

CAUSAL ATTRIBUTIONS AND THE SEARCH FOR A SENSE OF PURPOSE  
IN WOMEN WITH INFLAMMATORY ARTHRITIS

by

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## ABSTRACT

This study sought to understand the ways in which women with inflammatory arthritis, including rheumatoid arthritis (RA), juvenile rheumatoid arthritis (JRA), and psoriatic arthritis (PA), developed their own causal models over the course of their illness, and the ways in which the elements of these causal models influenced the way they live their lives. By asking patients "why do you think you got arthritis?" and by tracing the route these patients took in arriving at their causal conclusions, the world views of the co-investigators were revealed, to some extent, as were the ways in which these world views had been modified in order to make sense of chronic illness.

This study included 12 co-investigators, and took a qualitative approach. Repeated in-depth, open-ended interviews were conducted with each co-investigator, and data is presented here in the form of life schemes. Data analysis involved an examination of similarities and differences across stories, and a determination of the kinds of events that influence the formation of causal conclusions.

This study found that the causal models of the co-investigators developed in a fairly typical manner, starting first with physical causes, then expanding to

incorporate psychological causes, then expanding further to a consideration of existential explanations. A general story was written to synthesize the information, and to show the overall pattern of development of the causal models. Within the general story differences across causal models are highlighted, as are the different meanings assigned to the same causal attribution by different co-investigators.

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## Chapter I: Introduction

The feeling that one's life is meaningful has, according to Thompson and Janigian (1985), two prerequisites. First, one must view the world as a place in which order prevails, in which the principles of cause and effect are known to the individual to the extent that he or she can prevent, or at least anticipate, the occurrence of negative events. Second, one must have a sense of purpose, a set of goals that can reasonably be realized given the way the world is perceived to work.

The onset of a disabling disease such as rheumatoid arthritis (RA) can strip the individual of a sense of meaningfulness. The inexplicable intrusion of RA throws the individual into chaos, not only in terms of his or her day-to-day existence, but also in terms of the world view from which he or she operates. As Bury (1982) states, the onset of RA implies "a 'premature ageing' for the individual. As such it mark[s] a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal" (p. 173). Most people, at least in mainstream North American culture, espouse a world view characterized by an overestimation of the justness, predictability, and controllability of life's events (Lerner, 1980), and this may prove functional most of the time, and for most people, but

unsatisfactory in the face of an unexpected negative event. Unable to detect congruence between the event of RA and a world view that disallows unpredictably, the RA patient is left with two choices, to reconstrue the event, or to reconstruct their world view to accommodate the occurrence of RA.

One way to get a sense of the way patients fit their illness into their world views is to explore their causal attributions. By asking patients "why do people suffer?", and more specifically, "why have you been made to suffer with arthritis?", we can begin to understand how people reconcile suffering with the just, orderly world that we want to believe exists, and how they place themselves in the world as they perceive it.

Because the current state of scientific knowledge about the etiology of RA is such that practitioners can only offer limited and incomplete explanations to their patients, medical explanations are typically "supplemented by, and set against, a body of knowledge and meaning drawn from the individual's own biography" (Bury, 1982, p. 181). One's biography incorporates elements such as family, religious, social, and

cultural influences (Kleinman, 1988; Williams, 1984). Several causal hypotheses may be tentatively formed and then rejected along the way as RA patients move through different stages of the life course (Bury, 1991), and as they attempt to find a fit between their world views and their illnesses.

The process of developing a causal explanation may occur simultaneously with a reexamination of the path one's life is taking. Life goals may be reassessed and modified in accordance with the physical limitations imposed by RA and with shifting priorities. Reestablishing a sense of purpose for oneself is an important task with which RA patients must cope.

#### Purpose of the Study

The purpose of this study is to explore the causal attributions of RA patients and the world views in which these attributions are embedded. In addition, I address several related sub-problems:

1. What is the process by which causal conclusions are reached, and what are the key events that facilitate this process?

2. How do significant others (e.g., family members, close friends, clergy) influence the formation of these conclusions?

3. How do people with RA find a sense of purpose in their lives?

In order to preserve the contexts in which respondents place their experience of RA, I present these experiences in narrative form (Kleinman, 1988; Mishler, 1986).

#### Definition of Terms Used

In the present study, it is especially important to clearly state a definition of attribution because the way I use the word "attribution" is distinct from the way it is commonly used in psychology. In adopting this word, I return to the original dictionary definition of "causal explanation" (Stien, 1983), and then widen my focus to include philosophical or existential explanations as well. In addition to considering internal and external factors that people perceive as having an influence on the course of the disease, I consider the explanations people construct in order to understand why they became ill in the first place.

When I refer to the coping strategies used by RA patients, I am not using the word "coping" to mean "adjusting" or "adapting". Rather, I use the definition of coping proposed by Lazarus and Folkman (1984): the "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). This definition is process-oriented, as opposed to trait-oriented, and is context-specific. In this study, I seek to ascertain the ways in which RA patients cope specifically with the task of finding a purpose in life. This involves an exploration of the aspirations each patient had before the onset of RA, and the process by which these aspirations were reevaluated, and modified as the disease progressed.

#### Strengths and Limitations

There are both strengths and limitations to any study that presents data in narrative form. Viney and Bousfield (1991) evaluated the usefulness of narrative analysis in understanding the experiences of AIDS-affected men. Advantages include the fact that narratives come closer than other methods of data

collection and presentation to conveying the unique experiences of respondents. Narratives are respectful of respondents, treating as important not only the details and the nuances contained within their stories, but the ways in which they tell their stories as well.

The very strength of this approach is also its weakness; while it allows for very full and rich portraits of individuals, it disallows the formulation of conclusions that will generalize to a population. Further, narratives cannot conform to the same standards of objectivity demanded of quantitative research; narratives are, in a very real sense, collaborations between respondents and the investigator to whom they tell their stories; they are interpretations of the tellers' stories, and as such they inevitably reflect the biases and assumptions of the investigator (Mishler, 1986; Williams, 1984). As Mishler (1986) states, "the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondent" (p. 34).

#### Significance of the Study

This study may have clinical implications. First, an understanding of the world views of RA patients, and

the causal hypotheses that have sprung from these world views, may help medical clinicians to give more effective treatment to their patients. Kleinman (1988) advocates an approach to the practice of medicine that is "captured by the words *empathic listening, translation, and interpretation*" (p. 228); he says that these are the skills of the clinician who treats illness, the lived experience of disordered physiology, as opposed to just disease. Although, the full range of perspectives taken by RA patients cannot possibly be represented here, perhaps an indication of the diversity of these perspectives might persuade medical practitioners to set aside some of their assumptions in the interest of their patients.

Second, psychotherapists working with RA patients will be more effective if they are sensitive to the existential crisis often provoked by the disease. They might choose to use some logotherapeutic, meaning-based, or cognitive reframing interventions to facilitate the restoration of a sense of order and purpose after the onset of RA.

Russell (1991) points to the importance of narrative in cognitive therapy. He espouses the

narrative paradigm that assumes that to exist as a human being is to perceive one's life as a story later to be told. If a client has a defective or dysfunctional view of his or her relation to the world, the task of the cognitive therapist is to assist the client to construct a new and more functional personal narrative. This new personal narrative competes with, and eventually subsumes, the old personal narrative.

Reminiscence, or life review, is gaining respectability as a therapeutic method. Haight (1991) reviewed the literature on therapeutic reminiscence from 1960-1990 and found that of 97 published articles, only 7 reported negative outcomes; the remainder were either positive or non-evaluative. Poulton and Strassberg (1986) list the adaptive consequences of reminiscence as the resolution of previously-unresolved conflicts, the maintenance of goal-directed behavior, and the maintenance of feelings of self-esteem and personal significance.

The stories contained within my study may be of value to the psychotherapist, not only because of the insight they might impart with respect to the existential issues that face RA patients, but also

because they will allow him or her to witness the struggle toward wholeness embedded in the narrative, and the ways in which the narrative functions as a symbolic field in which to enact and resolve this struggle.

### Personal Perspectives

I have had RA for 25 years, and in that time I have spent several lengthy periods in hospital, including one period of almost two years when I was an adolescent. During these hospitalizations, I met hundreds of other people with RA, many of whom were hospital roommates, and I recall many a night lying in bed and talking to people, in the dark, about the struggle to come to terms with the disease.

Illness does not respect cultural, ethnic, or socioeconomic differences in people, and the education I received in hospital far surpassed anything I might have learned in junior high school. I was fascinated to explore with people the various belief systems from which they operated, each one grappling with the same task of making sense of a seemingly senseless affliction, and each doing so in his or her own way. I was also witness to the problems that arose when

patients' belief systems were incongruous with those of medical personnel.

Research shows that the functional capacity of RA patients often has little to do with the severity of their disease. My own observations support this empirical finding. It has always seemed to me that one's philosophical outlook has a great effect on how well people deal with their illness. This study is an outgrowth of years of informal observation.

## Chapter II: Literature Review

The last few decades have seen a barrage of research studies that deal with psychosocial aspects of rheumatoid arthritis (RA). These studies have looked at the physical, social, and psychological factors associated with coping and with adjustment in RA patients. The trend in this research has been toward focused quantitative inquiry, and away from holistic examination of the experience of RA.

Although there have been numerous studies that have examined the existential questions, the "why me?" of illness, that arise for people with health problems such as spinal cord injury and cancer (e.g., Bulman & Wortman, 1977; Gotay, 1985; Timko & Janoff-Bulman, 1985), there is very little research that focuses on these questions as dealt with by RA patients.

The search for meaning often provoked by a disabling injury or illness is a two-pronged search. First, one must adjust one's perceptions of the event, or of the world and how it operates so that a sense of order is restored. Second, one must reexamine and modify one's life goals in order to achieve a sense of purpose (Thompson & Janigian, 1988).

Existing research in the areas of coping with RA, causal attributions for illness and injury, and the search for meaning is reviewed here.

#### Coping with Rheumatoid Arthritis

RA is a disease characterized by damage to the joints; the severity of the damage and its consequent disability varies widely between individuals. Many researchers have noted that, for many patients, the severity of the physical damage bears little relationship to functional impairment (Genest, 1983; Moos & Solomon, 1964; Moscovitz, 1971), where functional impairment is defined broadly as disruption in the capacity to function in all aspects of daily life, in work, family and social roles, and in one's sense of emotional well-being (Genest, 1983). This finding has prompted a search for the psychological variables that mediate between physical impairment and functional capacity. Many investigators have considered the ways in which patients cope a critical determinant of functional status, noting that some ways of coping are adaptive, and others maladaptive (Smith & Wallston, 1992).

Over the last several years, numerous studies have investigated the relationships between coping antecedents (i.e., patients' appraisals of their situations as determined by functional status, and by beliefs regarding abilities and internal and external resources), and the employment of particular coping strategies such as distraction, information-seeking, self-blame, and downward comparison (Zautra & Manne, 1992). Other studies have looked at the relationships between coping strategies and various outcome measures such as health status, psychological adjustment, and severity of pain (Zautra & Manne, 1992).

Recently, in an effort to integrate the findings of previous studies, Smith and Wallston (1992) conducted a longitudinal study that sought to incorporate coping antecedents, coping strategies, and outcome measures into the stress and coping framework proposed by Lazarus and Folkman (1984). In doing so, they considered the contribution of factors from the physical, psychological, and social domains to coping, and ultimately to well-being, in RA patients.

The work of Smith and Wallston (1992) is a first step in establishing causal direction in data that

previous research has shown to be correlated. However, despite the large number of subjects, the eight waves of data collection over a four-year period, and the complex statistical analyses, this study has some shortcomings. Several of the measures used by the investigators give only superficial consideration to very complex variables. For example, the investigators used a 7-item measure, apparently of their own construction, to gather data about psychosocial impairment; this measure asked RA patients to assess the degree to which RA had interfered in each of seven areas: family relationships, hobbies and sports, sexual activities, sleeping, social activities, working, and comforting and helping others. The complexity and diversity of these areas can hardly be addressed adequately by a measure such as the one used in this study. The researchers report the internal consistency of the measure in order to substantiate its psychometric properties, but they do not provide support for its validity.

Another weakness in the study is its narrow focus on pain in the coping measure. Smith and Wallston (1992) ask their readers to believe that the way RA

patients cope specifically with their pain mediates between several coping antecedents only indirectly related to pain (e.g., life satisfaction and depressive symptomatology) and health outcomes.

My strongest reservation about this study, however, lies in the fact that, as a member of the population to which the findings are intended to apply, I feel that the study is so abstracted from the experience of RA patients, so absorbed in its own manipulations of data and complicated path analyses, that it actually says very little about the lives of the people it has set out to understand. This study has convinced me of the need to retreat from the path of increasingly complex quantitative research on RA patients.

In addition to my reservations about the methodological directions research on RA patients has taken, I have noticed an omission in the literature. To date there is virtually no research that examines the influence of the philosophical beliefs of RA patients on coping and on adjustment. Researchers have largely ignored the "noological dimension", as Viktor Frankl (1969) calls it, the active search for meaning

that people tend to engage in when confronted with serious illness and disability (Janoff-Bulman & Timko, 1985; Kleinman, 1988; Wong & Weiner, 1981).

#### Causal Attributions for Illness and Disability

One aspect of the search for meaning involves the conclusions patients reach to the question "why me?", the problem of bafflement (Kleinman, 1988), or, to use the language of psychology, the causal attributions people make in order to explain why they have been injured or afflicted with disease.

Affleck, Pfeiffer, Tennen, and Fifield (1987) dealt somewhat superficially with RA patients' philosophical beliefs about the cause of their illness in a larger study of patients' etiological theories. They posed the question, "Some people who become seriously ill say they have asked the question 'Why me?'. Others say they have never asked themselves this question. Did you ever find yourself asking 'Why am I the one to have this condition instead of someone else?'. If so, do you still find yourself asking this question or have you found an answer to it?" (p. 928-929). Responses to this question were assigned to categories such as "Fate", "Purpose for the illness",

"Never asked 'Why me?', and "Still ask and no answer". The researchers offer little discussion or elaboration on these categories, except to say that patients who continue to search for a causal explanation report greater functional problems, and greater helplessness, and are rated by health care providers as exhibiting less positive psychosocial adjustment.

There have been a number of studies of causal attributions that have used samples drawn from other patient populations. For example, researchers have looked at the attributions of people who have suffered spinal cord injuries. Bulman and Wortman (1977) conducted extensive interviews with 29 spinal cord patients, chosen for the study because chance seemed to define the selective incidence of their injuries, and found that all of their respondents had posed the question "why me?". Further, they found that 28 of the 29 had developed specific hypotheses to explain why their accidents had happened to them.

Thematic analysis yielded six categories of explanations: probability, chance, fate, divine plan, positive reinterpretation, and deservedness. When the researchers compared the causal explanations offered by

the respondents with coping scores, they found that certain attributions were predictive of poor coping whereas other attributions were predictive of good coping.

A major limitation of this study is to be found in the coping measure. For each respondent, a nurse and a social worker familiar with the case marked a 16-point scale with endpoints of "coped very poorly" and "coped extremely well". When the researchers were asked by raters what was meant by "coped", the researchers provided suggestions offered by other raters. As is true in so much of the literature, the word "coped" is used without an operational definition; here it seems to be synonymous with "accepted", "adapted", or "adjusted", in themselves vague terms.

Bulman and Wortman's (1977) study lends support to the Just World Hypothesis proposed by Lerner (1980). This hypothesis is based on the notion that the world is a just place, that people get what they deserve and deserve what they get. Lerner remarks, "people want to and have to believe they live in a just world so that they can go about their daily lives with a sense of

trust, hope and confidence in the future" (Lerner, 1980, p. 14).

Most of the respondents in the Bulman and Wortman (1977) study developed hypotheses consistent with Just World views. Seven respondents suggested predetermination as an explanation for their disabilities: "these things are always planned before your time by a Supreme Power" (Bulman & Wortman, p. 359). In more fully-developed hypotheses, 10 people explained that God must have had a reason to allow or to cause the accidents. Although God's design might not be readily apparent, surely there are benefits to be derived. For example, one individual responded, "it's a learning experience; I see God's trying to put me in situations, help me learn about Him and myself and also how I can help other people" (Bulman & Wortman, p. 358).

Six respondents reevaluated their circumstances as positive, stressing that the benefits of their new situations outweighed the negative consequences:

Since the accident, I've learned an awful lot about myself and other people. You meet different people in a hard-up situation that I never would have met. I was leading a sheltered life, I suppose, compared to what it is now. Now I'm just

in a situation which I enjoy (Bulman & Wortman, 1977, p. 359).

These individuals were able to hold on to both their self-esteem and their Just World views by reconstruing what might appear tragic to others as positive.

Two respondents explained their fates in terms of deservedness. These people recalled their past behaviors and believed that their accidents were fair and logical outcomes of their own wrongdoing: "if you do wrong, you reap what you sow" (Bulman & Wortman, 1977, p. 360).

Four of the respondents attributed their accidents to probability, and three others solely to chance, and these attributions would seem to contradict the Just World Hypothesis. But as Thompson and Janigian (1988) remark:

On the surface it may appear that orderliness is diametrically opposed to chance or probability. However, a belief that specific events happen according to chance does not mean that there is not an underlying order to the world. One might engage in a certain action with the understanding that there is a high risk of injury. A resultant accident would follow orderly from the belief that certain actions are more risky than others and that one "takes one's chances" by engaging in them (p. 263).

Numerous studies cited by Lerner (1980) indicate that, when misfortune strikes, people tend to engage in self-blame to an extent that far exceeds their own objective blameworthiness. This observation holds true in the Bulman and Wortman (1977) study, and, consistent with other studies cited by Lerner, respondents who engaged in self-blame were better adjusted than those who blamed others. Bulman and Wortman speculate that perhaps justice and control issues might explain these findings. That is, patients who blamed themselves for their injuries were able to see them as fair and logical outcomes to their actions, whereas those who blamed others were unable to place their injuries in the context of a just and orderly world.

The work of Bulman and Wortman (1977) illustrates several points related to the Just World Hypothesis. First, it shows the extraordinary need people have to see the world as orderly, and to see catastrophic events as predictable. Second, it demonstrates the need we have to imbue the events of our lives with meaning. Finally, it shows the many ways in which

people cognitively reconstruct events so as to align them with Just World views.

Researchers who have attempted to replicate the work of Bulman and Wortman (1977) have tended to focus primarily on the psychological dimension, rather than the noological dimension. For example, Sholomskas and Steil (1990) divided their respondents into two groups, those who engaged in self-blame, and those who engaged in other-blame. In doing so, they stayed within the arena of internal and external locus of control, a distinctly psychological domain that has already been addressed in the arthritis literature (Zautra & Manne, 1992).

Gotay (1985) asked 31 cancer patients, and 20 of their mates, to address the problem of bafflement, and attempted to determine whether certain types of causal attributions were predictive of adjustment. Two methods were used to collect data on causal attributions. First, cancer patients and their mates were asked the open-ended question, "with respect to your health problem, have you ever asked the question 'why me?' How did you answer it?". Responses were content-analyzed and coded according to the

classification scheme developed by Bulman and Wortman (1977). Second, respondents were given a structured questionnaire that read "I'd like to know how much you blame each of the following factors for your health problem. Please assign a percentage of blame for each factor. If a given factor has no influence, you may assign it a zero". The four factors from which respondents could choose were "Yourself - the kind of person you are", "Things you have done", "The environment and other people", and "Chance".

When Gotay examined the data elicited by these two methods, she found considerable discrepancy. Although some respondents were unable to answer the open-ended question posed in the interview, none were unable to complete the questionnaire. However, the questionnaire's format precluded certain types of responses and the investigator found it necessary to supplement it with additional measures, such as a measure of religiosity. Indeed, one of the more interesting findings of this study is that the kind of causal question asked greatly affects the answers obtained.

Gotay's (1985) study makes other important contributions as well. Jaber, Steinhardt, and Trilling (1991) remark that the family is the most important sociocultural context in which meanings and values are learned (and, I would argue, constructed), and this study, by including cancer patient's mates, acknowledges the role of significant others in the construction of meaning.

In addition, Gotay compared the attributions of early-stage cancer patients (i.e., patients with precancerous conditions, as well as those whose colposcopy indicated that further treatment was necessary) and their mates, and the attributions of advanced-stage cancer patients (i.e., patients with Stage III or Stage IV gynecological or breast cancer) and their mates. Attributions to the self or to the patient showed a main effect for stage, such that advanced-stage patients were more likely to say that the individual herself bore some responsibility for the development of the cancer. Advanced-stage patients were also more likely to cite religiously-based reasons. By comparing the attributions of these two groups, Gotay suggests

the possibility that attributions change over the course of an illness.

Timko and Janoff-Bulman (1985) studied breast cancer patients in an effort to understand the relationships between causal attributions, perceived vulnerability to cancer recurrence, and adjustment. Respondents were asked to indicate the extent to which they thought other people, the environment, and chance were responsible for the development of their cancer. They were also asked to indicate the extent to which they thought they had developed cancer because of the kind of people they were physically, because of the kinds of personality they had, and because of their past behaviors. In addition, respondents answered questions about their perceived vulnerability to the occurrence and recurrence of cancer.

The results of this study indicate that there is not a direct link between causal attributions and adjustment; rather the attribution-adjustment relationship is mediated by perceived invulnerability and its associated cognitions. For example, respondents who pointed to past behaviors as causal in their cancer were better adjusted than respondents who

attributed their cancer to characterological flaws, or to others. Whereas behaviors are controllable and modifiable, one's character and the characteristics of others (e.g., the genes of relatives who have passed along vulnerability to cancer) are relatively stable and uncontrollable. Like the Bulman and Wortman (1977) study, this study lends support to the idea that people who are able to frame their illness as the logical outcome of a modifiable behavior tend to be better adjusted.

A study of Israeli breast cancer patients by Baider and Sarell (1983) highlights the effect of culture on the kinds of attributions patients make. 'Oriental' women (Jews born in the predominantly Moslem cultures of North Africa and the Middle East) were likely to see their disease as caused by themselves or others, or as a punishment, whereas 'Western' women (Jews born in Europe or the Americas) tended to explain their illness in terms of divinity, fate, or chance. The ways in which these two groups coped differed as well. The investigators labelled the characteristic modes of coping of the 'Western' group 'rational-scientific' (i.e., active, self-reliant), and the

'Oriental' group 'non-rational, magical' (i.e., passive, fatalistic). However, the investigators did not draw explicit connections between the causal attributions of their respondents, and the ways in which respondents coped.

Jenkins and Pargament (1988) studied the cognitive appraisals of cancer patients and their results were consistent with the findings of others (e.g., Timko & Janoff-Bulman, 1985) who showed that people seek to gain a sense of personal control over threatening events, and that higher levels of perceived personal control promote more favorable adjustment.

They made some other interesting findings as well. For example, they found that "perceived control over emotional reactions seems to be a useful predictor of psychosocial competence, distinct from perceived control over the events themselves" (Jenkins & Pargament, 1988, p. 626). This finding is reminiscent of Frankl's (1969) assertion that, although we can not always control the events around us, we are free to choose the stance we take with respect to misfortune.

The design of this study was such that respondents were able to elaborate on their beliefs regarding God-

control. Their remarks tended to describe an active process of exchange with God, rather than a passive submission to an external force. Respondents often expressed the belief that God worked through their own efforts, and through the efforts of their physicians. They also spoke of prayer and faith as means of accessing control from God. Thus, some respondents, saw God not as an impersonal external force, but as a being with whom one could interact, a collaborator. The subject of religious attributions and religious coping efforts is extremely complex (Pargament et al., 1990), and few studies in the area of illness and causal attributions give more than superficial treatment to it.

