ABSTRACT

Ruth was the diarist of a Medical Log, the main research archive, which documented 40 years of lived experience with rheumatoid arthritis. While informants described Ruth’s coping as exemplary, the latter months of her life were marked by progressive, severe and unremitting pain. At the age of 73, Ruth committed suicide, an act that was generally viewed as rational by informants. Using a critical discourse analytic approach, informed by Parker (1992) and Willig (2001), the present research investigated the cultural discourses (i.e., biomedical, psychological and socio-cultural) that constituted Ruth’s identity, subjectivity and agency over time. In turn, Ruth’s embodied experience was used to illuminate the constituting discourses as to the explicit and implicit gaps, ambiguities and contradictions contained within. Hopelessness, at the end of Ruth’s life, was explored as a dialogically co-constructed reality, deeply embedded within constitutive discourses, rather than simply reflecting a maladaptive cognitive state. The research substantiation of Ruth’s embodied experience as a public archive was viewed as a moral response to suffering, an invitation for empathetic engagement and understanding as well as an endorsement of Ruth’s experience as having truly mattered.
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ACKNOWLEDGEMENTS

Towards the beginning of this research project, I had a dream that I was following two women up a steep path cut into the side of a mountain. A frail woman in orthopaedic shoes was taking the lead, with a stockier woman following in behind. Both women were warm and welcoming, passing back articles of clothing as I was poorly dressed for the journey. As they passed out of sight, I found myself trying on large leather orthopaedic shoes that were too big for my feet.

Towards the end of this research project, I had a dream that Ruth was sitting beside me on my living room couch, shifting and rocking towards the edge, as she was getting ready to leave. She leaned towards me, gave me a quick hug, and said, “I love you.” I stood up to face her, offering my hands on her arms for assistance. I quickly let go, realizing that only Ruth could find her center of balance.

Ruth, my hope is that you have been honoured throughout this research project and that your experience has been compassionately witnessed and understood in a way that approximates your truths. Elizabeth, I am so grateful for your generous introduction to Ruth, an event that has enriched my life beyond measure. How I wish that you had lived to celebrate the finished “story,” although your presence is constant whenever I speak of Ruth.

I want to thank you, Marla (Dr. Buchanan) for your steadfast encouragement, your passionate endorsement of this research project and your persistent belief in my adequacy and competence to carry it through to completion. Likewise, I want to thank you, Dr. David Kuhl and Dr. Marvin Westwood for your constant encouragement and support, a committee that embodied hope in both spirit and practice.
So many wonderful friends and family members have been constant companions throughout this journey, frequently offering writing places of quiet and solitude. A special thanks to you, Ruth and Stanley Martin, Bev and Rick Binder, Mary and Mick Champness, Joella and Gordon Smith, Jennifer and Gary Roosma and Brenda Murphy. Thank you, Michele Secret, for your assistance with this manuscript. I have rested in your knowledge, skill and ethics.

Finally, to my children, Helena, Stefan and Justin, you continually remind me of goodness, grace and gratitude. To my husband and beloved friend, Karl, thank you for “carrying the torch.” You shine so bright.
CHAPTER 1: INTRODUCTION

This chapter will begin with a brief introduction to Ruth, the author of a Medical Log that documented 40 years of lived experience with rheumatoid arthritis. Throughout the research context, the confidentiality of third parties, whether professional or otherwise, has been maintained through the use of pseudonyms, with steps taken to alter or omit other identifiers, such as location, ethnicity and gender, when appropriate.

The introduction will be followed by an overview of rheumatoid arthritis, a statement of the problem and the underlying rationale for the present study. The purpose of the present study will then be provided, along with the research question and chosen research methodology, with the research design more fully elaborated in Chapter 3. Background information regarding the researcher, including professional and theoretical orientation, will be also be provided in order to situate the researcher within the research context.

Ruth

Ruth was an unusual single woman for her era, born in 1929, university educated and well respected within her chosen field. While Ruth was diagnosed with rheumatoid arthritis in 1971, symptoms, such as joint inflammation and displacement, were first documented in 1962. Progressive disability, coupled with the physical and financial demands of caring for an ailing mother, precipitated an early retirement from a university position at approximately age 40. Ruth eventually relocated to western Canada in 1980, starting a patient-physician relationship with Dr. Lawson, who remained Ruth’s attending physician for 23 years.

Ruth’s enquiring mindset and proactive stance towards the management of her health care was viewed as exemplary by health care providers as well as significant others. In
general, Ruth’s engagement with life was viewed as remarkable, particularly her pursuit of aesthetic interests, such as international travel, given the existence of severe and progressive deformities of her hands and feet.

In her early 70’s, Ruth experienced an increased level of pain, which eventually became severe and unrelenting in nature. In the weeks prior to her death in 2003, Ruth sought medical assistance, initially through a locum physician for Dr. Lawson, and, finally, with a consulting rheumatologist, a referral that was instigated by Ruth at the recommendation of friends. According to the impression of significant others, Ruth understood, following these medical encounters, that nothing more could be done for her pain, and that she could only expect the pain to worsen.

Over the next two days, Ruth made a final phone call to several close friends and extended family members. The used facial tissues later found surrounding Ruth’s couch bore witness to an emotional state that was otherwise private during these conversations. Without informing anyone of her intent, Ruth meticulously planned her suicide and left detailed instructions regarding the notification of others, including relevant professional contacts. After placing a note warning against entry on the bathroom door, Ruth took an overdose of pills, entered a full bathtub and slit her wrist. After several days, concerned elderly neighbours gained access to her apartment and discovered her body. A suicide note, quoted from the memory of the primary informant, Elizabeth, as related by the attending police officer, stated as follows:

I, Ruth Williams, being of sound mind, have decided to take my own life. I have not been abetted or assisted by anyone. This is wholly my decision. I have been in severe pain since October and it is only getting worse. I am sorry for the distress this might cause my friends and family.
Signed, Ruth Williams.
During the sorting of Ruth’s possessions, Elizabeth also discovered a video based on the book *Final Exit: The practicalities of self-deliverance and assisted suicide for the dying* by D. Humphry (1991). A detailed 40 year “Medical Log,” documenting Ruth’s lived experience with rheumatoid arthritis was also discovered and, eventually, forwarded for research purposes.

**Overview of Rheumatoid Arthritis**

Rheumatoid arthritis is a chronic, painful and debilitating disease that affects approximately 1% of the Canadian population (Health Canada, 2003). Inflammation of the synovia (joint lining) leads to progressive degenerative changes which results in increasing disability and pain over time. Less frequently, general systemic disease activity may occur in the eyes, lungs and heart (Grennan & Jayson, 1994). There is no known etiology, although autoimmune dysregulation and microbacterial infections and genetic factors are predominant current theories (Grennan & Jayson, 1994; Walker, Littlejohn, M’Murray, & Cutolo, 1999; Woolf & Pfleger, 2003). Likewise, there is no known cure.

There are also significant gender related differences in both the occurrence and presentation of rheumatoid arthritis. Prevalence rates for women, as compared to men, are estimated to range from at least a 2:1 ratio (Health Canada, 2003) to a 4:1 ratio (Harrison, 2003). According to research by Weyand, Schmidt, Wagner and Goronzy (1998), the incidence rate for onset peaks for women between ages 31-35 and, again, after age 46, whereas men have a single peak incidence rate at age 36. According to Harrison’s (2003) research review of sex-based differences, women reportedly have higher levels of disease severity, disability, more surgical interventions, greater pain and higher rates of depression in comparison to men. Female gender, longer disease duration, worse functional class, low
disease activity and prior use of disease-modifying antirheumatic drugs (DMARDS) are all associated with the reduced effectiveness of pharmaceutical treatments (Anderson, Wells, Verhoeven & Felson, 2000). In particular, disease duration exerts a strong effect on treatment response, with a 53% response rate for \( \leq 1 \) year, 38% for 5-10 years and 35% for \( \geq 10 \) years of disease duration (Anderson, et al., 2000).

Unfortunately, 36% of women do not receive treatment with DMARDS (Weyand et al., 1998), identified by Harrison (2003) as useful in providing symptomatic relief and slowing disease progression particularly when delivered aggressively during the early stages of the disease. Harrison (2003) underlined such treatments as particularly critical for women in the maintenance of an optimal quality of life, given the higher incidence of pain and disability in comparison with men. In addition, rheumatoid arthritis carries an increased risk for osteoporosis, with an associated risk of fractures with minor trauma (Woolf & Pfleger, 2003), which accentuates the need for active treatment as a preventative measure.

Unfortunately, premature mortality is also associated with rheumatoid arthritis, given the effects of disease activity, comorbid conditions, such as cardiovascular and kidney disease, and toxicity from pharmaceuticals, as in the case of gastro-intestinal bleeding from non-steroidal anti-inflammatory drugs or NSAIDS (Health Canada, 2003).

As a disease, rheumatoid arthritis is marked by uncertainty, given an unknown prognosis, unpredictable flare-ups and brief remissions of disease activity and pain. Pain, chronic fatigue and an unpredictable yet progressive disease course create considerable stress on the lives of affected individuals and their families (Bury, 1988; Revenson, 1993). Physical limitations and loss of control, as in maintaining independence and pain
management, are significant stressors for those with longstanding rheumatoid arthritis (Melanson & Downe-Wamboldt, 2003).

According to a Finnish study by Hakala, Nieminin and Koivisto (1994), two-thirds of patients with rheumatoid arthritis were found to be mild to moderately disabled, with less than 10% severely disabled, the latter finding largely attributed to the early use of DMARDS and surgical interventions. Approximately 50% of individuals with rheumatoid arthritis are classified as work disabled 10 years following onset (Brooks, 1997, as cited in Woolf & Pfleger, 2003).

There are significant financial and social costs with respect to lost productivity and health care costs for those with arthritis. In 1998, direct and indirect health costs from arthritis exceeded $4.4 billion dollars, excluding treatments and expenses not covered by universal health care (Health Canada, 2003). These costs are expected to increase given projections that 1:5 Canadians will have an arthritis-related condition by the year 2026 (Health Canada, 2003). Compared to other chronic illnesses, Canadians with arthritis, and related conditions, report more frequent utilization of health care services, greater pain and disability, greater levels of depression and sleep disturbances and greater need for daily assistance (Canada Health, 2003).

**Statement of the Problem**

Sociologists have situated the experience of chronic illness within the intersection of the self, body and culture (Bury, 1982; 1988; Charmaz, 1983; 1995; Corbin & Strauss, 1987; Frank, 1995; Williams, 1984). Morris (1991), in particular, has likened the understanding of pain to a mystery, rather than a puzzle, given the influence of the socio-cultural context coupled with the uniqueness of individual experience. However, psychological research,
situated within the standard biopsychosocial model, has typically marginalized the socio-cultural context when investigating the process of adjustment to rheumatoid arthritis, with researchers also noting that there exists “little understanding of the meaning that individuals with rheumatic conditions construct about their illness and its impact on themselves, life, priorities, and future” (Walker, Jackson & Littlejohn, 2004, p. 467). Likewise, there has been no psychological research that has investigated the role of predominant cultural discourses within the constitution of identity or a coherent sense of self (Mahoney, 1991), subjectivity, or ways of being and seeing in the world (Davies & Harré, 1990) and agency, or what can be said and done (Potter & Wetherell, 1987) within the experience of rheumatoid arthritis. Lived experience has, therefore, been marginalized as a source of illumination as to the constitutive effects of predominant cultural discourses (Foucault, 1963/2003; Foucault, 1980; Scarry, 1985; Willig, 2000) and the inevitable contradictions, ambiguities and gaps contained within (Foucault, 1976/1990; Parker, 1992).

While research has repeatedly documented the relationship between chronic illness, depression and suicide in the elderly, there is a lack of understanding as to the complex psychological, socio-cultural and biological risk factors (Conwell, Duberstein & Caine, 2002; Pearson, 2000). Given existing demographic trends regarding the aging of western populations, the incidence of chronic and painful degenerative illness and the potential for suicide will become increasingly relevant (Conwell et al., 2002). Likewise, there is widespread philosophical acceptance of suicide as a potentially rational option, particularly in the face of unremitting suffering, with endorsement extending to both physical concerns, such as pain and incapacitation and psychosocial concerns, such as being dependent or a burden to others (Humphry, 1991; Kleepsies et al., 2000; Rosenfeld, 2004; Sorenson, 1991).
Researchers have found that the majority of psychologists (psychotherapists) and registered social workers similarly endorse rational suicide (or physician-assisted suicide and euthanasia), a finding that underlines the need for psychological research to inform both standards and practice (Ogden & Young, 1998; Werth & Corbin, 1995).

Rheumatoid arthritis has been identified as a chronic illness with an increased risk for suicide (Dorpat, Anderson, & Ripley, 1968; Pokorny, 1960). Treharne, Lyon and Kitas (2000) found that almost 11% of hospital outpatients with rheumatoid arthritis reported suicidal ideation, with gender (female), longer disease duration and depression associated with greater suicidal ideation. However, only one Finnish study (Timonen et al., 2003) has investigated the demographic and psychosocial characteristics of those with rheumatoid arthritis that have completed suicide based on a hospital discharge registry and death certificates. Timonen et al. (2003) found that women with rheumatoid arthritis were overrepresented when compared to the total suicide population, identifying depression as a significant influence in 90% of these suicides. However, such findings offer limited understanding of the inter-relationships between the chronic illness experience, psychological distress and eventual suicide within the intersection of culture, self and body over time.

**Rationale for the Study**

The present research was based on assumptions that are situated within postmodern ideas regarding the social construction of reality, in general, and the self, in particular (Berger & Luckmann, 1966/1967; Burr, 1995; Gergen, 1999, 2001). Constructions of reality exist through the interpretative stance of the knower with truth, or meaning characterized as multiple, partial and indeterminate, rather than absolute in nature (Derrida, 1988). According to social constructionist thought, truth claims are, therefore, discursive productions situated
with specific historical and socio-cultural contexts, established through processes of moral persuasion in that the taken for granted also becomes the right way of being and seeing (Berger & Luckmann, 1966; Gergen, 1999).

Burr (1995) has defined discourse both as “a systematic, coherent set of images, metaphors and so on that construct an object in a particular way” and as “the actual spoken interchanges between people” (p.185). The latter presumes the influence of predominant cultural discourses within any spoken interaction, as with the implicit biomedical discourse typically represented within physician-patient interactions.

According to Michel Foucault (1980), power and knowledge are inseparable given the effect of cultural discourses on the objects that are constructed. In this regard, a dominant cultural discourse, or “regimé of truth” will create:

the types of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true (p. 131).

While interested in the historical development of cultural institutions, Foucault was particularly interested in disciplinary practices that exerted social control by defining normality while segregating the abnormal in institutions such as the asylum (1961/1988), the medical clinic (1963/2003) and prisons (1975/1979). According to Foucault (1975/1979; 1980) individuals were also instrumental in their own subjugation through processes of self-surveillance through which their own minds and bodies were policed with respect to the normalizing gaze of disciplinary power.
As such, dominant cultural discourses are constitutive of individual identity, subjectivity and agency (Parker, 1992; 2002; Willig, 2000; 2001). In this regard, various “subject positions” (Davies & Harré, 1990), within these dominant discourses, such as “patient” or “expert” within the biomedical discourse, opens up various “interpretative repertoires” (Potter & Wetherell, 1987) and ways of being.

Numerous metaphors have been used to describe constructions of the socially emergent self, including the “saturated self” (Gergen, 1991); the “relational self” (Gergen, 1999); the “discursive self’ (Harré & Gillett, 1994); “the dialogical self” (Hermans & Kempen, 1993); “possible selves” (Markus & Nurius, 1986); the “polyphonic self” (Baktin, 1986) and “self as internalized others” (Tomm, Hoyt, & Madigan, 1998). While socially constructed, the individual also has a need to organize ongoing awareness and experience into meaningful and coherent life narratives (Bruner, 1986; Polkinghorne, 1988). These narratives are expressed in language, both literally and figuratively, and are co-constructed within available personal, familial, social and cultural discourses (Burr, 1995; Bury, 2001; Polkinghorne, 1988). These embodied narratives explain, organize and proscribe lived experience.

While constitutive of identity, subjectivity and agency, as well as, ongoing life narratives, the effect of cultural discourses are not necessarily apprehended by individual consciousness. According to Foucault (1980), “power relations can materially penetrate the body in depth, without depending even on the mediation of the subject’s own representations. If power takes hold on the body, this isn’t through its having first to be interiorised in people’s consciousness” (p. 186). The individual is, thereby, so immersed and constituted by
dominant discourses that alternate ways of being may be very difficult to both comprehend and access.

Foucault (1976/1990) viewed the body, or the embodied text, as the primary site where discourses, or “bio-power,” (p. 140) were both enacted and resisted. Likewise, pain theorist, Scarry (1985) noted that the politics of various discourses are most evident at the intersection between the body and society. According to Scarry (1985):

it might even be argued that the attributes of a particular political philosophy, its generosities and its failures, are most apparent in those places where it intersects with, touches or agrees not to touch, the human body—in the medical system it formally or informally sponsors that determines whose body will and whose body will not be repaired; in the guarantees it provides or refuses to provide about the quality and consistency of foods and drugs that will enter the body; in the system of laws that identify the personal acts toward another’s body that the state will designate “unpolitical” (unsocial, uncivil, illegal, criminal) and that will thus occasion the direct imposition of the state on the offender’s body and the separation of that unpolitical or uncivil presence from contact with the citizens (p. 111).

Dominant cultural discourses are, however, inherently unstable, and amenable to change in response to challenges by those otherwise marginalized. According to Foucault (1976/1990):

discourses are not once and for all subservient to power or raised up against it, any more than silences are. We must make allowance for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an
opposing strategy. Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it (pp. 100, 101).

An understanding of the power of discourse within lived experience therefore includes the influence of both explicit and implicit references as well as inherent gaps, contradictions and inconsistencies.

As with other dominant cultural discourses, the discipline of psychology (and related practices) has developed within a specific historical and socio-cultural context rather than reflecting a pre-existent discovered truth (Foucault, 1961/1988; 1980; Gergen, 1999; 2001; Parker, 1992; 2002). As a disciplinary power, psychology also has the potential to marginalize knowledge based on lived experience, a situated wisdom which may otherwise empower the individual (Freedman & Combs, 1996; Neimeyer & Raskin, 2000; White & Epston, 1990). The practice of psychology is, therefore, a political act necessitating reflective practices on the part of researchers and practitioners as to how the “truths” of psychology restrain or facilitate preferred ways of being.

According to Wetherell, Taylor and Yates (2001) the study of discourse has become a valid methodology for examining psychological issues for the following reasons:

If language, however, is constructive and constituting, performative as well as referential, then any simple notion of good data as neutral and transparent descriptions of states of mind or events in the world becomes complicated. The turn to discourse in psychology, therefore, has involved a shift to studying talk in itself rather than quick detours past the words and the doing with words to some assumed mental state or underlying behavioural pattern. Discourse has become interesting per
rather than being taken for granted as a direct access route to the real psychological business (p. 188).

Burr (1995) has defined discourse analysis as “the analysis of a piece of text in order to reveal either the discourses operating within it or the linguistic and rhetorical devices that are used in its construction” (p.185). Discourse analysis has been promoted as a methodology critical to understanding notions of subjectivity and agency (Burr, 1995; Parker, 1992, 2002; Potter & Wetherell, 1987; Wetherell, Taylor, & Yates, 2001; Willig, 2001), particularly within the experience of health and illness (Lupton, 1992; Roger, 1996; Willig, 2000; Yardley, 1996). However, as a research methodology, discourse analysis has been largely ignored within the fields of health or counselling psychology. In particular, there have been no research studies utilizing a discourse analytic approach to investigate issues of identity, subjectivity and agency within the lived experience of a painful chronic illness, such as rheumatoid arthritis.

As a discipline, psychology has, therefore, been hindered from comprehending the impact of various cultural discourses (including psychological) on lived experience, remaining disempowered as an agent for change. According to Gergen (1999), if we create our worlds largely through discourse, then we should be ever attentive to our ways of speaking and writing. Through reflexive inquiry on our ways of constructing the world, and the practices which they sustain, we open doors to emancipation, enrichment, and cultural transformation (p.115).

While strongly influenced by social constructionist thought, the present research viewed the research subject, or diarist of the main archive, through a constructivist-narrative lens (Freedman & Combs, 1996; Mahoney, 1991; Neimeyer & Mahoney, 1995; Neimeyer &
Raskin, 2000; White & Epston, 1990). In this regard, the body (Williams, 1999) and organic core-ordering processes (Mahoney, 1991) were regarded as essential to being, or ontological reality, whereas epistemological reality, or ways of knowing were regarded as socially constructed and, therefore, relativistic. As such, the self of the subject was viewed as relatively stable but amenable to change over time.

**Purpose of the Study**

In the present research, I investigated various cultural discourses that constituted the identity, subjectivity and agency of Ruth, a woman who had lived with rheumatoid arthritis over a 40 year time period. A 40 year medical log, which documented Ruth’s lived experience with rheumatoid arthritis, served as the primary research text. In this study, I addressed a critical gap in research understanding regarding the impact of cultural discourses on the lived experience of chronic illness, in general, and rheumatoid arthritis, in particular. Documentation of lived experience over a 40 year period also provided a unique opportunity to understand how identity, subjectivity and agency was constituted over time, including how various discourses were appropriated and resisted. In turn, research findings illuminated gaps, ambiguities and inconsistencies within various discourses, while articulating benefits and losses to self, others and institutions within their practice. In particular, the investigation of Ruth’s lived experience illuminated discourses that were constitutive of her decision to commit suicide in the presence of severe end of life pain.

In addition to the above theoretical interests, I was motivated by significant ethical considerations. According to Scarry (1985), those in intense physical pain require an advocate, or, at least, an empathetic witness, in order to provide “worldly self-extension,” (p. 50), thereby maintaining the individual’s life engagement and hope. This moral imperative
rests on understanding that those in severe pain are otherwise disempowered, given the annihilating and totalizing effect of pain on consciousness, coupled with the inherent difficulties in self-expression and representation (Scarry, 1985).

Scarry (1985) links difficulties with verbal representation and social visibility to political representation and advocacy, noting that physical pain remains more under represented that any social concern as it is not simply somewhat less easy to express than some second event, not simply somewhat less visible than some second event, but so nearly impossible to express, so flatly invisible, that the problem goes beyond the possibility that almost any other phenomenon occupying the same environment will distract attention from it. Indeed, even where it is virtually the only content in a given environment, it will be possible to describe that environment as though the pain were not there (Scarry, 1985, p.12).

In response to the above ethical dilemmas, Scarry (1985) has recommended that the “de-objectifying work of pain” (p. 6) be undone through objectifying pain in the arena of public discourse. Scarry (1985) has recommended many avenues for doing so, including through the externalization of the voice of the sufferer, either in personal recollection or through the memory of others or through medical contexts, such as patient-doctor interactions and medical case histories.

In this regard, through the present research, I sought to give voice to Ruth’s experience of pain and chronic illness, both through first person documentation, as in medical and personal archives, and through the recollections of others. Given that shared sentience forms the basis of empathy (Scarry, 1985; Williams, 1999), the research substantiation of Ruth’s embodied experience will potentially foster empathetic engagement
in the reader, and in turn, an enlightened advocacy on behalf of those who are suffering severe pain.

**Research Question**

The research question was stated as follows: “How does the 40 year Medical Log of a woman with rheumatoid arthritis illuminate discourses that are constitutive of the experience of living with a chronic painful illness?”

A discourse analytic methodological approach (informed by Parker, 1992 and Willig, 2001) was used to investigate the Medical Log, the primary research archive. Such an approach, explicated in Chapter 3, permitted the analysis of discourses that were constitutive of Ruth’s identity, subjectivity and agency, within lived experience with rheumatoid arthritis, at the intersection of self, body and culture.

**Locating Self as Researcher**

As a practitioner and researcher, I situate myself theoretically within a constructivist-narrative framework (Freedman & Combs, 1996; Mahoney, 1991; Neimeyer & Mahoney, 1995; Neimeyer & Raskin, 2000; White & Epston, 1990). I have had the privilege of caring for individuals with various chronic illnesses, including rheumatic diseases, both as a former nurse and, presently, as a counsellor in private practice. I have witnessed the impact of various cultural discourses in the lives of clients as they attempted to create a meaningful present and future. Their metaphors have frequently become gifts as I have faced the inevitable suffering that comes with living. I have learned, through their sharing, to become a more empathetic witness.
During this research project, my husband was also diagnosed with a devastating painful illness, metastatic cancer. While I am not ready to openly reflect on this experience, his suffering, and that of my family, has profoundly influenced my understanding of the lived reality of a chronic, painful and deteriorating illness. I have experienced the social and medical world, in particular, through the multiple lenses of spouse, former nurse, counsellor and researcher. I am well acquainted with the hopes and limitations of the medical discourse.

I have been influenced by the ideas of White (1988) regarding the ongoing social presence of individuals who have died and the need to bring forward and honour that social reality in the present. I believe that Ruth is socially present, particularly to those who love her, and that she is deserving of the same ethical processes given to individuals who are living. Secondly, I regard suffering as existing primarily within a moral realm (Charmaz, 1999; Frank, 1995; Scarry, 1985) and, as such, see myself as standing on sacred ground.
CHAPTER 2: LITERATURE REVIEW

This chapter will provide a broad overview of biomedical, psychological and suicide-related discourses deemed relevant to the study of rheumatoid arthritis. Each section begins with a brief historical overview, situating various discourses within specific historical and socio-cultural contexts. The overview is limited to historical influences underpinning western thought and practices with the understanding that other cultural and historical contexts would vary considerably as to how discourses have developed and, in turn, constituted lived experience.

Special emphasis will be given to research regarding the elderly and those with longer disease duration given that Ruth, the author of the Medical Log, was 73 years of age at the time of her death, having lived with rheumatoid arthritis for approximately 40 years.

MEDICAL DISCOURSE AND RHEUMATOID ARTHRITIS

Historical Overview of Medical Discourse

Grossman (1966) traced historical references to arthritic diseases back to the time of the Greek physician, Hippocrates, although the term “rheumatoid arthritis” was not introduced into the medical lexicon until 1859 (Bywater, 1988). According to ancient Greek formulations of rheumatism or “rheumatismos,” symptoms were thought to be caused by “mucus (catarrh),” an “evil humor” which flowed from the brain to body and joints causing pain. (Hollander, 1966, as cited in Shafii, 1973, p.86) Throughout the 19th century, humoral notions of causation predominated, with an etiology determined by the influences of climate, trauma, toxins and constitutional predispositions (Bywater, 1988). The exact nature of the disease was deciphered through an exploration of each patient’s lifestyle, morality and
environmental context, with equilibrium restored through treatments such as cupping, bleeding and purging (Lawrence, 1994 as cited in Bury, 2001).

The Greek tradition of mind-body holism was challenged during the Renaissance by the dualistic views of Descartes in the 17th century (Gatchel, 1999). For example, Descartes conceptualized pain as a peripheral stimulation transmitted directly to the brain without reference to constitutional or environmental influences (Gatchel, 1999). Likewise, the development of the medical clinic in the 18th century situated care apart from the patient’s environment, further justifying the exclusion of the person in order to comprehend the “truth of the pathological fact” (Foucault, 1963/2003, p.7). The discovery of the role of microorganisms in the etiology of disease during the 19th century further consolidated the bioreductionistic lens of the physician (Gatchel, 1999). In consequence, the physician’s role shifted from that of teacher and spiritual advisor to that of a scientist, with disease understood as a deviation from a standardized norm, rather than a disturbance within an otherwise natural equilibrium (Gatchel, 1999; Lawrence, 1994 as cited in Bury, 2001).

By the early 20th century, theories of micro-biological causation predominated, remaining at the forefront for approximately 70 years (Bywater, 1988). Various body parts, such as teeth, tonsils, appendices, gallbladders and colons, were presumed to be infected, and, in consequence, surgical removal, with vaccine therapy an associated treatment of choice (Bywater, 1988). Other seemingly innocuous theories, such as the presumed etiological role of calcium in the 1930’s, led to treatment by parathyroidectomies and Vitamin D which occasionally resulted in irreversible kidney failure and death (Bywater, 1988). Theories implicating the central nervous system and psychogenesis resulted in the use of electroconvulsive and insulin shock therapies as part of treatment (Hart, 1976).
Hundreds of extraordinary folk cures and medical treatments have been recommended over time, in part fueled by a disease process that is unpredictable in both exacerbations and inexplicable remissions (Hart, 1976). For example, purported cures have included the ingestion of fresh crow meat, the topical application of fermented earth worms and standing inside the carcass of a whale (Hart, 1976). Hart (1976) referenced the Lourdes-like atmosphere surrounding rheumatology clinics following the discovery of cortisone in 1940, an enthusiasm that quickly subsided on discovery of adverse side effects and a lack of long term benefit (Mooreland, Russell, & Paulus, 2001). In general, much of the 20th century was marked by poor treatment outcomes, with medical management focused on the identification and prevention of adverse treatment effects (Wolfe et al., 2001).

**Present Biomedical Discourse**

The etiology of rheumatoid arthritis remains unknown, with present theories implicating genetic and microbiological factors (Grennan & Jayson, 1994) and autoimmune dysfunction (Walker, Littlejohn, McMurray & Cutolo, 1999). According to the American College of Rheumatology (ACR) 2002 guidelines, treatment goals are geared towards prevention or control of joint damage, loss of function and pain. Assessment of disease activity includes a number of subjective measures (including joint pain; morning stiffness; fatigue and functional limitations), physical examination (including the number of affected joints; mechanical joint problems; extra-articular involvement and radiography), laboratory tests (including erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) and the Rheumatoid Factor (RhF), with the latter performed only at baseline assessment if found positive. (ACR, 2002). Complete remission reportedly occurs infrequently and is determined
by the absence of subjective and clinical indicators, the absence of progressive joint damage as well as normal ESR and CRP laboratory findings (ACR, 2002).

The treatment of rheumatoid arthritis is primarily pharmaceutical, with nonsteroidal anti-inflammatory drugs (NSAID) used to control pain and inflammation. Newer NSAIDS, such as COX-2 inhibitors, avoid some of the serious toxic side effects of generic NSAIDS, such as Aspirin, but are more costly and carry the risk of cardiovascular complications (ACR, 2002).

Disease-modifying anti-rheumatic drugs (DMARDs) are used early in diagnosis to slow or prevent joint damage as well as for the symptom management of joint pain, morning stiffness and fatigue (ACR, 2002). While the use of DMARDs has been universally endorsed since the mid-1980’s (Hakala et al., 1994), 36% of women do not receive such treatment (Weyand, Schmidt, Wagner & Goronzy, 1998). The underutilization of DMARDs is particularly significant for women given the greater pain and disability experienced by women in comparison with men (Harrison, 2003). A lessened treatment response is also associated with gender (female), disease duration of over 10 years, low disease activity, higher disease functional class and previous use of DMARDs (Anderson et al., 2000), the latter finding underlining the partial and temporary benefit typical of present treatments (Moreland et al., 2001).

Newer biological response modifiers directly block inflammatory processes but carry considerable risks as they also inhibit defenses against infections and the growth of tumours (Moreland et al., 2001). Surgical interventions may include joint fusion and joint replacement (ACR, 2002), with the reported incidence of procedures higher for women than men (Weyand et al., 1998).
While the American College of Rheumatology (ACR, 2002) endorses a multidisciplinary approach, including nurses, physical therapists, social workers and psychologists, they are referred to as nonpharmacological treatments, a term that appears to position their importance as adjuncts to drug regimens. Patient adherence to recommended treatment is variable, with a 33-78% rate reported for prescribed medications and 38-66% for physical therapy (Bradley, 1989 as cited in Young, 1992).

Given the limited benefits of available treatments, those with rheumatoid arthritis frequently consider various alternative and complementary treatments for symptom management. According to Herman, Allen, Hunt, Prasad and Brady (2004), 86.4% of patients with rheumatoid arthritis within a primary care setting had tried alternative and complementary treatments, with 70.7% reporting current use. At the time of the study, the most frequent treatments reported included relaxation (16.3%); glucosamine (15.8%) meditation (11.1%) and Vitamin C (10.0%). Utilizers tended to be younger, more highly educated and had a mean disease duration of 15.3 years.

Herbal and dietary supplements that have shown promise in the treatment of inflammatory pain include Vitamin E, gamma-linoleic acid (GMA) and fish oil (Taibi & Bourguignon, 2003). In addition, research has suggested that dietary modifications, such as the removal of allergens, nightshade vegetables (white potatoes and peppers) as well as meat and dairy products, may result in symptomatic improvement (Taibi & Bourguignon, 2003).

There are justifiable medical concerns as to whether or not such treatments have been scientifically validated, or whether treatment contraindications exist for prescribed medications (Taibi & Bourguignon, 2003). For example, commonly used herbal supplements, such as melatonin and echinacea, may have potentially harmful effects for
those with an impaired immune system (Taibi & Bourguignon, 2003). In addition, certain alternative treatments, such as acupuncture, yoga and Tai Chi may be beneficial for various health-related concerns yet lack empirical support for their use with rheumatoid arthritis (Casimiro et al., 2005; Taibi & Bourguignon, 2003).

In her autobiographical account below, Grace Stuart (1953) spoke eloquently of the search for a cure both within “quackery” and within the standard medical treatments of her time that, in retrospect, were pointless.

But there might—or so one thought—always be some other, some more acceptable discipline, and so, even within respectable confines of the medical world, how wildly we dashed, we others, from the favoured approach this year to the favoured approach of the next, losing as we went our teeth, our tonsils, our appendixes, and retaining with difficulty some odds and ends of stomach and intestines with which still to function—losing as we went, I’m afraid, our confidence, our hope and our heart! Protein shock therapy, insulin, vaccines by the score, massage, rays, injections, diets, those revolting poultices of sticky grey anti-phlogistine—on and on and on—self-tied, and socially and medically bound, to the endlessly turning wheel of the endlessly failing ‘cure’ (p. 94).

**Limitations of Biomedicine**

Medicine, as a disciplinary power, exists as an “objectivated” (Berger & Luckmann, 1966/1967, p. 34) human activity, or a product of cultural values and practices that exist within a specific historical context (Berger & Luckmann, 1966/1967; Foucault, 1963/2003). In this regard, the present biomedical reliance on science and technology also reflects western culture’s allegiance to rationalism and the grand narrative of scientific progress
However, medical sociologists, such as Lorber (1997) and Turner (1987) have critiqued the biomedical model as neglecting the complex social, personal and environmental factors which not only intersect with the body in the etiology and expression of disease and disorders but also have serious ramifications in the delivery of medical care. Lorber (1997) uses a feminist critique of medical practice research, highlighting the differential effect of gender in the delivery of health care for women. For example, Lurie et al. (1993) found that women were less likely to have regular Pap smears and mammograms if their physician was male, particularly in a general practice or internal medicine setting. Turner (1987) singled out societal attitudes towards aging as a factor in the marginalization of health care resources for the elderly, a population that carries the largest symptomatic burden associated with chronic illness (Conwell et al., 2002).

Charmaz (1983) has also critiqued westernized medical care as geared towards acute, rather than chronic care, rendering inadequate information, fragmented care and insufficient support to patients and their overburdened care givers. These critiques are relevant for those with rheumatoid arthritis, given that patients typically describe a lack of support, education and partnership within their relationships with health providers (Fair, 2003), while informal caregivers, typically partners, report a substantial care-giving burden (Brouwer, et al., 2004).

According to Waitzkin and Britt (1989) direct medical encounters with patients also frequently reinforce oppressive social-cultural conditions in that technical responses are encouraged while disclosures related to social context are marginalized and micromanaged by the physicians’ use of “interruptions, cutoffs, deemphases, or silences” (p. 438). Likewise, ten Have (2002) described the typical medical consultation as proceeding according to a biomedical agenda, with the physician acting as a professional host and the
patient as a lay guest. According to ten Have (2002) tension frequently exists during the verbal examination as the patient may want to elaborate a personal story whereas the physician may seek diagnostic clarity. However, physicians appear to shift responsibility for the outcome to patients during times of dilemma, diagnostic conflict, or interactions regarding psycho-social concerns (ten Have, 2002). In recent decades, the social structure of physician-patient interactions has shifted, given patient challenges to the implicit power asymmetry within the relationship (ten Have, 2002). Likewise, Dixon-Woods (2001), in an investigation of patient information leaflets, discovered two predominant discourses regarding the health care provider-patient relationship, that of the patient as inexpert and in need of direction and education and that of the patient as educated and empowered, capable of a collaborative relationship with professionals.

Anspach (1988) investigated the rhetorical devices used in medical case presentations and found that patients were depersonalized in that their personhood was separated from biological processes and that their accounts were marked as subjective, as in “states,” “reports,” and “denies.” (p. 368) leaving implicit questions regarding accuracy and validity. In contrast, physician’s accounts were offered as objective, as in “note,” “observe,” or “find,” while technology “revealed,” or “showed,” information, the latter suggesting processes of revelation rather than interpretation (Anspach, 1988, p. 368).

Unfortunately, the objective assessment of rheumatoid arthritis is fraught with difficulties, given inconsistent symptom presentation, unexplained exacerbation and remissions of disease activity coupled with a low rate of incidence that may result in physician inexperience (ACR, 2002; Newman & Revenson, 1993). Pain is also a subjective
experience that may occur without objective clinical markers that coincide with the persistence and severity of patient reports (Boulanger et al., 2007; Rich, 1997).

According to a recent Canadian survey, (Boulanger et al., 2007), of the 25% of the general population who reported chronic pain, 37% reported moderate pain and, 51%, severe pain, with 28% of the latter group also reporting that they were not taking any prescribed analgesics. Primary care physicians identified arthritis (types unspecified) and inflammatory conditions as the most frequent cause of chronic pain (31%), followed by back and spinal conditions (21%) (Boulanger et al., 2007).

According to bioethicist Rich (1997), the undertreatment of pain, particularly noncancer pain, persists in spite of the ethical imperative to relieve pain and suffering, as contained within the Hippocratic Oath. Rich (1997) attributed the under prescription of analgesics by physicians, particularly opiates, to inadequate education, fears regarding prescription abuse as well as fears regarding regulatory or legal repercussions. According to Scarry (1983), one of the most frightening aspects of severe pain is that it may remain unacknowledged and, even denied, by others while dominating consciousness. While understanding pain depends on the physician’s ability to “coax it into clarity, and interpret it,” the experience of many patients “would bear out the opposite conclusion, the conclusion that physicians do not trust (hence, hear) the human voice, that they in effect perceive the voice of the patient as an ‘unreliable narrator’ of bodily events, a voice which must be bypassed as quickly as possible so that they can get around and behind it to the physical events themselves” (Scarry, 1985, p. 6).

Rich (1997) identified the substandard medical management of pain as a significant factor inherent within the physician-assisted suicide debate, a dialogue now represented
within the regulatory and legal arenas. The Joint Commission of Accreditation on Healthcare Organizations has identified pain as the fifth vital sign that requires monitoring (Gatchel et al., 2007) while the Federation of State Medical Boards of the United States recommended that under treatment of pain be a practice violation along with other prescribing violations (Barclay, 2004).

The bioreductionism implicit within medicine also has direct effects on the experience of chronic illness, given that the body becomes objectified as “a project for the self to work on” (Gordon, 1988 as cited in DiGiacomo, 1992, p.122). According to Charmaz (1983), Anglo-Saxon values privileging independence, privacy and family autonomy further consolidate feelings of personal responsibility, while an underlying Protestant work ethic may further constrain the acceptance of assistance without guilt. Grace Stuart (1953), in her autobiographical account of life with rheumatoid arthritis, *A Private World of Pain*, alluded to the social consequence of the work ethic, noting that strenuous treatment efforts received social endorsement while time off as a self-care strategy was questioned.

The biomedical model has been frequently critiqued for the marginalization of the chronic illness experience and the attendant suffering (Bury, 2001; Charmaz, 1983; Hauerwas, 1990; Kleinman, 1988). Within the experience of rheumatoid arthritis, such marginalization frequently creates a disjuncture between physician-patient understanding of the significance of symptoms. According to Hewlett (2003), “patients’ assessments may be influenced by their needs, priorities, experiences, expectations, and attitudes, while professional opinions may be more directly related to the patient’s physical health status—perhaps patients rate their illness while professionals rate the disease” (p. 878). Such disparities contribute towards less effective clinical interventions, with patient dissatisfaction
leading to treatment noncompliance, referral to another provider, or complete withdrawal from traditional treatments (Fair, 2003). According to Bury (1982), biomedicine provides a significant cultural service to those affected by rheumatoid arthritis in the provision of “an objective fixed point on a terrain of uncertainty” (p. 179). However, Bury (1982) identified such knowledge as problematic in that “such knowledge itself often turns out to be ambiguous and limited. Rheumatoid arthritis thus appears as a definite entity, yet its implications for the future are uncertain. Such knowledge is incomplete and has to be supplemented by, and set against, a body of knowledge and meaning drawn from the individual’s own biography” (p. 179).

According to Bury (2001), the increase in degenerative chronic illness, the greater egalitarianism in physician-patient relationships and the proliferation and accessibility of health-related information has spurred sociological investigation into illness narratives. In this regard, Bury (2001) identified three types of illness narratives: contingent narratives, or beliefs about etiology, symptom causes and their immediate effects; moral narratives, which address changes between the person, illness and social identity, as well as core narratives, which reflect deeper cultural connotations associated with the illness experience.

Kleinman (1988) has called for the “remoralization” of medical practice through “empathetic witnessing,” “the existential commitment to be with the sick person and to facilitate his or her building of an illness narrative that will make sense of and give value to the experience” (p. 54). According to Hauerwas (1990) such narratives must be individually constructed given that western society lacks a grand communal narrative of suffering which would otherwise direct the process.
The complete relational separation between the medical professional and the experiential reality of the patient was poignantly evident within the autobiographical account of Grace Stuart (1953). This emotionally evocative narrative documented a life lived with the pain of rheumatoid arthritis from the age of 19 onwards, published when the author was 55 years of age. Grace Stuart (1953) dedicated her memoir to her physician, describing him as beloved, whereas Dr. Malin’s commentary focused on the significance of the discovery of cortisone while making no mention of their relationship. The medical discourse apparently hindered the physician from voicing anything other than “scientific” knowledge.

**Summary of Biomedical Discourse and Rheumatoid Arthritis**

Past and present medical discourses, particularly regarding the etiology and treatment of pain and rheumatoid arthritis, are embedded within specific cultural and historical contexts, underlined by shifting philosophical orientations (Bury, 2001; Bywater, 1988; Gatchel, 1999). As is evident in the excerpts taken from the autobiography of Grace Stuart (1953), biomedical discourses have real effects on the creation of meaning within the experience of rheumatoid arthritis. The body of the elderly, in particular, constitutes an archive of professional discourses that have shifted over time.

The predominant biomedical discourse has been extensively critiqued for the use of a scientific lens which marginalizes the social-cultural surround as well as the lived experience of a chronic illness, such as rheumatoid arthritis (Charmaz, 1983; Bury, 1982; 1988; 2001; Fair, 2003). However, the epistemological rationalism inherent within such bio-medical practices also reflects the institutional reification of societal values (Berger & Luckmann, 1966/1967; Foucault, 1963/2003), such as those represented by the grand narrative of scientific progress (Hauerwas, 1990). As such, the biomedical lens situates rheumatoid
arthritis and symptomatic pain, as a rational puzzle to be solved rather than as a mystery to be understood within the intersection of self, body and culture (Morris, 1991).

**PSYCHOLOGICAL DISCOURSE AND RHEUMATOID ARTHRITIS**

**Historical Overview of Psychological Discourse**

Psychogenic factors were implicated in the etiology of rheumatoid arthritis as early as 1909 during the time of Freud (Jones, 1909 as cited in Lerman, 1987). Franz Alexander (1950), “the father of psychosomatic medicine,” included rheumatoid arthritis among seven diseases that were purportedly caused by unconscious conflicts, including “hypertension, neurodermatitis, bronchial asthma, hyperthyroidism, ulcerative colitis and peptic ulcer” (as cited in Brady, 1998, p. 77). In particular, the rheumatoid personality or “rheumatoid” (Spergel, Ehrlich & Glass, 1978, p. 79) was characterized as perfectionistic, controlling and self-sacrificing with repressed hostility somatically enacted through muscular tension and bone deformities (Brady, 1998; Lerman, 1987; Shafii, 1973; Spergel et al., 1978). Such individuals also had unresolved conflicts with parental figures who were, in turn, described as authoritative and unaffectionate (Brady, 1998; Spergel et al., 1978). In addition, difficulties with intimacy appeared to be presumed given references to a higher than normal divorce rate (Spergel et al., 1978), an impression that has not been confirmed by research over time (Revenson, 1993).

Shafii (1973) described the ancient wisdom of a Persian physician Razi (AD 850) as consistent with the modern psychodynamic treatment of rheumatoid arthritis. According to Shafii (1973), Razi created a threatening therapeutic encounter with King Amir Mansur ibn Nuh ibn Nasar that helped him “to unleash and liberate his internal anger and hostility. This dramatic encounter helped the patient realize the destructive forces within himself and
encouraged him to experience and express these aggressive feelings directly” (p. 85). Razi’s treatment included pouring hot water over the immobile body of the king (until the humours flowed), shouting and swearing until the enraged king rose to his knees, and then threatening the king with a knife until the king stood up, a recovery that eventually resulted in lavish gifts of gratitude (Shafi, 1973).

The impact of the discourse of the rheumatoid personality, as characterized by repressed instinctual anger, is clearly evident within the autobiographical account of Grace Stuart (1953) as follows:

Suppose a person to be born with some latent defect whose nature is as yet insufficiently known but whose effect is to produce an increasing disability of muscle and joint, and to lead in due course to a state in which all energetic movement of the body (not only walking and running but releasing movement of the hands in, shall we say, mixing a cake or pounding a typewriter, or even writing out the urgent catharsis of words through the end of a pen) is impossible!….

For myself, in moments of very reasonable anger which might very reasonably have been dispersed in any more normal life than mine, I have found that unable to bear any longer the unexpressed rage of the body in the ‘relaxed’ lying position which best preserves what is left of the mobility of the joints, I have gone and cleared up the kitchen, or made a batch of cakes. But even then I cannot clean a pan or a sink with enough speed and vigour to work off the slightest impulse of aggression. And in the midst of mixing a cake the eyes may fill with tears of rage and frustration because the hand and arm will not move the mix.

There is no release! No catharsis!” (p. 45)
This brilliant woman, educated in literature and psychology at Oxford, married to a minister, wrote an autobiography in response to notions that symptoms of pain and disability were symbolic of a desire to avoid the challenges and responsibilities of life.

The existence of a premorbid “rheumatoid personality” has not been established by research (Brady, 1998; Lerman, 1987), with Spergel et al. (1978), in particular, finding a lack of distinction in the Minnesota Multiphasic Personality Inventory (MMPI) personality profiles of those with rheumatoid arthritis in comparison to those with other chronic illnesses, such as peptic ulcers, low back pain and multiple sclerosis.

While Freud’s theories of psychogenesis created an additive burden to suffering through psychopathologizing, such theories also challenged the Cartesian split between organic and psychological influences, particularly in regards to the experience of chronic pain (Gatchel, 1999). However, the gate theory of pain, as advanced by Melzack and Wall (1965) was the first model to fully integrate psychological and physiological processes, given the inclusion of the central nervous system in the perception of pain (as cited in Gatchel, 1999). In 1977, psychiatrist Dr. Engle critiqued the biomedical model as essentially reductionistic, proposing a more comprehensive “biopsychosocial model” through which to understand the social, psychological and behavioral aspects of illness (Engel, 1977). Most recently, Gatchel et al. (2007) and Walker et al. (2004) advocated for the theoretical inclusion of the stress regulatory system within biopsychosocial models of chronic pain and rheumatoid arthritis, respectively.

