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**Giving Voice to the Experiences of Hospitalization:
Individuals with Rheumatoid Arthritis**

by

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Abstract

In this study constituents of the hospitalization experience are explored by asking the question: How is hospitalization for surgery experienced by individuals who have rheumatoid arthritis?

Using narrative inquiry, I interviewed adults with rheumatoid arthritis who had undergone hospitalization for surgery. In attempting to increase understanding, to achieve a higher level of awareness, and to give those with chronic illness a voice in their hospital care, I offer a probing look at the experience of hospitalization for surgery in the context of also dealing with a chronic illness. The participants' narratives describe an inter-relatedness between the relational aspects of their hospitalization trajectory and the quality of their illness management trajectory after dismissal from hospital.

What was learned from the study participants' stories mines the often-challenging relationships between the self-managing chronically ill and the acute hospital practice community. It has implications for both health care practice and educational preparation for practice.

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CHAPTER 1

Silences: They Have No Idea How That Is For Me

Entangled Encounters: A and B

A. They do forget. They brusquely come in and say to you, "Just get up." It's day three after my hysterectomy. They don't look at me as a person; they look at me as a hysterectomy. They have no idea how that is for me. Having the nurses try to help me is sometimes the worst thing in the world because I have no control. They patronize me. Calling me "Dear" or "Sweetie" only increases the aggravation. They make assumptions about what I can and I can't do. I always think that if someone has arthritis then the nurses might ask, "How can I best help you?" They only attend to what you are admitted for. Every other thing that you are dealing with is apparently gone. So that is why my stress level goes up and my arthritis gets worse when I go into hospital. —Lil

B. I had seen Mary just the day before. These were days of blue skies and autumn scents. We had talked of how things would be if they could be the way she wished. This is not how she wanted it to end. She was 83. The diagnosis of cardiac failure did not change how the decreased cardiac output affected her living. Indeed, she had been living with the contingencies for some time. However, her life, henceforward was changing profoundly. A recent spate of cardio-pulmonary crises precipitated a hospital admission where the appropriate approaches provided temporary reprieve. What she had thought of as a temporary need for help had evolved into a mandated move to "long term care." As a nurse, I know what

that means. Mary is not a nurse. She, too, knows what that means. She has seen its meaning played out among her friends.

Hence, I strategize. She had noticed and I had noticed the effects of what the cardiologist had described as “thirty percent of normal cardiac output.” The diagnosis on her chart now reads: chronic cardiac failure. She fatigues easily; she sleeps fitfully, she eats little; she communicates sparingly; but she still thinks of herself as the same person she was. She is the same person. She is precious and I will advocate for her. I discuss the situation with the long-term care facility’s patient care manager (PCM). I go to the meeting holding several assumptions. My first assumption is that the nurse, who is the PCM, plans the care of new admissions based on the situation that brings them to her facility. My second assumption is that the knowledge that I have of Mary’s circumstances, if shared, will help the PCM to plan her care in a way that will optimally support Mary’s functional capacity. I share with the PCM that Mary’s finite energy reserves are quickly exhausted and that she very much values carrying out her own personal care if allowed to use her energy in that way. The PCM’s preference is that she should walk or be wheeled to the dining room for meals like everyone else. I highlight the merits of allowing Mary’s day to unfold somewhat differently in order to optimize her self-care ability. We discuss the plan. I relay it to Mary. The PCM and I agree that I will come at 8 a.m. to help Mary with breakfast in her room.

I return at 8:00 in the morning. Mary is gray with fatigue. Her mouth is set and she is silent. She is unable to care about the usual points of dignity, which are central to her integrity. She is a changed woman. We

drift through the day together. I come to understand that she was awakened at 6 a.m. and walked to the dining room for breakfast.

"How was that?" I ask.

"Awful," she replies, her gaze averted. "I couldn't eat."

I offer the things which I know she values: continence, personal hygiene carried out in privacy, short diversions of activity and long periods of silent rest. I feel like I am trying to protect an endangered dignity and a fragile body. I discuss the situation with the physician and, later, with the PCM. The physician understands what is meant when I communicate Mary's preferences for how she would like to use her limited energy. She understands that maintaining continence and personal hygiene are more important to this woman than is joining the other residents for breakfast at 6 a.m. Given her biophysical realities, Mary cannot do both in a day. In contrast, the discussions with the PCM help me to understand, hauntingly, the consequences of comprehending entirely from the outside. I know that this nurse is seeing the situation in a dry, impartial light. Mary is not the only individual whose care is the responsibility of this PCM and her staff.

"It's what we do here," she says, objectively, "I assure you that she will get used to it. I think that she is just angry about the change."

On that day I comprehended language and nursing in a profoundly personal way. A single word collided with itself in a paradoxical way—the "care" of which the PCM spoke had nothing to do with caring, as I knew it with respect to Mary, who is my mother. The PCM's statements resonated sense and sensibility, her sense and my sensibility. It was a dry, impartial

message, which metamorphosed on its way from sender to receiver, into a dead and de-humanized message.

These are two fundamentally different encounters, which are entangled in my experience. A patient tells the first story to me. Her story and other similar stories that were told to me by other patients with chronic illnesses, bring me back again and again to a dilemma. In such stories I, by virtue of my professional capacity as a hospital nurse, am implicated as one of the “they” referred to by the patient who is telling that story. The second encounter is a story of my personal experience. I share this story reluctantly, out of fear that it may be received by the reader as the rhetoric of conclusions drawn from a personal wound. Dwelling on such an experience can be considered dangerously narcissistic. I concede that I have sometimes thought such intimately personal experiences, when used as formal teaching devices, to be somehow unprofessional and too subjective to be taken seriously from a theoretical perspective. Nevertheless, the two stories depict the interface of my personal and professional experience. Each holds meaning for me and thus they comprise narrative knowledge in my practice. They are perturbations that evolved into the challenge that was to become the impetus for this research endeavor. These entangled encounters are central to the person, the nurse, the learner, and the researcher that I am.

From Ingress to Egress

Having realized, long ago, the relational differences between practicing nursing with and without the connection of participating with patients, I practice with the possibility of participatory connection as part of my knowledge base. Schön (1983) characterizes such a process as reflection-in-action. Nonetheless the

awakenings of ingress are limited when kept to oneself. Clandinin and Connelly (1995) suggest that, for knowledge to be truly transformational, the outward motion of egress must necessarily follow reflective ingress. They advise that there is epistemological significance in moving beyond the safety of secret stories. They believe that transformational possibilities are increased when stories are shared in public conversations, despite the risk that such conversations may be portrayed as nonexpert and romantic.

The question for this inquiry grew out of the dilemma of silence. I was gripped by the realization that to remain silent while my private repertoire of stories and experiences swells, is not helpful in tipping the balance away from the morass of “they’s” to whom Lil refers; “they” are those who are unaware of how it really is for their patients. Accordingly, I committed to contemplate analytically the experiences of a select group of patients and to articulate publicly the process through this inquiry.

From Contemplation to Purposeful Inquiry

The purpose of this research was to explore the experiences of persons who have a chronic illness and who have undergone surgery in an acute care hospital. Specifically, the study focused on the experiences that stood out for individuals who have rheumatoid arthritis (RA) and who were hospitalized for surgery.

This research was aimed at listening to stories and discovering knowledge that reveals the particularity of patients’ hospital experiences. It is based on the theoretical premise that subjective experiences are both valid and valuable sources of knowledge (Atkinson, 1998; Chinn, 1997; Gadow, 1995; Clandinin & Connelly, 1995; 1994; Connelly & Clandinin, 1990, 1987; Morse & Johnson, 1991;

Polkinghorne, 1988). Mathieson & Barrie (1998) suggest that stories represent the most internally consistent interpretation of presently understood past experiences. They express the essence of personal experience and such storied knowledge can be explicated through narrative (Connelly and Clandinin, 1990). Therefore, narrative inquiry was employed in this study. Narrative inquiry is the study of the ways that people experience the world as told through their stories (Connelly & Clandinin, 1990; E. McKiel, personal communication, May 06, 1999).

From Purpose to Question

The purpose of the inquiry gave rise to the question: How is hospitalization for surgery experienced by individuals who have rheumatoid arthritis (RA)?

From Silence to Significance

For Lil and for Mary there were everyday realities that remained absent from the consciousness of hospital personnel whose decisions impacted these two individuals in profound ways. Gerhardt (1990) notes that in the area of long-term illnesses it is vital for those involved in care and treatment to know what effect interventions have, not only in clinical terms but also, in terms of an individual's everyday realities. Cott (1987) suggests that health professionals can better serve patients when they recognize the patients' personal experiences of their illnesses. Ailinger and Schweitzer (1993) found that optimizing functional capacity is a primary concern for patients with RA. They suggest that nurses caring for such patients should heed their particular concerns and the possible impacts of the care setting and of interventions. More recently, Leidy and Haase (1999) investigated functional status from the perspective of the

chronically ill individual. Their results support the inter-relatedness of functional capacity and personal integrity. On the basis of their results, they suggest that preservation of personal integrity should be a central aspect of care provided to persons with chronic illnesses.

Coles (1989) espouses that the stories of other people, written or spoken, can lead us to a deeper knowing of ourselves. Hence, he advocates that an important part of our lives should be spent listening to the stories of others. Personally, I find Cole's advice compelling and paramount to supportive care in nursing. Examining a situation from multiple perspectives enhances one's understanding of that situation. When the story of another reverberates within us and calls forth one of our own, it enables us to understand each of the stories more comprehensively and thereby it enhances our understanding of ourselves and of others (Conle, 1996).

As a nurse, I practice in two places in the hospital culture: at the side of the patient with whom I engage and, within the hospital matrix wherein I am a constituent of a larger element. In both circumstances, I share a measure of moral freedom as I respond to dilemmas that present themselves. I am a moral agent. I am in charge of my responses to the situations that present themselves. What can be learned from this inquiry is valuable, not only for me as I encounter the chronically ill in hospital, but also for the greater hospital community. In order to develop a more informed basis for supportive hospital practice, there is a need for research which reveals how patients experience their illnesses in specific hospital circumstances (Brown & Williams, 1995; Dennis, 1990; Miller & Crabtree, 1994).

CHAPTER 2

Voices in the Literature

The quest for understanding is like a journey into a strange territory. Such a journey is best guided from multiple perspectives. One can venture toward a new experience in a strange land without prior study about that territory, relying entirely on interaction with the locals; however, seeking out what is already known about the territory prior to arrival there can greatly enrich one's learning as one passes through. Prior knowledge heightens one's sensitivity, stimulates one's interest and informs the questions that one asks of the locals as one travels through new territory.

In a similar fashion reviewing the existing literature prior to a research journey enriches what can be learned. Such a review stimulates thought and raises questions that are relevant to the research focus. Literary voices informed and provided background and thereby support the present research.

The research question reflects three components fundamental to the exploration of the hospitalization experiences of individuals who have a chronic illness such as rheumatoid arthritis (RA): the nature of rheumatoid arthritis, living with a chronic illness, and the experience of hospitalization for surgery. These components provided my organizational framework for probing the literature.

First, literature pertaining to key medical aspects of RA and to the personal implications of RA is highlighted. Rheumatoid arthritis presents itself as a condition for which medical treatment is sought. It also results in life contingencies that construct the condition as a chronic illness. The term 'chronic' in relation to illness is defined as "persisting for a long time" (Hawkins, 1994,

p.263). Aside from the temporal and medically incurable nature of chronic illnesses, diverse trajectories and iatrogenic outcomes of interventions also characterize chronic illnesses such as RA. Therefore, I review literature pertaining to the personal and social impacts of the vagaries of chronic illness as well as the responses and management choices that constitute illness work and that shape the course of illness trajectories as described by Corbin and Strauss (1988, 1991). Some key differences between chronic and acute illness are outlined. The chapter concludes with a review of research regarding hospitalization and the chronically ill.

Rheumatoid Arthritis

It is estimated that between 1% and 2% of the adult population, world wide, is afflicted by rheumatoid arthritis (Lambert & Lambert, 1988; Wilder, 1993; Wolfe & Pincus, 1994). Rheumatoid arthritis (RA) is a chronic, auto-immune disorder of unknown etiology that exhibits systemic manifestations as well as articular inflammation (Anderson, 1994; Wilder, 1993). Extra-articular manifestations of RA may include dryness of the eyes and mouth, scleritis, subcutaneous nodules, cutaneous ulcerations, vasculitis, pericarditis, pulmonary nodules or interstitial fibrosis, neuritis, neuropathies, and anemia (Anderson, 1994; Halverson, 1995). However, its major distinctive feature is chronic, erosive synovitis of peripheral joints, which leads to progressive destruction of tendons, cartilage, ligaments, and bone. The severity of the joint disease may fluctuate over time, but the most common outcome of established disease is progressive development of various degrees of joint destruction, deformity, and disability. The joint destruction impacts the surrounding supportive structures.

There is no cure for rheumatoid arthritis. The current approach to treatment advocates disease modification through interrupting the complex inflammatory process. However, treatment success is difficult to prove and therapeutic decisions also rely on symptomatology. The aims of therapy are to: provide pain relief, decrease joint inflammation, maintain maximal joint function, prevent deformity, and retard bone and cartilage destruction. The basic treatment program for RA consists of patient education, the use of drugs, and achievement of balance between joint rest and exercise. The goals of exercise are to maintain or improve muscle tone, to prevent or correct deformities, and to maintain or increase joint mobility and function (Parker et al., 1988; Wilder, 1993; Williams, 1993).

The individual experiencing RA is faced with a reduction in personal resources; (resources) that are taken for granted by the “healthy” (Leidy, Ozbolt, & Swain, 1990). Mobility reduction may occur from the incapacitating effect of pain and from the fact that weight-bearing joints may be deformed or acutely inflamed. Reduction of dexterity may occur, attributable to increased pain, loss of strength, and loss of mobility. Joints that are affected by RA have decreased range of motion, and the disease can lead to joint subluxation and deformity of the hands and feet. Muscle atrophy causes loss of strength. Reduction of energy occurs, caused by the metabolic effect of the disease on connective tissues and also by the systemic effect of pain which contributes to fatigue. In turn, fatigue results in intensified perception of pain. Pain may decrease mobility, thereby successively increasing fatigue. The biopsychosocial components of RA (environmental stress, disease activity, insomnia, fatigue, immobility, depression, anxiety, and pain) are found to be dynamically reciprocal, although

the apparent interactivity is not yet clearly understood. Recently, investigators have begun to examine relationships among stress, the immune system, and other biologic variables (Bradley, 1993; Crosby, 1988; Rankin, 1993; Schumacher, Klippel and Koopman, 1993; Solomon, 1993; Wolfe and Pincus, 1994).

Individuals with rheumatoid arthritis learn to accommodate unpredictable disease manifestations, and peaks and valleys of quiescence and flare-up. They also experience the day to day unpredictability of fluctuating energy levels and other extra-articular manifestations of the RA (Halverson, 1995). The management of RA involves a combined approach that includes medications, physiotherapy, physical, psychological, and social support, as well as education (Miller, 1991; Rankin, 1993). Daily self-management decisions for the maintenance of optimal joint mobility and function reside with the individual, who must consistently work toward maximizing muscle strength and flexibility in concert with the vicissitudes of the condition (Wiener, 1984). It has been found that persons with RA who engage in active coping strategies (in contrast to passive strategies) are those who optimize their functional and psychosocial status (Bradley, 1993; Lorig & Holman, 1993; Parker et al., 1988). Based on these findings, a major thrust of patient education is directed toward self-management.

As well as experiencing the disease, people with RA frequently encounter side effects from drugs used for management of the RA, which adds the burden of balancing drug side effects against relief achieved by using drugs. Thus, both the disease and its treatment impact the quality of their lives. Although RA and its impact may vary widely in severity, it has been clearly shown that RA can affect many areas of life, including mood, emotions, social and work life, leisure

activities, everyday tasks involving role responsibilities, personal and social relationships, and physical contact (Allaire, Anderson, & Meenan, 1996; Fex, Larsson, Nived, & Eberhardt, 1998; Whalley, McKenna, DeJong, & Van Der Heijde, 1997).

Positive correlations have been shown between emotional stress level and RA disease activity. The finding of such correlations supports the notion of a psychophysiological feedback loop response (Crosby, 1988). It is therefore important that nurses, in their practice, respond to the biophysical and psychosocial implications of RA, thereby maintaining an holistic approach when providing care to persons with RA.

Chronic Illness

Living with a chronic illness dismantles the usual perspective from which one views one's functioning body. Bury (1991) has referred to this process as biographical disruption. Generally, whatever one chooses to do assumes that one has a functioning body capable of carrying out desired or expected activities without undue consideration for the role that the body plays in carrying out those actions, or the image that the body presents to oneself and to others. During periods of acute illness or injury, activities may be limited and functioning may be temporarily curtailed. However, chronic illness may permanently affect body functioning (Corbin & Strauss, 1988).

Corbin and Strauss (1988) have revealed something of the multifaceted and profound impact of chronic illness on the lives of the ill and of their families. They suggest that accommodating the chronic illness requires "illness work" which they define as "a set of tasks performed . . . alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of

the illness and the lives of ill people and their [families]" (1988, p. 9). The work involved in managing the illness and managing life with the illness is contextualised in the ill person's biography and everyday living.

The chronic illness life passage can be characterized as an illness trajectory. Corbin & Strauss (1988, 1991), in their usage of the term, state that:

trajectory denotes not only the potential physiological development or "course" of an illness but also the *work* involved in its management, the *impact* of illness, and the changes in the lives of the ill and their families that in turn affect their management of the illness itself" (1988, pp. 47-48).

The nature of a particular illness trajectory encompasses a dialectic of fatefulness and action; it embodies managing illness and experiencing illness.

The term *trajectory* focuses on the active role that people play in shaping the course of an illness. This course is shaped not only by the nature of an illness and a person's unique response to it but also through actions taken by health personnel as well as the ill . . . in its management (Corbin and Strauss, 1988, p. 34).

Chronic illnesses have particular trajectories that are contingent upon specific physiological changes. Chronic illnesses also have commonalities. Having a chronic illness involves the formation of a vision of the potential paths the illness may take as well as potential courses of action that may impact that projected vision. Successful trajectory management generally rests upon a meshing of the trajectory projections and action plans of the ill, of their families, and of the health professionals with whom they are involved (Corbin & Strauss, 1988).

A chronic illness such as RA is characterized by prolonged stable phases wherein change in either direction is minimal, or is slow. Illness management involves the work of maintaining stability in order that the ill and their families are able to actively engage in living. Properties of stable trajectory management include routinized dedication and creativity. Often, neither health professionals nor others recognize the amount of time and effort put forth to keep the illness stable and to maintain balance with other life roles in society. Moreover, Corbin and Strauss (1988) suggest that it may not be recognized by those actually engaged in the continuous work of illness management. Stability involves not only maintaining optimal function; it also involves energy management. The dissemination of energy must be balanced among that expended for three interrelated and reciprocal types of work: illness work, biographical work (maintaining one's sense of self), and everyday life work which encompasses the contingencies of day to day occurrences and task roles (Corbin & Strauss, 1988).