#### Illness Narratives and Causal Attributions

Causal attributions are dealt with incidentally in a study of the autobiographies of people with multiple sclerosis (Robinson, 1990). Respondents in this study were asked to write their "life stories, including anything in their lives--events, experiences or feelings--which was important to them" (Robinson, 1990, p. 1177). The investigator deliberately refrained from telling respondents what to write about, how to write,

or how much to write. The narratives were then analyzed and assigned the labels of progressive, regressive, or stable narratives according to the emotional trajectories of the stories. Robinson calls a subset of the progressive narratives 'detective stories' because they are essentially concerned with the mystery "why me?" and the immediately following question "what can I do about it?". Some of these detective stories are accounts of searches for medical explanations and treatments, but others are centred on the intervention of the supernatural. "The narrative may embrace the intervention of a malevolent supernatural force which is being engaged in a personal struggle... [or] may embrace the discovery of positive divine intervention, in which God may not only prove to be an ally after the onset of the disease, but in some cases be perceived as offering salvation" (Robinson, 1990, p. 1181). Because this study is based on narrative accounts, we are able to see the range and the nuances of responses that might otherwise be grouped under a single heading such as "God-control".

Williams (1984) undertook a study of 30 arthritis patients, both men and women, in which he conducted

lengthy interviews that began with the question "why do you think you got arthritis?". Most of the narratives written by the investigator are lay accounts of the etiology of arthritis. One respondent, for example, hypothesized that his arthritis resulted from exposure to toxic substances in the factory in which he worked; another respondent felt that the stress of her family life had caused her arthritis. Williams entitled the former respondent's story "narrative reconstruction as political criticism", and the latter respondent's story "narrative reconstruction as social psychology"; his tendency is to take a sociological perspective with respect to his respondents' stories. He seems somewhat frustrated as he recounts the story of one respondent who believes that her arthritis was preordained by God; he feels that she has transcended causality, and thus rendered the narrative quest for causality unnecessary.

Williams' (1984) decision to present his data in narrative form allowed him to preserve the rich detail provided him by his respondents. He states in the introduction to his study his desire to "elucidate the styles of thought and modes of cognitive organization employed by... people suffering from RA in making sense

of the arrival of chronic illness in their lives" (Williams, 1984, p. 176). So rather than distilling the explanations of his respondents into the discrete, investigator-defined categories they seemed to fit best, Williams traced the routes respondents took in arriving at their causal conclusions.

Williams (1984) regards accounts of the origins of illness as attempts to establish "points of reference between body, self, and society and to reconstruct a sense of order from the fragmentation produced by chronic illness" (Williams, 1984, p. 177). Thus, the creation of the illness story is an act of meaning-making, of restoring oneself to wholeness and balance, of reckoning with a body that has betrayed the self and a society that reassigns identity according to the status of one's health. The story represents an imaginative reconstruction of the past whose purpose is to lend meaning to the present.

My study is similar to Williams' (1984) study in its respondents, in its consideration of the social and cultural forces that shape causal attributions, and in its presentation of data in narrative form. However, my study allows for multi-factor causal theories, and

embraces the philosophical notions of the co-investigators. Williams' study might be called hermeneutical because it is heavily interpretive; the author extrapolates from the raw data provided by respondents to construct sociological arguments. In presenting my respondents' stories, I have tried to be less interpretive.

#### Life Schemes and the Search for Meaning

Thompson and Janigian (1988) refer to the kind of story told by Williams' (1984) respondents as a life scheme. A life scheme has several elements; first, its protagonist is the self as seen from one's own perspective; second, it reveals a particular world view, that is, a set of beliefs and assumptions about the world and how it operates; third, it says something about the goals of the protagonist, whether they be specific and measurable, such as the attainment of a certain job, or loose and ill-defined, such as the betterment of oneself; finally, it recounts events relevant to the attainment of these goals, including events that render impossible the achievement of desired goals, events that necessitate goal-

modification, and events that facilitate goal-attainment.

Life schemes can be accounts of the search for meaning. 'Found meaning' (as opposed to implicit meaning, the product of the appraisal process that occurs when one is faced with a potentially stressful situation) has, according to Thompson and Janigian (1988), two components: a sense of order and a sense of purpose. A person with a sense of order believes that he or she lives in an orderly world governed by rules, laws, or principles. Meaningful events are those that follow from or fit within this order, and seem to have some purpose or reason for being.

The life scheme integrates these two aspects of found meaning; order is provided by stable world and self views, and purpose by goals and by the possibility of their attainment. The search for meaning occurs when one's life scheme no longer provides a sense of order, or a sense of purpose, or both. The advent of a disabling illness such as RA may challenge the components of the life scheme, casting doubt on the accuracy of one's world views, for example, or causing one to rethink one's goals and reevaluate the

possibility of their attainment. The search for meaning is an attempt to restore the sense that one's life is orderly and purposeful.

Attributional questions often arise as part of the challenge to the life scheme posed by RA. If, as Lerner (1980) asserts, people want to believe that the world is so ordered that people get what they deserve and deserve what they get, then one might expect RA patients to view their illness as punishment for past wrongs. Yet numerous investigators (e.g., Bulman & Wortman, 1977; Robinson, 1990; Schussler, 1992) have found that relatively few patients see their illness as punishment; contrary to expectations, a large proportion of patients see their illness in a positive light. Schussler (1992), for example, found that 60% of the 50 RA patients he studied viewed their illness as a challenge, whereas only 10% viewed it as a punishment.

A negative event such as the onset of a disabling illness is likely to pose a challenge to world and self views. The sick person then has two choices: he or she may either change the life scheme, or change perceptions of the event. Piaget (cited in Solso,

1988) might have used the terms 'accommodation' and 'assimilation' to describe these two adaptational processes.

By questioning people about their causal attributions for their illness, one might get a sense of which of these two processes has been chosen, and of the cognitive journey taken in the reordering of one's world view, or the reconstruing of the event of illness. Causal attributions encompass the larger question of why people suffer, as well as the more specific question of why a particular individual suffers; they provide the researcher, therefore, a glimpse of the world views of his or her respondents, a perspective from which to view the struggle towards the reestablishment of a sense of order.

The other component of found meaning is, as mentioned, a sense of purpose. The means by which one achieves a sense of purpose, the goals to which one aspires, may be profoundly affected by a disabling condition, whether by physical difficulty or impossibility, or by a reordering of one's priorities. The rethinking and the possible modification of one's goals often demanded by RA is one aspect of coping.

For example, one may respond to RA by abandoning one's goals, regarding goal-setting as pointless in the face of the unpredictable and sometimes unrelenting course of RA; conversely, one might feel inspired to direct one's work in a particular way because of their experience of RA; a further possibility is the abandonment of action-oriented goals in favour of a bettering of the inner self.

#### Assumptions

In embarking on this study, I assumed that the findings with respect to causal attributions in the spinal cord injury and cancer literature do not generalize to the arthritis patient population. Several facts support this assumption. First, the demographics of the populations are different. For example, patients with spinal cord injuries tend to be young and male, whereas arthritis patients tend to be older and female. The samples from which the data on spinal cord patients are derived are comprised of a relatively large proportion of Black and Hispanic individuals; the prevalence of RA amongst First Nations individuals is likely to be reflected in a sample of RA patients. Second, the nature of the disabilities or

illnesses differ. Spinal cord injury is sudden and the patient's functional capacity remains relatively static. The course of arthritis, like the course of cancer, can be unpredictable, with a general decline in functional capacity over time. RA differs from cancer in many ways, not the least of which is the fact that it is rarely fatal. Third, the degree to which different patient populations can make external attributions varies. Because the cause of spinal cord injury is to be found in the environment, the spinal cord patient is afforded the opportunity to construct plausible external attributions. Although cancer patients are not able to make such direct external attributions, they may be able to point to environmental contributors to their disease. Arthritis, with its unknown etiology (Berkow, 1987), affords no such opportunities.

#### Summary

Aside from the fact that findings about the causal attributions of other patient populations might not apply to RA patients, none of the studies cited gives consideration to the development of causal hypotheses over time, and none, except Gotay (1985), take into

account the influence of the family and social environments on the formation of these hypotheses. Further, none of these studies looks at the ways in which causal attributions might be associated with a particular kind of coping, that of achieving a sense of purpose. This study endeavours to extend the findings of previous studies by addressing these deficiencies.

### Chapter III: Methodology

This study takes a qualitative approach to understanding causal attributions, and is based on in-depth, open-ended interviews. The decision to take this approach reflected my desire to gain a broad understanding of the causal attributions of RA patients rather than test a specific hypothesis (Hammersley & Atkinson, 1983), and my own belief that the meanings constructed by individuals are best understood when the context from which these meanings arose are explored and preserved. The respondents' data are presented in narrative form, as a life scheme, to use the term employed by Thompson and Janigian (1988).

#### Rationale

This method was chosen for several reasons. First, although there are standardized instruments available to measure attributions in the psychological realm, attributions related to concepts such as locus of control (e.g., Multidimensional Health Locus of Control) and helplessness (e.g., Arthritis Helplessness Inventory), no such instruments exist to measure attributions in the noological realm, i.e., philosophical constructions that individuals use to

explain causality. In any case, it is questionable whether any standardized instrument would be adequate or appropriate for understanding the experience of chronic illness. Kleinman (1988) makes a case for the inadequacy of traditional quantitative research in this area; he states:

the thinned-out image of patients and families that... must emerge from such research is scientifically replicable but ontologically invalid; it has statistical, not epistemological, significance; it is a dangerous distortion... to evaluate suffering requires more than the addition of a few questions to a self-report form or a standardized interview; it can only emerge from an entirely different way of obtaining valid information from illness narratives. Ethnography, biography, history, psychotherapy--these are the appropriate research methods to create knowledge about the personal world of suffering. These methods enable us to grasp, behind the simple sounds of bodily pain and psychiatric symptoms, the complex inner language of hurt, desperation, and moral pain (and also triumph) of living an illness (pp. 28-29)

Second, the type of attributions that I sought to discover were below the level of conscious awareness for some, or had never been publically expressed by others; the interviews allowed co-investigators to bring into consciousness their modes of thinking and to express verbally ideas that seldom enter everyday conversation. Third, the nature of the subject matter

is such that some people had difficulty in understanding what I was looking for (particularly as they were so accustomed to giving accounts that were purely medical as opposed to experiential), or found it difficult to articulate their beliefs; the language I used therefore had to be appropriate to the understanding of each co-investigator, and I had to continually probe and clarify to ensure that I understood accurately what the co-investigators were telling me. Indeed, many of the co-investigators in this study were quick to give their consent to participate, believing that they would simply be required to repeat oft-told chronologies of medical events. Finally, as mentioned, this study does not focus narrowly on causal attributions and the seeking of a sense of purpose at a single point in time, and in isolation from the context that gave rise to them; rather it traces the thought processes of the co-investigators as they developed their causal hypotheses and their life goals over time, noting the social and cultural forces that shaped them.

Kleinman (1988) emphasizes the value of the life scheme, both for the patient and for the clinician. He refers to the

sick individual's personal myth, a story that gives shape to an illness so as to distance an otherwise fearsome reality. The clinician attends to the patient's and the family's summation of life's trials. Their narrative highlights core life themes--for example, injustice, courage, personal victory against the odds--for whose prosecution the details of illness supply evidence.

Thus, patients order their experience of illness--what it means to them and to significant others--as personal narratives. The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways and for effectively communicating those meanings. Over the long course of chronic disorder, these model texts shape and even create experience, (p. 49).

Thus, the story itself is the meaning unit. To extract attributions or coping strategies from the story, wrenching them from the context in which patients so carefully place them, is to collapse the structures that support their meaning. The stories that were told to me by my co-investigators illustrate that meaning-making is a process, a process that can be understood through a narrative.

### Co-investigators

Research participants were solicited from the in-patient arthritis service of Pearson Hospital, Vancouver, British Columbia. This hospital is the provincial referral centre to which people with severe disabilities are sent for specialized care.

My decision to interview only hospital inpatients was based on several factors. First, because their arthritis was severe enough to warrant hospitalization, I believed that my co-investigators would be more motivated to search for causal explanations than would people whose arthritis was a minor inconvenience. Secondly, my own experience suggested that people's inclination to engage in a causal search is heightened in the hospital environment where attention is focused so intensely on the disease, and where people are witness to so much suffering. Third, the hospital atmosphere was conducive to the kind of thoughtful reflection that I tried to encourage. The women I interviewed were free from the demands and distractions of their homes, and had the privacy that allowed them to speak freely; this point was reinforced for me when

I talked to them by telephone after they had returned home.

The advantages of interviewing only hospital patients could have been outweighed by the disadvantage of not being able to get the kind of demographic diversity I wanted. For this reason I initially arranged for permission to solicit research participants from the Arthritis Society support group population as well. Fortunately, this problem did not arise.

I chose to interview 12 individuals, based on the fact that other research in the department of Counselling Psychology with a similar design has found this sample size useful for illustrating both the diversity and the commonalties in respondents' stories (e.g., Marshall, 1993; Swain, 1990).

I interviewed my co-investigators in the evening so that they would not be distracted by the necessity of meeting appointment times or having to attend their medical programs. I approached the charge nurses, all of whom were familiar with my study, and asked them to suggest patients who met all of the criteria for my study, and who might be willing to be interviewed. The

nurse would go alone to the patient's room, and explain who I was and what I was doing. I was then formally introduced to prospective co-investigators by the nurse. Only one person who was approached, an elderly Asian woman, declined to be interviewed, apparently because she felt too shy.

After several co-investigators had been interviewed, I began to engage in theoretical sampling, looking for participants whose demographic characteristics were not already represented in my group; for example, it was very easy to find willing participants in the 40-60 age range, but I had to actively seek younger and older co-investigators.

The criteria for inclusion in the study were as follows:

1. for the reasons stated below, co-investigators had to be women;
2. co-investigators had to have been diagnosed at least 3 years previously as I wanted to see how causal models developed over time;
3. co-investigators had to have a systemic, inflammatory form of arthritis, rather than osteo-(wear-and-tear) arthritis; and

4. co-investigators had to speak English fluently so that I could be sure I had a thorough understanding of their stories.

Other than these basic criteria, I strove for diversity in the participant group, especially with respect to age, culture, and socioeconomic status. The requirement that participants speak fluent English limited the degree of cultural diversity in the group, but some diversity was possible.

Appendix A contains a table of co-investigator demographics. The ages of the co-investigators ranged from 22-78, with a mean of 45.3 and a standard deviation of 14.3. The age of onset ranged from 2 to 51, with a mean of 29 and a standard deviation of 13.3. The number of years since onset ranged from 4 to 32, with a mean of 16.3 and a standard deviation of 8.5.

A number of occupations were represented in the group; there were two nurses, four full-time mothers, a career military person, a clerical worker, a student, an unemployed retail worker, and a tribal elder. It was very apparent to me that there was a wide range in their skill as historians, in their propensity to

engage in introspection, and in their capacity for abstract thinking.

Six of the co-investigators were of the dominant white, English-speaking North American culture, one was a first-generation English immigrant, one a first-generation Welsh immigrant, one French-Canadian, one second-generation Sikh, and two were First Nations women.

Nine of the women were diagnosed with the adult form of RA, and two with juvenile-onset RA. According to Medsger and Masi (1985), "clinical and epidemiological differences between the onset types of juvenile arthritis suggest that a variety of syndromes overlap age limits, and that the age distinction between adult and juvenile cases is an artificial one." The remaining participant was diagnosed with psoriatic arthritis, a form very similar to RA except that psoriasis is present as well as joint inflammation (Berkow, 1987); I felt that it was worthwhile to include this participant as she can be viewed as someone with the symptoms of RA, and a minor secondary skin problem.

### Rationale for Including Only Women in the Study

There were several reasons for including only women in this study. The biological and acquired risks for developing RA are different for men and women (Reisine, 1993). Women are three times as likely as men to develop RA (Medsger & Masi, 1985), and this may be indicative of genetic or hormonal influences. Women with RA experience more disease flares than men with RA, though men have higher rates of osteonecrosis (Reisine, 1993). Men tend to have more physician visits, longer hospital stays, and earlier joint arthroplasties (Reisine, 1993), possibly because they tend to be more active in their leisure pursuits and to have more physically demanding jobs. On average, women tend to be five years older than men at the time of joint replacement, and have more severe disability (Reisine, 1993).

Women with RA are less likely to be married, and tend to have fewer supports available to maintain their functional status than do their male counterparts (Reisine, 1993). They are more likely to label symptoms as illness, and tend to report more pain and disability than men, even though their condition might

not be worse (Reisine, 1993). The ways in which they tell their stories, therefore, is apt to be quite different. Women are also more likely than men to develop depressive symptoms (Frank et al., 1988).

In summary, the risk factors for RA may be different for women than for men, access to and utilization of medical and social resources is different, psychological outcomes are different, and the experience of the disease itself is different. These differences point to the need to study women's causal models separately from those of men.

#### Data Collection

Mishler (1986) states: "the complex and varied procedures that constitute the core methodology of interview research are directed primarily to the task of making sense of what respondents say when the everyday sources of mutual understanding have been eliminated by the research situation itself" (p. 3). There are several factors that may widen the gap between interviewer and respondent. For example, the respondent must understand what the interviewer is looking for, and must try to narrow his or her responses to the phenomenon of interest to the

researcher; respondent and interviewer must share a common language; the interviewer must be familiar enough with the 'culture' of which the respondent is a member to ask fruitful questions.

In the course of my study it became very obvious to me that there is a common language shared by people with arthritis. Not only is there a short-hand way of speaking about arthritis when two people have had similar experiences, but the very words chosen may be misunderstood or heard wrong by others unfamiliar with the language. For instance, in reviewing the transcripts returned to me by my typist, I found that she had substituted the word "exasperate" for "exacerbate", and could not make out certain words commonly used in the culture of arthritis. I have had to make major revisions to many of the transcripts because the transcriptionist was not familiar with the language of arthritis. Because I have lived with arthritis for many years I have an extraordinary advantage in understanding the stories of my co-investigators.

Dyck (1988, cited in Carpenter, 1991, p. 65) defines "insider research [as the] study of one's own

society, with the researcher participating as a member of the group being studied." The advantage to insider research is, of course, the potential for true understanding of respondents' perspectives. On the other hand, I am acutely aware that my own experience with RA means that I bring to the research certain ideas about the experience of RA that may not be shared by others. I kept a field journal to record my own thoughts and feelings as the research progressed and used the technique of 'bracketing': I included my own story of arthritis (Appendix B), so that I can show that I am not simply overlaying my own experience on my co-investigators' stories.

The interviews tended to be quite lengthy, with most exceeding 2 hours, and 11 of the 12 co-investigators were interviewed more than once. The original interviews were tape-recorded and transcribed, as were follow-up telephone interviews that occurred during the writing of the stories. Unfortunately, my recording equipment failed both times that I interviewed one particular co-investigator, but I took copious notes from which I constructed her story, and I

phoned her as I was completing the written story to check my understanding and to seek elaboration.

During the first interview, I began by saying:

I am doing a study to understand the ways in which people make sense out of the fact that they have arthritis.

I wonder if you could tell me about the experience of your arthritis. When I say "the experience of your arthritis" I am not just talking about your medical history, although that is a part of it. I'd like you to tell me about your arthritis as though you were telling a story with a beginning, a middle, and an end. While telling your story, try to remember as many details as you can about what you were thinking, feeling, and doing at different points in time. Any questions?

This interview was open-ended, and, depending on the philosophical orientations of the respondents, explored such topics as why God causes or allows people to suffer, whether people who become sick are to blame for their sickness, whether there is heroism in suffering, the truth of sayings such as "God never gives us burdens greater than we can bear", and the degree of randomness in the universe. Appendix C contains a more complete listing of interview questions. I was cautious to avoid leading the respondents to any particular conclusions.

At the start of subsequent interviews, I checked my understanding of the co-investigators' stories. I then asked them to elaborate, and to answer questions directly related to causal attributions, particularly if this element was not spontaneously offered in the storytelling.

Eight of the 12 co-investigators received follow-up telephone calls; these calls were separated from the original interviews by a year or more, and interestingly, I usually found that I was offered very valuable information that had not been offered in the original interviews. Perhaps the passage of time had allowed the co-investigators to reflect more fully on their own attributional processes, or perhaps they were simply in different frames of mind at home than they were in hospital, and able to approach the questions from different perspectives. Another possibility is that over the course of interviewing several co-investigators my appreciation of what information was relevant had broadened, making me more attentive to things that at first I might have disregarded.

### Data Analysis

To begin, the respondents' stories were analyzed individually. A story has a beginning, a middle, and an end. "In the beginning, the story is bounded by two poles, is and ought to be (Cochran, 1990, p. 18). For the RA patient, the "is" might be a state of chaos, confusion, a sense of disorder and injustice. "Ought to be" might be the restoration of a sense of order and peace. The gap between "is" and "ought to be" defines the movement of the story. The middle of the story is an account of the protagonist's efforts to move from "is" to "ought to be". The end of the story might be an achievement of "ought to be" as originally envisioned by the protagonist, it might be an unanticipated, yet satisfying, new set of circumstances, or it might be an abandonment of the quest for "ought to be". Analysis of the story involves a determination of the situational and psychic events that propelled the protagonist from the beginning of the story to the end.

The interviews often started with a clear beginning then meandered or jumped backwards or forwards in time, making the stories difficult to

follow. Also, second and subsequent interviews, when overlaid on preceding interviews, filled in gaps and fleshed out details. So in order to give myself a coherent framework from which to reconstruct the stories, I drew timelines for each co-investigator, gleaned information from the transcripts, and placed significant life events below the lines and, for clarity, the causal elements that were incorporated into the stories above the lines. A simplified example of one of the time lines is contained in Appendix D.

I used the time lines to write chronological stories. Often I began the stories with the co-investigators own words, but sometimes other approaches seemed to give more information. For example, when I wrote Stacey's story I started by describing some of the nurturing behaviour I had observed before I even met her; the theme of the disabled nurturer, or wounded healer, was critical to her story, and I wanted to underscore this theme by starting and finishing her story with vignettes that illustrated its importance to her. With Jess's story I wanted from the outset to dismantle any stereotypes the reader had about Sikh women because none of them apply to Jess. When I

reconstructed Madeleine's story, I decided to tell the story of the story-telling, as opposed to just telling the story. Madeleine spent most of the time in our interviews dispassionately describing her relationship to her arthritis, and all the while her talk served to cover the real story; this became blatantly apparent when an innocent question from me unleashed a flood of emotion and the real story spilled out. In writing this story I tried to give a sense of what happened in the interviews as a way of illustrating her relationship to the real story without resorting to too much overt interpretation.

In each of the stories I tried to give a sense of the person, and of the language they used to tell their story. I included all of their causal attributions and tried to give a sense of how these attributions came to be. The stories provide the context for the attributions and provide details about their sources and their meanings.

The evolution of causal models is documented in two ways in this study: the stories provide the context and detail, and the bare-bones outlines of the causal models contained in Appendix E facilitate the

clustering of themes and comparisons across stories. These outlines contain columns for key life events, causes incorporated into the model, influences incorporated into the model, and causes rejected. An implied time line runs down the left-hand side of the page, to give an indication of where these various elements were introduced in the course of the illness. The life events give some indication of what was happening around the time each element was incorporated.

From these outlines I began to cluster causal themes. The attributions fell very easily into physical, psychological, and metaphysical themes. I subdivided these themes into one more level; for example, within the physical theme there were causes that were "from the outside" (e.g., viruses, physical abuse), "constitutional" (e.g., genetic, "in your system"), reflective of "the way you are" (e.g., menopausal, overweight), and reflective of "what you are doing" (e.g., working too hard, working in inclement conditions). All of these themes and sub-themes are very low-inference; they did not require me to make subjective interpretations of the data or

difficult decisions about which theme or sub-theme a particular cause should fall under. Appendix F contains a summary of the elements contained within the themes and sub-themes.