**Present Biopsychosocial Discourse**

According to the biopsychosocial model within the field of chronic pain, pain perceptions result from a complex interaction between physiological, neurological, genetic,
psychological, cognitive and social factors that are unique to the individual (Gatchel et al., 2007). Likewise, within the field of rheumatoid arthritis, pain, functional limitations and associated disability are conceptualized as under the reciprocal influence of biological factors, psychological factors, such as affect (i.e., depression and anxiety), personality traits and coping strategies (including appraisals of self-efficacy), as well as social-environmental factors, such as psychosocial functioning, interpersonal stress and support (Keefe, Smith, Buffington, Gibson, Studts, et al., 2002; Walker et al., 2004). For example, for those with a painful chronic condition, such as rheumatoid arthritis, emotional distress, such as anxiety, depression and anger, may “predispose people to experience pain, be a precipitant of symptoms, be a modulating factor amplifying or inhibiting the severity of pain, be a consequence of persistent pain, or be a perpetuating factor” (Gatchel et al., 2007, p. 599).

Within the field of rheumatoid arthritis, cognitive-behavioural strategies that attempt to alter maladaptive cognitions, thoughts and emotions, are theoretically based on Lazarus and Folkman’s (1984) transactional model of stress and coping, whereby stressors, such as pain, are interpreted as harm/loss, threat or challenge, followed by a secondary appraisal as to whether or not resources and agency are sufficient for successful coping (as cited in Walker et al., 2004). The work of Bandura (1982) theoretically underlines the linkage of agency to self-efficacy within coping (as cited in Walker et al., 2007). In general, coping strategies are typified as those that are active, or problem-focused (such as information seeking and actions towards problem remediation), or those that are passive, or emotionally focused (such as cognitive reframing and avoidance) with the appropriateness of the strategy context-driven (Walker et al., 2004).
The relationship between pain, emotions and coping has been extensively researched within the field of rheumatoid arthritis, with findings that underline the complexity of the relationships between variables (Huyser & Parker, 1999; Keefe, Lumley, Anderson, Lynch & Anderson, 2001). In a population of 361 patients with rheumatoid arthritis (mean disease duration of 3.37 years), active coping was associated with a greater self-efficacy and lower depression, helplessness, pain and functional impairment with passive coping correlated with opposite effects (Brown & Nicassio, 1987). Likewise, Flor and Turk (1988) found that for individuals with either chronic back pain or rheumatoid arthritis (average disease duration of 10.5 years); coping self-statements and measures of resourcefulness were associated with less pain and disability with reverse findings for catastrophizing self-statements and measures of helplessness. Other researchers have similarly linked catastrophizing, or a perception that pain cannot be reduced or controlled, to higher levels of pain, disability and depression (Keefe, Brown, Wallston & Caldwell, 1989).

Research by Katz (2005) underlined certain coping strategies as particularly significant for the preservation of function for those with an established disease process (mean disease duration of 18.6 years). According to Katz (2005), coping through perseverance (in response to pain, fatigue, physical limitations, joint changes and symptom unpredictability) rather than through accommodation, active remediation or social strategies, resulted in the greatest maintenance of function over time.

van Lankveld, van’t pad Bosch, van de Putte, Näring and van der Staak (1994) found that specific coping strategies were also particularly important for the maintenance of well-being for those coping with the challenges (i.e., pain, limitations and dependence) of an established disease process (mean disease duration of 13 years), even when measures of
disease activity, functional limitations and pain were controlled for. While higher levels of pain were found to be negatively associated with well-being in general, comforting cognitions, as a coping strategy, was positively associated with well-being, whereas decreasing activity was negatively associated with well-being. In addition, distraction, as a coping strategy for pain, was found to be positively associated with cognitive measures of well-being but not associated with affective measures of well-being. Optimism was found to be the strategy most positively associated with well-being in regards to coping with limitations whereas consideration (for the needs of others) was positively associated with well-being for coping with dependence. Acceptance was not associated with well-being in regards to coping with dependence.

In contrast, Treharne, Kitas, Lyons and Booth (2005) found that optimism, or a belief in positive future outcomes, was associated with less pain, depression and greater life satisfaction for those with early and intermediate disease duration but higher pain levels for those with an established disease process. The authors suggested that optimism, as a coping strategy, might be detrimental to adaptation for those with severe pain (Treharne et al., 2005).

Bartlett, Piedmont, Bilderback, Matsumoto and Bathon (2003) also found that measures of spiritual transcendence were predictive of positive affect and positive health perceptions, even when controlling for age, disease activity, physical functioning and depression. In this regard, Zautra and Manne (1992) suggested that coping strategies may be effective through the enhancement of positive affect, rather than through the altering of negative affect, a distinction that requires further research elaboration.

The assessment of depression, in particular, is fraught with methodological difficulties given that the somatic features of rheumatoid arthritis, such as fatigue and a sleep
disturbance, render assessment tools vulnerable to an inflation bias (Young, 1992). Research efforts to establish consistent casual links between pain, depression and coping remain controversial (Parker & Wright, 1995). For example, psychological variables, such as anxiety and depression, have been found to be predictive of pain and functional impairment, even when disease activity and severity were accounted for (Hagglund, Haley, Reveille & Alarcón, 1989). Likewise, Smith, Christiansen, Peck and Ward (1994) found that cognitive distortions (catastrophizing, overgeneralization, personalization, and selective abstraction) and helplessness predicted higher levels of depression over a 4 year period for 92 patients with rheumatoid arthritis. However, in a longitudinal study involving data collection at six month intervals over a three year period, Brown (1990) found that pain predicted depression, particularly during the last 12 months of the study. Likewise, Schiaffiano, Revenson and Gobofsky (1991) found that severity of pain was associated with greater depression and disability at baseline for those recently diagnosed with rheumatoid arthritis, with pain severity associated with greater depression at 12 month follow-up.

In a four-year longitudinal study involving 648 individuals with rheumatoid arthritis, Katz and Yalin (1993) found a prevalence rate of 15-17% for depression, with those who were depressed reporting 3.6 times more painful joints, 69% higher pain ratings and 2.3 more times active disease activity in comparison to those who were not depressed. In addition, those who were depressed had significantly more medical and inpatient hospitalization for treatment of the disease process. Depression was also associated with an unmarried state, a disease of longer duration and more comorbidities in contrast to those not depressed, with previous depression greatly increasing the probability of depression in subsequent years. Covic, Tyson, Spencer and Howe (2006), in a cross-sectional survey involving 134 patients
with rheumatoid arthritis, found numerous psychological and physical variables that were predictive of depression. The top three psychological predictors of depression, also the most significant globally, included tension (including difficulties with relaxation), self-esteem and the perceived impact of the disease, particularly in recreational and physical arenas. The top three physical predictors of depression included fatigue, pain and disability. In addition passive coping, a perceived lack of control over pain and a perception that medications were unimportant, ineffective, or of concern (given side-effects) were also independently predictive of depression.

Nagyova, Stewart, Macejova, van Dijk & van den Heuvel (2005) investigated the relationship between self-esteem, adjustment to disease, pain and psychological well-being in 160 patients recently diagnosed with rheumatoid arthritis over a 4 year period. The authors found that pain explained 36% of the variance in measures of psychological well being whereas self-esteem and pain explained 52% of the variance while adjustment explained 42% of the variance in measures of psychological well-being. Higher levels of pain were also associated with higher anxiety and depression, as well as decreases in self-esteem and adjustment. Self-esteem and adjustment were identified as important mediators between pain and psychological well-being, with the former variables particularly important with disease progression. This finding was consistent with longitudinal research (over a four-year time span) by Smith and Wallston (1992) who found a reciprocal and “vicious” (p. 151) link between helplessness and passive coping that contributed to deceased function and psychosocial impairment, which decreased perceived competence and emotional support, reduced life satisfaction, lowered perceptions of health and contributed towards increased depression and pain. Likewise, Covic, Adamson, Spencer and Howe (2003) found an inter-
relationship between coping, depression and pain, with helplessness and passive coping
identified as mediators of future pain and depression, accounting for 29-43% of the variance
in pain and 21-33% of the variance in depression over a 12 month period.

Research findings by Katz and Yalin (2001) underlined the significance of the
meaning of psychosocial impairment in the etiology of depression. The authors found that,
for those with greater functional disability, the onset of depression was linked to the inability
to engage in valued life activities, particularly those that were recreational and social in
nature (Katz & Yalin, 2001). Likewise, Neugebauer, Katz and Pasch (2003) found that
poorer functional status, greater disability in valued activities and unfavorable social
comparisons all predicted low satisfaction with abilities, which was, in turn the most
significant predictor of depression.

According to Revenson’s (1993) research review, social support has been found to be
beneficial for those with rheumatoid arthritis in regards to measures of self-esteem,
adjustment, life satisfaction or coping. Findings by Fitzpatrick, Newman, Lamb and Shipley
(1988) suggested that satisfaction with support, whether within close or more diffuse
relationships, was more important to psychological well-being than the availability of
support. For example, Manne and Zautra (1989) found that a supportive spouse had a
beneficial effect on psychological well-being, given that patients engaged in more problem-
focused coping, whereas as a critical spouse had a detrimental effect, with partners leaning
towards emotionally-focused coping, such as wishful thinking. However, Fitzpatrick et al.
(1988) also found that a more extensive social network was associated with higher self-
esteeem and lower depression, irregardless of the severity of disease and disability.
Research investigating the effectiveness of various cognitive-behavioural programs for those with rheumatoid arthritis appears ambiguous in findings. A meta-analysis of 31 randomized controlled studies investigating patient education interventions reported that significant effect sizes were obtained at first follow-up for disability, joint count, patient global health assessment, psychological status and depression (with no significant effects found for anxiety, pain and disease activity), although benefits were not maintained at follow-up (Reimsma, Kirwan, Taal & Rasker, 2004).

Parker et al. (1995) also investigated the effectiveness of stress-management programs for arthritis patients, with significant improvements reported in measures of helplessness, self-efficacy, coping and health status (as in improved lower extremity function) that persisted to 15 months follow up. However, research findings were less clear for pain, with no difference reported between the treatment and control groups at 3 months follow-up, with marginally significant results reported at 15 months follow-up. In addition, there were no significant long term effects on measures of anxiety, depression or daily stress, a finding that was partly attributed to low baseline scores (Parker et al., 1995).

Astin, Beckner, Soeken, Hochberg and Berman (2002) investigated the effectiveness of relaxation, biofeedback and cognitive behavioural therapy through a meta-analysis of 25 controlled studies. While significant postintervention effect sizes were found for pain, disability, psychological status, coping and self-efficacy, at approximately 8.5 months follow-up, effect sizes were nonsignificant for pain and functional disability (although persistently significant for tender joints, psychological status and coping). No significant differences were found in the efficacy of various treatments. The authors remarked on the
low treatment effect sizes for patients with longer disease duration, speculating that psychological interventions were less appropriate for this population (Astin et al., 2002).

Likewise, other researchers have questioned the appropriateness of various cognitive-behavioural strategies for those with a more severe disease process (Affleck, Tennen, Pfeiffer & Fifield, 1987; Affleck, Urrows, Tennen & Higgins, 1992; Erdal & Zautra, 1995; Treharne et al., 2005). For example, Affleck et al. (1987) reported that perceptions of control over daily symptoms were associated with less mood disturbance for those with moderate or severe symptoms. However, a perception of control over disease course was associated with a greater mood disturbance for those with a more severe disease, but not for those with a mild disease. Affleck et al. (1992) also found that distraction and emotional support were associated with a more positive mood for low pain, whereas the reverse was found for high levels of pain. Schiaffino, Revenson and Gibofsky (1991) found that greater self-efficacy beliefs were linked to greater depression for those with severe pain in spite of the psychological benefits found for those with less pain.

However, Gatchel et al. (2007) has stressed the possible risks in acceptance based approaches for those with chronic pain, noting that “to simply give up or give in would appear to be a certain route to depression” (p. 604). Research has not determined whether or not acceptance and the relinquishment of behavioral control may be psychologically adaptive for those with rheumatoid arthritis (Zautra & Manne, 1992). This research frontier is particularly relevant for those with established arthritis, given that pain is a significant stressor (Melanson & Downe-Wamboldt, 2003; Minnock, FitzGerald & Bresnihan, 2003) that exists alongside the challenges of coping with physical limitations and the associated maintenance of independence (Melanson & Downe-Wamboldt, 2003). According to research
by Erdal and Zautra (1995), those with chronic arthritis (type unspecified) experienced the greatest psychological distress, pain and least reported psychological well-being in comparison to three other conditions (chronic vision problems, new vision problems and new arthritis problems), when confronted with the physical and psychological effects of an illness downturn. Contrary to expectations, previous experience with coping had not psychologically prepared individuals to weather the storm, but rather added a burden to existent suffering (Erdal & Zautra, 1995).

Recent recommendations for the inclusion of the stress regulatory system in biopsychosocial models of pain (Gatchel et al., 2007) and adaptation to rheumatoid arthritis (Walker et al., 2004) has underlined the environment and socio-cultural context as particularly salient issues in understanding rheumatoid arthritis as an autoimmune disorder. However, understanding the impact of stress on disease activity remains elusive, given that major stress, such as the death of a spouse, may have a suppressant effect, while interpersonal stressors, such as conflict, may trigger an exacerbation given different effects with the stress regulatory system. (Potter & Zautra, 1997; Walker, Littlejohn, McMuray & Cutolo, 1999; Zautra et al., 1989). Likewise, research investigating the role of stress in relation to disease onset remains inconclusive (Brady, 1998; Stewart, Knight, Palmer & Highton, 1994; Walker et al., 1999).

However, extensive research has documented the adverse effect of minor life stressors (Potter & Zautra, 1997; Zautra et al., 1994; Zautra et al., 1989) and interpersonal stressors, in particular (Zautra et al., 1994; Zautra et al., 1998; Zautra et al., 1997) as evidenced through heightened markers of immune response and disease activity. For example, Zautra et al. (1994) investigated the relationship between minor desirable and
undesirable events, interpersonal stress, coping style, depression, subjective and objective
ratings of disease activity as well as blood markers of immunostimulatory activity for 33
women with rheumatoid arthritis and 37 women with osteoarthritis. While both groups were
similar on numerous baseline measurements (i.e., pain, stressful events, positive life events,
clinician ratings of disease activity and depression), findings suggested that those with
rheumatoid arthritis were more physiologically and psychologically reactive to interpersonal
stress than those with osteoarthritis. For example, interpersonal conflict was significantly
associated with increased measures of depression, immunostimulatory activity and clinician
assessments of disease activity for those with rheumatoid arthritis, but not for those with
osteoarthritis. In addition, those with rheumatoid arthritis with higher scores on depression
and those who rated their coping as ineffective showed higher levels of immunostimulatory
activity.

Zautra and Smith (2001) subsequently investigated the relationship between
depression and weekly measures of interpersonal stress, pain and negative affect for older
women with rheumatoid arthritis (n= 87) and osteoarthritis (n= 101) over a minimum 12
week period. While both groups reported greater pain during weeks of interpersonal stress,
depression had a more significant influence on the relationship between interpersonal stress
and pain for those with rheumatoid arthritis. In addition, interpersonal positive events had a
buffering effect between perceived stress and pain for those with rheumatoid arthritis but not
for those with osteoarthritis.

Zautra et al. (1997) investigated the relationship between interpersonal stress, disease
activity (based on self-report and clinical ratings) and blood markers of immune activity over
a 12 week period for 41 women with rheumatoid arthritis. Blood markers of immune activity
as well as objective and subjective appraisals of disease activity were taken during times of high interpersonal stress. An increased number of interpersonal stressors in a week were associated with increases in joint tenderness and pain as well as blood markers of disease activity. Zautra et al. (1998) subsequently reported that women with a critical spouse had significant increases in blood markers of immunostimulatory and disease activity in response to interpersonal stress while a strong spousal relationship had a buffering effect. In particular, interactions with highly supportive spouses buffered the increased levels of anxiety and depression associated with interpersonal stress whereas interactions with emotionally or physically affectionate spouses buffered blood markers of disease activity following interpersonal stress.

Affleck, Tennen, Urrows and Higgins (1994) also used a prospective daily research design to investigate the relationship between stress (undesirable daily events), disease activity and mood for 74 individuals with rheumatoid arthritis over a 75 day recording period. A significant relationship was found between same-day mood and stressful events, with a positive relationship reported between stress and same-day and next day-pain for those with a more active disease process, with the latter also reporting more pain and negative mood in general. In addition, those individuals with higher levels of social support had less emotional distress after undesirable life events, in contrast to those with low levels of social support.

Based on the assumption that emotional inhibition has an adverse effect on the immune system, researchers have also explored the benefits of expressing negative emotions. Kelley, Lumley and Leisen (1997) randomly assigned 72 rheumatoid arthritis patients to either a control group, or a disclosure group, with the former group instructed to describe a
landscape picture and the latter group instructed to recount a very distressing experience for 15 minutes per day over a four-day period. While no significant differences were found between groups at two weeks post intervention, at three months post intervention, the disclosure group reported less affective disturbance and better physical functioning in comparison to the control group, with no significant differences reported for either pain or disease activity. Likewise, Smyth, Stone, Hurewitz and Kaell (1999), investigated the effect of emotional disclosure for a group of asthma patients and a group of rheumatoid arthritis patients, with random assignment into a disclosure group (with instructions to write about their most stressful experience) and a control group (with instructions to write of an emotionally neutral topic). While significant improvements in lung function were reported for the asthma disclosure group (in contrast to the asthma control group), at 2 weeks, 8 weeks and 16 weeks post intervention, the rheumatoid arthritis disclosure group (in contrast with the rheumatoid arthritis control group) had significant reductions in ratings of overall disease activity at 16 weeks post intervention, but not prior.

**Summary of Biopsychosocial Discourse**

Psychological discourses associated with the etiology and treatments of rheumatoid arthritis have shifted over time, based on the philosophical premises that are situated within specific historical contexts. The theory of psychogenesis, and related psychodynamic treatments (Lerman, 1987; Shafii, 1973; Spergel et al., 1978, Stuart, 1953) has been replaced by the biopsychosocial model (Gatchel et al., 2007; Walker et al., 2004), with treatments primarily cognitive-behavioural in nature. However, the biopsychosocial model, while intended to challenge medical bioreductionism (Engel, 1977), has been critiqued for the typical exploration of biological, psychological and social influences without holistic
considerations (Yardley, 1996). The recent theoretical acceptance of the reciprocal, rather than independent, relationship between emotions and pain (Gatchel et al., 2007; Keefe et al., 2001), suggested a shift towards greater holistic consideration. Likewise, recent recommendations for the inclusion of the stress regulatory system within the biopsychosocial model (Gatchel et al., 2007; Walker et al., 2004) has the potential to incorporate socio-cultural influences that have been otherwise marginalized.

While researchers have questioned the effectiveness of various cognitive-behavioural strategies for those with a more severe disease process (Affleck et al., 1987; Affleck et al., 1992; Astin et al., 2002; Erdal & Zautra, 1995; Schiaffino et al., 1991; Treharne et al., 2005), alternative coping recommendations are lacking. Elderly women with a longstanding disease are particularly vulnerable to challenges to their psychological well-being, given the requirements of adaptation within ongoing physical deterioration, limitations and pain (Melanson & Downe-Wambold, 2003; Minnock et al., 2003) coupled with the reduced effectiveness of medical treatments over time (Anderson et al., 2000; Moreland et al., 2001).

According to Walker et al. (2004), there is limited psychological research that has investigated the subjective experience of rheumatoid arthritis and the associated reconstruction of meaning within the illness experience. While physicians have been invited to empathetically enter the experiential world of chronic illness (Kleinman, 1988), such an invitation was ironically lacking in the psychological discourses reviewed. As such, the predominant psychological discourses situated the client as an individual to be fixed or educated, rather than empathetically supported and understood.

The following excerpt from the autobiography of Grace Stuart (1953) underlined the contradictions and ambiguities implicit within attempts to psychologically comprehend affect
outside of the complexities of lived experience, observations that remain astute to the present day.

But as to hospital psychology, I did just wonder what ‘they’ taught ‘them’. It was a young student in his final year who made, on one small sheet, the record of my thirty-three years of disease! ‘Are you worried about anything?’ he asked me paternally, ‘No,’ said I, and the lie went down. Hadn’t ‘they’ told him that one would be bound to lie in answer to such a question, to which, in any case, in such circumstances, only a few minutes could have been devoted? That even a semi-mature person would and should only have discussed all the psychological and human implications of worsening disability with some very chosen, some very wise person? And that, even then, it would take a very long time. It needs no ‘modern’ psychoanalyst! If he had read his Shakespeare he would know that not in a moment is the stuff’d bosom cleansed of all that perilous stuff which weighs upon the heart.

Had he known my worries—even then? Well, he would have had to know how ‘real’ these were; what objective case there was in my life for concern; and in what manner I, personally, reacted to ‘real’ anxiety. Or, if my ‘worry’ were subjective, and in no way connected the contemporary circumstances of my life, he would then have had to know if it were also a repetition of an anxiety situation to which I had always been prone, and with which I was emotionally incapable of coming to terms? And, further, whether this state of affairs maintained at, and before, the onset of the disease.

Even then——What, after all, do we know yet of the exact relationship between endocrine and emotional disturbance, and which predates which, and how
they interact? Very little! Most of it is still to be learnt. But it has long been in my mind that if more thorough personal records had been kept we might have been on to the nature of the very complex disturbance, which is rheumatoid arthritis, a long time ago (p. 165).

**Subjectivity and Rheumatoid Arthritis**

While psychological research is lacking in regards to the subjective experience of rheumatoid arthritis, nursing and sociology scholars have made significant contributions towards the understanding of the chronic illness experience. Fair (2003), explored the disparate explanations of rheumatoid arthritis between 17 female patients (aged 26 to 40 years) and 5 health care providers. Themes identified by the women reflected physical and emotional suffering, interferences in daily life, and aggravations in receiving health care. In addition, the women described the ways in which rheumatoid arthritis had redefined them, both positively and negatively. In contrast, health care provider themes typically focused on efforts geared towards the maintenance of function and the control of the disease process. Patients described the provider-patient relationship as typically lacking in regards to partnership, education and support. Fair (2003) identified the implicit power imbalance with the provider-patient relationship as a dynamic that interfered with effective communication, also noting that disparate understandings adversely effected treatment outcomes.

Iaquinta and Larrabee (2004) explored the experiences of 6 women with rheumatoid arthritis (ranging from 43 to 67 years of age; disease duration of 7 to 38 years), including questions regarding their experience with nurses and their role as comanagers of healthcare. The authors identified several research themes that encompassed experience, including that of grieving while growing, an essentially transcendent experience gained through the
experience of loss (Iaquinta & Larrabee, 2004). Participants described difficulties in receiving validation for symptoms, in part due to the invisibility of symptoms as well as efforts taken to socially mask illness. Participants were also reluctant to discuss their symptoms with others, given past unwanted reactions. Participants were unanimously described as cultivating resilience, primarily through perseverance, although negative feelings, such as anger, frustration, fear and depression were commonly experienced. In particular, fears were associated with the potential adverse effects of pharmaceuticals, the disease process in general, including future deformities and dependency, and difficulties in the maintenance of professional and personal roles. Participants also identified numerous dissatisfactions with medical care, including inadequacies in appointment duration, education provided and treatment focus, as well as difficulties with access during times of disease exacerbation, while also noting the relative absence of nurses in their health care. In general, participants were described as masterful in their management of symptoms and their lifestyle adaptations. Similar research themes were identified by Brown and Williams (1995) in the narratives of 7 women with rheumatoid arthritis including the process of help-seeking (and associated dissatisfactions with health care providers), a search for the meaning, in regards to the etiology of the disease, and the impact of symptom uncertainty within changing roles and dependency.

Shaul (1995) explored the process of adaptation through the research narratives of 30 women with rheumatoid arthritis. The first stage of adaptation, defined as “becoming aware,” was marked by initial symptom presentation and experiences associated with obtaining a diagnosis. Participants reported that initial symptoms were frequently misdiagnosed or minimized, with one participant referred to a psychiatrist as symptoms were
diagnosed as psychosomatic. The second stage, defined as “learning to live with it,” was characterized by symptom management, including a reorganization of personal priorities and goals. According to Shaul (1995), symptoms universally reported included depression, stiffness, joint swelling, fatigue and pain, with the latter two symptoms most frequently associated with increased feelings of depression and despair. Participants reported that guidance, referral to restorative therapies and coordination of services was lacking within health care. This finding was consistent with research by Fair (2003), given that research participants frequently described a lack of coordination between health care providers. Shaul (1995) defined the final stage of adaptation as “mastery,” or an ability to live with, rather than control, rheumatoid arthritis, a stage that was associated with a redefinition of normality and a reconstruction of identity.

Likewise, Dildy (1996) investigated the process of suffering associated with rheumatoid arthritis within the experience of 14 participants, identifying a progressive movement through a disintegrated and shattered self to a reconstruction of self within the chronic illness experience. The first phase was marked by fears related to the loss of independence and self-sufficiency with the second phase characterized by severe pain, exhaustion, mental anguish, as well as extreme physical limitations and restrictions. The final phase was marked by a determination to overcome feelings of hopelessness (occasionally marked by suicidality) while working towards a state of acceptance and personal growth. Neill (2002) and Schmidt, Brauer, and Peden-McAlpine (2003) have likewise stressed the experience of rheumatoid arthritis as providing an opportunity for personal growth and positive transformation.
Plach, Stevens, and Moss (2004) investigated the experience of 20 women with rheumatoid arthritis (average age of 61 years and disease duration of 5 to 10+ years). Research themes identified within the category of corporeality, or “being one’s body,” included that of relating to a noncompliant body, a body out of synch, and a private body made public. Participants described frustrations with noncompliant bodies, voicing feelings of humiliation when they were not able to perform intimate self-care, negatively evaluating their bodies against earlier expectations and those of their peers. In addition, participants described efforts directed towards hiding their pain, impairments and deformities from others, given that “smiling through the discomfort and acting normal was the goal” (Plach et al., 2004, p. 145). Hand deformities were identified as particularly humiliating, given the impossibility of maintaining social privacy. The authors found that the reality of corporality permeated the experience associated with rheumatoid arthritis, including self-appraisals, disease-appraisals, as well as the coping strategies utilized (Plach et al., 2004).

Melanson and Downe-Wamboldt (2003) interviewed 48 individuals (39 women; mean age, 75 years; mean disease duration of 18 years) in order to assess the illness-related stressors that were particular to the elderly with established disease. The predominant illness-related stressors explored included physical limitations, lack of control or difficulties maintaining independence, and pain. While coping strategies were context driven, the predominant strategy utilized was confrontative or problem-focused in nature. Very few participants described any sense of benefit gained from stressors associated with rheumatoid arthritis, with emotional responses to illness-related stressors primarily negative. These findings were consistent with research by Minnock, Fitzgerald and Breshnihan (2003), who reported that pain was the predominant impairment to health for those with an established
disease (mean disease duration of 14 years), albeit in a younger age bracket (mean age, 50.5 years), with 52% of respondents rating their health status as fair, poor or very poor in comparison to their peers, with the majority anticipating continued deterioration.

Hewlett et al. (2005) interviewed 15 rheumatoid arthritis patients in the United Kingdom as to their experience of fatigue, a predominant somatic symptom frequently referenced by other researchers (Dildy, 1996; Plach et al., 2004; Shaul 1995). Two types of fatigue were identified, that of a severe intrusive weariness and that of sudden and overwhelming fatigue, symptoms that had physical, emotional and cognitive components, with consequences that permeated every aspect of life. Participant’s efforts at self-management were limited in their effectiveness with professional assistance rare. The primary reliance on perseverance as a coping strategy was attributed to the participant’s Anglo-Saxon background.

Edwards, Mulherin, Ryan and Jester (2001) investigated the inpatient hospital experiences of 9 women with rheumatoid arthritis with a disease duration ranging from 3 to 42 years. Five research themes were identified, including the experience of uncertainty associated with the first admission to hospital, the process of becoming an experienced patient, the positive and negative effect of other patients, experiences with staff and the impact of loss of privacy. While the first hospital admission was marked by feeling of loss of control, experienced patients described a sense of comfort during hospitalization. Younger participants, in particular, described contact with elderly patients as distressing, given their exposure to the physical effects of an established disease process. Younger participants also found the lack of privacy as degrading, referencing the reinforcement of a negative body image.
Numerous sociologists (Bury, 1982, 1988; Charmaz, 1983, 1995; Corbin & Strauss, 1987; Williams, 1984) have also explored the experience of chronic illnesses using narrative means to explicate the process of meaning reconstruction. Using the research narratives of 30 individuals with rheumatoid arthritis, Williams (1984) explored the process of narrative-reconstruction focusing on the influence of biomedical and lay etiological beliefs. Three research narratives were presented in depth, a process which underlined the uniqueness of situated meaning in the reconstruction process. For example Bill viewed the etiology of his illness as due to toxicity and exploitation within the workplace; and Gill viewed her illness as stress-induced, both within the context of the suppression of her needs as a woman and as related to devastating loss within the context of her roles whereas Betty did not voice any beliefs in etiology, positioning her experience within the transcendence of God’s purposes.

Pinder (1995) investigated the work-related experiences of 25 chronically ill individuals (11 with rheumatoid arthritis), in order to explore the intricacies of the challenges and dilemmas that exist within the intersection of self, body and the work environment. One participant, Elaine, a woman with rheumatoid arthritis, was abruptly forced out of the workforce when her boss was unwilling to accommodate her needs. Sally, a woman with psoriatic arthritis, in spite of moderate disability, was able to maintain employment with relatively minor disruption given the understanding and support offered by her supervisor.

Charmaz (1983) identified the loss of self as a fundamental form of suffering within the chronic illness experience, particularly for those who were seriously debilitated or housebound. Based on interviews of 57 chronically ill individuals, four interrelated sources of suffering were analyzed including the experience of living a restricted life, the experience of social isolation and social discreditation, or devaluation, as well as the experience of
becoming a burden to others. Charmaz (19983) poignantly singled out the experience of a young woman with rheumatoid arthritis who was the target for bullying by school age children, a vulnerability that was attributed to her small stature and laboured gait.

Charmaz (1995) described the final stage of adaptation to loss and physical impairment as one of ultimate surrender, a relinquishment of control over the chronic illness experience that was replete with spiritual overtones. According to Charmaz (1995), “…surrendering to the sick body strips the journey of routine distractions and obstacles, conditions exist for ill persons to experience self anew and to continue the odyssey with renewed clarity and purpose. In this sense then, adapting to impairment fosters redemption and transcendence of self” (p. 675).

Likewise, Frank (1995) highlighted the moral nature of suffering in the description of the three core illness narratives (i.e., restitution, chaos and quest narratives) that follow the “narrative wreckage” of chronic illness. According to Frank (1995), the recounting of one’s story is essential to the reconstruction of meaning, with others under moral imperative to provide a witness to these accounts. For Frank (1995), embodiment was central to re-narration, given that, “the body sets in motion the need for new stories when its disease disrupts the old stories. The body, whether still diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told” (p. 2). While the restitution narrative was defined by a return to the former self, the quest narrative bore witness to personal heroism within the search for meaning and personal change. Frank (1995) underlined the chaos narrative as marked by ongoing chaos and a lack of narrative coherence in regards to the past, present and future. According to Frank (1995), such embodied
accounts require empathetic witnessing, consistent with Scarry’s (1983) observation of the need for witness and advocacy for those disempowered by severe pain.

Bury (1982), using the research narratives of 30 individuals with rheumatoid arthritis, also described the chronic illness experience as a process of biographical disruption. According to Bury (1982), disruption occurred in three ways, through the effects of the physical illness, within the self-concept and explanatory systems of biographies and in the disruption incurred by the mobilization of resources. Bury (1988) subsequently described the pragmatic meaning of rheumatoid arthritis as having two aspects: one, the consequences of the illness for the individual and, secondly, the cultural connotations or significance of the illness that infuses the social context. Within the family system, in particular, the legitimacy of the illness and the negotiation of support are fraught with ambiguity, with the meaning of the illness emerging over time (Bury, 1988). According to Bury (1988), “the sufferer and ‘significant others’ are pitched into a situation of considerable insecurity where past, present and future meanings, are placed ‘at risk’. Images of self, of others and the disease are tested against the constraints of practical social life and of the expectations governing behaviour in the wider culture” (p. 113). Anxiety stems “not so much from the individual’s personality or intelligence, or the ‘coping skills’ they have at their disposal, but from the clash between loss of confidence in the body and the implications this has for maintaining culturally ordered meanings” (p. 113). Additional social ambiguities exist for those with rheumatoid arthritis, given a disease process that may be inconsistent and unpredictable, leaving the requirements of treatment and support in a state of flux (Revenson, 1993).

Sociologists Corbin and Strauss (1987) likewise situated the process of biographic disruption and reconstruction associated with the experience of chronic illness (cancer,
cardiovascular disease and spinal cord injury) within the reciprocal interactions of self concept (identity), biographical time (past, present and future) and the body. According to Corbin and Strauss (1987), the body is the medium through which self concept is formed, the conduit of communication, an object as evaluated by others and the vehicle for performance. Corbin and Strauss (1987) described biographical reconstruction as precipitated by body failure, given the need to accommodate changes within the present and future. In the process of adaptation, “embracing the future,” and the associated acceptance of present circumstances remained predicated on hope, as “without hope there is no incentive” (p. 271). According to Corbin and Strauss (1987), acceptance does not imply happiness but rather “a way of biographically accommodating to an illness through altered or changed performances, and in doing so to give meaning to life despite ongoing and progressive body failure” (p. 271). Occasionally, acceptance shifts to transcendence, in that the body is “overcome,” (p. 271) and personal meaning enhanced (Corbin & Strauss, 1987). However, a persistent downward illness trajectory was found to shatter narrative coherence and associated adaptation, with the impact feeding despair and the potential for suicide (Corbin & Strauss, 1987).

The theoretical importance of embodiment within the process of meaning reconstruction was similarly reflected in the research findings of Dildy (1996) and Charmaz (1983). Dildy (1996) identified lack of pain control as constraining positive (or transformative) meaning-making within the experience of suffering associated with rheumatoid arthritis. Likewise, Charmaz (1983) identified the need for physical improvement with stabilization prior to any benefit finding within the experience of a debilitating chronic illness, such as rheumatoid arthritis.
Summary of Subjectivity and Rheumatoid Arthritis

Research investigating the lived experience of rheumatoid arthritis has reflected themes of loss, endurance, accommodation and transcendence. Sociologists (Bury, 1982; 1988; Charmaz, 1983; 1995; Corbin & Strauss, 1987; Williams, 1984) and nursing scholars (Iaquinta & Larrabee, 2004; Plach et al., 2004; Shaul, 1995) alike, position identity reconstruction and subjectivity (as part of the chronic illness experience) within the intersection of the self, body and socio-cultural context. In this regard, researchers identified embodiment, either explicitly or implicitly, as an essential influence within the chronic illness experience (Bury, 1982; 1988; Charmaz, 1983; 1995; Corbin & Strauss, 1987; Dildy, 1996; Frank 1995; Iaquinta & Larrabee, 2004; Plach et al., 2004; Shaul, 1995) with the need for physical stabilization frequently accentuated as a precondition for constructive meaning-making (Charmaz, 1983; Corbin & Strauss, 1987; Dildy; 1996; Frank, 1995).

SUICIDE DISCOURSE AND RHEUMATOID ARTHRITIS

Historical Overview of Suicide Discourse

Ancient Greco-Roman thought was philosophically permissive towards suicide, even glorifying suicide as a willful act of heroism when the preservation of honour was at stake (van Hooff, 2000). In a case study review of 89 ancient suicides, Siedal (1995) found that suicide was associated with old age, pain, illness, military catastrophe, political conflict, madness, mental decline as well as grief, depression and anxiety.

According to a historical analysis by van Hooff (2000), St. Augustine (342-430) established the doctrine of self-killing as a mortal sin, an act that was subsequently criminalized during the 14th century. Van Hooff (2000) traced the development of a more tolerant view to the Reformation and Renaissance (16th -17th century), partly in response to
the reinterpretation of biblical texts given that self-killing was reframed as potentially holy, as with the martyrs and the crucifixion (van Hooff, 2000). According to van Hooff (2000), by the 19th century, self-killing was associated with mental suffering, philosophically shifting suicide from the religious to the scientific realm.

Present Suicide Discourse

Present cultural discourses regarding the morality of suicide center on whether or not the act may be regarded as rational, particularly as a response to unremitting suffering (Kleepsies, Hughes & Gallacher, 2000; Maris, Berman & Silverman, 2000), a discourse that mirrors early Greco-Roman thought (van Hooff, 2000; Siedel; 1995). Suicide, as a rational option for the elderly, has gained widespread acceptance within western cultures (Humphry, 1991; Kleepsies et al., 2000; Rosenfeld, 2004), with societal endorsement extending to more global issues, such as incapacitation, deteriorating health, limited resources and being a burden to others (Sorenson, 1991). According to Kleepsies et al. (2000), such acceptance reflects a desire to exert control over the dying process, given the increased mortality from chronic, rather than acute illness, and the availability of technology that may extend life beyond a meaningful existence.

The acceptance of rational suicide extends to psychologists, with 88% of psychotherapists endorsing suicide as potentially rational for situations involving terminal illness and physical pain as well as, psychological pain (such as severe intractable psychosis and depression), physical deterioration, mental debilitation (such as with Alzheimer’s or Huntington’s chorea), a poor quality of life (such as the completion of a life’s work) and hopeless nonmedical conditions, such as a catastrophe (Werth & Corbin, 1995). According to a survey of registered social workers in British Columbia, Canada, 75.9% of respondents
thought that voluntary euthanasia should be legalized, with 78.2% similarly endorsing
physician-assisted suicide (Ogden & Young, 1998).

Conwell, Duberstein and Caine (2002) predicted that suicide amongst the elderly will
be increasingly relevant given the aging of a post-World War II cohort group marked by
higher suicide rates than preceding or subsequent generations. According to the World
Health Organization (2002), suicide rates in Canada peaked in the 45-54 age groups per
100,000 for both sexes (28.0 for men; 7.7 for women). There was a gradual decline for men
until age 75+, whereupon rates increased to 23.7 per 100,000. Women experienced a more
marked decline in the 65-74 age groups, to 3.4 per 100,000, and continued to decline in the
75+ age group to 2.7 per 100,000. In contrast, suicide rates for the United States of America
showed a similar peak for both sexes in the 45-54 age group, with a gradual decline for
women, but a marked increase for men in the 75+ age group (at 40.7 per 100,000). In spite of
differences in the magnitude of elderly suicide rates between the United States and Canada,
these findings suggest that elderly suicide, particularly in the 75+ age group, is a significant
later-life mental health issue, particularly for men.

Increasing age, gender (male), ethnicity (Caucasian) and marital status (unmarried)
have been associated with an increased risk for suicide (Pearson, 2000). In general, elder
suicides have more depressive illness, less psychotic disorders and less substance abuse as
compared to younger suicides (Conwell & Brent, 1995). The stressful life circumstances
which precede elder suicide also vary with younger suicides in that they are more related to
physical illness and loss rather than relationship, financial or legal difficulties (Conwell,
1997). Goldblatt (2000) identified numerous characteristics of physical illness that may
create a predisposition to suicide including chronicity, debilitation, unremitting pain, forced dependence and cognitive impairment.

However, the exact relationship between the burden of physical illness, depression, and suicide remains elusive. While physical illness and functional impairment have been identified as risk factors for elderly suicide, research has suggested that the presence of an affective disorder (typically the first episode of a unipolar depression) mediates this relationship (Conwell & Brent, 1995; Conwell, Duberstein & Caine, 2002). In a case-controlled study of elderly suicides in primary medical care (Conwell et al., 2000), completed suicides were found to have more depressive illness, greater physical burden and functional limitations than age-matched controls although physical health measures and overall function did not distinguish between groups once mood disorders were controlled for.

According to Conwell (1997) 62% of elderly patients had seen a primary care physician in the 30 days prior to suicide with an average 36% having seen a primary care physician within the prior 7 days. Likewise, Luoma, Martin and Pearson (2002) found that 58% of older adults (age 55 and older) had contact with a primary care provider within a month of suicide, while 11% had contact with a mental health professional in contrast to younger adults (aged 35 and younger) with contact rates of 23% and 15% respectively. In general, crisis intervention with the suicidal elderly is more difficult than with younger individuals in that they are more determined to commit suicide, take steps to avoid detection and also use more violent means (Conwell et al., 2002).

According to Leenaars (2003), elderly suicide notes differ from younger suicides in that they are less ambivalent, less suggestive of redirected aggression and more direct regarding reasons for suicide. In contrasting the elderly suicide notes of the terminally ill
with the nonterminally ill, Leenaars (2003) found that both contained psychological pain, cognitive constriction and unresolved life difficulties, yet the former notes made specific reference to their illness as the primary motivating factor. Using the physician-assisted suicide of Freud as an exemplar, Leenaars (2003) suggested that such suicide be more appropriately described as a “dignified death,” “assisted death,” or a “self-chosen death” (p.10).

Research has repeatedly found hopelessness (defined as a cognitive distortion marked by negative future expectancies) to be highly correlated with suicidal ideation and predictive of eventual suicide in psychiatric adult populations (Beck, Brown & Steer, 1989; Beck, Kovacs & Weissman, 1975; Beck, Steer, Beck & Newman, 1993; Beck, Steer, Kovacs & Garrison, 1985). In this regard, hopelessness, rather than the severity of depression, was found to be predictive of eventual suicide for those previously hospitalized with suicidal ideation (Beck et al., 1985). Likewise, Beck et al. (1993) found that hopelessness was 1.3 times more effective than depression in predicting suicidal ideation in hospitalized patients diagnosed with or without a mood disorder. Beck et al. (1975) also suggested that hopelessness was the mediating variable between depression and suicide, also providing an explanation for those suicides that occurred without evident depression.

However, the role of hopelessness has not been clearly demonstrated in research investigating elderly suicides (Pearson, 2000). For example, hopeless, as measured by the Geriatric Hopelessness Scale, was found to be significantly correlated with depression and behavioral measures of cooperation and social contact but not suicidal behavior or ideation for a group of inpatients in an acute psychogeriatric unit (Trenteseau, Hyer, Verenes & Warsaw, 1989). Hill, Gallagher, Thompson, and Ishida (1988) found that health status,
depression and hopelessness were all predictive of suicidal ideation in a group of elderly psychiatric outpatients, with depression, rather than hopelessness, contributing the greatest percentage of predictive variance.

Other studies have found a central role for hopelessness as a predictor of elderly suicidal ideation and completed suicide. Rifai, George, Stack, Mann and Reynolds (1994) found that hopelessness was significantly associated with a previous suicide attempt in a group of elderly psychiatric outpatients with a major recurrent depression, with a high degree of hopelessness persisting following the treatment and remission of depression. In a study of traumatic deaths within a retirement community, Ross et al. (1990) found that marital status (widowed or divorced), hypersomnia, excessive alcohol use and a poor mental outlook were all significantly predictive of suicide. The two mental status questions most highly predictive of suicide included “not feeling hopeful about the future,” and “not feeling useful and needed” (Ross et al., 1990). The authors also reported that, of the 5 chronic illnesses identified, including diabetes, myocardial infarction, stroke and cancer, only rheumatoid arthritis was significantly predictive of accidental death (Ross et al., 1990).

Research has also linked hopelessness and suicidal ideation for elderly patients with a terminal chronic illness. Chochinov, Wilson, Enns and Lander (1998) found that hopelessness (defined as a lack of purpose), while significantly correlated with depression, was independently the most predictive of suicidal ideation for palliative inpatients (average age 71 years) with advanced cancer.

Research investigating attitudes and requests for euthanasia (or hastened death through direct physician intervention) and physician-assisted suicide (or suicide through indirect physician intervention), also underlined the relationship between suicide, depression,
hopelessness and debilitating chronic illness in the elderly. Wilson et al., (2000) reported that 73% of palliative cancer patients (average age 64.5 years) associated with two Canadian oncology wards, were in support of euthanasia or physician-assisted suicide. Reasons provided for such endorsement included the right to choose (43%); pain (43%); diminished quality of life (35%), suffering (24%); hopeless situation (24%); mental symptoms (18%); burden for others (14%); physical symptoms (other than pain) (10%); and knowledge of others’ end-of-life experiences (8%). Amongst participants, 8 (12%) also said that they would have requested a hastened death if such actions had been legal at the time of the interview. Such individuals differed significantly from those with no such desire on numerous measures, including the severity of physical symptoms, as in drowsiness and weakness, rather than pain severity, loss of interest or pleasure in activities, hopelessness, loss of control and desire for death, as well as a higher incidence of depressive disorders although methodological inconsistency was reported in the latter finding. While 7 of these 8 patients died within 4 months, one patient medically improved and lived for a further 20 months.

According to a Canadian National Palliative Care Survey of 379 palliative care patients, 62.8% believed that euthanasia or physician-assisted suicide should be legalized; with 39.8% indicating that they would contemplate such actions in the future, if legalized (Wilson et al., 2007). In addition, 5.8% of patients indicated that they would choose such actions if legal (at the time of the survey), with the top 5 symptoms and concerns reported including weakness (86.4%); a desire for death (81.8%); general malaise (68.2%); drowsiness (59.1%) and being a burden to others (59.1%). The desire for a hastened death was associated with lower religiosity, reduced functional status, a diagnosis of depression as
well as a greater number of symptoms and psychosocial concerns in comparison to participants who did not report such desire. In addition, those who expressed a desire for a hastened death reported significantly more hopelessness (27.3% versus 10.1%) in contrast to other participants. Nine and a half percent of participants also said that they would have requested euthanasia or physician-assisted suicide in the past, if legal, but that they had changed their mind given the resolution of physical and psychological concerns (Wilson et al., 2007).

Ganzini et al. (2000) investigated requests for physician-assisted suicide in Oregon, USA, based on a questionnaire mailed to physicians who were legally capable of providing lethal medications through the Oregon Die With Dignity Act. Of 165 patient requests (average age 65 years), 20% were diagnosed as having depressive symptoms and subsequently refused suicide assistance. The top five conditions or values associated with requests included the loss of independence (57%); a poor quality of life (55%); a readiness to die (54%); a desire to control the circumstances of death (53%) and the perception that continued existence was pointless (47%). Financial burden or lack of social support was identified by only 11% and 6% respectively. Physical symptoms, whether present or anticipated, that were relevant to requests included pain (43%), fatigue (31%), dyspnea (27%), confusion or unconsciousness (22%), incontinence (19%) and nausea (8%). However, 46% of patients who received substantial medical interventions, such as symptom management, referral to a hospice program, or a prescription for anxiety and depression, retracted their request for assisted suicide in contrast with 15% of those who received no such intervention (Ganzini et al., 2000).
Back, Wallace, Starks and Pearlman (1996) also investigated patient requests for physician-assisted suicide and euthanasia in Washington State, USA, a state where such practices were illegal. As with the study by Ganzini et al. (2000), physicians identified the predominant concerns precipitating requests as value-driven, rather than symptomatic in nature. In this regard, the top five concerns included future loss of control (77%); being a burden (75%); being dependent on others for physical care (74%); loss of dignity (72%) and being restricted to bed greater than 50% of the time (57%). In contrast to the study by Ganzini et al. (2000), 55% of patients were perceived as having severe depression or a depressed mood. In regards to physical symptoms, 50% of patients had severe physical discomfort with 35% experiencing severe pain. Consistent with the study by Ganzini et al. (2000), financial concerns were less important than others, with 23% of patients worried about the cost of medical care. While physicians frequently responded to requests with medical interventions aimed at symptom management, 24% of patients requesting physician-assisted suicide were provided with prescriptions while 24% of those who requested euthanasia received a lethal injection. Physicians rarely (15%) sought a second opinion from colleagues, which was attributed to fears of legal repercussions for the medical interventions provided.

**Suicide and Rheumatoid Arthritis**

There are a limited number of studies that have explored the relationship between rheumatoid arthritis and suicide. According to a study by Pokorny (1960), of the 44 known patients associated with a Veterans Hospital who committed suicide, 6 had bone or joint disease (predominantly arthritis) as compared to 2 ex-patients within the control group. Dorpat, Anderson and Ripley (1968) examined the medical records of 80 suicides and
identified 70% with a physical illness, with 51% of these illnesses identified as a contributing factor. A high prevalence rate was found for rheumatoid arthritis in contrast to the general population (15% versus 2-3%), with years of pain, progressive disability and isolation noted in the majority of individuals.

