practices rather than looking at overall patterns of daily living that protect and promote health. This study suggested that the notion of self-care is problematic because of its emphasis on the individual. Engaging with others to manage health and illness was a necessary component of the self-care experiences of these women. Social concepts of health, as articulated by Epp (1986) and the World Health Organization (1986), and determinants of health (Health Canada, 2001) take into account the socio-economic and environmental aspects of self-care that was experienced by these women.

The Arthritis Self-Management Program has been implemented widely across Canada. The program is offered as a way for people to learn skills in symptom management and build good communication with health care providers. It is a generic program, with specific protocols, designed to be offered to people with all types of arthritis. It is taught or facilitated by people who usually have arthritis themselves. Despite being heavily promoted in Arthritis Society literature and on posters throughout the Mary Pack Arthritis Centre, only one woman in this study participated in this program and she described it as "depressing".

The ASMP has been extensively researched and has demonstrated its effectiveness for improving the health status of people with RA through enhanced self-care strategies. The findings from this study of women with RA, however, raises some questions about the lack of appeal of the ASMP for these women. The women in this study revealed high levels of self-efficacy for management of their RA. Their stories

revealed a personal sense of empowerment related to their ability to control and manage their health care. Perhaps the ASMP has appeal for those who perceive themselves or their situations as deficient in some way. Could it be that the ASMP operates on a deficit model of self-care? The findings of this study suggest that these women may have been interested in a program that offered a more participatory approach that allowed for development of skills to influence some of the broader key determinants of their health.

The women in this study also wanted factual information on what was wrong with their bodies. They wanted detailed information on RA, what caused it, medications, and treatments. They were trying to make sense of what was happening to them and to determine new, relevant ways of managing their lives with RA . An examination of the some of the underlying theoretical assumptions and values of the ASMP may provide some answers as to why this program had no appeal for these women.

The program's aim is to enhance participant's self-efficacy for changing certain behaviors such as management of pain, developing an exercise program, or building good communication with health professionals. The basis for the efficacy enhancing strategies is Bandura's (1977,1982, 1986) social learning theory. The goal is behavior change for certain activities. These changes in individual behaviors eventually will improve health status, but the two are not causally linked. Why and how the improvement in health status occurs has not been fully explained in the literature to date. Another underlying goal of the ASMP is to reduce health care utilization and this is an explicit goal of the program. The implication for people with RA is that their personal behavioral choices will lead to either "good" or "poor" health status. Assigning personal

responsibility for health behavior choices to individuals with RA assumes they can make choices regardless of their social environments. The women in this study were deeply enmeshed in their social environments and the health care system played a huge part in their daily lives. An emphasis on individual responsibility for health care choices ultimately blames the person with arthritis for health related problems or non-improvement by ignoring the social, political, and environmental context where health care decision-making occurs. This is particularly true for chronic illnesses where improvements sometimes never occur and illness is characterized by episodes of recurring health related problems.

The role of family and friends was not addressed to a large extent in this study. The women talked about family as being "very supportive" or being a comforting presence, but these comments were not explored in depth. Families were certainly a presence in their lives, but remained in the background as they told their stories of self-care. This is in contrast to the studies by Corbin and Strauss (1988) who told richly detailed accounts of this aspect of chronic illness management in the home.

The meanings and understandings of self-care discussed by these women were embedded in the realities of their day to day lives. Self-care was not a discreet event or a specific behavior; self-care was living with RA. Their experiences of self-care were framed and described from within their whole experience of RA. The literature related to health promotion takes into account the broad range of determinants that influence health and acknowledges its role in determining quality of life. These key determinants include income and social status, social support networks, education, employment and working conditions, social environments, physical environments, personal health

practices and coping skills, healthy child development, biology and genetic endowment, health services, gender, and culture (Health Canada, 2001). The Ottawa Charter for Health Promotion (World Health Organization, 1986) as well as the framework for health promotion proposed by Epp in 1986 set the strategic course for Canadian efforts at advocating for healthy public policy, strengthening communities, and reforming health systems. Today, that strategic direction remains relevant and continues to provide a useful way of understanding the influences on health other than disease and illness.