From this summary of causes and influences I constructed a "general story" of the development of causal models for arthritis. This process was facilitated by the fact that across stories the causal models developed in a fairly typical way, first incorporating the physical, then the psychological, then the noological. The challenge in constructing the general story was at once to illuminate the similarities and the differences across stories. The data lent themselves well to this approach because the framework was similar across stories, but the elements within the framework varied widely.

#### Summary

The general direction of psychosocial research in RA is toward increasingly complex statistical treatment of data that measures extremely specific aspects of the experience of this disease. I undertook this study with the belief that a different methodological approach would provide fresh insights into living with

RA, and, in particular, would increase our understanding of the way people develop causal models. This study demonstrates not only that causal models are more complex than existing literature would suggest, but also that in-depth qualitative methods are suited to this type of inquiry.

## Chapter IV: Results

Diana

Shortly before Diana's birth in 1942, her family travelled from their home in Bristol, England, to Bath, because their home city was being bombed. Her mother was admitted to a hospital for the impending birth. The night Diana was born, the hospital was bombed.

Diana's father stayed at the hospital with his wife and new child, and said to his wife "if you and the baby are going to be killed, I want to be with you." The wing that Diana's family inhabited was spared, whereas the rest of the hospital was destroyed.

The circumstances of Diana's dramatic arrival into the world were rarely discussed in her family, and then only matter-of-factly. Hers was a family that preferred not to make a fuss about hardship for it was an inevitable part of life.

Despite the fact that Diana was born into war-time England, she remembers only one period during which her family suffered some difficulty that made any impression on her. When she was 16, her fraternal grandfather, who was dying of cancer, came to live with the family. Her mother had reasoned that she would be

well-advised to take in her father-in-law so that when her own mother became ill she would be entitled to a similar arrangement. Diana does not recall how her family dealt emotionally with the addition to the household of her dying grandfather, but she does remember herself a "little bitch," saying to her mother "well if he's staying here I'm going!". It seemed that each of the family members concerned themselves primarily with the personal practicalities of this situation.

Diana's first arthritis symptoms appeared in 1972 when she was 30 years old, shortly after the birth of her only biological child. She does not consider herself particularly maternal, and felt pushed into motherhood by social expectation; as well, she and her husband were struggling financially at the time, so the baby's arrival was quite stressful.

At first one arm was badly affected, "almost as though it were paralyzed"; then, she began to feel pain whenever she bumped her fingers and toes. The doctor told her "you've got plain old arthritis--you haven't got rheumatoid which will cripple you". She understood this to mean that she only had osteoarthritis, the

"wear-and tear" form of arthritis that comes with age or injury, and this relieved her.

Diana responded, "oh good--I can put up with the pain, as long as I don't get any crippling or deformities." For the first two years she regarded her arthritis as merely "annoying," although, in retrospect, she says many of the tasks associated with caring for a small child were difficult.

In 1974 Diana moved to Canada with her husband and child, and came under the care of a new doctor. He did not suspect rheumatoid arthritis either. It was only when he went away, and was replaced by another doctor, that a correct diagnosis was made. This temporary doctor took one look at her swollen knee and said "I know rheumatoid arthritis when I see it, and you've got it." He recommended immediate admission to G.F. Strong, the provincial rehabilitation centre.

Again, practical considerations took center-stage as Diana's parents were coming from England for a six-week visit. Eventually she was admitted to hospital, and when her physiotherapy program failed to achieve satisfactory results, she went for knee surgery.

At the time, Diana had no idea what had caused or exacerbated her arthritis. She had no family history of it, and accepted that, like multiple sclerosis, arthritis was simply a disease about which little was known. She says now that she must have "had it in [her] system," and that the physical and emotional stress of having a child probably triggered it.

After Diana was diagnosed as having rheumatoid arthritis, she recalled that when she was an adolescent she had had symptoms consistent with this diagnosis. She was always extremely tired, and found it necessary to sleep in the afternoons. She recalls pain upon kneeling in the bathtub, and pain in her chest that she now attributes to inflammations of the joints that join the sternum to the ribs and clavicles, joints that she did not know existed in years past. So having the correct diagnosis allowed her to make sense of symptoms that previously she had tried to ignore.

When Diana was admitted to the rehabilitation centre, she saw several older arthritis patients who were confined to wheelchairs. Upset by the ravages that had been wreaked on these people by the very disease she knew she had, she denied the possibility

that she might become similarly affected. She attributed their severe disability to poor medical advice: in the 1940s and 1950s they were told to just go to bed. Looking at them she thought, "oh, I'll never progress to that." Reflecting on what she thought then, she now says "I guess you're in a form of denial." She was confident then that the new medical wisdom that prescribed a balanced program of rest and exercise would keep her from becoming seriously disabled.

Diana had one roommate in G.F. Strong for whom she developed a particular fondness. This woman was more severely affected by her arthritis than Diana was at the time, and Diana would help her with many of her daily tasks. Now, others do for her what she once did for her roommate. "You don't realize that progression is going to come to you," she now says. "When it does you realize that you don't have as much control over your body as you think you do... Some things you can't control by positive thinking."

After her knee surgery, Diana functioned relatively well until about 1979, by which time her feet had worsened considerably. She was determined to

wear "nice shoes," however, and was delighted when she discovered that there was an operation that would fix her feet. She had this surgery, as well as another knee operation, and again she was able to continue with her regular activities.

Diana is a great lover of dogs, and during the early 1980s she took two of her three dogs to extended care homes on a regular basis to do pet therapy. She was active in other volunteer pursuits as well: she was involved in her children's school, in Beavers, and in the Welcome Wagon, and she was a block parent coordinator. She also tried to take courses at Douglas College, but found that they made her too tired.

Diana remembers 1984 as the landmark year when the "fatigue really started to settle in." One of her dogs had puppies, and this experience took her to the point of exhaustion. "I couldn't do that again," she says. "That's how I know that in '84 fatigue caught up with me." She says now that she was doing too much. "You're told to rest, but you want to keep going. I don't always rest when I know I should."

Since the time that Diana's way of life began to be altered by her arthritis, the question "why me?" has

weighed heavily on her mind. "When I die, if there's a heaven and I go up there, the first question I'm gonna ask 'why did I get this?'" The joviality that had characterized Diana's storytelling fell away after she said this. "I say it in a joke context, but, I mean, it's kind of, sort of, I'm serious." She is especially confused when she thinks about alcoholics and smokers, and others who abuse their bodies, yet are seemingly healthy: "why do they get away with it... that's not fair, is it?"

Although she was raised to believe in God, Diana now considers herself an agnostic, perhaps because of the suffering she has experienced herself, and the suffering she has seen in others. "If there's a God up there, why is there all this suffering in the world?", she asks. The search for the answer to this question continues, and to date the only answer that she can muster is that people are hurt through "quirks of fate."

Diana struggles to quell the resentment she feels about having arthritis. "Deep down I can be quite bitter about being lumbered with this," she says, but

at the same time she recognizes that "you can't live bitterness."

For Diana, one of the most difficult aspects of having arthritis is the fact that the seemingly normal and modest expectations one has for one's life will not be met. In the early days of motherhood, she dreamed of the day when the children were grown and gone, when she would be free to pursue her own interests, but "it didn't work that way." Though her desires were "not grand... just day-to-day" things like hiking and digging in the garden, she has had to settle for less than she would have liked. She now derives pleasure from her dogs, from feeding wild birds, and from belonging to garden and naturalist clubs.

Diana has two distinct groups of friends: those with arthritis, and those without. With the latter group she is able to escape a focus on her illness, and pursue the interests that preceded the onset of arthritis; with the former group she gets genuine understanding of the physical, social, and emotional consequences of having arthritis, and is able to contribute through her leadership of arthritis support groups.

During our interviews, Diana was inclined to laugh easily, and several times seemed to apologize for what seemed to her to be complaining. It seemed to me that she was struggling with herself to maintain the appearance of lightheartedness, but that a flood of emotion was barely contained, particularly when she spoke of the lack of support from her husband.

"Men haven't got the same understanding of things as women do," she said, then added, "at least when they're over 50 and English they haven't." Although these comments were made with laughter, later comments suggest that she harbours great sorrow over the state of their relationship. She acknowledges that if she did not have arthritis she would probably have left him, so frustrated is she by his emotional distance. Feeling that this option is closed to her, she seeks solace instead from her women friends, from her dogs, and from the peace she finds in the outdoors.

#### Marlene

In 1978, two weeks after her 30th birthday, Marlene developed swelling and pain in the bottom of her feet. A career military person, she lived in a society inclined, she says, to attribute sickness to

either smoking or overweight; this inclination delayed her diagnosis, first by making her reluctant to complain for fear of being blamed for her condition, and second, by inhibiting the doctors' willingness to entertain the possibility of other explanations. When Marlene first sought medical attention, she was told that her problems were caused by her being overweight, although she says that she was no more than 5 pounds overweight, if indeed she were overweight at all.

Marlene's mother and grandmother had both had rheumatoid arthritis, so she was very familiar with the disease's manifestations. Yet, despite this, she was not prepared to accept the possibility that it might be arthritis, even when it was eventually suggested to her. She thought to herself that "they didn't really know what they were talking about, that it was probably some dreaded disease that wasn't arthritis." Asked why she would not consider the possibility that it might be arthritis, knowing that her symptoms were not unlike her mother's, she responded, "because I didn't want it. I mean I could see what it did to my mom, and I didn't particularly want it." So afraid was she that she had the same disease that her mother had, she preferred to

think that she might have some "dreaded disease." Some years later, when Marlene's sister developed the symptoms of RA, she engaged in the same sort of denial, claiming for 2 years that she did not have arthritis, that it was something else, despite her full knowledge of Marlene's experience.

Six months after Marlene's symptoms first appeared, after she had been forced to take considerable time from work, a civilian doctor, aware of the history of RA in Marlene's family, and having made a diagnosis based on clinical signs, began to treat her for arthritis. Even then, Marlene was reluctant, as was her sister years later, to accept her diagnosis until it "showed up in [her] blood," a reference to the appearance of a blood factor often found in RA patients.

Once the physical evidence, the blood factor, had convinced Marlene of her diagnosis, she began to think about why she had developed arthritis. Aware that her doctor had based her diagnostic hunches on Marlene's family's medical history, she looked to the role of genetics, and came, with some assistance from her doctor, to a certain understanding. It is "not

necessarily hereditary because I've been told that it... can run in families, but it's not hereditary because there is a gene that carries... the arthritis, or the rheumatoid arthritis factor, and if you inherit that particular gene from... your parents, then you are likely to get it." She has some inkling that RA is associated with a particular gene, and that having the gene makes one more likely to develop RA, but does not have the language to express well her theory of genetic transmission.

In retrospect, Marlene looks back on the time during which her arthritis first developed as a stressful time. She was a single mother with a five-year-old son, and was among the first single mothers to live in housing designated for military families. Her stressors were many: she had sole responsibility for a young child, she lived in a society where there are few single women, and fewer single mothers, and she was regarded by other women in her neighbourhood as a threat. Her 30th birthday was something of a crisis for her as she feared that she would never marry, and now she wonders whether that crisis might have precipitated the onset of her arthritis.

Marlene's work was extremely important to her, both because it allowed her to support herself and her son, and because she took great pride in the quality and quantity of the work itself. "I guess I thrive under stress at work," she says, "and that's the only time I'll really enjoy my job is when you give me too much to do and I have to prove to you that I can get it all done by myself."

But the culture of Marlene's work environment was not tolerant of weakness or sickness. Further, the job was different than a civilian job; even those in administrative and clerical positions were expected to participate in physical exercise and military parades. "They don't want a bunch of sickies in the military," she says.

Marlene tried for many years to carry her full work load, and she managed to be excused from exercise and military drills. She kept her eye on the 20-year mark, knowing that then she would be able to collect a pension. Eventually, however, her disability was so apparent that she was called before a review board, and asked to sign a paper acknowledging that she would have "career and geographical restrictions" because of her

arthritis. She was not bothered by the geographical restrictions, as they were intended to keep her near a large medical facility; she had no choice but to accept that she would never be promoted because she needed her job.

Marlene had gone from a high-pressure, responsible, and fulfilling job to sorting mail and putting things in numerical order. She was given the option of working only half-days, and, discouraged by the meniality of the work she was given, she did so. But she forced herself to work in the mornings rather than the afternoons, a time when she, like most people with arthritis, have the most difficulty. She wonders now whether her condition might be worse if she had not forced herself in this way.

Marlene feels that stress greatly affected the course and severity of her arthritis. Specifically, the "mental stress" of trying to conceal her physical difficulties while producing copious amounts of work "played havoc" with her arthritis, resulting in a few hospitalizations. She also believes that weather has some effect, though in the opposite direction to what

others claim; when the sun shines she feels terrible, but when the rain comes she recovers.

Marlene has often asked the question "why me?," particularly when her pain was severe. Though she still struggles with the question, her tentative answer is that it is "just the way things are, the way life is... some are luckier than others."

Marlene seems to have the notion that one's willpower has an affect on one's physical status. Even her mother, who she says had worse arthritis than anyone she has seen, did not rely on a wheelchair. "It isn't the future for me. I will never be like those people who have to stay in wheelchairs... my mother never was in a wheelchair." Her optimism also stems from her relative youth, and the fact that she was told by doctors in the beginning that if she started on medication immediately her arthritis would "progress, but [she] wouldn't be as bad off".

Marlene's fears about never finding a husband were unfounded. A man who befriended her son through the Big Brothers organization eventually became her husband. Her son is now an adult and has recently moved away from his parents' home.

Marlene has now retired, and is able to collect her hard-won pension. She plans to spend her retirement reading, doing crafts and volunteer work, and travelling with her husband. The struggles of being alone and of raising a son alone, of trying to conceal an illness in a society that disallows physical weakness, of taxing her body beyond its limits, and of having to accept reassignment to meaningless work despite her best efforts, are now behind her.

Marlene maintained quite a disciplined, unemotional tone in our interviews. But when we were finished, I noticed on her bedside table a book that lay with its pages pressed open, its own cover concealed by a red plastic cover. I asked her what she was reading, and blushing, she admitted that it was a romance novel. Although she had told me the facts of her fears about being alone, that novel and its disguise seemed to tell me something about the depths of the fears that she had felt.

Marlene must still cope with flare-ups, hospitalizations, and surgeries, but the worst seems to her to be over, and she plans to savour the victory.

Sophie

In the late 1940s, 79-year-old Sophie worked for the Victorian Order of Nurses, as a nurse who cared for patients in their own homes. She recalls one patient in particular who had rheumatoid arthritis, and who required a nurse to assist her in bathing. "She was propped up on a hospital bed in her living room with pillows all around her. I'll never forget it," Sophie says. "Every breath she took she moaned. I thought, my gosh, never let me get this. Anything but this."

Twenty years or so later, Sophie suffered acute flareups in her joints over three consecutive weekends. First her thumb flared, then her shoulder, then a third joint she can't recall, and she knew to go to the doctor right away. Her family doctor booked an appointment with an internist two weeks from then. When the internist examined her he was alarmed enough to march her immediately next door to see a rheumatologist. Her RA was diagnosed and she was told that she would need to be admitted to hospital for a week to "stabilize."

After returning home from hospital Sophie continued to worsen as she and her doctor tried to find

medications that she could tolerate. Two or three months later, having met with little success, her rheumatologist told her she needed to go into a convalescent home for a month or so. She started to cry and said "I can't do that. I have children at home." But her 10-year-old daughter and 15-year-old son finally became the reason for her admission: she knew she had to "forget about everything except getting better" because her children needed her.

During her admission in the convalescent home and after her return home she had her worst shoulder injected with cortisone two or three times, and she had a "very good" physiotherapist who bent her shoulders back until she screamed. She also had her knees aspirated and injected with cortisone every six weeks. But mainly she took to bedrest, a practice that is very much discouraged now.

When her arthritis was new, Sophie concerned herself less with the fundamental causes of arthritis than with what things made her feel better or worse. The one thing that seemed to most influence the severity of her arthritis was heat. She spent her first summer with arthritis at her cousin's house where

she could lay on the couch and enjoy the air conditioner. "The hot weather kills me," she says. "That's the worst thing that happens to me, the hot, humid weather." This belief in the detrimental effects of heat would lead her, some years later, to move from her home province of Quebec to the more moderate climate of the West coast. Even here she finds herself spending time in the parkade below her condominium, trying to cool down.

For the first few years Sophie spent much of her days lying in bed. Yet, anxious to conceal the seriousness of her illness from her children, she always arose in their presence, and always made dinner for them in the evenings. She hid from them the fact that she was taking medications because she feared, given the social climate of the sixties, that they would be more apt to turn to drugs themselves if they knew.

Sophie's friends tried to coax her into social participation. "They say well a long walk will do you good, or come over, we're having a party, it'll do you good to get out." But Sophie became very firm in turning down these invitations, fearful that excessive

physical activity would exacerbate her arthritis.

Though she has become much more aware of the need for physical activity, she still struggles with trying to strike a healthy balance between rest and activity:

The hardest thing about arthritis is learning to balance what you can do and what you want to do. I'm always testing the waters, always wanting to do a little more than I should. You know I always wanted to climb that hill over there, or walk an extra block. That way, I found out what I could do and what I couldn't do.

Some years into the course of her disease, Sophie's ideas about its cause started to take shape. At first she looked to physical causes, and pointed particularly to her enthusiasm for tennis. She had been playing tennis for a year or two before the onset of her arthritis after a period of relative inactivity, and says that perhaps she "went at it too strong".

Further reflection led to the incorporation of stress into Sophie's explanatory model. She says that around the time of onset she was having problems in her marriage because of her jealous husband. She now says that "everything sort of came together at the same time" to produce her arthritis.

Sophie had also come to notice that the severity of her arthritis was influenced by changes in

barometric pressure, an idea that is commonly held by people with arthritis, and a notion that was reinforced by her own observation.

Over the years, Sophie was in and out of hospital many times, and underwent several operations. She says that her hospitalizations reminded her of how "lucky [she was] getting after the arthritis right away" because she saw its devastation in people whose treatment was delayed.

Sophie was also witness in hospital to the struggles of many young people who had been injured in accidents. Of them she says, "you drive too fast, you're liable to get into trouble. You light a match, you're going to get burned." Thus, she sees the misfortunes of many others as the logical outcomes of their behaviour. Yet at the same time she shies away from any notions of blameworthiness, preferring to look simply at the links in the causal chains rather than the character of those affected. This kind of thinking, she believes, may have been partly an outcome of her experiences as a nurse.

This detached attitude toward suffering may also have been fostered by the emotional climate of her

family-of-origin. The family did not have any mystical beliefs about causation, and shows of strong emotion were extremely rare. Sophie recalls only one event during which she witnessed the grief of a family member. She had returned home from overseas shortly before the end of the second world war. Though two of her brothers had been killed in the war, the family would not speak of them, instead holding their sorrow to themselves. One day Sophie and her mother had a slight disagreement, but so close to the surface were people's emotions that the disagreement sent her mother crying to the upstairs bedroom. But that was the end of it: "somebody said she'd never cried after the war."

Sophie likewise took an unemotional approach to her arthritis. Asked whether she had ever asked "why me?" she frowned and recoiled, hastily dismissing the utility of such questions. "I'm a realist and it would never occur to me to say 'why me?'" she says adamantly. "My philosophy is a problem is something that you do something about. You deal with things as they come along as well as you can." An atheist, she does not look to the supernatural to explain events but instead explains the unexplainable in terms of chance. "People

get all sorts of things and all sorts of things happen because, lots of things happen per chance. I mean you go around one corner instead of another corner and what happens."

Eleven years after the onset of her arthritis, at the age of 62, Sophie separated from her husband. This was a time of transformation for her; buoyed by her newfound freedom, she flew to Europe, purchased a Eurorail pass, and travelled the continent on her own, testing the limits of her physical endurance. "I certainly learned that I could look after myself with that trip," she says. Though she has been able to travel less in the past few years, she still attends jazz festivals all over North America, satisfying her love for music through listening and studying, rather than playing as she did in the past.

Humour plays a big part in Sophie's life, and she tries at all times to laugh at herself and her situation:

I had a black lab dog for 22 years and I finally had to put him down -- he was getting too old. He used to go down the stone steps from our front door to our sidewalk, he used to go down the steps just like me. I mean he used to go down with his legs bent like that. I used to stand and laugh. He was just like me.

Overall, Sophie feels she has gained much from her experience of arthritis. Though she has not undergone a profound shift in her world view because she has arthritis, her focus has shifted, she says for the better:

When you've had this happen to you it's usually good. If you come through. You know if you work it through you're better off because you've learned an awful lot. Understanding other people. Not only in the pain area of other people. It's understanding of other people generally, because you're lying back and observing a lot. I mean you're sitting back and you're observing. You're not rushing around and doing so many things and keeping busy. Your horizons are widened in that way. Trivialities go by the board.

#### Tamara

Fifteen years ago, at the age of 36, Tamara went to bed a very healthy person and woke up the next morning "completely paralyzed in all [her] major joints like knees and feet and elbows and hands." At first, she says, doctors thought she had blood clots, but after ruling out this possibility they were at a loss to explain her symptoms. She had been living in northern Quebec and was sent to Montreal General, the closest major medical centre, where she was eventually diagnosed as having polyarthritis.

Tamara had recently had a tuberculosis vaccination, and it is for this reason, she says, that the "Rh" factor did not show up in her blood, thus precluding an initial diagnosis of rheumatoid arthritis. "The doctors must be totally scientific" and refrain from calling it rheumatoid until after the blood factor shows up, an event that could, according to Tamara, follow the TB vaccination by 5 or 10 years.

Nevertheless, Tamara says she knew she had RA because her father had shown its symptoms, and because "genetic testing" had revealed that she carried "the gene" for RA. She believes that this genetic predisposition, combined with the fearfully cold conditions in which she had worked, and the fact that she had been an athlete, caused the arthritis to be "activated."

The onset of Tamara's arthritis was sudden and its course was rapid. It completely destroyed some of her joints within the first two years, necessitating very early joint replacement. Doctors suggested to her that the rapidity of its progression could be attributed to her lack of estrogen, for she had undergone a hysterectomy nine years earlier.

Before her illness Tamara had been a dissatisfied Roman Catholic. She had been, by her own description, very status-conscious, very materialistic, overly concerned with her own physical beauty. She was, at the same time, "searching for the answers to life and not getting them... I had trouble believing in a God who created all things and sent X number of people to hell for eternity," she says. "I didn't like God. I thought God was a male chauvinist. As a Catholic I thought the highest you could go was to be a Pope, and the fact that I'm female I couldn't even make it. I also had trouble during wars. One country would pray to its God and the other country would pray to its God, and whoever won, well that was the side God favoured. So I didn't like God very much."

While she undergoing diagnostic tests, Tamara was in a hospital in which many of the elderly patients were cared for by private nurses. One of these nurses who worked the night shift was about the same age as Tamara, and took a special interest in her, bringing her books and talking with her long into the night. This nurse introduced her to the writings of Edgar Cayce, whose ideas about reincarnation and natural

justice provided some explanations about the injustice she saw in the world, and were an important stepping stone to some later spiritual beliefs.

A couple of years into her illness Tamara incorporated psychological stress into her causal theory as well. She had noticed that the onset of certain diseases such as cancer was often preceded by a period of excessive stress. Looking back at the period preceding the onset of her arthritis she was able to point to several factors which, taken together, had produced mental and physical exhaustion for her. She had recently adopted two young children, 15 months apart, and she was taking four university courses at night while working full-time as a teacher. The belief in the strong influence of psychological and physical stress on the course of her arthritis has been reinforced for her several times over the course of her disease as flareups have always coincided with periods of excessive stress.