In a more recent study, Treharne, Lyon and Kitas (2000) found that almost 11% of hospital outpatients with rheumatoid arthritis reported suicidal ideation. Longer disease duration (over 4 years), as compared to shorter duration (less than 2 years) was associated with such ideation (12% versus 7%), with females reporting greater suicidal ideation as compared with males (14% versus 3%). Depression was the most significant factor, with 30% of depressed patients reporting suicidal ideation in comparison to 7% of those who were not depressed.

Timonen et al. (2003) investigated the demographic and psychosocial profiles of patients with rheumatoid arthritis who committed suicide within a 13-year period (1988-2000) in the northern Finnish province of Oulu. The total suicide population consisted of 1296 men and 289 women, with 19 (9 males and 10 females) diagnosed with rheumatoid arthritis. Suicides within the rheumatoid arthritis group were compared against two control groups consisting of suicide victims with osteoarthritis (OA) and those with neither osteoarthritis (OA) nor rheumatoid arthritis (RA). The authors reported that females in the RA group were significantly overrepresented when compared to females in the neither RA nor OA group (52.6% versus 17.3%) but not when compared to the OA group (32.7%). Significant age differences were also reported for females in the RA group when compared to females in the neither OA nor RA group (median age of 65.5 years versus 45.5 years) but not when compared to the OA group. A significantly higher proportion of females in the RA
group had been hospital-treated for depression (80%) as compared with females in the OA control group (31.1%) and females in the neither OA nor RA control group (56.3%). When information from death certificates was added to data from the hospital discharge registry, 90% of females in the RA group were found to have had a comorbid depressive disorder. In addition, 50% females in the RA group had made at least one prior suicide attempt as compared with 11% of the males in the RA group. A significant number of females in the RA group chose a violent suicide method (90%) as compared with females in the OA control group (35.5%) and the neither OA nor RA control group (56.3%). Males in the RA group significantly differed from females in the RA group in hospital treated depression (11.1% versus 80%) and disease duration (median 3.2 years versus 14.9 years). In addition, the number of hospital admissions for the treatment of rheumatoid arthritis was lower for males in comparison to females (median number of 1 versus 6). Alcohol use was also a contributing factor in the suicides of 44.4% of males in the RA group in contrast to 10% of females in the RA group. 100% of males in the RA group chose a violent suicide method as compared with 66.7% of males in the OA group and 77% of the males in the neither RA nor OA group.

The relevance of euthanasia, intractable pain and rheumatoid arthritis has been poignantly documented by Wall and Malzack (1994) in the following account.

In 1992, a British rheumatologist was found guilty and given a suspended sentence for injecting a patient with a lethal dose of potassium chloride. The 71-year-old patient had been in the rheumatologist’s care for many years with rheumatic heart disease, widespread progressive rheumatoid arthritis and, eventually, collapsed vertebrae and infection. She legally requested a withdrawl of all therapy except for pain control. Within a few days, she was rapidly deteriorating and was clearly soon
to die but intravenous narcotics were failing to control her pain. On the urging of the patient and her two sons, the doctor terminated this shambles (p. 2).

Summary of Suicide and Rheumatoid Arthritis

Cultural attitudes towards suicide have shifted over time, depending on the philosophical lens employed (van Hooff, 2000). At present, attitudes have shifted towards the permissive acceptance of suicide as a rational choice, particularly in the presence of unremitting suffering (Kleepsies et al., 2000; Maris et al., 2000). While research has identified depression as the mediating factor between physical illness and suicide (Conwell & Brent, 1995; Conwell et al., 2000), research investigating attitudes and requests for physician-assisted suicide and euthanasia by the seriously chronically ill has suggested that hopelessness has a significant influence in the desire for a hastened death (Chochinov et al., 1998; Ganzini et al., 2000; Wilson et al., 2007; Wilson et al., 2000). The finding that 46% patients withdraw requests for a hastened death following substantive medical intervention (Ganzini et al. 2000), signaled the importance of the physician’s role in fostering hope in the midst of suffering, as described by Groopman (2004).

According to research by Timonen et al. (2003) women with rheumatoid arthritis who committed suicide were significantly over represented when compared with the total suicide population (52.6% versus 18.2%), with depression characteristic of the majority of these suicides. In contrast to the suicides of men with rheumatoid arthritis, women who committed suicide presumably carried a higher symptom burden, given a disease of longer duration and a greater number of hospital admissions for treatments associated with rheumatoid arthritis (Timonen et al. 2003). According to Harrison (2003), women generally experience more pain and disability than men, with the female gender and a longer disease duration also
marked by reduced treatment effectiveness (Anderson et al., 2000). However, the influence of hopelessness, as associated with depression or independently expressed, remains unexplored in the suicides of women with rheumatoid arthritis.
CHAPTER 3: METHODOLOGY

This chapter will begin with a description of the chosen research methodology, critical discourse analysis, and the rationale for its use within the present research. The research design will then be described, including a description of the main research archive (the Medical Log), the role of researcher and the informants, the procedures for collecting the personal and socio-cultural background of the research subject (or diarist), the guiding principles used for textual analysis and discussion, and the criterion for measuring the worth of this study.

Critical Discourse Analysis

In general, discourse analysis belongs to two distinct traditions: that of discursive psychology and critical discourse analysis, the latter of which is informed by the writings of Michel Foucault. A succinct summary of differences is provided by Willig (2001) as follows:

*Discursive Psychology* was inspired by ethnomethodology and conversation analysis and their interest in the negotiation of meaning in local interaction in everyday contexts. It is concerned with discourse practices; that is, it studies what people do with language and it emphasizes the performative qualities of discourse. *Foucauldian Discourse Analysis* was influenced by the work of Michel Foucault and post-structuralist writers who explored the role of language in the constitution of the social and psychological life. It is concerned with the discursive resources that are available to people, and the ways in which discourse constructs subjectivity, selfhood and power relations. While Discursive Psychology is primarily concerned with how
people use discursive resources in order to achieve interpersonal objectives in social interaction, Foucauldian Discourse Analysis focuses upon what kind of objects and subjects are constructed through discourses and what kinds of ways-of-being these objects and subjects make available to people (p. 90-91).

While discourse analysts agree that discourse constructs knowledge, they differ as to the nature of reality. For example, Potter, Edwards and Ashmore (2002) argue for a relativist position, in which all reality is a discursive construction, whereas Parker (2002) argues for a critical realist position. The latter position accepts the presence of a material reality, such as biological and social constraints (i.e., patriarchy, capitalism, racism) that may limit possible ways of being and seeing in the world independent of, yet influenced by, discursive practices. Within a critical realist framework, ontology is rooted in realism, while subscribing to epistemological relativism (Willig, 2001). For example, within the experience of rheumatoid arthritis, the critical realist perspective accepts that embodiment, as expressed by disease and deformities may constrain and shape reality in material ways, independent of thought and perceptions. However, the meaning of the disease or disability occurs through interpretative processes which are situated within unique personal, social and cultural contexts.

Parker (2002) has criticized the relativist position of discursive psychologists as morally reprehensible given the lack of a theoretical base through which to challenge oppressive societal structures. Parker (1992) also takes exception with Foucault (1980) in his formulations of discourse as a reflection of power/knowledge without attending to notions of power and oppression. According to Parker (1992) discourse and power need to be conceptualized as separate in order to enable the researcher to address issues of empowerment for the oppressed.
Researchers, across various disciplines, have advocated for the use of a critical discourse analytic approach in the study of health and illness (Boutain, 1999; Huntington & Gilmour, 2001; Lupton, 1992; Rogers, 1996; Williams, 1999; Willig, 2000; Yardley, 1996). In particular, Williams (1999) has argued that a critical realist approach brings the biological body “back in” to health related-research, underlying the importance of mind independent processes in the construction of self, identity and social interactions, particularly within the experience of a chronic disabling illness. In addition, Williams (1999) advocated for the use of a critical realist approach on moral grounds. According to Williams (1999) any discussion of ethics “must ultimately return us to our embodiment (i.e., our fleshy all-too-human selves), the contingencies this involves, and the carnal link it provides with other similarly mortal beings and enmattered selves, rich or poor, healthy or sick,” with the neglect of embodiment otherwise described as “an abrogation of our responsibilities in a real world” (p. 812).

A primarily discursive approach has been used to explore areas of health and illness. Research has included topics such as asthma and motherhood (Radtke & Van Mens-Verhulst, 2001), accounts of health and illness (Radley & Billing, 1996), the portrayal of depression in the media (Rowe, Tilbury, Rapley, & O’Ferrall, 2003), chronic fatigue syndrome (Horton-Salway, 2001; 2002) and breast cancer (Wilkinson, 2000). Dixon-Woods (2001) also explored the two predominant discourses constructing patient and health care provider relationships: that of the patient as inexpert and deferent or that of the patient as enlightened consumer, as contained within patient information leaflets. In addition, ten Have (2002) has investigated the discursive structuring of the physician-patient relationship during medical consultations.
According to Willig (2000), Foucauldian-informed discourse analysis has been applied to notions of health and illness in two major ways, the deconstruction of expert talk and the identification of dominant discourses reflected in the talk of lay persons. Examples include the discursive construction of culture, disorder and treatment for the indigenous psychiatric patient in the talk of South African psychiatrists and psychologists (Yen & Wilbraham, 2003), the impact of contested disease, as in chronic fatigue syndrome, and the construction of a self (Clarke & James, 2003), and accounts of coping with dizziness (Yardley & Beech, 1998). However, there is a noted lack of research investigating how discourses constitute the lived experience of rheumatoid arthritis, particularly in respect to identity, subjectivity and agency.

A critical discourse analytic approach was chosen for the present research for a number of reasons. Firstly, this methodological approach was consistent with the constructivist-narrative theoretical orientation of the researcher in the understanding of ontology as rooted in realism while accepting epistemology as relativistic (Parker, 2002; Willig, 2001). Secondly, a critical discourse analytic approach was ideally suited for the investigation of the constituting effects of discourse on identity, subjectivity and agency (Parker, 1992, 2002; Willig, 2001), particularly within the lived experience of a chronic illness (Lupton, 1992; Roger, 1996; Willig, 2000; Yardley, 1996). The use of a critical discourse approach also offered a unique opportunity to understand how various cultural discourses were appropriated and resisted over time, given the autobiographical format of the main archive, the Medical Log. Willig (2000), in particular, has advocated for such a longitudinal approach in understanding the interrelationship between discourses, practice, and subjectivity within the chronic illness experience.
A critical discourse analytic approach also permitted descriptive and critical reflections on how lived experience, in turn, illuminated constituting discourses, a focus which extended beyond discursive construction, while theoretically incorporating a view of power as both power/knowledge (Foucault, 1980) and as potentially oppressive (Parker, 2002).

Finally, there was also a moral imperative to utilize a methodology that recognized the material reality of the body (Williams, 1999) given the experiential effect of ongoing progressive deformities, pain and associated suffering, an ontological reality that existed beyond interpretive stances. The acknowledgement of embodiment was also viewed as essential towards fostering a critical yet empathetic understanding of how available discursive resources contributed not only towards Ruth’s lived experience but also towards the ultimate decision to end her life.

**RESEARCH DESIGN**

**Role of the Researcher**

Stake (1995) has identified the typical roles for the researcher within a case study as that of teacher, advocate, evaluator, biographer, theorist and interpreter. Within the present research, I had a biographical role in that the presentation of Ruth’s life history was used to enhance the personal, familial and socio-cultural context of the main research archive. I also had a theorist role in that the uniqueness of Ruth’s experience was used to illustrate complexity, ambiguity and contradiction, while also identifying experiences that were common to others (Stake, 1995). In addition, I had an advocate role, primarily through the research substantiation of Ruth’s private experience of pain into the public arena.
However, my principle role was that of interpreter. In this regard, understandings were constructions authored through personal biases and interpretations (Stake, 1995). A reflexive awareness of knowledge claims was facilitated through the use of a research journal. The journal documented theoretical understandings as well as personal reactions and interpretative responses throughout the research process.

**Texts for Analysis**

A series of Medical Logs, documenting Ruth’s experience with rheumatoid arthritis over a 40 year period were collectively used as the main research archive. The main document, identified as a “Medical Log” by Ruth, contained over 76 single spaced pages of (typically) typed meticulous documentation primarily focused on physical symptoms, treatments and interactions with medical, and other health-related professionals, over a 23 year time period (1980 to 2003). There was also a two page “Joint Log” (from 1962 to 1976), which preceded the Medical Log, that primarily focused on the process of diagnosis, treatment and surgery prior to Ruth’s relocation to western Canada. In addition, there was a one page “Curse Log,” (from 1978 to 1980) which documented Ruth’s concerns about her menstrual cycle and associated medical care, and a seven page “Flu Log” (dated November 1980 to February 1981) which contained meticulous documentation of “flu-like” symptoms alongside pharmaceutical and dietary intake. For research purposes, the use of the term “Medical Log” included all of the above archives. When quoted, few editorial changes have been made, other than the occasional spacing, spelling or punctuation change for purposes of readability. Otherwise, quotes have been represented as typed (or written) with idiosyncratic spelling and punctuation preserved in order to retain a sense of authenticity.
In addition to the above materials, the main informant, Elizabeth, provided a number of documents, letters and photographs belonging to Ruth that were reviewed for research purposes. These archives provided information in regards to the familial, personal, social and vocational arenas of Ruth’s life. In addition, the archives, listed below, offered a source of enrichment and reference for information obtained through interviews with informants.

**Familial Archives**

**Paternal:**
- certificate of birth (dated 1889)
- coroner’s court certificate (dated 1957)
- last will and testament (dated 1956)
- marriage certificate (dated 1921)

**Maternal:**
- certificate of birth (dated 1886)
- certificate of cremation (dated 1972)
- newspaper photograph of mother in uniform during the First World War (undated)

**Personal:**
- photographs of Ruth during childhood (n = 9), youth (n = 1) and adulthood (n = 10)
- a newspaper article, written in tribute to Ruth’s aunt, Margaret, with the notification of a memorial service (dated 1969)

**Personal-Social Archives:**
- Ruth’s address and telephone book
- 2003 calendar with personal notations by Ruth
- a 1975 travel journal (20 pages)
- personal letters (dated 2001) between Ruth and a long-term friend who was undergoing treatment for cancer (n = 2)
- papers (dated 1999 to 2004) related to Ruth’s will, estate and subsequent probate proceedings (47 pages)
- 2002 Representation Agreement (regarding personal and health care) including letter of notification to physician (17 pages)
- will and representation agreement working log (dated 1999 to 2002; 4 pages)
- a detailed list regarding notification of others “In case of accident or “sudden death” (January 2003)
- memorial book, with entries in Ruth’s honour (February 2003)
- poem written in remembrance of Ruth, with photograph attached (February 2003);
• cards and correspondence received by main informant following notification of
   Ruth’s death in January 2003 (n = 10)

_Educational-Vocational Archives:

• confirmation and letter of recommendation (undated) from school attended in the
  years 1938 to 1946
• college transcript (dated 1946-1950) and commencement program (dated 1950)
• educational certificates: corporate finance (dated 1952) and speedwriting (dated
  1951)
• record of employment (1957 to 1969) and resume (1951 to 1958)
• a letter (dated 1961) inviting Ruth to apply for the position of editorial assistant with
  a scientific journal and subsequent correspondence (dated 1961)
• a historical review article, authored by Ruth, published in the graduates’ society
  magazine (dated 1962) and subsequently republished in a scientific bulletin (dated
  1965)
• a historical review article co-authored by Ruth and published in a scientific journal
  (dated 1969)
• photographs of place of employment at university from 1957-1969 (n = 20)
• archival picture (date about 1880?) of faculty member with students (n = 1)
• letters of recommendation (dated 1960 and 1971) from science department at
  university (n = 2)
• letters (dated 1971) regarding bestowment of a federal centennial plaque for
  exemplary scientific contributions within the field (n = 2)

In addition, archival material (primarily personal correspondence), was forwarded by
several informants following the research interview. These archives included the following:

• written correspondence (dated March 2006) regarding detailed recollections of Ruth
  from an informant, an elderly extended family member (5 pages)
• personal letters (dated 1980 to 2002) between Ruth and an informant, an extended
  family member (n = 17). In addition, the same informant sent letters (dated 1974
  to1976) exchanged between Ruth and a university archivist regarding the transfer of
  her Aunt Margaret’s papers (n = 9)
• a list of papers (3 pages) and books (5 pages) subsequently delivered to the archivist
  was included. In addition, the informant forwarded 3 letters between Ruth and two
  university professors making research enquiries regarding Ruth’s Aunt Margaret
  (dated 1977; 1990; 1990)
• a letter (dated 1974) exchanged between Ruth and a collector as to the value of
  famous signatures in her possession was also forwarded
• personal letters (dated 1980 to 1996) between Ruth and an informant, who was a
  longstanding friend met while Ruth was employed at the university (n = 67)
Role of Informants

Informants were primarily interviewed in order to provide personal, social and familial contextual information to enhance understanding of the main archive, the Medical Log. The primary informant was an extended family member as well as Ruth’s designated health care representative. As a beneficiary of Ruth’s estate (and legal recipient of all personal, household and domestic articles), Elizabeth was also the primary source of archival material, including the Medical Log.

Elizabeth also served as the main gatekeeper to other informants, identifying possible informants with the provision of contact information. However, additional informants were occasionally identified through those interviewed. Informants interviewed also forwarded archival information, which primarily consisted of letters of personal correspondence with Ruth.

In total, 17 individuals (middle-aged or elderly), consented to serve as informants for the research project. Of these individuals, 6 were extended family members (as well as 2 spouses), 2 were friends, having met Ruth in the early 1990’s through shared musical interests, and 5 were friends (including 2 couples) having met Ruth while she was employed at a university in late 1950’s. The daughter of a childhood friend of Ruth and one of Ruth’s “godchildren” were also interviewed.

In addition to the above, two primary health care providers agreed to serve as informants, Dr. Bridges, Ruth’s podiatrist since 1997 (who first met Ruth during a locum in 1994) and Dr. Lawson, Ruth’s general practitioner since 1980. While providing knowledge as to Ruth’s personal, social and familial life, Dr. Bridges and Dr. Lawson also provided
information regarding Ruth’s health care, information that was useful towards understanding the medical context associated with the Medical Log, the main research archive.

**Collection and Use of Information**

Following the receipt of ethics approval for the research proposal (Appendix A), the primary informant was asked to sign a consent form documenting permission to use the Medical Log for research purposes (Appendix B). Once potential informants were identified, a letter of introduction by the main informant (Appendix C) was mailed along with a letter of invitation to participate in the research project (Appendix D). Following notification of interest, informants received a follow-up phone call during which an interview was scheduled at a mutually convenient time and place. Prior to the interview, informants were asked to provide informed consent regarding their participation (Appendix E). Informants were also given information regarding relevant counselling resources within their community, a precaution taken given the potential distress associated with disclosures. In addition, the researcher offered to meet with medical informants for a follow-up interview once the completed research was available for review.

A semi-structured interview (Appendix F) was used to gather contextual information regarding Ruth’s personal, familial, social, vocational and medical background, with questions tailored to the nature of the relationship at hand. For example, questions posed to medical informants were more focused on obtaining a relevant medical history, including ongoing treatment management and health-related concerns. Interviews were manually recorded, rather than audio-taped and transcribed, as interviewees were viewed as informants rather than research participants. Member checks were not performed as information received was treated as archival information.
Informants were interviewed for a total of 24 hours, with a duration range of 30 minutes to 2 hours, with the exception of the main informant who was interviewed for 5 hours. Of these interviews, 5 were conducted in person with the remaining 12 conducted through telephone contact. Prior permission was granted for the use of direct quotations.

In addition to the above, Dr. Bridges, Ruth’s podiatrist was interviewed in person for 2.5 hours (date: May 02, 2006). Dr. Lawson, Ruth’s general practitioner, was also interviewed through two sets of e-mail correspondence, a format that was his stated preference (dates: June 07, 2009 and June 25, 2006). Both Dr. Bridges and Dr. Lawson granted permission for the use of direct quotations.

Following a complete review of archival information, including interview content, two portraits of Ruth were constructed; one, a portrait of Ruth as seen through family and friends and, secondly, a portrait of Ruth as seen through Ruth’s primary health care providers. While portraits were primarily completed to provide a socio-cultural context to the main archive, the Medical Log, the portraits also served to foster vicarious understanding of Ruth’s experience through narrative means.

All individuals referenced within the research project, whether informants or third parties, such as those referenced in the Medical Log, were protected through the use of pseudonyms, with identifying information changed when needed to protect confidentiality.

RESEARCH PROCEDURES

Discourse Analysis

A series of steps, informed by guidelines suggested by Parker (1992) and Willig (2001) guided the analysis of the main archive in a nonlinear fashion. In addition, the steps
were used in an adapted form to reflect on the constructed portraits of Ruth. The steps which
served as guides to the research analysis are summarized in Table 1.

**Table 1: Steps for Discourse Analysis**

<table>
<thead>
<tr>
<th>Steps</th>
<th>Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>• Multiple readings of the text to identify the discursive objects of interest.</td>
</tr>
<tr>
<td>Two</td>
<td>• Identification of the ways that the discursive object was constructed throughout the text using both explicit and implicit references.</td>
</tr>
<tr>
<td>Three</td>
<td>• Identification of the location of the objects within various cultural discourses.</td>
</tr>
<tr>
<td>Four</td>
<td>• Identification of the action orientations, including the task or functions that were accomplished discursively.</td>
</tr>
</tbody>
</table>
| Five  | • Identification of subject positions.  
• This included both subjectivity (available ways of seeing and being in the world) and, practice or agency (what could be said or done within this position). |
| Six   | • Identification of the ways in which different discourses contrasted within and against each other with respect to the discursive objects. |
| Seven | • Identification of gaps, contradictions and ambiguities within different discourses in the text. |
| Eight | • Identification of changes over time with respect to discursive construction of the object and subject positioning (and related subjectivity and agency). |
| Nine  | • Identification of institutions which were reinforced or marginalized when a particular discourse was utilized. |
| Ten   | • Identification of losses or benefits stemming from the use of particular discourses for the subject, others, and institutions. |

Given that research analysis was only meaningful within the context of the interpretations derived, analysis and discussion of the Medical Log (and portraits) was presented together with archival excerpts as a series of reflections. While Willig (2001) recommended a separate conclusions chapter for clinical implications and suggestions for future research, significant theoretical findings were also summarized in the Chapter 5 in order to enhance readability.
CRITERION FOR MEASURING THE WORTH OF THE STUDY

The four research criteria used to establish worth included: propositional and naturalistic generalization, rhizomatic validity and pragmatic validity as described below.

Propositional and Naturalistic Generalization as Validity

Stake (1995) identified two generalizations relevant to case study research: explicated or propositional generalizations and naturalistic generalizations. Naturalistic generalizations were defined as “conclusions arrived at through personal engagement in life’s affairs or by vicarious experience so well constructed that the person feels as if it happened to themselves” (p. 85). According to Stake (1978), propositional generalizations typically lead to explanation and prediction whereas naturalistic generalizations enhance understanding, increase conviction and determine action. Both forms of generalized knowledge are viewed as empirically driven, with the latter frequently intuitive rather than predictive in nature. Likewise, Bruner (1986) has challenged the distinction between “logico-scientific” modes of knowing and “narrative” modes of knowing, describing both as reasoned forms of understanding reality. According to Bruner (1986) the former rests on a scientifically reasoned conviction of truthfulness, whereas the latter rests on a reasoned conviction of verisimilitude, or lifelikeness.

Propositional and naturalistic generalizations were used as interconnected measures of worth through out the research process, with explicated or propositional validity evident through the critical analysis of the constituting effect of discourses, with discourses, in turn, illuminated through lived experience. Given a research agenda geared towards understanding, rather than explanation, opportunities for naturalistic generalization were created through the provision of rich and detailed descriptions of contextual information,
along with detailed excerpts from the main archive, the Medical Log. The reader ultimately will be the judge as to whether or not vicarious generalization through identification or emotional resonance has occurred. As recommended by Stake (1995), detailed accounts and archival excerpts were included in order to foster transparency so that accuracy, completeness, bias and alternative interpretations may be considered. Likewise, the personal and theoretical background of the researcher was included, in order to situate interpretations within a specific context, creating an invitation for reflexive analysis by others.

According to Stake (1995), the transparent disclosure of the reactions of others to research findings offers a source of validation for the existence of vicarious generalization. In this regard, a draft of A Portrait of Ruth: Through the Lens of Family and Friends, was forwarded to Elizabeth, the main informant, by e-mail. Elizabeth sent an e-mail response, dated December 30, 2006, which included the following comments:

*I read the portrait of Ruth last night and I was so moved! You have managed to capture the essence of her Spirit so beautifully. I was thinking of a charcoal portrait, but you have done a masterpiece in oils! I really appreciated the reflections as well. I think I’ll print it and read it a few more times so I can comment more on it when we meet. I just loved it!*

Tragically, Elizabeth was not able to review the completed version as she died suddenly from an acute illness before completion. The final version contained revisions that were directed towards theoretical expansion and were, otherwise, primarily editorial in nature.

**Rhizomatic Validity**

Deleuze and Gauattari (1988) introduced the metaphor of the rhizome to describe postmodern conceptions of knowledge as analogous to an unpredictable root-like growth as contrasted with the modernist notion of knowledge acquisition as the unidirectional,
branching of a tree (as cited in Kendall & Wickham, 1999). Patti Lather (1993) has drawn on this metaphor to develop notions of “rhizomatic validity.” According to Lather (1993), rhizomatic validity is characterized by the following characteristics:

- unsettles from within, taps underground
- generates new locally determined norms of understanding;
- proliferates open-ended and context-sensitive criteria; works
- against reinscription of some new regime, some new systematicity
- supplements and exceeds the stable and the permanent, Derridean plan
- works against constraints of authority via relay, multiple openings, networks, complexities of problematic
- puts conventional discursive procedures under erasure,
- breaches congealed discourses, critical as well as dominant (p. 686).

Rhizomatic validity was represented within the present research through reasoned and complex interpretations and analyses, which also noted contradictions, ambiguities and gaps in understanding. In addition, rhizomatic validity was demonstrated through an interpretative stance, which challenged the conventional knowledge/power of dominant discourses (i.e., psychological and biomedical) by privileging the insights offered by lived experience.

**Pragmatic Validity**

Pragmatic validity was used as a criterion for measuring worth given that the research was geared towards fostering an empathetic understanding that had practical results, or real
effects, in the lives of those with a painful chronic illness, such as rheumatoid arthritis, as well as in the lives of significant others and those professionals entrusted with the provision of care. For example, the present research has the potential to empower individuals to reflect on the constituting effects of predominant cultural discourses within their lives, identifying the alternative ways in which they prefer to shape their life in the present and future. Likewise, the present research has the potential to empower professionals to reflexively consider their participation in dialogic influences that co-construct meaning, with enhanced understanding of the need to understand the unique experience of the other within the lens of empathetic regard.

The following comments were forwarded by e-mail (dated July 08, 2009) from a medical researcher and family physician (since 1981) serving as an independent research reviewer. The response of the medical reviewer both implicitly and explicitly endorsed and satisfied the criterion used for research validity on numerous grounds. For example, there was an emotional resonance with the reviewer on reading the Portraits and Medical Log, an extrapolation to personal experience, and a passionate call for changes to the health care delivery system in order to better serve the elderly and chronically ill. The research analysis was also viewed as logically derived, with the reader likewise endorsing experiential knowledge as “rhizomatic” in nature. Finally, the reviewer described enhanced insight into the link between empathetic engagement and hope, a pragmatic source of relational empowerment for physician and patient alike.

*It was a privilege to read Heather’s dissertation. I was very moved by Heather’s portrait of Ruth through the lens of her family and friends and through the lens of medical practitioners.*

*When I started out in practice, I assumed the practice of a 50-year old family physician, who had been diagnosed with cancer and died tragically within a year*
of her diagnosis. The practice had many independently wealthy elderly patients who lived in an established neighbourhood. As I read Heather’s dissertation, I found myself thinking back to some of these former patients, elderly women – some widowed, some single – who led similar lives to Ruth’s. Like Dr. Lawson or Dr. Bridges, my knowledge of my patients was often compartmentalised, limited by our medical office interactions, which eventually spanned over many years. During the office visits, they would invite me to bear witness to their medical-physical world: medications or somatic symptoms or some other defined medical questions. Their psycho-social lives would elude me, as if that was considered by them not part of my domain; I knew so little about their other worlds. These patients set the tone for their medical interactions with me and I was guided by this not wanting to offend by asking intrusive questions. After all, I was their junior. I believe Ruth’s log does mention her delightful new ‘young doctor,’ Dr. Lawson. I resonate with this ethos!

As I read Heather’s dissertation, I was struck by how unnecessary Ruth’s death was because of the failure of our health care system. Heather discusses the potential role of nurses working in collaboration with family physicians in the community, and so she touches on one non-functioning aspect of our province’s primary health care system. This resonates deeply with me. Women like Ruth, who suffer from debilitating chronic conditions, are served extremely poorly by our current fee-for-service primary health care model. The fee-for-service model is akin to family physicians running small business hardware stores, dependent on income provided by ‘the doctor’s visit,’ which occurs when a patient walks through the door and asks for something. However, a person like Ruth is reluctant to ask for any help. A different system, one based on a systems approach to patients, would have anticipated standard holistic care required for a person suffering from RA. This care and check list would have been made available to the patient, without her need to initiate it, and would therefore have normalised for her the RA condition. Having a multidisciplinary team available would have provided a psycho-social approach for Ruth, and her increased pain would have been anticipated and therefore recognized in the last months before her death. In addition, the incongruence between her reported symptoms (increased pain) and normal sedimentation rate (indicating lack of inflammation) might have been recognized earlier had a multidisciplinary primary health care team been caring for her.

Many of the same patients mentioned above in the first paragraph could have adopted Ruth’s mantra, “I must do it myself.” As they aged, and became frailer, they were not able to do it themselves. Gradually, as they lost more independence and agreed to assisted living situations, they were able to adapt to their changing life circumstances. However they died naturally; none of my patients hastened their own death because they lost the ability to do it themselves. Therefore, I find Heather’s analysis compellingly plausible that it was increased pain associated with hopelessness that caused Ruth to ‘hasten her death.’
And, this brings us to the pivotal question, ‘How can a family physician or other medical practitioner provide an ethos of hope for a patient suffering with a chronic illness while also providing the reality of honest assessment, prognosis and treatment options?’ Dr. Lawson persisted in minimizing Ruth’s pain even when her pain was apparently severe. And, it was following a series of visits with medical practitioners that Ruth hastened her own death. Herein lies the messiness of family medicine – the messiness that rhizomatic validity permits with all the complexities of contradictions and ambiguities. Heather’s analysis brings us to the only viable response to our pivotal question, which actually doesn’t provide a black and white answer but opens up more possibilities, and that is, ‘by being an empathetic listener.’
CHAPTER 4: RESEARCH FINDINGS WITH CRITICAL ANALYSIS

This chapter will provide a critical analysis of research findings in three separate sections. The first two sections will offer portraits of Ruth, as co-constructed by the researcher through the use of archival material, both written and verbal. The first portrait primarily relied on information provided by extended family members and friends with the second portrait primarily based on information provided by two medical practitioners, Ruth’s podiatrist, Dr. Bridges and Ruth’s attending general physician, Dr. Lawson. While providing socio-cultural and medical context to the main archive, the Medical Log, each portrait was also treated as a co-constructed research object, with critical reflections following presentation.

The third section will provide an analysis and discussion of the main archive, the Medical Log, using research methodology informed by the work of Parker (1992) and Willig (2001). The critical analysis of each research object under investigation occurs both alongside extensive log excerpts, if deemed appropriate, and as a series of critical reflections after excerpt presentation. A condensed summary of research findings, critical analysis and discussion will be provided in Chapter 5.

A Portrait of Ruth: Through the Lens of Family and Friends

Ruth’s mother, Amelia, the youngest of three siblings, was born into the home of a Presbyterian minister in 1886. After graduating from high school, Amelia attended the alma mater of her elder sister, Margaret, an Ivy League college in the United States. When interviewed by the media, Margaret once remarked that her parents did not share the
customary view that “it was extravagant and unnecessary for a girl to have a college education.”

Amelia met Ruth’s father, Harold Williams (Canadian-born in 1889), on a troop ship during a transatlantic voyage during the First World War. Amelia was part of an alumni group of college women sent overseas to entertain the troops. Harold became enamoured with the indomitable spirit of Amelia when she enthusiastically played the piano while traversing U-boat infested waters. Ruth later recounted this story with great amusement, remarking that her father later discovered that her mother had been totally oblivious of any present danger.

Amelia (age 34) and Harold (age 32) were subsequently married in 1921 with a son, Harold, born in 1924, and Ruth, second born in 1929. Ruth’s brother, Harold, was later described as a “black sheep” and a “disappointment” given parental expectations that he follow his father’s career path. Ruth’s brother, Harold, was subsequently diagnosed with a chronic mental illness and Parkinson’s (possibly from the side-effects of psychotropic drugs).

Following the First World War, Ruth’s father was employed as an engineer in a resource-based industry in eastern rural Canada. This was a significant lifestyle change for Amelia, who was described as a charming society woman with a taste for the finer things in life. Amelia’s friendship circle included women in the upper echelons of society.

Harold’s work eventually led to the family relocating to England when Ruth was 5 years of age. Ruth’s early childhood was apparently cosseted given the presence of a maid and cook employed by the family during this time. For the next four years, Ruth’s family resided in England while travelling extensively throughout Western Europe and the United
Kingdom. The outbreak of the Second World War was preceded by the family’s return to eastern Canada.

Ruth’s childhood was generally described as “loving” and “normal,” with no reported major traumas or experiences of loss. Ruth’s childhood books contain endearing entries by her father while childhood photographs speak of an affectionate relationship with both parents. According to others, Ruth appeared to have a closer bond with her father, speaking of him with warmth and affection, while her mother was referenced by her beauty and expensive tastes.

However, there was estrangement between Ruth’s father and his younger sister, Mary. Mary apparently refused family contact following an unresolved conflict with Amelia. In addition, Mary threatened Harold’s older brother, John, with the severance of their relationship if he did not follow her footsteps.

Ruth was later to meet numerous members of the Williams clan following the death of her mother in the early 1970’s. The adult Williams children were apparently determined to put an end to family hostilities. In this regard, Aunt Mary was forced to relent and subsequently agreed to meet with Ruth. Aunt Mary was immediately “taken” by Ruth and thereafter fostered an affectionate relationship.

Ruth attended a prestigious all-girls private school throughout her childhood. However, by age 12, Ruth was noticeably tired and frequently falling asleep in classes, symptoms which lead to parental concern and subsequent medical consultation. In hindsight, Ruth wondered if such tiredness had heralded the arrival of rheumatoid arthritis during her childhood.
Ruth’s maternal aunt, Margaret, was a seminal influence in her formative years, with frequent visitation during summer holidays. Margaret went on to become a university educator, a costly decision for women at that time. Approximately five years before her death, Margaret shared the portrait of a handsome young man with a visiting extended family member. She remarked that she had chosen against marriage in order to teach at the university, given societal constraints at the time. Margaret’s academic accomplishments included an honorary doctorate and a Guggenheim Fellowship. In general, Margaret was remembered as an outspoken critic in political and civic affairs, being an ardent supporter of minority rights and progressive employment practices.

On graduation from high school, Ruth attended the alma mater of her mother and maternal aunt, graduating with arts degree (high honours) with a minor in journalism. Ruth had a keen appreciation of her scholarly aunt’s pioneering work as a woman, later to become the archivist for her aunt’s professional and personal papers. In 1976, Ruth personally delivered four boxes (weighing 140 pounds) of meticulously recorded material to her aunt’s alma mater to ensure their survival in the public domain.

Following graduation at age 21, Ruth sought employment as a writer within the field of advertising as well as a position within the Canadian Broadcasting Corporation. After doing secretarial work from 1951 to 1954, Ruth returned to Canada to pursue a graduate arts degree. From 1955 to 1958, Ruth worked as a graduate research assistant within the university department, with duties that included editing, typing and the supervision of scientific reports. From 1958 to 1969, Ruth acquired a leadership position within the department, which she held until her retirement at approximately age 40. During this time, Ruth served as an expert witness in both civil and criminal court cases, reportedly
entertaining graduate students with many humorous tales regarding legal proceedings. In 1971, Ruth received a centennial plaque in recognition of scientific contributions to her discipline.

Ruth was confident in her professional abilities and apparently felt no need to advertise her accomplishments. In this regard, two informants (extended family members) were under the impression that Ruth had been a secretary while employed at the university.

Elizabeth, the main informant, remarked that Ruth was an unusual woman for her era, a curious and independent thinker who had also pursued an education and career. Ruth had an otherwise unusual life trajectory, in that she had remained single and childless. Elizabeth ruefully remarked that Ruth had lived at a time when it was appropriate for a woman’s name to be published three times, when she was born, when she married and when she died.

Archival letters also suggested a feminist orientation to life. For example, on one occasion, Ruth wrote, with apparent irony, that she knew of a female student who had returned to residence after being left with too much of the cooking and “Household Labour.” On another occasion, Ruth humorously cautioned a young woman against visiting St. Andrews in Scotland, noting that they permitted no admittance to women, including female cats.

While Ruth was working at the university, Ruth’s father purchased an expansive apartment within a “mansion” for her mother shortly before his death. The building was described as a “stone edifice” complete with a doorman at the entrance and a rickety elevator. One informant spoke of the apartment as being in a “time warp” given the pink silk down cushions on the sofa and a space under the stove for Queen Ann legs. It was furnished with antiques and oriental rugs.
Numerous informants conveyed the impression that Ruth’s mother was both domineering, or a “grand dame” and demanding, or “bossy” and “curmudgeonly,” as an individual. In the mid-1960’s, Ruth became her mother’s caregiver for a ten year period after her mother was bedridden in the aftermath of a stroke.

During this time period, Ruth also disclosed to a university friend that she was alarmed by her mother’s expenditures. In particular, Ruth did not know how she could pay for numerous bottles of spirits ordered by her mother for entertaining purposes. The informant concluded that Ruth’s mother was unaware of their financial state and that she was lacking in “common sense.”

Ruth eventually retired from her university position given care-giving demands, in spite of requests by colleagues that she reconsider her decision. At one time, Ruth temporarily returned to work after hiring day time in-home assistance. However, Ruth had difficulty managing both the expense and the demands of work and care-giving responsibilities.

Informants had different impressions of the meaning of this vocational loss. Many informants assumed that Ruth had retired given care-giving demands. In this regard, an entry in Ruth’s record of employment noted that she had left the university “in June 1969, to take care of AW (Replacd nurse.).” As such, Ruth’s retirement was met with consternation by some, as her actions were viewed as preventing both the development of career aspirations and opportunities for marriage. Two informants, both academic, had the impression that Ruth had regretted the loss of her career, with Ruth once referencing progressive disabilities as the reason for early retirement. However, another informant said that Ruth had been glad to retire, even though Ruth had retired in her early 40’s, as she reportedly hated getting up in
the morning. The decision was accepted at face value as a relief, in spite of the presumed reality that Ruth would have been getting up to care for her mother.

Following the death of her mother, Ruth moved to western Canada in 1980, given the harsher winters of eastern Canada. Ruth was afraid of falling during the winter months given icy conditions, having occasionally been confined to her apartment for three days at a time.

Ruth eventually moved into a condominium, an astute financial investment that also provided easy access to amenities (i.e., shopping and transit) and the offices of various health professionals (i.e., dentist, general practitioner and podiatrist).

Ruth’s intelligence and excellent managerial skills were quickly recognized by her strata council. Ruth became the business manager for the building, managing finances and overseeing work performed by contractors. As was typical of Ruth, financial accounts and repairs were documented in meticulous typed lists.

Throughout her life, Ruth had an extensive social network, known by others for her warmth, intelligence and a “wry” wit that could also be caustic when reserved for political commentary. Ruth had a “traditional” way of keeping up correspondence, through frequent letters, cards and gifts for special occasions. Visits were eagerly anticipated by both adults and their children, with Ruth frequently treating others to a dinner out. She was otherwise financially generous, providing assistance to a friend undergoing expensive cancer treatments, and, on another occasion, bequeathing an early inheritance in response to financial need.

Ruth was also a designated godmother to more than one child, a reality which reflected both the affection and esteem for Ruth that was held by others. She was described
as “psychologically astute” given an ability to relate to an individual whatever their age and interests.

Ruth was also described as an extremely frugal person. She frequented a local United Church bazaar and bought good quality used clothing with great personal satisfaction. She also slept on her childhood mattress, described by Ruth in a letter as “vintage 1936, but nevertheless, a recognizable Bed.” The bed was relinquished for guests, one of whom remarked that “if it didn’t cause her arthritis, it should have.” All other furniture in Ruth’s condominium had been inherited from her family home. A friend also told stories of “petty larceny” on Ruth’s part with great amusement, describing the pilfering of tea bags at a financial forum, the pocketing of biscuits, and a habit of reading the business and travel sections of the Globe and Mail at a bank “for free.”

Ruth’s frugal nature was viewed as a response to being disabled and living on inherited capital. An extended family member also described frugality as a family characteristic that had developed through the consequences of living through the Depression and the Second World War.

While informants were occasionally concerned about Ruth’s financial state, these concerns were without warrant. Ruth directed her own financial portfolio and was reportedly “brilliant” in making astute investments. Ruth’s stockbroker expressed considerable dismay on hearing of her death, noting that Ruth was frequently more up to date on financial matters than he was. At the time of her death, Ruth was very financially secure.

If Ruth spent money on herself, it was primarily to fund life passions, such as music, travel and friendship. Others described her spirituality as an “aesthetic spirituality.” Ruth laughingly referred to herself as the “heathen cousin” or “lapsed Presbyterian” when
speaking with Stevan, a retired Anglican minister who was also the husband of Elizabeth, the main informant.

Ruth practiced an ardent love of classical musical through membership in an opera guild, hand delivering sandwiches for opera rehearsals via the public transit system. Ruth also served as librarian for the guild’s music recordings, demonstrating an “encyclopaedic memory” in her ability to immediately identify the opera, year and artist of a particular recording. As part of the opera guild, Ruth went on numerous opera tours in the United States.

Ruth was otherwise a seasoned international traveller, having travelled regularly within the eastern United States as well as Egypt, Spain, Greece, Hawaii, Chile, Hong Kong, Thailand, the Caribbean, and the United Kingdom (a favourite destination). In this regard, Ruth could recite the chronology and biographies of various monarchs throughout English history.

Ruth was a keen observer of different cultures, as was evident in the following excerpt from a handwritten diary of an Egyptian tour in 1975:

_Friday, December 1975 (... Sunday) (Moslem holy day)_

_Had early brek and debarked from ship at 8:20 am. Went on bus to site of old Memphis, now green area with hi water table and date palms. Area densely populated – villages, donkeys pulling 2-wheeled carts with 7 or 8 people on, camels, water buffalo, goats, fat-tailed sheep, mud-brick houses, dust, lots of native outfits, numerous kids, a few bikes loaded like donkeys (even with oil drums!) Long robed men ride bikes. Schools with pix of Nasser on outside. Dogs (not too thin) mostly in sand-color, a few black, one white! A hen or two. Everything sand-color except lush irrigated fields (harvest thick, long green clover as fodder for animals) and date palms (dates mostly picked). Canals and ditches; saw shadufs and water wheels (tin or metal.) Intensive cultivation – rows between rows of cabbages, beans, etc. In ...village markets or stalls, tomatoes, lots of oranges, sugar cane, etc. Cane eating as a candy (our bus driver got one). Cultivated areas in dense population ends abruptly at desert edge; desert is a real fine soft sand, or_
stony gravely plain as on road to Faiyum. Some Bedouins who have moved to farm area, or to edge of it, live in shanties or mud-brick or brush huts, ... small, with goats, kids, etc. Very small circular mud-brick (spiral-shaped ... entrance) or brush shelters seen in fields – dono if for animals or people!

Ruth was also known for her emotional reserve and reticence to speak of personal difficulties. This was generally attributed to an Anglo-Saxon background in that a “stiff-upper lip” was viewed as an admirable strength in character. Any life difficulty alluded to was typically brushed aside by Ruth with the comment “enough of that.”

In this regard, informants typically said that they were not Ruth’s “confidantes.” However, such privacy was not viewed as problematic as others generally identified with Ruth’s way of being. Topics were generally avoided if there was concern with causing discomfort in the other. For example, an extended family member who had used her childhood bed as a guest told Ruth that she had slept well when questioned, to avoid potential embarrassment. One elderly informant remarked that recent cultural changes had created “more self study” than was the case during Ruth’s childhood and adulthood. She said, with apparent irony, that she had never told Ruth that she thought she was “incredible in what she had done” remarking that it sounded like an “obit” when said to a person in their 70’s.

One informant remarked that discussions of difficult family matters would have been viewed as dishonourable by both Ruth and others. In this regard, many informants were unaware that Ruth had a brother or, if aware, that he had a chronic mental illness. One informant noted that Ruth’s medical problems and her brother were part of a list of forbidden topics. In this regard, several informants had the impression that Harold’s mental illness was a source of stigma and personal stress.

Elizabeth noted that Ruth’s emotional reserve extended to the experience of pain and related distress. Elizabeth remarked that she had experienced similar early childhood
training to repress feelings for the sake of others. By way of example, Elizabeth recounted the following childhood memory: At the age of 4, Elizabeth had required blood testing as her brother had rheumatic fever. Just as the needle was approaching her arm, Elizabeth’s father exclaimed that she would be rewarded with a chocolate or butterscotch sundae if she did not cry.

According to Elizabeth, Ruth was fascinated with psychology but would have viewed counselling as “nonsense,” or perhaps “touchy feely” as it was not a “hard science.” Ruth gave the impression of being intrigued but puzzled by Elizabeth’s professional interest in palliative care.

Informants unanimously reported that Ruth never gave the impression that she was grappling with depression. She was generally described as a woman who had a “huge zest for life.” When confronting life challenges, Ruth was typically described as proactive regarding solutions, rather than obsessed or self-pitying. For example, Ruth discovered that there was a significant amount of damage to her possessions following her move to western Canada. She faced this challenge, made more significant through the presence of disabilities, with characteristic assertiveness and humour, as noted in the following excerpt from a letter written at that time:

April 06, 1980

Dear Constance,

My furniture arrived with quite a bit of damage to things like Dining-room Table (2 legs torn off), Chairs (slats knocked out), Mahogany chests (legs off), etc., but strange to relate, pictures, mirrors, and almost all things packed in boxes OK (though some boxes had actual holes in them). The large items were evidently packed badly in their container in..... So I have zapped them with a long, hairy Claim Form, original plus four (4) added typed pages, all in quintuplicate, with Appendix from Phillips (Fine Art Dealers & Appraisers) giving Values of Antique Furniture for Insurance. This document
was sent to them registered mail, and tomorrow morn I must lock horns with the unfortunate Claims Manager to see when he’ll come & view the damage. In the meantime, all things are left as is with tables waving their broken mahogany legs in the air, which sort of slows down Getting Settled (but let’s face it, I wouldn’t be moving that fast, anyway.)

As with depression, informants did not experience Ruth as anxious throughout her life. If anxiety was expressed, it was in the seeking of reassurance regarding the well-being of another. On one occasion, an extended family member informed Ruth that she was suffering from mercury poisoning. Ruth responded by researching the topic and sent her “every article on the subject.”

Ruth was also described as a woman of principle who did not impose herself or hold grudges towards others. She occasionally appeared to avoid possible conflict and hurt through indirect means. For example, she occasionally developed a “fake cough” to excuse herself from noisy family gatherings at Elizabeth and Stevan’s home. She was also known to submit letters critical of current affairs to the editor of the local newspaper under an assumed name and address. However, she was also known to deal with difficult situations in a direct assertive manner. In this regard, Ruth reportedly asked her brother to leave during the time of their father’s death. Harold was in an apparent delusional state, insisting that the man in the coffin was not his father.