The experiences of the women in this study, from dealing with the health care system to trying to resolve feelings of depression, all illustrate the contextual influences on health. Drawing on the principles and values of health promotion, Dean and Kickbusch (1995) understand self-care to be an active social behavior occurring in the context of daily living in the absence or presence of illness. The women in this study talked about self-care becoming more immediately relevant to them with the onset of RA. Coping with symptoms, searching for information, and dealing with the health care system became more urgent in the context of illness.

The influence of the health care system and its care providers was a significant factor in the women's lives and therefore wove a significant thread throughout their accounts of experiences of self-care. From the perspectives of these women, control within the system was critical in determining their access. A desire to maintain control over illness management did not mesh with the dominance and authority of biomedicine which is the framework underlying not only medical practice, but most health care delivery systems in Canada. The curative, disease-based structures were very influential in creating the problems with the health care system confronted by these

women, as it was in the studies done by Brown and Williams (1995), Corbin and Strauss (1988), Ryan (1996), Shaul (1995), Strauss, et al. (1984), and Thorne (1993).

It has been suggested that continuing to spend money on the biotechnical model of health care will do little to improve the health of the population (Edwards, 1997). This study found that self-care in the context of RA was influenced by many factors.

Refocusing the emphasis to life and health, of which RA may be one component requires a fundamental shift in thinking about our entire health care system. The meaningful benefits of a health promotion approach, which acknowledges the key determinants of health, for practice, policy and research should be embraced by health professionals interested in working with women with rheumatoid arthritis.

Implications for Practice

To address the reality of daily pain in the lives of women with RA, health professionals should adopt multidimensional pain assessments which broaden the information base to plan treatment which addresses the whole experience of pain. Inclusion of patient self-reports and perceptions of the pain experience should always be considered legitimate information which then determines the treatment plan. Understanding of the person's pain experience and the implications of living with pain everyday should also be considered valuable information. Treatment and management options should include the choice of medication, as well as non-drug methods, based on the preferences of the person with RA. In addition, health professionals should take into account the environmental, and social and emotional factors which all influence the pain experience. Collaborative planning, with the person with RA, could identify strategies or resources to manage the identifiable concerns.

Nurses in most health care settings and many other allied health care providers in Canada cannot prescribe medications. Doctors who have been educated in current pain management practices, and who can prescribe medications, should be sought out by health care providers advocating for people with RA. Current accepted pain management guidelines includes the use of narcotics and opiates for chronic, non-malignant pain, but many doctors are uninformed of current practices and avoid adopting this approach with patients with RA. Continuing professional education for medical doctors who provide care for those with RA should include evidence-based pain management practice guidelines. The Canadian Pain Society is active in providing this type of education and should be approached by the Mary Pack Arthritis Centre to develop strategies for ongoing education of all rheumatology health care providers.

Control over decision-making with regard to medical care has traditionally been the realm of doctors. It is a feature of health care system organization that allows only those in "authority" to control these decisions. From the perspective of women with RA, as much control as possible should be in their hands. Nurses, as well as other allied health care providers, have often been the person who has listened to patients' accounts of their illness experience at length and are in a key position to determine, with the patient, the most beneficial course of action.

Nurses, in their clinical practice with women with RA, should be active in developing a health promotion approach that operates within a determinants of health model. In this framework of practice, nurses can direct their efforts towards understanding a person's larger life context, personal goals, aspirations, and day to day life. The findings of this study suggest that women with RA would certainly benefit from

developing multi-faceted, holistic partnerships with health care providers that goes beyond focusing on developing self-care skills focused on activities of daily living. This frame of reference allows nurses to work creatively with women with RA to pursue strategies that value open-ness, playfulness, humour, and flexibility. Attention to the illness of RA, promotion of acceptance, and management of limitations are indisputably important components of care, but focusing only on these factors constrains the possibilities for health.

The allocation of time and effort to listening is a critical component of nursing practice and especially for those with RA who may have never had the opportunity to tell their story. The women with RA all suffered significant emotional distress at some point that was downplayed or ignored by health care providers. The opportunity to talk with someone who listened respectfully, didn't judge them, and treated them with dignity was a significant gap in their attempts to communicate their distress to doctors and other health care providers. Nurses should recognize the clinical encounter as a site of learning and always be attentive to the possibilities that arise as patients tell their stories or ask questions. The adoption of practices which encompass active listening and open ended questioning about the lives and the health of women with RA could potentially facilitate awareness of their own potential for health.