A doctor once told Tamara that, like cancer and MS, RA is one of the "anger-diseases." That is, people who carry around a lot of anger, hostility, and bitterness are vulnerable to these particular diseases.

She does not see herself as angry, hostile, or bitter, but instead thinks of arthritis as an "irritation-disease" or a "worry-disease."

A few years after the onset of Tamara's arthritis, a rheumatologist made an additional diagnosis of fibromyalgia, based on the excruciating pain she felt at key pressure points in her neck, shoulders, and back. This new problem complicated her treatment as the kinds of therapies that alleviated the fibromyalgia were often ones that exacerbated her RA. Tamara was not terribly perturbed by this new development, however, feeling that RA and fibromyalgia were both forms of arthritis, and that the different labels were meaningful only to the doctors.

At around this time, a life-changing event occurred one day when friends came to visit. In their presence Tamara tried to do some little task that was made very difficult by her arthritis. Frustrated, she made a comment to the effect that she must have done something really awful in a past life for this disease to have been inflicted on her. These friends, it turned out, were followers of Eckankar, a religion that teaches that our present lives are affected by our past

lives, that the difficulties visited upon us now are the natural consequence of wrongdoing in our past lives.

Tamara was captivated by the seemingly logical answers that Eckankar provided. "A whole lot of fears that I have in this life, I was shown that they were caused from another life," she says. "For instance, I never trusted my husband and I had no reason to mistrust him, so I asked why. And in past lives we've been married several times, and in a past life he was a womanizer. So I've carried that over. When I realized that I thought 'well, that's in the past and I can drop it'."

Devotees of Eckankar practice contemplation for 28 minutes every day. Through contemplation they are shown the past and how it affects life now. "It is like looking at a video," Tamara says. "Even though you are a different person, either male or female, different size, different looks, everything, you do recognize yourself." It was through one of the revelations that came in a period of contemplation, that Tamara learned why she had been struck with RA and fibromyalgia. In a past life, she says, she was a

Roman soldier who had thrown Christians to the lions. For that she must pay retribution. "What you do unto others is done unto you. So I believe right now I'm just paying off my karmic credit card."

Tamara's day-to-day life changed in tandem with her spiritual life. She had been a school teacher for a number of years but the great fatigue that accompanied her arthritis had forced her to quit teaching. In an effort to take her attention off of herself she returned to school, first completing a business diploma, and eventually a bachelor's degree in environmental geography. She credits her arthritis for these accomplishments, saying that it "opened doors for [her] that she never would have perceived." It exposed the shallowness of her former pursuits and forced her to look for other possibilities. So she sees her illness as both blessing and punishment.

One of the possibilities that Tamara chose to pursue was volunteer work with Cansurmount and hospice. As a child Tamara's family had lived on a small island off the coast of Newfoundland. There was no hospital there, let alone hospice, and when people were ill and approaching death they came to Tamara's mother for

care. This woman had a strong belief that the body was something quite distinct from the spirit or essence, and consequently had no fear of death. As people approached physical death she encouraged them to let go of their struggles and go towards the light. She tried to instill the same attitudes about death in her children, though Tamara says she did not fully understand until much later in life, when she learned about Eckankar, and when she had her own near-death experiences.

The first near-death experience occurred five years ago when Tamara was having hip-replacement surgery. She describes it this way:

The doctor left me paralyzed. He forgot to release the drug I had. As a result of that I was clinically dead for about twenty minutes. I had a choice to come back or stay where I was, because where you are is very, very, beautiful. You see the light and hear the sound. It's beyond anything comprehensible to this world. I did not want to come back but I realized I had small children and I took these on, and maybe I should continue with them. So the spiritual being said that was correct. It's like a test you're given.

Her second near-death experience occurred last year and was more immediately relevant to her arthritis. She had an idiosyncratic reaction to a large dose of prednisone; her heart enlarged, she says, pushing on

her lungs and esophagus and preventing her from breathing.

That was different. The children were raised now and I had a choice and I really wanted to stay on the other side. I said to the spiritual being "if I die now would I have to come back and finish the karma I have now?" and I was told yes. So I thought what the heck. I'm fifty-two years old now. What the hell. I'll come back.

The universe, according to Tamara's beliefs, operates such that in one's present life one has to pay retribution for past wrongs and experience a change in consciousness; otherwise one is doomed to experience the same hardship in the next life. When people pray for Tamara's healing she erects a "shield of light." She does not want to be denied the experience of her arthritis, lest she be forced to relive the experience all over again in the next life. Besides, she was shown in a revelation that although she would have to experience many years of suffering in this life, the suffering would end in the next few years, leaving her without pain and disability for the remainder of this life.

In explaining the etiology of her arthritis Tamara stills says "A, B, C, and D, E, F must come together before it is activated." If one starts with a genetic

predisposition, and meets with the right environmental conditions, say, cold climate, stress, hormonal deficiency, and a history of athletic injuries, symptoms will appear.

Now, however, having lived with her arthritis for 15 years, the spiritual explanation is most salient for her. Paying restitution for past wrongs is a logical and satisfying explanation for her suffering. Further, her involvement in Eckankar has provided her with a sense of purpose; she publishes a nationally distributed newsletter for Eckankar, and she regularly conducts workshops on subjects related to near-death experiences, fears, stress, and visualization. She is also writing a book on coping with illness, and dealing with doctors.

She feels at peace knowing her arthritis is part of the natural order.

If I had not gotten sick, I would not have been sent to Montreal. I would not have met the nurse that gave me Edgar Cayce's book, and after his book there was something missing in it, and then I searched and I found. I became a different person. I am not the same person I was 15 years ago. I'm very positive, seldom negative. I look at things now and figure the karma has been finished, and now I'm just sort of going to a purification. And each stage is an expansion of consciousness and a spiritual growth. Eventually

I will be finished with this and will learn in a new way.

Gwen

In 1980, Gwen was painting her family's home, preparing it for sale after the bank's foreclosure; so she began her story. She noticed that her toes were very sore but decided that the pain must have been caused by her having to stretch on tiptoe to reach high places with her paintbrush.

Over the next six months or so, other joints became involved as well: first her hands, then her knees. She went to see her family doctor who then referred her to a rheumatologist. Diagnosis of rheumatoid arthritis was prompt, and it was suggested that she be admitted immediately to G.F. Strong or to Rufus Gibbs, a lodge which houses people seriously-ill with arthritis while they attend intensive, full-time treatment at the Arthritis Centre. Gwen offered a plethora of excuses for not going to either of the two centres. "I'd use anything," she says. "'Oh, I've got two dogs', you know. Just to think really my arthritis is so bad that I've got to do something about it." She managed in this way to avoid hospitalization for the next four years.

In the early days of her arthritis, Gwen ruled out heredity as a possible cause of her arthritis as she could think of no other family member with similar symptoms. Instead she pointed to menopause as the trigger that set off her arthritis: "I would have been late 40s, really, and maybe I wonder sometimes if that age has something to do with the change, too, you know. Why would arthritis come at that particular age?"

However another explanation, stress, came to the fore as slowly Gwen began to come terms with the events that had occurred over several years preceding the onset of her arthritis. She had had a very traditional marriage; her husband was a prominent businessman and the sole breadwinner for the family, and Gwen's role was to care for the home and three children, and to play the supporting role to her husband, entertaining his colleagues and customers. They lived in quite a grand style in a "select" neighbourhood, and their children only attended expensive private schools.

But all was not as it seemed; Gwen's husband mortgaged their house to prop up his failing business and was behaving in ways she now calls "scandalous." He had developed a very serious drinking problem and

had become extremely "promiscuous." Gwen tried all the while to remain the stable, genteel wife, turning a blind eye to much of what was happening and draping the family's life with a veil of civility:

I was always there to be dependable. I would never have been able to depend on him really. Oh, the uncertainty of it all, you know, waiting. I'd have cheese souffle, you know, for dinner. He was taking courses at [a university] and he'd say, well, you know, "wait to eat." He'd be home at 11 o'clock after taking this course, so "let's have a souffle, you know, we'll have a late dinner." And I'd make the souffle but you know what happens if you don't eat it. You know 11 o'clock would go, maybe one day, two days, three days. Just an impossible way to live.

Yet Gwen's husband belonged to a sort of "culture" where this kind of behaviour was the norm.

Increasingly, Gwen resented the "phoniness" of this culture, and began to question her role in supporting it. "It was such a phony kind of life, you know, the friends that I had to entertain... I don't appreciate people who really abuse their families and don't treat them very nicely, and to have to entertain these people, you know, there was a lot of phoniness, too."

Gwen's husband's volatile behaviour had a profound effect on the children as well:

I was so oblivious, you know, to them being so hurt, but ah. Oh, it takes a tremendous toll, you know. I mean now when you hear of dysfunctional

families, I mean my goodness here we were, my children going to private school, I mean what a phony facade it was, really, and, you know, kind of a wall... [meanwhile at home] children never knowing what's going to happen when they come in through the door. It's a terrible way for children to live... I felt terribly guilty about it. Children are very forgiving and they say "well, you know, what could you have done about it?" I mean we were like helpless babies... we were such a pathetic bunch, you know, to think that really in a way this man was the engine, you know, that had kind of driven us to where we were. And without him there was total collapse.

In 1975 Gwen initiated divorce proceedings, determined to seek peace and stability for herself and her children. But her resolve crumbled beneath the weight of her husband's charm; on New Year's Day, 1976, a day which held great emotional significance for her because of its association with endings and beginnings, he made a surprise appearance at her house. "I was so exhausted and I remember him coming to the kitchen, you know, and he just hugged me and gave me a kiss and would you believe that was the start of the reconciliation, you know, but reconciling to the same patterns, even worse than before."

Her husband's drinking, lying, and infidelity continued despite the reconciliation. At one point he went to Seattle to admit himself to an alcohol treatment centre, but not only did this fail to solve

his drinking problems, he met a woman there with whom he began a long-term affair. Many subsequent trips were made to Seattle on the pretence of checking into the YMCA to "figure things out." Though Gwen became aware of this other woman, she was receiving mixed messages from her husband, and believed that he would not leave her to be with the other woman. She says, "I just thought I'd be married forever."

Gwen's life continued in this manner for the next four years or so, and she was ever-hopeful that things would improve. "I thought if he stopped drinking everything would be alright. And he did eventually, and when he did he left me." In 1980 Gwen's marriage broke down, her husband's business failed, and the bank took her family home:

To lose your home is such a waste in a way. It's quite scandalous to lose it in such a manner. You know, it meant that he had no value on home, children, marriage, or family. It meant nothing to him and for me those were, you know, what else is there in life--family, a roof over your head. So, you know, by nature I think I'm a calm person, but I must say that I remember feeling such fear.

At this point, too, her children were reaching adulthood and were leaving home. So it seemed to Gwen that the only thing she lived for, her family, had disintegrated. It was at this time, as she said at the

beginning of her story, that she developed the symptoms of arthritis. But it was not until some time had passed that she began to incorporate stress into her explanatory model. Looking back she says:

I knew that tremendous things were happening to my body. I mean the day I realized we owed the bank money, lots, you know -- \$40,000 -- and that's when the bank said it would send a truck. You know taking your beds and everything. I just paced like a madwoman. I mean something has to happen to your body, you know, either the heart gives out or you have high blood pressure. I think if you have stress where you really haven't a way of resolving it or doing something about it yourself, well I think it has to do something to your body, trigger something.

So began a very difficult new period. Suddenly she had no home, no savings, and no marketable skills with which to generate an income. Complicating matters was the fact that she did not have true closure on her marriage; her husband was still in and out of her life "like a wayward child."

Gwen describes the development of her arthritis as gradual and insidious, but probing reveals that its physical development was not gradual; rather, her recognition of its seriousness and her willingness to submit to treatment were slow in coming. She insisted, for the first few years, on being the stoic, the strong one on whom others could depend. Preservation of this

image of herself was essential to her coping, and precluded the acknowledgement that her body was degenerating.

In 1985, Gwen finally ended her relationship with her husband once and for all. In divorce proceedings she tried to argue that the physical abuse she had suffered from her husband had contributed to the development of her arthritis. He had kicked her many times over the years in the knees and in the ribs, a fact of which she is very ashamed and which she tells virtually no one, and to this day, she says, she is the only person she knows who has arthritis in the ribs. Though her lawyer told her that "you can't prove that a good kicking and a good beating cause arthritis," she continues to believe that they were contributing factors.

As Gwen closed the book on her marriage, the reality of her arthritis hit her face-on, both physically and emotionally:

I woke up one morning, awake all night, my hands and arms were quite sore. When I woke up I couldn't move either arm, you know, just as if you'd had a stroke. And I remember my hands being pale, pale and waxy, just shiny, you know, fruit - - artificial fruit in a bowl, shining like that. That's what my hands were like. Oh I felt so ill. That's what got me into the [Rufus Gibbs] lodge

then, you know. That frightened me because really something happened that I had no control [over].

It was at this point that Gwen began to question "why me?" She says she had lived in a "dream world" most of her life, and this was the time that the sting of reality was felt most acutely. On one hand she looked back at her life and all that she had suffered and wondered why a further cruelty had to be inflicted on her. But as time passed she saw that she had survived all that had happened and that she would survive this too. Indeed, though she does not consider herself a religious person, she had always had a vague sense that "someone was watching over [her]," and she came to believe that "someone" would see her through her arthritis as well.

In the years since this difficult period, Gwen has gone through several exacerbations of her arthritis, several surgeries, and several hospitalizations. Though she has seen improvements through physiotherapy, these improvements have only been short-lived. She has come to believe that "for some kinds of arthritis nothing works."

Nevertheless, Gwen says unequivocally that this is the best time of her life. Hers is a story of paradox:

only now that she has been stripped of all that she lived for, only now that she has to "be a contortionist to get into a dress," only now that she faces a degenerative disease for which little seems to work, has she been able to find peace. She says her life is "so sweet," "so calm," and she finds pleasure where she can: in a book, in the birds at her window, and "in a good cup of coffee."

#### Madeleine

In 1985, when Madeleine was 35 years old, she developed sudden and severe swelling in both of her index fingers. She had been camping recently, and at first thought that the swelling was due to something that had happened on the camping trip; perhaps she had banged her fingers or had been bitten by mosquitoes. But the swelling persisted beyond what Madeleine thought was a reasonable period of time, and she sought the advice of her doctor.

Madeleine's diagnosis of rheumatoid arthritis was very quick. Soon she developed pain and swelling in her knees and feet as well. "I had flare-ups like I could hardly walk," she says. "It was just so painful. I was very tired."

Madeleine started to read everything about RA that she could get her hands on. Much of what she read suggested that RA is a hereditary disease, and looking at her own family's medical history she had little trouble believing this. "My mother had arthritis, like in her 40s. And like on her side of the family there were 13 of them, and both men and women, just about all of them had [rheumatoid] arthritis."

Madeleine spoke to me in brisk tones as she described how she tried to adopt an unemotional, practical stance toward her arthritis: "When I got arthritis I thought 'well I've got arthritis, my mother lived with it, now I'll have to try to do my best'. I still feel that way. I can't say that I deny having arthritis, but I don't accept it either."

Madeleine is annoyed by the way that arthritis interferes with normal interpersonal interactions: "I resent the fact that some people before they say 'Hi, how are you?', they say 'how is your arthritis?'. And it's like 'arthritis? What arthritis? I don't have arthritis'. And I try to change the subject." She once attended an arthritis support group meeting, and though she found it very informative, she felt

alienated from the group because of her relative youth, and did not return. Besides, she is not one to sit around and complain.

Madeleine calls her approach to medical treatment "stubborn." Though she has tried many medications she is convinced that only one works, and that in any case the side effects of drugs are not worth their benefits; she does not want to add something like a liver problem to her list of medical ailments. She has frustrated her doctor by discontinuing new medications after three or four months when she doesn't see impressive results. "Most of the time I was going without drugs," she says. "Then when it would get really, really bad I went to see my doctor and then he'd say 'you just don't stay on the drugs long enough so we don't know'. But then I'd say 'well by three months I should be able to feel better or whatever'." Lately, though, she has begun to accept her doctor's argument that although the drugs will not arrest the arthritis, they will at least slow its progress. "I'm not sure I believe that but that's what they say. So I guess I'm not as stubborn as I used to be. I just finally gave in."

Madeleine spent most of her time during our interviews describing her relationship with her arthritis, talking in a very strong, dispassionate manner. But a certain question profoundly changed the tone of our interview; I asked "what was happening in your life around the time your arthritis started?" Madeleine's expression changed completely; she looked as though she had been hit in the head with a brick. She turned the tape recorder off and her trembling lip soon gave way to full-blown sobs. For a long while she could not speak.

"I had a handicapped daughter," she finally said. "She died three years ago when she was 14." When she was able to collect herself Madeleine told me the story of her daughter's illness, a story she seldom tells because the hurt is still so deep. Inga was born a seemingly normal baby. She started to walk a little late at 15 months, but her doctor was unconcerned. By the time she was two years old, however, her neurological symptoms were pronounced enough that she was diagnosed as having cerebral palsy.

Madeleine was dissatisfied with her daughter's diagnosis as it did not seem to fit with what she read

about cerebral palsy or with what the physiotherapists were saying. Further, whatever condition it really was seemed to be progressive in nature. Still, no further medical investigations were undertaken, probably because of the limited medical resources in the small northern town where Madeleine's family lives.

By the time she was 8 years old, Inga was walking with the use of a walker, but she had much difficulty doing so because her legs were "scissoring"; that is, the spasms in her adductor muscles that pull the leg in at the hip were so strong that they were actually causing her legs to cross over each other involuntarily as she tried to walk. She was sent to Children's Hospital in Vancouver for surgery to address this problem, but specialists here tried instead to diagnose Inga's true problem.

In addition to the symptoms that resemble those of cerebral palsy, Inga had others that had gone unexplained, such as "graying" around her eyes. The doctors finally diagnosed her with Cockayne's Disease, a condition so rare that only 19 people in North America have it. The prognosis for Inga was poor: continued degeneration and death at an early age.

It was around the time of Inga's diagnosis with Cockayne's Disease that Madeleine first developed the symptoms of arthritis. At the time Madeleine devoted her energies to Inga's care and did not stop to wonder about the effect that her stress had on her arthritis.

Inga's degeneration was rapid. Within a year she had lost her sight and was wearing a hearing aid. "Her muscles deteriorated to the point that she was folded in half like an accordion... she went from being able to walk with a walker and being able to eat by herself and doing all those things to basically doing nothing." At night Inga's condition required Madeleine to be up every 15 minutes or so, about 20 times per night. The responsibility for Inga's physical care rested squarely on Madeleine's shoulders, despite Madeleine's own physical problems. "Plus the worrying, I mean, just to see her like that."

Now that Inga has passed away, Madeleine's attention has finally been able to settle on herself, and she has started to consider the role stress might have played in the onset of her arthritis. "I've heard so many people who say that they had a part of their

life where they had so much stress," she says. "I think that personally that's what triggered it."

Now that Madeleine is in her 40s and has RA, she is becoming more and more frightened as she reflects on her mother's experience at the same age. Though her mother never complained and seldom even spoke of her arthritis, the disease was evident in the way she moved, in the way she had to cut back on her sewing, her most cherished activity, at times. "I can think back of when my mom was in her 40s, and sometimes I look at myself in the mirror... it's not that we just look alike, but now I know that there was pain on her face, and it was the pain of arthritis."

Now that Inga is gone, Madeleine is able to see the pain on her own face. She feels angry, and rails at the injustices that were done to her daughter and that are being done to her now. Asked if anything good has come of her arthritis she shoots back a horrified, emphatic "no!". The question "why me?" looms large in her mind, and she has no answer for it.

"Why [some] people suffer more than others [I have] no idea," Madeleine says. "It just isn't fair." She searches in her mind for life-events that might be

associated with subsequent misfortune, and comes up empty. Nothing she has done in her life leads logically to where she is now, for she had always tried to live a good life, a healthy life. Only half-jokingly she says, "In another life I'll be a drunk and a prostitute."

### Stacey

I first saw Stacey when I was waiting to talk to the charge nurse on the arthritis ward, waiting for a suggestion as to a who might be interested in participating in my study. The young child of one of the arthritis patients had been injured slightly when her father's electric wheelchair went astray, and Stacey was immediately on the scene tending to the wound and offering advice about facilitating its healing. She seemed very professional and knowledgeable, but she was dressed in a long gown, and although the dress code for nurses at Pearson is very relaxed, I did not think that she could have been one of the staff. She bandaged up the little girl and sent her on her way, then went into one of the patient rooms. When the ward nurse returned to the desk and I

asked her to introduce me to someone who might be willing to be interviewed, I was introduced to Stacey.

Forty-four-year-old Stacey first developed the symptoms of arthritis in 1986. At first she only had pain in her back and in her sacroiliacs, the joints between the spine and the pelvis. She had been working as a nurse in the emergency department of a large Toronto hospital and at first attributed her pain to the very physical nature of her job. But when the pain persisted she began to look to other explanations. The hospital where she worked had a large tropical diseases unit and her muscle aches were not inconsistent with a viral infection; she began to wonder whether she had picked up some unusual virus in the course of her work. Simultaneously, she began to wonder whether the hepatitis B vaccine that she had been required to take might have produced her symptoms.

Diagnosis of Stacey's arthritis took about a year. In that time several possibilities had been investigated including polymyositis, lupus, and lymphoma. Although her pattern of symptoms was somewhat atypical because it included, by this time, inflammation of the shoulders, knees, and fingers,

Stacey was diagnosed with Psoriatic Arthritis (PA). This condition is very similar to RA in that it is a systemic, inflammatory form of arthritis, but people who have it have a skin condition (psoriasis) as well, and typically have a different pattern of joint involvement than people with RA.

Stacey's physical tolerance for the heavy work and the 12-hour shifts that her job required was markedly reduced as her arthritis worsened. Her personal life was strained as well because her sick father, whose care had been her responsibility, had died unexpectedly within months of the onset of her arthritis. For the next three years she was only able to work on and off as she tried to cope with her illness and with the loss of her father.

Away from work, Stacey felt stripped of her identity. From the time she was a little girl she had devoted herself to learning as much as she could about nursing, voraciously reading her aunt's medical texts instead of doing things that were typical for girls of her age. When she became an adult, her nursing career was more important than anything else in her life:

The one thing I did really well was nursing. I mean I'm not married, I don't have any children.

Nursing was my life. And so that was the thing that - if I'd get up in the morning and I wasn't having a good day, I could say that I'll be working in emergency tomorrow and I'll shine there.

Stacey's forced withdrawal from work thrust her into deep depression. The question "why me?" tormented her, and she looked everywhere for answers. She says that she is Christian, and for a long while thought that God must be punishing her for something. One day a friend said to her "you know you're smart and you really love nursing. You must have been really bad in your last life because you're getting so badly punished [now];" this comment started Stacey wondering if there might be something to this idea.

At one point Stacey became involved with the Church of Jesus Christ, a fact that she is now loathe to admit because it is indicative of the desperation with which she searched for answers. Church members persuaded her to move out of her own apartment and into a communal house shared by other church members. There they tried to recruit her as a nanny to the evangelist's children saying "this is what God wants you to do." The pressure mounted until finally she

realized with a start that she had succumbed to a cult, and she quickly extracted herself from its hold.

Meanwhile Stacey's ability to work continued to decline until 1989 when she had to quit altogether. Over the three years that she had tried to keep her job in the emergency department, support from her nursing peers and supervisors had deteriorated considerably. "Nursing doesn't take care of nursing," she says. "It's not like other professions where they'll sort of crowd around and try and help you out. It's not like that in nursing." When she finally resigned, she received a very critical letter from her supervisor that was to have a devastating affect on her ability to secure future employment.