There was some evidence that Ruth used alcohol for general stress management and relaxation. On one occasion, a family member remarked that Ruth immediately asked for a glass of sherry upon arriving from a distressing visit with Harold in the eastern states. Ruth also disclosed to Elizabeth that she liked to have sherry at lunch as it made her “sleepy” for an afternoon nap. In this regard, Elizabeth remarked that sherry, particularly at lunch time, was a cultural way of life that had been fostered since late adolescence. Elizabeth further
noted that Ruth’s intake of alcohol was moderate, consisting of a small glass of sherry plus 
two gin and tonics later in the day. Informants reported that there were no behavioural 
indicators that Ruth misused alcohol.

Ruth’s was unanimously portrayed by others as highly rational, resourceful and 
resilient when coping with the lived effects of rheumatoid arthritis. While her condominium 
had been assessed by an occupational therapist, there were few obvious assistive devices, 
other than a raised toilet seat and a bar for the bathtub. In general, Ruth appeared to adapt 
implements that were available to her. For example, a hammer and screwdriver was used to 
open jars (until she received an electric can opener and a jar opener as gifts). A paring knife 
was brought when dining out, to cut meat, along with a tiny pair of scissors, for snipping 
packets of sugar. In the early 1980’s, Ruth drove with a pair of pliers in order to turn the key 
in the ignition and open the car door. She was described as a “bat in hell” when driving. A 
university friend described a hilarious, and presumably hair-raising, journey with Ruth along 
a treacherous coastal highway. Ruth had reportedly adapted to driving a standard vehicle by 
taking both hands off the steering wheel whenever she had to use the gear shaft.

A well organized system was clearly evident in Ruth’s home. Kitchen supplies were 
within easy reach, with the rest of the house spotless and well-organized. One family 
member commented that Ruth had systems for all acts of living (i.e., for cooking, for 
traveling, for dressing) as everything took effort. In this regard, informants noted the 
simplicity of meals served within her home, given the amount of energy spent in food 
preparation. For example, rice was served, rather than potatoes which required peeling. 
More than one informant commented on Ruth’s famous “toads foot casserole,” otherwise 
known as tuna casserole. Ruth appeared to couch this simplicity in humour, noting that her
imaginary temperamental cook and maid from Budapest (Mergatroid and Katrinka) had been “let go” for the evening. These imagined servants were a source of considerable amusement to others.

May 24, 1983

Dear Constance,

Today is a gorgeous day, and I had to force Katrinka (my very difficult, imaginary Household Help) to do a little cooking and cleaning in preparation for the coming visitors. (I don’t know if I ever introduced you to Katrinka or my butler, Murgatroyd. K. is from the Old Country (I think Transylvanian), and has fits of temperament, as well as being exceedingly lazy – I find it hard to get work out of her at all, at all. She throws plates at poor old Murgatroyd, who is well past retirement age, and finds it hard to take.)

Ruth hired a housecleaning service to provide practical assistance. However, there were inherent risks involved as Ruth dismissed two housecleaners for stealing. One informant thought that Ruth resorted to vacuuming with a hand held device. However, there were two housecleaners at Ruth’s memorial tea who had provided services for a year.

Ruth’s organized and simplified way of life was also evident when she travelled. For example, Ruth used two small attaché cases that could be carried by her forefinger and thumb when she travelled internationally. One friend also commented on Ruth’s arduous self-care during an opera tour involving attendance at four to six operas. Ruth had a night routine that included a long hot shower and extensive foot care. In the morning, she again applied creams and foot rolls prior to fitting orthopaedic foot wear.

Ruth also coped with obvious physical deformities with a self-depreciatory humour. For example, she referred to her hands as “claws” or “appalling-looking tentacles.” On numerous occasions, Ruth referred to herself as a tottering little old lady or a decrepit senior citizen.
Numerous friends challenged Ruth’s self-derogation in describing her physical appearance. In this regard, Ruth did not appear to view herself as attractive, even during her youth. On more than one occasion, Ruth remarked to several friends that they had no idea what it was like to be a plain girl at school when they were one of the pretty ones. In the last decades of her life, Ruth had a stooped posture and an “elfin” appearance, attributed to facial bone structures that had been affected by rheumatoid arthritis. Her hands had obvious deformities, with a classic ulnar deviation, characteristic of the deformities associated with rheumatoid arthritis. She walked with a pigeon-toed shuffle, an awkward gait. She did not dress in a feminine manner, preferring to wear tailored white blouses and slacks that were presumably worn for comfort.

Given Ruth’s self-image, it was not surprising that she did not like to have picture taken or displayed. On one occasion, Revenue Canada requested new information in support of her medical disability income tax deduction. Ruth was advised to send in photographs of her deformed hands and feet in support of the claim. One informant remarked that this process was likely experienced as humiliating, given the emotional impact of exposure on a woman who felt physically defective. However, on another occasion, Ruth provided a photograph of her hands, as a classic example of severe hand deformities, for an arthritis research journal at the Arthritis Centre. She spoke to numerous informants of this experience while referring to herself as a “centerfold.” In this regard, Ruth conveyed apparent pleasure with having provided a photograph as a contribution towards research. As such, Ruth’s experience of picture-taking appeared to be driven by both context and subjective interpretation.
Ruth appeared to deliberately mitigate any perceived discomfort that was created by her physical deformities. For example, restaurant servers, and fellow diners would be told “don’t worry, I’ll get there” given that a meal took three times the norm to consume. When new acquaintances offered their hand in greeting, Ruth would immediately engage in lively conversation in an apparent effort to avoid social embarrassment. On occasion, Ruth covered her hands when she was in public.

Numerous informants noted that Ruth was so adept at adapting and forging ahead that they were caught off guard when reminded of her disabilities. For example, Elizabeth recalled travelling through a historical exhibit with Ruth, noting that she was taking extra time at each exhibit. Afterwards, she realized that Ruth had likely been micro-managing the effects of the physical exertion in a non-obtrusive manner.

Ruth was also typically well informed on recent medical research, with subscriptions to medical newsletters from both Berkley and John Hopkins University. Ruth also kept A Compendium of Drugs for reference as needed. Family members and friends were frequently informed of recent research regarding disclosed physical ailments.

Ruth typically did not speak of her relationships with health care providers nor did she typically speak of the resources that she was using. Ruth conveyed a sense of satisfaction with the medical profession, and an appreciation for her general practitioner given a shared love of travel. However, one informant, who occasionally provided transportation to medical appointments, thought that Ruth was rarely physically examined, and that Ruth likely minimized her complaints, given that scheduled appointments were often perfunctory. The same informant, a former health professional, thought Ruth’s physical concerns were superficially addressed through standard laboratory tests. Elizabeth, in
particular, raised questions regarding the lack of holistic care given to Ruth, referencing the treatment of physical symptoms and pain after reading Ruth’s Medical Log. After Ruth’s death, one extended family member also raised concerns regarding the toxic effect of the combined use of Tylenol and alcohol. A few informants also questioned whether or not Ruth should have been under the care of a rheumatologist on an ongoing basis. In this regard, Ruth told one informant that ongoing treatment by a rheumatologist would provide no benefit as she was a “burnt out case.”

Ruth appeared to maintain the range of motion and function of her arthritic joints primarily through exercise, including the use of a heated pool and frequent walks. One family member understood that Ruth was eventually denied access to a heated pool at the Arthritis Center as there were “others on the waiting list.” As noted in the excerpt below, Ruth persisted in swimming as an exercise even though she did not enjoy the activity and thought the environment exposed her to infectious agents.

Feb, 10, 1987

Dear Constance

I go and do my duty once a week in a warm pool with adjoining hot Jacuzzi for dilapidated souls (one has to have a certificate of Dilapidation to get in), and I wave my tentacles about for about an hour or so, but it is so boring – my fellow delapidateds are appalled that I still have to follow a list of exercises, after all these years (without a list, I’d forget them quickly!) Feb 11 – At that point I paused to go catch the bus to that pool. Today I’m slightly stiff, which gives me a comfortable Presbyterian-Ancestor feeling that I Did My Duty!

One family member remarked that when she commented on various treatments available for arthritis, Ruth typically replied that she had tried various treatments but that they did not seem to work. When questioned, Ruth also disclosed that she had tried different medications, apparently for pain management, but had resorted to Aspirin given the
deleterious side effects of other medications. Whether or not Ruth was accurately disclosing her experience or deflecting unwanted advice was unknown. As noted in the correspondence below, Ruth was occasionally subjected to unusual and unsolicited treatment suggestions.

*February 11, 1975*

*Dear Constance,*

*Yes, my quilt dealer reappeared, wondering what the fuss was about, and why his wife was on the verge of flying to Bangkok! He also presented me with a weird-looking wooden snake bracelet with glittering eye, guaranteed to cure arthritis – I can’t get the durn thing on, which is probably just as well (it would scare anyone out of 10 year’s growth, outside of Indonesia, that is).*

Ruth also appeared to cope by minimizing her physical complaints when speaking with others. In fact, Ruth appeared to minimize the impact of rheumatoid arthritis in general. Ten years prior to her death, Ruth voiced concerns regarding the apparent ill appearance of a friend (diagnosed with rheumatoid arthritis) in the following manner:

*Nov 27, 1993*

*Dear Constance,*

*I hope that I’m not unduly alarmist, but surely it’s not just rheumatoid arthritis which is having that effect on him.*

To others, Ruth made reference to otherwise debilitating symptoms, such as long standing recurrent diarrhea (aetiology typically unknown) with euphemisms, such as the Green Apple Fox Trot or Tourista. However, occasional disclosures highlighted the persistence required to pursue a love of travelling, in spite of such symptoms. For example, following a trip to Spain, Ruth remarked that she had wondered if she could get on a bus, given her diarrhea. On another occasion, Ruth remarked that an Egyptian river cruise had been almost ruined as she had been confined to her cabin. There was no reference to such debilitating symptoms within a detailed diary kept for the trip.
Likewise, informants were typically unaware of the painful condition of Ruth’s feet and the constant physical care required, during travel and otherwise. Two informants became aware of the condition of her feet only through indirect observation. One observed the care taken to purchase shoes, given attention to known tender spots, and the other observed an extensive night routine for foot care while roommates with Ruth during an opera tour. Elizabeth reflected that others would have resorted to “armchair traveling” if they had grappled with Ruth’s symptom load.

Ruth’s coping style was also characterized as being “fiercely independent.” In this regard, Ruth typically refused offers of help, with a friend noting that the best way to offer assistance was non-obtrusively. One family member remarked that Ruth refused assistance threading a needle, while another remarked that she insisted on serving sherry even though it took three “rocking” attempts to get out of her chair.

Ruth’s independence was generally thought to stem from a desire to be a burden to no one. According to Stevan, Ruth invariably began telephone conversations with the question: “Is this a bad time? Am I interrupting?” He poignantly remarked that it would be “nice to be interrupted now.”

Other informants shared the impression that Ruth’s fear of being a burden had developed in consequence to caring for her bedridden mother and otherwise witnessing the effects of eleven years of institutional care on another extended family member. On one occasion, Ruth remarked that her mother had been “excessively demanding” while another informant disclosed that Ruth had voiced resentment that the caretaking role had been assigned to her as a woman. These personal disclosures were viewed as uncharacteristic of
Ruth, who was otherwise described as “extremely private.” A few informants wondered what impact the stress of care-giving had on Ruth’s disease process.

Ruth’s insistence on independence appeared to be an occasional source of frustration to others. One family member challenged Ruth’s refusal to accept household assistance from another family member. Ruth had reportedly told her that she was interfering but later called to apologize for being “so sharp.” Ruth reportedly said, “I have to take care of myself,” and that it was her sole responsibility to do so.

Stevan poignantly remarked that Ruth’s coping style prevented him from expressing his “protection,” or solicitous affection, or a “thanks” for her many gestures of generosity. He said that while Ruth did not want to be treated “like a cripple,” her independence also prevented him from expressing gratitude, which was experienced as a form of denial. Still another friend wondered if Ruth’s fierce independence had prevented her from knowing that she could have been helped more and loved the same.

The reluctance to seek assistance outside of self was poignantly stated by an older single informant. She remarked that you learn to be independent when you live alone, without family members, or a daughter, in particular, to provide advocacy and assistance. She remarked that she herself had said that she was “fine” when she “wanted the other person to push,” presumably in offering assistance or support. She remarked that “independence becomes a mantra when you are a single woman living alone.” This sentiment was echoed by another older single friend who reflected on Ruth’s “formidable defences” as expressed by her emotional restraint and persistent optimism. As a single older woman, she identified with Ruth’s way of being, remarking that such behaviour was driven in part by a desire to preserve friendships out of fear of becoming a burden.
Paradoxically, Ruth’s refusal to be a relational burden also contributed to her being perceived as courageous. Her lack of complaints was viewed as both spirited and inspirational, an exemplar for living with a chronic painful illness. For example, one family member noted that the impact of Ruth’s life had been “absolutely positive” in that Ruth had never burdened her with her problems for a moment, instead maintaining an optimistic outlook. Another family member described Ruth as “brave” as she had not moaned or cried about her difficulties. In fact, Ruth “made you think that nothing was wrong.” Ruth was described by others as a “good sport” and as an individual who “did not take advantage” or “presume on others” given her disabilities.

Informants also remarked on Ruth’s increasing infirmity over time. For example, in spite of being athletic in her youth, Ruth sold her skiing equipment shortly after her hand surgery in the early 1970’s. As early as 1976, Ruth’s letters were typed given difficulties with handwriting. A family member also remarked that Ruth had given her a piece of heirloom jewellery when she was no longer able to do the clasp. Informants described Ruth as having increasing difficulties with various tasks over time (i.e., hair brushing, food preparation, and rising from a sitting position). In particular, Ruth’s walking gait became increasingly laborious and awkward.

One informant also remarked that Ruth appeared thinner over time but that she still maintained a healthy appetite. Towards her later years, Ruth had groceries and prepared meals delivered to her home. During this time period, a few informants thought Ruth had relied on soup as a primary source for nutrition.

Elizabeth described Ruth as a “minimalist” in the later years of her life, apparently creating simplicity in response to life challenges. One family member noted that Ruth gave
her a personal possession each time she saw her during this time period. Traditional means of correspondence, such as letters and gift-giving, on special occasions, gave way to phone calls. As evident in the excerpts below, these losses and relational shifts were addressed through Ruth’s characteristic humour:

January 18, 1973

Dear Constance,

I sold off my ancient skis, boots etc. to a cute young thing who read my ad. in ... “Daily”, and I’m glad my skiing days are over, as I’m sure that I couldn’t even keep up with John and Jane.

January 12, 1990

Dear Constance,

This was my big year for receiving Shortbreads and Fruitcake, plus chocolate-covered Nuts....they are all being recycled frantically to people who didn’t send-’em! I loathe fruitcake and choc-nuts, and can eat maybe two shortbreads per day, not great galloping tins of them, and I’m now trying to think of a diplomatic, gracious way to discourage their arrival next year! This is a strain on my so called brain, to say the least. Maybe I’m getting Anti-Gift in my declining years, though I always appreciate your considerate and thoughtful ones – but perhaps we should swear a Great Oath on a plausible set of bones: No More Gifts, just the occasional letter or phone call! Think what you will be spared – you otherwise might be in danger of receiving a crumbling Fruitcake around Easter, encrusted with ageing choc-nuts, as I start to lose my grip!

November 23, 1996

Dear Constance,

Thanks for the labels, and that is a great new skill to have, but I don’t think I’ll take advantage of it, since I plan to cut down drastically on my hunt-and-peck correspondence. Fifty-five cards per Yule is a bit much, and so you will hear fewer bleats of complaint from now on! A phone call now and then to a favoured few will have to do.
May 06, 2002

Dear Sylvia,

In any case, perhaps you should keep any Williams things and not bother about sending me copies, though it’s a very kind thought. I am really at the stage of Getting-Rid-of-Things, and am trying hard to empty out my bulging old filing cabinet!

Ruth also grappled with constant exhaustion, noting that she could “sleep 24 hours a day” towards the later years of her life. She would frequently fall asleep upon sitting, once to the annoyance of concert goers as she snored during a performance by tenor Placido Domingo. In spite of chronic fatigue, Ruth continued to use the public transit system, typically with several bus exchanges, to either attend functions or to visit with friends and family members. Ruth occasionally ventured out simply to express care to another. One friend recalled Ruth travelling by transit to hand deliver soup when she was house bound with the “flu.” However, there was a noticeable decrease in the number of times that Ruth hosted others in her home or undertook international or local travel over time.

As noted in the humorous excerpts below, one of Ruth’s favourite mottos reflected a life lived with a consciousness towards inevitable decline:

January 18, 1980

Dear Constance,

My particular bug departed around New Year’s Day, and I am now tottering about in my usual, normal manner, somewhat behind with my correspondence, and once again beginning to entertain vague thoughts of trips here and there, galloping off in all directions as per Stephen Leacock. If nothing else, my limited pocketbook and energy should restrain me, though I have the feeling that both will be increasingly limited in coming years....Onward and Downward being, as always, my motto.
Sept. 21, 1983

Dear Constance

Time moves along at a rapid pace, in fact everything does except me – I get slower every year!

When questioned, informants were adamant that Ruth would not have used any instrumental assistance, such as a motorized wheelchair, if it had increased her dependence on others. One informant also remarked that Ruth would not have been able to use a cane, given her severe hand deformities.

Ruth was reportedly well informed of assisted living alternatives in her neighbourhood, having researched such facilities for a friend. However, any form of institutionalized care was viewed as “incompatible” with Ruth. In this regard, Elizabeth thought that Ruth’s care of her bedridden mother (coupled with witnessing Elizabeth’s mother in extended care for 11 years), had ultimately convinced Ruth to end her life out of a determination to avoid such circumstances.

Numerous informants remarked that Ruth denied that she experienced pain when directly questioned. They also noted the lack of nonverbal indicators that Ruth was in pain, such as grimacing or guarding behaviours. One informant remarked that Ruth discussed proposed hand surgery options with her husband, a physician, in the early 1970’s. In reference to her hands, Ruth had remarked that the “only good thing” about her disability was the lack of pain. However, the same informant remarked that Ruth had “fierce some trouble” finding comfortable tender tootsies shoes as she had “hammertoes.” Similarly, Ruth remarked to another informant that she was “lucky” that she did not have any pain, apart from that created by her disability, approximately 12 years prior to her death.
It was also noteworthy that Ruth disclosed to friends during the last few years of her life that she had decided against hand surgery in the 1980’s as she had experienced excruciating pain and minimal gain in functional ability through two previous hand surgeries in the early 1970’s. As noted below, excerpts from correspondence in the month following Ruth’s first hand surgery, a right hand thumb fusion, are devoid of any mention of pain and contain a glimpse into Ruth’s otherwise jocular manner:

January 09, 1974

Dear Constance,

My thumb and I have emerged from the hospital in good order, stitches have been removed, and so on. I missed the truly foul weather which afflicted ...Christmas week – blizzards with howling gales, followed by a thaw with buckets of rain, which then froze. Solid, irregular cakes of ice are still stuck to sidewalks, almost impossible to remove except with pickaxe – salt and sand don’t seem to help much. But no fuel shortage so far – just a lot of talk and an electric power failure or two (not unusual, as you know!).

Occasionally informants presumed pain in spite of Ruth’s verbal denial. For example, one extended family member recalled her obvious stiffness and discomfort on being picked up from a bus station while travelling in the eastern United States. The informant suspected that Ruth had regular evening hot baths as an aid to comfort. During their last visit, Ruth had noticeable difficulty shifting from a sitting position to a standing position. The informant remarked that she did not ask Ruth about her pain, as she “didn’t want her to be embarrassed.”

Another informant, a former health professional, said that she took it for granted that Ruth was always in pain given the extent of her joint fusion and the presence of a pigeon-toed gait that was noticeably awkward and slow. She said that on one occasion, Ruth made reference to the cotton rolls developed by her podiatrist, noting the wonderful difference they
had made. She took this to mean that Ruth had been uncomfortable prior to their use. While Ruth did not talk of her pain, she also noted that Ruth regularly took Aspirins, typically two tablets with each meal. In addition, approximately four years prior to her death, Ruth remarked that her arthritis had “flared up” while questioning whether or not a “flu” and subsequent diarrhea had been contributing factors. The informant understood this to have meant that Ruth had been experiencing no pain but that it had re-occurred.

Another family member remarked that she had accompanied Ruth when she had gone to purchase shoes. She had observed Ruth checking the fit against “familiar pain spots” on her arthritic toes. In this regard, she thought that Ruth had accommodated to her pain. The above informant also remarked that she had the distinct impression that Ruth had been using alcohol as a form of pain management for a number of years prior to her death. In this regard, she noted that Ruth brought a bottle of wine while visiting, in spite of the fact that she herself was allergic to alcohol. In later life, Ruth took wine with her Aspirin during dinner while remarking that “it was to help the Aspirins along.” In this regards, she thought that Ruth disguised her pain management as “fun.”

Numerous informants indicated that they thought that Ruth had used alcohol to manage pain, particularly in the latter years of her life. Elizabeth noted that the likelihood of her self-medicating with alcohol during the last months of her life was “huge” given the direct acknowledgement of severe pain. Prior to this, Ruth continued to deflect any questions regarding her pain management with the remark that “it was nothing that Tylenol couldn’t help.” Following a reading of the Medical Log, Elizabeth said that she had revised her opinion, stating that she now thought that Ruth had deliberately lied on occasion as to the nature of her pain experience.
Stevan, in particular, remarked on the difficulties inherent in comprehending the pain of another. He noted that “others could see her disability but did not know her pain. How could you know if it hurts or doesn’t hurt?” When referencing the intolerable pain experienced by Ruth at the end of her life, Elizabeth remarked “no one was privy to it,” “no one understanding it.”

There were a few noteworthy exceptions to Ruth’s characteristic privacy regarding personal difficulties. In this regard, Ruth openly discussed the stressors related to Harold’s deteriorating mental health while staying with a relative, known since childhood, on trips to oversee his care in the United States. On one occasion, Ruth disclosed that her brother was squandering his inheritance spending hundreds of dollars a month feeding stray dogs while living in a filthy trailer. His conversations were apparently bizarre, with a fixation on “the government” and politics. However, Ruth also protected her extended family member from carrying any relational burden in connection with her brother. For example, Ruth’s relative offered to pay for a magazine subscription for her brother given the cheaper rates in the United States. Ruth had at first accepted the offer but later called and declined the offer. The informant thought that Ruth did not want to reveal his address and, in doing so, “pass the burden” on to someone else.

Immediately following the last visit to her brother, close to the last year of her life, Ruth was unusually candid with close friends regarding the nature of the sibling relationship. Ruth alluded to the lack of intimacy in their relationship, attributing the cause to his mental disorder, describing Harold as “totally self-centered.”

Towards the end of her life, Ruth travelled to the eastern States as she had felt obligated to provide evidence of her functional limitations given pressure from health
professionals to take on the fulltime care of her brother. Harold’s caregivers apparently insisted on the advance payment of his funeral expenses before she returned to Canada.

Ruth described the trip to the eastern States as difficult given the heat and the exhaustion that came with walking. According to one informant, Ruth disclosed that she was “grief-stricken” that she could not provide physical assistance to her brother. Interestingly, Ruth’s American relative had the contrasting impression that Ruth had experienced closure, that following her last visit, she had left feeling no guilt, reinforced by the belief that she had done everything that she could for a “hopeless case.”

There was another significant exception to Ruth’s characteristic emotional reserve regarding difficult life circumstances. In June 2002, Ruth cancelled a dinner date with a friend who was attending a conference in town. Ruth later phoned her friend and asked to be driven to the hospital the next morning given concerns regarding her health. The next day, her friend, with the assistance of Ruth’s neighbours, traced Ruth to a local hospital. Ruth had reportedly taken herself to the hospital in the middle of the night by taxi given persistent abdominal pain stemming from a sudden gastrointestinal haemorrhage.

During her hospitalization, Ruth underwent intrusive procedures as part of the medical investigation, including a colonoscopy. These procedures would presumably have been painful for Ruth. When Elizabeth and Stevan subsequently visited Ruth following her release, Elizabeth remarked that she had never seen Ruth so angry. She reportedly told Elizabeth, as well as numerous other informants, that she would take pills rather than go through such “indignities” again. Ruth was encouraged to speak of her hospital experience but refused. Elizabeth noted that she appeared “physically weak” but “not mentally fragile”.
Interestingly, Ruth did not appear to give any indication of her emotional distress during this period of hospitalization. A friend noted that Ruth’s self-presentation during visitation was of someone who felt secure and appreciative of the experience of being cared for. She had the impression that the staff enjoyed interacting with Ruth given her jocular manner. The friend also said that she felt “choked” when she overheard the hospital social worker discussing discharge plans with Ruth. She said that Ruth minimized her difficulties and was adamant that she had no need of any home-based assistance. The friend said that she did not think that she had a right to interfere as Ruth had the right to live her life as she chose.

There are numerous indicators that Ruth was philosophically in support of suicide as a valid and “rational” option in the presence of unmitigated suffering. In this regard, Ruth was a member of the Right to Die with Dignity Society for 10 years prior to her death. Ruth also spoke with at least two informants about her support for assisted suicide for the terminally ill. At Ruth’s request, one informant shared information on assisted suicide that she was researching for a friend with a terminal illness. Numerous informants also regarded suicide as a rational form of self-deliverance from unmitigated suffering. Following Ruth’s suicide, a video copy of the book *Final Exit: The practicalities of self-deliverance and assisted suicide for the dying* by D. Humphry (1991) was discovered at the back of her closet.

In addition, Ruth created a Living Will, with the request that no extraordinary measures be taken for life preservation. Ruth also planned her own funeral arrangements in advance through the Memorial Society. In particular, Ruth requested that her ashes be placed in a common area with no memorial service or obituary notice. Elizabeth had the impression
that such arrangements had come from a pragmatic life philosophy coupled with a desire to avoid unnecessary “fuss” and expenditures.

Following her hospitalization in June 2002, Ruth also made Elizabeth her legal health representative. In retrospect, Elizabeth wondered if Ruth had appointed her to such a role in order to ensure that no heroic means were taken in the event that her suicide attempt was not lethal. However, entries in the Will Log (dated July 22, 2002) indicate that Ruth was considering further revisions to her legal will in a few years time. This suggested that Ruth was not actively making plans for suicide in 2002 immediately following her hospitalization.

There were numerous significant events in the months preceding Ruth’s decision to commit suicide. Three to four months prior to her death, Ruth disclosed an ear ache to friends. The pain eventually grew in severity, and encompassed one side of her head and neck. One informant, with a health care background, noted the significance of this disclosure as Ruth had never previously acknowledged or complained of pain. During a Christmas dinner in December 2002, Ruth acknowledged severe pain when questioned, as she was walking and holding her head with her hand. Ruth was reportedly encouraged to seek a referral to a rheumatologist that had been positively recommended by two friends.

Ruth subsequently met with a locum physician covering for her general practitioner. Ruth was apparently told that nothing could be done for her pain but that she could try acupuncture. While the physician supported a referral to the rheumatologist, informants had the impression that his manner was brisk and impersonal.

Approximately two weeks before the scheduled appointment with the rheumatologist, Ruth travelled by public transit to visit Elizabeth and Stevan, a mode of transportation insisted on by Ruth in spite of the time and energy involved. Ruth arrived looking very frail
and gaunt or “skeletal.” Wrapped up in a large knitted hat and bundled in a second hand down-filled coat, Ruth appeared to have aged considerably.

Throughout the two hour visit, Ruth acknowledged that she was in severe pain when questioned. Elizabeth noted that Ruth ingested numerous “thimble” glasses of sherry and Tylenol, six pills within a two hour period, in an apparent effort to self-medicate. In retrospect, Elizabeth thought that Ruth’s frequent trips to the bathroom were spent weeping given the knowledge that the visit would likely be her last. Elizabeth also suspected that Ruth had avoided physical contact during the visit as she likely did not want to show emotion as “her mind was made up.” In this regard, Ruth informed Elizabeth that there was no need to give her a calendar, a customary Christmas gift. She also told Elizabeth that she would not be celebrating her birthday in February. When Elizabeth attempted to cajole her into making birthday plans, Ruth replied in a jocular manner that she would be celebrating Saint Swither’s Day instead.

The impression that Ruth had tentatively made up her mind to commit suicide by mid-January 2002 was also supported by another informant who disclosed that Ruth gave her a family heirloom, a cartoon by a French artist, that she thought would be valued by her descendents. However, it was also noteworthy that Ruth expressed generosity by relinquishing possessions throughout her entire life.

Unfortunately, Ruth fell down by her bathroom entrance, hitting her head, on January 24, 2003, just prior to her appointment with a rheumatologist on January 27, 2003. The fall appeared to compound Ruth’s experience of pain. In this regard, a neighbour and a friend were concerned about internal injuries, or possible fractures, as Ruth reported pelvic pain.
following the fall. According to a neighbour, Ruth had been falling frequently in her condominium prior to her death.

Ruth refused to be taken to emergency department at the local hospital, noting that she had an upcoming appointment with the rheumatologist. This was considered typical of Ruth who minimized any physical difficulties or concerns. One informant wondered if the pending appointment had worked against Ruth receiving adequate care. She thought that Ruth would have likely been hospitalized if she had gone to the emergency department. Ruth spent her last few days lying down in her pyjamas as she waited for the scheduled appointment. During this time, Ruth received many expressions of concern and offers of assistance from significant others.

A neighbour subsequently accompanied Ruth to her appointment with the rheumatologist. Ruth reportedly left the appointment with the understanding that nothing more could be done for her pain, though she was advised that she could try acupuncture if she wished. According to informants, Ruth was also left with the understanding that her pain would only get worse. Ruth’s neighbour was reportedly furious with the cursory physical examination and impersonal manner of the rheumatologist. In this regard, Ruth returned to the office, at her insistence, to have a superficial cut on her head, suffered in the recent fall, examined by the rheumatologist.

The general consensus of several informants was that Ruth had suffered a significant loss of hope following her appointment with the rheumatologist. She was thought to have been prepared for suicide as an option for years but that her decision had likely been sudden. Numerous informants questioned whether or not Ruth’s pain had been sufficiently medically investigated.
In the two days following the above appointment, Ruth made a last phone call to several friends and extended family members. Numerous used tissues were found scattered around the couch by her phone following her death. Ruth’s conversations with others gave no indication of her suicidal thoughts or intentions.

In spite of her painful and debilitated state, Ruth cleaned out her condo (i.e., cleared her fridge, removed garbage and more private personal items, such as underwear). Ruth apparently made certain that no one would be visiting her for a few days. Ruth left a detailed list of people to be notified in case of accident or “sudden death” by her phone. She included an apology for her messy address book with the note that she had hoped to revise it.

Ruth instructed the reader to notify Elizabeth before all others. The following comments were added beside Elizabeth’s name and number: “Very helpful & devoted Cousin; knows about prearranged burial, etc. (files in paper file cabinet near bed; look also for cards in my wallet in purse, & bedside table. “Memorial Soc. of …”, etc.) (re locker downstairs: Nothing of value: throw it all out). The list contained names of family members and friends, including housekeepers, with instructions as to who should be notified first within a family, and the need for extra care with those who were ill or under great stress. Professionals identified by Ruth as requiring contact included the head of the nursing home where her brother lived, Ruth’s podiatrist, attending physician, dentist, insurance broker, stockbroker and the executor of her will. On her calendar, Ruth also left instructions for opera tickets to be given away and a scheduled medical appointment that required cancellation.

A note was left on Ruth’s bathroom door advising others against entry along with instructions to call the police. In her bathroom, Ruth arranged travel brochures, along with
specified instructions from travel agents, on the toilet seat and on the bathroom stool. These brochures were apparently intended for Elizabeth, who was bequeathed the contents of her condominium. Ruth had initiated previous conversations with Elizabeth as to where Elizabeth would want to travel if she had the financial means. Ruth then ingested a number of medications (specifics unknown), entered a tub full of water and slit her wrist.

Two neighbours eventually became concerned about Ruth’s well-being as they had not seen her for a couple of days. They contacted a local friend of Ruth’s who had also been attempting to reach Ruth daily by phone. After consulting with the friend, the neighbours obtained a key and entered Ruth’s condominium. One neighbour, an elderly woman bent over with osteoarthritis, entered the bathroom without noticing the sign on the door prohibiting entry. At first, the neighbour, who had poor eyesight, wondered why Ruth was doing laundry in her tub. However, they quickly assessed the true nature of the situation, contacted the police and then, contacted Elizabeth.

A suicide note was left for the police. A young constable eventually contacted Elizabeth and read the note over the phone. Elizabeth noticed that his voice was breaking with emotion as he read the note, a response that was much appreciated as it validated her own sorrow. Elizabeth quoted the suicide note from memory as follows:

I, Ruth Williams, being of sound mind, have decided to take my own life. I have not been abetted or assisted by anyone. This is wholly my decision. I have been in severe pain since October and it is only getting worse. I am sorry for the distress this might cause my friends and family.  
Signed, Ruth Williams.

When questioned regarding Ruth’s method of suicide, Elizabeth remarked that she did not think that Ruth had slit her wrist out of any sense of anger. Elizabeth viewed her actions as stemming from a steely determination that she be successful and ensure that she
not be left a “vegetable.” Such action was viewed as inconsistent with Ruth’s otherwise aversive sensibilities towards the macabre in life. Elizabeth thought that Ruth had likely decided on such action based on research regarding effective suicide methods. Elizabeth remarked that Ruth was found in the bathtub, clad in her housecoat and nightie, as if she had been seeking sleep. Elizabeth also said that Ruth had bequeathed her body to science, a request that was subsequently refused given the condition of her body post-mortem.

In early February 2003, approximately 20 extended family and friends gathered to remember Ruth as they sipped sherry together in her memory. A signed memorial book contained the following entries (among others):

*Ruth was a good friend, always cheerful, never complaining, as independent as I hope I can always be.*

*Ruth, when we would meet at the door, would always ask me “Do you think I have an honest face?” Yes, an honest, good, intelligent face – and always a cheerful one. God Bless!*

*Ruth, I’ll have to have a dinner every so often in your memory. Perhaps when I have a steak. You will be missed more than you know. Mum really misses you.*

*Ruth was my dearest friend.*

Elizabeth also received numerous letters and e-mails from loved ones who were not able to attend the memorial gathering. Excerpts of three letters from extended family members are presented below:

*Dear Elizabeth,*

*We know you will be meeting with Ruth’s friends on the 15th and we want to share our thoughts with them. Ruth was very dear to us. Although she was ... ’s father’s cousin, she was a contemporary of ours. When she visited with ... (father) and ... (mom) she called us “the kids.” We were amazed to find out that she graduated from ... in the Class of 1951. I graduated in 1951 and Ben graduated in 1950. She was such fun to be with; she always had an amusing anecdote to add to the conversation. Before moving to ... she had*
spent many years in ... caring for her mother who for about 10 years was bedridden. She found joy in helping others. Listening to the opera gave her great pleasure. She remembered birthdays and holidays, at first with cards and typewritten notes, and more recently, as typing became more difficult, with telephone calls. She was bright, witty, and at the same time self-effacing. She might be surprised at how much we all will miss her.

We hope the “get-together” goes well....Please let us know the address of the Opera Guild in which she participated. Thank you for all you are doing.

Joan and Ben Martin

Dear Elizabeth,

Thank you so very much for your thoughtful phone call - losing Ruth has saddened me deeply.... So I feel regret (trying not to feel guilt) - as our very dear daughter, ... said on the phone –“we always wish for one more last good-bye”....I planned to phone Ruth this week from here—as I set up International rates after a call to her that cost me $35.00!...

Perhaps Ruth has told you that I’m an amateur antique dealer with booth at MALL. A HOBBY! Some months I don’t sell to cover rent - but in Jan. I sold a very pretty silver overlay platter that I didn’t believe our children would want to inherit as it needed polishing, but I felt badly about parting with it - So it would cheer me up if you would use the amount towards your TEA party – if Ruth were there it would go towards SHERRY!

You are dear to assemble Ruth’s friends on her Birthday – my thoughts will be with you – wishing I could be with you all and saying thank you for being Ruth’s friends and supporters through the years. You made her life happy so many times.

With love to all –

Agnes

....P.S. If you don’t spend it all on “SHERRY”- please send balance to OPERA or appropriate charity. This postage was on hand for my next letter to Ruth.

Dear Elizabeth,

Thank you for your E-mails to my sister and especially you courage in giving Sylvia a detailed description of Ruth’s choices. I feel quite comforted by knowing that Ruth’s ability to think and plan and make her own decisions continued to be so strong in the past six months. She did let me know the hospitalization had been devastating and she was sent home with pills and she was emphatically not going to tell me more. For her to end her life while she could seems to me perfectly compatible with who she was and how bravely she lived.
My thought was to gather the four of five of us in ... who knew Ruth at my house and we may yet do that....

Regards,
Shirley

Elizabeth described the process of dealing with the aftermath of the suicide as a “service of love.” She spoke of spending time in Ruth’s condo surrounded by light and beauty, relishing the sense of Ruth’s presence. Likewise, Elizabeth spoke of a sense of consolation in knowing that she was thought of as Ruth committed suicide, as evidenced by the placement of the travel brochures. In this regard, Elizabeth thought of herself as being present during Ruth’s suicide, in a spite of a physical absence.

Numerous informants remarked on the perceived determination and courage reflected in Ruth’s methodically planned suicide. Any guilt expressed was typically mitigated by the fact that Ruth had protected others from the knowledge of her intentions and by the reality that she would not have been otherwise dissuaded given her determination and will. As Stevan remarked, Ruth was “the master of her ship.”

Numerous informants also rested on the knowledge that their relationship had been loving and practically supportive and, therefore, had no regret. However, Stevan remarked that he had wished for an opportunity to tell Ruth that he understood her actions and that he loved her. He disclosed “self-focused” anger over her death, noting the void brought by her absence. Likewise, another informant indicated that she had wished that she had known that she and Ruth were having their final conversation, even though she would have had no desire to stop her. She remarked that such desire created a paradox as a sudden death was wonderful for the suffering individual but more difficult for others as they missed the opportunity to say what they needed to say. At the same time, she remarked that it was more difficult for the individual to remain and suffer for the sake of others. Yet another informant
remarked that she wished that she had been aware that she was having a last conversation with Ruth as she had been preoccupied and had told Ruth that she would call her back. However, she reflected that Ruth might have preferred such a good-bye as it was typical of their relationship.

In spite of assumed anxiety regarding her pain management, informants unanimously remarked on the absence of distress signalling depression prior to Ruth’s death. At the same time, Stevan ruefully remarked that he wondered how happy someone could be when “you were falling to pieces and told that nothing could be done.”

With the exception of one informant, who was not questioned directly, there was unanimous agreement that Ruth’s suicide had been rational. The excluded informant assumed that Ruth’s suicide had come from a confrontation with intense suffering, but, according to his spouse, was against suicide “in principle.” At times, the impression of rationality appeared to be largely based on the informant’s experience of Ruth, as a consistently rational person, rather than on information regarding Ruth’s recent life circumstances. For example, one informant thought that her suicide was likely caused by financial concerns given recent stock market downturns. Another informant assumed that Ruth had simply “had enough of coping.” On one occasion, an informant endorsed Ruth’s suicide as rational in spite of reported outraged when first informed. Those informants, who were aware of Ruth’s severe pain in the last few months of her life, accepted her suicide as a rational response to perceived hopelessness and unmitigated suffering.

Clearly, Ruth’s absence did not prevent her from being a continued presence in the lives of numerous informants. For example, a quilt made in her memory was brought out at Christmas time as a tree skirt, a requested memento of Ruth invariable brought out memories
when it was handled, and a home garden provided a space for regular reflections regarding Ruth. Elizabeth’s and Stevan’s home was replete with Ruth’s possession (i.e., children’s books, pottery pieces and artwork). Stevan remarked that, if Elizabeth attempted to remove any of Ruth’s “baubles,” he told her to “leave Ruth alone.” Elizabeth spoke of frequently feeling Ruth’s presence, through her possessions, and that it made her “smile.”

Reflections on A Portrait of Ruth: Through the Lens of Family and Friends

According to informants, Ruth’s early childhood was marked by a nurturing home environment, as well as enhanced learning opportunities. Childhood photographs and an inscribed children’s book attested to an affectionate relationship between Ruth and her parents. There was no reported history of childhood trauma, abuse or neglect, nor was there any history of parental psychiatric illness or substance abuse, marking the absence of identified risk factors associated with adult suicide in general (Lester & Tallmer, 1994). While there was little information available regarding Ruth’s brother Harold, parental academic aspirations for their son suggested an adult onset to his mental illness.

However, as an adult, Ruth experienced significant family-related stress, particularly within her role as a caretaker to her ailing mother. On one occasion, Ruth confirmed the impressions of numerous informants that her mother had been excessively demanding while under her care. Likewise, Ruth occasionally alluded to stress within her role as next of kin and overseer of her brother’s care in the eastern United States. Towards the end of her life, Ruth disclosed distress that she was functionally unable to be Harold’s fulltime caregiver, a response that appeared reactive to pressure by health-care professions to take on the role. However, stress within the sibling relationship also appeared mitigated by Ruth’s realistic
expectations and strong interpersonal boundaries. This was particularly evident when Ruth asked her brother to leave their father’s funeral, given his reported bizarre behaviour.

Ruth’s experience of interpersonal stress was particularly relevant given extensive research has linked interpersonal stress with increased markers of immunostimulatory activity and disease activity as well as a depressed mood for those with rheumatoid arthritis (Affleck et al., 1994; Zautra et al., 1994; Zautra et al. 1998; Zautra et al., 1997). Likewise, Ruth’s experience of interpersonal support was relevant, given that supportive and affectionate spouses, high levels of general support, and positive interpersonal events have all been found to have a buffering effect on the adverse effects of minor stress, particularly those that are interpersonal in nature (Affleck et al, 1994; Zautra et al., 1998; Zautra & Smith, 2001). However, the actual import of interpersonal stress on Ruth’s disease process and her lived experience remains unknown.

According to archival material, Ruth first noted arthritic changes in her hands at the age of 33. In this regard, the estimated age of onset and Ruth’s severe disease presentation, as evidenced in progressive hand and foot deformities and associated disability, appeared consistent with gender reported differences (Anderson et al., 2000; Weyand et al., 1998). Likewise, Ruth appeared to fit the profile of those with rheumatoid arthritis (typically 50%) who are work disabled within 10 years of diagnosis (Brooks, 1997, as cited in Woolf & Pfleger, 2003) given an early retirement at approximately 40 years of age.

There was no evidence that Ruth grappled with the effect of psychodynamic theories of causation that were prevalent during the time of her diagnosis in 1971 (Lerman, 1987; Shafii, 1973; Spergel et al., 1978), unlike the earlier recounted experiences of Grace Stuart (1953). Ironically, Ruth may have inadvertently been protected from such psycho-
pathologizing given diagnostic uncertainty from 1962 to 1971. By the late 1970’s, research had challenged psychodynamic theories of causation, finding no differences between the MMPI personality profiles of those with rheumatoid arthritis when contrasted with other chronic illnesses (Spergel et al., 1978). Rather, Ruth appeared to use a scientific, rational lens, looking for physical precedents, such as flu-like symptoms, as precursors to an inflammatory process.

In regards to Ruth’s psychological profile, informants consistently portrayed Ruth as a woman who did not grapple with undue anxiety or depressive symptoms throughout her life. These impressions were unanimous amongst informants, whether they had known Ruth within the past 10 years or since childhood. Ruth did not exhibit the depressive symptoms identified by numerous researchers as typical of the chronic illness experience associated with rheumatoid arthritis (Dildy, 1996; Iaquinta & Larrabee, 2004; Shaul, 1995), although the reported incidence rates for depression vary significantly from 15% to 42% (Harrison, 2003). Ruth’s psychological robustness may have been associated with Ruth’s disclosures of minimal pain, until the later months of her life, given extensive research which has documented the reciprocal nature between measures of anxiety, depression and pain (Gatchel et al., 2007; Huyser & Parker, 1999; Keefe et al., 2001).

Likewise, Ruth did not express anger or grief regarding the multiple losses she had experienced, an emotional response that researchers have identified as common within the experience of debilitating chronic illness and rheumatoid arthritis, in particular (Bury, 1982; Charmaz, 1982, 1995; Dildy, 1996; Iaquinta, & Larrabee, 2004).

Clearly, Ruth experienced significant losses, both tangible and intangible, throughout her life, including the loss of physical comfort and predictability, the loss of functional
abilities, and the loss of a vocational identity. In regards to the latter, informants were unaware of the impact of the disease process, such as progressive disability, on Ruth’s decision to retire while assuming that she had quit work to care for her mother. On occasion, Ruth positioned her vocational loss in positive terms, as in the remark that she was relieved to not get up in the morning, when speaking with a godchild. Ruth did not appear to voice regrets if she thought that such statements would evoke sadness in others. Ruth was more forthcoming with regret regarding the loss of her vocation with two informants who were academics, perhaps understanding that such reflection would be expected.

Ruth also appeared adept at masking her emotions with others, with one informant remarking on her “formidable defences,” or emotional control, particularly in response to situational stress. In this regard, one informant remarked that Ruth appeared pleasant and appreciative with health providers while hospitalized in May-June 2002. However, following discharge, Ruth expressed considerable anger and feelings of degradation to Elizabeth (the main informant) and her husband, Stevan, with the remark that she preferred suicide to such an experience in the future. Such feelings of degradation, particularly in regards to the loss of privacy, were consistent with the experiences of those with rheumatoid arthritis that have minimal hospital experience (Edwards et al., 2001).

Most significantly, during the later weeks of Ruth’s life, informants and health care providers were unaware of the extent of Ruth’s hopelessness and despair regarding unremitting severe pain. However, the consistency of reports of Ruth’s emotional stability throughout her life suggested a psychological robustness that persisted until the last months of her life.
In this regard, Ruth typically exemplified many of the characteristics that researchers have associated with well-being for those with rheumatoid arthritis, including a rational cognitive style, an internal locus of control, a general attitude of optimism and a strong belief in self-efficacy, particularly in regards to symptom management and problem-solving (Affleck et al., 1987; Flor & Turk, 1988; Keefe et al., 1989; Nagyova et al., 2005; Smith et al., 1994; Treharne et al., 2005; van Lankeveld et al., 1994; Walker et al., 2004; Zautra & Manne, 1992). As such, Ruth’s active coping style presumably protected her from greater functional disability, depression and pain given research findings that have associated such adverse effects with a more passive coping style (Brown & Nicassio, 1987; Flor & Turk, 1988; Covic et al., 2003; Covic et al., 2006; Keefe et al., 1989; Smith & Wallston, 1992; van Lankveld et al., 1994). Likewise, Ruth’s life passions (or aesthetic spirituality) fostered a positive life engagement while presumably marginalizing the effect of functional disabilities and health-related concerns, given research linking measures of spiritual transcendence to positive affect and enhanced health perceptions (Bartlett et al., 2003).

Ruth managed symptoms of pain, fatigue and disability predominantly through the use of accommodation, active remediation and perseverance, mirroring the strategies favoured by others with an established disease process, including an apparent reluctance to seek social assistance to manage pain and fatigue (Katz, 2005). Likewise, Ruth favoured perseverance, rather than accommodation, particularly in her pursuit of valued activities, such as travel, music-related activities and socializing with extended family members and friends. Informants observed that Ruth persisted in these activities in spite of a large symptom burden (i.e., overwhelming fatigue, intermittent diarrhea, and severe deformities with associated biomechanical pain). The presence of such “zealous perseverance,” (p. 283)
in the face of disability and deformity, has been similarly identified within the lived experience of rheumatoid arthritis (Iaquinta & Larrabee, 2004). According to Katz (2005), for those with an established disease process, perseverance, rather than accommodation, was found to be the coping strategy most associated with the maintenance of function over time.

While Ruth’s fierce independence and determination likely preserved her functionality, these attributes may also have protected Ruth against the onset of depression that has been found to be associated with the loss of valued activities (Katz & Yalin, 2001; Neugebauer et al., 2003). Ruth’s appeared to successfully adapt to her chronic illness in that she was “living with an illness without living solely for it” (Charmaz, 1995, p. 5).