Continuity of care giver is another important element of nursing practice that should respond to women with RA. The mutually respectful partner relationship with a health care provider was highly valued by the women in this study. Nurses should strive to keep these caring relationships intact and work at resisting the efforts of administrators within the health care system to assign and delegate work to nurses on

the basis of tasks or as an extension of the biomedical work of illness care by doctors. Working with patients in settings that appreciate a health promotion practice should allow for ongoing relationships between patient and care giver. The value of participating in an authentic partnership with patients can't be measured as clearly as the number of patient attendances in a day, but the human costs can be determined by a person's sense of being understood, supported, and personally known by their health care provider.

The provision of information for persons with RA should be a priority for health care providers. Paying attention to the clinical encounter as a site of learning should motivate health care providers to be more responsive to patient's requests for information. Health or medical information should be provided in a manner that is best suited for that person's circumstances, as determined by them. Health care providers could improve their service to the educational interests of patients with RA by simply answering their questions. Taking the opportunity to help those with RA make sense of the new reality of a life with RA can be shaped by the substance of clinical encounter.

The women in this study found that the socially constructed role of doctors or other health care professionals as experts in all health or disease matters required substantial revision in order to adapt to their educational needs. Consideration of this issue could be addressed in the educational curricula of all health professionals. Building in philosophical underpinnings which support the patient as a partner, with an emphasis on shared expertise, into the curricula could provide a foundation for changing traditional clinical practices which place the health care provider as the authority in the clinical encounter. Shifting the care provider relationship to one that

fosters a genuine partnership that honours the expertise of both participants would also require continuing education for health professionals that includes information about programs, tools, and information resources. People with RA could be consulted and perhaps be involved in teaching health care professionals about how and where they access educational resources.

Implications for Policy

The findings of this study made it evident that there are no clear distinctions between health and other aspects of social life. Staying healthy for these women included financial security, supportive social relations, productivity and dignity. Where these are denied or inaccessible could put health, for chronically ill women with RA, at risk.

Addressing the social determinants of health requires a health promotion approach which influences policy decisions both inside and outside the health sector. The social and economic climate of the Ottawa Charter (1986) and the Epp (1986) report have changed considerably, but the founding principles of the strategic framework for health promotion can still be drawn on to make some public policy recommendations.

Within the health sector, there remain inequities in access to services particularly as it relates to those with chronic illness. Significant amounts of public money continues to be invested in hospital-based health care at the expense of services that would allow people with chronic illnesses to remain in their communities. There should be more health services available at the local level for those with RA who cannot afford, financially or otherwise, to travel to a large urban hospital to obtain health care services.

Focusing health promotion practice towards social determinants of health requires policies that facilitate healthy living conditions. These should include the provision of the resources to local or regional health authorities to support families, strengthen primary care, and improve community based services for people with RA. Strengthening communities requires a commitment of resources to utilize community development approaches with people with RA whose living and working conditions place them at high risk for health problems. Policies that support community participation in decision-making could strengthen the health of groups of people such as women with RA.

Keeping health promotion at the centre of the today's health reform debates requires the production of clinical evidence. This study can provide useful information for those who seek evidence for sustaining and strengthening a health promotion infrastructure within the health care system. Policy support for this type of infrastructure should include participation in alliances with other sectors such as social programming, environmental, or educational services. These sectors are not necessarily focused on health care, so it becomes important to position health care discussions within their frame of reference.

Policies which support health information technology initiatives could also reduce inequities in access to information and educational resources for women with RA. The knowledge gained from this study could be combined with existing knowledge to develop effective health promotion policies and to avoid the development of programs that have little relevance in the day to day lives of people with RA. This study also contributes evidence of the curative and medical treatment bias that exists in the

health care system. Educational curricula for health care professionals should address this bias. The knowledge of self-care experiences and what they mean to women with RA should inform policy makers of the fundamental role that people play in determining their own health.