Many of Stacey's friends also abandoned her in her illness. "Suddenly you're not Stacey anymore. You're Stacey with an illness." She even began to question the basis of their friendships with her, and wondered whether they only wanted to be friends so long as she was able to give to them. "'Oh gee, you know, she used to look after us when we had our children and when we were sick'," she imagines them saying.

Stacey moved to Vancouver in 1989. Her sister lives here, but she turned out to be little help or support. Partly, Stacey figures, this is because of the relative invisibility of her disease. But she also came to realize that her sister was still grieving their father's loss, and was not emotionally prepared to allow that another loved one could be seriously ill.

In Vancouver, Stacey took a job as a venipuncturist with the Red Cross, believing that the work's physical demands would not exceed her abilities. When she was hired she made it clear to her supervisor that she was seeking this work because her arthritis precluded further work as an emergency room nurse. However, she soon discovered that one of her duties was to unload medical supplies from trucks, a task well beyond her abilities. Frustrated, but anxious to work, she did her best to perform as required, but had to quit a couple of months later. Her supervisor "made [her] sound like the worst nurse in the whole world and how could [she] ever possibly have made it through so many years of ICU and emergency." She quit before she thought to apply for long-term disability benefits, and so began her descent into poverty.

By 1993 Stacey's arthritis had progressed to the point that she was admitted to G.F. Strong for a period of intensive treatment. Her condition improved, and she decided to start applying for work in the nursing field once again.

Three hospitals turned down Stacey's applications, and she started to get angry, believing that she was being discriminated against because of her illness. She laid complaints with the B.C. Human Rights Council against the three hospitals that had declined to hire her. She decided further to launch a legal suit against her supervisor in Toronto whose "reference" letter had so badly damaged her chances of finding work in nursing. "I feel very strongly about what they've done to me," she says. "I can't just sit and take it because it's like acknowledging that I am what they say I am, that I'm no good, that I'm useless. That I've got arthritis and how could I possibly be a good nurse anymore."

The stress of fighting her legal battles, of trips to the welfare office, of dealing emotionally with the loss of her beloved career, began to take its toll on Stacey. She began to notice that exacerbations of her

arthritis tended to occur in times of particular stress, and she began to wonder about the role of stress in bringing on her arthritis in the first place. She had always thought that she thrived on the high stress of working in an emergency room, but on reflection she started to think that perhaps she was just too busy to notice its physical effects:

In emergency they're coming in so fast and they're so acutely ill that you don't even have time to think of all the things that go on... like you know you have to go out and talk to a family and say your father's just died... but, you know, five minutes later you just clean up the room and you've got another trauma coming in.

But away from this whirlwind pace she could feel the direct effect of stress on her body. Looking back, too, she remembered the stress of her father's illness and death. She recalls that the night before he died she had taken her phone off the hook, not realizing that death was so near; perhaps he had tried to reach her to say something to her, she says, and for that she is filled with guilt. In the past few years, Stacey has come to believe that stress has played a part both in the onset and the worsening of her arthritis.

Stacey still experiences periods of profound depression, and has even considered taking her own

life. Yet she also experiences surges of firm resolve in which she vows to make something good of her illness. During the dark times she still struggles with the question "why me?", but in the good times she thinks she can see an answer:

I wonder if maybe I've gotten this because as a nurse I wasn't looking at [suffering] from inward. Now I can really look at it. Like I was always very understanding of people in wheelchairs, I thought -- until I got into one one day and I thought, My God, I had no idea it was this hard to work these things or no idea it would be this frightening to go in a wheelchair across the road... And I can teach somebody else that... maybe [that's] what I'll do my thesis on.

Stacey is trying to view her illness as something that will make her a better nurse, and as something that will nudge her into promoting systemic change in the practice of nursing, change that focuses on the "art" of nursing rather than the "science" of nursing.

Stacey still wrestles with the philosophical questions surrounding her illness, but at the same time she continues to look for medical clues as to its etiology. Recently she had an opportunity to review her own medical charts, and the possibility that the hepatitis B vaccine triggered her arthritis has come to the fore for her once again.

As we parted ways Stacey told me to call her if I ever needed any medical information.

Caroline

"In 1977, the beginning, I went to the doctor and he noticed--I noticed before--that my tongue was going a different way, going sideways." So began Caroline's story of her arthritis. At the age of 14, Caroline, a native girl living in a small northern community, was forced to undergo painful diagnostic procedures, such as spinal taps, as doctors suspected that she had a brain tumour.

Though Caroline's family was frantic with worry, Caroline was unperturbed, and she says now that the potential seriousness of what the doctors were saying was "lost on [her]," young as she was. She had heard from other people that stress could cause arthritis, but hers was not merely the stress of worry. The physical stress of these procedures, Caroline believes, was also responsible for bringing on her arthritis. Though she had been told that her spinal tap would not be painful, she found the procedure excruciating, perhaps, she says, because of the ineptness of the person performing it.

Caroline says that this causal theory was somewhere in her consciousness when a discussion with a certain nurse brought it forward:

She mentioned it and it really got me to thinking because I heard other people talking about something happened just before they found out they had arthritis, something happened before that. Like a husband died, something. It gets you to wonder, you know. It can't be a coincidence.

This theory has since been reinforced several times by fellow hospital patients:

It seems to me that a few people have said that stress has brought it on, their arthritis. Like a lady here had chickenpox. Right after she got chickenpox, she found out she had arthritis.

Within a few months of beginning the medical investigations, Caroline felt as though she were "walking on peas," and she woke up every morning with cramps in her legs. Despite these atypical complaints, it was not long before doctors diagnosed rheumatoid arthritis. The mystery of the crooked tongue has never been solved, though doctors tell her to watch for headaches and other symptoms that might suggest a brain tumour.

For two years after her diagnosis, Caroline spent a week or so every month in the hospital, trying to calm her frequent flareups. Attending school was

difficult; she could hardly step up onto the school bus, walking was exhausting, and her friends' lack of understanding made her feel isolated. So, at age 16, she "just gave up" and quit school.

Caroline recalls one particular day at around this time when she started asking "why me?". She was walking down a hill feeling so much pain that she was praying to reach the bottom. She was at a point in her illness where she was constantly yelling at her brothers and sisters, and feeling like a burden to everyone. The only conclusion that she could come up with then, and still the only answer she has, is that she must have done something bad in a past life. Asked whether she is joking when she says this she replies "no, I'm serious."

The urge to ask the question eased somewhat when she met the man who was to become her husband. "I felt like giving up, and then I met my husband. He's changed my life." At the age of 17 she married, became pregnant, and gave birth to a daughter. She became pregnant, she says, because she had heard that "if you're pregnant... your arthritis stops in most people." The opposite was true for her; she was

required to cut back on her medication, her arthritis worsened, and she spent most of her pregnancy in hospital.

Caroline had a strong support network from which to draw when it came time to care for her newborn. Her mother, sister, mother-in-law, and husband rallied around her, helping not only with the care of the baby, but with Caroline's return to school as well.

Caroline managed to complete grade 10, but her knees and hips were rapidly worsening, and she returned from school each day drained and unable to do anything else. She felt, too, as though her daughter barely knew her, because of her physical absence during the day and her physical and emotional withdrawal while at home.

When she was 21 Caroline made her first trip to G.F. Strong. Her knees were so badly deteriorated by this time that joint replacement surgery was suggested, but she felt emotionally unprepared. She met another young woman with RA while in hospital, and until then she had not realized that there were any other young people with arthritis. She felt some comfort in knowing she was not the only one. She also met

arthritis patients who had relatives with RA; one woman in particular had a mother and a sister who also had RA. Though she knew of no arthritis in her own family, she started to believe that arthritis has a genetic origin.

The next 7 years were hellish for Caroline. Not only was her arthritis progressively worsening, she was dealing with deep depression as well. She spent much of her time in bed, unable to move, and found herself crying all the time. It was during this time that she started to pay attention to what made her arthritis better and what made it worse. Not surprisingly, she found that overuse, "physical stress," made her joints flare up. But she also noticed that certain foods like strawberries and bread, which she considers "acidic," made her arthritis worse. Further, she started to consider hypotheses that she had read about; for example, she read in Reader's Digest that arthritis might be triggered by the amalgam used in tooth fillings.

After these 7 years Caroline finally mustered up the courage to return to Vancouver for joint replacement surgery. Within a few months she had one

hip and both knees replaced. Though these surgeries eventually led to some functional improvement, her progress was slowed because she developed an infection after having a root canal; this infection, she says, caused a flare-up of her arthritis.

The last five years have been filled with hospitalizations, with surgeries, and with the search for an effective medication. Caroline's doctor recommended that she try methatrexate, a drug commonly used in cancer chemotherapy. Stern warnings about not becoming pregnant accompany this drug, and she was told that she would have to have her tubes tied if she were to take it. The terrible decision has weighed heavily on her the past couple of years. She is very afraid of dying and leaving her daughter alone, without a brother or sister. But more and more, the desire to have another child "seems like an impossible dream."

For the most part it seems that Caroline has adopted a rather fatalistic stance toward her arthritis. At one point she went for surgery on her left ankle because it was very painful, and grating so loudly that other people could hear it. In the operating room the anesthesiologist commented that her

chart had "right ankle" written on it; rather than acting alarmed and insisting that they straighten out the mistake, she let it go. "At the time I was undecided," she says, "so I figured 'that's fate'."

Occasionally resistance swells up in Caroline, pushing her to question the dictates of medical wisdom and making her say "I never want to be this helpless again." But primarily, hers is a story of worry, of a life that peaked far too early. "I'm worried how I'm gonna make it through the next part," she says. "How can you be thinking of 40 when you're 31? I always wonder how it's gonna be because it's already getting this bad."

### Lorna

Lorna, a native woman from a small northern community, first developed rheumatoid arthritis at the age of 20, shortly after the birth of her third child.

She had had "one of the last of the arranged marriages" at the age of 15, had married a man 11 years her senior, the son of her grandmother's dear friend. He was a drinker and a rock 'n' roll musician, and Lorna barely knew him, but she loved her grandmother very much, and wanted to please her.

Lorna and her sister had been raised by their grandmother. Their own mother had been rendered emotionally incapable of caring for children because her husband, Lorna's father, had died when Lorna was two-and-a-half. What made his death all the more unbearable was the fact that the couple had been forced to separate before his death. Because they both belonged to the Bear Clan they were forbidden to marry. The clan had forced them apart, and had sent Lorna's father to live in another village. Lorna's mother never fully recovered from the loss of her husband.

Until Lorna was 12 years old she believed that her grandmother was her mother, and that her mother was her sister. It was only after many years that Lorna was able to forgive her mother for abdicating her maternal role; Lorna's brothers and sisters were never able to forgive.

When Lorna was 11 years old, her grandfather contracted tuberculosis. The rest of the family was tested, and their results were negative. However, Lorna and her sister were forced to leave their grandparents, and were put into a Catholic residential school. Lorna believes that authorities used her

grandfather's illness as an excuse to require their removal from their grandparent's home.

Lorna felt ambivalent about the residential school. On one hand she resented the tyranny that had put her there, and wanted to be home with her grandparents. But on the other hand, she had a great affection for Bishop O'Grady, the man who governed the school. Under his direction, Lorna's Catholic faith flourished.

Bishop O'Grady was held in such high regard that when he retired, "even the elders cried." His successor, Bishop O'Connor was not so well loved, and years later was charged with sexually assaulting some of the students in his charge.

As a girl, Lorna had had many dreams. She dreamed of becoming a lawyer, of becoming a master in martial arts. But when Lorna was 15, her ailing grandmother, fearful that she did not have much time to live, felt that it was time to pass the helm to Lorna. And so she arranged for Lorna to don the cloak of adulthood, of responsibility, and duty. She arranged for Lorna to be married to a man she barely knew, to become the family caretaker.

Lorna had always been destined for responsibility; from an early age she had been groomed to become a tribal elder. She granted her grandmother's wishes willingly, relinquishing her own aspirations in the service of others.

So, at the age of 20, she attributed her new diagnosis of rheumatoid arthritis to stress. But hers was not a simple theory, tied up as it was in the notion that arthritis can be overcome by a fighting spirit. She says that 3 of the 7 women who had arthritis and were in hospital with her when she was first diagnosed, have now experienced a remission, a fact that she attributes to their fighting spirits. Asked why, with her own fighting spirit, she had not experienced a remission as well, she replied that her spirit had been weakened by "three kids and a rock 'n' roll husband," responsibility for a wide circle of family members, and the legacy of a youth abandoned.

Lorna spoke of physical stressors as well. Her grandmother had pointed to the fact that she had spent some time as a tree planter; the cold and the damp must surely have contributed to the onset and the worsening

of the symptoms, she reasoned. Lorna accepts this explanation, coming as it does from her grandmother.

The first few years after the onset of her arthritis, Lorna became mired in what she then thought was depression. Overwhelmed and unhappy, she struggled on with her new condition, and with the stresses that brought it about. She now feels ashamed at the way she was back then, at the fact that she labelled her emotional state a "depression." She feels she now knows, given the events of recent years, and her reaction to them, "real" depression.

The person that emerged from those early years was a character she calls "Fighting Lorna." She made a resolution to learn as much as she could about arthritis and to take what she learned to her people, many of whom suffer from arthritis, and most of whom have little access to good medical information and treatment. She also took it upon herself to educate the new doctors, who undertook rotations in her community every two years, about what kinds of issues and problems her people were facing. Once, when she figured a particular doctor did not know enough about arthritis to be treating people, she sent him down to

Vancouver for more training. Now, she says, "he knows just about as much as I do." Her friends started to call her "Mrs. Ombudsman."

In 1977 Lorna gave birth to her youngest daughter. By this time her arthritis was quite bad, and for the first several years of her daughter's life, when the requirement for physical care-taking was greatest, she could not care for her child herself. It was then that she started asking "why me?." Her friends tried to console her, saying that she was meant for some higher purpose in this life, a purpose that would not be impeded by arthritis. Though she clung to their words she was hurting terribly inside.

Over the years Lorna has been heavily involved with the band council. Because she has such a tremendous knowledge of her people's heritage, and because she speaks her native language fluently, she was nominated three times to become chief. She declined, however, because she felt she was still too young.

Lorna says that when she was a child she only knew one person with arthritis, her paternal grandfather. Now, she says, so many people have it that it seems

epidemic. She is not sure whether genetics has played a role, but feels quite sure that the change in the food that her people eat has contributed to the rise in the incidence of arthritis.

But more importantly, Lorna feels that it is the tremendous stress of living on reservations, and of feeling stripped of cultural identity, that has caused so much arthritis in the native people. The stress has not only led to arthritis, it has led to excessive drinking, which in turn worsens the symptoms of arthritis. Lorna speaks with great sorrow about the state of her people, and seems to see arthritis not only as a consequence of this sorry state but also as a sort of metaphor for the spiritual crippling that has been experienced by the native people in the last few generations.

In 1989 Lorna started to go on "elder trips," gatherings of native elders from across the province. Usually people are not invited on these trips until they about 60 years of age, and she was only 40. But the knowledge that she had, combined with her leadership experience and the grooming that her

grandmother had done, had prepared her early to become an elder, a position higher than that of a chief.

But Lorna's ability to lead her people was curtailed for a long period starting in 1991. While in hospital she witnessed a shooting at close range. That experience, coupled with the fact that her name and face were shown on television coverage of the event (despite the probability that the killing was gang-related) put her into a profound depression from which she is now just starting to emerge. She had all of the symptoms of Post-Traumatic Stress Disorder, according to her psychiatrist; she had nightmares and panic attacks, and could not turn the lights out at night. The shooting incident even changed the way she thought of her arthritis, dwarfing it in comparison.

Now that Lorna is starting to recover, she is able to devote herself once again to her life's work in cultural teaching and native leadership. She says that her purpose in life is to bridge the gap between the native and non-native cultures, and to reach out to young native people, encouraging them to learn about and preserve their culture and heritage. Her grandmother always told her that "everything has a

purpose," and the elders always say that the truth will be revealed as one ages, that the pieces of the puzzle will come together. Lorna has come to believe this.

### Marilyn

In 1991, at the age of 27, Marilyn was working in the shipping and receiving department of a large hardware store, putting stickers on merchandise with a price gun. The joints of her fingers started to swell and at first she thought that the repetitive motions of using the price gun were causing the swelling. But after a while she started to worry that maybe it was something else; as she explains it in her own folksy way, "oh these are awful sore to be doing that."

Marilyn went to the doctor and was diagnosed almost immediately as having rheumatoid arthritis. She had not known anyone with RA and has very little knowledge of medicine, so she did not know what to expect. Still she thought of her arthritis as having been caused by overuse. Within a month of her diagnosis she started to get swelling in her knees, elbows, and shoulders as well. Since then her arthritis has been continually active; though some

times are better than others, the pain and inflammation have never let up.

At first Marilyn had a tough time emotionally, and had no one she felt she could talk to about her arthritis: "I find it hard [to have arthritis] when you are young 'cause you don't have someone to talk to, like me and you, and saying 'hey, how do you feel?'. Like we never did." Her family was not emotionally supportive either; they believe in keeping one's troubles to oneself. Privately, Marilyn spent much of her time crying and feeling very hopeless.

Marilyn's first stay at G.F. Strong happened early in the course of her illness and was helpful to her in learning to cope with her arthritis. "It helped a lot 'cause you would see worser people than you and would think 'well if they learned to live with it, and they are older, well I can, hey'." This idea that one just has to "learn to live with it" is repeated so often in Marilyn's story that it is like a mantra.

"Learning to live with it" means, in part, learning to follow the instructions of doctors and books to the letter. Marilyn follows a rigid program of exercise and rest, believing that both have a

beneficial effect. She puts ice on her joints regularly, and takes her medications exactly as directed. In fact, her adherence to the prescribed program has become her way of life, taking up so much time that she barely has time for anything else. Paradoxically, this focus on *treatment* takes her mind off of that for which she is being treated. "It takes your mind off of--I keep going, then you don't worry about things... like first, when I got the rheumatoid arthritis like I worried 'oh well, I got rheumatoid arthritis' and you would be stressed out, and you would cry, and that's no good."

Though Marilyn at first denied that she thinks stress affects her arthritis, she went on to explain that it is important to have a positive outlook so that the arthritis will not progress: "like you can't feel sorry 'cause you find if you do the stress--the arthritis is gonna get worse and you have to live with it." So she distracts herself with her medical treatment, shuts the future out of her mind, and repeats her mantra.

Marilyn's ways of coping with her arthritis reflect the kinds of coping in which her family-of-

origin engages. Asked if her family had struggled through some difficult times Marilyn could think of nothing. But she later said that her father had left her mother shortly after her own birth, leaving her mother to care for 7 children alone. She seemed to have no appreciation of the strain her mother must have been under, saying only that her mother didn't complain about anything. But when I queried her about whether she saw any similarities between how she was coping and how her mother coped she said that her mother "learned to live with it--like me."

The question "why me?" dogged Marilyn in the early days of her arthritis and she seems to have only one answer: she is being punished for doing bad things, particularly fighting with her sister: "When I have the cortisone injection, probably because I was mean to my sister, it's payback time. She hits me on the shoulder and I said 'Ow, I just got my injection, be nice'... I fight with her all the time. Like we're a year apart. So now it's payback time for her to get me." Such is Marilyn's simple logic. This explanation fits nicely with her belief that she must simply swallow the fact that she has arthritis and carry on as best she can,

(i.e., learn to live with it). Still, Marilyn looks to her Catholic faith for redemption. She prays to God that she might have a remission.

Marilyn continues to fill her days with activities prescribed to her by her doctor. She tried to return to her old job about a year after the onset of her arthritis but couldn't cope; that experience convinced her that once you have arthritis you are simply unable to work. Despite this she remains quite physically active, swimming everyday and even cross-country skiing occasionally. She sees herself continuing indefinitely in this manner and deliberately tries not to think too much about the future. Instead she has settled into stoic resignation: "I'm doing better. Like I learned to live with it now, by getting used to the pain and how to cope with it, and now it's a routine. You got used to it."

### Jess

Jess is a 25-year-old Sikh woman, born in London, England, and raised, for the latter half of her childhood, in Canada. Though her parents hold on to Indian traditions, she is far from traditional herself. Whereas Indian tradition discourages girls and women

from cutting their hair, for example, she shaves her head and dyes the stubble exotic colours when it grows back. She engages in body piercing and has even had herself branded. She is drawn to the underside of city life, saying she never wants life to be "too easy." She actively rebels against structure and institutions, and quit school in grade 10 because she felt as though she were being indoctrinated.

Five years ago Jess was working in London at a new job she adored when she started to have symptoms. At first one knee became painful and, although she walked a lot, she wondered whether she wasn't getting enough exercise because she was in the habit of taking the London tube. Her live-in boyfriend became increasingly concerned as her symptoms worsened and spread, and in the mornings he would say to her, "you were just like a radiator last night," referring to her feverishness.

Jess's condition deteriorated rapidly. It became harder and harder for her to get ready for work in the morning and before long it was taking her three hours. She tried her best to conceal her difficulties but within a month or two her performance at work was suffering enough that it was remarked on by her

supervisor. He asked her whether she had started losing interest in the job, and told her that she needed to increase her effort as she was still only in the probationary period of her employment.

At her boyfriend's urging, Jess finally saw a doctor after three months or so of progressively worsening symptoms. By that time, she says, she had inflammation "in all my joints, and I have joints I didn't even know I had." The doctor ordered blood tests and called her immediately, advising her to see a rheumatologist. But she was only two days away from a scheduled holiday back in Canada, and she ignored her doctor's advice. She says now that she was very much in a state of denial, and that she just "pretended it would go away." Besides, her boyfriend persuaded her that whatever was causing the symptoms might be stress-related and that a holiday would do her good.

When Jess arrived in Canada her mother thought she looked awful. But her mother's alarm was met with irritation from Jess; she felt impatient with what she saw as her mother's typical dramatic overreaction to things. Still she consented to go to her father's doctor who gave her "run-of-the-mill" anti-inflammatory

drugs without actually looking for the cause of Jess's symptoms.

A family trip to Calgary, in what was supposed to be the last week of Jess's 3-week holiday, finally convinced her that she needed to get to the bottom of what was happening to her. The car trip was 14 hours long, with only occasional short breaks, and she stiffened up so badly that it took several people to help her out of the car.

Immediately upon her return to Vancouver Jess went to another doctor who told her she needed to be admitted to hospital through emergency that same night. Her parents had to actually carry her out to the car; her pain was so bad that she could not coordinate her limbs well enough to walk. The orderly at the hospital asked if she were in for a coordination problem. "I thought I'd be out overnight," she says. "I was very, I guess, ignorant."

The doctor diagnosed Jess with "polyarthritis," a non-specific term that simply means "arthritis in several joints." She later learned that she has rheumatoid arthritis. "None of us knew what that meant," she says. "It wasn't something I could hang on

to, like cancer or something. I had no idea what he was talking about."

But Jess quickly realized that her disease was serious; an occupational therapist came to see her in hospital and spent four hours "bombarding" her with questions and information. "When she left I burst into tears," Jess says. "The way she made it sound she was giving me a life sentence. It was starting to dawn on me but I could [only] take it in bits and pieces, not like she'd presented it."

After two-and-a-half weeks in hospital Jess flew back to London, because that was where she felt her life was. But because her "holiday" had been extended unexpectedly, she returned to no job and no place to live. The stress of looking for work and a new apartment, plus the fact that she had discontinued her medications, "kept [her] in a flare-up state for quite a long time." The permanence of her condition was starting to become a reality for her:

It was a couple of months after that when I was living on my own, I found it really hard because I was still really sick and I was still getting things like fevers and my mobility still wasn't good. I started to realize that maybe this was something that I'd have to start adapting to.