Several cognitive factors have been found to influence well being among persons with chronic illnesses (Bradley, 1993). The positive role of participatory control over treatment decisions has been found to have an adaptive effect (Affleck, Tennen, Pfeiffer, and Fifield, 1987; Reid, 1984). The belief that one can perform specific behaviors or tasks to achieve specific health-related goals (i.e. self efficacy) such as decreased pain and increased functional ability has been found predictive of positive health status with respect to those specific elements (Buescher, Johnston, & Parker, 1991; Lorig & Holman, 1993).

Braden (1990) has identified a strong and positive relationship among enabling skill, self-help, and life quality, supporting the notion that nurses who promote enabling skills can make a positive difference in the quality of life for

patients with a chronic illness. In contrast to much of the work on living with the limitations of chronic illness, findings of a recent study (McWilliam, Stewart, Brown, Desai, & Coderre, 1996) highlighted the experience of persons with chronic illness creating health. The study participants definitively identified chronic illness as merely one component of life. They also identified that health, for them, meant accessing internal and environmental resources which enable them to attain a sense of fulfillment or purpose in life through doing.

Acuity and Chronicity

Burckhardt (1987) contends that, "Living with chronic illness is a task that demands coping skills beyond those needed for dealing with acute or self-limiting illness" (p. 543). Whereas biographical concerns and everyday life contingencies can generally be held in abeyance until an acute illness episode or period of hospitalization has passed, the same cannot be said of chronic illness. The trajectory of chronic illness encompasses a dynamic matrix of complex conditions and processes that require ongoing, strenuous cognitive and emotional work (Corbin & Strauss, 1988). Corbin and Strauss (1988, 1991) maintain that biographical concerns and everyday contingencies are constituent in chronic illness work and life. The concept of "illness work" is common to both acute and chronic illness; it connotes active involvement and focuses on making differences or effecting outcomes. A key difference, however, relates to the anticipated illness trajectory. Recovery, defined as the process of regaining what has been altered, or getting back to normal (Germino & Pole, 1990), is at the heart of acute illness work and has been a central focus of nursing care since Florence Nightingale. Recovery is a concept that implies reversibility. The context of chronic illness requires other types of work to facilitate integrity

despite the illness, or to achieve health simultaneously with the illness.

Reversibility from the disruption is less common for those experiencing a chronic illness.

Hospitalization and the Chronically Ill

The preceding sections of this literature review have highlighted the multifaceted effects of RA and some unique features of living with chronic illness. It is fitting to examine some research regarding the interface of chronic illness and the hospital environment.

Hospital care tends to be focused on the acutely ill (Daly, 1993; Germain & Nemchik, 1988; Gull, 1987; Miller, 1991; Thorne, 1993). Hospitalization in an acute care facility presents particular problems for the chronically ill. For chronically ill adults, much of life centers around monitoring and responding to symptoms and maintaining regimens related to minimizing the effects of the illness. The traditional acute-care philosophy embedded in the medical-surgical care given in hospitals assumes patient co-operation with, and privilege of, the structural context of the care setting (Gull, 1987). Miller (1991), through her work with chronic renal failure patients, submits that hospitalization results in loss of control and in feelings of powerlessness, and that hospital routines and efficiency are given higher priority than patient needs.

Using the naturalistic approach described by Lincoln and Guba in 1985, Thorne (1993) conducted a qualitative study involving ninety-one informants with a total of twenty-two different chronic illnesses. The study report chronicles a composite of informants' perspectives on the chronic illness experience. Thorne states that for many patients and families one of the most frightening features of the experience of chronic illness was being hospitalized.

In her informants' stories, hospitals represented places where patients were often prohibited from carrying on their normal therapeutic regimens. Losing control over the pacing and planning of daily routines was difficult for all patients.

Patients stated that:

They were often subjected to the whims of whatever health professionals happened to be on duty and to the routines by which the hospital functioned. According to many of these people, general hospitals did not seem to be planned with chronically ill people in mind. Others noted that while hospital staff were always eager to gather patient information, they were often less enthusiastic about applying it. . . . The vivid descriptions that chronically ill individuals and their families gave of their experience with acute episodes reveals the extent to which such episodes influence life with a chronic illness. For the chronically ill, it seems that acuity represents different challenges and conditions than it does for those in whom acute illness is a temporary aberration from a usual state of wellness (pp. 49, 50).

Thorne concludes that the predominant characteristics of the hospital environment work against meeting needs related to chronic illness. Others also suggest that the hospital culture is better suited to the demands of acute illness than to chronic illness (Margolese, 1987; Strauss, 1984). As stated previously, the illness trajectory for people with chronic illness is shaped by their management and balancing efforts (Corbin & Strauss, 1988). Their management efforts are compromised when, during hospitalization, " . . . the care givers take control, imposing their schedule as if the specific condition precipitating hospitalization

[was] the only focus of concern” (Daly, 1993, p. 25). In a 1990 study Dennis points to the importance of negotiating mutual expectations with hospitalized patients who have a chronic illness, thereby sharing control. Because many patients hospitalized for acute care are also persons with a chronic illness, it is important that caregivers reconceptualise their responsibilities to these patients in ways that move beyond the traditional paradigms of acute caregiving.

According to Daly (1993), in a 1947 issue of the *Journal of the American Medical Association* the general hospital is described as being geared primarily to the therapeutic and general requirements of the acutely ill and as lacking understanding of the needs of the chronically ill. Daly proposes that this statement remains true in the 1990’s. One wonders why, given our vast knowledge of the nature of chronic illnesses, so little has changed. Perhaps what has been left out of the knowledge landscape are stories which can effectively expand hospital caring practices to include practical knowledge of the needs of particular patient populations. Benner, Tanner, and Chesla (1996) maintain that stories of salient events can open up new areas of practice or teach the nurse something new about nursing practice.

In the following summary of a number of qualitative studies, there are stories told in “the language of scholarly treatise” (Kluczny, 1998, p. 20). In their own voice, they provide a background that lends support to the focus of this study. Patients have been asked about their satisfaction with hospital care (Niedz, 1998; von Essen & Sjoden, 1995; Zahr, William, & El-Hadad, 1991) and about the quality of care (Gardner & Wheeler, 1986; Leino-Kilpi & Vuorenheimo, 1992; Leinonen, Leino-Kilpi, & Jouko, 1996; Nash, et al., 1994). Primarily, these studies directed the patients to comment on predetermined aspects of care

through structured interviews and questionnaires. Several interesting points evidenced in a study by Micek (1993) were that qualitative methods of study yield more usable information for care providers and, that the data collected from the qualitative interviews were much less positive about aspects of care than the quantitative data collected. Quin (1996), in a summary study of chronically ill adults in acute hospitals, concluded that health service providers have the power either to impede or to enhance the capacity of the chronically ill and that “the acute hospital can lose sight of the person behind the illness” (p. 136). Helman (1994) advanced a similar notion in describing hospitals as places where relationship and conversation are largely characterized by indifferences to the patients. These findings are similar to those of Thorne (1993), presented earlier in this chapter. Kralik, Koch, & Wotton (1997) undertook a qualitative inquiry to examine surgical patients’ experiences with nursing following total hip replacement. The findings of their study highlight the important impact of the nurse-patient interaction with respect to patients’ wellbeing.

Ryan (1996) conducted a phenomenological exploration, which elicited the experience of living with RA from the patient’s frame of reference. Her findings supported those of Fitzpatrick and Hopkin (1982), that patients with RA wish the circumstances of their particular case to be considered by clinical practitioners. Brown and Williams (1995), employing narrative analysis, offered insights into what it means for women to live with rheumatoid arthritis. Following their research, they iterated the importance of researching patients’ experiences of illness as a basis for good nursing practice.

Daly (1993) found few studies that have measured or described the chronic illness experience in response to hospitalization. It can be seen from this

composite of literary stories that research is beginning to move in the direction suggested by Eisner (1988), of finding knowledge that is rooted in experience.

Literature as Starting Point

The literature that was reviewed in this section points to an increasing volume of stories that speak of patient-health care provider interactions and their impacts. The review is a practical starting point from which to study and describe more specifically, how a surgical experience in an acute hospital setting affects the illness trajectory of individuals who have rheumatoid arthritis. The intent of this study was to ask persons with rheumatoid arthritis to reflect on their experiences as hospitalized patients undergoing surgery, specifically with respect to their life with RA. Through the insights gained from listening to their experiences and by the mutual validation of the accuracy of what is heard in their stories, a more informed conceptualization of the experience can be achieved.

CHAPTER 3

Finding Voice in Narrative Inquiry

“We have a choice among ways of knowing” (Gadow, 1990, pp. 3). The question that I chose for this research sought to understand the nature of personal experiences. I asked, “How is that for you?” The question invited a dialogue with the individuals who had the experience, for the express purpose of giving voice to their experience. An approach that corresponds with this purpose is narrative inquiry. As identified in Chapter 1, narrative inquiry is the study of the ways that people experience the world as told through their stories. In narrative inquiry researchers explore, record, and write interpretive stories of human experiences. These stories, called narratives, are meant to represent experience in a way that is educationally meaningful for participants and readers. In this chapter I describe the nature, the philosophy, and the process of narrative inquiry; in short, the “what, why,” and “how” of narrative inquiry is explicated. Its appropriateness to my study question is clarified.

What: The Nature and Philosophical Perspectives

The Nature of Narrative Research

Several narrative researchers have addressed the history, scope, and place of narrative inquiry (Clandinin & Connelly, 1994; Connelly and Clandinin 1987, 1990; Polkinghorne, 1988, 1995, & Janesick, 1994). They identify narrative inquiry as a multifaceted strategy for conducting qualitative research. The stance of these authors is informed by Dewey’s notion that the meaning in events can be lost in the processes of objectification and decontextualization. As followers of Dewey, Clandinin and Connelly (1994) identify the power of keeping experience in the foreground and of artfully conveying the experience

through narrative which stays close to the data and which convincingly informs the audience. Narrative inquiry can be metaphorically described as a window through which we might see how a socially organized setting is experienced (Miller & Dingwall, 1997).

Narrators control the degree to which a narrative passage represents experience. By this I mean that the experiential status of a narrative passage depends upon what the narrators choose to convey. Connelly and Clandinin (1990) explain it in this way: people tell stories of their lives, whereas narrative researchers describe such lives, collect and tell stories of them, and write narratives which focus the audience on particular experiences.

Bruner (1986a) describes two complementary but distinctive ways of reasoned knowing: *paradigmatic*, which is abstracted and decontextualised, and *narrative*, which is contextualised and imbued with particular meaning. While paradigmatic and narrative cognition both generate useful and valid knowledge, the distinction between them is significant. Whereas paradigmatic knowledge focuses on each new episode as an instance of a general type, narrative cognition focuses on the uniqueness of different situations, the cumulation of which provides a basis for understanding analogous but distinct episodes. From the latter perspective, as one's repertoire of described episodes accumulates, one's initial understanding of a new situation is enhanced while cognitive space is made for identifying the differences that are germane to the new situation.

Narrative and storytelling are processes that convey an interpretation and a representation of human experience that display the significance of events (Denzin & Lincoln, 1994; Polkinghorne, 1988). Polkinghorne (1988) asserts that narrative explains by clarifying the significance of events that have occurred on

the basis of the outcome that has followed. An assumption inherent in his assertion is that narrative language is a display rather than pure reflection of meaning. Edward Bruner (1986b) supports this view. He illuminates the differences among *life as lived* (what actually happened), *life as experienced* (what was felt, perceived, desired, and known to the person whose life it is), and *life as told* (what is remembered and narrated).

Narrative method as a research technique is necessarily value laden and context driven. It includes the informants' value orientations and the acknowledgement that the researcher's values also influence and filter perceptions throughout the research process. The audience or readers of the narrative configuration hear the meaning of the account through the filter of their own experiences. Insight and discovery remain possible when all those involved in the process come to understand something familiar in a new way or they are led " . . . to places beyond their original horizons" (Mitchell, 1994, p. 227).

The Philosophical Orientation of Narrative Inquiry

Philosophical approach to human inquiry is shaped by the researcher's intent to understand the complex world of lived experience from the point of view of those who live it, feel it, and undergo it (Schwandt, 1994). Reciprocally, intent to understand is shaped by the researcher's philosophical assumptions. I am helped by Schwandt in my understanding of whether narrative inquiry falls under the rubric of *interpretivism* or *constructivism*. In his 1994 article on the topic, Schwandt effectively supports his stance that "these terms are best regarded as sensitizing concepts that suggest directions along which to look rather than provide description of what to see" (p. 118). Schwandt contends, and

I agree, that the aim of studying human actions and experiences can be achieved through a variety of methods. Further, drawing too fine a distinction between interpretivist and constructivist perspectives for the purpose of understanding narrative inquiry obscures the important fact that they share a common intellectual heritage. By that is meant that they fall under the postmodernist paradigm which assumes that there can be no “right” or privileged form of authoritative knowledge. The postmodernist position allows that some things can be situationally known and not everything can be known (Richardson, 1994). Narrative accounts, by their very nature, are *interpretively constructed* representations of actual experiences. Rendering an interpretive account is the act “ . . . of pointing to some aspect of the world beyond our immediate ken, thereby allowing us to experience some phenomenon via vicarious participation” (Schwandt, 1994, p. 129).

Increasing understanding through interpretation rests on the researcher’s assumption that reality is constructed and interpreted by human beings who are already embedded in a world of meaning, language, culture, and history. It has been proposed that it is not possible to have objective knowledge of human reality since all persons are already situated in it (Lincoln & Guba, 1985; Mitchell, 1994).

The Possibilities and Limits of Narrative Research

Polkinghorne (1988, 1995) submits that narrative research may have a descriptive or an explanatory purpose. The aim of descriptive narrative research is to produce an accurate description of the stories which individuals tell; these are stories which, through their telling, make experiences meaningful. A descriptive narrative account reports what informants identify as their

experiences and the events surrounding their experiences. Descriptive narrative inquiry is undertaken in response to the question: What was this experience like for you? Its appropriateness relies on the coherence and accuracy of the inquiry, of the analytic process, and of the narrative report.

The aim of explanatory narrative research is to construct an account that ties together causal aspects of events, experiences, and outcomes. It responds to the question of how or why a situation or event happened as it did. The usefulness of explanatory narrative research is predicated on the retrospectivity and coherence of the narrative account. In qualitative inquiry the term “cause” refers to anything that has implications for something else. Causality is contextual and individual. This use of the term contrasts with its technical use in the natural sciences and in quantitative research where cause is viewed as a constant antecedent that has generalizable purposes (Polkinghorne, 1988).

To bring a rich understanding of the hospitalization experiences of my study participants to the reader I have employed aspects of both descriptive and explanatory techniques. Through capturing a coherent and accurate description of the experiences, the reader is given an account of what the experiences were like for the study participant. Additionally, the retrospectivity of the descriptive account provides a vantage point from which to reflect on the influences and implications of what happened through linking the described experience with other forms of knowledge, both practical and theoretical. Josselson (1993) suggests that story cannot stand alone; story must be linked to the conceptual, thereby providing a knowledge bridge to other situations in a useful way.

The subjective uniqueness of each story in this study precludes generalizability of what is learned. Nevertheless, the essence of what is learned

has transferable potential for relevance in other situations. Knowledge, or how one understands any given situation, can be transformed or reformulated by gaining an additional perspective from a different situation. In this way whatever stimulates thought as a result of human inquiry narratives generates a better understanding of praxis and is therefore useful (Sandelowski, 1997).

Why: Rationale for Choosing Narrative Inquiry

Strategies for inquiry are selected on the basis of their relevance to the particular knowledge one seeks to uncover (Field & Morse, 1991; Janesick, 1994; Miller & Crabtree, 1994; Polit & Hungler, 1995). In narrative inquiry, as in other qualitative research approaches, the researcher endeavors to achieve proximity to the actual experience. Clandinin and Connelly (1994) make the case that “. . . when persons note something of their experience, either to themselves or to others, they do so . . . in storied form. In effect, stories are the closest we can come to experience . . . Experience, in this view, is the stories people live” (p. 415). Stories educate those who are new to the storytellers’ community and context. Hence, narrative inquiry is particularly useful for the purpose of this study.

Personal experience is multifaceted. It includes historical and environmental aspects. Experience is simultaneously comprised of internal and external environments, that is, the realities of what matters and of the settings and circumstances in which one finds oneself. Experience also occurs in an historical context, between past and future horizons. Methods for the study of personal experience must focus in the directions that comprise the experience. In doing so, questions are raised about internal conditions such as feelings and hopes, the context of the story, as well as referents from the past and intended

futures of all who are involved in the story (Clandinin and Connelly, 1994).

Thinking about inquiry in these terms directs us to follow the premise that if we wish to know and understand something of the lives of specific persons in specific circumstances, we need to engage in conversation with them about their personal experiences (Gluck, 1991). Conversation, as proposed in this study, entails listening and caring about the experience that is described. It differs from interview on two accounts; whereas interview relies on tactic and preconception, conversation depends on tact and collaboration (Field, Marck, Anderson, & McGeary, 1994). Conversation begins the process by which experiential knowledge is shared and assumes the centrality of relationship among researcher, participants, and audience (Clandinin & Connelly, 1994). Sharing conversations in this way is both an interpretive and a constructive process.

Use of Narrative in Nursing

The human-health interrelationship is central to nursing. Mitchell (1994) reminds us that it is generally agreed in nursing that the discipline is committed to providing supportive care that respects the uniqueness of each human being and family in ways that promote health and in doing so, contributes to society. One way to “know” individuals’ uniqueness is through their stories. Storied knowledge juxtaposed onto clinical nursing praxis has a high likelihood of challenging dominant clinical perceptions that sometimes constitute a disempowering experience for those seeking support.

The objective of narrative inquiry is to gain insight through looking back on an experience with those who were engaged in it and who can describe it. The method’s objective contributes to “. . . the understanding of lives in health, illness and transition” (Sandelowski, 1991, p. 164). Tellings are remembrances.

What is remembered is an indication of what preoccupies the storyteller and therefore informs the listener how the experience is endowed with meaning (Sandelowski, 1991).

Benner, Tanner and Chesla (1996) have shown the function of narrative accounts, presented by nurses, as a way of opening up new areas of practice or teaching nurses something new about nursing practice. They studied “paradigm cases” presented by nurses. Paradigm cases, as defined by the authors, “are stories that the nurse carries forward The narratives are experientially given as a result of engagement in concrete situations. Some aspects of the situation are emphasized where others do not figure in at all” (pp. 250, 251).