Nursing researchers Plach et al. (2004) identified embodiment as central to understanding the lived experience of those with established rheumatoid arthritis. In particular, Plach et al. (2004) identified three predominant themes within the experience of corporeality (or being one’s body) including relating to a noncompliant body, a body out of synch, and a private body made public, all of which appeared to be relevant to Ruth’s experience. For example, like research participants (Plach et al. 2004), Ruth meticulously prepared for ordinary tasks given the difficulties associated with a body made non-compliant through the presence of deformities, pain and, presumably, pervasive fatigue. As noted by Corbin and Strauss (1987), the restructuring of “clock time” (p. 261) around the requirements and performance of the body, underlined the significance of the body as the medium through which life was constructed and experienced.

Ruth’s gait and manual dexterity also became increasingly awkward or non-compliant over time, a body that was experienced as out of synch with able bodied peers, as was consistent with research participants (Plach et al., 2004). Ruth’s humourous, yet disparaging
comments regarding the appearance of her hands also underlined the humiliating effect of inescapable public exposure that has been associated with such deformities (Plach et al. 2004). As with research participants (Plach et al., 2004), Ruth kept “pain, impairment, and changing appearance hidden from public view. Smiling through discomfort and acting normal was the goal” (p. 145). Corbin and Strauss (1987) have similarly identified the ways in which the chronically ill conceal or minimize the negative aspects of their body’s appearance and performance. Ruth’s success at concealment was evident in Elizabeth’s (main informant), disclosure that she became aware of the condition of Ruth’s feet from reading the Medical Log, in spite of a close relationship that spanned 30 years. Ruth’s decision to appoint Elizabeth as her health care representative spoke of an otherwise established trust and ease within their relationship.

Ruth’s description of herself as a decrepit senior citizen, or as prematurely aging, was also consistent with the self-appraisal of others with rheumatoid arthritis (Bury, 1982; 1988; Iaquinta & Larrabee, 2004; Plach et al., 2004). Likewise, Ruth’s humorous motto “Onward, Downward” reflected a consciousness awareness of the ongoing physical decline that has been found to permeate the experience of others with established rheumatoid arthritis (Minnock et al., 2003).

The impact of embodiment was particularly relevant for Ruth’s end of life experiences, given that researchers have questioned the appropriateness of various cognitive behavioural strategies for those with a severe disease process (Affleck et al., 1987; Affleck et al., 1992; Astin et al., 2002; Erdal & Zautra, 1995; Schiaffino et al., 1991; Treharne et al., 2005). For example, while Ruth’s high self-efficacy and active problem-orientated approach may have fostered optimal adaptation throughout life, the persistent application of these
attributes in the presence of severe pain may have fostered greater mood disturbance given research that has found such an association (Schiaffino et al., 1991). However, the adaptive value of acceptance and the relinquishment of control has not been established within the field of rheumatoid arthritis (Zautra & Manne, 1992), with Gatchel et al. (2007) cautioning that such strategies may foster the development of depression for those with chronic pain. For example, van Lankeveld et al. (1994) found that acceptance was not associated with well-being for those with an established disease who were coping with challenges related to dependency.

While Charmaz (1995) identified the relinquishment of control as the final stage of adaptation within the experience of chronic illness, for Ruth, the relinquishment of control, particularly in the pursuit of pain management, brought forward suicide as an option. As Ruth was a longstanding member of the Die with Dignity Society, suicide was presumably viewed as a rational choice, given the presence of unmitigated suffering (and possible concerns about increased dependency, as suspected by numerous informants). Ruth’s permissive attitude towards suicide mirrored the widespread societal acceptance of elderly suicide as potentially rational (Humphry, 1991; Kleepsies et al., 2000; Ogden & Young, 1998; Rosenfeld, 2004; Werth & Corbin, 1995), an endorsement that extends to global issues such as physical debilitation and the loss of independence, control and dignity (Back et al., 1996; Ganzini et al., 2000; Sorenson, 1991; Wilson et al., 2007). According to the majority of informants, Ruth’s permissive attitude towards suicide mirrored the rationalism that defined the coping strategies employed throughout her life.

The western cultural values of independence, privacy and family autonomy (Charmaz, 1983) were implicit within Ruth’s style of coping with rheumatoid arthritis. In
psychological terms, Ruth’s core-ordering processes (Mahoney, 1991), particularly in connection with coping with illness-related stressors, was perhaps crystallized in her statement that “I must do it myself.” This assertion also implied a strong Protestant work ethic, identified by Charmaz (1983) as a western value that frequently hinders the acceptance of external support within the experience of chronic illness.

According to Elizabeth, the main informant, Ruth’s experience of care-taking her bedridden mother, as well as Ruth’s observation of the adverse effects of institutional life on Elizabeth’s mother, further consolidated the determination to avoid such dependency. Ruth was well informed of various residential care facilities in her community; having investigated such resources on behalf of another individual. However, Ruth adamantly declined additional home-based assistance on her own behalf, whether offered through an extended family member or through a health professional, as was witnessed during a hospitalization in May-June 2002. According to the impressions of numerous informants, increased dependency and institutional living were not conducive with Ruth’s construction of a meaningful existence.

While Ruth’s “fierce independence” was a source of frustration for significant others, given their concern and desire to reciprocate kindness, her coping style was also viewed as exemplary and courageous. In this regard, Ruth’s social network shared Ruth’s Anglo-Saxon values and preferred ways of being. As such, others reflected a deep appreciation for Ruth’s interpersonal style which was presumably co-constructive of Ruth’s preferred lived narrative (Burr, 1995; Polkinghorne, 1988), particularly within the process of meaning-making associated with chronic illness (Bury, 2001).

According to Bury (1982, 1988), the legitimization and negotiation of support is fraught with ambiguity for those with rheumatoid arthritis, given the constraints of social life,
implicit behavioural expectations and the cultural connotations of disability and illness that infuse the process. For example, the acceptance of the need for increased instrumental assistance would have socially redefined Ruth’s disability, and, according to Bury (1988), increased social anxiety within all parties, given the lack of cultural role prescriptions to guide behaviour. Likewise, an inability to sufficiently reciprocate assistance may constrain acceptance, given the otherwise negative effects on self-esteem (Revenson, 1993). According to van Lankveld (1994), consideration (i.e., making self useful or not asking too much from one person) was the coping strategy most positively associated with well-being for those with an established disease process in positions of dependency. The negotiation of support is particularly difficult within the experience of rheumatoid arthritis, given that symptoms may be inconsistent, unpredictable and marked by shifting treatment requirements (Revenson, 1993).

Ruth’s general reticence to accept instrumental or emotional support from others was consistent with findings by numerous researchers, both in the experience of pain (Katz, 2005; Plach et al., 2004) and fatigue (Katz, 2005; Hewlett et al., 2005). Likewise, Melanson and Downe-Wamboldt (2003) found that the older adult with an established disease process (average age of 75; average disease duration 18 years) were more likely to use problem-oriented or palliative strategies before support when coping with illness-related stressors. Research by Hewlett et al (2005), in particular, underlined the cultural influence of an Anglo-Saxon background in such reticence, referencing the need to maintain stoicism, even in the presence of overwhelming and debilitating fatigue. According to Iaquinta and Larrabee (2004), the maintenance of privacy regarding disease activity may also be associated with
past untoward reactions, or, as found by Bury (1988), motivated by a desire to avoid unwanted interpersonal effects, such as burdening others or unwanted caretaking.

Given the above cultural and interpersonal dynamics, Ruth’s significant others were constrained in their ability to directly advocate on Ruth’s behalf, as such action would presumably have been viewed as disrespectful. For example, in spite of a health care background, an informant did not speak to the hospital social worker when Ruth declined home-based assistance as part of discharge planning as such actions were viewed as an infringement on Ruth’s ability to live life as she chose. In addition, informants occasionally questioned the adequacy of Ruth’s medical care but felt constrained in their ability to intervene directly. This relational dilemma was cogently referenced when one informant remarked that Ruth lacked an advocate in the form of a daughter. Within a western worldview, direct advocacy was not seen as an infringement of personal boundaries when performed by immediate family members, the accepted and rightful position of a daughter, in particular.

The above informant’s comments perceptively highlighted the increased vulnerability of the single, elderly and infirm within western culture, particularly given Scarry (1985) observations linking social advocacy to the allocation of cultural resources. As noted by Turner (1987), the chronic symptoms of the elderly patient are otherwise frequently medically under treated because of an implicit attitude of normalization towards the aging process. The provision of health-related services for the elderly also occurs within a delivery system already biased towards acute, rather than chronic care (Charmaz, 1983).

While significant others were marginalized within Ruth’s health care, an extensive support network provided assistance and advocacy, albeit in an indirect fashion. In this
regard, Ruth’s experience was inconsistent with research linking a restricted social life to a debilitating chronic illness (Charmaz, 1983, 1995) and rheumatoid arthritis, in particular (Bury, 1982; Fritzpatrick et al., 1988). Such assistance included the occasional provision of transportation to medical appointments as well as unobtrusive assistance, such as instrumental aids in the form of gifts, shared research and recommendations for resources.

Ruth’s extensive engagement with others continued throughout her entire life. For example, during the last few days of life, Ruth sought a referral to a rheumatologist recommended by friends, a neighbour offered transportation to the appointment while another friend made a follow-up phone call. Prior to her suicide, Ruth made a final phone call to numerous individuals and wrote an extensive list regarding the notification of others, including professionals, friends and family members. Ruth’s body was eventually discovered by two neighbours and a friend who were alarmed by her absence and lack of response to phone calls in the preceding days. An extended family member in the United States also disclosed that she had unsuccessfully tried to contact Ruth during the same time period. Ruth was not only socially engaged; she was actively valued and appreciated.

Informants gave mixed impressions of Ruth’s pain, with several reporting that Ruth experienced minimal or no pain, while others assumed pain based on physical manifestations and behavioural indicators, such as a laboured and awkward gait, the need for orthopaedic shoes, the presence of severe hand deformities and the regular ingestion of Aspirin. Different impressions were perhaps reflective of the difficulties in accurately portraying a disease process that may have been inconsistent in presentation and unpredictable in nature (Newman & Revenson, 1993; ACR, 2002). However, informants consistently reported that Ruth did not complain of pain until the last couple of months of her life, in spite of many
invitations to speak of her experience with pain. In this regard, Ruth may have had periods when she was relatively pain free, she may have minimized or otherwise reframed pain, or she may have deliberately denied the existence of pain, an alternative suggested by Elizabeth, following a reading of the Medical Log. Such denial, or minimization, may have been motivated by a desire to preserve privacy and maintain autonomy while also protecting others from vicarious suffering, an implicit emotional burden.

As such, Ruth’s reported pain experience appeared to contradict research which has identified pain as a predominant symptomatic stressor for those with established arthritis (Melanson & Downe-Wamboldt; Minnock et al., 2003). The nature of Ruth’s pain experience was particularly relevant given extensive research findings that have identified a reciprocal nature between affect and pain (Gatchel et al., 2007; Huyser & Parker, 1999; Keefe et al., 2001), with high levels of pain, in particular, associated with higher levels of anxiety, depression and lessened self-esteem and poorer adjustment (Nagyova et al., 2005) and well-being (van Lankveld et al., 1994). Research, using a longitudinal design, has also found that higher pain levels were predictive of higher depression over time (Brown, 1990; Katz & Yalin, 1993; Schiaffiano et al., 1991) although the nature of the relationship between pain, depression and coping remains controversial (Parker & Wright, 1995). Ruth’s lessened experience of pain, if accurately portrayed, may have contributed towards the maintenance of psychological well-being within the experience of rheumatoid arthritis throughout her life.

Numerous informants were aware that Ruth’s pain had become severe and unremitting during the last months of her life. However, Stevan, in particular, raised a central ethical dilemma in the comprehension of Ruth’s pain, noting that her disability could be observed and yet her pain remained invisible. Likewise, Elizabeth remarked that no one
was “privy” or “understanding” of the extent of Ruth’s pain at the end of her life. Ruth, like Grace Stuart (1953), essentially lived in a private world of pain.

Pain theorist, Scarry (1985) has articulated the attributes of severe pain which jeopardize both understanding and compassion within community. According to Scarry (1985), the most frightening attribute of pain is its inherent resistance to objectification through language, essentially rendering pain unknown, and even denied, by others, even when totalizing the consciousness of the sufferer.

According to Scarry (1985), severe relentless pain may be likened to torture in its totalizing effect on the person and its ability to be world destroying. Given the collapse of the world, self and voice, Scarry (1985) highlighted the moral responsibility of others in providing advocacy, or, compassionate witness, in order to maintain hope. According to Scarry (1985):

An act of human contact and concern, whether occurring here or in private contexts of sympathy, provides the hurt person with worldly self-extension: in acknowledgement and expressing another person’s pain, or in articulating one of his nonbodily concerns while he is unable to, one human being who is well and free willingly turns himself into an image of the other’s psychic or sentient claims, an image existing in the space outside the sufferer’s body, projected out into the world and held there intact by that person’s powers until the sufferer himself regains his own powers of self-extension. By holding that world in place, or by giving the pain a place in the world, sympathy lessens the power of sickness and pain, counteracts the force with which a person in great pain or sickness can be swallowed alive by the body (p. 50).
The insights of Scarry (1985) mirror those of Williams (1999) in the recognition of the embodied self as central to an ethical and compassionate response to suffering by others. In other words, shared sentience enables human beings to act beyond their own narcissist concerns.

Likewise, Corbin and Strauss (1987) identified embodiment as essential to understanding the narrative reconstructive process inherent within the chronic illness experience. As is highly relevant to Ruth’s experience, the authors identify a persistent downward health trajectory as a force that shatters narrative coherence while potentiating feelings of hopelessness and despair (Corbin & Strauss, 1987). According to Dildy (1996), a lack of pain control constrains the development of positive or transformative meaning-making within the experience of suffering associated with rheumatoid arthritis. Charmaz (1983) has also identified physical improvement and stabilization as preconditions for any benefit-finding within the experience of loss associated with a debilitating chronic illness. According to Melanson and Downe-Wamboldt (2003), very few older adults with established rheumatoid arthritis report any benefit from the illness related stressors associated with rheumatoid arthritis.

In this regard, Ruth’s core illness narrative appeared to shift from that of a “quest” narrative, marked by a search for meaning and personal change, to that of a “chaos” narrative, marked by ongoing chaos and a lack of narrative coherence (Frank, 1995). As such, Ruth appeared to enter an existential crisis regarding the value and meaning of continued existence. For Ruth, principles of personal control, independence and autonomy would, presumably, have been central to any constructions of a meaningful future. However, the presence of severe pain highlighted the need for external resources outside of self,
whether in the form of an advocate (Scarry, 1985) or an empathetic witness to her suffering (Frank, 1995; Kleinman, 1988; Scarry 1985). However, given a characteristic preference for independence, autonomy and privacy, Ruth would presumably have refused direct advocacy, particularly if offered by friends and extended family members, just as she had refused home based assistance as part of discharge planning while an inpatient in May-June 2002.

Informants who accompanied Ruth during the last months of her life unanimously thought that Ruth was demoralized and had suffered a complete loss of hope following her consultation with the rheumatologist in the last week of life. While Ruth entered the appointment with some hope, fostered by two individuals who spoke highly of the recommended rheumatologist, she left with the understanding that nothing more could be done for her pain and that it would only worsen over time. Dialogue with the rheumatologist reportedly consolidated impressions of hopelessness established through prior conversations with the locum attending physician. While the exact nature of the dialogue remains unknown, Ruth left the rheumatologist’s office with an imagined future that was apparently worse than death.

While Ruth’s interactions with physicians during the last month of life were thought to have fuelled hopelessness, their perceived curt and impersonal manner also presumably fuelled one of Ruth’s greatest fears, that she was becoming a burden. In this regard, Ruth was immediately sent back to the rheumatologist following consultation, given anger on the part of a companion that an obvious head wound (suffered in a recent fall) had not been attended to.

Numerous informants thought that Ruth had committed suicide as she likely predicted increased dependency in the near future. As such, Ruth’s motivational intent appeared
consistent with the identified causes for elderly suicide in general, including physical illness, functional limitations, and a lack of independence or threat of institutionalization as well as multiple losses, whether present or foreseen (Conwell, 1997; Conwell et al., 2002; Lester & Tallmer, 1994). In the later months of life, Ruth grappled with numerous physical challenges, including difficulties maintaining control and independence as well as pain management within the context of significant physical limitations, all identified as predominant illness-related stressors for older adults with an established rheumatoid arthritis (Melanson & Downe-Wamboldt, 2003).

Given extensive research findings of the reciprocal interactions between pain, anxiety and depression (Gatchel et al., 2007; Huyser & Parker, 1999; Keefe et al., 2001), the presence of severe pain presumably heightened any underlying affective distress in a reciprocal fashion. Ruth’s apparent use of alcohol to self-medicate, albeit in small amounts, particularly at the end of her life, may also have contributed towards a depressive state. While research has commonly identified a unipolar depressive episode prior to suicide in the elderly (Conwell & Brent, 1995; Conwell et al., 2002) the relevance of depression in Ruth’s experience remains unknown.

However, there were also various behavioural indicators that suggested the absence of a significant depression in the later months and weeks of Ruth’s life. For example, Ruth remained both socially engaged and proactive in her pursuit of pain relief. Likewise, Ruth’s attendance to her social world, just prior to her suicide, suggested a consciousness of her personal worth to others.

While researchers have questioned the role of depression and hopelessness as mediators between pain and the desire for a hastened death (Lester & Tallmer, 1994;
Rosenfeld, 2004), Ruth’s experience underlined the role of hopelessness in her decision to commit suicide. Hopelessness, as an integral part of depression, has been found to be independently predictive of suicidal ideation and completed suicide in psychiatric adult populations (Beck et al., 1989; Beck et al., 1975; Beck et al., 1993; Beck et al., 1985) and as predictive of suicidal ideation and completed suicide in the elderly (Hill, et al., 1988; Rifai, et al., 1994; Ross et al., 1990). Likewise, research has linked hopelessness, or a lack of purpose, with suicidal ideation for palliative patients with a terminal illness (Chochinov, et al., 1998; Wilson et al., 2007).

Research investigating requests for physician assisted suicide or euthanasia have also found predominant motivations were value-driven, such as a loss of control, independence and dignity rather than symptomatic in nature (Back et al., 1996; Ganzini et al., 2000). However, Wilson et al. (2007) found that palliative patients, who indicated a desire for a hastened death (if legally permitted), had a greater number of symptoms and psychosocial concerns in contrast to palliative patient who did not desire a hastened death. The top five identified symptoms and concerns underlying the desire for a hastened death included: weakness, a desire for death, general malaise, drowsiness and concerns regarding being a burden to others. In addition, the desire for a hastened death was associated with lower religiosity, reduced functional status, as well as higher degrees of depression and hopelessness in contrast with those who did not desire a hastened death (Wilson et al., 2007).

Rosenfeld (2004) has suggested that a large overall symptom burden, rather than depression, may be the overriding determinant in the elderly desire for a hastened death. Physicians have a seminal role in regards to alleviating such burdens, while also situated to engender hope for those in despair of a meaningful future (Groopman, 2004). For example,
Ganzini et al. (2000) found that 46% of requests for physician-assisted suicide were withdrawn following substantial medical intervention, whether symptomatic relief or psychosocial in nature. Likewise, Wilson et al. (2007) reported that 9.5% of palliative patients indicated that they would have previously requested a hastened death (if legal) but they had changed their minds following the resolution of physical and psychological concerns.

Ruth carried a large overall symptom burden, including chronic and intermittent acute pain, recurrent gastro-intestinal disturbances, functional limitations and overwhelming fatigue. However, Ruth appeared to cope adequately with all of the above symptoms, for numerous years, until she experienced the additional burden of severe and unremitting pain.

Ruth had contact with two primary care providers (a podiatrist and locum attending physician) within the month preceding her suicide, as well as contact with a consulting rheumatologist (a self-initiated referral) within a week of her death. This finding was consistent with the reported contact rates preceding elderly suicide, with 62% having seen a primary care physician in the 30 days prior to suicide and 36% having seen a primary care physician within a week of suicide (Conwell, 1997). As was characteristic of elderly suicides in general (Conwell et al., 2002), Ruth was very determined in her intent, avoiding detection while engaged in meticulous planning.

In comparison to the demographic characteristics of women with rheumatoid arthritis who have completed suicide (Timonen et al., 2003), Ruth’s suicide was similar given her older age (as compared to female suicides with neither osteoarthritis nor rheumatoid arthritis), the existence of a longer disease process (as compared with male suicides with rheumatoid arthritis) and her use of a violent method, the latter characteristic mirroring 90%
of women with rheumatoid arthritis who have committed suicide. However, Ruth also appeared to significantly differ in that she had no prior history of depression, in contrast to 90% of women with rheumatoid arthritis who have committed suicide, with 50% also having made a prior suicide attempt (Timonen et al., 2003).

Ruth’s suicide note, with its direct reference to unbearable suffering and instructions intended to protect others was also characteristic of elderly suicide notes (Lester & Tallmer, 1994). Analysis of the content of Ruth’s suicide note was consistent with Leenaars’ (2003) analysis of a terminally ill cancer patient in regards to motivational intent, including the desire to avoid unbearable psychological pain, a cognitive constriction focused on pain, unmet needs regarding control, traumatic injury (i.e., progressive, severe and unremitting pain) and an unwillingness to accept life circumstances coupled with a desire to escape through death. Using Freud’s physician-assisted suicide as an exemplar, Leenaars (2003), suggested that such deaths be described as a “dignified death,” “assisted death,” or a “self-chosen death” (p.10) rather than suicide. Likewise, when Ruth left final instructions to others in case of “accident” or “sudden death,” she appeared to position her actions within the euphemism of “hastened death” rather than suicide, a term referenced by Humphry (1991).

A video recording based on the book Final Exit: The practicalities of self-deliverance and assisted suicide for the dying by D. Humphry (1991), was discovered at the back of Ruth’s closet following her death. Ruth apparently followed numerous recommendations outlined by Humphry (1991) prior to her suicide. For example, Ruth spoke to a general practitioner and a rheumatologist prior to action, determining that she was a “hopeless case,” (p.114) particularly in regards to pain remediation (Humphry, 1991). In the preceding
months, Ruth also created a revised legal will, naming an institutional executor and identified Elizabeth as her legal health care representative (in addition to a pre-existent living will). In addition, Ruth left directions regarding burial wishes and public notification with the Memorial Society.

As recommended by Humphry (1991), Ruth also informed significant others that she was a member of the Die with Dignity Society, an organization that advocates for rational suicide as a legal option. In particular, Ruth informed numerous informants approximately six months prior to death that she would choose suicide rather than endure the indignities of re-hospitalization. In her suicide note, Ruth also protected others against recriminations by clearly noting that she was solely responsible for taking her own life, and that she had not been abetted or assisted in any way. As recommended by Humphry (1991), Ruth also ensured that there were no scheduled home visits in the hours and days following her suicide attempt and she left her phone on the hook, so as to not alarm others. In summary, Ruth planned meticulously and left “nothing to chance” (Humphry, 1991, p. 115).

Informants were unanimous in their perception that Ruth’s suicide was rational, with the exception of one informant who was not directly questioned. Informants who were not aware of Ruth’s severe end of life pain appeared to make this assumption based on Ruth’s characteristic rational approach to life. Notions of rationality may also have been constructed retrospectively given that one informant was reported by another to have been initially outraged by Ruth’s actions but later described Ruth’s suicide as rational when interviewed. As such, notions of rationality appeared to be based on the subjective and retrospective lens of the individual, rather than based on objective criterion. In this regard, informants chose a lens which focused on stories of rationality rather than those which might have raised
ambiguity or contradiction. For example, while numerous informants questioned the adequacy of pain management, this issue was not raised when constructing notions of rationality within Ruth’s suicide.

Ruth was surrounded by a community of internalized others (Tomm, Hoyt & Madigan, 1998) who implicitly, and occasionally explicitly, endorsed her philosophical views regarding assisted suicide and euthanasia, particularly within the context of unremitting suffering. Such social endorsement would presumably have led Ruth to believe that significant others would understand her decision, even while she enacted her suicide, thereby mediating concerns of a painful, social aftermath.

However, philosophical conversations with others, regarding assisted suicide and euthanasia, appeared to have been largely intellectual in nature. There was no apparent dialogue regarding the interpersonal meaning of such a hypothetical death, particularly within Ruth’s life circumstances and relationships. As such, Ruth’s social world appeared to co-construct notions of rational suicide as outside of the interpersonal realm, a social exclusion typically reflected within the pro-choice discourse (Maris et al., 2000).

However, one informant noted the significance of the other in determining the morality of a self-chosen death. While suffering with the end stages of terminal cancer, he remarked that Ruth’s suicide was highly rational but that he would not consider such actions in his own circumstances as he had dependent children. In comparison, Ruth was not hindered by pragmatic or ethical concerns created by the existence of dependents. Another informant remarked that Ruth had fulfilled filial obligations prior to her death, including arrangements for Harold’s future funeral expenses, apparently completed during her last visit in April-May 2001.
The situated interpersonal meaning of Ruth’s philosophical views regarding rational suicide was likely avoided for various reasons. Ruth characteristically avoided emotionally-laden topics while others typically did not pry out of respect for Ruth’s preferred way of being. In this regard, Ruth and her significant others were constrained by co-constructed meanings of interpersonal intimacy, a dialogic process of meaning-making, as described by Shotter (1993). Secondly, informants were aware of Ruth’s determination to be solely responsible for her life, while being a burden to no one. Ruth viewed as a woman who could not be dissuaded from a proposed course of action. However, the most poignant reason was perhaps stated by an informant on the implicit unfairness of asking someone to extend their suffering for the sake of others. At the end of her life, others accepted Ruth’s appraisal that her situation was indeed hopeless.

According to Scarry (1985), intense physical pain “always mimes death” (p. 31). The collapse of the voice, self and world of the sufferer is coupled with an overwhelming desire to escape the body’s aversive reality, an existential reality where murder and suicide converge (Scarry, 1985). In this regard, Ruth’s suicide may be viewed as an escape from pain, passivity and reality constriction. As such, Ruth’s suicide physically substantiated her experiential reality to others, an escape from an unbearable existence predominated by pain. In the process, pain and hopelessness, otherwise inherently unknowable, were made “real” or visible to others.

In addition, Scarry (1985) states that, for those in severe pain, “the claims of the body utterly nullify the claims of the world” (p. 33). The marginalization of the social voice within the experience of severe pain mirrors the relatively absent social voice found within Final Exit: The practicalities of self-deliverance and assisted suicide for the dying.
(Humphry, 1991), Ruth’s reference material, found after death in video form. Within the experience of severe pain, Ruth was particularly vulnerable to the individualistic rationalism implicit within such discourses.

However, in the process of Ruth’s suicide, the social world was not entirely absent. While Ruth’s decision ultimately privileged the claims of a body in pain, Ruth appeared to carry a consciousness of those held dear throughout the preparation and act of her suicide. Ruth’s last phone call to loved ones, her suicide note, and her final instructions all spoke of a careful attendance and concern for the needs of others. In addition, Ruth appeared to bring forward the presence of Elizabeth as she committed suicide given the presence of scattered travel brochures that were thick with interpersonal meaning. Ruth’s gesture, at the time of such hopelessness and apparent despair, spoke comfort into the life of Elizabeth.

**A Portrait of Ruth: Through the Lens of Medical Practitioners**

The following impressions of Ruth were based on interviews with two medical professionals, Dr. Lawson, a general practitioner, and Dr. Bridges, a podiatrist that occurred approximately three years after her death. Dr. Lawson had been Ruth’s attending physician for over 22 years, starting in 1980 through to the time of her death, in January 2003. Dr. Bridges had been Ruth’s podiatrist for six years, having first provided podiatric care to Ruth as a locum physician in 1994.

In reference to Ruth’s prior medical history, Dr. Lawson reported that Ruth received hand surgery, specifically for joint fusion, in 1973 and 1974. Pharmaceutical treatment prior to 1980 was reportedly restricted to Aspirin. Dr. Bridges was unaware of Ruth’s prior medical history other than Ruth’s regular use of Aspirin.
Dr. Lawson noted that there was “nothing unusual” in Ruth’s childhood or familial background (i.e., accidents, traumas, or parental medical and mental health histories). Dr. Bridges reported no knowledge of Ruth’s family or personal history nor was he aware of Ruth’s marital status or if she had children. Both physicians reported no knowledge of any surviving siblings.

According to Dr. Lawson, Ruth spoke of a cousin, who lived locally, as well as a few friends in her neighbourhood. In this regard, Dr. Lawson thought that Ruth was a single woman who was “very much a loner.” In Dr. Lawson’s opinion, Ruth spent much of her time reading and travelling until her health deteriorated. However, Dr. Bridges thought that music and friends brought meaning to Ruth’s life. During appointments, Ruth spoke to Dr. Bridges about her frequent trips, such as San Francisco and Seattle opera tours, and also asked him questions about his life.

Dr. Lawson described Ruth as very open and friendly within their professional relationship. Likewise, Ruth was noted to have an excellent relationship with Dr. Lawson’s office support staff. Dr. Bridges described Ruth as engaging, well-liked, and even “adored” by both himself and his medical assistant. During scheduled appointments, Dr. Bridges also described Ruth as frequently jovial in manner. With apparent amusement, Dr. Bridges described Ruth joking as she posed for pictures of her hand and foot deformities, taken to justify a disability claim with Revenue Canada.

Dr. Bridges described Ruth as a “very happy person,” in spite of the physical setbacks that were part of her medical care. Both physicians noted that Ruth never appeared to be under personal stress nor did she exhibit or disclose symptoms of anxiety or depression. In this regard, Ruth did not discuss the nature of her 2002 hospital experience with Dr. Lawson.
nor had she discussed her views on suicide or otherwise voiced suicidal ideation. Ruth’s manner was reportedly unchanged during the last scheduled appointment with both physicians prior to her death.

In reference to Ruth’s coping style, Dr. Lawson thought that Ruth coped extremely well with her arthritis and pain (as it did not seem to bother her). He noted that Ruth never complained about her physical deformities and did not appear bothered by the physical appearance of her hands or feet. Dr. Lawson thought that Ruth never let rheumatoid arthritis get in the way of her daily living while noting that she had travelled extensively despite her deformities. Dr. Lawson described Ruth as “well-adjusted.” Likewise, Dr. Bridges described Ruth’s ability to travel, in spite of severe foot deformities, as “exceptional.” Dr. Bridges noted that Ruth did not let her deformities “stop her from enjoying life,” that it was “not her focus.”

Dr. Lawson described Ruth as methodical in her approach to her medical care, typically arriving for scheduled appointment with written questions and concerns. In addition, Ruth characteristically sought comprehensive knowledge of available treatment options. Dr. Lawson indicated that all decision-making regarding treatment was “open-ended” and that there were no areas of conflict or disagreements throughout their professional relationship. Dr. Lawson also denied any difficulties in providing ongoing medical care other than noting that he “did not see her suicide coming.”

Likewise, Dr. Bridges described Ruth as well-informed regarding her disease process and open regarding any foot-related difficulties, also remarking on the absence of pessimism or self-pity in response to health challenges. Ruth’s coping style was framed as “rational” given her willingness to follow recommended treatment. Dr. Bridges also described their
professional relationship as “collaborative” given the need for Ruth’s feedback as to the effectiveness of the treatment provided. In this regard, Dr. Bridges noted that a treatment might “look perfect” but that the patient ultimately decided if it was “working,” based on the reported level of discomfort. In general, Dr. Bridges thought that Ruth would endorse research regarding her experience with rheumatoid arthritis.

Dr. Lawson described Ruth’s rheumatoid arthritis as “burnt out” in that there was no further painful inflammation. However, Dr. Lawson noted that residual deformities, by their very nature, could be painful, depending on the degree and type. Dr. Lawson noted that Ruth “never really complained of too much pain” with pain management typically restricted to Aspirin. In this regard, Dr. Lawson described Ruth as a “stoic” with the observation that Ruth did not like to take any medications. Nonsteroidal anti-inflammatory drugs (NSAIDS) were not prescribed as there was no perceived need given the absence of an ongoing inflammatory process. According to Dr. Lawson, disease-modifying anti-rheumatic drugs (DMARDS) were also deemed to be inappropriate as he understood that they were generally administered prior to joint destruction in the presence of ongoing inflammation. Dr. Lawson noted that Ruth was given a prescription for Plaquenil (a DMARD) by a rheumatologist at the end of her life but that she never took the drug.

According to Dr. Lawson, alternative and complementary treatments had not been recommended as part of Ruth’s medical treatment as he did not think they were useful with rheumatoid arthritis. While Ruth took multiple vitamins and minerals, Dr. Lawson reported a lack of empirical studies to demonstrate benefit. Both Dr. Lawson and Ruth had reportedly decided that the expertise of a rheumatologist was unnecessary, given the lack of new
treatment modalities. In this regard, Ruth was not involved with an ongoing rheumatologist for the last two decades of life.

Dr. Bridges described his medical treatment as primarily focused on manifestations of the disease process (i.e., joint misalignment and skin pressure areas) rather than on the disease process itself. In this regard, Dr. Bridges provided general foot care at least once a month which included callous removal, treatment of infections and foot stabilization (i.e., shoe fitting). Alternative or complementary therapies were not discussed as treatment was “cut and dried,” or primarily biomechanical in nature. Dr. Bridges thought that most patients in his practice would find alternative treatments as unhelpful given that presenting difficulties were largely biomechanical in nature. However, Dr. Bridges’ attitude was one of endorsement if a particular alternative treatment was experienced as beneficial by the patient.

Dr. Bridges also reported that Ruth did not disclose arthritic pain. However Dr. Bridges thought that Ruth must have had pain at some point in her life given the presence of severe foot deformities. Ruth reportedly had one arthritic “flare-up” in her ankle in June 2002. Dr. Bridges also noted that Ruth had progressive foot deformities that required the fitting of new orthopaedic shoes over time. During the interview, Dr. Bridges also recalled that Ruth had referred to neck pain during a scheduled appointment towards the end of her life.

Dr. Bridges was not aware of Ruth’s medication regimen, an oversight that he attributed to personal inexperience at the time. Dr. Bridges defined himself as a “sub-specialist” working on the assumption that Dr. Lawson was the provider for ongoing comprehensive care. In this regard, Dr. Bridges had never consulted with Dr. Lawson as there was no perceived need.
Dr. Bridges also assumed that Ruth had received ongoing care by a rheumatologist. In this regard, Dr. Bridges said that general practitioners would typically not treat such a severe disease process as patients would not receive the diligence needed. Even in the absence of an active inflammatory process, Dr. Bridges assumed ongoing follow-up by a rheumatologist, on a 6 month or yearly basis. Towards the end of the interview, Dr. Bridges remarked that family physicians had difficulties providing comprehensive care given inadequate financial reimbursement.

Neither Dr. Lawson nor Dr. Bridges expressed any concerns regarding Ruth’s use of alcohol. In this regard, Dr. Lawson had no recollection of any conversation with Ruth regarding her use of alcohol.

Dr. Lawson noted deterioration in Ruth’s physical status over time that included increased fatigue, unexplained weight loss, neck pain and progressive deformities. In this regard, Dr. Lawson thought that Ruth’s unexplained weight loss was likely due to inadequate caloric intake and attributed neck pain to degenerative changes in Ruth’s spine. While Dr. Lawson thought that Ruth would become less independent over time, plans for future deterioration were apparently restricted to a Living Will (dated 1997) that Ruth provided.

However, Dr. Bridges had the impression that Ruth’s physical status had stabilized following an arthritic “flare-up” in June 2002, given no further signs of deterioration in her feet. According to Dr. Bridges, Ruth appeared physically frail, and, perhaps, susceptible to infections, but had not appeared more frail over time. If needed, Dr. Bridges thought that Ruth might have considered a motorized scooter but likely would have been ambivalent if such assistance necessitated increased dependence on others.
Dr. Bridges understood that Ruth had received three blood transfusions as part of treatment for anaemia as an inpatient in June 2002. However, Dr. Bridges was unaware of the cause of Ruth’s anaemia, noting that it could have been the result of a gastro-intestinal haemorrhage or even bowel cancer. During her second to last visit, Ruth reportedly told Dr. Bridge’s medical office assistant that she was “scared” about her health. Dr. Bridges had been surprised when informed of this disclosure, as Ruth had not raised any specific anxieties with him. Any specific worries were assumed to be related to the maintenance of Ruth’s independence. During their last contact, approximately two weeks prior to her death, Dr. Bridge noted that Ruth’s manner had been almost jovial. In retrospect, Dr. Bridges wondered if “Ruth presented better than she was.”

While Dr. Lawson had been informed of Ruth’s death, he was not aware that Ruth had committed suicide until invited to participate in the present research. In this regard, Dr. Lawson assumed that Ruth had committed suicide out of a fear of increased dependence on others. He did not think that Ruth had primarily committed suicide because of intolerable pain, in spite of being informed that the suicide note identified pain as the motivating factor. As such, Dr. Lawson viewed Ruth’s suicide as a “very rational” choice given that Ruth was very independent in nature. Dr. Lawson personally thought that suicide was a valid personal option while noting that neither physician-assisted suicide nor euthanasia was legal in Canada. Dr. Lawson described a preference for the Dutch system (i.e., physician-assisted suicide) as he otherwise viewed such self-committed suicide to be inhumane. When asked how Ruth’s life and death had impacted him personally, Dr. Lawson responded with the following: “I dealt with her death and the deaths of all patients. Embrace the good that I have done for the patients till the end and learn how to be a better person from the lessons
that they have taught me through their illnesses.” When asked how Ruth’s death had impacted him professionally, Dr. Lawson wrote that “Suicide can be an option. But there has to be a more humane way to end it all.” When questioned, Dr. Lawson indicated that he was “not sure” of any hopes associated with his research participation.

Dr. Bridges had been unaware of Ruth’s death, or suicide, until he received an invitation to participate in the present research. Prior to our interview, Dr. Bridges had assumed that Ruth had committed suicide in reaction to receiving devastating news (i.e., a serious diagnosis of cancer). Dr. Bridges appeared surprised when informed that Ruth’s suicide had been well planned and that her suicide note identified intolerable pain as the motivating factor. When questioned, Dr. Bridges said that he did not think Ruth’s suicide was rational. In this regard, Dr. Bridges thought that Ruth’s suicide appeared to be an “over reaction” based on her apparently normal behaviour and the lack of obvious deterioration present during the last appointment.

When informed of the consulting rheumatologists’ alleged statement that nothing more could be done for Ruth’s pain, Dr. Bridges remarked that, ethically, uncertainty can only be limited to what can be offered personally, rather than blanket statements about treatment in general. In this regard, Dr. Bridges thought that Ruth had additional treatment options that could have been considered. For example, Dr. Bridges noted that other rheumatologists could have been consulted, and other medications, such as different analgesics and treatment with cortisone, considered. In addition, Dr. Bridges thought that an occupational therapist might have provided assistance in stabilizing Ruth’s neck to potentially reduce pain. Dr. Bridges also questioned whether or not anaemia had contributed
to Ruth’s fall, experienced a few days before her death, noting that the elderly frequently have difficulties with proprioception.

In general, Dr. Bridges hoped that the present research would help health care practitioners treat their patients with more insight. Dr. Bridges remarked that patients were far more complex than what was known, noting that a professional could not “just go by what people say” but at the same time had to respect resistance to inquiry.

**Reflections on A Portrait of Ruth: Through the Lens of Medical Practitioners**

Dr. Lawson and Dr. Bridges described a professional relationship marked by considerable enjoyment, admiration and respect for Ruth as a person. However, Ruth’s medical care typically reflected a predominant biomedical orientation that was primarily body focused. The general exclusion of the influence of Ruth’s cultural, personal and social worlds mirrored persistent critiques of medicine as driven by science and technology, with a marginalization of the meaning of symptoms within lived experience (Bury, 1982; Charmaz, 1983; Kleinman, 1988; Walker et al., 2004). Likewise, the lack of consultation between Dr. Lawson and Dr. Bridges, suggested a mechanistic view of the body as a machine, with distinct parts that could be deciphered without holistic considerations. Such abstraction and division of the person has been traced back to the influence of philosopher René Descartes within the field of medicine (Bury, 2001; Gatchel, 1999; Walker et al., 2004) with Foucault (1963/2003) noting that such mechanistic views fostered the scientific justification for the exclusion of the person in order to comprehend the “the truth of the pathological fact.” (p. 7) However, the relative exclusion of the person also marginalized issues of existential meaning and attendant suffering (Bury, 2001; Charmaz, 1983; Kleinman, 1988; Scarry, 1985). In this regard, sources of compassionate understanding were traded for scientific objectivity.
If interactions of a social nature occurred between Ruth and her medical providers, they typically centered on shared interests and activities rather than on eliciting an understanding of either positive or negative psychosocial influences within Ruth’s lived experience. For example, both medical providers were unaware of extraneous sources of stress, such as the existence of Ruth’s brother, Harold, and Ruth’s role in overseeing his care. In this regard, researchers have found that minor life stressors (Potter & Zautra, 1997; Zautra et al., 1994; Zautra et al., 1989) and interpersonal stressors (Zautra et al., 1994; Zautra et al. 1998; Zautra et al., 1997), in particular, create a heightened effect on markers of immunostimulatory response and disease activity.

While medical providers were unaware of the impact of psychosocial stressors, a limited knowledge of Ruth’s extensive social network also prevented the identification and recruitment of the socio-cultural resources that were available to Ruth, both in regards to advocacy and practical support. The lack of dialogue regarding future health-care planning also suggested a critical gap in treatment management, given the presence of an established deteriorative disease process, with the foreseeable need for increased dependency in the future.

Dr. Lawson identified neither difficulty in the management of Ruth’s medical care nor areas of conflict within their relationship. This disclosure was remarkable given the duration of their professional relationship and the unpredictability and complexity of a progressive disease such as rheumatoid arthritis (ACR, 2002; Mooreland et al., 2001; Newman & Revenson, 1993. Such disclosures suggested that Ruth’s disease presentation, and the nature of their relationship was exceptional, or that medical difficulties were unacknowledged and conflicts hidden within the professional relationship.
As was characteristic of other informants, Dr. Lawson and Dr. Bridges analyzed the rationality of Ruth’s suicide based on their general impressions of Ruth as a person, rather than on knowledge of preceding events and the impact within Ruth’s lived experience. In this regard, Dr. Lawson appeared to view Ruth’s suicide as rational based on the presumption that she was confronting the loss of independence, an impression that was reiterated after Dr. Lawson was informed that the suicide note referenced pain as the motivating factor. However, motivating factors, such as pain and loss of independence are not mutually exclusive, typically existing as predominant stressors in the lives of older adults with established rheumatoid arthritis (Melanson & Downe-Wamboldt, 2003). In addition, research investigating requests for physician-assisted suicide have identified motivating concerns as primarily value driven, such as a loss of control and independence, a poor quality of life, or being a burden, rather than strictly symptomatic in nature (Back et al., 1996; Ganzini et al., 2000). Presumably, concerns regarding the loss of independence coexisted with concerns about pain management as Ruth reached a decision to end her life.

In contrast, Dr. Bridges appeared to view Ruth’s suicide as irrational given her self-presentation during their last appointment, which occurred two weeks prior to her death. Ruth’s apparent jovial manner was taken at face value as an indicator of her psychological state.

Dr. Bridges did not apparently notice any of the signs of physical deterioration observed by others, as he was presumably focused on the care of Ruth’s feet while enjoying her presence. While Ruth referenced neck pain towards the end of her life, Dr. Bridges identified pain management as Dr. Lawson’s responsibility. However, Dr. Bridges also
appeared to question whether or not his enjoyment of Ruth had prevented a recognition that she had “worsened” at the end of her life.

While medical practitioners typically used a biomedical lens in deciphering Ruth’s needs, Ruth also had a significant role in the co-construction of her professional relationships. Ruth appeared to maintain a characteristic privacy regarding personal matters both within, and outside, professional relationships. For example, Ruth did not inform Dr. Lawson of the distressing nature of her hospital experience in May-June 2002. Most significantly, Ruth did not disclose the extent of her desperation regarding unmitigated severe pain nor did she disclose any suicidal ideation to medical providers during the last weeks of her life. According to Dr. Bridges, Ruth’s positive self-presentation appeared unchanged during her last scheduled appointment. As such, Ruth presumably wanted to avoid being “a burden” within all relationships, whether professional or otherwise. Given that western values are reified and implicit within medicine (Berger & Luckmann, 1966/1967; Charmaz, 1983; Hauerwas, 1990), Ruth’s coping style was admired and respected, rather than compassionately explored or questioned.

While Ruth’s general emotional reticence was presumably shaped by a desire for privacy, autonomy and independence, her disclosures, in turn, were presumably shaped by professional inquires and responses. As noted by Bury (2001), the recounting of illness narratives depends on context and motive as well as the influence of the listener. In this regard, a consistent lack of professional query into the personal and emotional aspects of Ruth’s life, other than valued activities, likely created a powerful force in selectively shaping which disclosures were viewed as appropriate or preferred, a discursive patient-physician dynamic that has been explicated by Waitzkin and Britt (1989). Inherent medical
disciplinary power (Foucault, 1963/2003; 1980) further influenced discursive patient-
physician dynamics, with the shaping of the patient as guest and the physician as host during 
medical consultations (ten Have, 2002). In summary, the social construction of relationships, 
as identified by Gergen (1999, 2001) was evident within Ruth’s professional relationships, 
just as these dynamics were implicit within social relationships.

It was also noteworthy that there was no formal process whereby Ruth’s primary 
health care providers were notified of her death. As noted previously, while Dr. Lawson 
received notification of Ruth’s death through an extended family member, he was unaware of 
the cause of her death. On the other hand, Dr. Bridges had not been notified of Ruth’s death 
until he received an invitation to participate in the present research. Both Dr. Lawson and Dr. 
Bridges appeared astounded by Ruth’s decision to commit suicide. Presumably, the 
rheumatologist contacted in the few days prior to Ruth’s death, remains unaware of Ruth’s 
suicide as well as the rationale provided within the suicide note.

The absence of a death notification process suggested that the medical profession, as 
a whole, may be hindered when reflecting on critical issues related to service delivery (i.e., 
prevention, assessment, treatment and maintenance) that would be available through a 
medical case review. In particular, physicians may be hindered in acquiring knowledge and 
insight into the possible iatrogenic effects of their medical practice. Such professional 
notification would also potentially convey the message to significant others that a life 
mattered.

The Main Archive: The Medical Log

For research purposes, relevant “objects” under research investigation include the 
general organization of the medical archive, diagnosis and surgery, complementary care by
paramedical professionals, pain (biomechanical and inflammatory), valued activities (including social and familial excerpts), general medical care, end of life decisions, psychological references and the last six months of life (with excerpts documented in chronological order). As noted previously, research reflections were coupled with log excerpts to foster comprehension, reflective analysis and emotional resonance for the reader.

**General Organization**

The main archive, identified as a “Medical Log” by Ruth, contained over 76 pages of meticulous documentation primarily focused on physical symptoms, treatments and interactions with medical, and other health-related professionals, over a 23 year time period (1980 to 2003). A two page “Joint Log” preceded the Medical Log (from 1962 to 1976) which was primarily focused on the process of diagnosis, treatment and surgery prior to Ruth’s relocation to Western Canada. In addition, there was a one-page “Curse Log,” (from 1978 to 1980) which documented Ruth’s concerns about her menstrual cycle and associated medical care and a seven-page “Flu Log” (dated November 1980 to February 1981) which contained meticulous documentation of “flu-like” symptoms alongside pharmaceutical and dietary intake. For research purposes, the use of the term “Medical Log” included all of the above archives.

Ruth’s use of a “Medical Log” as the primary reference for documentation of health-related concerns was consistent with Bury’s (1982) description of medicine as an important cultural resource for those with a chronic illness, such as rheumatoid arthritis. While a predominant biomedical orientation constrains the comprehension of existential meaning, Bury (1982) has noted the same process benefits the individual by separating the disease from the self while socially legitimizing clinical intervention. According to Bury (1982), “to
be able to hold the disease ‘at a distance’, as it were, assists the claim that one is a victim of external forces. To do anything less is to accept fully the burden of responsibility” (p. 173).