Implications for Research

All the women in this study stated their desire to help others with RA by participating in this study. By telling their stories they were hoping to influence changes in the health care system. Talking about their experiences provided opportunities to consider other ways they might change the health care system and other resources or services to assist people with RA. Health professionals and adult educators interested in research with women with RA should consider adopting participatory action research approaches to involve women with RA in changing the health care system. Kemmis and McTaggart (2000) discuss using this research approach where participants in a particular social setting "take an active, agential role in changing the processes of construction of social realities" (p. 573).

Many further opportunities exist for understanding the meaning and relevance of self-care in the day to day lives of people with RA. Qualitative research approaches that explore the perspectives of men, those of other ethnic and cultural origins, different age groups, different educational and economic circumstances, as well as those living outside of urban centres could all contribute to our current understanding of self-care. In addition to understanding the meaning and relevance of self-care to those with RA, researchers should consider how self-care is understood by other communities where chronic illness is a collective concern.

The ASMP course facilitators include women with RA. These women should be invited to tell their stories about self-care and what it means to them. It would also be informative to hear their views on the ASMP program and its relevance in self-care experiences.

The role of family and friends within the experience of self-care in the context of RA should be explored further. RA is thrust into the lives of families and friends and is part of the social environment where the person with RA is deeply enmeshed in a variety of relationships. Extending research to include these accounts would add further richness to the detailed findings of this study.

The women in this study were all recruited from a health care centre providing a range of medical and health services. Three of the women were or had worked outside their home as health care professionals. It would be interesting to conduct further research studies involving women with RA recruited from settings where health care or medical services were not the focus, such as community recreation settings or educational institutions.

In Closing

This study with women with RA has revealed a complex personal and social experience. The meanings and understandings these women had about self-care involved many social, environmental, and emotional factors. Interactions within a complicated health care system stood out as the primary force shaping their stories of self-care and living with RA.

The strength these women demonstrated as they grappled with personal physical distress, demoralizing communications with health care providers, suffering

many losses, and a paternalistic health care system was remarkable. Their attempts at acquiring knowledge, understanding their bodies, determining actions to deal with problems, and how they maneuvered themselves through the bureaucracy of the health care system were understood to be self-care. Self-care occurred in the context of health and RA. This study found that health and illness were intertwined in the day to day lives of women with RA.

Today's climate in health care, as well as other sectors, is one of economic constraint. Health system reform seems to be focused on keeping biomedical, acute health care systems afloat and the effects have been to marginalize systems that support the chronically ill. Mass layoffs in health care and social services have resulted in fewer health care providers to work with those with RA at a time when they most need it. Supports for a health promotion approach to my own nursing practice have been realigned without consideration for the health of those patients, primarily women, with whom I have maintained ongoing relationships. As people become more vulnerable, they will have less access and interface with health care providers to support them in working their way through an intensely insecure and ever more authoritative health care system.

My day to day practice with chronically ill women will be challenged in many ways as our clinical encounters become sub-optimal from the perspective of a health promotion approach that recognizes and responds to determinants of health other than disease. Access to other care providers will also be less available and affordable, as recent health policy decisions have delisted certain services, such as massage therapy and chiropractors, from fee-for-service eligibility. Those who are disabled and rely on

income assistance will be more severely restricted in access to services which can support and maintain them in their own communities. It becomes more imperative to firmly place myself as an active partner with women with RA by advocating on their behalf within the health care system. I will continue to strive to be a role model for other health professionals to demonstrate the potential benefits of developing multi-faceted, holistic partnerships with patients.

At the end of this study, it appears the struggle will persist to maintain these valued partnerships with chronically ill women with RA in a health care system that is profoundly shaped by policies, rules, and procedures that serve the interests of acute illness care. Such a system that organizes its interests around the clinical interests of acute or emergency illness reflects the assumption that patients are resources that feed the system rather than the intended beneficiaries of its existence. Health care systems oriented towards the provision of curative services, with rigid admission and discharge rules, generally do not recognize the health care interests of chronically ill. From the perspective of the women in this study, this suggests that an important element missing in the way health care systems are organized is the recognition that their illness is chronic and not curable. For the women in this study, the health care system had enormous difficulty adapting to the very nature of RA, with its everyday-ness characterized by flares and remissions. This set the stage for frustrating and tense clinical encounters within that system. It becomes even more urgent, in this context, for myself and other health care providers to acknowledge these limitations within the current health care system. We need to take measures to adopt and advocate for an expanded health care practice which is framed by the determinants of health.