How: The Process of Narrative Inquiry

As a process, narrative inquiry does not proceed from a formal theoretical framework and the boundaries of the inquiry are not defined in advance (McKiel, 1995). The process does, however, proceed from the researcher’s purpose, which is influenced by personal and disciplinary values (Mitchell, 1994), and it moves directly to the stories of people’s lives. The stories are germinative. The researcher’s purpose and the participants’ stories are expected to influence the tone of inquiry. It is anticipated that the boundaries of the inquiry develop as both parties identify meanings in the stories, which extend their original horizons (Clandinin & Connelly, 1994; Mitchell, 1994).

The Participants

The number of participants is determined as the study is being conducted. As suggested by Morse (1991, 1994), the sample size is small and is determined by informational considerations as the study proceeds. Strategically, when one is collecting in-depth, reflective data about essences over a sustained period,

wherein raw experiences are converted into language, the quantity of data can very quickly become daunting. Therefore it is wise to heed the advice of Huberman and Miles (1994) who suggest that qualitative studies are vulnerable to data overload which, if not guarded against, may paralyze the entire process. Participants are purposively sought on the basis of their knowledge and experience in the area of research interest, as well as on the basis of their ability and willingness to articulate and reflect on their experience (Lincoln & Guba, 1985; Morse, 1994).

Data Collection

When the research question seeks descriptive data about personal experiences, it is anticipated that the interviews will unfold from a broad perspective in the form of conversations. Each of the participants is encouraged to examine, verbally and reflectively, a particular experience. The research relationship begins with an invitation to the individual participants to tell their stories related to these experiences. Clandinin and Connelly (1994) propose that events are experienced simultaneously in four ways: inward, outward, backward, and forward. Consequently, it is important to search for these aspects in the participants' stories. Conversation entails listening. As the listener, my response " . . . may constitute a probe into experience that takes the representation of that experience beyond what is possible in an interview" (Clandinin and Connelly, 1994, p. 422). The probing will be undertaken in a relationship of perceived mutual trust.

Cynthia Stuhlmiller (1996) describes a mode of narrative picturing which can be employed to access more detailed descriptions when a participant may have left the researcher puzzled or unclear. For example, one might ask the

individual to picture what happened in a particular interaction or experience by firstly picturing it in a “frame-by-frame” way and then articulating it.

Stuhlmiller convincingly explicates how sensibilities are awakened through picturing or creating a mental image, explaining that the right cerebral hemisphere is utilized for this purpose whereas the left hemisphere functions in a more analytical way to translate such images into oral language (Stuhlmiller, 1996; Stuhlmiller & Thorsen, 1997).

The duration and frequency of researcher and research-participant encounters is guided by their content. They cannot be predicted prior to the research process. Borrowing Sally Gadow’s (1990) metaphor, the researcher can be viewed as a stranger in the participants’ landscape who persists until something is seen of what it is like to live there.

As researcher, I accept responsibility for my role, my values, ideology, and biases through active reflections and deliberations that are recorded and brought to awareness (Aamodt, 1991; Janesick, 1994; Lipson, 1991). They become a constituent part of the narrative account. The aforementioned authors, as well as Clandinin and Connelly (1994; 1992), clarify the important impact of the researcher’s autobiography to the research process. Consequently, it is the researcher’s mandate to assume reflexive consciousness—monitoring and acknowledging personal orientations, subjectivity, and states of affairs in relation to the research activities; all of the research activities are interpretive and are intertwined. Indications of researcher subjectivity will be evident within the field texts and will be acknowledged in the research text.

Data Analysis

In the context of narrative inquiry, participants’ stories are solicited as

data to describe human action in a specific circumstance. The elements contained in the data are identified and interpreted through analysis in preparation for their synthesis into a coherent account. Polkinghorne (1995) describes two primary kinds of analysis in narrative inquiry: *analysis of narratives* and *narrative analysis*. *Analysis of narratives* is a paradigmatic process whereby the data from the narratives are examined to identify themes or notions that are common to various stories. Relationships among categories may also be determined. *Analysis of narratives* results in general knowledge derived from particular instances.

In contrast, *narrative analysis* focuses on the stories of individuals in a specific context. It is a process that configures data elements into a meaningful, plausible and understandable account of a particular experience in a person's life. Blumenfeld-Jones describes the process as "aesthetic reconstruction" (1995, p. 26). *Narrative analysis* results in particular knowledge, which conveys something significant about a human episode.

During *narrative analysis*, connections between events and actions are examined from a retrospective stance. The process begins from the present and looks back over the choices, happenings, dispositions, and environmental circumstances which were experienced along the continuum and which were noteworthy enough to be brought into language by the participant-storytellers. The final narrative is arrived at through recursive movement between participant-storyteller and narrator-researcher to ensure that it fits the data, "... while at the same time bringing an order and meaningfulness that [may not] be apparent in the data themselves" (Polkinghorne, 1995, p. 16). The motivation for this process is to increase the poignancy of the description for the audience

through the smoothing effects of “perspicuity and brevity” (Polkinghorne, 1995, p. 16). In this study, I undertook narrative analysis.

Field texts. The goal of data analysis is to maintain the context and the richness of the individual stories in a comprehensive way (Connelly and Clandinin 1990). The following are considered data: field notes, journal entries, audiotapes and their transcripts—all of the text, which represents aspects relevant to the inquiry. Field texts embody an interpretive process shaped by the researcher and the researcher-participant relationship. Sometimes field texts may seem so compelling that they will be left to speak for themselves. Sometimes they will reveal meaning and social significance and in those cases they will be reconstructed as research texts. Clandinin and Connelly (1994) remind the reader that:

Field texts are not, in general, constructed with a reflective intent; rather, they are close to experience, tend to be descriptive, and are shaped around particular events. Research texts are at a distance from field texts and grow out of the repeated asking of questions concerning meaning and significance (p. 423).

The analysis process, as put forward by Connelly and Clandinin (1986) identifies narrative threads, themes, and patterns that become evident within individuals’ personal experiences. This process begins early in the inquiry and continues as the inquiry proceeds. I use the term “thread” as a way of describing the nature of the connection between an event and the context of the event. Threads are unifying elements that both point to the origin of the event and converge to new events at different points in time. They effectively weave multiple aspects into a whole and thereby help clarify one’s understanding of

how something is known. Theme is defined as a prominent or frequently-recurring element, which may be a comment, observation, or statement that has the effect of a recurring melody in a musical composition. It draws one's attention. These elements become part of a central construct known within the narrative perspective as narrative unity. Narrative unity is a way of understanding how individuals' life experiences translate into their experiential knowledge (Connelly & Clandinin, 1986).

Lincoln and Guba (1985) describe a similar process in somewhat different terms. They identify categories as being comprised of "incidents" or "units" of information which recur in the stories and which may be interpreted as "chunks of meaning" (p. 345). Recognition of incidents as having significance relies on the investigator's tacit and referent knowledge. Through a process of comparative analysis, both descriptive and explanatory categories are developed. Category development depends on two principal features: the expression of substantive behaviors by the respondents and, the analyst seeking explanations or understanding of these expressions.

Presentation. Narrative has been defined in various ways but Barone (1995) clarifies that its root is in the Latin word, *narrare*, "to relate." The narrators relate accounts of incidents and events in their lives. The accounts are related in the language of story. By that is meant everyday, informal language. Story can be considered a subspecies of narrative. Barone (1995) suggests that story is characterized by two specific attributes. One hallmark of story is the everydayness of its language. A second is its form. The form of story has generally been segmented into three phases that broadly encompass the introduction and the situation of characters within a human dilemma. The story

then moves to a phase that includes complications imbued with meanings. The final phase of story involves the emergence of denouement or resolution, which may be tenuous, may be merely suggested, or may be clarifying (Barone, 1995; Clandinin & Connelly, 1994; Polkinghorne, 1988).

Narrative accounts. The narrative account is constructed from the interviews. It is the written configuration of the participants' personal knowledge of the referent experience. Personal knowledge refers to how individuals know their life situation. The narrative account is the first formal step in the interpretive process. The narrative account is comprised of event descriptions configured into a meaningful whole through connecting event patterns around themes. The account transforms a chronicle of events into a schematic whole by highlighting the significance and contribution of individual events in relation to other events and in relation to outcome. It is a plotted story that includes historical and social contexts (McKiel, 1995; Polkinghorne, 1988). The research accounts develop from analysis of the narrative accounts.

Research account. The researcher's personal and professional experiences and style of discourse shape the interpretive process. The research text is jointly authored to the extent that it is neither solely the researcher's, nor solely the participants'. Its purpose is to highlight the significance of the narrative account and why it might be of interest to others. Whereas narrative accounts are descriptions that bring experiences nearer, research accounts are responses to questions of meaning and significance. Relationships, which are established in the field and reflected in narrative accounts, are also central to the research texts. They are evident in the thematic interpretations that are presented as the research account (Connelly & Clandinin, 1992).

Writing: Voice and Signature

The jointly authored research text shares the voices and signatures of researcher and respondents with the audience, whose voice will also become a part of the research as it is read (Connelly and Clandinin, 1994; McKiel, 1995). It is important to ensure open space in the text for readers wherein they may write themselves into the story by focusing on their own life experience. As a narrative inquirer, my ethical relationship to the participants, my dedication to the inquiry, and my professional relationship to the proposed audience guides the authorship balance. Writing is always partial, local, and situational and the writer is always present. The impact or usefulness of the account rests in its offer of, or its focus on, alternative practices which incorporate experiential with conceptual knowledge (Richardson, 1994). "In producing the story the researcher draws on disciplinary expertise to interpret and make sense of responses and actions" (Polkinghorne, 1995, p. 19). Connelly and Clandinin (1986) refer to narrative inquiry as the "... process of joining reflection-in-action with reflection-on-action in a written dialogue ... that results in the development of a more or less coherent narrative [which] yields experiential understanding" (p. 306).

Addendum

Connelly and Clandinin (1987) make a helpful distinction between narrative and biography. Whereas biographies inhere in narrative, a characteristic of narrative is its interest in understanding. This fundamental characteristic makes narrative epistemologically significant for the study of interactive processes such as teaching or nursing: it offers a way to understand nursing support as a temporal process contingent upon the biographic histories of its participants.

CHAPTER 4

Seeking the Voice of the Experienced

In this study personal stories were solicited from individuals with rheumatoid arthritis. The stories were about the experience of being hospitalized for surgery. Clandinin and Connelly (1994) have used narrative methods of inquiry to study experiences expressed through stories and they suggest that the story is the closest proximity the researcher can get to the actual experience of the informants. Their work and that of Polkinghorne (1988, 1995) primarily inform the research process explicated in this chapter.

Design

As described in Chapter 3, the principal feature of narrative inquiry is the reconstruction of stories of experience. In this study, stories of human experiences are explored, recorded, and reconstructed to represent the experiences in a way that the knowledge inherent in them becomes known.

Recruitment

Individuals were invited to participate through the Alberta and Northwest Territories Division of the Arthritis Society. The Society executive agreed to forward a letter of explanation about the research to attendees at various arthritis support-group and information meetings (Appendix A). To ensure confidentiality I had no access to membership lists. Individuals who were interested in finding out more about the study were asked to contact me directly. Additionally, I requested permission to attend a support-group meeting where I was given an opportunity to briefly present the purpose and nature of my study to the attendees. Interested volunteers contacted me

following that meeting. All potential participants were given the letter of explanation (Appendix A).

Participants

Inclusion criteria for participation in this study were those adults:

- in whom a positive diagnosis of rheumatoid arthritis had been established by a rheumatologist;
- who had been hospitalized for a surgical procedure within the past three years; whose duration of hospitalization was two days or longer (the impact of the hospital environment was more likely to be characterisable if the hospital stay was not too brief);
- who were English speaking; who agreed to articulate and to critically examine their experiences with me, and;
- who consented to participate (Appendix B).

In coming to a decision about the number of participants to recruit, I followed the guidance of Morse (1994). Morse states that, in qualitative research, sampling “is determined according to the needs of the study” (1994, p. 229). Since the purpose of the inquiry was to illuminate individual persons’ realities, the value of the inquiry relied less on sample size and more on the heuristic quality of the data from each participant (Sandelowski, 1995). The volume and the usefulness of data that each communicated influenced the number of respondents sought. As with other studies using narrative inquiry, the object of the sampling was to detail the many specifics that teach the reader about the uniqueness of the context (Connelly & Clandinin, 1990; Lincoln & Guba, 1985).

Four volunteer participants were enrolled through their association with the Arthritis Society. All of the participants were female and ranged in age from

twenty-three to sixty-seven years. Three remain professionally employed and one is retired. All were educated at the post-secondary level. Two had always been single and two were married. The participants were not acquainted with one another.

Data collection

Participants were interviewed individually at locations of their choice. Although use of the term “interview” connotes a cognitive activity, in this study it is perceived as more than merely requesting descriptions of events. The interviews unfolded in the form of conversations in which I was the listener, seeking responses to the question, “What was your experience of having rheumatoid arthritis while being hospitalized for surgery?” In an open and exploratory way, the participants were asked, firstly, to tell the story of their rheumatoid arthritis journey and then, to talk about what it is like to live with the arthritis while in hospital for surgery.

With respect to their hospitalization experience, I sought their expression of aspects of the experience that stood out for them. Although I was prepared to ask for descriptions of aggravations, concerns, and facilitating or helpful situations, in most cases the participants volunteered these without prompting. It was anticipated that questions such as the following would be employed to encourage or sustain the flow of their stories and the expression of their personal knowledge and experiences: “What was that like for you; When do you find that . . .; How do you think that . . . and; How would you describe . . .?”. I found that the participants required very little verbal encouragement. Upon inviting them to tell me their story of life with the RA and then their story of how hospitalizations were experienced, they were spontaneous and informative.

All initial interviews were audiotaped and transcribed verbatim. In addition to the interview transcripts, data comprised journal entries and field notes with descriptions about the circumstances in which the interviews occurred, the nature of the environment, any personal interpretations related to our interactions, and any conversations apart from the interviews. Narrative accounts were constructed from the interviews, with reference to the field notes.

Data analysis

The analytic process was ongoing, integrated, and concurrent with data collection. It began as data were received (Lincoln & Guba, 1985). Interpretation commenced with the interviews and in the field notes. It continued in the construction of the narrative accounts as aspects of the participants' stories were chosen for inclusion. Analysis culminated in a research account.

Narrative accounts. The process of moving from transcripts to narrative accounts included listening to the conversations as they were being transcribed. The transcription process provided an opportunity for me to hear both participants in the interview (interviewer and interviewee became a conversational unit and I, in essence, became a third party listener). Each interview transcript was read initially to get a general sense of its meaning. It was read again to look for expressions and notions (i.e. elements) which infer meaning for each participant. The focus of each narrative account was to include elements that were significant to the storyteller. To assist this process I engaged in a series of readings of the transcripts:

1. To get a sense of the participants I went through each story sequentially, recording active words, phrases, and metaphors which

were used about themselves and about events.

2. Next, I directed my attention to contexts. Working through each list of words and phrases, I identified topics and grouped the descriptors by asking the following questions: What is she saying about herself, before RA and with RA? How does she describe her interactions with physicians, with health professionals? Which words and phrases are about hospitalization?
3. I then examined each grouping of descriptors for types of content - beliefs, values, action preferences. Connelly and Clandinin (1986) refer to “threads” or “unifying elements” which weave through a story as dominating or pervasive representations. These representations shaped my understanding of who each story teller was in relation to her contextual realities.
4. Following the initial sorting, I engaged in the more focused and reconstructive analyses described below and detailed in Chapters 5 and 6.

The purpose of my writing was to *re-present* the world, as my participants know it. After reviewing the narrative accounts with two members of the nursing graduate faculty at the University of Calgary, it became clear that the chronicled nature of the accounts lacked the element of plot. They did not capture the soul of my study participants’ worlds. Therefore, I was challenged to evoke the cogency of the stories in my writing. Tyler (1986) points out that, “Questions of form are not prior, the form itself should emerge” (p. 127). Norris (1997) concurs, stating that “Form is not superimposed, or merely associated with a work, it is *of it*” (p. 93). Ultimately, each narrative account was configured

into a unified story of the experience of each participant, written in the voice of the teller (Chapter 5).

Each story was discussed with the respective participant and modified, where necessary, to yield a coherent and accurate depiction of what the participant had found meaningful in her experiences (Connelly & Clandinin, 1986; Polkinghorne, 1995). During the second conversation with each participant we discussed my developing notions of meanings and of social significance embedded in their stories. In this way we engaged in collaborative analysis (Lather, 1991). Connelly and Clandinin (1986), in their narrative study of teaching describe this process as the second step of a two part analysis. They use the terms “reflection-in-action” and “reflection-on-action” (p. 306). In this study, reflection-in-action refers to the various observations which I, as the writer noted in the transcripts and field notes, and which I recorded in the narrative stories. Reflection-on-action refers to the next step, that is, the second interviews with the participants based on my observations. These interviews occurred after the stories had been returned to the participants.

Research Account. It was my purpose to listen, to capture salient elements of the participants’ stories, and to illuminate these in a research report. The analytic process in this study culminated in a research account (Chapter 6), which communicates my conceptual understanding of what was learned in response to the research question. In the research report I drew from existing scholarship when highlighting observations from the participants’ stories. Schwandt (1994) advises that what the researcher “sees, he or she must eventually say” (p. 129). In the research account, questions are raised and openings are left for ongoing rumination about the processes and relationships

that sustain social realities. My aim was not to prompt a single, closed convergent reading of the situations, but to persuade the reader to contribute answers to the dilemmas that have been posed (Barone, 1995).

Goodness of the Study

A number of writers contend that when evaluating the integrity of research one must employ criteria that are congruent with the nature and spirit of the research (Blumenfeld-Jones, 1995; Connelly & Clandinin, 1990; Guba & Lincoln, 1989, 1994; Janesick, 1994; Sandelowski, 1997; Schwandt, 1994; Strauss & Corbin, 1990; Thorne, 1993). Connelly and Clandinin (1990) clarify that, "Like other qualitative methods, narrative relies on criteria other than validity, reliability, and generalizability" (p. 7). Guba and Lincoln (1989,1994) offer that the issue of quality criteria in the constructivist paradigm, in which narrative inquiry inheres, is not well resolved but they propose two sets of criteria which were applied to this research: trustworthiness and authenticity.

Trustworthiness addresses methodological rigor and *authenticity* focuses on the intersubjective intent of interpretive inquiry. Trustworthiness and its sub-criteria are characterized as conceptually paralleling the criteria of validity and reliability, which are more appropriate for evaluating quantitative research. Authenticity is suggested as an appropriate criterion for evaluating research that identifies the influence of context.