The organization of the Ruth’s Medical Log mirrored a biomedical orientation given the predominant focus on physical symptoms with frequent categorizations according to the body parts under consideration, such as “FEET,” “EYES,” and “TEETH”. Log excerpts were characteristically meticulous and, occasionally exhaustive, in their documentation. For example, within Ruth’s “Flu Log,” temperatures were regularly recorded along with detailed recordings of food and fluid intake as well as the frequency and nature of bowel movements. As such, the main archive reflected the power of the biomedicine, as a dominant cultural resource, in defining taken-for-granted realities, or truth (Berger & Luckmann, 1966/1967; Foucault, 1963/2003; 1980) and as constitutive of identity, subjectivity and agency (Parker, 1992; Willig, 2000; 2001). The subject “position” of patient (Davies & Harré, 1990) presented Ruth with particular “interpretative repertoires” (Potter & Wetherell, 1987) through which to experience rheumatoid arthritis as defined through the biomedical discourse.

In addition, Ruth’s meticulous observation of bodily manifestations and related actions, or self-surveillance, was consistent with the subjugating effects of dominant cultural discourses, as identified by Foucault (1975/1979; 1980). In this regard, Ruth’s body became a cultural archive through which the dominant biomedical discourse was both enacted and resisted (Foucault, 1976/1990; Scarry, 1985). The excerpt below demonstrated how Ruth’s documentation matched the requirements of a biomedical agenda with a predominant focus on physical pathology.
December 7, 1999

DR. LAWSON – annual exam, 8:30 am. No food since 8:30 pm night before (blood lab people asked me this; Dr. Lawson said exam doesn’t have to be at 8:30, “can be any time”) tho his nurse when I made apptmnt said it had to be 8 or 830. I told him about daily pills I am taking (see blue list below) (next page)

I said I still get sleepy fast; in Newf. “falling asleep in mid-sentence!”

Mentioned recent (Sept. 27) eye exam – eyes seem a bit better; fewer floaters; no more “double vision” (see above).

Ears – I’m a bit deaf, esp. in right ear; “Earplanes” (plugs) useful on plane trips to prevent pain. “It’s just old age: - Dr. L.

Blood Pressure was checked – it’s normal, or a bit below average.

Knob on back – middle of back; sticks out a bit, but doesn’t hurt. Due to Osteoporosis, said Dr. Lawson.

Nose – almost always blocked; mouth breathing frequent; Dr. Lawson gave me a prescription for nasal spray.

Living Will which he signed Sept. 1997; I made new Will in July/99. Did I give Dr. Lawson names & tel nos. of my cousin, my new lawyer and Executor (T-D Trust Co.) for his file? He said no. I should send these.

I went to Blood lab on 2nd floor of same building (below Dr. Lawson’s office) & had blood samples taken, and did urine sample.

Bony growth under tongue in mouth – Dr. Lawson said, mention it to dentist. (see below).

Throughout the Medical Log, Ruth also occasionally referred to various body parts in the third person. For example, following a home visit with an occupational therapist, Ruth wrote “I like insoles, but don’t wear expensive shoes much due to angry corn on top of crooked joint on right foot – toe next to big toe – it feels better now but was acting up this winter & likes to be pampered with slippers, etc.” (excerpt dated March 14, 1983).

Subsequent to the first appointment with a podiatrist, Ruth also wrote that her “feet are much happier with pads she puts on.” (excerpt dated February 28, 1990). On another occasion, Ruth reflected on a Caribbean cruise with the note that “feet, in black shoes, behaved well, though on many island excursions I did more walking than usual.” (excerpt dated November 9-24, 1997). In this regard, both the Log organization and Ruth’s writing style reflected a
process of objectification in that her body became “a project for the self to work on” (Gordon, 1988, as cited in DiGiacomo, 1992, p. 122; Charmaz, 1995).

According to Elizabeth, the main informant, Ruth’s meticulous documentations were also consistent with Ruth’s scientific background and her rational approach to problem-solving. Elizabeth also noted that Ruth had no partner with whom to share health-related observations and concerns. Ruth’s records were viewed as an effort to both maintain control and provide reassurance that her symptoms were “in black and white,” or “in her body” and not imagined, or “in her head.” In other words, Ruth’s external records provided a psychological sense of containment as well as a means for external conversations with self.

Researchers within the field of rheumatoid arthritis, and chronic illness, in general, frequently make reference to the co-management of symptoms between the individual and health care providers, both as a late modern cultural shift and as a part of successful adaptation (Bury, 1988, 1991, 2001; Fair, 2003; Iaquinta & Larrabee, 2004; Shaul, 1995). Typically, Ruth appeared to exemplify the preferred way of being identified by researchers in the field of arthritis, particularly in reference to her pursuit of knowledge regarding health-related issues, diligent self-management and implicit desire to be included in decision-making regarding her medical care (Iaquinta & Larribee, 2004; Shaul, 1995). The following excerpts documented Ruth’s first meetings with various medical practitioners and her implicit invitation to a collaborative relationship.

General Practitioner:

*Feb. 12, 1980*

3pm – saw my first actual Dr., Charles Lawson (recommended by Dr. Woodward) ..... Office: ..... just opposite ..... Hospital. Tel: ..... (day & nite).  Paid $12.50, got receipt. He is a young ... grad (not long in practise, said Woodward’s nurse). – looks good. I showed him letter of introdux. from Dr.
Baker, also list of Drs. (my list) – asked if he could refer me to (6) arthritis society, and (3) gynaecologist. He said that he thot direct referral to a rheumatologist would be better than (6) society (which is a team clinic – you have to wait, don’t always get the same person, etc.) He recommended a Dr. Weiss as an excellent rheumatologist (who in turn can refer me to McFee is as & when surgery necc.) He said in ...., G.P.’s like himself do ‘everything; including gynaecology – would not refer me to a specialist unless he needed help. I then described my menopausal problems (!) –ie: no curse since last May until Christmas, then had period (climatic change? oysters??). Dr. Jones said on Jan 11 (when he took pap smear) ‘if periods continue regularly, OK, no problem but if there is, say, another pause of 6 mo. and then another period, use a gynaecologist – perhaps a ‘D&C’ will be necc.’ At the moment, (I told Dr. Lawson) I am having a ‘mini-period’ (ie – very light one), but missed the one in Jan. (This ‘mini-period’ came right on time, but is much lighter than normal, and was preceded last week by a few days of diarrhea, as was the heavier one in Dec.) Dr. Lawson said, keep track of it, and if after 6 mo, here it happens again, call him. (He agreed with Jones).

Rheumatologist:

April 23, 1980

2 pm: Saw Dr. Weiss (3rd floor, ... Bldg. adjoining .... Hospital). He is a nice youngish man (in late 30’s or 40’s?) and we had a very good interview & examination. I gave him a copy of my ‘Joint Log’, which I updated last night (covering period May 1974 to 1980 (to date)). He took case history, asked various questions (quite comprehensive, & examined all my joints. I then went & had X-rays of hands & feet taken at hosp. and had blood test taken at hosp. Dr. Weiss said he works with the arthritis clinic and Dr. McFee (I told him about my refs. from ... to Dr McFee and Dr. Woodward in ...). They will phone me when they are ready to see me (physiotherapists, occupational therapists, etc.)

Dr. Weiss said swimming is OK (I told him re plan to swim!) and has a mild exercise program in mind!

Ophthalmologist:

c. April 26 or 27, 1980

-had a pink, slightly swollen left eyelid condition similar to June 1975 and Dec. 1976 in ..., for which Dr. Wiebe prescribed “Blephamide” eye drops. (4 x a day, apply hot compress for 15 min, then put in drop.) NB had been planning to see the eye Dr. recommended by Dr. Wiebe in ..., for regular checkup in June. Because of this eyelid problem, I went to see him April 30th.

Dr. E. Graham

..... Tel: ....
He’s another ... grad! Gave me a good eye exam, prescribed “Blephamide”, & I got it filled at pharmacy in same bldg. I gave him a copy of “Eye Log” (see this file) which I did esp. for him yesterday. Also showed him my glasses (big pair). Had regular eye examination. I’m to see him again next year.

Podiatrist:

February 3, 1997

FEET – My 1st apptmt. with Dr. S. D. Bridges, who has taken over Dr. Robertson’s practice. I told him about past yr. main footy events (new extra-depth shoes, new orthotics, pbm. with right big toe & other toes joints until ‘lumps’ were put into new shoes, & I started wearing discs(around Xmas). Dr. Robertson had ordered 15 new discs for me from ..., and I picked them up today (cost: $18.00). They are “Silopad Pressure Sensitive Dots with aperture, no. 1026” (15 dots per sheet. Gel dots contain medical grade mineral oil to soften and lubricate skin, and they are available with or without a central depression (#1025 – flat dots; #1026 – dots with aperture, which presumably means ‘depression’). They are washable & reuseable (see booklet with dots).

The Medical Log also reflected the apparent reality that Ruth was living on inherited and invested capital. In apparent consequence, Ruth kept meticulous financial records of expenses, such as orthopaedic shoes, physiotherapy equipment, dental work, prescriptions and fees for service. Examples of Ruth’s attendance to financial matters were evident in the selected excerpts below (along with her characteristic frugal nature).

June 19, 1980

I also bot weights today – 5 lbs. shot (in 1 lb packets) and a belty thing to put them in..... I will be billed for weights ($12.) plus $1. for each physio session at end of month (prob, July).

November 5, 1980

TEETH. I had my first apptmt. with Dr. Richard C. White .... – nice Australian man with wife as nurse. I gave him all the X-rays from Dr. Dayton, plus letter of introduction. He examined my fangs, took new X rays, and cleaned them (cost: $47.00, paid with check on spot – they don’t send bills). He said my fangs were riddled with little holes – I have 6 fillings to do
(some of which are very small on May X rays, but have developed quickly for some reason: others, near base of teeth (or edge of enamel) don’t usually show up on X rays.) I have 6 fillings to be done, at estimated cost of $202.00! Need 2 appointments of ¾ hr ea. and one of half an hour (Horrid thot). I said OK.

May 6, 1993

- GLASSES: Went to “Kristan Myers, Designer Optical” in .... – they are having a sale featuring some free frames; I selected a frame and they will insert Dr. Graham’s latest prescription for reading....

March 6, 2002

SHOES: Got letter from Foster Shoe Corp. Ltd., Scarborough Ont. – they are closing their ... store April 30/02; are having Sale. I went over & bot 1 pr stretchy-top Comfort Rite shoes, like last pair (taupe, bot last fall) “Valerie” style, size 7 ½ W in black, $152. plus tax, total $173.28. (See bill in 2002 Inc Tax envelope)

**Diagnosis and Surgery**

Ruth first noticed physical abnormalities in a right thumb joint in 1962, which apparently prompted a medical consultation. As noted in the excerpts below, the subsequent medical investigation was marked by a long process of diagnostic uncertainty in the midst of baffling symptom expression, a common experience for those with rheumatoid arthritis (Brown & Williams, 1995; Bury, 1982; Shaul, 1995).

**September 1962**

Noticed misshapen right thumb joint (base), and swollen joint on right hand’s ring finger (not painful). Saw Dr. Brown, had hand X-rays, and was told (a) thumb base is out of joint, and (b) ring finger joint swelling is result of old accident.

**November 1966**

Some occasional aches & pains in right thumb joint (base) and in wrists.
September 1971

Regular annual checkup with Dr. Baker, who suggested hand X-ray to check on knobbly, arthritic-looking hands. X-ray indicated arthritis. Both hands noticeably stiffer & clumsier during year, with some joints swollen & occasional aches (not bad). Cannot straighten fingers fully, & can no longer “touch type”. Some joints swollen, but don’t hurt; others look OK but do hurt.

When Ruth was finally diagnosed with rheumatoid arthritis in 1971, hand surgery was recommended given the presence of joint deformities that were affecting hand mobility and function.

October 1971

Saw Dr. Brown, who said I have rheumatoid arthritis & mentioned possibility of operation – “synovectomy” to make hands more mobile.

August 1972

Saw Dr. Brown again, who asked if I had trouble with any other joints. I mentioned suspicions re feet, wrists, knees & shoulders, & displayed right foot, which he thought looked somewhat arthritic also.

The excerpts below chronologically document (from 1972 to 1982) interactions and events relevant to surgery as an object for research analysis as follows:

September 1972

Saw Dr. Froese to get a 2nd opinion; had hand X-rays done. He didn’t think synovectomy was indicated at this time; I may need plastic implants eventually. Was surprised at mobility of hands, in view of X-rays. Suggested possibility of (a) right thumb base fusion (to give better pinch): (b) plastic joint in right hand’s bent finger. Had blood tests done, re rheumatoid factor – results all OK. Suggested I see Dr. Lapierre at ... Hospital.

October 1972

Saw Dr. Lapierre, who said that operation could be done, & favoured plastic implants, & right thumb fusion to give better pinch, & plastic joint for bent finger on right hand. If nothing done, fingers would continue to drift & mechanical disability increase (probably at a slow rate, as it has so far).
Had some physiotherapy sessions at Dr. Brown’s office (exercise, heat, etc.)
Felt good, but didn’t seem to make much change. Hand had been feeling well,
no pain, working well, etc.

December 1972

Had hand X-rays done & saw Dr. Brown. He said, change in hands since last
year "barely perceptible”.

Some joints (i.e., base of little finger on right hand) are “sub-lex”. He
suggested physical implants, to be done by Dr. Lapierre. (I stalled on this, as
hands had been doing well & did not hurt.) He looked at feet. It was agreed
to put off hand operation.

August 1973

Right thumb problem noticed (won’t bend at middle joint unless I make it,
using left hand; some pain; when applying a bit of pressure on thumb tip, a
slight popping noise was heard). Rest of hand much the same, perhaps a bit
less mobile & stiffer – mild discomfort when in use. (Thumb tendon evidently
broken.)

October 1973

Dr. Brown returned. Decided to fuse thumb.

December 1973

Operation done by Dr. Brown at ... Hosp. Thumb bone fused at base. In
right hand, a few changes were noticed after operation, & slight loss of
mobility, position of a couple of fingers changed a bit, etc. (Reaction to
operation, or bandage, or natural progression of disease? Not sure.)

February 1974

Had thumb X-rays. Dr. Brown said that a tendon graft is not advisable, he
had decided, after consultation with other doctors. Said middle joint of thumb
should be fused or fixed in slightly bent position.

March 1974

Operation was done by Dr. Brown. Pin put in, etc. (Same as last time-later
removed.)
May 1974

Pin removed.

Approximately two years following the above surgery, Ruth was referred to another surgeon with a specialty in hand surgery. Their interaction was documented as follows:

April 1976

Hands now much better, but not working as well as before Dec./75. Dr. Brown said that a new surgeon has come to ... Hosp., specializing in hand surgery: Dr. Roy M.W. Wolfe. I went to Dr. Wolfe for the first time Apr. 14/76, and have been seeing him at 6-mo. intervals up to Oct./79 to check on hand condition. (He said that, unless great disability exists or pain – real inconvenience – he has a conservative approach & prefers to avoid surgery, but eventually hand may be too ‘closed’ to work with, and something will have to be done before fingers reach ‘point of no return’ where effective measures can’t be taken.)

According to the excerpts below, hand surgery was again considered in the early 1980’s, following a comprehensive assessment by an interdisciplinary team at the Arthritis Center.

March 26, 1981

Saw Dr. McFee 11:30 am at the Arthritis Center, with team (several people – nurse, another Dr (i tq), Tom Gilbert the physiotherapist, etc. Mtg. was brief – Dr. McFee is willing to operate, but I must tell him when I want the operation. (ie: He won’t tell me when it is necessary.) (At the present time, I seem to be doing reasonably well, and am not too eager to have any operation, tho I’d like to find out if something should be done this yr rather than next. Knees are getting a bit stiffer – harder to get going after sitting for some time, etc.)

November 18, 1981

NB in ..., – saw Dr. Wolfe (I arranged this by telephone in advance). I told him that Dr. McFee is willing to operate, but wants me to say when I want operation (I don’t feel qualified to judge when it should be done.) Dr. Wolfe looked at my right hand (didn’t examine it closely), and said, it is worse than when I saw it last – suggested that ‘something be done about it soon’. Interview was brief and friendly.
February 02, 1982

11 am – saw Dr. Weiss. (NB had asked for appointment; got referral from Dr. Lawson’s nurse – didn’t see Dr. Lawson.) I told Dr. Weiss about seeing Dr. Wolfe in….., and what he said. (‘something shd be done soon’) He didn’t seem to think that an operation was necessarily indicated – might not necc. be the best thing. He asked me about disabilities, etc. and examined my joints, feet, range of movement, etc. I mentioned problem with writing, some car doors, etc. I mentioned suspicious re wrists and knees, knobs on elbows, etc. Also told re trip to US, renting cars, etc.

Dr. Weiss said, ‘I know you don’t like taking pills, but ‘…said I should take 2 aspirin four (4) times daily with milk or meals (or I could take another new pill, but it’s more expensive; I said that I react well to aspirin, and opted for it). He is also going to contact the Arthritis Centre re more physiotherapy and also hand assessment by occupational therapists, to see if there has been any change in my hand function; he finds my legs very weak – ‘those legs will give out on you’ – they shd be strengthened.

February 08, 1982

- Dr. Weiss called back (I had called him a few days before, saying that I had forgotten to ask him something.) I asked him: (1) Does he think that seeing Dr. McFee is the right thing to do at this time (c April 16-to make appointment) – I didn’t ask his advice, but automatically assumed it was. He answered, yes, see him- no rush, but he will tell me if something shd be done soon. (Otherwise, it is elective surgery, and whether I myself am keen on it has an important effect) But if there is some medical urgency, I will be told. (I told Dr. Weiss about seeing Dr. McFee last March at Clinic, when mtg. was brief – he was willing to operate, but I was supposed to tell him when I want the operation – he wasn’t prepared to tell me when it should be done.) (2) I asked Dr. Weiss his opinion re investing in a coop apt. with steps – say, c. 7-10 steps to front entrance. He said, not a good idea. Should have elevator.

May 20, 1982

3:30 pm – saw Dr. McFee in his office. (This was much better, I thot, than at Combined Clinic – more time, & fewer people around.) I said, I would love to find out & would like to ask him if there was some solid medical reason why something should be done with hands this year, or if I could safely postpone until next year or future. (Said, if something should be done soon, I’m quite happy to have it done, but otherwise feel I am getting along quite well, and if nothing drastic is impending, would postpone it further – but don’t want to postpone to the point of foolishness).

I also mentioned idea of time on my side (?) – getting benefit of new research!
He said he never talked people into having operations; said nothing drastic was going to occur if I didn’t have one now; but felt something could be done to open hands up further, make them able to do more things, etc.  (He examined hands & dictated a few notes to Sec’y.) He had gotten new hand assessment (commented on Arth Cntr efficiency, looking at date!) I told him about my trip to US last Nov as example of ‘getting along OK’

He said that he would like me to meet a Miss Walton, one of his post-operative hand patients, now staying at the ...Inn (nr Arth. Center).  (This is the lady who was written up in the Feb issue of ...Hosp. magazine... on Orthopaedics (the same one I had my hand photo in). He gave me note: “I would like Miss Williams to meet Miss Walton who is post-op hand surg. Please check with Miss Walton first”. (signed Dr. W.M. McFee, May 20, 1982). I took this note to ‘Martha” at front desk of Arth Cntr, and will also show it to Francis Henry (O.T.) when I see her for follow-up appointment on Wednesday May 26 (1 pm)

May 26, 1982

Saw Eileen Walton at her physio at 9:15 am (she gets daily hand physio with ‘Margaret’). She has had a number of operations on feet, knees, etc. as well as hands, in last few yrs; uses cane & has a lot of difficulty climbing stairs, going downhill, etc. Dr. McFee has recently operated on her hand-same op. I would have: she does physio exercises with hand to help restore function, exercise muscles, etc. She used to be a nurse, travelled in Europe, etc. After meeting her, we had lunch several times, and on Sept. 17 (I rented car) we went to ....for lunch.

June 01, 1982

-had appointment at Arthritis Centre with Francis Henry (O.T.), also June 11 and 16; she made plaster casts of my feet and made insoles to fit my feet – then she took me to ....where a Mr. White helped us select a pair of Miller ‘Foot Defender’ shoes to take the new insoles (cost $120.00 – I paid by check). Shoes are made of deerskin (see bill in this file). I was later billed by Arth. Center for Insoles ($32.75; see bill in this file)

(Nice Irish girl Francis left at end of June.) (She said there was not much change in my ability to do O.T, things now, vs. 2 years ago.)

Exercises: continuing thru May and June – group exercises with hip class; also had a few sessions with them in warm pool at Centre – June 4, 8, 11, 15. On June 23rd I had a physio assessment, and the young Asian aide of ‘Helen’ (Physiotherapist) gave me a list of exercises which I can do in the warm pool at ...pool, where I swim every Tuesday. After June 23, no further group exercise sessions – I stopped going to Centre (ie – all reassessments, etc. etc. are over.)
The next documented reference regarding possible hand surgery occurred approximately six years later during an annual check-up with Dr. Lawson as follows:

_November 04, 1988_

_I examined hands & fingers; I pointed out knobbly right wrist joint, & said I was told years ago to watch it, in case it saws thru tendons; he showed me where tendons go (just to centre of wrist from that joint, just this side of knob, so to speak.) He noted that we had spoken sometime ago of possibility of hand operation, but said that of course it involves prostheses (ie: artificial joints) which can sometimes have side effects – I agreed. He said, if I'm getting along OK, operation not really necessary now, or words to that effect._

During a subsequent annual check-up, Ruth had the following interaction with Dr. Lawson regarding the advisability of foot surgery.

_October 23, 1989_

_I displayed stiffish right wrist, which doesn’t bend well; also left big toe, which is descending & doing crossover under little toes (right toe is not as bad). He said only thing for toe problem would be an operation, but they don’t’ always work out well; he suggested avoiding it unless condition gets really bad._

When surgery was under consideration in the 1970’s, discussions with medical professionals largely focused on “what could be done” rather than if surgery was desirable within the context of Ruth’s lived experience. At the time, Ruth reported that she was able to maintain a preferred lifestyle, without the presence of debilitating pain.

The following excerpt, taken from personal correspondence, described Ruth’s experience of seeking second and third opinions regarding recommended surgical interventions during this time period.

_October 09, 1972_

_Dear Constance,_

_Meanwhile, back at the ranch, I have been surreptitiously (sp?) seeking Second Opinions while my doc. was away on holiday. Also 3rd Opinions._
They seem to differ re techniques, mainly. Now I’m back to square 1 and will ask him about the techniques mentioned by 2 and 3, saying “I read it in the paper” which is true, the Gazette had an article last week. I feel somewhat rodent-like, but doubt that I have the nerve to tell #1 about 2 and 3, for fear he might take professional umbrage at my surreptitious (sp?sp?) act. My dentist was amused when I told him about the problem I was having with Medical Etiquette, and said I was feeling increasingly rodent-like. (He and his nurse have taken to asking about my tail.) Not sure when I’m going to hosp. – “sometime before Xmas”, said no. 1 – but I Won’t descend on you afterwards because I Would be a bother (voracious eating habits, loud snores, tail, etc.)

In spite of Ruth’s investigative spirit, Ruth apparently feared that a lack of unquestioning deference to expert opinion would be viewed as a betrayal of doctor-patient role expectations. However, Ruth was faced with the dilemma of reaching a decision amidst contradictory opinions as to the appropriate surgical interventions. For example, Dr. Brown had initially recommended a synovectomy, whereas Dr. Froese had advised against a synovectomy, with recommendations for a right thumb fusion and a plastic implant. The latter recommendations were similarly forwarded by Dr. Lapierre.

As a result, Ruth sought second and third decisions regarding surgical options but hid the source of her information, for fear of creating “professional umbrage.” Differing opinions regarding surgical options were attributed to a newspaper article, a source that was apparently viewed as more palatable than the differing opinion of a colleague. As such, Ruth appeared to be responding to the implicit power differential within the patient-physician relationship, avoiding open conflict while maintaining a stance of deference. Such power dynamics illuminated the dilemmas inherent within patient self-management, in spite of recent cultural shifts towards greater egalitarianism in health care, as identified by Bury (2001); Dixon-Woods (2001) and ten Have (2002).

In spite of initially resisting surgery, Ruth eventually consented in 1973 given an apparent increase in pain associated with progressive hand deformities. Ironically, Ruth was
subsequently referred to Dr. Wolfe in 1976, a surgeon with a specialty in hand surgery, who indicated that he preferred to avoid surgery unless there was “great disability” or pain.

Ruth subsequently disclosed to friends that she had decided against further hand surgery in the 1980’s, given the severe pain involved coupled with the lack of functional improvement. However, there were no excerpts within the Medical Log, or in Ruth’s correspondence with others, that referenced severe post-surgical pain. Rather, the excerpt below suggested that Ruth minimized her pain to others.

*January 09, 1974*

*Dear Constance,*

*My thumb and I have emerged from the hospital in good order, stitches have been removed, and so on. I missed the truly foul weather which afflicted ...Christmas week – blizzards with howling gales, followed by a thaw with buckets of rain, which then froze. Solid, irregular cakes of ice are still stuck to sidewalks, almost impossible to remove except with pickaxe – salt and sand don’t seem to help much. But no fuel shortage so far – just a lot of talk and an electric power failure or two (not unusual, as you know!)*

The Medical Log also contained no indication that post-operative home care was discussed or provided to Ruth. However, Ruth typically adamantly refused home-based assistance, whether through extended family members or a health care professional, as was witnessed during a subsequent hospitalization in May-June 2002.

In 1981, Ruth considered the prospect of additional hand surgery. While surgery was first discussed within an interdisciplinary meeting, presumably to provide comprehensive and integrated case management, Ruth did not appear to regard this process as meeting her needs as a patient. According to the May 20, 1982 excerpt, Ruth appeared less overwhelmed during a subsequent consultation with Dr. McFee, given the self-report that she had more time and had to contend with fewer people.
According to the March 26, 1981 team meeting at the Arthritis Center, Dr. McFee informed Ruth that he was willing to perform hand surgery but that he would not tell her when it was necessary. In consequence, Dr. McFee conveyed the implicit ambiguous message that surgery was medically valid but not medically necessary. This appeared to create a dilemma for Ruth, as she was functioning adequately and preferred to avoid surgery. What was apparently missing, or marginalized, in the conversation was an exploration of the meaning of surgery within the context of Ruth’s life.

Following the integrated team meeting at the Arthritis Centre, Ruth traveled out of province to consult with Dr. Wolfe, who had been previously consulted in 1976. Interestingly, Dr. Wolfe’s previously reported conservative stance towards hand surgery appeared to coincide with Ruth’s documented position that she did not want to have surgery as she was functioning reasonably well. Subsequently, based on the deterioration in Ruth’s hand, Dr. Wolfe recommended immediate surgery. However, Ruth did not follow through with this advice, presumably because an examination of Ruth’s hands could not answer a critical question: Was she functioning adequately, (i.e., maintaining valued activities and a preferred lifestyle), in spite of severe and progressive hand deformities?

During a consultation with Dr. Weiss (excerpt February 02, 1982), Ruth appeared to have a significant discussion regarding the level of disability associated with her hand deformities within the context of her daily living and lifestyle. Dialogue regarding Ruth’s daily activities may have invited Dr. Weiss to regard Ruth in a holistic manner given recommendations for physiotherapy (given the weak state of her lower extremities and the risk of falling) as well as a reassessment of hand function. Interestingly, Dr. Weiss’ holistic approach appeared to invite Ruth to consult with him regarding her lifestyle. During a
subsequent telephone consultation, Ruth queried the advisability of investing in a co-op with stairs. Dr. Weiss also appeared to release Ruth from the decision-making burden by stating that he would be responsible for monitoring the medical need for surgery apart from her personal preference.

During a subsequent meeting with Dr. McFee on May 20, 1982, Ruth appeared less conflicted in the decision-making process, apparently validated by Dr. Weiss in her perception of adequate functionality and desire to avoid surgery. Dr. Weiss’s holistic consideration of physical deformities, functionality and lifestyle appeared to build trust within the professional relationship while also strengthening Ruth’s trust in her own judgment.

In spite of the above, Ruth deferred to Dr. McFee’s medical expertise regarding whether solid medical reasons necessitated immediate surgery, in spite of her personal preference. A comment imbedded in their discussion perhaps contained the psychological crux of the matter; Ruth did not want to postpone hand surgery “to the point of foolishness.” Personal preference was marginalized in Ruth’s apparent resolve to make decisions predominately based on reason. However, Ruth also bolstered her preference by rationalizing that a surgical delay could potentially reap the benefits of future research. As such, Ruth asserted her belief in scientific progress even though she had experienced uncertainty and conflict in the process of investigating the need for surgery. Throughout her inquiries, Ruth remained a firm disciple of science and the grand narrative of enlightenment and progress.

Dr. McFee ended the interview by recommending that Ruth meet with a post-operative patient, Eileen Walton, who had recently undergone hand surgery similar to the one
under consideration. Within this suggestion, there was the implicit idea that Ruth would have an enhanced ability to make a decision regarding surgery based on the experience and life of another, rather than on the unique context and meanings associated with her own lived experience. A further recommendation to consult with significant others could perhaps have facilitated a discussion regarding the meaning and value of surgery within the context of Ruth’s life. The recommended meeting with a fellow patient appeared to primarily serve a medical agenda, a demonstration of what could be done, rather than Ruth’s query as to the value of such an operation within the context of her life.

In typical fashion, Ruth met with Eileen Walton, noted Eileen’s various surgeries, in an apparent meticulous fashion, present functioning and former lifestyle and rapidly gained a friend. Presumably, Ruth decided against surgery as there were no further consultations with Dr. McFee following the meeting with Eileen Walton. Ironically, Ruth’s involvement with Dr. Weiss also ended, in spite of his offer to monitor the medical need for surgery on an ongoing basis. Ruth’s next documented self-initiated referral to a rheumatologist occurred a few days prior to her death, over 20 years later.

Given Ruth’s scientific mindset, medical experts, rather than herself, were viewed as better equipped to make a judgment regarding the desirability of hand surgery. However, within the information-gathering process, Ruth came face to face with the experiential reality that medical certainty was surrounded by ambiguity, a science that was deciphered through the subjective lens of the expert. For example, Ruth received the following opinions from various medical professionals regarding the advisability surgery in the 1980’s: Dr. McFee – said that he was willing to operate but said that she must decide as to whether or not to proceed; Dr. Wolfe – suggested that ‘something should be done soon’ after noting the
deterioration in her hands; Dr. Weiss – surgery was not necessarily indicated; Dr. McFee – said that nothing drastic was going to occur if Ruth did not have surgery but indicated that something could be done to open her hands to improve their function; Dr. Lawson – said that hand surgery involved prosthesis with potential side effects and that surgery was not necessary as she appeared to be functioning adequately; Dr. Lawson later recommended that foot surgery be avoided because of uncertainty regarding a beneficial outcome.

The above findings mirrored Bury (1982) astute observation that medicine provides “an objective fixed point on a terrain of uncertainty” for those with rheumatoid arthritis but that such knowledge frequently becomes both “ambiguous and limited” (p. 179). Ruth exerted considerable time, energy and finances in the exploration of surgical options only to discover that eventual surgery did not result in significant gains in functional ability, in spite of the pain endured.

**Complementary Care by Paramedical Professionals**

For purposes of research, physiotherapists, occupational therapists, educators and nurses are referred to as paramedical professionals. The following excerpts documented various interactions with paramedical professionals (in chronological order) throughout Ruth’s Medical Log.

**October 1972**

Had some physiotherapy sessions at Dr. Brown’s office (exercises, heat, etc.) Felt good, but didn’t seem to make much change. Hands had been feeling well, no pain, working well, etc.

**April 23, 1980**

Dr. Weiss said he works with the arthritis clinic and Dr. McFee (I told him about my refs. from ...to Dr. McFee and Dr. Woodward in ...). They will
phone me when they are ready to see me (physiotherapists, occupational therapists, etc.)

Dr. Weiss said swimming is OK (I told him re plan to swim!) and has a mild exercise program in mind!

June 10, 1980

11:30 am – I had first physiotherapy session at Arthritis Centre…. (Had referral from Dr. Weiss.) Physiotherapist: Joan Holmquist (Swedish) did assessment, measured my degree of movement in various joints, etc., took case history, etc. (She would like to see copy of Joint Log). I am to see her again this week (Fri. June 13 2 pm, since I can’t come Thurs) and then twice a week, Mondays at 3:15 pm and Thursdays at 3:15 pm. I am also attending “R.A. Ed” course – 4 sessions of gen. education re rheumatoid arthritis, with first session 2:15 -3pm (June 10) (Others are Thurs, June 12 at 2:15pm, Tues. June 17, and Thurs. June 19 2:15 pm.)

June 12, 1980

2:15 pm – 2nd arthritis lecture, by physio & occupational therapists.

June 13, 1980

2:00 pm – my second physiotherapy session with Joan at Clinic. (Arth. Centre). I gave her a copy of my Joint Log, also showed her exercise program man in … had done for me 2 years ago. She completed my hand assessment (separate one for each hand) – angles of each finger, joint facility, web width, etc! Thot hands not in good shape – she probably can’t do much for me with exercises etc.

June 16, 1980

3rd physio session with Joan at Arthritis Centre. I lay down, did some exercises with her with elbows, shoulders, and knees (mainly isometric), and she looked at ankles and feet. Ankles are OK, but feet..! She wondered how I walk on them (I once again mentioned Tender Tootsies and Metropolitan Museum!) And if I have a lot of resistance to pain. She has put in a requisition to occupational therapists for Feet & Hands, to see if any of their devices can help. (They will call me when ready) She examined feet closely – all small toe ‘knuckle’ joints are out of socket. Big toe base joints are OK. I also have worn wrong shoes at some time in the past. (I told her some of my foot history, incl. catching little toe of right foot on hosp. bed caster – she doesn’t think this made it any worse than it was already.) I should try to extend joints to their full range daily – ie: lift arms above head as far as possible, straighten elbows, et. Swimming would be good, but not distance walking or stairs – the latter put a lot of strain on joints. The thing is to
exercise joints & maintain their full range of movement without putting weight or strain on them. I should get weights, 5 lbs (they come in little 1 lb sacks of lead shot) with belty-type container, to put on feet & exercise knees- put rolled catalog under knee, weight over foot, and straighten knee. (I can buy these at front desk of Arth. Centre.)

June 17, 1980

2:15 pm – 3rd arthritis lecture at Centre. (Stages, of the disease – types of exercise, etc.

June 19, 1980

2:15 pm – 4th & last arthritis lecture (they showed us some labour-saving devices, and then we wrote a little test.) 3:15 pm – another physio session with Joan – isometric exercises (lift arms above head, straighten elbows, etc.) Then she gave me list (2 sheets) of exercises to maintain range of motion and also isometrics to increase muscle strength (or at least keep them from wasting away completely). I also got weights today – 5 lbs. shot (in 1 lb packets) and a belty thing to put them in. (I shd put rolled catalog under knee & weight on top of ankle, then straighten knee to lift weight) I will be billed for weights ($12.) plus $1. for each physio session at end of month (prob, July).

June 30, 1980

Had another physiotherapy treatment at Arthritis Clinic with Joan (some isometric exercises; mainly re shoulders & elbows). It was agreed that I shall come once a week (Mondays) instead of twice, until further notice (ie: until hands assessment is done, and they decide what to do with me). I now have been given my regular exercises to do daily and there is not too much she can do for me (esp. my hands) – once a week is enough.

July 07, 1980

another physio session at 3:15 with Joan.

July 11, 1980

1 pm appointment at Arthritis Clinic, occupation therapy dep’t., for Hand Assessment. Nice young German (?) occupation therapist, (Heidi Schütz), and another girl (assistant?) spent about 1 hour and a half doing outlines of my hands in various positions, measuring fingers here & there, and giving me various little tests of things to do with hands, such as turning keys, opening doors, cutting ‘meat’, picking up coins, pouring water from measuring cups into bowls, lifting various weights with luggage-type handle, etc. – assorted
everyday-type skills. I showed them my Swiss jar opener and screwdriver, and answered various questions about how I do things (incl. writing - my writing ability has declined noticeably in past year, I have problem controlling my signature at bank, etc. – use typewriter a lot, with 2-finger method). The examined hands and the way they do things thoroughly, made notes, etc.

She would like to see my ‘joint log’ (and I also might bring them pliers I use next time – my idea.)

July 21, 1980

2 pm appointment at Arthritis Clinic, occupational therapy department, for Foot Assessment with Heidi. From 2 to about 10 to 3 pm we talked about Feet, Shoes, etc. She examined feet, but no measurements were made. I gave her a history of feet in some detail (incl. smaller toes ‘going up’ increasingly over past few years, necessity of buying new boots a couple of yrs ago, new boots giving me bleeding blister on 2nd toe of right foot when worn a lot last Jan (while doing trunks in ...), necc. for Scholl pads under big toes, little toe pbm on right foot (maybe did something to it when I caught it on caster of bed c. 10 years ago??) and so on. I gave glowing account of my new Tender Tootsies shoes, bot c. April, worn c. 6 hrs on marble floors of Met. Museum in N. Y. without ill effect, etc. – due to soft uppers, no blister on 2nd toe! Work better than any shoe I’ve had for years. She said, since they seem to work, go on wearing them, but if any other pbms arise (ie: with arch, etc.) I can see them again. My feet are in ‘fairly good shape’ except for toes, she said; left big toe is now stiff & won’t bend at all; right one still can (not by itself, but she can bend it) Little toes wave in the air & do little work. etc.

I forget to take her copy of my Joint Log, but will send her one in mail.

July 24, 1980

1:15 pm – met David Jenkins, head of education for Arth. Clinic, for hand photo session at ...Hospital. (Joan had sjj me as fine example of typical hand deformation for photo re research work being done at hosp.!) Closeups done by young photographer with help from David and Janice, Public Relations Officer.

Joan is being moved to ..., so I’ll have to change physiotherapists. New one, starting Mon. Aug. 11, will be Tom Gilbert (Aug. 4 is a holiday)

August 12, 1980

3:15 – Had 1st physiotherapy session with Tom Gilbert. Did isometric exercises, esp. with arms & shoulders; discussed case, etc. (He is taking over for Joan, as she has gone to clinic in ...). I will see him once a week also.) Also a cane-lifting-with-weights exercise.
August 19, 1980, 3:15 pm – ditto
August 26, 1980, " "
September 2, 1980, " "
September 9, 1980, " " (Shoulder range of mvm- B)

September 11, 1980

11:45 – went to ‘Combined Clinic’ at Arthritis Centre, and was seen by Dr. McFee, with physiotherapist Tom Gilbert also in the room....

September 16, 1980

had another physiotherapy session with Tom Gilbert. He thinks I might as well continue exercises at home – no need to come in for further physiotherapy. I am to see Dr. Weiss Oct. 2 – see what he says, and then tell Tom Gilbert.

October 02, 1980

I saw Dr. Weiss, who agreed with Tom Gilbert idea (see above.) (I phoned T. Gilbert later & told him this.)....

March 26, 1981

Saw Dr. McFee 11:30 am at Arthritis Center, with team (several people – nurse, another Dr (i tq), Tom Gilbert the physiotherapist, etc. Mtg. was brief – Dr. McFee is willing to operate, but I must tell him when I want the operation....

July 7, 1981

went to Arthritis Center for their ‘reassessment’ (or some such name). Young physiotherapist called Ruth measured my joints again to see how I’m doing – shoulders, hip, knees, wrists, elbows, feet, etc. Some seem to have improved a bit from last measurements; right elbow doesn’t straighten as well as it did – I shd work on it with exercises.

February 02, 1982

11 am – saw Dr. Weiss....He is also going to contact the Arthritis Centre re more physiotherapy and also hand assessment by occupational therapists, to see if there has been any change in my hand function; he finds my legs very weak – ‘those legs will give out on you’ – they shd be strengthened.
March 25, 1982

Arthritis Centre finally called – had space for appointment with physiotherapist “Rose” for a reassessment, 1245 pm Fri. March 26/82. Rose is a very nice, older Swiss lady – I told her a bit about my case, we chatted about the possibility of a hand operation, etc. I told her that Dr. Weiss feels my legs could use some exercises (I agree!) I also told her about the ‘sock’ I have with 5 little weights inside (1 lb each?), but at Arth Centre 2 years ago – I’m starting to use it more (put it around my ankle & sit on side of bed, lifting leg up & down – seems to help a bit. Some difficulty getting off buses, etc.; stiffness after sitting awhile.

An appointment was made for group exercises with another physiotherapist, who I met (Liz?) (Liz Stein) – also met Joan again.

March 30, 12 noon, group exercises – bring shorts
Apr. 1 " " " " " "

Thru April/82 – continuing with group exercises twice a week at Centre. Exs. designed to strengthen leg muscles (see instruction sheet).

May/82 – continuing with group exercises at Centre.

May 11, 1982

Heard about heated pool at .... Pool, .... – notice on bull bd. at Arthritis Centre, wc said to phone ...at .... Cost: 75 cents per person; open Tuesday 3:30-7:30, Thurs. 5:30-7:30 (kids & teens) & 7:30 -9:30 pm for others. I submitted application, was accepted, and took 1st swim on Thurs May 13.

Arthritis Center at last called re appointment for hand assessment. May 19, 1982 – hand assessment was done by Francis Henry (nice young Irish girl). She got it done just in time for my apptment with surgeon, Dr. McFee, on May 20 (had made this apptment on April 16)

June 1, 1982

had appointment at Arthritis Centre with Francis Henry (O.T.), also June 11 and 16; she made plaster casts of my feet and made insoles to fit my feet – then took me to ....where a Mr. Wright helped us select a pair of Miller ‘Foot Defender’ shoes to take the new insoles (cost $120.00 – I paid by check). Shoes are made of deerskin (see bill in this file). I was later billed by Arth. Center for insoles ($32.75; see bill in this file)

(Nice Irish girl Francis left at end of June.) (She said there was not much change in my ability to do O.T. things now, vs. 2 years ago.)

Exercises: continuing thru May and June – group exercises with hip class; also had a few sessions with them in warm pool at Centre – June 4, 8, 11, 15. On June 23rd I had a physio assessment, and the young Japanese aide of ‘Janice’ (Physiotherapist) gave me a list of exercises which I can do in the
warm pool at ..., where I swim every Tuesday. After June 23, no further group exercise sessions – I stopped going to Centre (ie – all reassessments, etc. etc. are over.)

March 14, 1983

Had house call from Occupational Therapist from Arthritis Society – nice young Susan Jones, re insoles and feet – use & value of insoles, etc. She had long questionnaire, asked me questions & noted answers, etc. (I like insoles, but don’t wear expensive shoes much due to angry corn on top of crooked joint on right foot – toe next to big toe – it feels better now but was acting up this winter & likes to be pampered with slippers, etc. Tender Tootsies are a bit easier on this corn (esp. my oldest pair) due to very soft plastic uppers – almost like a slipper.

(See her letter asking for appointment in this file)

August 13, 1991

FEET. Dr. Robertson found left toe in good condition; right toe not as good, but not really bad (second layer of skin not broken through yet at pressure point). She scraped right toe as usual, and put crescent-shaped moleskin bandage held in place with ‘wondertape’, like left toe, instead of sock & bedroll. Both toes now have bandages, which can be left on ‘indefinitely’. She noted puffy swelling on top of left foot, still there due to ... fall on July 5th; suggested physiotherapy with Nancy Williamson....

August 15, 1991

I went to Nancy Williamson (very good, Scottish), who applied electric machine to top and sole of puffy left foot (giving ‘tickly’ sensation), and then ultrasound, to improve circulation and reduce fluid (which causes puffiness).

August 23, 1991

Went again to Nancy Williamson, foot physio was done again; ‘tickley’ machine is called “Interferential” (I think!) Electrical current helps reduce swelling, fluid accumulation, etc. Also ultrasound, for longer period this time. Foot looks much more normal, less swollen; no pain at all on trip to Victoria earlier this week.

August 26, 1991

Another session with Nancy Williamson-the last one necc., she said. Did same as Aug. 23; foot is now almost back to normal.
December 6, 1995

FEET: Right big toe not too good – has puffy bluish patch below know (pressure point) – knob has had small blood (dried?) spot since last appointment. Blue pad is infection, said Dr. R., full of pus, which she scraped out; put antibiotic powder & bandage on (crescent with wondertape). Said to bathe it twice a day in warm salty water & put on antibiotic ointment with bandaid.

She wants to see me in 2 weeks. (Dec. 20)

I mentioned legs getting weaker with sore toe, less walking. She said I shd see ...physiotherapist, Nancy Williamson (One I saw after I fell down in ... in 1992(?)) – gave me a note for her.

January 05, 1996

PHYSIO again, with Nancy Williamson. I haven’t been doing much with blue rubber stretchy thing, due to Yule rush, as I told her; I did 10 min rock-and-roll plank (5 min roc n roll forward, & 5 min sideways). Measured it – board is 22 in square (plywood) and rockers under it have max depth of 2 inches. I took blue rubber thing along; she doesn’t need to see me again.

October 7, 1996

Called DR. Johnson again; she returned call next day. Went to see Nancy Williamson, ...physiotherapist, in pm; she thinks it’s bursitis – gave me ultrasound & other treatments to help muscles & cut pain down. Thinks I’m taking too much aspirin; gentler exercises good, also something called “TENS”. I told her my thyroid pills for hypothyroidism) run out Oct. 12. (thyroid pills don’t seem to have any effect on bursitis) Still can hardly walk. Taxi home.

October 11- November 6, 1996

Seven visits to Nancy Williamson, physiotherapist (2 per week, then 1 per last 2 weeks) – c. ½ hr or more each visit. Ultrasound, TENS, and also exercises to strengthen legs, which were weak & wobbly. Twinges in left knee & hip, etc. (Oct. 25-1c Chesa; Oct. 27-Terfel recital (could hardly get up from chair).

April 3, 2000

re Fall: dull pain, stiffness & weak shakiness continuing from fall in .... Library; taking c 7 or 8 aspirin per day. I phoned ... Physiotherapy (where Nancy Williamson fixed me up after fall in ... years ago). She now works only Tuesdays & Fridays – made apptmt for Fri Apr. 7. (I can do this
April 7, 2000

Saw Nancy Williamson – quite a long session, with hot pads, massage, etc. She said it will take c 3 weeks to feel normal; see her next Tues & Fri, and keep moving gently; muscles & tissue below surface of bent (osteo) back are prob. bruised – not on surface. Heat is good; don’t stay immobile too long. I told her what had happened, and mentioned extreme weakness in am.

April 11 & 14, 2000

Saw Nancy Williamson, physio, again & she worked over right upper back area, gave heat treatment, etc. (User fee at physio is now $20. per visit.) Slowly feeling better, tho feeling very weak (esp. in am ) and needing much sleep. Didn’t have to see her Tues. 18th, or after that. (From Mar. 28 fall on, took many extra reg. strength aspirin, 6 or 7 per day instead of usual 2,....

As noted in the April 23, 1980 excerpt, in consultation with Dr. Weiss, Ruth initially appeared eager to engage in proposed exercise programs, including those offered through the Arthritis Center. Once involved with the Arthritis Center, Ruth actively collaborated with health providers and appeared diligent in efforts to maintain joint mobility and function through recommended exercises. However, according to the June 13, 1980 excerpt, physiotherapists, apart from the assessment and treatment provided, had little to offer in respect to either improving or maintaining ongoing functional ability. As noted in the September 16, 1980 excerpt, Ruth’s ongoing involvement with the Arthritis Centre terminated, with recommendations for a self-directed exercise program.

However, according to the February 02, 1982 excerpt, Dr. Weiss subsequently referred Ruth back to the Arthritis Center for physiotherapy after finding extreme weakness in her legs. Given Ruth’s diligence in following recommended exercises, this finding suggested that Ruth was not able to sufficiently maintain or assess lower extremity strength through a self-directed program.
Ruth subsequently participated in group exercises at the Arthritis Centre while she was also undergoing a reassessment of her hand function for proposed hand surgery. However, according to the excerpt dated June 1, 1982, Ruth again terminated her involvement at the Arthritis Centre with recommendations for a self-directed exercise program. There was no apparent resistance from Ruth, a finding that was not surprising, given Ruth’s apparent value of privacy, autonomy and independence in all aspects of her life.