Resources and strategies for addressing health and chronic illness would best be addressed from a health promotion perspective, utilizing a determinants of health model, where health and illness are not viewed in isolation from each other. Public policy development should be aimed at support for and development of strategies that attend to the determinants of health that are a daily reality for women living with RA.

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Appendix A

Interview Guide

This interview is to assist me in understanding and learning about your experiences of self-care of rheumatoid arthritis. The experiences and stories I hear from you will be eventually used to help improve services and support for people with rheumatoid arthritis. My research study is not to test your knowledge about rheumatoid arthritis or to evaluate how well you are managing. I am more interested in understanding and learning about your own personal experience.

1. Tell me about your current life circumstances. For example: age, education, home & family, employment, # years of RA.....
2. How would you describe your life and experience with rheumatoid arthritis?
3. Since you have had RA, what is a typical day like for you? A really good day? A really bad day?
4. Tell me about your experiences/encounters with the health care system (specialists, pharmacists, nurses, therapists, etc...) and other health care professionals you've had to deal with because of RA.
5. How have these individuals helped or not been helpful with regard to your daily routine and how you are managing living with RA?
6. What does the term "self-care" mean to you? Some of the literature I've read to prepare for this study talks about the importance of self-care; what do you make of this idea?
7. What kind of advice would you give to health professionals about working with people with RA? What would you like to see changed that would allow you or others to manage better?
8. Any questions about the study? Any suggestions for areas you think are important, but have not been covered?

Appendix C

Letter of Introduction

[Date]

Dear [name]

My name is Cheryl Magnusson and I am a graduate student in the Adult Education Program, Department of Educational Studies, Faculty of Education at the University of British Columbia. Thank you for indicating your interest in participating in my research study on rheumatoid arthritis and experiences with self-care. The purpose of this study is to explore the experiences of self-care in people with rheumatoid arthritis and to investigate the factors that influence their self-care experiences. My research supervisor is Shauna Butterwick, a faculty member of the Department of Educational Studies.

My contact with you will consist of two, possibly more, in-depth interviews for a total of two to three hours of your time. We can break the interview sessions down into the lengths of time you feel you will be able to tolerate sitting and talking with me. With your permission I would like to use a tape recorder to record our interviews. If you agree, you will be able to shut the recorder off at any time or I will follow your instruction to shut off the recorder at any time.

You have the right to withdraw from this study at any time without an explanation. Your access to services at The Mary Pack Arthritis Centre will not be jeopardized.

Measures will be taken to ensure the information obtained from you remains anonymous and confidential. The tapes and files of our interviews will be identified only by code number. Your name will not appear in any published results. All data gathered will be kept in a locked cabinet and any data stored on a computer hard drive will be password protected. A handbook with a summary of self-care strategies from the study findings will be made available to you when the analysis is completed. The estimated date of completion is August, 2001. Tapes will be erased and files of our interviews will be destroyed five years after the end of the study.

Appendix E

Agency Consent

Self-Care Experiences of People with Rheumatoid Arthritis: A Qualitative Study

September 25, 2000

Cheryl Magnusson, candidate for MA
University of British Columbia
Faculty of Education
Department of Educational Studies
2125 Main Mall
Vancouver, B.C. V6T 1Z4

Dear Cheryl:

On behalf of the Mary Pack Arthritis Program's Research Committee, I am granting you permission to recruit potential research study participants with rheumatoid arthritis from within the Mary Pack Arthritis Centre building. Recruitment will be conducted by posting and having staff distribute an advertisement. Potential recruits will either contact you themselves or leave their phone number with a staff person for you to call. Participants will be asked to volunteer two to three hours of their time to be interviewed by you. The number, length of time, and place of the interviews will be negotiated depending on the participant's preferences and abilities related to their rheumatoid arthritis.

Participants may be recruited once you have received approval from UBC's Behavioral Research Ethics Board for your study. Please forward a copy of your Certificate of Approval to Marilyn Choy when approval from that board has been granted.

Sincerely,

Andrew Chalmers, MD, FRCPC
Chairperson
Mary Pack Arthritis Program Research Committee