Trustworthiness

Trustworthiness addresses issues of *credibility*, *transferability*, *dependability*, and *confirmability*.

Credibility. Credibility refers to the plausibility or believability of the findings. An interpretive study is credible when it demonstrates recognizable

similarity between the constructed realities of the study respondents and the reconstructions attributed to them. Credibility is enhanced when researchers provide evidence of their relational involvement with the participants and the text (Andrews, Lyne & Riley, 1996; Leininger, 1992; Sandelowski, 1986, 1993; Streubert & Carpenter, 1995). Techniques for ensuring credibility include:

1. Adequate periods of engagement between researcher and respondents–
 - *I engaged the participants respectfully and conducted the conversational interviews in a manner that facilitated their ease*
 - *the duration of each interview was between sixty and ninety minutes, however, the act of building trust began with our very first encounter and continued as we established and confirmed appointments by telephone, prior to the actual interviews*
 - *I sought both scope and depth of information in order to enhance the exploration and identify salient factors in the data.*
2. Peer debriefing, which entails challenges to the inquirer by a non- study participant for the purpose of clarifying working hypotheses and tacit assumptions and their effects on the inquiry–
 - *I shared my participants' stories and my methodological design with two different groups of colleagues in the graduate program, some of whom are doing qualitative research. By consulting in this way I requested critique of my working hypotheses, interpretations, and assumptions; I received both written and verbal responses and critique.*
3. Maintaining a record of the inquirer's developing constructions throughout the process –

- *I maintained an electronic journal, which reflected my deliberations in relation to the data and to existing scholarship;*
4. Member checks to test the ongoing accuracy, adequacy and representativeness of factual and interpretive reconstructions (Guba & Lincoln, 1989) –
- *I returned my constructions of the participants' stories to them for verification of their accuracy, both in fact and spirit. Having allowed them a period of time with the document, I re-scheduled a meeting to review what they had read. They were invited to add information. We shared our mutual impressions in a co-analytical discussion.*

Transferability. Transferability refers to the probability that the study's findings can be usefully transferred to another similar context or situation while retaining its particularized meanings, interpretations, and inferences (Guba & Lincoln, 1989; Leininger, 1994; Streubert & Carpenter, 1995). Verification of the transferability of a study's findings necessarily rests with its readers or potential appliers within their specific contexts. Degree of transferability is also subject to future disconfirmation or reassessment at later periods in time as new understandings are gained. Through eliciting and providing extensive, comprehensive descriptions, which include salient aspects of context I argue that the findings of this study have transferable potential. Purposive selection of participants who were able to comprehensively and eloquently articulate their experiences provided " . . . a new and richly textured understanding of experience" (Sandelowski, 1995, p.183), thereby enhancing transferability (Baker, Wuest & Stern, 1992; Guba and Lincoln, 1985; 1989).

Dependability. The dependability criterion parallels the reliability

criterion in quantitative research (Guba & Lincoln, 1994; Streubert & Carpenter, 1995). Dependability is ensured through documentation of data processing so that the process and decisions can be tracked and explored by those outside the study. This tracking process clarifies which salient factors in the context led me to the decisions and interpretations that were made. “The technique for documenting the logic of process and method decisions is the dependability audit” (Guba & Lincoln, 1989). The acts of consulting my colleagues outside of the study, maintaining a journal of my decisions and recounting my process in this document were for the purpose of ensuring the transparency of my decision making processes.

Confirmability. Confirmability is concerned with assuring that the research account is rooted in data that can be tracked to their sources (Guba & Lincoln, 1985, 1989; Streubert & Carpenter, 1995). Confirmability is engendered through the documentation that reveals this logical progression. The objective is to illustrate, as clearly as possible, the evidence and thought processes which led to the conclusions by describing fully how the information flow from participants to research text was accomplished (Polkinghorne, 1988). Earlier in this chapter I described fully how I handled the information flow from data to research account. Additionally, earlier in this section I described the actions that I took to ensure the accuracy and consonance of my writings with the participants’ stories, through validation checks, co-analysis, and peer critiques.

Authenticity

Whereas trustworthiness is expected in the methodological processes, authenticity is anticipated in the interactions and outcomes of qualitative inquiry. Guba & Lincoln (1989, 1994) suggest that all interpretive research should

be subject to the following authenticity criteria: *fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity.*

Fairness. Because qualitative inquiry is value-bound and value-situated the researcher must present, clarify, and honor differing values in an unbiased way (Lincoln & Guba, 1989). The interactive nature of narrative study accepts that the voice and signature of both researcher and participant will be written into the research account (Moccia, 1986). Given that they may have differing value systems and personal philosophies, each must be free of any conscious or unconscious constraints on self-expression and the researcher, in particular, must take responsibility for fairly presenting the voice and signature of the participants in the research account. I sought fairness through personal reflexivity, as documented in chapters one and six. Further, I returned to the participants during the analysis and writing processes, for the purpose of mutually reflecting on my impressions of their stories and inviting their comment, elaboration, correction, revision, and expansion of the constructed narratives. All suggestions were incorporated in the final version of the narratives. These activities of cross-checking are, respectively, documented in the literature as “audit trails” and “member checks” (Greene, 1994; Janesick, 1994; Lincoln & Denzin, 1994; Lincoln & Guba, 1985; McKiel, 1995; Richardson, 1994).

Ontological authenticity. Ontological authenticity, as described by Guba and Lincoln (1989, 1994), relates to the benefits that study participants gain from participating in the research. The researcher will know that ontological authenticity has been achieved when participants indicate increased awareness or broadened understanding of the phenomena being studied. Ontological authenticity is demonstrated in the researcher’s audit trail wherein changes in

researcher and respondent understanding of issues are documented. Evidence of my changed understanding is documented in my electronic journal. The respondents were particularly candid in sharing new insights that had emerged for them from reading my constructions of their stories.

Educative authenticity. Increased understanding, among research participants, of the constructions of others and how these are evoked by different value systems constitutes educative authenticity. In this way the benefits of the research are extended beyond increased understanding of the research participants' personal worlds. Educative authenticity is demonstrated in the verbal expressions of the participants and in the researcher's audit trail (Lincoln & Guba, 1989). The respondents in this study, after reading my construction of their stories, indicated interest in my impressions and in the stories of other study respondents, demonstrating insightfulness beyond their personal worlds.

Catalytic authenticity. If the research process or findings from the research stimulate action or re-orient thinking it can be said to have achieved catalytic authenticity (Guba & Lincoln, 1989, 1994). Lather (1991) directs this point of impact toward all of the research participants—informants, researchers, and readers. It is safe to say that I, personally, have been stimulated to greater awareness in my clinical practice on a daily basis. The informants articulated a renewed energy upon reading and discussing the narratives. Catalytic authenticity is strengthened when recipients of the research information are stimulated to act for change. Its achievement is dependent on the substantive aspects of the research (the, So what?"'), as well as on the clarity and style of writing which presents the research account to the reader. If readers are not led to keep turning the pages its achievement is precluded (Richardson, 1994;

Sandelowski, 1991). As described by Guba and Lincoln (1989), the reader impact related to catalytic authenticity can only truly be demonstrated if the research effort is followed by an evaluation of its outcome, and is therefore beyond the scope of a current evaluation with respect to this work.

Tactical authenticity. Whereas catalytic authenticity will have been achieved if the reader of the research report is stimulated to action, tactical authenticity will have been achieved if research participants experience empowerment, if they are energized (Guba & Lincoln, 1989). The process of narrative inquiry rests on reciprocal interactions between the researcher and the participants who inform the researcher. Collaborative construction and reconstruction of the research narrative are activities that give voice to the participants and make their realities visible (Brunner, 1994; Connelly & Clandinin, 1992; Guba & Lincoln, 1989; Polkinghorne, 1995). Being heard supports integrity, which, I believe, confers power. By fostering an open, honest, respectful, and trusting relationship with the participants, I observed their positive response to my affirmations of their worth and their strength. Consistently, the study participants expressed surprise that anyone would be interested in their story; they hadn't thought that their stories would be interesting to anyone else.

Throughout the research process I was profoundly aware of the immense privilege that the study respondents had afforded me in generously sharing their time and very personal details about themselves with me, a stranger to them. I was imbued with a sense of deep responsibility to strive toward ethically producing an account that would be inviting, plausible and useful to potential readers. Barone (1995), Connelly and Clandinin (1990), and Sandelowski (1995,

1997) inform my notions of plausibility, usefulness and invitingness. As a follow-up action, I will be writing a letter of commendation and appreciation to each of the participants (refer to Appendix D). I acknowledge the influence of Wright, Watson and Bell (1996) in this endeavor.

Ethical Considerations

The study proceeded after it had been reviewed and approved by the Faculty of Nursing, University of Calgary Ethics Review Committee. Written consents (Appendix B) were obtained from all participants, after they had been informed about the study and the nature of their involvement in the study. Participants were advised that written consent did not prevent their later withdrawal from the study without negative repercussions for them.

All data collected will remain confidential; only the subjects' code names will remain on any data sheets. Fictitious names are used in the report to ensure anonymity. Data from interviews, in the form of excerpts, may be used in future presentation of findings but participant identification will not be divulged. Care has been taken to ensure that any participant quotations which are used do not make the speakers recognizable through contextual references (Morse, 1994). Only the researcher has access to the audio recordings which identify the participants. Access to transcribed data has been restricted to the researcher and the supervising committee. Audiotaped recordings will be erased at the completion of the study. Transcriptions of the interviews and notes will be stored, under lock, for three years after termination of the study. Only the researcher will have access to these materials. Results will be shared with all participants if requested. Provision for requesting written results is included in the consent form (Appendix B).

At no time during the study have clinical advice or interventions been offered or provided by the researcher. The boundaries of the researcher's role as interviewer, interested in gaining understanding, were made clear. The nature of the study required relational rapport, which precluded accurate prediction of potential risks and benefits to participants.

Ongoing "process consenting" was undertaken (Hutchinson & Wilson, 1994; Munhall, 1989). Process consenting, in the context of this study, refers to an interactive and ongoing process whereby the researcher actively sought confirmation that the participant wished to continue the research relationship.

The locations for meeting with each of the participants were decided by the participants in order to optimize their convenience, their comfort level, their dignity, and confidentiality.

CHAPTER 5

The Experiences

The soloist has to establish for the listener what the important point, the motif if you like, is, and then show, as much as he can, what it is that he sees in that motif (Coker, cited in Oldfather & West, 1994, p. 24).

In this chapter, I collaborate with the research participants to directly address the research question, writing-in the important points of their experiences. In doing so, I hope to entice you, the reader, into living vicariously within the world of someone who has rheumatoid arthritis and is encountering an episode of hospitalization. These stories are needed to engage a process of discourse among people who may be quite different from one another but who are tumbled into connection in a world where it is difficult to get out of each other's way (Geertz, 1988). The acute care hospital is such a world.

The stories are of lived experiences, detailing familiar minutiae of life as lived within a particular moment of their histories and contexts (Barone, 1995; Bruner, 1987). Based on the premise that experience and context are inseparable, each person's story of the hospitalization experience exists within the context of her history of life with RA.

Rae

Meeting Rae

I met Rae just after she had taken physiotherapy in a nearby facility. Our previous, brief meeting had been at her work place. At that time I had introduced the nature of my research to her. I found Rae to be a petite, well-groomed and quietly spirited woman. In her work setting she epitomized

professionalism. After her physio workout, on the day of our interview, she radiated a quiet energy, stopping to chat with one of the rheumatologists whom we encountered on the way to our destination. She queried whether he had received a letter from her rheumatologist regarding a therapy that she had requested. I waited while they had a brief discussion. I observed that Rae had a comfortable relaxed carriage, which de-emphasized the overt physical signs associated with her rheumatoid arthritis (RA); her attractive bearing and energy diminished the crippling effects of RA.

Rae's story

I have had rheumatoid arthritis (RA) for thirty years. I was a student nurse when I was diagnosed. At that time I was advised to choose a career that was less physically taxing than nursing. However, I have not regretted my decision to remain in nursing albeit, the RA has necessitated particular choices with respect to the focus of my nursing career. I have had to be selective about which areas of nursing work I pursued and I have had to modify my career. I have not worked full-time since 1985.

The disease activity has been continuous since I was diagnosed in my late teen years, but the ways in which I respond to it have changed. In the early years I treated it somewhat like a cumbersome nuisance. It wasn't a big focus in my life. It was not until the early 1980's that it hit home what this disease was doing to me and how destructive it was. I had been through all of what are known as the disease-modifying anti-rheumatic drugs by that time, and had taken different combinations of them, as well as a lot of the anti-inflammatory medications used for RA. In looking back, I see that my disease was not well controlled. I was always dealing with sore joints. However, in my twenties and

thirties I was more able to cope with the changes. I got quite crafty at camouflaging some of the functional changes that were brought on by the joint destruction. But, as I've gotten older I have really noticed more marked and accelerated changes and the joint pain is more relentless than it used to be. I also notice that everything just takes longer for me to do. Dressing and getting ready for work in the mornings, for example, takes me upwards of forty-five minutes now. That used to take me only twenty to thirty minutes. Nonetheless, I think that I've done well. I'm working three-quarter time.

It is really important for me to be working. It's important both psychologically and emotionally to be getting up each day and putting make-up on and going out the door. For me, those activities constitute getting away from merely living with the arthritis. Work has been a godsend for me. I am fortunate to be working in a very supportive environment. My colleagues are very helpful to me and they anticipate my needs so well; we're a real team. I value my work opportunities and challenges so much. If I weren't able to work, I hate to think where my self-esteem and self-confidence would be.

I do realize that part of my functional deterioration relates to the loss of muscle tone that comes with having RA. I have always worked with physiotherapists but I am working harder at my exercise program lately. I exercise at home on a regular basis and I go to physio at a clinic twice a week. I'm noticing a difference but it's very slow. When you're working with bad joints it's not like somebody who has spent six weeks in a cast and who can come back quickly to the strength level they had before. I have to go very slowly with the physio and to be very careful about it, because too much work with weights just irritates the joints and makes everything worse. It's a fine balance. I do

prefer to work with physiotherapists who know my joints well. I find that it helps if they know me and they know my joints; then we can work together more confidently and I make more progress. Right now I am systematically working at strengthening exercises to prepare me for my next knee replacement surgery because I'm concerned about how I'll cope with ambulation after the surgery.

Ambulating after surgery, especially surgery of the lower extremities, is a big issue. As the joints increasingly deteriorate the problem increases. Like me, most people with RA have multiple joint involvement that makes it really challenging to use the usual assistive devices and to follow the standard course of rehabilitation after surgery. Weight sparing on the operated leg means we are expected to weight bear entirely on our non-operative leg and off-load weight with crutches onto upper extremities with diseased joints. For an arthritic, that's virtually impossible. You just can't do it. But I am trying to strengthen everything in anticipation of my rehabilitation period. I have had a number of surgeries now and I learn from each one of them. I use that knowledge to prepare me for the next time that I have to go into hospital for surgery.

When I think about the various hospitalizations that I've had, specific incidents stand out for me. At the time of my first major surgery I really had quite wonderful nurses and things progressed really well after a single, but unforgettable, pain experience. It was so profoundly difficult that I hope no one else would ever have to experience it. I think that it was avoidable. At the root of the problem were a resident physician who had no understanding of the severity of post-surgical orthopedic pain and nurses who seemed to feel powerless to take action. I remember it vividly as an experience of contrasts.

Firstly there were the nurses whose response to my requests stopped at, "You have been ordered this and we can't give you anything more for pain." I remember the picture so clearly: me, lying there clutching the side rails in agonizing pain, my family around my bedside, me trying to listen to nice, soothing music on my Walkman and trying to do deep breathing exercises. It was horrible. Then, I also remember the nurse who came in at change of shift and, after taking a look at me, could tell I was in agony. She just took charge and got the people and the medications that were needed. It had been an agonizing afternoon of excruciating pain and, within a few minutes, I was feeling much better. Memory has not diminished the stupidity of that scene nor the contrast between nurses who did not help me get any relief from the pain, and the nurse who came on shift and said, "What the hell is going on here?" She took immediate action to get my pain under control.

Except for the absolute need for pain relief I don't ask for a lot when in hospital. I know they are busy and they don't have time for the extras, the little things that would make such a big difference, like helping me to position myself properly or setting up my tray so that I can get at it with my floppy arthritic fingers. They're in a rush and they have things to get done. So, you cope on your own. You just sort of wait until someone has a few minutes to spare. A lot of the time you are asking the cleaning staff to do it for you, or the person next to you, or someone just walking by. If I have visitors they run for me. It's just really hard, when you have had surgery and you still have the arthritis so your joints and muscles are not very strong. I guess I think that life could be made so much easier if we had nurses at the bedside who were intuitive. They would be nurses who didn't only focus on the surgery that you're in for. They would be

nurses who see that there's a person there who may have had foot or knee surgery but who still has bad shoulders and bad wrists and bad hands because the arthritis is still there.

Let me tell you about the Johnny shirt, another graphic memory for me. When I think of being hospitalized it conjures up this certain picture for me. The Johnny shirt epitomizes the metaphor of raw exposure for me, like cattle being herded to the stalls. Because I have had several surgeries on my knees, ankles and feet I haven't been able to bear weight post operatively. As a result, I have had to endure the experience of being put onto a commode or other movable chair wearing only my Johnny shirt, and being wheeled down the hall for a bath with my butt end hanging out. It is so demeaning! The bath is a welcome opportunity but the indignity of the trip down those corridors almost negates the pleasure of the bath! What I find most disappointing is that there are some nurses who just don't see what is bad about that picture.

As a nurse, I feel let down that there are still nurses who don't recognize the difference in importance between changing bed linens and talking to the patients. I have watched nurses come into a four bed ward and change bed linens every day, although all of us were spending most of our day out of bed. And yet, they never had time to sit and talk to any of us about what was going on in our day. Even if you'd say, "You don't have to change that bed every day. I only slept in it at night," they'd say, "Oh we've got time. We'll do it." I was wishing they would just consider what was most important in that room; was it the task of changing bed linens or would it have been more helpful to find out what was happening in the patients' lives. Sometimes you would really like them to spend just three minutes sitting on the side of your bed saying, "How's

your pain control? How are you feeling now that you are up on your feet? How is your physio going?" But that isn't happening.

I don't know whether it is mere coincidence, but in my recent hospitalizations I have noticed a difference between the younger nurses and those who have obviously been nursing for a longer time, both registered nurses and nursing assistants. The younger nurses are interested in learning more about the disease that I am dealing with and in focusing on the reason why I am there. They seem genuinely curious to know what it is like to have RA. In contrast, it seems like the more experienced nurses aren't interested in learning anything new. They just seem too tired to listen to the patient and they're quick to get defensive about any suggestion about how I need to move, for example, within the restrictions imposed by the arthritic joints.