Jess remained in London for the next two years, only working off-and-on because she was so sick. Then, missing her friends and family, and tired of the frustration of trying to get medical and social services in England's floundering economy, she decided to return home to Vancouver.

Jess's return to her parents home delighted her mother whose life's purpose as an Indian woman is to care for her family. But Jess felt smothered by her mother, felt that she had been put in an "invalid box." Her parents believe that arthritis is "in your system" and that "something triggers it," a belief in line with what Jess has heard and read, and a belief that she therefore espouses (though they think the trigger must have been the cold of London, a notion she rejects). But some of their ideas are less palatable to her; for instance, one of her aunts in India was supposedly miraculously relieved of her arthritis by ingesting a plant that only grows in India. Jess is definite about not jumping to any treatment on the basis of anecdotal evidence: "I'm not there and I'm not about to go over for a treatment that I've only ever heard of done on one person."

Another thing that rankled Jess when she lived with her parents was the tendency of relatives and friends, particularly those newly-arrived from India, to come over to show their concern, then to talk to her parents about her in her presence. "Women in India [are] not seen as human beings in society," she says. "There is no reason why they should be talked to; they are either talked at or talked about. But they are not talked to as equals, especially by men." After eight months of living with her parents she decided to strike out on her own.

Over the past three years or so Jess has gone through periods of work, of unemployment, of hospitalization, and of sitting waiting for surgery. She worked for a year with the Disabled Women's Network on a project dealing with suicide and disabled women. She was an active volunteer with an AIDS organization, and worked on a peer counselling video project for people with arthritis. In general she has a strong interest in the advocacy issues of people with disabilities. "I've been told from the beginning that I'm doing too much," she says. "A lot of that's got to do with the fact that I'm not 84 years old."

Jess's concern for herself focuses less on the physical aspects of her arthritis than on their social and emotional consequences:

I know the physical part of it is important, but I guess what gets me is the other ways that it has affected me. Because, like, I'm a real control freak. I feel I have less control over them than I do over what it does to me physically... The first thing that I always state that it has affected is self-esteem. And then that branches off into other things. Like that's the core from which things like not being able to work or not being able to go out or how I feel about myself emotionally or physically.

After she had stopped denying her arthritis she went through a long period of trying to conceal her arthritis from other people. She dislike people's reaction to her when they learned she had arthritis. She was afraid of being babied, on one hand, but on the other hand she did not want her problems minimized either. Often on hearing that she had arthritis people would say something like "oh yeah, I had tendonitis in my arm," not realizing the vast difference between a local mechanically-produced problem and a systemic illness. She was afraid, too, of things liked being denied a job because of people thinking that they couldn't count on her. So she pushed on, denying her

pain to other people, and replacing vulnerability with attitude.

The question "why me?" makes Jess cringe because it "reeks of hopelessness." When she hears of people asking this question she feels irritated and wants to say "get your shit together." For her it is a useless question that takes people away from dealing with practicalities:

I don't think there's always a reason for something and life is too short going around looking for them if they are not there. I'm not saying I didn't, but I guess the reasons I would look for would be more practical. Like more things that I think that might have been in my control that brought it on. Like stress or foods that I eat, or the environment I live in.

This focus on practicalities may be a product of her cultural background. In India, she says, "disability is the norm... because of things like environment, poverty, and malnutrition, so people don't think twice about it."

Jess still struggles with flare-ups and with the setbacks produced by lengthy hospitalizations. But she says she has learned something about her own inner strength from the experience of arthritis:

Now knowing that I have the strength that I have. Like before it wasn't something that I would ever doubt, but I never had any cause to put it into

action... I didn't know that I wouldn't give myself a pity trip and I didn't know that I wouldn't give in to a lot of things I didn't want to give into... I didn't know that I wouldn't just get tired of myself after awhile. I guess I really didn't know what my attitude would be because a hypothesis is something so different from what you have to live with.

### Robin

In around 1962, when Robin was 2 years old, she developed a fever, swollen joints, and symptoms suggestive of a strep throat. She was taken first to a family doctor, then to a specialist in internal medicine. Several tentative diagnoses were offered, among them rheumatic fever and scarlet fever. But her parents "were never happy with that because [the illness] did not resolve itself like a virus would do... in their experience scarlet fever doesn't last for a year, and rheumatic fever, if it does last for a year, certainly doesn't keep going on and on with all this joint involvement." When a new American specialist came to town, Robin's parents took her to see him, hoping that he could shed some light on her ailment. Within 5 minutes of seeing her he pronounced her as having juvenile rheumatoid arthritis. Though she lived in a small town an hour or two outside of Vancouver, she was referred to the Arthritis Centre

here for specialized treatment, and she established with them a regular pattern of check-ups and treatments that continues to this day.

The prevailing wisdom in the 1960s was that parents who have young children with arthritis ought to treat them as they would any other child, not giving them special treatment or privileges. Robin's parents tried to follow this advice to the letter, though they found it difficult to do so. She says: "They were, I think, always upset," because they knew so well her pain and her struggle. Though she did not know it at the time, her parents hypothesized that her arthritis had been triggered by chicken pox, by strep throat, or by the DPT vaccination.

By the time Robin started school her arthritis was physically apparent:

I looked different. I mean from the time I was about 6 years old I was starting to look arthritic. I had a stiff neck that I couldn't move, I had sore and swollen knees, had puffy wrists and hands, and bent elbows, and, you know, that started fairly early, and it wasn't too deforming at that point, but I was very stiff and I moved stiffly, my gait was stiff... and I felt like I was sick.

Though she had four or five good friends at school, her arthritis was noticed by the other children and some of

the boys used to tease her and call her names. Sometimes people would ask her how she got arthritis and she would have to say "Nobody knows what causes it, nobody knows why I have it."

Robin was well aware that she was different from other children. "I saw myself as disabled," she says. Her physical limitations prevented her from participating fully in school activities. When the class played team games in gym class, for example, she was always appointed scorekeeper by the teacher. But, she says, "I did lose interest. I was a bit of a daydreamer so I usually kept score and then I'd kind of start thinking about something and kids would yell at me 'what's the score?'. And I'd go 'gee, I don't know'."

Things were not easy at home either. "I had a brother and a sister and often I would get more attention than they would," Robin says, "and they would feel really resentful. So it was sort of a difficult thing. It was hard for me and it was hard for my siblings." Her mother bore most of the responsibility for her considerable physical care, and had to endure

the constant feeling that her efforts were only torturous for Robin:

I just couldn't move my joints in the morning, and my mom would have to run a bath for me so that I could actually become mobile enough so that I could actually walk to school. I remember having a bath every day from the time I was about 7 or 8 until the time I was a teenager. I would always have this warm bath in the morning and I'd go in there and I'd not move very much and my mom would be coaxing me in the tub "move a little bit, try to bend your knees, try to move your toes, try to bend your elbow, try to move your wrist", things like that. And I used to cry. I remember crying a lot. I remember crying at night because I was in pain. I remember crying in the mornings and not wanting to go to school, and my mom would have to force me out of the door with my little lunch bucket and I remember crying sometimes as I was going out the door because I felt so tired and I felt so much pain that I didn't want to go to school.

Occasionally, even as a young child, Robin would start to wonder if maybe this were all in her head, if there were something wrong with her psychologically. Yet her many trips to the doctor, and the serious concern of those around her seemed to refute this possibility. So then she would start to think maybe if she "tried to be really good, or maybe if [she] tried to work really hard, it would go away." She occupied herself with thinking that "if [she] just found some key to this puzzle [she] could unlock this puzzle and everything would be changed." But at the same time something

inside her told her that "lack of exercise didn't cause it, or laziness didn't cause it, so even as a little child [she] kind of understood that there was not much [she] could do about it. So [she] learned to live with it."

During her elementary school years Robin developed a rich fantasy life, and she read books voraciously. At school she was a high achiever, and she also excelled in her musical studies, developing a great fondness for the piano.

High school introduced a whole new set of problems into Robin's life. The physical demands on her were much greater because she had to use a locker, to change classrooms between subjects, and to climb stairs for a couple of classes. Also, her appearance became a much bigger issue for her and her poor self-image increased her sense of alienation from her peers. "It just made it hard," she says. "Especially when you are in puberty and looks are so important and teenagers are always trying to look good for each other and fit into groups and fit into cliques. And then I think more than ever I felt on the outside." The physical difficulty, the exhaustion, and the sense of isolation

began to take their toll and her condition deteriorated rapidly. It was at this time that she began to notice a relationship between the disease activity of her arthritis and stress.

Around this time her spirits were at an all-time low:

I think by the time I was a teenager I basically had almost given up. I had a very big chip on my shoulder at that point and felt that after having all this all my childhood that there was no use fighting this disease anymore. It was just gonna do what it wanted anyway. So why exercise? And why make myself exercise because I would be in more pain after exercising and I would still have nothing to achieve... it was like an uphill battle and I was always slipping back a little more. I guess somewhere in my head I always had sort of a sense of desperation.

To add insult to injury Robin was forced to give up the piano because her fingers were so badly affected. This was the last straw in the great battle and it was then that she started asking "why me?". For a long time she found no answer to this question.

Robin's condition deteriorated to the point that she had to be admitted to G.F. Strong for treatment. She calls this a real turning point for her; she had grown up in a small town, more isolated than other children because of her arthritis. She felt as though she were on a "bit of an adventure because [she] was by

[her]self in this place with other adults and [she] could pretend to be an adult." Though she was a little frightened by some of the people she saw there, especially young male patients who used drugs and engaged in rowdy behaviour, the experience was a very good one for her. She learned a lot about her disease and how to care for it, and she also felt happy that her parents could have a break from her.

At the age of 15 Robin became the youngest person ever at G.F. Strong to have hip replacement surgery. "There's a little notoriety in that!" she laughs. In fact, she says, she felt like a real celebrity, getting a lot of attention both from the staff and the older arthritis patients. After having felt isolated for so many years, she revelled in all the attention that was showered upon her. She used to play her guitar and sing for other patients. But more importantly, she felt that she was in a position to help many of them:

So many people were wracked with pain with arthritis and dealing with getting the disease. I had it so long it was like old hat to me by that time. I'd pretty well dealt with all these awful things early on in my wee youth. I know that thinking back on it possibly that maybe I gave people hope that just had the disease, that maybe had fears that they would become unhappy, bitter people. They could see that after having the disease a long time you don't have to be unhappy

and bitter, that you could have a good quality of life.

This experience started Robin thinking that she had an ability to help other people, and she set her sights on becoming a social worker.

Robin had three more stays at G.F. Strong over the remainder of her high school years. These stays gave an unexpected boost to her social status back home:

I was a celebrity in my home because I was the only kid in my school that was allowed to take a month off and go away without anything terrible happening to them in class... Because I was from a small town there was a little bit of "she's gone to the city, she's gone to Vancouver for a whole month. How does she rate?"... They were kind of jealous. So in a way the whole G.F. Strong thing sort of gave me a real celebrity status that I was badly in need of at that time of my life.

After high school Robin was forced to attend a community college at first, rather than a university, because her long absences from school had prevented her from keeping up with her French. She got good marks there, but her self-image problems visited her once again, and she felt socially ill-equipped to be in the college world. Nevertheless, she continued, taking social science courses with the hope of transferring to a university social work program. When she did transfer to a university, she not only felt socially

ill-at-ease, she felt academically unprepared as well. She had problems with roommates and trouble getting the courses she wanted, so when she was offered a job back in her hometown she quit school and returned home.

So began a new phase in Robin's life. For the next two years she had a "really good job" tutoring First Nations children. She was the first non-native person to be given such a position and she felt very privileged. She learned much about the native culture during this time, and satisfied herself that this was learning relevant to her ultimate goal of becoming a social worker.

Meanwhile she had taken up residence with her first real boyfriend. At first her life with him was happy but, as time passed, troubles overtook their relationship. He went through a prolonged period of unemployment, and he and Robin were constantly harassed and manipulated by his former wife. She was laid off from her job and couldn't look for work because she was awaiting more surgery. When he eventually found a job he had to commute to another town to perform work which was only menial.

Towards the end of their relationship, they moved to the basement of Robin's parent's home, largely because she "felt safer there." "I think I really knew in the back of my mind," she says, "that things were not gonna go well with us, and I wanted to be sort of safe." Six years into their relationship, and two weeks after Robin had completed a 6-month full-time computer course, he left her a note and she never saw him again.

For the first year or so after the break-up Robin was devastated:

My worst fears were realized... There's always been a bit of anxiety where I'm concerned where either I would be abandoned because I'm arthritic or I would have to deal with something so devastating to me that I couldn't fight any longer, that my spirit would just abandon me... I thought it was going to happen when he left me because I had really been abandoned by someone. For the first time in my life I had really been abandoned by someone I thought I loved.

Her arthritis had progressed considerably over the years that they had been together, and looking back Robin came to believe that their bad relationship might have "kick-started" her "dormant" arthritis.

Then came another period of surgeries and rehabilitation; she had a second knee replacement and coerced her surgeon into fusing both ankles at once, a

practice that is extremely uncommon because it leaves one completely unable to weight bear for an extended period of time. She managed to get an interview with a housing co-op which she attended in a wheelchair with casts on both legs; "let's say I didn't have to work hard to get the place," she says. Within a couple of months she began a series of temporary jobs, and when those finished, she was offered two jobs in one week, both good jobs with major corporations. She chose the more attractive of the two and she still works in this job.

In the past five years or so since she started to get her life together, Robin has "come back to spirituality." She attends church regularly and is a strong believer in the idea of free will. She does not think in terms of predestination, and therefore she thinks of her arthritis as the "the luck of the draw." Through the patient education she has received she has come to think of her arthritis as the product of a fault in the immune system, possibly genetically-based.

Though moments of desperation still overtake her sometimes, overall Robin has gained some peace in her life. She has let her goal of becoming a social worker

slip away because she is faced with the more immediate concerns of a woman surviving alone. Instead she has to be content with smaller things, giving to a homeless person on the street, for example, or contributing to the efforts of her church. She tries to focus on the positive, and says that if she didn't have arthritis she "wouldn't have met some very interesting people."

## Chapter V:

### The development of causal models of arthritis:

#### The general story

##### Overview

In what has been one of the most complete studies of the causal attributions of arthritis patients to date, Affleck, et al (1987) summarized the attributions in tables with percentages given for each of several categories of investigator-predicted and investigator-defined attributions. Such an approach gives no consideration to the development of explanatory models over time, to the life events that coincide with the incorporation of causal elements into the model, nor to the complexity of the models themselves. Though the reader of such a study would notice, if he or she added up the percentages given for each attribution, that some people were citing more than one cause, there is no discussion of the interaction of causal variables in people's causal models. Further, by collecting data through questionnaires on a one-time basis, they have restricted the range of responses they might get and have precluded the possibility for the thoughtful reflection of their participants.

The present study, because it employed open-ended interviews separated by considerable periods of time, gave the co-investigators the opportunity to present their own attributions, without having to interpret and fit themselves into categories presented to them. It also gave them the time to remember causal ideas that were sometimes teetering on the edge of conscious awareness, affecting the way they lived their lives, yet never being expressed verbally.

The results of this study indicate that people with arthritis have very complex causal models, that expand over the course of the illness, incorporating more and more diverse elements. Further, the models tend to develop in a fairly typical way, with a focus in the beginning on physical causes, moving toward the incorporation of stress as a causal contributor, and finally towards the existential, the cosmic explanation that addresses the question "why me?". It is important to note that these are not stage models; the first causal element is not abandoned as the second causal element is embraced, for example. Rather, the second element sums to the first and is equally important in producing symptoms.

The idea that several factors must be present at once in order to trigger the onset of arthritis was explicitly expressed by several of the co-investigators. Jess's mother, for example, said to her daughter "maybe you always had this but it just never triggered until you were 20." Sophie says "everything just sort of came together" to produce arthritis. Tamara has a similar idea, though more elaborate, when she says:

A,B,C, and D,E,F must come together before it is activated. So what conditions activate it? Is it the fact that I was working up north in this extreme cold? Was it the fact that I had spent a large part of my life on an island in the Atlantic Ocean, cold Atlantic current, warm current, fog? Did I have extra stress? And the combination of maybe five factors that just made it.

This belief that multiple factors must be present in order to trigger the arthritis is not present in the beginning, and only develops over time.

Though several causal factors make up a causal model, the prominence of different factors varies over the course of the illness. For example, a person might hold the belief that arthritis has a genetic basis and that an environmental trigger is necessary to produce symptoms, but may be focused, at some particular time, on the existential "cause," say, the punishment for

wrongdoing. Though the physical, the psychological, and the existential might seem to be very different planes of explanation, people seem to move quite freely between them, pausing on the one that seems most salient to them at any given time.

In general, the development of my co-investigators' causal models proceeded from the physical through the psychological to the metaphysical. The expansion of the causal models was necessitated by the inadequacy of simple explanations, and by the accumulation of information that grew out of living with arthritis and observing the kinds of things that influenced its course; in a sense, the co-investigators became self-styled medical detectives, observing various environmental and psychological factors and noting the influence these factors had on their arthritis. The expansion of the models was also necessitated by the quest for meaning, for an understanding of the place of arthritis in the universal order; for all but one of my co-investigators this was as important a search as the more medically-oriented search for physical and environmental causes.

Though there is a pattern to the way people's causal theories develop, there is much diversity within each of the broad themes. The general story that follows should give a feel for both the similarities and differences across the stories of my co-investigators.

In the beginning: A focus on the physical

All of the co-investigators in this study looked first to physical causes to explain their symptoms. There may be several reasons for this. First, it is customary to look for physical causes when we are injured or in pain; when we burn ourselves we blame it on something hot that has touched us, when we scrape ourselves we blame it on friction. When we break a bone we do not look to psychological or existential explanations. Before people are diagnosed with arthritis they naturally engage in the kind of attributional thinking that they would for any other kind of hurt. Even after they are diagnosed, they may not know much about inflammatory arthritis, its nature and its prognosis, and so they continue to hold a very simple view as to its cause. Complicating matters further is the fact that when many people think of

arthritis they think of osteo-arthritis, the "old age" form of arthritis that results from mechanical wear-and-tear; this may be why several of the co-investigators attributed their arthritis, in the beginning, to overuse, injury, or to working too hard.

A second reason that people may look first of all to physical causes is that the medical profession encourages people to do so. During the diagnostic phase people may be asked questions such as "did you injure yourself?", or "do you have arthritis in your family?". Further, the diagnostic process is itself intensely physical, focusing on physical examination and laboratory blood tests.

A third reason that people may look first to physical causes is that physical causes often offer the hope of easy physical solutions; if one touches something that is too hot one need simply remove oneself to alleviate the problem; if one scrapes oneself, one just keeps the wound clean and waits for it to heal; if a bone is broken one need simply have it set and wait for it to mend. For many people the reality of an incurable, progressively worsening disease is too much to countenance in the beginning.

This reason may hold for those co-investigators who had the belief that their symptoms were caused by injury or overuse.

Within the theme of physical causes four distinct sub-themes emerged from the interviews:

External causes. A variety of external causes were cited by the co-investigators, many having to do with infectious agents. Two co-investigators pointed specifically to certain types of viruses, and one to the bacterium that causes strep throat. Vaccinations for tuberculosis, hepatitis B, and diphtheria-polio-tetanus were blamed by three different co-investigators.

Two co-investigators attributed their arthritis to physical hardship, Caroline to painful medical testing, and Gwen to physical abuse. Another woman believed reports from the popular press that arthritis is caused by the amalgam in tooth fillings.

Constitutional. Four of the women interviewed pointed specifically to heredity as a causal factor in the development of arthritis, Marlene and Madeleine because they knew of people in their family who had arthritis, and Caroline and Tamara because they had

heard or read that arthritis has genetic origins. Two other women speculate that genetics may play a role, but are unsure because they know of no one in their families with arthritis.

Another three of the co-investigators believe that arthritis is "in your system", but cannot be more specific about what they mean by this.

The way you are. Two of the co-investigators blamed transient physical states for the onset of their arthritis; Marlene thought she had developed arthritis because she was overweight, and Gwen because she was menopausal.

What you are doing. Five of the women interviewed said that they had been "overdoing it," working too hard or engaging in repetitive or injurious activities around the time that their arthritis began. Tamara and Lorna said that they had been working in damp or cold environments.

For Lorna and Diana, arthritis followed very closely after childbirth, and they point to this as the precipitating event. Of these two, one also said it was genetic, and the other also said it was "in your

system," so even at the physical level multifactorial hypotheses can arise.

Though the physical explanations are attractive because of their simplicity, and because of their promise of "fixability," they are lacking in some respects. If arthritis is constitutional, why does it wait many years before it becomes manifest, and what triggers the symptoms? If arthritis is caused by "overdoing it," why do the symptoms not subside when people rest? If arthritis is caused by a common infectious agent, why does not everyone who becomes infected develop arthritis? These kinds of questions illustrate the incompleteness of purely physical explanations for arthritis, and the reason why people feel compelled to expand their causal theories.

In the middle: The incorporation of stress into the causal model

There is a common assumption in our culture that there exists an association between stress and illness; when we catch a cold we might say it is because we are "run down," for example. This assumption is quite strong in the culture of people with arthritis, and there may be several reasons for this.

First, the incompleteness of a purely physical causal model leads people to look for other factors, particularly factors that explain why arthritis symptoms present themselves at a particular time. Retrospection, in most cases, leads to the identification of excessive psychological stress around the time of onset.

For nine of the co-investigators, the stress was chronic in nature. Marital and family dysfunction was held responsible by four of the women, and Madeleine, Marlene, and Tamara pointed to difficult family situations involving, respectively, a sick child, single parenthood, and responsibility overload. Stacey and Jess identified work stress as causal contributors, and Lorna, a First Nations woman, looked to the strain experienced by native people who have lost their culture and their identity.

Three of the co-investigators cited specific stressful events that coincided with the onset of their arthritis. Diana gave birth to a child though she loathed the thought of motherhood, Stacey's father died after a long illness, and Madeleine's child was diagnosed with a fatal disease.

A second reason that people look to stress is the prevalent belief in the arthritis culture that stress is a causal factor. When people hear suggestions from medical personnel that stress might have triggered their arthritis, as several of the co-investigators have, they are prompted to examine the psychological climate in which they were living around the time of onset. Further, when they hear from other people with arthritis that they had had a lot of stress around the time of onset, the belief in the power of stress to trigger arthritis is strengthened.

Finally, as mentioned, people with arthritis often become astute observers of those things that affect the state of their arthritis, things that cause their arthritis to quieten down, and things that cause it to flare up. At least six of the co-investigators in this study believe that emotional stress exacerbates the symptoms of their arthritis. It is a rather small leap of logic to think that if stress can cause arthritis to flare up, then perhaps it can trigger arthritis in the first place in those who are vulnerable. The causal models outlined in Appendix D show that often stress will move from the column labelled "influences

incorporated into the model" to the column labelled "causes incorporated into the model" as time passes.

Towards the end: A consideration of the metaphysical

Though the incorporation of stress into the causal model does much for people in terms of elucidating the mechanism by which they developed arthritis, the question "why me?" still lingers. An understanding of the disease mechanism does nothing to give meaning to the experience of arthritis, and does nothing to address the question of why such a devastating disease would be visited so unfairly upon someone. So people move beyond the physical and the psychological to look for the universal or cosmic reasons for their disease.

All of the co-investigators have at some time in the course of their illness concerned themselves with the question "why me?" Only two of them, Jess and Sophie, got annoyed at themselves for asking this question. The rest searched or continue to search in earnest for an answer to this question.