Ruth was not involved with a physiotherapist, on an ongoing basis, for the remainder of her life. This finding contrasted with the identification of physiotherapy as a standard complementary care within rheumatology guidelines (ACR, 2002). Apart from podiatric care, Ruth was implicitly made responsible for the prevention and maintenance of lower body strength and function, an area of heightened vulnerability given the presence of chronic foot pain, progressive deformities and vulnerability to skin infections. In addition, Ruth’s susceptibility to diarrhea and infectious diseases occasionally contributed towards a debilitated and weakened state. Unfortunately, the lack of ongoing physiotherapy appeared to contribute towards Ruth’s vulnerability to falls. For example, as noted in the excerpts below, a fall in March 2000 was preceded by foot pain, skin infections and limited walking, symptoms that were presumably associated with lower extremity weakness and greater instability.

February 22, 2000

FEET: Problems lately, esp. last week. 1) right foot big toes – now gets sore with skin buildup on right side of toe, not left side as before, where weight on toe used to leave brown spots (bone very close to surface) I have not been doing much walking, but Dr. B. noticed poor toe condition. I asked him, do I need bigger hole in right orthotic, to right of old toe hole? He agreed & made the hole bigger (shoe felt better when walking home).
(2) Last week, noticed base of left foot big toe (which twists abnormally leftwards on foot) getting mucky, damp & gummy at back of big toe; red, puffy skin; some dead skin, which rubbed off in bits, etc. I applied Bactroban to avoid infection, c Feb. 18 or 19. Toe is immobile – can’t see what’s going on in back crack (can’t open it up to look). Dr. B. applied more Bactroban with gauze – I shd replace after each shower. He wants to check it again next week (Feb. 29).

March 28, 2000

fell down in Library (knocked over by Chinese kid, c 11) – nothing broken, but shaken up – sore bones for next week or so, esp. back & right shoulder. Took aspirin for dull constant ache, which helps a lot (about 7 aspirins on Mon. May 3, esp. in am.) No bruises that I could see.

Subsequent to Ruth’s involvement at the Arthritis Center, Ruth’s podiatrist referred Ruth for short term physiotherapy on two occasions; following a fall in 1991, given persistent left foot swelling, and in 1995, given lower extremity weakness that was associated with limited walking and foot pain.

According to the Medical Log, the last two involvements with a physiotherapist occurred through self-referral. Ruth sought physiotherapy in 1996, for acute pain, diagnosed as bursitis by the physiotherapist, and in 2000, for pain, stiffness and weakness following a fall.

Ruth considered physiotherapy in the months prior to her death for the treatment of pain. However, according to the Log excerpt below, Ruth was discouraged from seeking physiotherapy treatment given the lack of perceived benefit.

October 08, 2002

Saw Dr. Lawson in office; he thinks it’s just arthritis (not rheumatoid); warned me re codeine & constipation; doesn’t think physiotherapist or acupuncture will help. (Oct. 10 was date of my very bad constipation). Got “Sennosides” laxative pills, & took 2 after dinner, which cleared me out twice Oct. 11.
According to an informant, Ruth was frequently falling in her apartment in the weeks prior to her death.

Ruth’s encounters with physiotherapists and occupational therapists focused primarily on bodily symptoms and functional ability rather than on holistic consideration of Ruth’s lived experience with rheumatoid arthritis. For example, there were no apparent conversations regarding Ruth’s plans for the future, in spite of progressive physical deterioration, nor an exploration of attitudes towards assistive devices, such as a motorized scooter. In addition, there was no discussion of Ruth’s debilitating fatigue or a general assessment of Ruth’s sleeping patterns. Ruth presumably did not disclose that she was sleeping on her childhood mattress, which was presumably inadequate in providing support. This finding was consistent with research that has identified fatigue as a predominant yet ignored health concern for those with established rheumatoid arthritis (Hewlett et al., 2005).

In addition, as with the biomedical orientation of Ruth’s medical providers, there was an apparent lack of dialogue regarding personal-emotional issues within lived experience or an investigation of Ruth’s social context and existing networks of instrumental support. However, Ruth may have deflected such queries given her characteristic privacy and resolve to maintain both autonomy and independence, or may have viewed such conversations as irrelevant for documentation. In this regard, an overheard conversation between Ruth and a social worker (May-June 2002) regarding an offer of home-based assistance on hospital discharge, was not documented or discussed with ongoing health care providers or significant others.

The lack of ongoing care by a physiotherapist also appeared to increase Ruth’s exposure to assessments and treatment recommendations that were offered without medical
consultation. For example, subsequent to Ruth’s involvement with the Arthritis Centre in 1985, Ruth took a fitness test at a Seniors Citizen’s Centre. In a rather bizarre encounter, Ruth’s fitness level was found lacking when contrasted with senior norms (see excerpt below).

April 17, 1985

- took Fitness test at ... Senior Cits. Centre (cost, c. $45.00), given by Fitness Testing Canada Corp. Boy said, I have c. 20.5% body fat (shld have 18%), esp. nr waist and upper thighs; I’m about 4 lbs too heavy. My flexibility is very poor – He put me on an exercise bike, & got heart rate up to 143 beats per minute – he recommends that several times a week (3 km of cycling at 60 rpm’s (tension: ¾ kg). My oxygen uptake is well below normal (bottom 15%) – this has something to do with oxygen intake into blood (?), reaching heart, etc. Could be improved, he said with more exercise – more than once a week.

Clearly, standardized senior norms for fitness assessment were inappropriate for Ruth, given readily apparent physical deformities and limitations. According to the excerpt below, Ruth’s health was also impaired in the months preceding the fitness test, with a marked fatigue and stiffness that suggested an underlying inflammatory process.

Winter ’84-’85

I bot sheepskin for bed, under bottom sheet, & removed mohair. Sheepskin helps somewhat – a bit lumpy, but softer. Winter was OK without any bad ‘flu or cold; occasional ‘turista’ (loose bowel movements) for no apparent reason, but no fever, etc. I try to do gentle exercises every night, & swim once a week (more or less) at warm pool at ... Hospital on .... Have little energy, get stiff easily & seem to require a lot of sleep & rest. Stiff knees – going up & down stairs not easy.

Oozing right ear problem is now OK – it responded well to Polysporin ointment (‘sterile Ophthalmic’) which I got awhile back for small eyelid infection. (Self-medication!)

As noted in the excerpt below, Dr. Weiss had previously contraindicated the use of cycling as a form of exercise.

February 26, 1981

1:00 pm – saw Dr. Weiss. Told him about my dilapidated condition, due to ‘flu, successive colds, etc. Feeling weak, sleepy, hungry etc. A bit stiffer than
previously, prob. due to ‘flu. I told him that pharmacist had recommended 3 grams of Vitamin C daily while one has a cold (Dr. Lawson said 1 gram daily all the time – he takes it himself). Dr. Weiss said, a lot of people do this – it might be a good idea. Also vitamins and Halibut Liver Oil pills (which were previously recommended by pharmacist). Told him I will be seeing Dr. McFee at the Arthritis Centre in (exactly) a month, and I saw Dr. Lawson on Monday last…. He said rest is good for recovery from colds, etc. (‘your body is trying to tell you something’). I asked him also about riding a bike – he didn’t recommend it. Not a good idea!

He also said, Coricidin is good for post-nasal drip, etc. to help dry up sinuses, if necc.

There was no evidence that Ruth followed the recommendations of the fitness specialist. However, to be found wanting in regards to the “norm” likely reinforced Ruth’s view of herself as a “decrepit senior citizen,” or a woman who was prematurely aging, negative self-appraisals common to those with rheumatoid arthritis (Iaquinta & Larrabee 2004; Shaul, 1995). In consequence, an opportunity was missed, given the presumed goal of fitness enhancement for seniors. If Ruth had been visible, rather than the standardized norm, perhaps her physical tenacity would have been both acknowledged and celebrated.

According to the excerpt below, Ruth subsequently initiated a referral for fitness counselling given lower extremity weakness.

**August 22, 1996**

_In Aug., I also phoned ....Rec Centre for personalized fitness counselling, in my case, exercises for leg muscle strengthening. Joan Peary, one of their fitness people, phoned me & made a house call. I bought plastic exercise ball from her & she gave me a set of exercises to do on it – see file under “Exercises, Nutrition, etc.” She also sells Shaklee vitamin products, & I bot some (see file “Shaklee”). As Aug. 23, I am using up old vitamin pills and taking some “Shaklee” as well- phasing in supposedly purer S. Pills as old ones get used up._

Once again, advice was offered by a fitness instructor that was presumably based on normative data, rather than specific to Ruth’s disease process and evident deformities. As with the previous fitness assessment, recommendations appeared to be offered without
medical consultation. In addition, the above encounter suggested that Ruth was vulnerable to social persuasion during the home visit as she purchased Shaklee vitamins from the fitness instructor, in spite of reservations about health claims. While a home-based fitness assessment appeared tailored towards Ruth’s limited mobility, the subsequent business transaction served the interests of the fitness instructor.

While nurses theoretically have a critical role in providing comprehensive care for those with rheumatoid arthritis (Iaquinta & Larrabee, 2004), there were no reported interactions within the Medical Log. However, nurses may have offered input while Ruth was involved in the Arthritis Center in the 1980’s, as their presence was referenced during an interdisciplinary team meeting. Otherwise, Ruth erroneously referred to secretarial support staff and a medical office assistant as nurses.

The apparent lack of involvement of nurses in Ruth’s care was consistent with the health care experience of others with rheumatoid arthritis (Iaquinta & Larrabee, 2004). While their absence in the offices of primary care providers may be a cost-cutting measure, given recent cultural shifts to a business orientation in health care (Bury, 1991), their limited involvement sharply contrasted with extensive nursing research geared towards understanding the needs and experiences of those with rheumatoid arthritis (Brown & Williams, 1995; Dildy, 1996; Edwards et al, 2001; Fair, 2003; Hewlett et al., 2005; Iaquinta & Larrabee, 2004; Melanson et al., 2003; Plach, et al., 2004; Shaul, 1995). Such professional absence hinders the provision of comprehensive care presumed to be within the nursing mandate (Iaquinta & Larrabee, 2004) while also hindering the translation of research findings into clinical practice.
Pain

Pain, as an object for research analysis, was subdivided into two categories: biomechanical pain, or pain that was associated with progressive joint deformities and, inflammatory pain, or pain that associated with an active rheumatoid disease process.

Biomechanical Pain

While informants provided mixed impressions regarding Ruth’s pain experience, the Medical Log clearly indicated that Ruth managed chronic biomechanical foot pain that was associated with severe and progressive foot deformities. When Ruth initially made contact with the Arthritis Centre in the 1980’s, pain-related difficulties appeared to be managed primarily through personal resourcefulness. As noted in the entry below, health-related professionals were amazed at her ability to walk during their initial assessment.

June 16, 1980 (interaction with physiotherapist)

Ankles are OK, but feet..! She wondered how I walk on them (I once again mentioned Tender Tootsies and Metropolitan Museum!) and if I have a lot of resistance to pain.

July 21, 1980 (interaction with occupational therapist)

2 pm appointment at Arthritis Clinic, occupational therapy department, for Foot Assessment with Heidi. From 2 to about 10 to 3 pm we talked about Feet, Shoes, etc. She examined feet, but no measurements were made. I gave her a history of feet in some detail (incl. smaller toes ‘going up’ increasingly over past few years, necessity of buying new boots a couple of yrs ago, new boots giving me bleeding blister on 2nd toe of right foot when worn a lot last Jan (while doing trunks in ...), necc. for Scholl pads under big toes, little toe pbm on right foot (maybe did something to it when I caught it on caster of bed c. 10 years ago??) and so on. I gave glowing account of my new Tender Tootsies shoes, bot c. April, worn c. 6 hrs on marble floors of Met. Museum in N. Y. without ill effect, etc. – due to soft uppers, no blister on 2nd toe! Work better than any shoe I’ve had for years. She said, since they seem to work, go on wearing them, but if any other pbms arise (ie: with arch, etc.) I can see them again. My feet are in ‘fairly good shape’ except for toes, she said; left
big toe is now stiff & won't bend at all; right one still can (not by itself, but she can bend it) Little toes wave in the air & do little work. etc. I forget to take her copy of my Joint Log, but will send her one in mail.

March 14, 1983

Had house call from Occupational Therapist from Arthritis Society – nice young Susan Jones, re insoles and feet – use & value of insoles, etc. She had long questionnaire, asked me questions & noted answers, etc. (I like insoles, but don’t wear expensive shoes much due to angry corn on top of crooked joint on right foot – toe next to big toe – it feels better now but was acting up this winter & likes to be pampered with slippers, etc. Tender Tootsies are a bit easier on this corn (esp. my oldest pair) due to very soft plastic uppers – almost like a slipper. (See her letter asking for appointment in this file)

Ruth was eventually referred to a podiatrist, on the recommendation of friends, in 1990. As noted below, the Log excerpt subsequent to the first podiatric appointment suggested that treatments immediately brought symptomatic relief.

February 28, 1990

Another FOOT appointment. Feet are much happier with pads she puts on....

Ruth subsequently met with a podiatrist on a regular basis, with scheduled appointments three to four weeks apart during the later years of her life. As noted in the excerpts below, biomedical management by podiatrists frequently involved the prescription and adjustment of new orthopaedic shoes, given Ruth’s severe and progressive foot deformities.

October 31, 1996

I taxied to ... to get “bump” put in new left shoe over the above toe (toe next to big toe on left foot, which overlaps big toe & hits shoe top, developing sore. “Bump” done at ... (Mr. Coleman) was helpful-joint less painful, & looked better by Nov. 2 foot apptmt.
October 17, November 2, November 14, November 28, 1996

FEET appointments with Dr. Robertson. Feet in new shoes were not helpful – right big toe, with bone very close to surface still needing scraping, bandages, etc. Nov. 2- toe next to big toe on left foot very red & swollen due to hitting top of new left shoe. Sore over its joint look infected, but wasn’t.

September 10, 1997

FEET: ... Shoe store in ... - I went there & Mr. Kipper put new and/or bigger “bubbles” in both my black and beige extra-depth shoes, to give more room for various joints & corns. Exp. sore spot with scab on joint of little toe next to smallest toe on left foot – top of joint rubs against leather of both shoes; also a small-toe joint on right foot, and big toe of right foot (he bulged up top of big-toe space a bit). No charge.

The Medical Log excerpts below provide a very limited glimpse of Ruth’s extensive involvement with podiatrists over time, with a particular interest in pain as the object under consideration.

July 27, 1990

2:10 pm – FOOT appointment with Dr. Robertson. (My toes had been painful to walk on for last day or so, esp. right one.) She found infection – blister with yellow pus on right toe, and ‘skin breaking down underneath’ on left toe. (Cause? Hot weather lately, lots of showers, walking with visitors, more walking than usual?? Not sure.) She said, bathe twice a day for 15 min in warm water with salt (2 Tbspn salt per bucket), then apply antibiotic ointment (“Polysporin” (I bot a new one.) She put on a bandage on each toe with lift-off brown tape for bathing, etc. Getting it dry is important – sjj hair blower-drier or space heater! I shd not wear slippers at home – running shoes are better (she may put in special inserts). I am to see her in 2 weeks.

July 23, 1991

FEET. Left toe OK; right one “a bit nasty”, perhaps because I had been favoring left one? After I fell in ...July 5, I couldn’t wear foot sock or ‘bedroll’ on left big toe, due to swollen condition; I left toe bare. Right toe wore toe sock & bedroll when going out. Right ‘nasty’ toe got scraped & had antibiotic powder put on; bandages (crescent moleskin held on with wondertape) were put on both toes – no foot sox or bedrolls. Left bandage can be left on, Dr. R. said; right toe one shd be left on for 2 or 3 days, then take it off & go back to Polysporin ointment & footsock. July 26 eve – I took
bandage off right toe (Jy 24 – wheelchair outing to Lillooet – did walking, in heat.) Put footsock & ‘bedroll’ on instead.

May 13, 1992

FEET. Dr. Robertson found left toe OK, but right not as good – lots of pressure, callus buildup, and brown spot (“ulcer”) underneath, caused by surface skin pressure & breakdown. Usual callus scraping job & nail cutting was done, & small bandage with antibiotic powder was put on right toe temporarily.

July 2, 1993

FEET: Dr. Robertson looked at toe & scraped it – said it is doing better, but I shd keep on with above routine (soak toe in salty water, apply Bactroban, etc.) I told her this right toe didn’t appreciate toe sox, but liked her bandage better, so I used it in daytime (took it off at night). She also looked at left toe, peeled it a bit, filed it, & cut toenails.

December 23, 1994

FEET: Dr. Robertson, about to go to Thailand, has finished my latex toe sock for right big toe; it has a pad underneath sore bit (bit with brown spot, & 2nd bit with brown spot to the right of it). At appointment, she scraped off dead skin as usual, and trimmed nails; toe was a bit sore on way home, but not bad when walked on (perhaps due to my new shoes )”Allstar sports”) and their harshish liners (she filed off a bit from right one) which are being “broken in”.

November 8, 1995

FEET: (Right toe getting uncomfortable for last week, tho I haven’t been walking too much. (Buildup of callus?) Dr. Robertson did usual toe job, & made slight adjustment to pad in my right running shoe. (It hurt, tho, on way home – I had been on feet all day.)

November 28, 1996

FEET. Mentioned occasional pain in left heel, outside (left) back, making walking painful. (Could orthotic be a bit too high there??) The pads she put on right foot orthotic (c Nov. 14??) to ease pressure on right big toe are working quite well. She scraped toe as usual & put on bandage, also on little left toe (see above); said, put Bactroban on both.
June 12, 1997

FEET. New orthotic not recd yet. Dr. Bridges did usual scraping job, & bandaged both big toes, tho both in good condition.
c June 9/97 – I bot Dr. Scholl “Heel Guard” (c $10.) which seem to be helpful on trial for c 2 days) in steadying feet, esp. left one with ankle pronation, & frequent heel pain.

June 4, 1998

FEET. The toe felt OK, Dr. Bridges found right big toe not in good shape – gory patch on left side & much dead skin buildup – painful when scraped. He applied bandage with antibiotic ointment (or powder), and made adjustment to orthotic insole (right foot). Put thick (“woolly” pad I had been using on top of that. (This was painful – maybe too much pressure – I took it out after lunch, when I got home.)

June 5 – took toe bandage off & soaked toe a bit in Dettol solution, then applied antibiotic ointment. Toe a bit puffy; I found a skin crack (open) on toe front, along crease where toe cannot bend (similar to cracks on hands occasionally). Put antibiotic ointment into crack, & sore healed a few days later.

Wore new beige ... shoes when I went out – they work very well, even with no pad or bandage at all on toe.

December 21, 1999

FEET. For last wk or so, right foot big toe has hurt a bit, not on left side as before, but on right side of toe bottom, where I now have more buildup of skin & brown spot bigger than left bottom. Why? Possible slight change in toe position? Don’t know. But part of problem is due to hard blue pad insight right beige or black shoe – I took it out & things rapidly improved.

Told Dr. Bridges, who did usual scrape-&-clip nail job on feet. I had put little gel-type circle pad over right toe right side with wondertape; he put it back on after cleaning job. Am now wearing older beige shoes with no Scholl’s paddy insole over orth. insole and arch support; works OK.

February 22, 2000

FEET: Problems lately, esp. last week. 1) right foot big toes – now gets sore with skin buildup on right side of toe, not left side as before, where weight on toe used to leave brown spots (bone very close to surface) I have not been doing much walking, but Dr. B. noticed poor toe condition. I asked him, do I need bigger hole in right orthotic, to right of old toe hole? He agreed & made the hole bigger (shoe felt better when walking home).
(2) Last week, noticed base of left foot big toe (which twists abnormally leftwards on foot) getting mucky, damp & gummy at back of big toe; red, puffy
skin; some dead skin, which rubbed off in bits, etc. I applied Bactroban to avoid infection, c Feb. 18 or 19. Toe is immobile – can’t see what’s going on in back crack (can’t open it up to look). Dr. B. applied more Bactroban with gauze – I shd replace after each shower. He wants to check it again next week (Feb. 29).

Ruth’s ongoing relationships with podiatrists appeared collaborative in nature. While Ruth diligently followed treatment recommendations, attending podiatrists also relied on Ruth’s feedback in determining the effectiveness of treatment interventions. Given the implicit acceptance of Ruth’s assessments, Ruth was free to improvise if a particular medical intervention proved inadequate or uncomfortable. In this regard, differences regarding recommended treatment was transparent within the relationship, an openness that contrasted with Ruth’s fears of creating “professional umbrage” when she forwarded differing surgical options to her surgeon, Dr. Brown. Transparency and negotiation was apparently fostered within the patient-doctor relationship when Ruth’s experience was viewed as valid and necessary by the health care provider. According to Bury (1991), a stance of physician-patient negotiation around treatment regimens acknowledges the limitations of knowledge available to both parties, while expectations of patient compliance fail to acknowledge the complexities associated with the chronic illness experience.

**Inflammatory Pain**

Documentation within the Medical Log suggested that Dr. Lawson viewed Ruth’s rheumatoid arthritis as inactive based on laboratory readings of the rheumatoid factor (Rh Factor) and the erythrocyte sedimentation rate (ESR). This assumption appeared to be shared by a specialist consulted in September 1972 prior to Ruth’s involvement with Dr. Lawson. The following excerpts document interactions with medical professionals regarding the
perceived significance of a negative Rh Factor reading and the associated understanding that Ruth’s rheumatoid arthritis was “inactive.”

**September 1972**

_Saw Dr. Froese to get 2nd opinion; had hand X-rays done. He didn’t think synovectomy was indicated at this time; I may need plastic implants eventually. Was surprised at mobility of hands, in view of X-rays. Suggested possibility of (a) right thumb base fusion (to give better pinch); (b) plastic joint in right hand’s bent finger. Had blood tests done, re rheumatoid factor – results all OK. Suggested I see Dr. Lapierre at … Hospital._

**November 4, 1988**

_2:40 pm – I saw Dr. Lawson & was given flu shot (they arrived a bit late this year). I told him about recent stiffness (& wrist decay), and my increase in aspirin intake to 5 or 6 per 24-hour period; he asked if aspirin upset my stomach, I said no…._

_He said I should have blood test (‘sedimentation’) to find out if arthritis still active….I am to phone him when I get back from Hawaii (Nov. 20th) for the results. I forgot to do this – asked him Oct. 23/89 what results had been, & he said OK- arthritis no longer active._

**January 24, 1991**

_Dr. Lawson telephoned; said all results of blood tests taken yesterday (at Lab. on 2nd floor of his bldg, at his request) were normal, incl. cholesterol; also, one for Rheumatoid Arthritis factor – I am ‘burnt out’ case – factor no longer present._

_When questioned, Dr. Lawson reiterated that Ruth’s rheumatoid arthritis was inactive, also referencing the lack of reported inflammatory pain. Disclosures of pain were typically thought to be due to either osteoarthritis or the biomechanical effects of foot deformities. In spite of these assumptions, there were considerable reported symptoms throughout the Medical Log that suggested the presence of an active inflammatory disease process, including recurrent joint aches and morning stiffness, with an occasional sudden onset, as well as chronic debilitating fatigue and the presence of progressive joint deformities. All of these symptoms have been identified as indicators of an active disease_
process by the American College of Rheumatology (2002). The Log excerpts that suggested a possible but unrecognized inflammatory process are chronologically documented below.

**September 1971**

Both hands noticeably stiffer & clumsier during year, with some joints swollen & occasional aches (not bad). Cannot straighten fingers fully, & can no longer “touch type”. Some joints swollen, but don’t hurt; others look OK but do hurt.

**May 1974 to April 1980**

- no remarkable new developments, but slow, gradual deterioration of hand action & capability (almost imperceptible, until one notices change in handwriting from year to year, increased difficulty with such things as car doors, etc.) No pain, but increasing awkwardness from yr. to yr.

**January... 1976**

At home, sudden onslaught of aches & pains; aspirin helped noticeably. (A type of ‘flu in ... at this time was making many people complain of the same thing.) Started dressing very warmly & resting a lot.

**April... 1976**

Hands much better, but not working as well as before Dec./75. I went to Dr. Wolfe...(He said that, unless great disability exists or pain – real inconvenience – he has conservative approach & prefers to avoid surgery....)

**February... 1981**

Told him about my dilapidated condition, due to ‘flu, successive colds, etc. Feeling weak, sleep, hungry etc. A bit stiffer than previously, prob. due to ‘flu.

**March 26, 1981**

(At the present time, I seem to be doing reasonably well, and am not too eager to have any operation, tho I’d like to find out if something should be done this yr rather than next. Knees are getting a bit stiffer – harder to get going after sitting for some time, etc.)
February 24, 1982

another cold or form of ‘flu. Not as nasty as last one, but nearly – woke up early am with fever of 101.5 and sore throat (not upset stomach or bowel). Very sore throat was main feature of this bug, also fever (not high – I continue to take 8 aspirins per day as Dr. Weiss said – some headache, aching bones and stiffness (not severe), need to sleep a great deal and no energy....

March 25, 1982

I also told her about the ‘sock’ I have with 5 little weights inside (1 lb ea?), but at Arth Centre 2 years ago – I’m starting to use it more (put it around my ankle & sit on side of bed, lifting leg up & down – seems to help a bit. Some difficulty getting off buses, etc.; stiffness after sitting awhile.

October 18, 1984

On Oct. 18, he gave me checkup, examined breasts, asked questions, etc. I told him re stiffness & aches in bed at night causing turning more frequently, & mentioned Sheepskins (woolly) under sheets over mattress which I had heard about – he said they are good.

Winter 1984-1985

I bot sheepskin for bed, under bottom sheet, & removed mohair. Sheepskin helps somewhat – a bit lumpy, but softer. Winter was OK without any bad ‘flu or cold; occasional ‘turista’ (loose bowel movements) for no apparent reason, but no fever, etc. I try to do gentle exercises every night, & swim once a week (more or less) at warm pool at ... Hospital on .... Have little energy, get stiff easily & seem to require a lot of sleep & rest. Stiff knees – going up & down stairs is not easy.

May 14, 1987

Right wrist getting knobbly & harder to turn (stiff & slight ache; harder to use soup spoon).

I am now taking 3 aspirins per day, after meals – am, noon & eve. (Tried taking none, but was stiffer).

October 3, 1988

- woke up very stiff & aching; I have been taking only 1 aspirin every morning for sometime. Oct. 3 – took 7 aspirin from 4:30 am to midnight, and between 4 and 6 on succeeding days, which was a great help.
October 3-27, 1988

had one recurrence of this, not as bad; then on am. of Oct. 27, another one (not as bad as first one, but very stiff. I again upped aspirin intake. 

For past few months, I notice deterioration in right wrist hard to bend, knobbly, & harder to wield spoon (soup, etc.)

November 4, 1988

2:40 pm – I saw Dr. Lawson & was given flu shot (they arrived a bit late this year). I told him about recent stiffness (& wrist decay), and my increase in aspirin intake to 5 or 6 per 24-hour period; he asked if aspirin upset my stomach, and I said no. I said I felt much better than at this time last year, and loose bowel problems has stopped – everything seems to be normal. He asked about blood or leaks from anywhere, & I said no. I examined hands & fingers; I pointed out knobbly right wrist joint, & said I was told years ago to watch it, in case it saws thru tendons; he showed me where tendons go (just to centre of wrist from that joint, just this side of knob, so to speak.) He noted that we had spoken some time ago of possibility of hand operation, but said that of course it involves prostheses (ie: artificial joints) which can sometimes have side effects – I agreed. He said, if I’m getting along OK, operation not really necessary now, or words to that effect.

....He said I should have blood test (‘sedmentation’) to find out if arthritis still active. I thus went down to lab on 2nd floor of same building and had test; I am to phone when I get back from Hawaii (Nov. 20th) to get results. I forgot to do this – asked him Oct. 23/89 what results had been, he said OK- arthritis no longer active.

October 23, 1989

I said I had had some gassy bloat problem with sore lowest right rib and gas, about 2 months (?) ago – when I rubbed right rib, I burped a lot – it felt like a pocket of gas under rib. Dr. Lawson said, yes, this is possible. I asked if gassy bloat could have any connection to taking aspirin over a long period, and he said, yes, it could; I said I had cut down aspirin intake from 3 per day to one per day, taken after breakfast, and this seems to be OK.....I mentioned occasional cracks between toes, & said that I was applying zinc oxide ointment – he said this is fine. I displayed stiff right wrist, which doesn’t bend well, also left big toe, which is descending & doing crossover under little toes (right toe is not as bad)....


Got small cold in early Dec., which I thought was over, but then got ‘flu shortly after New Year’s Jan 6/90 – had swollen, red right eye lid, and fever of 102º in evening. Took aspirin, first 4 per day, the 6; Jan 9, 9am, 102º
again. No sore throat or dripping nose. Just fever, felt very cold even with many clothes, sweating aching bones, sleepiness and weakness – felt weak for some time. Flu gradually tapered off c.Jan 22, tho still felt weak c. Feb. 2. (But no upset bowels!)

February 27, 1990

(Gen note on winter 1989-1990): Not a good winter- NB weak, sleeping a lot, afternoon naps, no longer staying up late, often too tired to take evening bath; not sleeping thru night, getting up once or twice to urinate, etc. (Never did this 2 or 3 years ago.) No energy at all, and even routine jobs take much time & leave me very tired.

April 9, 1990

(Jane Goodall lecture) – small eve. sore throat. Small cold developed. Apr. 12 – lunch at … with Jessica Lord. Apr. 13 (Good Fri) Lost voice; no voice at all over weekend. For next few weeks, was sick, good & proper – throat, nose, ears, chest – much coughing (almost gagging) with balls of rather solid green phlegm, nose blowing, sinuses full, ear ache, etc. (right ear). No diarrhea or vomiting. Cancelled all appointments, just went out for food, etc. Weak & sleeping a lot. Aching bones-taking 6 asp. per day, nsd of 2.

May 16, 1990

Had dizzy spells in laundry room downstairs, fell down (& had trouble getting up!) I phoned Dr. Lawson & asked if this could be side effect from penicillin; he said, he thinks dizziness is part of the infection. “Let me know early next week if you are still having them”. (Movement of head seems to cause dizzy spells-could it be a problem in my funny-feeling right ear, which aches a bit between aspirins?)

May 22, 1990

Woke up extremely stiff (every joint, esp. wrists.) Took 6 aspirin, 3 in morning.

May 23, 1990

Phoned Dr. Lawson; I told him I am still having dizzy spells, esp. when sitting up & lying down, but I think not as bad as last week. Have funny feeling still in right ear; in am (before am. aspirin), have slight ache in head and behind right ear; a bit of coughing, but very little phlegm; throat is better (not sore). Lawson said, he thinks it’s just due to ‘flu, nothing serious; no further antibiotix req’d.
May 23-28, 1990

taking more aspirin than usual, about 5 daily (before this ‘flu, I was taking one or two in am. only.)

June 18, 1990

Better, but not 100%; still taking c. 5 aspirin per day, hobbling around stiffly, legs weak; last week or so had partially white, fuzzy tongue and somewhat upset bowel (2 loose BM’s per day, mild cramps). Very little energy (but better than last month), & still take some pm naps – sleep a lot.

January 23, 1991

Saw Dr. Lawson for medical checkup with cholesterol test (9am; have to fast for 12 hours before test – no food after 9pm on previous night – water only). He gave me more complete check than usual – stethoscope, pap smear, uterus & ovaries, chest listening, etc etc – “complete physical examination”. Approved of mammogram done last Nov. – “should have it done yearly”. I mentioned dry mouth, dizziness wearing off, etc. – recent medic. hist. (recent entries above on this log), and lack of energy (sleeping a lot) He thinks lack of energy is due to rheumatoid arth – not much can be done about it. Asked if my apt, is dry; I said windows are open, but heat may make it dry. Dr. L thinks I’m healthy & doing ok.

March 10, 1991 ff

had small cold of some sort, featuring sleepiness, lack of energy, white furry right tongue, need for more aspirin to combat stiffness, joints aching a bit, some throatiness. Still there (tho not really bad) March 20.

October 16, 1992

FEET: Dr. Robertson did usual job; right toe, which has been wearing new toe sock, seems OK – ‘left big toe not as good this time’, she said; she put horseshoe-type pad & wondertape on left toe, & said, leave it for a week. (Left big toe, now at quite a slant, seems to be moving over a bit more, pointing towards 11 toes)

September 17, 1993

Loosish, but formed BM in am. Red face, & pink speckles (rash?) on body. 11:30 am- very loose BM, liquid BM. Temperature normal. Weak & wobbly, but no nausea. Very cold hands & feet, & “prickly” legs; I lay down under electric blanket, & slowly warmed up.
4pm-got up & had 1 aspirin with apple juice. (For slight headache, aching bones & legs)

Red face; weak & wobbly. No lunch. (Have not taken aspirin all week – just Vit C now & then.) Mush soup & turkey breast f supper. No antibiotic today.

**October 7-21, 1994**

I had a cold sore throat, weakness, strong desire to sleep, etc., which was not helped by my short trip to Cariboo ranch Oct 14-15 (cold, rainy). Some watery diarrhea and headache, plus deafness in ears (esp. right one), but weakness was main feature & slow improvement.

**August 02, 1995**

Had free ear examination at ....with Belton man, George Ashcroft “Hearing Instrument Specialist”) He tested my hearing in each ear with his exotic machine, and made record of test for their files (will send a copy to my doctor if he wants it). He told me I have lost about 40% of hearing in right ear, and 30% in left (figs. not exact, just approx as I remember them). I should have ears tested every year (they will come weekly to .....)

**September 6-7, 1995**

little finger of right hand – is joint out of socket? Lots of arthritic pain, also along that side of right hand. Had trouble using that hand for anything; took several extra aspirin; by Sept. 10, almost back to normal.

**April 09, 1996**

FEET: usual job – bandage on right toe (“Bone is very close to skin surface.”) I told Dr. Robertson about left ankle – whole joint sort of bulging inward (ie to right); when I walk, left foot turns out a bit (“duck-footed”). Do I need boot, or special support? I wear slippers around house, but this is bad, she sez. (But shoes are uncomfortable due to toes which burn – running shoes work better when walking than when sitting still: she said they were designed for action.)

**September 30, 1996**

Got “small cold”, which turned into (October 3, 1996) very sore left hock, from hip to knee-painful.
October 1996

_bursitis_. Very painful left side from waist to knee; aspirin not helpful. Oct. 8 Dr. Johnson said 222’s might do better (I took the until Oct. 28, then went back to aspirin.) Other joints affected, stiff & painful; legs very weak.

July 06, 1999

FEET: Dr. Bridges did usual job (scrape toes & cut nails). Feet are OK. (I wear beige ‘stretchy shoes at home almost all the time – not flat slippers to give more support to left (pronated) ankle, which is gradually getting worse).

July 20, 1999

FEET: Dr. Bridges on holiday; his ‘locum” (Dr. Jessop??) did very good, careful job scraping both big toes and bandaging right one. He said (of right toe) “you are almost walking on the bone”, which accounts for rapid buildup of skin, soreness, etc. He put back little disc with usual “wondertape bandage”.

August 4, 1999

All has been going reasonably well, tho I was tired after return from Railway assn 5-day tour north (…) and had arthritic-type ache for several days (off & on) in right foot big toe joint and left wrist; these disappeared after a week or less. (Did a lot of walking, early rising, etc on trip.)

January 8-9-10, 2000

Left EAR & throat problems. On 8th, noted earache, sore base of throat, and slight headache – left ear only (Not ‘normal’ sore throat.) Sunday 9th was a bit worse – took 2 extra aspirin; by 11th much improved and just about back to normal by Jan. 12, cause unknown.

April 3, 2000

re Fall: dull pain, stiffness & weak shakiness continuing from fall in …. Library; taking c 7 or 8 aspirin per day. I phoned … Physiotherapy (where Nancy Williamson fixed me up after fall in … years ago). She now works only Tuesdays & Fridays – made apptmt for Fri Apr. 7. (I can do this without getting referral from Dr. Lawson; I phoned his office Apr. 4 to check.)

April 7, 2000

Saw Nancy Williamson – quite a long session, with hot pads, massage, etc. She said it will take c 3 weeks to feel normal; see her next Tues & Fri,
keep moving gently; muscles & tissue below surface of bent (osteo) back are prob. bruised – not on surface. Heat is good; don’t stay immobile too long. I told her what had happened, and mentioned extreme weakness in am.

April 11 & 14, 2000

Saw Nancy Williamson, physio, again & she worked over right upper back area, gave heat treatment, etc. (User fee at physio is now $20. per visit.) Slowly feeling better, tho feeling very weak (esp. in am ) and needing much sleep. Didn’t have to see her Tues. 18th, or after that. (From Mar. 28 fall on, took many extra reg. strength aspirin, 6 or 7 per day instead of usual 2,....

June 6, 2000

FEET: Left (pronated) ankle problem: ankle lopping to right, swollen and hurts when walked on; little arthritic flareup? Aspirins dispel pain. (Cause? Too much walking-ie to ...? Wearing slippers too much in am around house??)..... By June 11 (when Landons came from Fla.), after restful week, not walking much, & taking one or 2 extra aspirin each day, I felt much better – swelling gone down. I now spend little time in slippers – shoes with ortho insoles go on before breakfast. I also removed crescent-shaped disc from front of one orth. insole, which improved comfort of right foot’s big toe (which has had problems recently).

October 30, 2000

Saw Dr. Lawson, since my Didrocal prescription has run out. (He wants to see all patients before renewals made.) He gave me new prescriptions for both Didrocal & Synthyroid although my nearly-empty Synthyroid bottle has 2 refills still on it. I also got my annual flu shot. I asked him about UK people telling Kay Jones to take Synthyroid on an empty stomach; Dr. Lawson said it doesn’t matter just when you take it. I mentioned my puffy, slightly achey left foot, & cold – said foot improved with one extra aspirin per day. Cold is obviously a small one, but is hanging in with barking cough, etc. & general tired-weak-sleepy feeling.

May 24-June 18, 2001

- it has taken a long time to “recover: from trip to .... More arthritic aches, esp. in right upper arm & shoulder (due to being pulled up into vans?) Very sleepy, little energy, & taking extra aspirin.

November 12, 2001

Felt tired, weak, esp. in am – no reason. Slept a lot
November 15, 2001

- small sty in puffy right eye; right ear ache, some headache, felt tired, etc. – perhaps small cold? But bowel movements returned to normal beige. Rested a lot & ate lightly.

March 5, 2002

Dr. Lawson: (12:30 pm-waited until 1 pm) Annual Exam. I said I had not had a bad winter – no cold or ‘flu- but had odd reaction to my ‘flu shot (see Dec /01 notes), and whined about slowing down & getting older, need for much rest & sleep (he thot due to my arthritis) gassy fore and aft (too much tonic water? He said no, it does you good) Sore right ear with headache, esp. when I’m tired, neck click when head turned (but not always) little muscle ‘bump’ on right upper leg (not important). Did he say a few mo. ago I am ‘borderline diabetes? He thinks no. He checked back – no moles; skin OK. I showed him Income Tax Disability form which he filled in last Nov., and he added “SLOW” to description (I will send it in with photos. I went down for various blood tests; he will phone with results.

March 9-11, 2002

slept a lot. Mar. 11 am-almost lost voice in am; bright red area at back of mouth, slightly swollen; tired, weak, etc.

Month of April 2002

Not feeling too well, no energy, & Indigestion- lots of Gas! on advice of 2 pharmacists, I bot “GAS-X Extra Strong” tablets, about 11 over a few days – very helpful. (It’s Income Tax season!) Tried cutting down on aspirin Apr. 15-20 (instead of usual 1 full 325 mg asp. in am. after break, and 1 in eve after dnr, took ½ a pill only.) This didn’t help, & left toes got swollen & stiff, so went back to usual full pills May 1 (am & pm).

September 05, 2002

Saw Dr. Lawson. Described period since I got out of hosp.: I have been thin, weak & wobbly, eating carefully & resting a lot. Osteoporosis getting a bit worse? Stiff creaky neck clicks, right ear slightly deaf and makes occasional typewriter “clicking” noises – worse when tired, but Tylenol helps. Little energy; can sleep anywhere, at once! Fell down gently on Marion’s steps Sept. 1 – nothing broken. Left bruise on tail.

I asked for a follow-up blood test to see if slow interior blood leak is still going on. (In Spring, when leak was occurring I couldn’t tell-no evidence until black stools appeared.)
Sept. 6 Dr. Lawson phoned: results of blood test on 5th all OK (Sept. 5 cont’d) I told Dr. Lawson my Didrocal prescription and Synthyroid will run out soon (Sep. 14 & 17). He gave me percrip for both. I told him & gave him list of pills I take daily (2 or 3 reg. Tylenol, no aspirin, 1 Synthyroid, 1 Didrocal, & Vitamins. Should I take a bit of aspirin daily, for non-arthritic reasons? He said YES, take one 80 mg ASA (kid size) daily.

I asked re Folic acid 1 mg. & Iron pills brot from hospital (expire 2004). Dr. Lawson said, take folic acid; keep iron pill (Iron is 300 mg) Present Synthyroid dose, 125 mcg, is OK.

September 11, 2002

TEETH: “Barnacles” removed from tips of front teeth, and edges smoothed over. These hard, (calcium?) scratchy edges have been there for years, tearing at inside of upper lip which gets sore; not as bad in last two years or so, perhaps due to change in placement of front teeth (moving out a bit, “buck” teeth). Have caused a bit of trouble for last few months.

October 02 to 04, 2002 (weekend) ff:

Problems. Increased pain in right neck & ear; hard to turn over, esp. on right side. Woke up at night, felt cold (heat helped) – better when sitting up.

October 08, 2002

Saw Dr. Lawson in office; he thinks it’s just arthritis (not rheumatoid); warned me re codeine & constipation; doesn’t think physiotherapist or acupuncture will help. (Oct. 10 was date of my very bad constipation). Got “Sennosides” laxative pills, & took 2 after dinner, which cleared me out twice Oct. 11.

until c. October 24, 2002

Some boiled prunes every morning (brek). Lots of Tylenol Regular (no codeine); and occasional old Winthrop suppository helpful; occasional arth. twinges in right hip & thigh; weak & wobbly, & very sleepy.

October 17-18, 2002

took more codeine tabs (Tylenol 325 with 8 mg codeine) for head, neck and right ear pain, & 1 Sennosides lax tab.
October 19, 2002

Tried stool softener for 1st time; it worked well. More codeine pills & 2 Senno lax pills (result- too much loose BM on 20th) BM’s & baths very weakening; mornings bad, eves much better.

October 21, 2002

I switched my pill timing to taking almost all pills in am, with brek. Eased up on no. of Tylenols after Oct. 24/02.

See separate yellow page “Notes re Tylenol: for more info re Tylenol varieties, lax, stool softener, etc. Oct. 21 – was able to see “AIDA”.

December 2002

Not feeling well. Take fairly frequent Tylenol regular (325 mg, not with codeine); no constipation, but headaches, ear aches, head aches, back of neck stiff, “prickling” feeling at right back of head, itchy, etc. Had to opt out of 2 Yule parties, and was uncomfortable at dinner on Christmas Day (Marion & Lee). Sleeping a lot; hot sweaty spells; very cold-sensitive, esp. right ear & neck.

(Was also taking white Didrocal pills (c60% of ea Dec. 16 to 28)

December 18, 2002 ff

(All those Yule cards!) Dark, gloomy weather – feeling worse (is this psychology, or weather?) Taking c. 6 to 8 Tylenol Regular (no codeine) per day, with a Ty. Extra Strength” now and then. Quite Weak, very sleepy, esp. after bath or BM; better (as usual) in pm than am. (esp 10 am) Taking occasional lax (Phillips) (1 or 2 chewed pills) esp. after Extra-Strength Tylenol with codeine.

January 08, 2003

Went to Dr. Lawson’s office: found his replacement Dr. Cook (until the end of April). (Tel. same as Lawson: ....) I complained about various symptoms (see Dec/02 above), esp. right ear (sore & deaf), right side of head & neck; can’t raise head when walking or upright. Is itching due to pss. Tylenol allergy? Dr. Cook doubts this. Should I go back to aspirin for a week or so? He thinks not – might cause bleeding (suspected last summer). He sent me down to Lab. in .... Bldg. for another blood test, also for an X-ray (in adjoining bldg.) Jan. 16 or 17- Lawson office phoned me & said Dr. Cook told them results of blood & X-ray were ‘normal’.

I asked him for referral to Dr. Joan Knowles (see Jan 6 above), & gave him info, billing no., etc.
According to Dr. Jolanda Cibere, MD, PhD, FRCPC, a research scientist at the Arthritis Centre of Canada (personal communication, August 22, 2006), aspects of the Medical Log suggested the presence of an active underlying inflammatory disease process. In particular, Dr. Cibere confirmed that the sudden onset of arthritic-type pain reported within the Medical Log was more characteristic of rheumatoid arthritis, rather than osteoarthritis.

In addition, Dr. J. Cibere noted that a negative Rh Factor, or a reversal from a positive to negative reading, as was apparently evident in Ruth’s case, was not a reliable indicator of the presence or absence of inflammatory disease activity. Dr. Cibere noted that the Rh Factor was used primarily for prognostic purposes, with an initial positive reading suggestive of a more severe disease process. As was consistent with current treatment guidelines (ACR, 2002), Dr. J. Cibere said that testing for the Rh Factor was not repeated once a positive reading was obtained at baseline. In addition, Dr. J. Cibere observed that it was rare but possible to have laboratory findings of a normal erythrocyte sedimentation rate in the presence of an underlying inflammatory process.

According to Dr. J. Cibere, reliable clinical indicators of an active inflammatory process included joint tenderness and swelling, the degree of morning stiffness and the results of various blood tests, such as the erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP) levels. In addition, Dr. J. Cibere identified fatigue, sore muscles and a low grade fever as symptoms that could be associated with an inflammatory disease process. An inflammatory process, possibly low grade in nature, was presumed in the presence of ongoing joint damage.

According to present rheumatologic guidelines, physicians are advised to evaluate subjective and objective measures of disease activity during each follow-up visit (ACR,
Periodic examination measurements of ESR or CRP, radiographic examination of involved joints and measurements of functional status (such as the Arthritis Impact Measurement Scales or Health Assessment Questionnaire) are also recommended given the inadequacy of joint examination as a reliable measure of disease activity and damage.

Within the Medical Log, there were numerous excerpts that suggested an underlying inflammatory process given the presence of progressive joint deformities. These included Ruth’s hands (September 1971; May 1974 to April 1980; April 1976; May 14, 1987; October 3-27, 1988; November 04, 1988; October 23, 1989), feet (October 23, 1989; April 09, 1996; July 06, 1999; June 6, 2000), and jaw (September 11, 2002) and bones effecting the auditory system (August 02, 1995) In addition, symptomatic complaints of “creaking” or “clicking” sounds in the neck and ears, accompanied by persistent pain, suggest progressive deterioration and inflammation in Ruth’s spine and auditory system towards the end of her life (see excerpts March 05, 2002; September 05, 2002; October 02 to 04, 2002; December 2002; January 08, 2002).

Numerous Medical Log excerpts also suggested that an underlying inflammatory disease process was present but managed through the use of Aspirin, given both reported symptomatic relief and the exacerbation of symptoms, such as aches and stiffness, associated with a reduced dose (see excerpts Jan. 1976; May 14, 1976; Oct. 3, 1988; Oct. 3-27, 1988; Nov. 4, 1988; March 10, 1991; Sept. 17, 1993; Sept. 6-7, 1995; June 6, 2000; May 24-June 18, 2001; April 2002).

In addition, numerous Log excerpts referenced a general fatigue, frequently overwhelming in nature, a common symptom for those with rheumatoid arthritis (Hewlett et al., 2005), although Ruth also occasionally reported the presence of associated flu-like
symptoms (see excerpts February... 1981; February 24, 1982; Winter 84-85; February 27, 1990; April 09, 1990; June 18, 1990; January 23, 1991; March 10, 1991ff; October 7-21, 1994; August 4, 1999; October 30, 2000; May 24-June 18, 2001; November 15, 2001; March 5, 2002; March 9-11, 2002; Month of April 2002; September 05, 2002; until c. October 24, 2002; and December 2002). In addition, a few Log excerpts referenced early morning fatigue (see excerpts April 07, 2000; April 11 & 14, 2000; November 12, 2001; October 19, 2002 and December 18, 2002 ff), a general indicator of an active inflammatory disease activity (ACR, 2002).