When someone with a chronic illness comes to hospital for surgery, that person is not just "the knee in room 11." People with chronic illnesses, like those who have RA, are on specific medications that have to be taken in certain ways. They, like me, have lived with the disease for a long time. There are certain routines which work well for us at home but which we can't carry out on our own in the hospital. It becomes exceptionally important for us to be very cautious and vigilant in the hospital. When the nurses don't understand the importance of certain medications and how they must be taken they just don't get it right. For that reason I think that every person with a chronic illness needs to pay very close attention, to recognize if medications don't look right, and to assert themselves. For example, if our pills don't look right or aren't given the way they should be, then we need to question that. We have to take responsibility and then things will work out better.

I've felt a greater sense of being part of a team with the nurses during my more recent surgeries because they've come to know me and know more about me. Furthermore, I am becoming smarter about what to expect and about how to better prepare myself. Both of those aspects make it a more positive experience. I have also found that the my recovery period at home seems to be influenced by how things went for me in hospital. When I've had very stressful and painful hospital experiences I have come home exhausted and then I seem to take longer to recover. On those occasions when my hospital experience was positive, my post-hospital recovery has gone so much better too. I don't know exactly what to relate it to but I have noticed differences.

One very outstanding memory for me happened recently when I was preparing for a major surgery. During the pre-admission visit I told them my concerns about the uncontrolled pain I had after a previous surgery. I was forceful with the surgeon and with the pre-op assessment nurses. I told them that I didn't want to have to worry about whether I was going to be in excruciating pain. I asked to see the pain control nurse. She saw me and everything was so well coordinated from there onward. It was just so remarkable. After talking to me she put me in her appointment book. She met me in the preoperative area. She was even in there for part of the surgery. Everything was so well coordinated and went so well. The nurses were fabulous. They seemed to know that something had been missed somewhere previously and they saw to it that I got through okay.

I have learned from the good experiences as well as the bad and the ugly. Now, I get all my questions organized. I leave nothing to chance. I want to build a good experience. For me, part of that will be having the confidence to

assert myself and become an active member of my hospital team. I am getting smarter about how to prepare and I am also getting more confident that things will turn out well. Making it a positive experience takes a lot of effort. It is psychologically very taxing. You are really fragile, emotionally, when you go into hospital and you're very vulnerable. You are at their mercy. When you are in that Johnny shirt and you're stripped of your identity, you feel so exposed. It's a journey that I don't look forward to. I look forward to the destination, the better joint, but not to the journey.

Wally

Meeting Wally

Wally responded to my invitation to participate in the study after I was given an opportunity to present information about the study to an RA support group meeting. I was made aware of the meeting through the Arthritis Society and given permission to attend and present my proposed study information. Wally ably chaired the meeting. I found myself very impressed with the forthright and natural enthusiasm that she radiated. When we met at a coffee shop for our interview appointment I experienced the same sense about her. She strode in with complete ease. Her aura of natural energy had an engaging effect. Wally is a thirty-four year old graphic designer who works part-time now that she is the mother of four-year-old twin daughters. I engaged the audiotape very early in our conversation, immediately after having the consent forms signed and after thanking Wally for taking time out of her day for our meeting.

Wally's story

I came to know that I have rheumatoid arthritis (RA) in the office of a well-respected rheumatologist. My diagnostic results confirmed what had been

suspected for the previous several months. I remember that day vividly. It was a strange experience, an irony, really. I was being told that I had RA. I didn't believe it. I couldn't believe it. I was just 30 years old, had infant twins and I hurt; I wasn't sleeping; I was exhausted. I thought that I must have an infection. My mind was functioning on another plane as I was being told the statistics on various treatment options, their side effects, outcome percentages and how drugs work. I thought, I don't have this. I've got something else - an infection or something. I couldn't understand how I could have this condition which was being described to me. The doctor was telling me all these statistics and I couldn't even listen to him. Every time I asked a question he would brush it aside. It was like, you know, if you are diagnosed with cancer or something, the last thing that you want to hear is, how many people die or how many people live with this disease. I just didn't get what I needed from him. I didn't get any understanding; I got statistics.

I left that physician's office feeling silenced. I wanted him to know how much pain I was experiencing. I wanted to understand why I had this pain and I wanted him to tell me what would help me so that I could care for my babies and carry on being me. He didn't seem to have time to listen to how much pain I was in and that I wasn't able to care for my kids.

The best thing that could have happened for me at that time did happen. I was enrolled in RA classes through the rheumatologist's office. Over a period of several weeks I received explanations from various professionals and gained understanding. I was given information that made a huge difference for me. The people at the course were explaining things to me that I needed to know. I learned about nonsteroidal anti-inflammatory drugs (NSAID's), about cortisone,

about other disease modifying drugs, and about exercise approaches. My knowledge level increased. Knowledge is power, total power. With the knowledge and understanding that I had gained I was able to return to my physician and tell him what I really needed and how I needed to be helped.

We tried a treatment plan for about six months but it was not helping me, so I took action in a different direction. I shared my concerns with a friend who also had an inflammatory disease. She had lupus and she could see that I wasn't benefiting from the prescribed treatment. She said, "Go see someone else." Before going to another new person I just needed to be able to discuss all of my concerns with a professional whom I knew and to whom I could talk. So, I returned to my obstetrician. While under her care during my pregnancy I really felt that she was a very smart woman and I trusted her opinion. I asked her all of the questions that my rheumatologist didn't seem to have time for. Although she agreed with the diagnosis, she seemed to know that I was struggling with all of this and she recommended that I see another rheumatologist for another opinion. I did, and that was the start of getting my RA under control.

It wasn't that the change in medications worked immediately; the difference was that I could work with this doctor. One of the first things that she said to me was, "Oh my God, you have twins. We have to get you fixed up!" I remember that so clearly. I just burst into tears. I sensed that here was someone who was going to help me.

The treatment plan was to first try the drug that was the best, statistically. But, after seven months of trying Methotrexate® we realized that it wasn't working, even at the maximum recommended dose. About every six weeks I'd

be phoning my rheumatologist and telling her, I'm in agony. I need another shot of cortisone. Unfortunately, seven months was enough time for the RA to have done some serious damage to my hip.

My rheumatologist went on sick leave and I was left in the care of her replacement. I urged for change because the "statistically best" drug wasn't helping me. The change was to be one of my most hated things - needles! Gold[®] injections weekly for six months were a challenge. They hurt! Sometimes I was in so much pain from them that I was barely able to bend over and put on my shoes. I think that the hope that this treatment would work is what kept me going back for the painful injections. It did become easier to go for the injections after I began noticing improvement in my RA. For the first time, I was starting to get some relief. I was so excited. My whole family was excited it was working.

By this time my right hip, which had been causing me a lot of pain, had deteriorated to the point where only surgery would be the ultimate solution. The news was devastating! The advice from doctors was "You're too young for this. You don't want to have this done now." I didn't want to have it done. One doctor said something very helpful to me. She assured me that I would know when it was time. About six months later I was feeling really great except for my hip. I was in a lot of pain and walking with a cane. It was my hip that was holding me back from life--my life when my twins were young. Moreover, just at the time that my surgery was scheduled my body began to show signs of gold therapy side effects. The drugs were affecting my kidney function! That doctor was right when she said, "You will know when it is time to have surgery."

After three years of struggling with agonizing pain, where every day's goal was to merely get through the day, life began again for me following the hip replacement surgery. When I think back on that time, I am convinced that, had someone told me how it was going to be to have twins and have RA, I would have thought only a hero could proceed. Now, I don't feel like a hero. I realize that people overcome things and I, too, somehow got through it. I think that is probably why I volunteer with the Arthritis Society. I would like to give something to others to help them get through.

A turn-around point for me occurred about six months after my diagnosis, when I enrolled in the Arthritis Self-Management Program (ASMP). That was the first time that I was exposed to other people with RA. Seeing all these people in the room going through the same things as me was like starting a new life. When you're young and have RA and don't know anybody else like that, you're pretty lonely. Just to connect with people who are going through the same things allowed me to go through a grieving process, I believe. I had to grieve for my past life. Once I was able to get beyond that and realize that I could have a new life, and could lead a productive life with this disease, that was a huge thing to come to terms with for me. The self-management program included a few people in the class who were very enthusiastic and very energetic. I could see how productive and positive they were and that helped me immensely. In reflecting on this whole concept of "a new life" I recognize that I lost the freedom of taking my health and an active life style for granted but I gained insights that were not available to me before. Now, every day just seems more livable in a changed way. I feel more inspired by the possibilities.

I was first inspired by key people in the self-management program and

have since become inspired by others who remain the same people after adverse incidents but have adapted and who take charge of their lives with disease. I realized I could do that. I could inspire others too. There was a time when I used to say, well, I have RA. Now, I don't. The RA is not who I am. It's part of my life but I am bigger than it is now. It is not everything that I am about. I am no longer consumed by it. You can't put it behind you all of the time but I set goals and that prevents it from remaining in the foreground for me.

You are really vulnerable when you have RA. You can't just run, or take-off. If someone were to grab you, they've got you. When the disease flares up, I feel fragile, like a piece of glass or a china doll. You just feel weak. Even a simple activity like going down stairs leaves me thinking that if I trip, I'm toast. At those times, I just know that I would break if I fell!

But, when the RA is under control and I feel stronger, I experience critical victories. I recently felt so good that, without thinking, I jumped on my mountain bike and took off over some rough terrain. Of course I turtled! But, I just lay there and laughed at what I had done: I fell; it hurt a little; but no damage was done. That was so exhilarating.

I think that it's about seizing the opportunities of each day. I still have to listen to my body. I have to decide whether I can or cannot do activities on a given day. But sometimes I just have to do things like, I water-skied last summer. It made me think of all the times when I was able to unthinkingly do these activities but chose not to do them, like those other people in the boat on that day. They weren't interested in taking a ski, saying, "No. I don't feel like it." They just didn't get it in the same way that I now do. For me, it's about having an opportunity to do it and to seize the moment. To me, that's what it is

about.

As I said, when I finally was feeling good and I started having side effects on the gold therapy, it seemed like a good time to go ahead with the hip replacement surgery. My right hip had been the place where I had the worst pain for three years and we knew that it had deteriorated a lot, really quickly, early on.

As I look back on my time in the hospital for the hip replacement surgery I am amazed. It all went so well. It was a very good experience. The nurses and physiotherapists were so great. They were very helpful and very caring. They understood when I was having a bad day. There were no negative occurrences at all. Even the staff who cleans was all very nice.

One of the biggest challenges about the hospitalization that comes to mind for me was having visitors. You don't have control over that. People seem to think that they need to come and visit you in hospital. It was a problem for me when there were too many people in the room. I was in pain but the nurse didn't come in because all these visitors were there. You can't really ask them to leave. It was like people coming to your home and visiting. I felt like the hostess and didn't know what to do, although I was in pain and just wishing for an injection. It's hard because they think that they are making you happy by being there. It's a hard thing to control. But, for me, it was an incident with visitors that resulted in me being really embarrassed by my own actions. After my visitors finally left, on one occasion, I was rude to the nurse and didn't mean to be. That left me feeling really badly. Because I was in so much pain when the nurse arrived, I was sharp with her and came across as demanding. I felt really horrible after; I had snapped at her.

The nurse really understood when I snapped at her and she didn't take it personally. But, I guess that it's because of my beliefs that the incident left me feeling badly. I believe that, as a patient, one needs to be cooperative and show respect just as in any relationship with people. I think that how you ask determines how they respond. The way that I see it is like: I'm here; you're helping me; I'm grateful. It's a relationship. If I am complaining or demanding, then I'm not showing respect and can expect less help from others. That's how I understand it.

I think that people who are good people surround themselves with other good people too. My surgeon is one of those people. She is fantastic and it really made a difference to me when I went for surgery. All the operating room personnel put me totally at ease. They were very chatty and interested in answering my questions. I found that, while letting them hook me up to all these things I was just more curious than scared. I was relaxed as you can be, I think. I did have a very scary experience while coming out of the anesthetic (I found out later that I had pulled my own airway out before waking up). I had this frightening sensation of being unable to breathe. I was gasping and unable to get air. Amid my panic someone was holding my hand and trying to calm me. It is very difficult to calm down when you can't breathe. But I remember that she was holding my hand throughout that choking feeling.

I can't say enough good things about the nurses. I have another memory of when I really was afraid during a bone aspiration procedure, and the highlight of that memory is this one nurse who came down there with me and she held my hand the whole time. She distracted me by asking me questions about my girls. That was a huge help. I am sure that she might have had other

things to do but she stayed there with me throughout the procedure.

The nurses were terrific and I am still benefiting from what one of the nurses did for me. She brought in a relaxation tape and a tape recorder and everything, and she said, enthusiastically, "Oh you've got to listen to this. This is great." It helped me to get to sleep. She got me turned on to the relaxation tape. In my teaching with the ASMP, one of the favorite parts for me is the relaxation tape and telling the class how good it is and how well it works. Since that hospital experience I've bought several tapes and I listen to them on my own at home.

Before I was hospitalized, I was concerned about whether my wrists could endure the strain of crutch walking and using a walker while my hip recovered. I was pleasantly surprised to find that I had no difficulty. My rheumatologist had kept me on my medications and a cortisone injection until just a couple of days before surgery and the physiotherapists were really helpful.

Staying on my medications until shortly before my hospital admission was a challenge. During my Preoperative Assessment Clinic visit I was told that I would have to go off all my drugs for a week to ten days in advance of my surgery. When I heard that, I was just, like, well, I said, "I can't. How do you expect me to go off all these things that are controlling my pain and my inflammation and I've got two little kids?" I remember telling the clinician all of this but it wasn't until I burst into tears that she listened to me. It was like she didn't have an understanding of what these drugs meant to my getting through the day. It was a really cold feeling. In the end I was thinking that she must do this every day. So, if she does this every day then I just become another person going through. After it had become very clear, through my crying and anguish,

that this was a really big deal for me, she did call my rheumatologist and things worked out well. So, it was just this one incident around my surgical hospital experience that I recall as being really negative. My experience with the nurses in the hospital was fantastic. I think that I could have shared a real friendship with some of them. They were so great!

I don't remember very many details of my post-hospital recovery period at home other than the loneliness, for two weeks, of having to send my girls out for care by a family member. I missed them so much and was very lonely and depressed. The Home Care support was excellent but I didn't need help for long. I managed without any setbacks that I remember.

Now, I swim three times a week and I utilize what I've learned from the various physiotherapists. What they have told me makes sense to me so I keep it in mind. They are knowledgeable and I know that I can consult them whenever I feel the need to. They've told me so. They've taught me the importance of stretching and of how to protect my joints while strengthening my muscles. They know the unique features of the arthritic's joints and I can trust them.

Most people don't know that I have arthritis. That's kind of nice. My arthritis is not incredibly obvious to others. The treatment that I am now on is working well for me.

Tess

Tess's setting

On a Sunday in December I was received into a modern, well-appointed, clean and bright home. We settled around the dining room table. Tess had laid out papers relating to her history of rheumatoid arthritis (RA), the consent,

which I had sent in the mail, as well as travel documents to which she was attending in preparation for imminent travel to Hawaii and California with her husband. Tess explained that her husband was napping and that his previously robust health had recently been failing remarkably. Clearly, she was in charge of all their affairs at the present time. I observed that Tess was an attractive, well-groomed woman who projected vitality even though her hands and gait demonstrated RA characteristics. She warmly invited me through her kitchen to the dining room.

Tess was aware of my role as an acute care hospital nurse as well as my student researcher role in which I was presently acting. She had read my participant information letter and had agreed, by telephone, to participate. We signed the consent form at the outset of our time together.

During the time we were together, Tess's adult daughter and son-in-law made a brief visit on their way to a social event at which Tess and her husband were also expected later that afternoon. They conversed warmly and good-naturedly with one another. We were introduced. I stopped audiotaping at that time and resumed after their departure.

Tess's story

I am 68 years old. I first felt the effects of rheumatoid arthritis (RA) at age 27. I used to swim every day in the ocean, with my little girl. I lived in southern California at the time and I was really athletic. The RA symptoms appeared abruptly. I came up from the ocean one day to do some ironing. My arm really hurt. And my glands were swollen. The doctors thought that I had mononucleosis.

After I was diagnosed, the doctors treated me with Prednisone® for a month, which helped with the inflammation and reduced the pain. After that, I seemed fine for about three or four years. I guess the arthritis was in remission. My family and I then moved back to Canada from the warm climate of California. My first winter was devastating. I was in so much pain and all my joints were extremely swollen and were beginning to become deformed. I got really ill and was admitted to hospital. They did everything they could. They taught me exercises and they had my family get involved. I think that's one of the most important things. They told my family, "This is a serious problem and it isn't just her problem, it's the whole family's problem. So, if you're on her side and you give her support then she'll do a lot better." My family was always supportive. We are not a family though that dwells on illness. They teased me about my gait and my swimming style. When I was very ill they used to call me the crab because of my bent arm swimming posture. But, I didn't stop doing things. The positive approach is the only way that you can deal with this disease. If you ever allow yourself to feel sorry for yourself, you will never, never improve. I dragged a lot but I didn't stop. I did everything, really.

I believe that if you make time for yourself early in the day to look good then you will feel much better for the entire day. As the day goes on you might begin to feel lousy but at least part of the day is productive, which is a big plus. I hurt a lot but I make myself get up and look good. I don't say that I feel good. If someone asks, I say I'm fine and then I try to be fine. Mind over matter makes me feel better. I believe in hope and I believe in thinking positively. Sometimes I can get into trouble thinking I am well and I'm not; that isn't such a good idea.

On the other hand, I have always read and researched different approaches to help me decide what to go after next for the RA. I also believe it is important to keep informed so I can communicate with the doctor intelligently. I was always determined to stay out of a wheelchair and so far I've succeeded.

There were times, in spite of all the usual RA medications and treatments, that I got so crippled that I couldn't do anything. It hurt so badly. I was really crippled. The doctors seemingly weren't able to help me. I had been reading all the books. You'll try almost any remedy when you're that sick. There are lots of quacks and guru's around with the immediate answer and cure. There was one in Montreal, which I was tempted to see but the meeting places seemed shady and the treatment was too costly. I have tried all kinds of dietary changes over the years but nothing stopped the crippling. When it got really bad I did get to feel desperate and it just seemed like the doctors weren't moving fast enough. I couldn't even get up the stairs in our split-level home. There were no signs of improvement. It was an up-and-down battle when my mother-in-law told me about a physician in Mexico whose medicines had helped someone with RA in her family. I went down there and got what he prescribed. The first visit was a frightening experience, waiting in line for eight hours in that extreme Mexican heat and strange culture. But it was worth it. He gave me real hope. I took the medications that he prescribed and followed his regimen. After one month, I was almost normal--no pain, no swelling. What a miracle! I wanted my rheumatologist here to work with me and to research the treatment legitimately, to find out what was in the medications and to do a study that we would help fund. But he wanted nothing to do with it because there was too little known about it. Nevertheless, it worked very well for me and I carried on taking it for

ten or twelve years.