Four of the women attributed their arthritis to chance, although they had slightly different ways of saying it. Sophie used the word "chance" when she annoyedly dismissed the notion that a powerful being

might be conspiring to damn her with punishment or bless her with a higher purpose. Marlene and Robin put their fates down to "bad luck" and "luck" respectively, because they could think of no other explanation. Robin, in particular, denounced the idea of pre-destination as it is contrary to her faith. Diana described her arthritis as a "quirk of fate," but is profoundly unsatisfied with this answer and says that she wants to ask some serious questions of her maker. So although these four co-investigators all cited chance as the "cosmic" reason for their arthritis, they did so with different attitudes.

Three of the co-investigators thought that their arthritis was a punishment for wrong-doing, and a fourth considered the possibility. Marilyn's thinking was simple and child-like--she thought she was being punished for fighting with her sister. On the other end of the spectrum, Tamara embraced a religion that teaches that the suffering of this life is the consequence of wrong-doing in a past life; her explanations are detailed and elaborate--this is no passing notion for her. In fact she has built her life around the belief that she has to bear the suffering in

this life in order to be freed from it in the next. Tamara's story is undeniably the most dramatic example of the kind of shift in world view that can occur with a disabling illness. Caroline also believes that her arthritis is punishment for the sins of a past life, but she has not developed a parallel system of logic the way Tamara has; instead the simple explanation suffices.

Three of the co-investigators reframed the experience of arthritis as something that was purposeful or would ultimately lead to good. Lorna believes that "everything has a purpose," even if we do not know what that purpose is; the native elders have persuaded her that the purpose for her life will be revealed to her as she ages. Though she struggles with the feeling that arthritis has "kept [her] down," disallowing the fulfilment of her life's goals, she tries to hold to the faith that her true purpose in life will be fulfilled. Gwen, who has endured so much suffering even beyond her arthritis, has always believed in the back of her mind that "someone is watching over [her]." This belief saw her through years of terrible abuse, and continues to give her hope

now; in some ways it is akin to the notion that God never gives us more than we can bear. Stacey's *raison d'être* has always been her nursing, and though she struggles with depression and despair, she is kept afloat by the belief that she has "something to learn," that her experience with arthritis will make her a better nurse. One might argue that the fact that one can learn something from the experience of arthritis, for example, or the notion that the achievement of a higher purpose will be facilitated or prompted by arthritis, are not causes of arthritis, but rather are consequences. But these women, struggling to make sense of their suffering, want it to be otherwise; they want to think that the universe is ordered in such a way that their arthritis will lead to ultimate good.

Two of the co-investigators have no answer to the question "why me?", although, again, they feel differently about the absence of an answer. Madeleine is dealing not only with the fresh reality of her arthritis, but with the grief of losing her young daughter as well. She is extremely angry at the hand that has been dealt her and is stunned by the injustice of it all. She has no answer and she wants one. Jess,

on the other hand, says she feels quite comfortable without an answer; in fact she claims that there simply is no answer and that the search for one is not only useless, it diverts attention away from influences, such as stress and foods, that are under one's control.

#### Influences incorporated into the models

As noted at the beginning of this paper, people have a powerful need to control, or at least anticipate, the occurrence of negative events. All of the co-investigators in this study realize that the current state of medical knowledge does not hold a cure for their arthritis, and none of them are waiting for a miracle. Instead, they concern themselves with factors that are at least partly under their control, things that make their arthritis better or worse. Appendix F contains a full listing of the influences cited by the co-investigators.

Diana, Marlene, and Sophie all had a "delusion of reprieve" (Frankl, 1984, p. 28) at some point in their illnesses. Diana and Marlene had held fast to the idea that the recency of their diagnosis would spare them the degree of disability experienced by people whose arthritis began before effective treatment was

available. Diana, in particular, has been stripped of this delusion, and now says that eventually "you realize you don't have as much control as you think you do." Sophie believed that the fact that she received treatment early in the course of her illness meant that severe disability would be forestalled.

Surprisingly few of the co-investigators cited medical treatment as something that influenced the course of their illness. This may be because of the way I posed my questions, or it may be because these women have arthritis severe enough to warrant lengthy, and often repeated, hospitalizations, and therefore are a select group who failed to respond adequately to medical treatment.

It is also surprising that only two of the women believe that environmental conditions influence the state of their arthritis, given the prevalence of this belief in the general population. Marlene was non-specific when she said that the weather influenced her, but Sophie was more specific, saying that heat and changes in barometric pressure worsened her arthritis.

A few of the influences cited, such as the food one eats or one's level of physical exertion, are

simple and clearly within one's control. Some, such as pregnancy are transient, and others are easily addressed, such as the lack of estrogen, and infection in a tooth. By pinpointing these influences and taking appropriate action, the women gain a sense of control over their disease activity.

Psychological influences were named by almost all of the co-investigators. Six women said that an increase in stress produces a corresponding increase in disease activity. This may be a somewhat satisfying explanation because periods of excessive stress are often transient, and because people experiencing stress can often do something about their stress, by dealing with its source, by removing oneself from the source, or by changing the way one sees the situation, for example.

The influence of stress is often mediated, in the minds of the co-investigators, by personality or dispositional variables. An idea often mentioned is that one has to have "willpower," or a "fighting spirit," or "positive thinking" in order to deal effectively with arthritis. Interestingly, when people speak in these terms, they are not speaking of the

importance of these attributes when coping emotionally with their arthritis, they are saying that these attributes actually influence the physical course of one's disease.

#### The nature of the general story

The general story is one of the expansion of the causal model; it moves simultaneously toward completeness and toward the recovery of meaning. As it moves from purely physical explanations to those that incorporate the psychological, it moves toward a more complete explanation of the etiology of the disease itself. As it moves from the psychological to the metaphysical, it moves toward an understanding of the place of arthritis in the cosmic order.

Many of the women, upon hearing my introductory request that they tell me the story of their arthritis as if it had a beginning, a middle, and an end, recoiled at the idea that they might be ready to tell the end of their stories. For many, the quest for meaning is ongoing, and therefore the noological attributions offered to me were only tentative, sometimes unsatisfactory, explanations. For some, the direction is toward reconstruing the event of arthritis

to make it a positive one. For others the direction is toward reconstructing one's world view, to seeing the world as a place in which punishment follows orderly from wrong-doing, for example, or to seeing the world as a place where one's "fighting spirit" actually has an influence over the course of nature.

In some cases, one's sense of purpose derives directly from one's altered world view; Tamara, for example, lives her life according to the causal forces she feels are responsible for bringing on her arthritis. In other cases, one lives one's life with the faith that one's arthritis is intimately tied to some higher purpose, even if that purpose is as yet unknown. For others, arthritis has taken away the striving for some grand goal, and has encouraged people to focus on and enjoy the simple things of life, as Gwen says, a book, a bird at the window, and "a good cup of coffee."

## Chapter VI: Discussion

The results of this study go far beyond what I expected at the outset. When I first considered doing research in the area of attributions, I wanted to see whether there is a relationship between the kinds of psychological attributions people make and the way that they cope with their arthritis. Yet simply determining what the attributions are is insufficient in terms of understanding the meaning that people attach to them. A single attribution, such as punishment for wrongdoing, can mean vastly different things to different people, as this study has shown.

By focusing solely on the answers people generate to the question "why me?", I would have missed important clues in their models of how the world operates. I would have missed, for example, the belief of many people in the power of their own willpower to influence the forces of nature; I would have missed the sorting out of what factors people feel they have control over and what factors they feel they have no control over. At first I tended to disregard this kind of information, thinking that it was extraneous, but after a couple of interviews I started to have faith

that what my co-investigators were telling me about physical and psychological causes was important to the movement of the story, and that it contained important clues about the way people think the world operates. This meant returning to the co-investigators whose information I had arrogantly discarded, and listening again to their stories, this time with the belief that what they were telling me was relevant was indeed important.

#### Summary of the findings

The following constitute the major findings of this study:

1. The causal models of the co-investigators developed in a fairly typical way, with a focus first on the physical, then an incorporation of psychological factors, then a consideration of the metaphysical;
2. The causal models of the co-investigators are not stage models; the incorporation of a second element into the model expands the model, and does not replace the first element. Once incorporated into the model an element is seldom subsequently rejected;
3. Within the framework of the general story, the elements of the physical, psychological, and

metaphysical themes vary substantially across causal models;

4. At various points over the course of the illness, different elements of a co-investigator's causal model become more or less salient to her;

5. The co-investigators are keen observers of the factors that influence the course of their disease;

6. Factors that were at one time considered "influences" on the course of arthritis can come to be considered as "causes" with the passage of time;

6. At times the noological attributions of a co-investigator's model can have a direct bearing on her stated purpose in life; at other times the relationship is more tenuous;

7. To know what a co-investigator's attributions are is insufficient. Often, the co-investigators had very different attitudes about the same attribution.

#### The life scheme framework and the study's findings

The stories presented in this study conform to the framework of the "life scheme" (Thompson & Janigian, 1988). In each of the stories the story's teller, the protagonist, describes how she views her self and her circumstances; each story reveals something of how the

universe is thought to operate (i.e., the teller's world view). Each story provides evidence of the goals of the protagonist, though in many cases the goals are very simple, and may involve such things as maintaining a sense of optimism, or discovering the lessons that arthritis has to teach. Finally, each story details those things that frustrate or facilitate the attainment of goals.

According to Thompson and Janigian (1988), the life scheme provides the context for making attributions. Life schemes are cognitive representations of one's life "which organize one's perspective on the world and oneself, goals one wishes to attain, and events that are relevant to those goals" (p.260). Cognitive representations of how the world is perceived to operate might be called one's world view. Attributions are particular instances of one's world view; they demonstrate how the principles of the world's operation might be applied to a particular situation or problem.

In this study I use the framework of the life scheme to provide a context for the co-investigators' attributions. Within the life scheme framework I have

chosen to focus on each co-investigator's world view, and more particularly on the attributions for a specific problem, the problem of why that individual has arthritis.

The negative event of arthritis provides a challenge to every aspect of an individual's life scheme, including views about the world and oneself, as well as the possibility of achieving one's goals. The life schemes presented in this study focus primarily on the challenge presented to one's world view by the onset and progression of arthritis. Many people have positive, benign assumptions about the way the world operates (Thompson & Janigian, 1988), and these assumptions are tested, and often discarded, when one is burdened with a serious health threat such as arthritis.

Certainly, many of the co-investigators in this study express bewilderment at the injustice that has been visited upon them, and are actively trying to re-order the way they see the world in order to accommodate their arthritis. Their life schemes detail their evolving causal models and, in so doing, describe

the evolution of their world views after the onset of arthritis.

The life scheme, as conceived by Thompson and Janigian (1988), is an account of the search for meaning. Interestingly, this search for meaning occurs on two levels in the life schemes presented in this study. On a broader level the co-investigators' stories are accounts of changing perspectives on self, one's goals, and the world; they address all of the elements of a generic life scheme. On this level, they describe efforts to restore a sense of order and a sense of purpose after a negative event.

On a second level, if one follows a single thread in the fabric of the story, that of causal attributions, movement towards the establishment of a sense of meaningfulness can easily be detected. As we witness the expansion of causal models from purely physical explanations to ones that consider the metaphysical, we are witnessing the grasping for meaning, for an explanation of how arthritis fits in the cosmic order.

Though the co-investigators' life schemes are the stories of a search for meaning, not all of the co-

investigators feel that they have meaning in their lives; indeed several of them struggle every day to keep from being overcome by depression. This does not mean, however, that the stories presented here are deviations from the life scheme framework. Thompson and Janigian (1988) say:

Having an attribution for a negative event is not equivalent to finding meaning in the experience. The lack of an attribution for an important event is associated with the loss of meaning, but the ability to identify a cause does not mean that one has found order and purpose in the experience (p. 273).

The search for a cause is one aspect of the search for meaning.

#### Implications for counselling

This study suggests that most people have a natural inclination to look for causes to diseases such as arthritis. In part, this causal search is motivated by a desire to know what causes and influences the disease process itself, as such knowledge can, at times, impart a sense of control. However such knowledge seems to be insufficient for most people, as it fails to address the existential issues that accompany serious illness and disability.

The counsellor who treats clients attempting to come to terms with arthritis has many levels of functioning to consider. For example, behavioral methods might be directed at the problem of pain management, individual psychotherapy at problems such as depression, and family systems approaches at the marital and family problems that can arise as a consequence of arthritis.

This study suggests that many clients have a need to resolve existential problems as well as practical ones. Some of the co-investigators in this study, such as Tamara and Gwen, feel at peace with the noological conclusions they have reached. Many others, however, feel ill at ease with their tentative conclusions, and yearn for more satisfactory explanations.

It was quite evident during the interviews that the co-investigators were very unaccustomed to speaking on the noological level. It was equally evident that many appreciated the opportunity to do so; some made comments such as "I really needed to have this talk and here you are." Counsellors should recognize the existential crises often provoked by illness and

disability and give permission to clients to explore the noological realm.

#### Limitations of the study

The major limitation of the study relates to the small number of co-investigators who participated. It is probably safe to assume that not all of the kinds of attributions that people with inflammatory arthritis might make were cited by participants in this study. Further, no claims can be made that the proportions of people making attributions of a certain kind, for example, saying that their arthritis is punishment for wrong-doing, is representative of what one might find in a larger group.

Though the themes and the sequence of the general story fit quite well for nearly all of the co-investigators in this study, one might expect that in a larger study there would be a certain proportion of people for whom it does not fit.

The women in this study were all hospitalized for their arthritis, and are at the upper end of the spectrum with respect to the severity of their arthritis. Perhaps people whose arthritis is less severe might not be inclined to engage in as intense an

attributional search as these women have been, and might have fewer elements in their causal models. Certainly this group of co-investigators does not constitute a representative sample.

The demographics of the co-investigators in this study are so varied that it is impossible to come to conclusions about the influence, for example, of age on the kinds of attributions people make. Likewise I cannot comment on the influence of culture, marital status, occupation, or disease duration on the kinds of attributions that were made.

#### Implications for further research

The limitations outlined above point to directions for further research. A test of the general story with a larger group of co-investigators is an obvious first step. Beyond that, studies that restrict the range of certain demographic variables, such as age, would help us to understand the influence of those variables on the kinds of attributions people make, and on the meanings behind those attributions.

It would also be interesting to do comparisons of broad groups, say comparisons of men and women with arthritis, or adults and children, or children with

arthritis and their parents. Such studies would give us an understanding of how these different groups relate to their arthritis. I would also be interested to see whether the framework of the general story applied to other degenerative diseases of unknown etiology, such as multiple sclerosis.

Another direction might be explore more deeply people's metaphysical attributions, and the influence these attributions have on the way people live their lives. The results of this study suggest that such an investigation would require a very thorough exploration of the meanings attached to the attributions, as the same attribution can mean different things to different people.

A footnote: What the medical profession says about the etiology of arthritis

How close are the co-investigators, in their theorizing about what causes arthritis, to the ways in which medical professionals theorize about the same thing?

Medsger and Masi (1985) state that "most chronic acquired [rheumatic] diseases are now believed to result from the interaction of multiple factors related

to the host, environment, and, at times, infecting agents" (p.9). Thus, like the co-investigators, medical researchers are looking at multifactorial models of etiology for arthritis. With regard to genetic influences Medsger and Masi (1985) say, "analysis of twin and family studies confined to probands with erosive seropositive arthritis showed a six-fold increase in RA prevalence among siblings or dizygotic twins versus controls" (p. 13). Zvaifler (1985) says that "although the pathology of RA is undoubtedly related to an inflammatory response involving the immune system, the initiating event that triggers this response is most likely a specific etiological agent" (p.557). Among the specific etiological agents being investigated are various types of bacteria, and various types of viruses.

The role of stress in the onset of arthritis has also been investigated. According to Banwell and Ziebell (1985), "it has been suggested that psychological and biological variables interact to influence the onset, pattern, and course of rheumatoid arthritis. In a group of adult monozygotic twins, all of whom were discordant for rheumatoid arthritis,

evidence was found for stress as the initiating factor in those who developed rheumatoid arthritis" (p. 506). Another study concluded that although the role of psychological factors in the development of RA is unclear, psychological factors do appear to play an important role in its course (Anderson et al., 1985).

According to Medsger and Masi (1985) sex plays a role as well: "sex-related host factors seem to play an important role in determining the onset and severity of RA. This concept is consistent with recognized pregnancy-induced remission and post-partum exacerbation or new onset of RA."

Some of the co-investigators in this study have made explicit reference to medical professionals as sources of etiological information, and have had varying levels of understanding of what they have heard. Others have collected ideas about etiology from other people with arthritis, who, in turn, may have received information directly from medical professionals. Still others have reached conclusions based on observation, in much the same way that medical professionals form hunches on the basis of clinical observation.

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Appendices

Appendix A

Co-investigator Demographics

<u>Co-investigator</u>	<u>Age</u>	<u>Age at Onset</u>	<u>Years since Onset</u>	<u>Occupation</u>	<u>Marital Status</u>	<u>Culture</u>	<u>Diagnosis</u>
Sophie	79	51	28	nurse	Divorced	white Canadian	RA
Gwen	63	48	15	mother	Divorced	Welsh	RA
Diana	52	30	22	mother	Married	English	RA
Tamara	50	36	14	writer	Married	white Canadian	RA
Marlene	46	30	16	military	Married	white Canadian	RA
Madeleine	44	35	9	mother	Married	French Canadian	RA
Lorna	44	20	24	tribal elder	Married	First Nations	RA
Stacey	44	35	9	nurse	Single	white Canadian	PA
Robin	34	2	32	clerical worker	Single	white Canadian	JRA
Caroline	32	14	18	mother	Married	First Nations	JRA
Marilyn	31	27	4	unemployed	Single	white Canadian	RA
Jess	25	20	5	student	Single	Sikh	RA

X=45.3    X=29  
S=14.3    S=13.3  
X=16.3  
S=8.5

Diagnosis Key

RA=Rheumatoid Arthritis  
PA=Psoriatic Arthritis  
JRA=Juvenile Rheumatoid Arthritis

## Appendix B: My own story

When I was ten years old, and living in northern Alberta, I went on a hike with my Brownie troupe in the dead of winter. I remember this hike very vividly, because at one point we came upon a grisly scene; someone had slaughtered about twenty rabbits, and their dismembered bodies lay strewn carelessly about, staining the snow blood-red. We were out in the woods for several hours, much longer than reason might have allowed given the cold, and I remember saying to one of the leaders that I had lost the feeling in my feet. One of the other girls decided to test whether or not this were true, and stomped as hard as she could on my right foot.

Within a few weeks of this hike my right ankle started to swell and ache. I would wake up in the middle of the night and go sobbing into my parents' room. My mother was quite dismissive at first, regarding these episodes as plays for attention, a reaction that baffles me to this day, but my persistence as well as my hugely swollen ankle eventually persuaded her to take me to the doctor.

After taking x-rays the doctor told us that my ankle was fractured and put my foot in a cast. It was all quite confusing; when the kids at school asked me how I had broken my ankle I had to say "I don't know". A few weeks later when I returned to have the cast removed, my ankle still as swollen and painful as ever, the doctor told us that in fact my ankle was not fractured and that I needed to have some blood tests. My doctor interrogated my mother and me in a frustrated search for an explanation of my condition, but the only explanation we were able to offer him was that I had frozen my feet on a Brownie hike, and that some girl had stomped on my right foot.

It took several tests and several weeks, if not months, to finally arrive at a diagnosis of rheumatoid arthritis. I remember that on the way home from the doctor the day I was given my diagnosis, my mother stopped at the grocery store, and I stayed in the car while she went in. I had no idea about the implications of what I had just been told, but I sat there stunned, my body buzzing.

I was not altogether unfamiliar with rheumatoid arthritis as my grandfather had a very severe case of

it. I first started to know him when I was around eight years old as our family had lived overseas before then. He was tall and thin, and moved with difficulty, but what really struck me was the way his hands looked. The joints of his fingers were huge, and they jutted this way and that way in strangely unnatural angles.

"Why don't the doctors fix his hands?", I implored my parents. They explained that Grandpa's arthritis was as bad as it was because of the horrendous conditions he had had to endure as a soldier in World War II. They further explained that his condition was beyond repair because it was so longstanding. When we returned from our first visit to his home in Kelowna I told my friends about my grandfather's hands with the same intonation in my voice that I might have used were I describing some grotesque creature from a Saturday matinee.

For the first year after my diagnosis, my arthritis was confined to my ankles and I looked completely normal, except for my crutches. When we visited my grandparents at Easter that year, my parents asked me not to use my crutches, an odd request since I was forever meeting with resistance from them when I

suggested the same thing. When I asked why, they told me that my grandfather would be upset if he knew I had arthritis. On one hand, I understood their concern; this was a man so sensitive that he would not allow cut flowers in his house because he could not bear to watch them die. But the secrecy that was requested of me somehow changed the way I looked at my own arthritis; it was at that time that I started to sense how serious it might become.

My grandmother was seriously ill that year, and we knew that her condition was terminal. My father told me that Grandpa had said to him out in the garden that summer, "if your Mom's not here to see these flowers in the spring, I'll take them to her". I didn't understand what that meant, and when I asked my father to explain, he told me that, like animals, when people lose the will to live, they die.

We moved to Victoria at the beginning of the next school year, and I was quite traumatized by the move. No longer were we living on an air force base where everybody's dads worked together, and where children were accustomed to making new friends because they moved so often. The children in my new class had

progressed through school together since kindergarten, and were not welcoming to newcomers. I had only one friend that year, the other new girl in the class, and she drove me to the point of desperation with her compelling need to surprise me with broad brushstrokes of rubber cement to my arms.

Shortly after school started that year, my arthritis started to spread. It hit my knees, my shoulders, my elbows and my hands. Even my jaw was so affected that I could hardly move it. I remember one morning before school I sat down on the floor to put my shoes on, and when I tried to get up I couldn't. My father was anxious to get going, and told me to hurry up so we wouldn't be late. I tried rolling on to one knee, and then the other, and then back again. My hands were of no help to me. "I can't get up", I said.

A look of what I thought was anger flashed across his face. "What do you mean you can't get up?", he said gruffly, "get up right now!". As an eleven-year-old I did not realize that fear sometimes sounds like anger.

That was a miserable year for me. At a time when my peers were becoming more and more independent, I

couldn't even put my own socks on. My arthritis alienated me further from my classmates. Once, when the class was walking down the hall to the library, Floyd, the most popular boy in the class, noticed me limping and sneered, "can't you walk yet?". Everyone laughed as they were supposed to, and I became Floyd's personal popularity meter.

When I asked my mother why my arthritis had become so bad, she told me that stress could cause flare-ups, an explanation that had apparently been offered to her by health professionals. It seemed a satisfactory explanation at the time because my life was certainly stressful.

I managed to weather that school year, and by the time I started grade seven, I was doing quite well. I had a few residual problems; opening the heavy front door to the school was difficult, as were turning the taps in the bathtub, and using the hand brakes on my bike. I set myself the goal of being able to sit on my heels, a task which requires full knee flexion and ankle extension, and spent many hours in the bathroom with my knee up on the counter, pressing down hard

and forcing my joints to comply. After some time had past, I had not only reached this goal, but was even taking jazz dance lessons.

I spent over two years quite free from arthritis. It was during this time that we decided that my grandfather ought to come to live with our family. I felt as though he and I were kindred spirits, not because of our shared diagnosis, but because of things like our shared love for art. I was very drawn to him. He stayed with us only a short time because he had serious circulatory problems that forced his hospitalization. The doctors decided that they would have to amputate his legs in order to save his life. He said that he would rather die than lose his legs, and he did.