After fourteen years, suddenly, I got into this state where my bones were no longer holding me and I was having lots of breakdown. My joints and bones were getting deformities and were very painful again. The medical communities both in Canada and California agreed that the Mexican therapy plan was contributing to the breakdown and they strongly advised me to stop taking it. So I did, and I said, "Fine. What will you do for me?" I've been on a lot of different medications. Some of them would work for a little while. But none of them stopped my arthritis.

I have had some very good doctors. They were the ones with whom I had a mutual understanding. If they disagreed with me, I would say, "If you were in my boat, what would you do?" They were interested in treatments that I had pursued elsewhere. A good doctor doesn't belittle what the patient says and doesn't take hope away. The best doctors are those who listen and have concern for you. Doctors are only as good as the way they treat you and the research they've done for you. If they are going to help people, doctors also need to all work together. They need to communicate. If they send you to other specialists they need to see that you get the input and test results from all the doctors involved in your problem. It works well if they submit their letter of recommendations to the main doctor, who referred you, and if they have spoken with you, and you know exactly where you are going.

I also have had some very good hospital experiences. In the early days with my arthritis they did everything they could in hospitals to help me with the RA. They taught exercises and ways of moving to protect your joints, and they got my family involved. I couldn't have functioned without my family's support

and my strong willpower. I want to be well so badly. I have had many surgeries and have also been hospitalized for some complications from surgeries. There have been times when I would have to say the surgery was a success but the hospitalization was a nightmare!

Recently, my surgeon booked me for urgent surgery because my joint replacement site was showing signs of infection. I knew it was urgent when my surgeon said to me, "We've got to get you in to surgery right away or you'll lose your arm." He told his assistant, "Get her in to the hospital and onto intravenous antibiotics right away. We'll operate at 4 p.m." I went to the triage desk in the Emergency department, as directed, and the girl in the office said to me, "Now, Mrs. Gundy, you are only one of a group and you will have to go into the line up." I said, "Well that's fine but I have to be in the operating room at 4 o'clock." She said, "Now you go over there and wait in the waiting room." I gave them my papers and I sat there all day until twenty minutes before four, without being on the intravenous antibiotics that I knew I was supposed to have. When I told them, "I have to get hooked up because I'm going to surgery" they said, "Oh, you'll get looked after. Now go and sit down." So I went and sat down. At ten minutes before four o'clock a porter came to take me to my room on a surgical floor. No one was at the desk to check me in so he took me to a private room. At about 3 minutes before 4 the nurses came down to the room. They said, "We didn't know you were in here." I was exasperated, and I said to them, "No one seems to know that I am in this hospital so I put on a gown to get ready for surgery."

Well, I did get off to surgery but the hospitalization nightmare only got worse. It was three days after the surgery before they realized that I wasn't

getting my antibiotics. I heard the doctor discuss it with his resident. It seems she forgot to order it. The next day I became very ill with a fever and I started going into shock. I was losing clarity by then but my instinctive need to protect myself was intact. I told my daughter, when she telephoned, that I had to get out of that hospital before I lost not only my arm, but also my life. I wanted her to make arrangements for me to go elsewhere for help. I felt desperate to do something. I didn't realize at the time that I was too sick to act on my intention.

Then, my doctor got involved. Special intravenous lines were put in, x-rays taken and plans made for antibiotic treatment. By that time they had given me some form of relaxant under my tongue as well as the narcotics for pain. I started seeing double and I knew things were not right. While sitting in a chair beside my bed I became very faint and told the nurses, "I think I'm going to pass out." They didn't believe me. They said, "No, your cheeks are rosy. You're in a chair. You'll be fine." I said, "Look, I think I'm going to faint. Be sure to hang on to me." Instinctively, I tried to get back to the bed. They didn't hang on to me. I fell and slid under the corner of the bed, catching my artificial knee joint between the bed and the side rail. They panicked. I couldn't pull myself up because my surgical arm was all bound up and my other arm was tied to an IV. The nurses gave orders to get a hoist to pull me up and my biggest worry was the protection of my new elbow and my artificial knee joint. When you have lost your joints to the RA you don't take a good artificial joint for granted. I needed time to figure out how to untangle my leg so that the knee joint would be protected. Through all the pain I knew that I just needed time. They wanted to move me too quickly so I asked them to leave until I could figure out the best way to move.

Everything went wrong. Nobody seemed to be responsible. It was not because it wasn't the best people working in those jobs. They were good people. The problem was the breakdown in communication in the hospital. I truly believe that it isn't just the nursing care. It's also the doctors who don't talk to each other and don't have confidence in each other. I went to the best person I knew to have my surgery. I usually get at least two or three different opinions before I choose. When I choose my doctor I've got to have faith and confidence in him and I do. During this time in hospital I had another doctor come in and argue about the surgery in front of me. You tend to lose your respect for them when that happens. I know each specialist protects his area. But, as I said to them, "You've got to start talking to each other." It's a vicious circle right now. They are all just kind of passing the buck and covering their own little territory. I don't know where it's going to end but I'm just trying to get my health back.

I was so relieved to get home six days later. The Home Care Nurses that came to help me with my intravenous antibiotics were super. They were so good and so concerned. They looked after me and were available to me around the clock. Unfortunately, after eleven days at home, I had to go into hospital for another surgery. Once again the medications were administered incorrectly. I checked myself out to finish weeks of intravenous antibiotic treatment at home. My story goes on and I suppose will never end.

I have learned so many things by trial and error and would suggest that hospital care must change. The way that people get treated in hospital is, many times, unnecessary, very unkind, and irresponsible. It would be helpful if the nurses would give one confidence while in hospital rather than frightening and worrying people by suggesting that they are addicted to pain medications.

People who have RA usually take pain medication at home and they do understand the difference in their pain levels. Just to tell someone they shouldn't have pain isn't the answer and that doesn't stop the pain. It only causes a lot of stress. Everyone has different levels of pain and drugs need to be prescribed accordingly. Teaching different options for controlling the pain while you are in hospital would be more helpful than scaring you into not trying new pain control approaches. There are things that are not medications that can help the pain. I use some of them. But these are not approved of, in hospital. Nurses do need to be more open minded rather than just telling you that you have had too much pain medication. They make you feel that you will become addicted.

The problem in hospital is that their routine takes over, not yours. Nobody has time for you now. Getting to payday seems all-important. There are those who, clearly, just carry out routines, like clock-punchers. Will more nurses make the situation better? I don't know. Nursing comes from within and from a personal interest in the job. The sad thing is that no one will escape illness – we all get our turn.

Finally, my experiences have taught me that doctors and nurses must be a team and respect each other's superb, individual training. Each has something special to give. It would help the patient to heal, just recognizing that the team members have confidence in one another and that they really do work together like a team. I suppose that nobody knows just what I mean unless they have been there.

Sandra

Meeting Sandra

I met Sandra at a support group meeting of Youthful Active Arthritis

People. It was a meeting at which I was given an opportunity to introduce my proposed study. Sandra introduced herself to me immediately after the meeting adjourned, stating that she would be happy to participate in the study since she understood how difficult it can be to find participants for research work, having been in that position herself.

Sandra had been hospitalized, within the previous year, for back surgery unrelated to her diagnosis of RA. After assuring me that she had no problem with having our interview audiotaped we immediately set an appointment to meet. On the appointed date we met in a quiet clinic room, at the end of Sandra's working day, in the hospital where she is engaged in doing a Pharmacy residency. Sandra is twenty-four years old, has completed the requirements for her degree in Pharmacy and was accepted into the hospital residency program, a position which is open to only a few of the most highly qualified graduating pharmacists.

Sandra's Story

It was seven years ago, while working out for the National Basketball team tryouts, that I noticed extreme tiredness, and I was hurting. That hadn't been unusual when I participated really hard in other sports. I thought, "It happens." What happened next, though, was totally unexpected. I got really sick. I had fevers of 104 degrees and my throat was swelling so that I could hardly breathe. I was so sick that it wasn't a question of waiting to go to the doctor. He immediately had me moved by ambulance from our small hospital to a large city hospital. Fortunately for me, my family and the doctor were good friends. I say that was fortunate because sometimes it is who you know that becomes important. My doctor very quickly referred me to the right specialists

and the diagnosis of rheumatoid arthritis (RA) was made within several days. Little did I know that my life would never again be as I had known it—carefree and sports filled.

I missed an entire semester of grade twelve that year. In fact, I spent seven out of the following eighteen months in and out of hospital. Happily, each hospitalization period became shorter. However, I had to return to grade twelve the following year after all of my friends had graduated and moved on. It was horrible. I had competed in virtually every sport known to man and now I couldn't do any. That was hard. I tried to coach basketball but I wasn't able to demonstrate any of the plays. So, I was left with all this time on my hands; all my friends were gone from my hometown and there was nothing to do. So, I did something which would turn out to be the best thing that I ever did. It was something that I had never even considered. I got involved in theatre. It opened a whole new group of friends—of all ages—to me. It was great.

As for the RA, I was fortunate, right from the beginning, that my mom was a nurse. She fed me properly. I've always taken vitamin and iron supplements. I walked and did physiotherapy. I found that I needed a lot of rest. I have a lot more pain if I don't get enough sleep. Even after that year, when I left home and was taking my pharmacy degree at university, I continued to be quite careful about what I ate and about getting enough rest and exercise. I didn't want anything else to go wrong with me. Unfortunately, once I started the pharmacy residency program this year, things have changed. The program is really rigorous, very demanding. And, I have to work part-time to look after my finances. Consequently I am left with too little sleep, and when I'm tired I just don't eat properly. The outcome is that my arthritis is not as well controlled

just now. Nonetheless, I enjoy the challenges of the residency program tremendously. It's interesting. I'm learning lots and I do want, very much, to succeed. Hopefully it will also lead to a hospital pharmacy career.

Having RA while being a part-time employee and pharmacy resident at the hospital is kind of tough. On the one hand there is understanding and empathy for me as people realize the challenges that I face. It's nice that they care. On the other hand, I worry that, because they know about my RA, my future potential employment options here may be limited. I hope not. Occasionally I need to take time away from work because of the RA or because of my back problem. So I worry that I might be viewed as an employment risk and that bothers me. I am confident that I will be a valuable employee but I don't know whether my potential employer understands that. I wonder, will they prioritize my abilities above the fact that I have RA when they evaluate me? I sometimes wish that I could keep the two completely separate. I am afraid of losing my chance at a certain job that I covet.

It's kind of like that in my social life too. My friends are all great and they are very supportive. I just don't like to tell them all the things that I'm going through. It drives me crazy if they baby me. Even if I feel like crap and they ask me how I'm doing, I just say, "I'm fine. How are you?" I don't want them to make a big deal about it. I am twenty-four years old and I have had to miss a lot because of being sick with the RA. So, even if I don't feel well I usually go along to do whatever because other people my age, and all my friends, are doing it. I'm not ashamed of the RA but it comes up more often than I'd like.

My RA medication regimen has been fairly consistent over the past seven years. After about a year of getting good control of the RA on gold therapy it

stopped working and we added Plaquenil®. That has worked for me and I'm still on it. I still need to get joint injections of cortisone periodically. I try to go as long as possible but after about a year I seem to need an injection in at least one of my joints--either the elbows, my shoulders or my knees. After I've had an injection it gets better for a while. I have managed that way without changing my RA drugs. It seems like I have had a bazillion cortisone injections in my joints though!

There have been times when the doctors have wanted me to change my RA medications but I prefer to leave things as they are. I'm a pharmacist so I look at possible medication changes from a risk versus benefit perspective, together with my rheumatologist. I involve him in every decision about my arthritis. I just feel more comfortable that way. I have been fortunate to have a really good relationship with my rheumatologist; I can go see him directly when I need to. It means a lot to me that after seven years with RA I still have the same rheumatologist. I respect him. In fact, he's my hero!

I have moved a lot so my family physicians don't know my situation as well and they are somewhat more in the background. They always consult with my rheumatologist. It works better that way. Another thing that works for me is to keep my own written health history. It not only informs all the different physicians, it also helps me to remember things. Keeping my file helps me know who is doing what because all of my health problems are somewhat inter-related. It works in my favor. I always use it when I see a new doctor or if I'm admitted to hospital. That way I avoid having to repeat my whole health history each time because I am not very patient about doing that, and you do forget just

exactly when things happened.

When you have RA, being a health professional has both positive and negative aspects. One of the good things is, I am totally comfortable interacting with physicians and with my colleagues on that professional level since I have spent so much time in hospital. The other pharmacists are surprised at how comfortable I am in talking to the patients too. So that's a bonus. For me, it's easy because I spent so much time being a patient. However, when I was in hospital for back surgery, I think that the health professionals had a problem with me because I was so young and yet so knowledgeable about the arthritis, about my own health situation, and about how the system works. They actually seemed to resent my communication skills and my comfortable interaction with my physicians! I had this sense that the staff weren't able to deal with me on the level of someone who is knowledgeable; that's the level on which I wanted to be dealt with. Residents and nurses sometimes came across as condescending. I resented being made to feel like I didn't know what I was talking about when I really did. It was an irony, really, because I found the staff wasn't very knowledgeable about RA. And yet, they wouldn't believe me. They seemed to doubt my ability to know things that they didn't know. I got really upset when a staff member challenged whether I really even had arthritis!

Although I told the nurses that I had the RA, I don't think they even considered that. They didn't seem to have time to focus on anything except the back surgery for which I was there. Surgery was what they were trained in and the arthritis wasn't their concern. When I told them about the RA medications, which I needed to take, they seemed to think me rude. Or, maybe they just forgot, I don't know. I had told the doctors and the nurses and had asked for the

medications several times. I didn't make a big deal of it when I didn't receive them; I wasn't going to demand them. I just took my own medications and told them what I was doing. Being a pharmacist, I knew that it wouldn't hurt me to take my own meds. That's just the way I am; I look at risk versus benefit.

Taking my arthritis medications helped with the joint pain. After my surgery I guess they just figured that I wouldn't need my anti-inflammatory medications because of having had my back surgery. They forgot that I had other things for which I take the anti-inflammatories; fixing my back didn't cure my arthritis.

I don't want to make things difficult for them when I'm in hospital and I don't want to be a nuisance. I believe that if you are a good patient and don't make too much trouble then people are more willing to help if you really seriously need their help. That's just the way it is in life. I managed. But, it would have been nice if I had gotten my RA medications when I was in hospital; to have had them ordered, brought to me and properly charted would have been nice. I also would have liked some kind of physio that would have allowed me to work out the stiffness of my arthritis. I know that it would not have been easy to figure out exercises that protect my back after the surgery. But, I didn't see a physiotherapist while in hospital.

For me, physio began six weeks after surgery. After both surgeries I found that it is difficult to balance the physio. I can't be as aggressive nor can I do all of the recommended post-operative stretches, due to damage from the arthritis. Conversely, I can't do all of the exercises for my arthritis because of the back surgery. So, it is frustrating, not only for me, but also for the therapist. And, I was getting different advice from different physicians. There are lots of physicians involved in my care, some for the RA, some for the surgery and some

for the sequelae of surgery. Medical specialists and surgeons differ in their ideas about things. That is a challenge because I need to be able to work with all of them.

My arthritis is usually pretty well controlled but after both surgeries, it flared. I don't know the whole rationale behind that. I don't know exactly what to attribute that to. I do know that I slept badly in hospital and the immobility after the surgery surely contributed, because exercise is the best thing for the arthritis. I also know that stress of all sorts, physical, psychological and emotional, can be a factor. I found it stressful when I wasn't acknowledged as a person.

Post-script

My exploration continues. These stories are distinct moments in an ongoing dialogue. "The end of a story is best seen as an invitation to begin a new phase in the conversation" (Barone, 1995, p. 72). My next effort, then, was directed toward vigilantly and thoughtfully re-reading the stories, blending the voice of the study participants, voices from the literature, and my voice. It was my intent to leave openings in the writing of Chapter 6 for the reader's voice.

CHAPTER 6

Reflections on the Experiences

The purpose of this study was to contribute to our understanding of the experience of persons who have rheumatoid arthritis and who have undergone surgery in hospital. In this chapter I initially give an account of how my life experience has contributed to this study. Then I relate what I have learned. Finally, I discuss implications for nursing and hospital care when patients with chronic illnesses, such as rheumatoid arthritis, enter an acute care hospital for surgery.

The Contribution of My Experiences

“The interpretation of any text is never a neutral act” (Schick, 1994, p. 17). The intermingling of my outlooks and views were central to my choice of research question and to the relationships that I established with the research participants. They will be evident in this chapter. Ultimately, all research is autobiographical to the extent that researchers have an effect on the studies which they undertake (Norris, 1998). As a researcher I must be attuned to, and acknowledge the contribution of personal experience to the knowledge which is constructed in this study (Connelly & Clandinin, 1992; Polkinghorne, 1995). There are several aspects of who I am which are pertinent and will be discussed.

Personal self. The person that I am is comprised of relationships in all directions, as parent, child, mate, individual, friend, colleague, associate, observer, and reader. My experiences in these relationships have inward, outward, forward and backward aspects of meaning (Connelly & Clandinin, 1992). I make choices about places, people and pursuits that provide shelter, calm, and stimulation in ways that contribute to my well-being. My subjectivity

makes me who I am as a person and as a researcher (Glesne & Peshkin, 1992).

All of my relationships and pursuits create a context. Nonetheless, I persist as an individual. My sense of being an individual is of central importance to the essence that I think is I.

Nurse self. I have been a registered nurse for three decades. Throughout that time I practiced, primarily, in an acute care hospital. I have tended to gravitate toward one-to-one relationships in my clinical work. In this way I realize that I have created, for myself, a means of working as an individual in a setting that is large, is hierarchically oriented, and whose very size and nature tend toward challenging the sense of persons-as-individuals, whether they are staff or patients. I adapt to the dilemma that is posed by being a single organism in the nexus that is a large organization by steadfastly adhering to a sense of agency.¹ I am also cognizant of the freedom that I have had to negotiate within the rich resource that comprises a large hospital organization, and of the advantage that such freedom affords my nursing work.

Learner self. Being a generalist by nature, I have been drawn toward diverse learning experiences, each of which have excited, intrigued, or inspired me in different ways; sometimes the concrete and sometimes the esoteric have appealed to my need to know and understand. Most recently, during my graduate studies I have been informed in ways that equip me to more clearly articulate the approach to nursing that I find most meaningful. In doing so I have also come to realize a new appreciation for valuing all forms of knowledge, not as more or less important, but as equal and vital, though different.

¹ Agency, as used here, refers to the sense and possibilities for acting in particular clinical situations (Benner, Tanner, & Chesla, 1996)

Researcher self. I came to research rather late in my professional life. My experience is in nursing practice. A desire to know the “how” and the “why” of what is done in practice has always driven me, but I have been a consumer of research rather than a researcher. Becoming a novice researcher has entailed a journey into new ways of talking and thinking and accepting, with respect to methods of inquiry for nursing.

I arrived at my desire to do research bearing a certain level of distrust in personal stories as research. The notion seemed too presumptuous. I doubted that it could achieve critical significance. Moving forward with this research endeavor has required altering my stance. Rather than assessing story as a potential revealer of truth my assumption now is that a single truth, as a static occurrence, does not exist.

By co-writing someone’s story I understand myself to be engaged in exposing a particular perspective (Barone, 1995). As a writer of this research account I do write from a political perspective as I offer readers a configuration of a life world for their consideration. My aim, though, is “ . . . not to prompt a single, closed convergent reading” (Barone, 1995, p. 66). On the contrary, I aim to coax the reader to contribute possible answers to the dilemmas posed by the storytellers in this research endeavor. Alternatively, I offer the reader an opportunity to gain a sense of heightened awareness, akin to an epiphany. “Epiphanies are interactional moments and experiences which leave marks on people’s lives” (Denzin, 1989, p. 70).

Interpreting the Narrative Accounts

What do I do with another's story, now that I have it? How do I "read" it? How do I understand it? How do I convey an understanding of the participants' worlds that is beyond a mere literary account? I do not wish to subsume these unique individuals into typologies or composite characterizations (Atkinson, 1998; Zeller, 1995). At this stage of the inquiry I am acutely aware of Atkinson's (1998) admonishment that the meaning and the validity of each story may be different for the one who has told it than for the one recording it. Having approached this research from the premise that these stories are texts that have something to say about these four particular lives, I will now identify ways in which each unique perspective provides a facet of learning for me, as researcher and as nurse.

Learnings

Sometimes our field texts are so compelling that as researchers we want to stop and let them speak for themselves They may be captivating stories. But researchers cannot stop there because the task is to discover and construct meaning in those texts: field texts need to be reconstructed as research texts. [Field texts] are the texts of which one asks questions of meaning and social significance. Research texts . . . grow out of repeatedly asking questions of meaning and significance (Clandinin & Connelly, 1994, p.422).

As a preliminary step to developing a research text I took the following actions: I contacted the participants by telephone and arranged the return of the written stories to them. They agreed to review the stories which I had written

from what I heard them tell me. A brief covering letter accompanied the returned stories (Appendix C). Following each participant's reading of her account, we met for discussion on its accuracy in representing the experience. We discussed any required changes or clarifications, and we discussed my developing notions of meanings and of social significance inherent in their stories. This approach assumes that there is meaning and social significance to be found in the participants' personal, practical knowledge. By "personal, practical knowledge" is meant the way in which these specific individuals know their situations (Connelly & Clandinin, 1986). Through the process of mutually developing the research account I endeavored to enhance its accuracy and to uncover the personal philosophies of the participants. The following section represents what stood out for me in the individual experiences of the four participants.

Learning from Rae

While developing Rae's story it was my sense that, as a surgical patient who also has a chronic illness, Rae experiences two fundamentally different realities. Her emotional sense of herself is vastly different in each, although at the core she knows herself to be the same person throughout. Her story describes how she experiences herself in both realities, that of a person who deals with a chronic illness and that of a person with a chronic illness who is hospitalized for surgery. At our second visit I shared my notion with her. Rae said, "I am uncomfortable as a person while in hospital. I'm not the same person that I am outside of hospital." Rae described herself as fiercely independent. She profoundly values independence. When she is hospitalized she experiences anxiety related to the loss of her identity as an independent individual.

Rae described how she feels in hospital, using the following terms: *surrendering; dependent; vulnerable; at their mercy; detached from myself; not in control; disoriented; I withdraw to preserve my energy.* The thread of significance lies in the intense energy which, Rae said, is required to “make it through” the hospitalizations. She identified how her long history with systemic illness has resulted in a finite energy reserve. Through a disciplined life style she maintains energy resources which allow her to continue those aspects of her life which have importance: her professional career, living independently, enjoying social relationships, maintaining a well-groomed appearance, and exercising regularly to enhance joint function and mobility. When she is hospitalized she channels her energy into the day to day requirements of getting through the post-surgical routines. She uses energy to be vigilant about the RA medications to ensure no errors are made, and to protect her arthritic joints from injury at those times when the nursing staff are focussed on attending to her surgical site rehabilitation. Rae knows that her surgical recovery is of paramount importance to the nurses; “that’s what they are focussed on.” However, she senses that she is solely responsible for her RA self care. She finds hospitalizations “very exhausting.”

Although Rae is also solely responsible for her RA self care at home, she finds that she is not able to carry that self-care out in the hospital in the same ways. At home, she manages her routines in specific ways to conserve energy and minimize pain. Her medications have specific dosing particularities that make them optimally useful to her. Rae times the taking of her medications and her activities in specific ways that work for her. In hospital she does not feel at liberty to do so, in part, because the setting is not facilitative for someone who

has physical impairments. Specifically, the furnishings are arranged in ways that make it difficult for her to maneuver without assistance. The meal arrangements and regimens of hygiene are different from that to which she has adapted at home. At every turn she seems to need assistance to carry out routine activities which she is able to carry out independently at home. The nurses are rushed and busy. Their hurried pattern of getting other things done while they are in the room to help her does not fit with how she must function in order to optimize her independence. Rae experiences incongruence.

Rae pointed out that her RA has advanced considerably over the years. Until recently, she successfully maintained a good deal of symptom control, through what she describes as “dogged determination” and through working closely with her rheumatologist. Rae characterizes her relationship with her rheumatologist as a partnership. A belief in personal control over RA symptoms has been shown to correlate with positive mood and optimal adaptation to chronic illness (Affleck, Tennen, Pfeiffer, & Fifield, 1987). Mood and psychosocial adjustment were found to be directly related to participatory control. The finding emphasizes a partnership between the chronically ill and their health care providers (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Reid, 1984). When Rae feels victimized by her inability to influence her hospital course she feels disabled in the management of her RA.

With respect to her hospitalizations, Rae identified two very difficult and sudden transitions. She finds the transition into hospital is more difficult when she is admitted on the day of a surgical procedure. She described how that generally entails rising by 0500 hours in order to be at the hospital before 0700 hours, only a short time before entering the surgical suite. Upon return from

surgery, compromised by the influence of the anaesthetic and pain control medications, she feels intensely disoriented because she has not had an opportunity to go about the unit and “get a feel for the lie of the land, so to speak.” She finds that the sense of disorientation does not entirely clear throughout her stay, partly because she needs to focus her energy so intently on “the day to day activities.” Although she looks forward to discharge from hospital with anticipation, she finds the transition from hospital to home is difficult. In reflecting on that, Rae explained that she assumes a somewhat suspended state in hospital and, upon discharge, feels temporarily dissociated from the person she was before entering hospital.

Rae’s intense focus on the responsibilities of self care related to her RA while in hospital, coupled with fatigue and loss of orientation to the self with whom she is comfortable, as well as environmental disorientation, might be confusing to the staff. For those nurses whose conceptual approach to nursing is one of responding to expressed need for help, Rae’s concentration on functional performance may be mistakenly interpreted as aloofness and self-sufficiency. This apparent incongruence takes on different and more coherent meaning when seen in terms of Rae’s personal philosophy. Because she has been intensely independent she is not comfortable with a dependent role. She is also not comfortable with herself when she is not well groomed. In hospital she finds herself dependent on assistance in order to carry out her grooming activities. Nonetheless her story expresses how helpful she found it when nurses had anticipated her needs in a facilitative way. She welcomed assistance and attention from nurses who were genuinely interested and intuitively aware that she required understanding and, at times, help.

To understand how Rae's hospital journey might have been expedited means, at the very least, to understand Rae's personal philosophy.² Further, one needs to understand the kinds of things that comprise post-surgical functional performance for Rae who faces unique challenges related to advanced RA. Based on the results of their study, Leidy and Haase (1999) suggest that people who are ill face an ongoing challenge of preserving their personal integrity as they encounter a variety of changes that can interfere with day-to-day activity. Qualities most salient to integrity are a sense of effectiveness, or "being able" and a sense of connectedness, or "being with" (p. 67). Rae's story and her discussion concerning her experience reveals a sense of having her integrity truncated while in hospital. She clarified that she becomes "just the knee in room 11" or the person who would like to enjoy a shower or bath, as an end in itself. For Rae the shower/bath is a means to an end. It is part of grooming that is integral to her sense of personal dignity. Unintentionally, her sense of herself is neglected when she is wheeled down the corridor in a revealing "Johnny shirt." My observation of Rae reveals an exceptionally well-groomed individual who demonstrates composure in her carriage. Rae, in her story, had explained how important it was to her sense of self, to be getting up each day and applying make-up, and going out the door. The hospital corridor scene, which she described, is incongruous with that picture of herself as a whole person; it reflects a situation of overwhelming challenge that threatens her sense of personal integrity.

Leidy and Haase (1999) explicate the notion of connectedness as a

² "Personal philosophy" as used here, is a way one thinks about oneself in one's situation (Connelly & Clandinin, 1986).

component of personal integrity. They define connectedness “as a sense of significant, shared, and meaningful relationship with others ... or with aspects of one’s inner self” (1999, p.72). Characteristics of connectedness include “familiarity, comfort, shared experience, understanding, and trustworthiness” (p. 73). In the same study it was found that connectedness with health care providers occurs when participants perceive the providers are consistently responsive, conscientious, and personally invested in the participants’ well being. Rae’s story identifies connectedness with the more recently graduated nurses similar to that described by Leidy’s & Haase’s study participants. She also identifies connectedness that is conditional to her social status; she was more apt to feel connected with nurses who had “recognized” her from previous encounters.

When Rae struggles, post-surgically, to reach her tray and carry out the everyday tasks of eating, ambulating, and hygiene, her sense of personal effectiveness is challenged and in some instances, curtailed. She feels unable to count on understanding and vigilance from health care providers. Rae expressed appreciation for some of the “excellent young nurses” who helped her preserve her integrity in specific instances, through actions that show understanding of her challenges. She shares her past experiences with them when they show interest. She trusts them enough to ask for their help to bolster her own effectiveness. These nurses are engaged with Rae’s situation and with her personal world. Some of the behaviors which portray their engagement, include: asking about the RA, being cheerful and kind, making themselves available, and making Rae feel that nothing is too much trouble for them. Kralik, Koch, and Wolton (1997) have studied the concept of engaged and detached care

by nurses in hospital. Participants in their study identified *engaged care* as positive, and *detached care* as negative. Detached care promoted feelings of vulnerability and insecurity in the participants. Rae used the term vulnerability when she described, in poignant detail, the Johnny-shirt scene and the routinized bed-making incidents. She found the nurses' approach in those episodes made her feel like an object without dignity and without personal needs.

Rae's biography with RA reflects an individual who plays an active role in the work of shaping her illness trajectory. Properties of stable trajectory management include routinized dedication and creativity, both of which require time and effort (Corbin & Strauss, 1988). In hospital, when Rae is identified as a surgical patient, like any other, her RA is not legitimized. Legitimization refers to the process of establishing an acceptable and legitimate place for the RA within her life as a surgical patient (Bury, 1991). Rae's RA management work and her personal integrity, which is directly related to remaining in control of the illness management, are diminished when she is identified as simply a post-surgical patient in hospital. I wonder whether the profound energy consumption, which she associates with hospitalization, may be related to this exclusion experience?

Learning from Wally

The predominant theme in Wally's hospitalization story is expressed in positive terms: "It all went so well. It was a very good experience. Everyone was terrific--so caring and understanding. We could have been friends." Wally's story highlights several occurrences that stand out for her. Each occurrence is expressed as a time when she experienced the least control over her circumstances and she most needed and appreciated understanding and support

from the nurses. Three such occasions were: when well-meaning visitors were insensitive, when she was in pain and frightened during a bone aspiration procedure, and when she was afraid as she struggled to breathe in the post-anesthetic phase of her hip replacement procedure. She recounted how nurses supported her in regaining control when she was challenged by difficult circumstances. Through Wally's reflective articulation of how she experienced these incidents a unified image of engagement and community emerges.

Engagement constitutes a relationship. It implies sharing and collegiality, akin to a friendship (Clandinin & Connelly, 1988, 1990; Kralik, Koch, & Wotton, 1997). For Wally, these incidents represent hospital life in a caring community. She and her care providers participated in ways that made her hospital experience good. Wally felt valued as a friend and she, in turn, valued the practitioners' commitment to her. She felt like a friend to them. She also stresses that she valued their professionalism. Friendship, as referred to by Wally, is characterized by "not taking advantage of them" but knowing that she had open access to them as a resource. The incidents exemplify the kind of reciprocity that is central to Wally's relational belief system. Wally expresses it in this way; "I'm here. You're helping me. I'm grateful. It is a relationship. There is respect. That's how I understand it."

Wally experienced generosity and genuine warmth in practitioners who demonstrated an intuitive sense of knowing what would help her. As a result, she felt "connected" with them (Leidy & Haase, 1999). Her examples include the nurse who brought in relaxation tapes and equipment, the nurse who stayed with her during the bone aspiration procedure, and the personnel in the surgical suite. She believes that these actions were above and beyond what she had

anticipated. She found their concern for her to be genuine. They made her feel comfortable in what would otherwise be a cold and unfamiliar place. Wally uses the term “cold” when she recounts the pre-operative assessment episode wherein her voiced needs and concerns were overlooked. The practitioner acknowledged the urgency of her concerns only after her desperation precipitated tears. Wally had previously experienced a similar “coldness” response when her rheumatologist had delivered a diagnosis of RA but had failed to help her understand RA in relation to her life. Wally values and respects relationships with health professionals who demonstrate an understanding of what will help her. She becomes actively engaged in such relationships.

Particularly apparent throughout Wally’s story is her active engagement and interaction with her internal and external environments in ways that create health (McWilliam, et al., 1996). Wally accesses inner resources such as “inspiration” and “respect for” and “seizing the day” in ways that reframe her situation from one of having a chronic illness to one of creating personal health. She also accesses external resources in several ways. Comparing herself favorably to others helps Wally to take positive actions; “they haven’t had any physical challenges so they just don’t get it like I do now” and, “I thought that if he can overcome the challenges and be so inspirational, I want to help inspire others too.” Wally shows reciprocity and intention in her interactions when she says, “good people surround themselves with other good people and that is what I try to do too” and, “I know that I can call on them any time but I don’t take advantage of that. I decide if it’s important enough.” Wally decides what is important, which actions she needs to take based on what she has learned, and

when she will trust professionals for the help that she requires. Her decision making suggests that she advocates for herself by drawing on the resources of others and she reciprocates with respect for the resources that they provide. Wally's hospital experience exemplifies continuity with the rest of her life. Is her positive hospital experience attributable in part to that congruence?

Learning from Tess

When Tess speaks of her life with RA she describes how she feels the RA in her life. She uses the following words and phrases: *ill; crippled; hurt; feel desperate; bones break down; pain; you only know if you are in my boat or if you have been there*. These descriptors indicate what the RA does to her.

In contrast, when Tess tells of her life with the RA the active verbs and phrases that she uses describe the active role that she plays in creating her life with RA. Her story explicates the notion of health as responding positively to the challenges of her environment. Tess uses the following words and phrases to describe how she lives with RA: *I believe that if I look good, I feel good; mind over matter; get my health back; don't quit; do everything; make myself; you need hope; positive thinking; go after treatments; determined; will power; I tried to change things; try anything; get action going; I went and got; I carried on if it worked; stop the RA; find answers; get input; work together; know exactly; want to be well; research; choose; believe in; solve problems; do something; figure out how; take responsibility; go for the best that I know; respect; have confidence*. Reading Tess's story in this way was an epiphanic experience for me. At a "turning-point-moment" (Denzin, 1989, pp. 70, 71) I saw Tess's personal philosophy captured in those active words and phrases.

When Tess is hospitalized she experiences challenges and impediments to living with the RA in the usual ways which have worked for her. Some ways in which these challenges are expressed, follow. When she wants to make time for herself early in the day, *to look good so she can feel good*, the hospital routine is a barrier. When she *tries to make things happen* she feels blocked by people who tell her to “go sit down.” She wants to *get her health back* but she feels like she is at risk of “not only losing the arm, but dying.” When she is determined to act she is told to stop, to wait, to just sit down. She is given a pill under her tongue to relax. When she feels urgency *to get things done*, she is told that she is just one of many and that she must wait. When she wants to *try things to get through the day*, she is told they aren’t sanctioned, or, that she might get addicted. When she wants *to find answers, to get input*, the doctors argue among themselves. Tess has a need *to know exactly, to research, to decide, to solve problems*, but in hospital Tess feels that she is dealing with people who “act routinely” and “don’t make decisions”. She always *took responsibility* for her treatment decisions but in hospital she observes behavior among health care professionals that indicates to her that people do not take responsibility for their actions or inactions. Tess needs to *figure things out, to solve problems*, but in hospital she feels outside of control.

For Tess, hospitalization for surgery is experienced as dissonant from her usual mode of operating and pattern of managing her life with RA. Historically, she has developed ways of partnering with people whom she finds credible. She negotiates to make decisions that affect her well being. Tess’s life with RA is constituted by having agency, in the sense that she acts with an understanding of the impact that she can have on what happens. Tess advocates for herself, both

independently and as a member of her own health care team. Her life is characterized by self-reliance and taking responsibility for personal judgment about whose advice she will seek.

By contrast, in hospital she seems reduced to passivity. Tess feels excluded from decision making. Her days seem to be organized and structured according to demands and requirements that are external to her immediate needs. In hospital Tess defers to others and, although distressed, does not feel at liberty to disagree with those who authorize decisions and those who are involved in carrying out decisions. Whereas Tess clearly occupies a central role in her health care decisions outside of hospital, in hospital she feels very peripheral to decisions involving her well being. Rather than creating her personal health environment, as she usually does at home, while in hospital Tess's capacity to engage in goal achieving actions is impacted largely by directives that are external to her immediate personal experience of the situation. Her agency derives from the hospital environment and it is, thereby, diminished.

Being heard, being believed and being informed, from Tess's point of view, are essential elements that help her to shape her life and guide her health with RA. From her story emerges a hospitalization odyssey of discontinuities. During hospitalization she experiences losses; loss of control over her day to day personal routines, loss of voice regarding the knowledge that she has gained from forty years of experience with her disease, loss of voice regarding what is most important to her, and loss of connection with the people on whose expertise she relies. The significance of these losses lies in the profound vulnerability that they produce and the vulnerability in which Tess felt immersed while in hospital.