Around Christmas time the year I was in grade nine I started to notice clicking in my knees. Within a few weeks I was in a full-blown flareup and my doctor told me I would have to be admitted to hospital for about three weeks. When I was not called in by the hospital in short order, he admitted me on an emergency basis.

Although I was in appalling condition at the time, I couldn't understand why this was any different from

my previous flareup, and fully expected that I would have to go through a tough year or so, followed by a lengthy rebuilding, but that eventually things would be back to normal. When I mentioned to one of my therapists that I was expecting to be in hospital for three weeks, she said it would probably be more like five or six.

I was finally released after more than three months, and much agitation, in worse shape than I had been in at my admission. A girl from my school had briefly shared my room near the beginning of my admission, and when she came back to visit towards the end, she said to me "you look a lot more... crippled than you did". It was a great blow to hear this, especially since I was holding fast to the idea that I had the kind of arthritis that would come and go, not the kind that would progressively destroy me like it had every other arthritis patient that I met in hospital.

I was different. I wasn't like Judy, a girl only a few years older than me, whose arthritis had ravaged her body, leaving her frail and skeletal, and in need of constant nursing from her mother. I remember Judy's

mother having to lift her from her wheelchair into a standing position so that she could be helped into the pool. I told my friends about Judy in such a way that they would believe that I was not another Judy, that I was not to be written off as a cripple, that this was all going to pass. "Poor Judy", I said, "she has the kind of arthritis that doesn't go away".

Although I had fought long and hard for my release from the hospital, life on the outside was not what I imagined it would be. My friends were not as supportive or as available as I would have liked, and my best friend, who came from a strongly fundamentalist family, asserted that my arthritis must be punishment for the wrongdoing of my parents. My body was wracked with pain and I could hardly move. Once my mother came into my room to help me sit up in bed. She put her hand under my neck and I winced and said "no!"; she tried putting her hand under my shoulders, then my back, then anywhere else she could think of, but I couldn't stand to be touched.

Finally she said "where can I hold you?"

"Grab my nose", I said because I couldn't think of anything else that didn't hurt, and we both laughed and cried.

Being at home allowed for a release of emotions that was not possible while I was housed with four roommates in the hospital. I cried continuously, and told my mother I didn't want to end up like Colleen, my twenty-five-year-old hospital roommate who was finding it impossible to continue working because of her arthritis, and who wanted to be married but seemed destined to remain single. I was grappling with all of the evidence that seemed to define my previous remission as a lucky, last-time reprieve.

At night, when I went to bed, I would cry as my mother turned out the light, believing that that was the last time I would see her. Like my grandfather who believed that the loss of my grandmother would leave him so broken-hearted that his spirit would be released to be with hers, the man who died rather than lose his legs, I believed that my will to live was depleted, and that I would die in the night.

This state of utter despair lasted for months until two very profound psychological changes occurred

to lift me out of my depression and restore my optimism and will to live. I was fifteen years old at the time, and typically self-centred and unappreciative of others. An almost inexplicable change came over me when suddenly I began to see the love which flowed between me and my family. This new realization was especially acute because of its sharp contrast with what had gone before. So intense was my feeling that I began to regard it as more than adequate compensation for what I had lost; my love for my family was an extraordinary gift whose price had been my disability.

A second, equally profound change in my thinking bolstered my new optimism. I embraced what Frankl calls "the last of the human freedoms -- to choose one's attitude in any given set of circumstances" (1984, p. 86). Like most people I had believed that my emotions were contingent upon my situation, and, of course, they were as long as I held this belief; in a sense I had felt that my situation "entitled" me to my feelings. But with great suddenness everything became clear to me; my condition was a given, but I could be happy and in this condition or unhappy and in this

condition. In what felt like a decision between life and death, I chose happiness.

This change occurred despite a steady worsening of my arthritis. My doctor felt that I should be sent to a hospital in Vancouver, but I flatly refused to heed his advice, mostly because I did not want to be away from my family. But as the days went by, it took longer and longer for me to lock my legs underneath me so that I could make the short trip from my bedroom to the bathroom. Finally, the day came when I was completely unable to do it, and I was re-admitted to hospital in Victoria.

I spent six months in that Victoria hospital, and made no progress whatsoever. However, my spirits were good; I had met another patient, a Polish fellow who had been in a car accident while visiting his Canadian relatives. He was in hospital with me the entire length of my stay, and we had great fun together. He spoke virtually no English in the beginning, and I gladly became his tutor. We drew funny pictures, and acted out silly role plays, and were almost inseparable. He also taught me to speak some Polish,

and we had plenty of private jokes in a language no one around us spoke.

My doctor told me, some months into my admission, and after seeing my x-rays, that my hips were so damaged that they would need to be replaced, but that the surgery could not be done until I was nineteen. This meant, he said, that I would be confined to a wheelchair for the next four years or so. It also meant that I would have to attend a different school, one that would accommodate wheelchairs. This was devastating news, and confirmed my worst fears about the permanence of my disability. Although I had already come to the understanding that one's happiness was not contingent upon one's circumstances, my physical pain was almost unbearable, and I found it very difficult to incorporate the idea of a wheelchair into my identity.

My doctor was very concerned about my psychological health as well. Unaware of my relationship with my Polish friend, and unable to conceive of anyone in such rough shape as I was then being anything but miserable, he referred me to a psychologist. I was absolutely bewildered by this, but

played along anyway. The psychologist did two things. First, he arranged for a young woman who had been seriously and permanently disabled in an accident to come and visit me; this woman tried to sell me on the idea that being disabled was wonderful, and that she would not have it any other way. Second, he decided that I needed some sort of a pastime, and he put me in contact with another patient who was a painter. This painter and I produced many watercolours in the occupational therapy room, and, in retrospect, I suppose that the psychologist must have felt some satisfaction at his two model patients, whiling away the hours in what might have appeared to be serene resignation.

After six months, my doctor concluded that there was really nothing he could do for me, and once again proposed that I go to G.F. Strong, the rehabilitation centre in Vancouver. This would mean leaving my beloved two-year-old sister, whose gentle, funny spirit made me forget all of my woes, my father, who brought me chocolate milkshakes when I was almost perishing from starvation (the consequence of my refusal to eat hospital food) and who sneaked into the hospital the

puppy he had gotten to keep me company, and my mother, whose constancy, forgiveness and generosity gave me so much strength.

Another thing bothered me as well; as long as I was in the Victoria hospital where the most common reason for admission was the removal of knee cartilage, where most patients were discharged after a week or so to resume their old lives, I could maintain the fantasy that this was all a temporary inconvenience. To enter G.F. Strong, a place where people were learning to live with serious and permanent disability was, I imagined, to enter another sphere altogether, a nightmare world where people moaned and drooled, their eyes at half-mast.

Many of the patients at G.F. Strong had indeed endured the unimaginable; sometimes several members of the same family who had been in a single accident were dealing with devastating injury while at the same time grieving the loss of loved ones who had not survived. I saw criminals who had been injured in the commission of their crimes and many young men struck down by isolated acts of foolishness. The woman in the room

across the hall would shriek and cry every time she went to the bathroom, believing she was giving birth.

Yet despite the horror of all of this, I found the experience very uplifting. G.F. Strong was not a depressing place. Although there were some pathetic souls, they were not necessarily those with the greatest physical disability. Many of those with the greatest misfortune were those most resilient, best adjusted. My fellow patients confirmed for me that there is no correlation between one's situation and one's capacity for happiness, and this was tremendously freeing.

I was released from G.F.Strong after many months, and soon returned to high school after a two-year absence. I returned to school determined to repay my parents for all they had done for me in those difficult two years, and resolved to use the gift I still had, a capacity for academics. I pursued my studies so doggedly that I actually did myself great physical harm that resulted in several surgeries and many months hospitalization after my graduation.

I had wanted very much to be a doctor, to take up arms against some of the diseases I had seen in

hospital. I started university taking pre-med courses with the full intention of fooling all of the naysayers who had deemed a medical career impossible. But eventually I came to realize that I would feel pretty silly saying to one of my patients, for example, "excuse me, but could you help me put this stethoscope in my ears?". In any case, my attentions were diverted by the man who was to become my husband.

We married two weeks after my university graduation and I spent a year trying to be a traditional stay-at-home wife, a role for which I am miserably ill-suited. At the end of that year I enrolled in teacher training, determined to get out of the house and put my talents to use. I taught elementary school for three years after that and loved every minute of it.

It was during this time that I started to see that my disability could be a teaching tool; the fact that I was a person with a disability, working like any other person, would teach the children something about disability, I hoped, and would help them feel comfortable around people with disabilities. Of course I answered the children's questions when they came up,

but my approach was one of "normalizing" disability by simply living with it. I guess this was when I started to feel that my experience of arthritis could be put to good use.

Meanwhile my marriage was very difficult, not because I didn't love my husband or because he was a jerk, but because of all the things that go along with disability. My arthritis constrained not only my own movements and my own possibilities, it hindered his as well. Relations between my husband and my family became strained because he felt that they were critical of him, that they believed he was not doing a good enough job of caring for me. He resented what he saw as the intrusion of home support workers into our home, yet he had far too much on his own plate to do everything himself. Though I feel that I can handle the effects that arthritis has on me, I feel great sorrow for the effect it has had on him. The difficulties that he has experienced have become the source of my greatest regret about having arthritis. So although I've stopped saying "why me?", I sometimes find myself saying "why him?".

Two other health crises have compounded the difficulties presented by my arthritis. About 5 years ago I was hospitalized for pressure sores caused by sitting too long in my wheelchair. This hospitalization lasted nearly a year and involved the most horrendous of conditions: I had 7 operations, and had to stay in a fluidized sand bed for over 6 months, not even having the head of my bed raised, let alone getting out of bed. I could not eat by myself, go to the bathroom, or have a shower. I could not hold a book to read and I could barely see over the ledge of the bed. Several big life events passed me by as I lay there, including my father's heart attack and my beloved brother's wedding. When, after many months, I was finally allowed to sit up, it was only for one minute, 3 times a day. Gradually the length of time was extended, first to 5 minutes at a time, then 10. After 3 months or so I had progressed to the point where I could sit up for 4 hours at a time. I fully expected that my time-up would be extended until I could sit as long as I wanted. Just before I was released from hospital my plastic surgeon told me that was it, that for the rest of my life I would be

constrained by having to lay down every 4 hours. I was devastated; it was like another equally large disability. I wondered how I would ever hold a job, go to school, or go on a trip. Even going on a one-day workshop would be almost impossible.

The other medical crisis happened 3 years ago. Doctors had known for some time that my aortic valve had been leaking very badly, but their attention lapsed and a critical echocardiogram was not read, and my heart failed completely. One night I found myself virtually unable to breathe, and feeling as though I were going to pass out. I went to the emergency department and my distress was so apparent that I was taken in and hooked up to machines before they even knew my name. I arrested within minutes, and by some miracle was resuscitated. The doctor in the ICU told that my heart was so badly damaged that I would not survive surgery. Very coldly she told me "we all have to die and you'll just have to accept it". I didn't accept it; I found a surgeon who was willing to operate and the surgery did wonders.

I describe these two medical crises because I think that either one of them would have provoked a

"why me?" response in most people. But I feel I have pretty much resolved this question, not just with respect to my arthritis, but with respect to other things that happen to me as well. (I must say, though that my resolution of this question has to do with things that happen to me; I don't think that it would apply if something were to happen to someone I love.) I've come to the conclusion that the answer to the question "why me?" is inaccessible to us, that it is really fruitless to ask it. But at the same time I try to live as if there were a divine purpose to all of this. By doing this I am constantly focused on how I might turn my experience to good.

This approach guides me always in the choices that I make in my life. At the same time the importance of physical and psychological influences rises and falls with different observations and as different pieces of information come to light. At the moment I am intensely interested in the possible genetic origins of my arthritis. In the past when people would ask me if I had arthritis in my family I would say no. But in the last few years, two of my sisters have been diagnosed with lupus anticoagulant, a clotting disorder

that is often seen in people with lupus, a disease closely related to arthritis. My grandmother had lupus, and some recent correspondence with a long-lost cousin has revealed that she has had miscarriages that might have been associated with lupus anticoagulant, that her sister has arthritis, and that her father has lupus. I find myself so intrigued with these discoveries that I actually search the internet for scientists doing research in the area, in case they could make use of the information.

The development of my causal model is quite consistent with the pattern of development of my co-investigator's causal models. Yet before I undertook this study I was not conscious of the way my own model had developed. I saw the pattern in my own model only after I had seen it in the models of my co-investigators. So rather than using my own model as a template with which to construct the models of the co-investigators, the opposite occurred. Their stories helped me understand my own.

## Appendix C - Interview Protocol

### First interview

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[I began by introducing myself and reviewing the consent form with co-investigators. Then I initiated the storytelling by saying:]

I am doing a study to understand the ways in which people make sense out of the fact that they have arthritis.

I wonder if you could tell me about the experience of your arthritis. When I say the "experience of your arthritis" I am not just talking about your medical history, although that is a part of it. I'd like you to tell about your arthritis as though you were telling a story with a beginning, a middle, and an end. While telling your story, try to remember as many details as you can about what you were thinking, feeling, and doing at different points in time. Any questions?

### Second interview

[Second and subsequent interviews were used to fill in details that were not forthcoming as respondents told their stories in the first interviews, and to clarify vague or ambiguous statements. After reviewing the transcripts or the tapes from the first interviews, I asked questions such as these:]

Why do you think you have arthritis (when so many other people don't)?

Did you ever ask "why me?" What did you conclude?

Did you ever feel like you were being punished for something?  
Did anyone ever suggest this to you as a possibility?

Is religion important to you?

Do you think that, in general, that life is fair, that people get what they deserve and deserve what they get?

When you were growing up, how did your family deal with suffering? Has that carried over into the way you deal with suffering as an adult?

What kind of goals, values, and priorities did you have before you got arthritis? How have these changed?

Do you think you have gained anything because of your arthritis?

Has your sense of meaning in life changed? In what ways?

Appendix D - Simplified example of a timeline (Caroline)

Attributions:

overuse	stress - physical and psychological	"why me?" punishment for sins of past life	genetics	fillings in teeth		
<b>age: 9</b>	<b>14</b>	<b>16</b>	<b>17</b>	<b>21</b>	<b>28</b>	<b>32</b>

Life Events:

<u>pre-diagnosis</u>	kness and bottoms of feet were painful	spinal taps	quit school	married, became pregnant and had a daughter	returned to school, finished grade 10, then quit	mother had stomach cancer	two knees and one hip replaced	hip redone
	diagnosis of JRA	stress- physical and psychological		sleeplessness, wierd dreams			could not get out of bed, crying all the time	methatratate proposed
							depression	wrong ankle done
								identity changes

### Appendix E: Outlines of the causal models

There is an implied timeline down the left-hand side of each of these pages.

These outlines show:

1. The elements of the causal models and the order in which they were incorporated;
2. That sometimes elements in the "influences" columns will appear in the "causes" column later in the chronology, showing that some of the co-investigators came to believe that things that could influence the severity of their arthritis might have been responsible for initiating it in the first place;
3. That causes, once incorporated, are seldom rejected;
4. That causes rejected can become cause incorporated;  
and
5. That the incorporation of many of the elements can be tied to life events.

Diana

Age: 53  
 Diagnosis: RA, 1974  
 Culture: English

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1961	p r e d i a g n o s i s	pain on kneeling  chest pain, possibly associated with small joints joining ribs to sternum			
1972	o s t e o	birth of only biological child - flareup of symptoms	stress - did not want to be a mother, financial struggles		
1974	r h e u m a t o i d a r t h r i t i s	moved from England to Canada - new doctor, correct diagnosis      severe disability	accepted that R.A. is a disease of unknown etiology  combination of having R.A. in her "system" ( <b>physical</b> ), plus <b>stress</b> of newborn child  "why me?" rejection of God "quirk of fate"	positive thinking	no family history   positive thinking

Marlene

Age: 47  
 Diagnosis: RA, 1978  
 Culture: English Canadian

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1978	r h e u m a t o i d a r t h r i t i s	<p>"traumatic" 30th birthday</p> <p>symptoms appear</p> <p>RA factor appears</p> <p>workplace stress - demotion to menial, part- time position</p> <p>pain severe</p>	<p>heredity (<b>physical</b>)</p> <p><b>stress</b> of being only military single mother</p> <p>"<b>why me?</b>": Luck</p>	<p>weather</p> <p>willpower</p> <p>stress of trying to conceal physical problems</p>	<p>heredity</p>



Tamara

Age: 51  
 Diagnosis: RA, 1980  
 Culture: English Canadian

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1980	r h e u m a t o i d a r t h r i t i s	<p>woke up "completely paralyzed" - diagnosed with polyarthritis</p> <p>learned about Edgar Cayce</p> <p>fibromyalgia diagnosed</p> <p>became devotee of Eckankar</p> <p>revelation</p> <p>near-death experience</p>	<p><b>physical</b> - heredity, cold weather, athletic injuries</p> <p><b>psychological and physical stress</b> related to chilcare, school, and work</p> <p>RA is a "worry- disease"</p> <p>"why me?" retribution for sins of past life</p> <p>learned specific sin for which she is paying</p>	<p>lack of estrogen</p> <p>stress</p>	

Gwen

Age: 63  
 Diagnosis: RA, 1980  
 Culture: Welsh

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1975	p r e -	alcoholic, promiscuous husband			
1980	d i a g n o s i s	initiated then dropped divorce proceedings  husband left for another woman  foreclosure on family home  symptoms appear	physical exertion		
1985	R h e u m a t o i d A r t h r i t i s	diagnosis  husband in and out of life  husband left once and for all	<b>physical:</b> menopause  <b>physical:</b> abuse from husband  <b>stress:</b> family problems  <b>"why me?":</b> "someone watching over me"	"for some kinds of arthritis nothing works"	



Stacey

Age: 44  
 Diagnosis: PA, 1986  
 Culture: English Canadian

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1986	p r e	symptoms appear father very ill	<b>physical:</b> very physical job  viral infection?  hepatitis B vaccine?		
1987	P s o r i a t i c	diagnosis father dies  only able to work off and on because very sick	<b>"why me?":</b> punishment for sins of past life?		
1989	A r t h r i t i s	had to quit work altogether  involvement in cult  poverty	<b>stress:</b> work and father's illness and death	stress	
1993		admission to G.F. Strong	<b>"why me?":</b> something to learn		
1995			hepatitis B vaccine		

Caroline

Age: 32  
 Diagnosis: JRA, 1977  
 Culture: First Nations

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1977	J u v e n i	spinal taps symptoms appear; diagnosis	<b>physical</b> hardship mental <b>stress</b>		
1980	l e R h e u m a t o i d A r t h r i t i s	married daughter born	"why me?": punishment for sins in past life	pregnancy	
1984		G.F. Strong admission	<b>physical</b> genetics	overuse acidic foods	
1991		depression G.F. Strong, surgeries	<b>physical</b> fillings in teeth?	infection after root canal	

Lorna

Age: 44  
 Diagnosis: RA, 1970  
 Culture: First Nations

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1970	R h e u m a t o i d	birth of third child, symptoms appear	<b>physical:</b> working in inclement conditions		
1975		Rufus Gibbs	<b>stress:</b> family stress	"fighting spirit"	
1977	A r t h r i t i s	birth of youngest child- couldn't care for her	<b>"why me?":</b> higher purpose?		
		observes rising incidence of RA amongst native people	genetics? <b>physical:</b> change in food		
1991		witnessed shooting - PTSD	<b>stress</b> of living on reservation and loss of native identity  <b>"why me?":</b> everything has a purpose		

Marilyn

Age: 31  
 Diagnosis: RA, 1991  
 Culture: English Canadian

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Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1991	R h e u m a t o i d A r t h r i t i s	working in shipping and receiving, fingers swelled  diagnosis    tried to return to work but couldn't   crying and loneliness	<b>physical:</b> overuse          <b>"why me?":</b> punishment	exercise  rest  medications  emotional stress	

Jess

Age: 25  
 Diagnosis: RA, 1990  
 Culture: Sikh-Canadian

Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1990	R h e u m a t o i d  A r t h r i t i s	<p>symptoms appear; return to Canada; hospitalization; diagnosis</p> <p>return to London; no job or apartment</p> <p>moved back to Canada</p>	<p>not enough exercise? <b>stress</b></p> <p><b>physical:</b> . foods</p> <p><b>physical:</b> "in your system" and is triggered</p> <p><b>"why me?":</b> surfaces periodically and is pushed away; no answer</p>	<p>stress</p>	

Robin

Age: 34  
 Diagnosis: JRA, 1962  
 Culture: English Canadian

Year	D x	Life Events	Causes incorporated into model	Influences incorporated into model	Causes rejected
1962	p r e	fever, swollen joints	(parents) chicken pox? strep throat? DPT vaccine?		
1963	J u v e n i l e	diagnosis  started school, looked disabled		working hard / being good	
1975	R h e u m a t o i d	G.F. Strong, surgery  started college	"why me?": no answer  <b>physical</b> fault in the immune system, may be genetic	stress	
1988	A r t h r i t i s	started long-term relationship  relationship ends		stress of bad relationship	
			"why me?": luck		

Appendix F

Summary of causes and influences cited by co-investigators

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Physical causes

From the outside

1. TB vaccination - Tamara
2. Hepatitis B vaccine - Stacey
3. DPT vaccine - Robin's parents
4. virus, chicken pox - Robin's parents  
virus, tropical (unknown) - Stacey
5. bacterium, strep throat - Robin's parents
6. physical hardship, medical testing - Caroline  
physical hardship, abuse - Gwen
7. fillings in teeth - Caroline

Constitutional

1. genetic - Marlene, Madeleine, Caroline, Tamara, (Robin),  
(Lorna)
2. "in your system" - Diana, Robin, Jess

The way you are

1. menopause - Gwen
2. overweight - Marlene

What you are doing

1. childbearing - Lorna, Diana
2. working too hard / repetitive motion / injury - Marilyn,  
Stacey, Gwen, Tamara, Sophie
3. working in inclement conditions - Lorna, Tamara

## Stress

### Long-term / chronic

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1. family / marital dysfunction - Lorna, Diana, Sophie,  
Gwen
2. difficult family situation - Madeleine, Marlene, Tamara
3. work stress - Stacey, Jess
4. loss of culture / identity - Lorna

### Events

1. unwanted child - Diana
2. child's diagnosis - Madeleine
3. father's illness and death - Stacey

## "Why me?"

### Chance

1. luck - Marlene, Robin
2. quirk of fate - Diana
3. chance - Sophie

### Punishment

1. for wrongdoing - Marilyn
2. for sins of past life - Tamara, Caroline, (Stacey)

### Eventual / ultimate good

1. everything has a purpose - Lorna
2. something to learn - Stacey
3. someone watching over me - Gwen

### No answer

1. no answer and angry - Madeleine
2. no answer and OK - Jess

Influences - things that make arthritis better or worse

Disposition / personality

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1. anger - Tamara
2. willpower - Lorna, Marlene, Robin, Tamara
3. positive thinking - Marilyn, Diana
4. being good / trying hard - Robin

Stress

Robin, Tamara, Stacey, Marilyn, Marlene, Jess

Timing

1. recency of diagnosis - Diana, Marlene
2. early treatment - Sophie

Hormonal

1. pregnancy - Caroline
2. lack of estrogen - Tamara

Treatment

1. exercise - Marilyn, Sophie
2. rest - Marilyn, Sophie
3. medications - Marilyn, Sophie

Environmental

1. weather - Marlene
2. heat - Sophie
3. changes in barometric pressure - Sophie

Other

1. overuse - Caroline, Sophie
2. foods - Caroline, Jess
3. infection - Caroline