Tess's history with RA has resulted in compromised joint function. She deeply values the restored function that joint replacement surgeries have enabled in her life. Having experienced loss of joint function, Tess is vigilant in protecting the replaced joints from harm. Her graphic description of a fall while in hospital relates her fear of compromising a replaced knee joint. When she senses a gap between her level of understanding and that of the nurses with respect to protecting the joint, she is unable to accept the help that is offered by the nurses. Her story points to a desire by the nurses to be supportive. The support that Tess needs requires that she remain in charge and that the nurses lend a hand. However, Tess senses that the nurses want to help her get up from the fall by taking charge, and that is problematic for her. She believes that they are not cognizant of the nature of the replaced knee joint nor of her special needs and her expertise with respect to care and handling of the joint. Consequently, neither their desire to effectively help her nor her potential benefit from their support is realized. The situation results in tremendous energy consumption on Tess's part and on the part of the nurses, who are unable to help her, as they struggle to maintain their role integrity (Brown & Williams, 1995; Hart, 1985).

As a response to her experience of hospitalization, Tess calls for health professionals to listen, to communicate with one another, and to remember the patient who is before them. Tess identifies inadequate communication and absence of a sense of accountability among health professionals to be at the root of her experience of hospitalization as a "nightmare." Although she recognizes the resource inherent in the expertise of the professionals, referring to them as "the best people," she observes that they did not connect with one another and with her in ways that supported her well being (Leidy and Haase, 1999). Tess's

story exposes the hegemony of a hospital culture of exclusiveness. Tess appears to be excluded from the hospital community and yet she is profoundly impacted by immersion in it. How could Tess have experienced a more inclusive connection with the resources of the hospital community?

Learning from Sandra

Sandra came to her hospitalization experience with inside knowledge. She works in the hospital setting and therefore it is familiar to her. Additionally, she possesses professional knowledge and expertise as a pharmacist. Sandra had anticipated that, because of this knowledge, she could make certain assumptions. One assumption she held was that, knowing how the hospital day unfolds, she would not demand attention inappropriately. She did not “ask for things” around change of shift and other times when she knew that the nurses were particularly busy. Secondly, she assumed that, because she could accurately detail her medication needs with respect to the RA, these would be ordered appropriately. Furthermore, Sandra assumed that because she could articulate her RA history in the language of the professionals, she would be believed. When the medications were not ordered as expected, Sandra knew from her pharmacy experience that she could take these without harm. She also knew that appropriate documentation and communication of what patients are taking is important therefore she informed the appropriate people of what she was doing and of the need to get the medications ordered appropriately. She found that the expected action was not taken.

Sandra experienced disappointment when nurses presumed that, because she had had back surgery, she did not require her RA medications. Her disappointment related not only to her ongoing need for the medications but

also to the fact that nurses, whom she had considered to be professional colleagues, didn't believe her. She thought that they would know that RA "does not go away just because someone has back surgery." Their knowledge level was less than she had anticipated. Moreover, they showed a lack of interest in learning from her. Following her back surgery, the neurological nurse discounted Sandra's practical knowledge. The nurse's neurological assessment revealed deficits that Sandra knew were related to her RA. However, the nurse did not accept Sandra's expertise about her RA. Sandra experienced a loss of confidence in the nurses' professional judgment after she was treated as if she didn't know what she was talking about.

Although Sandra entered hospital for back surgery unrelated to her RA, the RA fundamentally impacts her daily life. During her time on the surgical unit in hospital she found that "... the RA was not considered. They only focused on the back surgery." She was left on her own to deal with the RA and its impact. Moreover, she felt that she was "considered rude" for reminding staff of the added impact of the RA. Sensing the negative responses from the nurses resulted in Sandra withholding requests. She would have liked to have physiotherapists work with her to help optimize her RA related function while protecting her post-operative back. Physiotherapy did not occur and she did not ask for it. Sandra did find that the RA flared following her hospitalization for back surgery.

Sandra summarized her story of the hospital experience by saying, "It wasn't a big deal. I managed." In reflecting on this statement, I wonder whether Sandra "managed" by acting like she didn't have RA, so that she fit the role of a post surgical patient in hospital. It was, figuratively, as if the RA needed to be

left just outside the hospital entrance. There was a perceived mandate to be purely a neuro-surgical patient while on the neuro-surgical unit. So, Sandra made no big deal about her rheumatoid arthritis.

It seems that Sandra's integrity was being challenged by the nurses' need to maintain their role integrity. The notion of professional impotence has been described in studies relating to the chronically ill patient-practitioner relationship (Brown & Williams, 1995; Hart, 1985). In these studies it was shown that chronic illness can lead to difficulties in the patient-practitioner relationships because the inability to treat the illness undermines the image of superiority of the practitioner. In Sandra's case, the surgical nurses' lack of knowledge about RA seems to undermine their self-image as effective practitioners and therefore their focus is restricted to the post surgical pathway. Their dismissal of Sandra's RA effectively discounts its impact on her reality. Their approach, which is felt as condescension by Sandra, locates her in a constrained position within the social power structure of the nurse-patient relationship; a position from which collaboration is barred (Goodson, 1995). Sandra "manages" her hospitalization without collaboration, but at what cost to her?

Research commentary

In narrative inquiry, narratives are constructed at several levels. The stories of personal lives contained in this study can be considered personal narratives. They exist within shared narratives (Clandinin & Connelly, 1994; Connelly & Clandinin, 1992; Gadow, 1995; Polkinghorne, 1988, 1995). There are elements in each story that identify unique aspects of individual lives and there are common elements and issues that are shared among the stories and that we all share as human beings. These stories are interpretations of experiences and

they are illustrations of the way in which a sense of personal continuity is maintained as events are experienced and as experiences are reflected upon. They highlight influences and adaptive strategies in the lives of individuals (Atkinson, 1998). Although the narratives are responses to a research question about the experience of hospitalization, they are also retrospective accounts of the personal contexts within which the hospitalization experiences occur.

The participants in this study experience hospitalization as a means to an end. They, like all humans, are immersed in the business of maintaining their health while dealing with challenges that are uniquely theirs. By that is meant that they live with the impact of RA while they also exert influence on its obtrusiveness. Maximizing function has been found to be a primary aim for individuals with RA (Ailinger & Schweitzer, 1993). Achieving that aim is complex. Its achievement requires multifaceted discipline and dedicated attention. Hospitalization for surgery occurs within the biographical context of the complexities surrounding RA management. The narrative accounts convey these complexities.

At another level in narrative inquiry, following Clandinin and Connelly (1994), the narrative researcher is compelled to move beyond the collaborative telling of the lived story. This latter endeavor is one where the researcher's voice takes precedence. What follows is my reflection about the ways in which the participants' stories impact my horizons of knowing.

In drafting remarks on what I have learned, I want to avoid framing the discussion from a partisan perspective, although I was selective in seeking only the stories of hospitalized patients and not those of health professionals working with patients in hospitals. Attention to the latter is beyond the scope of this

inquiry. Notwithstanding, in highlighting what inheres for me in these narratives of experiences, I want to direct the reader's attentions away from a restrictive focus, on either the patients or the health professionals, to the relationships between them. Together they co-create a situation that is experienced in a particular way by each of the individuals who participated in this study.

When hospitalization is experienced along the life continuum in a way that is consonant with the overall life aim and with personal values and beliefs, then the experience has a validating effect. It preserves well-being and nurtures integrity in a way that supports the intactness of one's world (Grundstein-Amado, 1992). Gadow (1995) suggests that one's world can remain intact under a variety of circumstances when there is engagement between at least two people in the situation. In the stories presented here, engagement between health professional and patient makes the difference between silence and voice, between aloneness and connection, between bewilderment and understanding, between disablement and enablement, and between constraint and support while striving to maintain an integrated sense of self.

Engagement is relational, personal, and active. As an outcome of this study I perceive the therapeutic relationship between health professional and patient to be an interactive partnership. The relationship requires that both participants are dynamically engaged in reciprocal leadership. Each brings a unique and vital perspective and body of knowledge to the relationship therefore each may, in turn, lead. The hospital, although seemingly claimed as the territory of health professionals, is actually a community of individuals having interwoven experiences. These experiences transform the horizons of the

individuals involved. As each individual acts, they can do so in more or in less thoughtful consideration of how the other will experience their actions. By being attentive to how each individual is undergoing the experience hospital care professionals can be reflective about the ways the relationship is shaping the horizons of their knowing. When reflection about the relationship does not occur, the boundaries of the relationship become static, thereby blocking the possibility for creative movement, or for reshaping a situation (Clandinin & Connelly, 1990).

My search for a way to respond to the question of how life with rheumatoid arthritis is experienced through a surgical hospitalization has led me to link RA to life and to seek the story of that life. I sought the answer to my question in the stories. Four individuals poignantly described their life with RA, creating the context for exploring their experiences of hospitalization. The stories may stimulate readers to see other possibilities of the experiences.

Limitations and Possibilities

This study was confined to investigating those aspects of hospital experiences that were perceived by the participants. Other voices, those of hospital personnel who had parts in these stories, are not heard herein. The participants in the study were purposively selected for their relevant experiential knowledge, their willingness to think about their experiences and to express themselves in story. I have inspected these stories away from where they first occurred, both physically and temporally. I did not seek absolute truth or detail in the facts of the story.

I visualize the process and benefits of retrospective stories like those of aging wine in storage casks. The aging process develops the flavor and bouquet

of wines. The retrospectivity of the stories intensifies their clarity and poignancy, thereby enhancing their descriptive texture. Rich description has the potential to actively uncover elements that might illuminate the storied situation's complexities. Awareness of complexities generally provokes an emotive response. Brunner (1994) suggests that an emotional response precipitates reflection, either critical or uncritical. The provocation of thought in this way has the potential of germinating possibilities.

Possible Ways Forward

The research participants and I have presented an invitation to reconsider comfortable attitudes and values, and to affirm latent perspectives that have not hitherto been sanctioned by the dominant acute care culture (Barone, 1995).

Merely "déjà vu" or Propitious for Practice?

Both! These stories, for me, provoke a sense of having been there before. Although they are told for the very first time they have a familiar ring. By that is meant, they elucidate the familiar. In a rhetorical way these stories confirm the literature and my personal practice experience. Additionally, they are propitious because "... many things foster reflection. These narratives may offer one more possibility ..." toward beginning a process that may lead to making the culture of hospitals more relevant to the lives of all patients (Brunner, 1994, pp. 30-31).

In the realm of patient-practitioner interactions in the hospital, these stories reflect a paradigm discrepancy. Whereas patients who come to hospital are on a health continuum, hospital practitioners are attending to these patients from within a cure/rehabilitate paradigm that is specific to the practitioners' practice areas. Narratives such as these provide practitioners with a vehicle to guide their practice relationships. From Wally's narrative it is clear that when

patients actively negotiate their relationships with hospital practitioners the patient's identity emerges, clarifying what matters most to particular patients in their pursuit of health. By engaging the patients' voices, practitioners gain expertise and can join in the patient's health journey in a therapeutic way during the hospitalization period.

Conceptualizing caring practice in this way constitutes an awareness of the therapeutic, or healing, value of understanding and being understood. Listening, for the purpose of understanding, then becomes a therapeutic intervention (McMahon & Pearson, 1991; Sandelowski, 1997). Integrating biologic and pathophysiologic expertise and clinical proficiency with understanding constitutes an holistic framework for engaged patient care. Narratives such as these are a practical reminder that ethical and competent practice requires knowledge of the literature as well as the life (Chinn, 1994).

Quite specifically, it is not uncommon for hospitalized surgical patients to be dealing with chronic illnesses such as rheumatoid arthritis. Attending to these patients from a purely surgical rehabilitative perspective is received as rhetorical practice. By that is meant that it is abstract, objective, and outside the context of that person's situation. Tess, Rae, and Sandra identified the tension of objectification that was not intentional on the part of the hospital practitioners. It seemed to arise out of neglect and disregard. The practitioners were disregarding the context of their practice. The individual patients were neglecting to assert their stories of what is integral to their personal well being.

The question remains. If we have heard stories like this before then why does the dilemma persist? The question begs further research and calls for the reflective stories of practitioners in hospitals. I believe that those stories, coupled

with stories such as those in this study, will create new relational narratives that would be educative. In these stories there was not always satisfaction with the hospital experience. Stories from hospital practitioners, specifically nurses, might help to solve the irony that prevents relational effectiveness.

This study is particularly apt in light of the current health system constraints with respect to the economic emphasis on reducing professional nurse to patient ratios. The storytellers in this study offer a probing and compelling view of the multifaceted social community of the hospital. The stories invite reflection about the professional communities of hospital nurses, about their practice realities, and the realities of patients who journey through these communities.

Finally, stories such as these can be made useful for the education of nursing students. They provide knowledge that is directly relevant to developing the students' understanding of their relationships with patients. Students develop their definitions of what constitutes a nursing care situation based on their own experiences and on what others have said about nursing. Knowledge such as that gained from these stories can become part of the developmental process of becoming a nurse.

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Appendix A

Information for Participants

My name is Marianne Siemens. I am a registered nurse and a graduate student in the Faculty of Nursing at the University of Calgary.

I have a special interest in better understanding what it is like for someone with rheumatoid arthritis (RA) to be in hospital. Because of this interest I would like to meet with individuals who have RA and who have had to be hospitalized for surgery. I am particularly interested in hearing from you if your surgery was not directly related to the arthritis. If you have been hospitalized for surgery (over the past three years) and are willing to discuss your experience, I invite you to join my study. Here is some information about me and some background information about the study.

During my years of nursing in hospital some patients who have chronic illnesses have told me that hospitalization has had a profound impact on them - either positively or negatively. It is important to learn more about the nature of that impact. The purpose of my research is to gain a better understanding of your situation when you were hospitalized. I have titled it:

Living With Rheumatoid Arthritis through a Hospitalization Experience

If you are willing to join me in this study, I would like to meet with you at least once, and hear your story. The meeting is expected to last approximately one hour. Our meeting would be at a time and a place that are convenient for you. I would like to audio-tape record our conversations to help me remember the conversations when writing my research report. I assure you that your identity will not be divulged in any way and the tape recordings will be held in strict confidence. During the time while I am writing my report, I would again

like to contact you to ensure the accuracy of what I have written.

I will not use your name, the name of the hospital, nor other identifying details about you when writing the report. Instead, I will use fictitious names. Only I will have access to your true names. The audiotapes will be kept in a locked file. When the study is completed, the tapes will be erased. I will be happy to provide you with a copy of the research report, if you would like one, at the end of the study.

Although you may not see any direct benefit to yourself by participating in this study, your participation may result in better hospital care for others. If you choose to participate and change your mind at a later time for any reason, you will be free to stop your participation at any time without risking any repercussions. You need just let me know. If you have any concerns or questions at any time during or after the research is finished, you may call my supervisor, Dr. Kathy Oberle, at the University of Calgary (ph. 220-6268), or you may call me.

If you are interested in being part of the study, or if you have questions about it, I can be contacted at 686-1344. If you encounter my voice-mail, please leave your name and phone number and I will return your call just as soon as I return home. I look forward to hearing from you. Thank you for your consideration.

Sincerely,

Marianne Siemens

Appendix B

Participant Consent Form

Project Title: **Living With Rheumatoid Arthritis
Through a Hospitalization Experience**

Researcher: **Marianne V. Siemens, R.N.**
 M.N. student

Research Supervisor: **Kathleen Oberle, R.N., Ph. D.**
 Associate Professor, Faculty of Nursing
 University of Calgary, Calgary, AB

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the study:

The purpose of this study is to learn about the experience of having rheumatoid arthritis while being hospitalized for a surgical procedure. From listening to you, the researcher hopes to better understand what that experience was like for you. Although you may not see any direct benefit to yourself by participating in this study, your participation may result in better hospital care for others.

Description of the study:

If you consent to take part in this study, you will be interviewed at least once. Our meetings will be at a time and place that are convenient for you. Because I am interested in hearing your story the length of our meetings will be determined by you. They may last from 60 to 90 minutes. Our conversations will be audio-tape recorded and later transcribed onto paper by a transcriptionist.

Voluntary Participation:

Your decision to take part in this study is voluntary. There should be no risks as a result of your involvement in this study. You may refuse to take part without any negative effects. If you decide to take part, you have the right to ask the researcher any questions concerning this study at any time. You also have the right to withdraw from the study at any time. If after an interview you wish to change your mind about taking part, you may call the researcher and have the interview tape destroyed.

Confidentiality:

No one will know that you are taking part in this study unless you tell them. All tape recordings will be kept in a locked file and will be erased at the end of the study. The typed recordings of our meetings will be stored in a locked file for three years after completion of the study, then shredded. Data from the interviews, in the form of excerpts, may be used in the presentation of findings and for teaching purposes. At no time will you be identified. Interview data may be used in a future study, but prior ethical approval will be obtained.

Implications of Participation:

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project

and agree to participate. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you have questions now or in the future concerning your rights as a participant in this study you may contact either:

Marianne Siemens, Principal Investigator, at 686-1344

Or

**Dr. Kathleen Oberle, Supervisor,
University of Calgary, at 220-6268.**

If you have any questions concerning your rights as a possible participant in this research, please contact the Research and Scholarly Development Committee of the Faculty of Nursing, University of Calgary, at 220-4646.

Name of Participant (please print)

Signature of Participant

Name of Researcher (please print)

Signature of Researcher

Date: _____

A copy of this consent form has been given to you, for your records and reference.

Would you like to receive a summary of the study report?

Yes: ____; No: ____.

If yes,

Name: _____

Address: _____

Appendix C
Letter to Participants

Box 8, Site 38, RR12
 Calgary, AB T3E 6W3
 ph: (H) 686-1344
 (W) 670-1387
 March 20, 1999

Dear _____,

It is now some time since you allowed me the privilege of a conversation with you in order that I might better understand the ramifications of rheumatoid arthritis and of being hospitalized for surgery. You openly shared with me some of your journey and your experience of being hospitalized on a number of occasions.

I have now taken the liberty to write a story, based on our conversation, and I am coming to you again for several reasons. Firstly, I want to be absolutely sure that you find this story to be accurate and that you are willing to let me continue to work with the information. Secondly, I hope that you will add any changes or reflections, or additional information, which will help me to better understand and convey your experiences.

I look forward to our meeting on _____ at _____ p.m. at _____.

Sincerely,

Marianne Siemens

Appendix D**Follow-up Letters**

99/08/ __

Dear _____,

[A letter of commendation and appreciation was written and sent to each of the participants, accompanied by a copy of the thesis in its entirety.]