The assumption that Ruth did not have an underlying inflammatory disease process had a significant impact on the nature and degree of medical diligence focused on Ruth’s treatment management. For example, while DMARDS were eliminated by Dr. Lawson as beneficial pharmaceuticals, the possible presence of an inflammatory disease process rendered Ruth’s joints susceptible to ongoing destruction and deformity. In this regard, Dr. J. Cibere indicated that DMARDS were routinely prescribed in the presence of severe joint deformities as other joints were assumed to be affected. In addition, Dr. J. Cibere described DMARDS as potentially beneficial for the treatment of symptomatic fatigue and joint stiffness. Present treatment guidelines likewise recommend that DMARDS be initiated in the presence of persistent joint pain, morning stiffness or fatigue, active synovitis, elevated ESR or CRP levels or persistent radiological joint damage (ACR, 2002).

In addition, NSAIDS, other than salicylates, might have been considered as potential analgesics in Ruth’s treatment management. While Ruth typically relied on Aspirin for pain management, Tylenol was prescribed following an episode of gastro-intestinal bleeding in June 2002. While Aspirin may have been contraindicated, cessation may have left an
underlying inflammatory process unchecked, which, in turn, may have contributed towards the intolerable pain that Ruth experienced at the end of her life. According to Moreland et al. (2001), an exacerbation of inflammatory activity frequently occurs following the withdrawal of NSAIDS for those with an active disease process.

The assumption of an absent inflammatory process also appeared to influence the decision to exclude the ongoing expertise of a rheumatologist in Ruth’s treatment management (subsequent to Ruth’s involvement with Dr. Weiss at the Arthritis Center in the early 1980’s). However, standard guidelines for the treatment of rheumatoid arthritis recommend ongoing consultation and support by a rheumatologist when primary care is delivered by a physician (ACR, 2002). Likewise, Dr. J. Cibere noted that ongoing care by a rheumatologist was necessary given that rheumatoid arthritis was incurable. As such, any inflammatory process required aggressive treatment management in order to prevent further joint destruction and deformity.

In addition, Dr. Lawson apparently viewed annual medical appointments as adequate for Ruth’s ongoing treatment management. Given Ruth’s ability to endure and self-manage health-related concerns, there was an occasional lengthy delay in the disclosure of significant symptoms and events to Dr. Lawson. For example, Ruth occasionally did not report the occurrence and aftermath of a fall until several weeks after the event. In addition, episodes of morning stiffness and joint pain, or body “aches,” frequently remained unreported for weeks or months. A message of normality inadvertently left Ruth reliant on self-management strategies, including endurance.

Given the above information, Dr. Lawson, and, subsequently Ruth, may have used a distorted clinical lens through which to “observe” and “decipher” Ruth’s bodily
manifestations. Ruth frequently attributed low grade fevers, body aches and stiffness with the “flu.” While a viral (or bacterial) infection may have been present, it was also possible that an infection accompanied an inflammatory process or that an inflammatory process occasionally existed on its own.

Likewise, when Ruth was diagnosed (in October 1996) as having bursitis by her physiotherapist, apparently attributed to a misaligned gait, it was also possible that Ruth had bursitis, or bursitis coupled with an arthritic flare-up or an arthritic flare-up alone. In this regard, Ruth reported generalized pain and stiffness in her joints, apart from the left sided pain that was attributed to bursitis.

In addition, Ruth was otherwise inhibited from connecting experiential reality with disease process and presentation. For example, the May-June 18, 2001 excerpt described an exacerbation of aches and fatigue, following a trip to the USA to oversee the care of her brother. According to informants, this trip was particularly stressful for Ruth as she was under pressure to take on the fulltime care of her brother and felt obligated to provide evidence of her physical limitations in order to justify her refusal. During the visit, Ruth also paid for her brother’s future funeral expenses, at the insistence of care providers. While research has documented the heightened effect of interpersonal stress on markers of immunostimulatory activity and disease activity (Zautra et al., 1994; Zautra et al. 1998; Zautra et al., 1997), Ruth did not make this possible connection, attributing an increase in aches and fatigue to the physical demands of the journey.

Most significantly, towards the end of Ruth’s life, pain may have been mistakenly attributed to osteoarthritis rather than rheumatoid arthritis (see October 08, 2002 excerpt).
According to Dr. J. Cibere, Ruth’s end of life neck pain suggested the presence of an inflammatory process in her spine.

While the lack of recognition of a possible inflammatory process raised questions regarding treatment management, at an experiential level, such recognition might have prevented a great deal of suffering through the provision of symptomatic relief. In addition, such recognition might have validated Ruth’s experience of pain as not “just arthritis” (see excerpt October 08, 2002) or “normal” based on laboratory investigations (see excerpt January 08, 2003) but as inflammatory pain that required aggressive treatment. Interestingly, Ruth used the term “flare-up” within the June 06, 2000 excerpt, as if she intuited an inflammatory process that was not otherwise acknowledged by Dr. Lawson. Dr. Bridges, Ruth’s podiatrist, also referred to Ruth having experienced a ‘flare-up’ in June 2002 when he was interviewed. Most significantly, at the end of Ruth’s life, an understanding that her severe pain was possibly inflammatory in nature, might have fed hope, given the possibility of relief with a remission, rather than fatalistic despair.

However, there was also information that suggested that other pharmaceuticals (specifics unknown) had been considered as part of Ruth’s medical treatment. On one occasion, Ruth told an informant, in response to questions regarding health-related treatments, that pharmaceuticals other than Aspirin had been tried but discontinued given undesirable side effects. Whether Ruth was accurately reporting past medication use, or deflecting unwanted queries or advice regarding medication and treatment regimens, remains unknown.
In addition, the log excerpt below (with Dr. Weiss, rheumatologist) suggested that other pharmaceuticals had been discussed as part of medical treatment, but that Ruth had chosen to continue with Aspirin.

February 02, 1982

11 am – ….Dr. Weiss said, ‘I know you don’t like taking pills, but ‘...said I should take 2 aspirin four (4) times daily with milk or meals (or I could take another new pill, but it’s more expensive; I said that I react well to aspirin, and opted for it). He is also going to contact the Arthritis Centre re more physiotherapy and also hand assessment by occupational therapists, to see if there has been any change in my hand function; he finds my legs very weak – ‘those legs will give out on you’ – they shd be strengthened.

However, whether or not medical providers had suggested other pharmaceutical treatments, Ruth was ultimately constrained in her ability to make informed decisions regarding her treatment options given an apparent misunderstanding that her rheumatoid arthritis had “burnt-out.” Given Ruth’s investigative spirit, her lack of knowledge regarding the unreliability of the Rh Factor for diagnostic purposes suggested that such information was not readily accessible to the lay person. Dr. Lawson’s apparent misreading of the significance of the Rh Factor was coupled with inherent difficulties in assessment, given that a poor correlation may exist between laboratory findings and clinical measures of disease activity (Newman & Revenson, 1993). Ruth’s “stoic” nature and minimal reports of pain further compounded the complexity of clinical assessment. Apparent inadequacies in Ruth’s treatment regimen were not addressed by numerous health care providers given that a treatment and medication review presumably occurred during Ruth’s hospitalization in May-June 2002 for gastro-intestinal bleeding.

Ruth’s interactions with Dr. Lawson’s replacement physician, Dr. Johnson, during an episode of acute pain in 1996, provided further insight into Ruth’s subjective experience
within the context of medical services that were provided. The relevant interactions with Dr. Johnson, as well as contextual excerpts, are provided below.

**September 30, 1996**

Got “small cold”, which turned into (October 3, 1996) very sore left hock, from hip to knee-painful.

**October 4, 1996**

I phoned to Dr. Lawson’s office – he was away on holiday, but I spoke briefly with his sub (doing a locum while Lawson is away), Dr. Johnson. (...) She said rest & taking aspirin are OK. (I had a lot of stiffness once before when having ’flu) Did not improve over weekend, in spite of taking lots of aspirin.

**October 7, 1996**

Called Dr. Johnson again; she returned call next day. Went to see Nancy Williamson, ... physiotherapist, in pm; she thinks it’s bursitis – gave me ultrasound & other treatments to help muscles & cut pain down. Thinks I’m taking too much aspirin; gentle exercises good, also something called “TENS”. I told her my thyroid pills (for hypothyroidism) run out Oct.12. (Thyroid pills don’t seem to have any effect on bursitis) Still can hardly walk. Taxi home.

**October 8, 1996**

Dr. Johnson called back. I told her the above, & why I couldn’t get down to see her. She said 222’s (no prescription req’d) might be better than aspirin. I mentioned thyroid pills – she told me to phone... pharmacy; they will phone doc., who will OK them & pharmacy will send them to me (they did, 6pm Wed. 9th) I mentioned osteoporosis test (I have weak bones). She said, if I can walk on it, it isn’t a fracture.

She was annoyed by my 10-min phone consultation. “If you’re going to talk for 20 min, you might at least come into office and at least I’d get paid”.

**October 9, 1996 (eve)**

Started taking codeine (222) pills (not perfect, but worked better for pain control than aspirin.
October 11- November 6, 1996

Seven visits to Nancy Williamson, physiotherapist (2 per week, then 1 per last 2 weeks) – c. \( \frac{1}{2} \) hr or more each visit. Ultrasound, TENS, and also exercises to strengthen legs, which were weak & wobbly. Twinges in left knee & hip, etc. (Oct. 25-1c Chesa; Oct. 27-Terfel recital (could hardly get up from chair).

Oct 9-27, 1996

Took 222’s daily, (max 5 daily) gradually easing off to aspirin (from Oct 28 on, 4 or 5 aspirin per day until Nov. 16. By end of Nov; 4 or less aspirin per day)

October 1996

**Bursitis.** Very painful left side from waist to knee; aspirin not helpful. Oct. 8 Dr. Johnson said 222’s might do better (I took the until Oct. 28, then went back to aspirin.) Other joints affected, stiff & painful; legs very weak.

October 17, November 2, November 14, November 28, 1996

FEET appointments with Dr. Robertson. Feet in new shoes were not helpful – right big toe, with bone very close to surface still needing scraping, bandages, etc. Nov. 2- toe next to big toe on left foot very red & swollen due to hitting top of new left shoe. Sore over its joint look infected, but wasn’t.

October 31, 1996

I taxied to ... to get “bump” put in new left shoe over the above toe (toe next to big toe on left foot, which overlaps big toe & hits shoe top, developing sore. “Bump” done at ... (Mr. Coleman) was helpful-joint less painful, & looked better by Nov. 2 foot apptmt.

c November 15-16, 1996

Had bump on top of left shoe enlarged, so I don’t bark or scrape small toe joint when putting on shoe.

November 28, 1996

FEET. Mentioned occasional pain in left heel, outside (left) back, making walking painful. (Could orthotic be a bit too high there??) The pads she put on right foot orthotic (c Nov. 14??) to ease pressure on right big toe are working quite well. She scraped toe as usual & put on bandage, also on little left toe (see above); said, put Bactroban on both.
In spite of the presence of severe pain, initially recorded on September 30, 1996, Ruth did not contact Dr. Johnson, a locum physician for Dr. Lawson, until October 04, 1996. Ruth subsequently attempted to re-contact Dr. Johnson on October 07, 1996 when recommended treatment proved ineffective. In an effort to manage pain, Ruth also self-referred to a physiotherapist, Nancy Williamson, a previous service provider. Lacking sufficient medical advice, Ruth subsequently discussed pain management with Nancy Williamson, receiving the opinion that Aspirin use was excessive. By the time Ruth again consulted with Dr. Johnson on October 08, 1996, she had been experiencing severe and unremitting pain for approximately nine days. However, Dr. Johnson’s manner appeared curt and cursory during the telephone consultation. This was apparently due, in part, to the limited or lack of financial reimbursement received for such services.

However, Ruth had more than one health-related concern that required attention. Ruth also required a prescription renewal, a service generally provided during direct patient-physician contact. Ruth also appeared concerned about the possibility of a bone fracture, given the nature of her pain coupled with the presence of osteoporosis. In response, Dr. Johnson agreed to a telephone prescription renewal but appeared impatient with Ruth’s fears regarding a possible fracture. The assumption that Ruth did not have a fracture as she could walk, as stated by Dr. Johnson, appeared precipitous, given Ruth’s extraordinary ability to endure chronic pain. In this regard, a Log excerpt dated October 07, 1996 documented Ruth’s difficulty walking, given the presence of severe pain. In addition, Dr. Johnson’s 24 hour delay in responding to Ruth’s second phone call appeared to convey the indirect message that difficulties with pain management did not warrant immediate medical attention. Likewise, Iaquinta and Larrabee (2004) have noted that dissatisfaction with medical care
included restricted access during times of arthritic flare-ups for those with rheumatoid arthritis. In spite of Dr. Johnson’s apparent perception that Ruth’s behaviour was unreasonable and burdensome, Ruth was, ironically, actively co-managing her care. For example, Ruth self-referred to a physiotherapist, monitored her pain management with analgesics and sought adjustments to her orthopaedic shoes, given apparent foot pain.

Unfortunately, Ruth appeared to receive no direct medical investigation of her pain during the above time period. As noted previously, the presence of stiff and painful joints (see October 1996 excerpt) suggested that Ruth was experiencing a systemic inflammatory flare-up. As such, the diagnosis of bursitis, suggested by the physiotherapist, Nancy Williamson, may have been erroneous or partially inaccurate.

In general, Ruth’s interactions with Dr. Johnson suggested that financially reimbursed medical services were geared towards those who were able bodied enough to attend medical appointments, rather than those who had difficulty accessing services given the presence of severe pain associated with a chronic illness. This finding was consistent with Charmaz (1983) critique of western health care as oriented towards the treatment of acute, rather than chronic illness, leaving individuals with fragmented care while relying on their own resources.

However, Ruth did not view Dr. Johnson’s annoyance as justified, noting, in apparent reaction, that the telephone consultation had lasted 10 minutes, rather than the 20 minutes alleged by Dr. Johnson. A subsequent log excerpt suggested that Ruth spoke to Dr. Lawson regarding her dissatisfaction with Dr. Johnson, an interaction that implied trust within their relationship while indirectly highlighting Dr. Lawson’s generosity in providing telephone consultations.
Valued Activities (including social and familial excerpts)

The selected excerpts below provide examples of the documentation of valued activities, as a research object, within the context of Ruth’s Medical Log.

July 21, 1980

I gave glowing account of my new Tender Tootsies shoes, bot c. April, worn c. 6 hrs on marble floors of Met. Museum in N.Y. without ill effect, etc. – due to soft uppers, no blister on 2\textsuperscript{nd} toe!

May 20, 1982

3:30 pm – saw Dr. McFee in his office…. He said he never talked people into having operations; said nothing drastic was going to occur if I didn’t have one now; but felt something could be done to open hands up further, make them able to do more things, etc. (He examined hands & dictated a few notes to Sec’y.) He had gotten new hand assessment (commented on Arth Cntr efficiency, looking at date!) I told him about my trip to US last Nov as example of ‘getting along OK’

February 5, 1990

EYE appointment (regular checkup) with Dr. Graham ….Gave me new prescription for Distance glasses, since my vision of things a short distance away is getting a bit blurry. (ie: Opera seat, 5\textsuperscript{th} row from front, fgs. on stage a bit blurry!)

October 11-November 6, 1996

(October 25-1c Chesa; Oct. 27-Terfel recital (could hardly get up from chair).

May-June/85

Went on 2-week trip to Greece. Didn’t have much energy, but climbed up Lindos & down thru Plaka, etc. Had a bit of ‘turista’ occasionally.

February 14, 1995

FEET: Dr. Robertson made another adjustment to latex toe sock; I told her I hadn’t worn it much since last appointment – toe mostly bald, since when I put it on again after last apptmt, it hurt a bit (perhaps I didn’t have pad in exactly right position). She taped it on again, and it was fairly comfortable for evening dinner & concert. Toe itself doesn’t look too bad – better than last time.
**December 3, 1996**

-small shopping walk in ... (to ...). Wore new shoes, & for 1st time, heel didn’t hurt (left one) – even occasionally!

**February 24-March 17, 1992**

trip to Chile. Went OK, except for c. 48 hrs of “turista” which meant cancellation of trip to La Serena (N. of Santiago). I did much more walking & climbing than usual, esp. in Chiloe, in old running shoes (very comfy) but bald toes – seemed to work OK.

**October 14, 1997**

FEET. Black shoes did very well in San F.; big right toe has worn Dr. Bridge’s bandage for 3 weeks (since Sept. 25) – he said this is OK, & found toe OK. (wearing bandage may reduce callus buildup).

**December 2002**

Not feeling well. Take fairly frequent Tylenol regular (325 mg, not with codeine); no constipation, but headaches, ear aches, head aches, back of neck stiff, “prickling” feeling at right back of head, itchy, etc. Had to opt out of 2 Yule parties, and was uncomfortable at dinner on Christmas Day (Marion & Lee). Sleeping a lot: hot sweaty spells; very cold-sensitive, esp right ear & neck....

In the above excerpts, Ruth appeared to evaluate her functional ability according to whether or not she could walk on museum floors, see figures clearly during an opera, or be sufficiently comfortable while socializing, attending music-related events and traveling. What appeared essential to Ruth’s appraisal was not the presence or absence of symptoms but whether or not symptoms interfered with valued activities. In other words, the meaning of symptoms appeared more important than their existence. This finding was consistent with research that has linked the onset of depression to the loss of valued activities in response to greater disability (Katz & Yelin, 2001).

It was also noteworthy that Ruth frequently positively evaluated an event, or season, if she was relatively free of “colds” and “flu” or other interfering symptoms, such as
diarrhea. Ruth’s tendency to minimize symptoms, such as diarrhea and cold symptoms in the pursuit of valued activities was also evident in the excerpts below.

**July 9, 1998**

LOOSE BM’s in am – usually only one per day, loose & (ugh) spattery. Aug. 16 – long trip to Seattle for “Tristan”; I took 1 Lomotil after loose early am BM, and was OK. Aug. 17 am – loose BM; 5:30 pm- another. Took 1 Lomotil. Aug. 19 am – 1 loosish BM; c 3pm another (but I took no Lomotil). Aug. 20: 1 loosish BM.

Apart from this, feeling quite well; eating well. July-Aug 1998 – good summer; warm & dry. Aug 7-10 trip to ... went well. No Lomotil req’d, tho still mostly looshish am BM’s.

**September 5-17, 1990**

Trip to Ashland with Eileen Walton – went well. But got small cold on return (when Laytons were here) for c. 1 week.

In addition, Ruth evaluated her symptoms (i.e., infections, flu-like symptoms, diarrhea and pain) within the context of her lived experience. The selected excerpts below document the process through which Ruth created meaning out of her symptoms by referencing her lived experience:

**December 1975**

Trip to Egypt. Picked up Egyptian germs, got quite sick.

**December 20, 1979**

a normal period, preceded by several days of diarrhea (since I was visiting in Florida at this time, I thought the diarrhea was probably due to climatic change or overindulgence in oysters).

**June 22, 1980**

at start of trip to Northern B.C., period started. Normal period, except for slightly nauseated feeling for a day or two (perhaps aggravated by travel by bus on rough roads), and diarrhea for 4 or 5 days.
**July 20, 1980**

another all-too-normal period, almost on time (c. 2 days starting July 28th, right at start of Seattle Opera Tour, Lasted several days (not bad – I didn’t eat much), and then faded away.

**April 11th to May 20th, 1983**

All went well except ‘turista’ in Paris (prob from drinking tap water) & same with nausea in Seville (prob. exhaustion & strange food). Didn’t catch cold, tho.

**August 10, 1990**

Another foot appointment (Dr. Robertson). My feet are much better, she said – “look like different feet”. (For last 2 weeks I have been careful, even on visit to Victoria and another 4 days in Seattle; max walking was thru Russian exhibit & to and fro (in running shoes) in Seattle. I also applied Polysporin ointment liberally, am. & pm, and soaked feet in salt water 15 min each pm. Couldn’t find good way to dry bandages & pads fast after soaking, tho I tried Sareen Dempster’s hair drier). Bandage covers (removable) started to come off, so I added a bandaid or two for added daytime protection; left them off at night. Weather was warm and dry thru period.

**July 23, 1991**

FEET. Left toe OK; right one a “bit nasty”, perhaps because I have been favoring left one? After I fell in … July 5, I couldn’t wear foot sock or ‘bedroll’ on left big toe, due to swollen condition; I left toe bare. Right toe wore toe sock & bedroll when going out. Right ‘nasty’ toe got scraped & had antibiotic powder put on; bandages (crescent moleskin held on with wondertape) were put on both toes – no foot sox or bedrolls. Left bandage can be left on, Dr. R. said; right toe one shd be left on for 2 or 3 days, then take it off & go back to Polysporin ointment & footsock. July 26 eve – I took bandage off right toe. (Jy 24 – wheelchair outing to … - did walking, in heat.) Put footsock & ‘bedroll’ on instead.

**October 7-21, 1994**

I had a cold with sore throat, weakness, strong desire to sleep, etc., which was not helped by my short trip to … ranch Oct 14-15 (cold, rainy). Some watery diarrhea and headache, plus deafness in ears (esp. right one), but weakness was main feature, & slow improvement.
September 20, 1995

FEET: Usual job. Feet are ‘muckier’ than usual (praps due to much walking in past week with Jean Hammer & sister)....

January 5, 1996

PHYSIO again, with Nancy .... I haven’t been doing much with blue rubber stretchy thing, due to Yule rush, as I told her;

May 1, 1996

FEET. Toes OK-have been in income tax mode (not much walking

June 16, 1996

FEET – Usual job, plus a bit of special attention for right big toe, which had had small gooey blister under black spot (too much walking on Community Day?))....

July 25, 1996

FEET:.....Toes were not bad, in spite of ... ... gardn tour last Sat. Bandages put on each.

August 22, 1996

FEET. Dr. Robertson said I have infection with yellow pus on right big toe, tho it doesn’t hurt (& didn’t on walking tour of ... yesterday).

September 11, 1996

EYES. Saw Dr. Graham for annual checkup; (he was more communicative than usual!) He said eyes are in good shape – I don’t need cataract operation yet. Small area of dark color on right eye near nose isn’t serious – just means eye surface there is getting thinner. I also told him about “double” vision effect – if I watch an object (say, door handle) and don’t blink or squint, a 2nd handle appears and moves slowly up and to right of first one, at an angle. He said, this isn’t serious or unusual (apparently just feature of ageing eye). I should see him next Sept.

November 9-24, 1997

Caribbean cruise trip. Feet, in black shoes, behaved well, though on many island excursions I did more walking than usual. Legs got a bit stronger, but
right toe (wearing bandage for whole trip) a bit sore for last few days (a bit of sand & salt water got into bandage Nov.20)

Got rid of cold on trip; slept a lot, ate a lot; coughing diminished.

August 4, 1999

All has been going reasonably well, tho I was tired after return from Railway Assn 5-day tour … (…..) and had arthritic-type ache for several days (off & on) in right foot big toe joint and left wrist; these disappeared after a week or less. (Did a lot of walking, early rising, etc. on trip.)

June 6, 2000

By June 11 (when Landons came from Fla.), after restful week, not walking much, & taking one or 2 extra aspirin each day, I felt better – swelling gone down….

October 5-19, 2000

- two-week trip to Scotland and England. Weather damp and cool – caught cold midway (small one), perhaps on plane Edinburgh to Heathrow. Long transatlantic flights tiring, esp one coming home with cold; “Ear Planes” ear plugs worked well to stop ear pain. Feet had tendency to swell a bit, tho recovered later.

May 24-June 18, 2001

- it has taken a long time to “recover” from trip to …. More arthritic aches, esp. in right arm & shoulder (due to being pulled up into vans?) Very sleepy, little energy, & taking extra aspirin.

In the above excerpts, Ruth linked symptomatic concerns to the weather, diet, ingestion of tap water, the aggravations of travel and exposure to foreign “germs,” seeking etiological explanations through the context of lived experience. This process was likened to Bury’s (2001) definition of the “contingent” narrative, an illness narrative in which “beliefs about the origins of disease, the proximate causes of an illness episode, and the immediate effects of illness on everyday life” (p. 263) were explored.
As evident in the excerpts below, valued activities, within the context of Ruth’s lived experience also provided meaningful markers for monitoring the progress of noteworthy symptoms.

**July 14, 1992**

DIzysty Spells when sitting or changing position have gone completely since my return from Chile – long plane flights with ups & downs evidently cured it!

**January 18, 1993**

Saw Dr. Lawson for annual checkup. No tests this year, or pap smear, (said the latter is now reqd only every 2 years), but he examined me from waist up with stethoscope, took blood pressure, checked for gory moles, examined breasts for lumps, etc. 
I told him (a) I have had a bit of diarrhea lately (he wanted to be sure there is no blood in stools; said, if it goes on and on, let him know) (PS – these “trots” continued until Feb 22, when I left NY for N.J.) 
(b) re pinkish mystery rashes under arm & on stomach (where pant elastic chafes) which I have had now and then since big UK cold last year; I use Polysporin ointment, which clears them up;
(c) head dizziness pretty well gone, since my long plane flight back from Chile;
(d) showed him list of pills I’m taking (dated Jan/93 – see this file)
(e) I told him re regular 3-weekly visits to foot Dr. Robertson in ...;
(f) I asked re procedure in real medic. emergency, if one would occur; he said, call 911, & they will take me to hosp. I ask for (if I’m unconscious, they would cart me to nearest hosp - ....)

**March 18, 1993**

FEET: (I got back from US trip Mon March 15). Usual foot Job with Dr Robertson – she found feet not too bad after trip, in spite of small (‘museum’) blister I got on right toe in NY; Right big toes is not too good, but has been worse; she put bandage on it.

**November 26, 1993**

FEET (before trip to Hong Kong). All OK. Dr. Robertson put bandage with wonertape on right big toe.

**December 23, 1993**

FEET; all OK, after successful trip to HK. Bandages put on both toes. (HK trip went well – only 1 or 2 loosish BM’s
December-January 1994


April 1-8, 1995

trip to Victoria. Trots gone.

May 22, 1997

FEET: (Dr. Bridges)....He did regular foot job, scraped toe, etc. – said all looks well. I told him about trip to Seattle with no bandage or “wondercircle” toe protector on either foot, but shoes were comfortable & feet OK! (Maybe shoes have gotten softer, or some slight change in foot?)....

December 7, 1999

DR. LAWSON- annual exam, 8:30 am. No food since 8:30 pm night before (blood lab people asked me this; Dr. Lawson said exam doesn’t have to be at 8:30, “can be any time” (the his nurse when I made apptnt said it had to be 8 or 830. I told him about daily pills I am taking (see blue list below) I said I still get sleepy fast; in Newf. “falling asleep in mid-sentence!” .... Ears – I’m a bit deaf, esp. in right ear; “Earplanes” (plugs) useful on plane trips to prevent pain. “It’s just old age” – Dr. L....

May 28, 2001

FEET: (Returned from trip to ... to see HJW late Thurs May 24) Dr. Bridges did usual job. Found feet OK, even crack behind left big toe-no oozing. Cut nails, etc – short job. (I wore black shoes with stretchy tops all the time on 2-week trip.)

The excerpts below also suggested that Ruth’s engagement in valued activities was occasionally instrumental in shaping the timing of medical (or health-related) interventions.

May 25, 1995

Dr. Lawson. ....Since I’m going away for weekend (Elizabeth), I will wait a few days before starting these (evidently strong) pills.

October 24, 1997

- saw Dr. Lawson. My cold is just about over, but still feel weak & wobbly, & right ear quite deaf. I told him about my Crib. Cruise Nov. 9-23; my
Synthyroid (100mcG) will run out on last day. (Dr. Lawson gave me a new prescription, which I filled Oct. 25) He doesn’t think any inoculations are necc. for cruise, or any note re my Synthyroid or Didrocal medications. He said, I shd come in for checkup, flu shot, and pneumococcal virus injection after I come back. (Dr. Lawson will be away for US Thanksgiving.)

August 24, 2000

TEETH: Dr. Chan’s office. His aide (dental technician??) Jennifer (?) took Xrays and cleaned teeth. Dr. C. will examine photos - an impacted tooth in eft side of jaw (lower?) may have to be removed (he will call). Total cost $99.00, (for today’s appointment.) I checked back later with girl at desk: she said, there were some small fillings to be done, but like bigger tooth job, can wait until I return from trip to U.K. on Oct. 19/00.

April 10, 2001

Dr. LAWSON. (I asked to see him before trip to US) Got 2 prescriptions for Synthyroid (125 mcg) and Didrocal, which will soon run out. Told him about HJW, Parkinson’s etc. Asked if I could postpone taking white Didrocal pills (which cause some diarrhea) until I return to ... May 24; he said OK – I will take blue (calcium carbonate) while I am away, instead of white ones. I got prescriptions filled same day at ....

Ruth’s lived experience provided the “context of meaning for medical interventions,” a context that provided an appreciation of Ruth’s “values and hopes” as well as “reservoirs of agency and strength” (Barnard, 1985, as cited in Hauerwas, 1990, p. 66). In this regard, an understanding of Ruth’s lived experience provided a framework for the both the feasibility and desirability of medical interventions, a framework that was required for successful application. In retrospect, decision-making regarding the advisability of hand surgery in the 1980’s would have presumably been expedited if Ruth’s values, hopes and reservoirs of agency and strength had been forefront in discussions with consulted medical specialists.

The Medical Log provided a very limited glimpse into Ruth’s extensive social network and engagements. However, Log excerpts clearly identified significant others as sources of practical assistance, such as occasional transportation to medical appointments,
consultation and advice regarding medications (i.e., preferred methods of ingestion, recommended dosages and adverse side effects) and recommendations for referrals to medical specialists and suppliers.

As noted in the excerpt below, Ruth appeared to mitigate the risk of inappropriate advice from significant others through consultation with Dr. Lawson regarding the appropriateness of received recommendations.

January 5, 1998

After pale-brown violent liquid grunt explosion on bathroom floor Mon. am, I phoned Dr. Lawson. (Phoned twice later in day; he didn’t call back until 6:15pm) I told story, & said Joyce Martin had recommended “Prodiem” a bulk-forming laxative; Dr. L said no, that would cause more diarrhea. I asked for Lomotil; he said, it requires a written perscrip. – he can’t phone it in. Said, try Imodium & Kaopectate together. (I told him, Imodium alone has not worked well for me in the past.) Have eaten orange jc only since Sat night.

I’m getting suspicious of the Didrocal white pills I’m taking, tho I didn’t mention them yet; I took the first of the 14 white pills Dec. 22, & last Sun night Jan 4 (c 12 hr before “explosion”). I am to phone Dr. Lawson within 24 hours.

However, as noted in the excerpt below, consultation with others also occasionally resulted in the discovery of a significant oversight by Dr. Lawson:

January 6, 1998

Joan Miles phoned late pm, & looked up my white Didrocal pill in “Can. Compendium of Pharmaceuticals & Specialties”; I am taking Etidronate Disodium USP 400 mg: Compendium says, if you are taking over 5 mg per kg. of body weight, it is too much”.

My weight, c. 115 lbs (about 52 kg)
Dose I am taking: 400 mg daily (for 14 days)
52 kg (my weight) is: 260 mg
(My dose shd not be higher than 260 mg daily; the 400 mg dose is OK for a 175 lb person.)

Had small dinner of cold sliced turkey, rice & broccoli, with a bit of banana and yoghurt, & went to bed.
As noted previously, in spite of an extensive social network, discussions regarding Ruth’s social and familial context were largely absent in conversations with medical professionals. Ironically, the only documented engagement of another individual, by a medical professional, within the Medical Log, occurred when Dr. McFee recommended that Ruth meet with Miss Walton, a post-operative patient, when Ruth was considering similar hand surgery. As noted previously, the general exclusion of Ruth’s social world prevented the identification of a strong network of practical support and potential advocacy.

More than one informant remarked on Ruth’s preference to keep her social circles, for example, family members, opera guild friends and long-term university friends, separate from one another. The main informant, Elizabeth, also remarked that Ruth’s extensive social network only became evident following her death. As such, Ruth’s limited disclosures regarding present (and past) familial and social involvements with medical professionals may have similarly reflected a preference to construct professional relationships as separate from others.

However, the excerpts below suggested that Ruth eventually informed Dr. Lawson about the existence of her brother, Harold (identified as HJW), approximately 1 ½ years prior to her death.

April 10, 2001

Dr. LAWSON. (I asked to see him before trip to US) Got 2 prescriptions for Synthyroid (125 mcg) and Didrocal, which will soon run out. Told him about HJW, Parkinson’s etc. Asked if I could postpone taking white Didrocal pills (which cause some diarrhea) until I return to ... May 24; he said OK – I will take blue (calcium carbonate) while I am away, instead of white ones. I got prescriptions filled same day at ....

The above excerpt does not clearly indicate whether or not Dr. Lawson was made aware of Harold’s chronic mental illness and the stress involved in overseeing his care.
Evidently, Dr. Lawson did not remember or recognize the import of this disclosure given his inability to recall the existence of an immediate family member when interviewed.

According to Log excerpts, Ruth tenaciously persisted in the pursuit of valued activities in spite of a large symptom burden (i.e., constant fatigue, chronic foot pain, chronic intermittent diarrhea and an apparent vulnerability to viral and bacterial infections).

However, in April 2001, Ruth travelled internationally for the last time, reportedly consolidating future care for her brother, who was in a long term care facility. According to Log excerpt below, Ruth returned home both exhausted and in pain.

_May 24-June 18, 2001_

- it has taken a long time to “recover” from trip to …. More arthritic aches, esp in right arm & shoulder (due to being pulled up into vans?) Very sleepy, little energy, & taking extra aspirin.

While Ruth’s health status subsequently improved, she was hospitalized for gastrointestinal bleeding in May-June 2002. Ruth remained in a persistent debilitated state for several months followed by the apparent onset of severe pain in October 2002. The excerpt below suggested that Ruth was no longer able to enjoy social engagements by December 2002, given the presence of severe and unremitting pain:

_December 2002_

Not feeling well. Take fairly frequent Tylenol regular (325 mg, _not_ with codeine); no constipation, but headaches, ear aches, head aches, back of neck stiff, “prickling” feeling at right back of head, itchy, etc. Had to opt out of 2 Yule parties, and was uncomfortable at dinner on Christmas Day (Marion & Lee). Sleeping a lot: hot sweaty spells; very cold-sensitive, esp right ear & neck….

In addition to Ruth’s diminished ability to enjoy life, the excerpt below suggested that social obligations or interactions were viewed as increasingly burdensome given inadequate pain management.
December, 18, 2002 ff:

(All those Yule cards!) Dark, gloomy weather – feeling worse (is this psychology, or weather?) Taking c. 6 to 8 Tylenol Regular (no codeine) per day, with a Ty. Extra Strength” now and then. Quite Weak, very sleepy, esp. after bath or BM; better (as usual) in pm than am. (esp 10 am) Taking occasional lax (Phillips) (1 or 2 chewed pills) esp. after Extra-Strength Tylenol with codeine.

General Medical Care

During a September 1998 medical appointment, Ruth asked Dr. Lawson if he “knew of a good lady GP” for a friend. This request suggested that Ruth typically trusted and valued the medical management provided by Dr. Lawson, a relationship that lasted from 1980 to 2003. According to informants, Ruth typically voiced no dissatisfactions with medical care received, conveying an enjoyment of Dr. Lawson, given a shared love of travel.

Throughout the Medical Log, Ruth frequently consulted with health professionals regarding ways in which she could treat health-related symptoms in a holistic and preventative manner. According to the excerpt below, Ruth spoke to a rheumatologist (associated with the Arthritis Center) about her susceptibility to the “flu” and “colds” having previously consulted a pharmacist and Dr. Lawson.

February 26, 1981

1:00 pm – saw Dr. Weiss. Told him about my dilapidated condition, due to ‘flu, successive colds, etc. Feeling weak, sleepy, hungry etc. A bit stiffer than previously, prob. due to ‘flu. I told him that pharmacist had recommended 3 grams of Vitamin C daily while one has a cold (Dr. Lawson said 1 gram daily all the time – he takes it himself). Dr. Weiss said, a lot of people do this – it might be a good idea. Also vitamins and Halibut Liver Oil pills (which were previously recommended by pharmacist). Told him I will be seeing Dr. McFee at the Arthritis Centre in (exactly) a month, and I saw Dr. Lawson on Monday last….He said rest is good for recovery from colds, etc. (‘your body is trying to tell you something’). I asked him also about riding a bike – he didn’t recommend it. Not a good idea! He also said, Coricidin is good for post-nasal drip, etc. to help dry up sinuses, if necc.
According to the excerpt below (personal correspondence), Ruth subsequently spoke to Dr. Lawson about the advisability of flu shots as a preventative measure three years later.

Jan. 27, 1984

Dear Constance,

It was good to hear your news, though I was sorry to hear about the (ugh) ‘flu smiting you and Jane at such an unpropitious time (or any time at all, for that matter!) How well I remember its awful smite….I have escaped its clutches so far this winter & last due to ‘Flu Shots, which I asked my clever young….doctor if he believed in. Eyeing me carefully, he said, that for people My Age and in My Condition, Yes! (He’s about 32 himself!) This sort of thing does make one feel a bit long in the tooth, but I am delighted with the result, and maybe all the other perks which seem to come these days with increasing age and decrepitude will please me also!

With reference to preventative health measures for gender-related cancers, Ruth received a Pap smear within the first year of Dr. Lawson’s care (in 1980). However, the Medical Log excerpt below suggested that Ruth did not have a pap smear on a yearly basis.

September 28, 1983

Had medic exam appointment with Dr. Lawson (annual) – but he didn’t do anything – even pap smear; doesn’t think it’s necessary now (“You are healthy”.) I will come in later (end of Oct) for ‘flu shot, when they have vaccine ready.

The above excerpt also suggested that Ruth did not have regular breast examinations as part of her annual medical check-up. The Medical Log otherwise first documented a breast examination in 1984, in spite of a professional relationship that started in 1980. The Log excerpt below suggested that the topic of breast self-examination did not surface until 1988, when Ruth initiated discussion with Dr. Lawson regarding mammography screening for breast cancer. As noted in the excerpts below, Ruth appeared both persistent and persuasive in her self-advocacy for such preventative measures.
November 4, 1988

2:40 pm – I saw Dr. Lawson ....I asked him if he believed in mammograms; he said, ‘we do use them, but he thinks best way is self-examination. I said I wondered how good a job I can do with these hands; he thus examined them for me, and found all OK.

November 1989

I phoned Dr. Lawson’s office & asked him, thru nurse, if he thot mammogram would be a good idea for me (had heard on TV about Breast Screening Mammography Program – see pamph. & letter in this file)  He said yes.

January 23, 1991

Saw Dr. Lawson....  He gave me more complete check than usual – stethoscope, pap smear, uterus & ovaries, chest listening, etc etc – “complete physical examination”. Approved of mammogram done last Nov. – “should have it done yearly”.

The apparent marginalization of gender-related preventative health measures within Ruth’s medical care was generally consistent with feminist critiques of the medical system as marginalizing women’s health concerns, with the caveat that treatment also depends on the gender of the practitioner (Lorber, 1997). In particular, Lurie et al. (1993) found that male physicians, particularly in the fields of internal medicine and family practice, were significantly less likely to perform routine pap smears and mammograms in comparison with female physicians.

In spite of advocating for preventative measures, such as a flu shot and a mammogram, Ruth raised these topics from a position of deference, asking Dr. Lawson if he “believed” in such measures. In doing so, Ruth’s sense of agency appeared situated between two contrasting constructions of the patient-physician relationship, as identified by Dixon-Woods (2001), that of an empowered and educated consumer in contrast with that of the deferent inexpert patient in need of education and direction. Ruth appeared to be well
informed yet constrained when making requests, given the implicit power imbalance during medical consultations, as described by ten Have (2002). Likewise, Fair (2003) found that patients with rheumatoid arthritis frequently felt dissatisfied and undermined by the implicit power imbalance, given a desire for partnership as well as ongoing education and support.

Ironically, Ruth apparently had to remind Dr. Lawson that she could not adequately perform his preferred method of breast examination. Dr. Lawson’s biomedical orientation appeared to marginalize awareness of the appropriateness of a preventative measure within the context of Ruth’s lived experience. Likewise, other medical professionals appeared to occasionally recommend treatment without apparent consideration to Ruth’s functional limitations. In the excerpt below, Ruth was apparently unable to apply an antibiotic eye ointment prescribed by her ophthalmologist.

September 26, 1998

I got the above eye prescription from ... Pharmacy ($7.99), who gave me a printout re “antibacterial: Cloramphenicol” antibiotic; name of ointment is “Cloromycetin Ophthalmic Ointment 1%”, to be placed along lower lid (Parke Davis div. of Warner Lambert). Box has warning (it’s obviously stronger than polysporin) (see printout in this file).
I tried it, but perhaps applied too much, clumsily. Eye was not happy – felt much better (& seems to be healing up OK) with hot compresses alone.

Throughout the Medical Log, Ruth also frequently consulted with medical professionals regarding vitamin and mineral supplements (as in the excerpt below with Dr. Weiss, rheumatologist).

June 29, 1982

- telephoned Dr. Weiss to ask if it is OK to try cutting down no. of aspirin taken daily from 8 to just a few; he said OK – can take more if needed. I also told him what pills I now take daily;
  8 aspirin;
  occasional Vit C (500 mg);
  1 Vitamin B compound with C forte;
1 Halibut liver oil;  
1 Calcium Gluconate 650mg (60 mg calcium)  
ocasional Mitrolan for diarrhea!  

He said, OK. (The diarrhea gradually faded away & Mitrolan was discontinued by me.)

However, as evident in the excerpt below, the recommendations that Ruth received were occasionally contradicted when Ruth consulted with more than one health provider:

October 21, 1983

I used to take Calcium Gluconate (650 mg) with halibut liver oil, B compound with C forte (Wampole), and Vitamin C. Should I continue? Dr. Lawson said no, except for Vitamin C, which is good. Calcium not good idea – predisposes one to kidney stones, he said.

While Ruth initially appeared to defer to Dr. Lawson’s regarding the inadvisability of taking calcium, she appeared ambivalent regarding his opinion. In consequence, Ruth persisted in raising the topic with Dr. Lawson, eventually reaching a decision to take calcium supplements based on her own research. Log excerpts that documented patient-physician interactions regarding the advisability of calcium supplements are listed below.

November 20, 1986

Saw Dr. Lawson for annual checkup. Told him re above symptoms. Asked re: shd I take calcium? (Osteoporosis?) He felt not – just drink milk & eat good diet. He thinks negatives re calcium supplements outweigh positives, which are not really proven.
I also asked re: shd I take hormone pills? estrogen? (like Mary with estrogen & progesterone) He thot not – similar answer to above calcium one. unless I have hot flashes or other problems – not a good idea (there are side effects – it may cause more cancer, etc.)
He also didn’t feel I need a diet consultant – ‘eggs aren’t so bad’, he said.
I showed him ‘TO MY FAMILY & PHYSICIAN’ form (‘Living will’, not to be kept alive by artificial means, etc.) and he approved – when I get them signed, he will put one in my file.

November 4, 1988

2:40 pm – I saw Dr. Lawson & was given flu shot (they arrived a bit late this year). I told him about recent stiffness (& wrist decay), and my increase in
aspirin intake to 5 or 6 per 24-hour period; he asked if aspirin upset my stomach, and I said no. I said I felt much better than at this time last year, and loose bowel problem has stopped – everything seems to be normal. He asked about blood or leaks from anywhere, & I said no....I asked him if he believed in mammograms; he said, ‘we do use them’; but he thinks best way is self-examination. I said I wondered how good a job I can do with these hands; he thus examined them for me, and found all OK. I asked re bone densitometer exam, saying I think I’ll be a prime candidate for osteoporosis; he didn’t think necessary (I think they concentrate on younger people) but said – eat high-calcium diet, milk, etc. I asked him if he believed in calcium supplements, and this time he said yes – any kind will do – but ‘if you drink 3 glasses of milk a day, you don’t need them’ (no mention of ‘predisposes to kidney stones’ this time, unlike last time I asked him.) I asked re hormone therapy (‘still controversial??’) and he said, if I were 50 he’d put me on them, abut now it’s too long after menopause....

November 11, 1992

CALCIUM: started taking more Calcium, 2 pills per day instead of one (due to having rather soft, easily cracked or snaggy nails). Pills are ‘natural source; calcium, 500 mg (calcium carbonate 1250 mg)(house standard) from Shoppers Drug Mart.

January 23, 1992

Saw Dr. Lawson for regular checkup. Told him re possible trip to Chile, & he gave advice re things to take & do (take antibiotic; drink bottled water; etc.) Told him past year not bad, ex. for ... fall July 5/91, bad Eng. cold in Oct, followed by rash, etc. Told him I am see foot Dr. Robertson c. every 3 weeks, & had a few sessions with physiotherapist re left foot after ... fall. Told him pills I am taking regularly: usually 2 aspirin (325 mg) (regular) per day, 1 am & 1 pm, after meals; 2 Vit C (500 mg) a big Calcium (500 mg) plus Vit D pill two or three times per week (he approved of all these, & thought no others necessary). (No iron or other vitamins). He inspected my back for gory moles (at my request) & found all OK. I also told him I had seen eye doc (Graham) & all was OK. He gave me pap smear, examined uterus & breast, etc., but no blood tests this year.

c. July 26, 1994

After reading the latest Medic Letters (Calif & Johns Hopkins), I started to take more calcium – 1 pill in am as well as pm (500 mg.)
Approximately eight years after Ruth first raised the advisability of a bone density scan with Dr. Lawson, she joined an osteoporosis study through self-referral, given persistent and astute concerns that she was a “prime candidate for osteoporosis.”

*December 19, 1996*

830 am – checkup with Dr. Lawson….Told him I was participating in osteoporosis study (new machine which scans heel – see ‘Osteoporosis file.’) He prescribed “DIDROCAL” (made by “Procter & Gamble, a non-hormonal bone metabolism regulator; I take 14 days of white tablets (etidronate disodium) and then 76 days of blue tablets (calcium carbonate) – totally 90 days of therapy. I took 1st on Dec. 23 evening (11:30pm) (See booklet with pills, “How to Take the Didrocal Bone Metabolism Regulator”.

Two years later, Ruth’s identification of osteoporosis as a personal risk factor was confirmed by Dr. Lawson.

*December 1, 1998*

ANNUAL CHECKUP with Dr. Lawson, and flu shot. He said my bones were thinning (osteoporosis) & recommended Vit D (“take code liver oil”). I had to remind him that I’m taking Didrocal already.) I told him about normal BM’s – no more turista, (thank goodness). I bot cod liver oil.

Ironically, Dr. Lawson also recommended the use of a fish oil supplement in 1998, a treatment that had been previously recommended by Dr. Weiss (rheumatologist) in 1982 but deemed unnecessary by Dr. Lawson in 1983. In this regard, research has suggested that fish oil may have a beneficial effect in the treatment of pain associated with rheumatoid arthritis (Taibi & Bourguignon, 2003). In addition, Dr. Lawson recommended the use of Vitamin D, a supplement that Ruth had self-initiated in 1992. Ruth also reminded Dr. Lawson of her present treatment regime with Didrocal, a bone metabolism regulator.

According to the Log excerpts below, Ruth informed Dr. Lawson of a free osteoporosis test at a senior’s center, took the test, and subsequently discovered that she was at high risk for osteoporosis given the results of the “heel scanner.”
**August 29, 2001**

Saw Dr. LAWSON, as “Didrocal” will run out soon. He gave me new prescription, which I had filled at ... Pharmacy today. My thyroid pills, “Synthroid” 125 mcg, won’t run out until Nov. 13 – about same time flu shots are ready - but he said I should take blood test today to make sure dose is OK – he will fone me next week. I asked him re publicity re Vit C – he said, of little importance – take one per day, or every 2 days. Osteo test (free) at Sr center is OK – do it. Told him re trip to US (tiring) and right should pbm, which is slowly improving (I didn’t have to have physiotherapy).

**October 4, 2001**

OSTEOPOROSIS test with heel scanner at ... Seniors Centre. I am near bottom of “higher risk scale (2.9; worst is 3)” (See “Osteo” file)

The above excerpts suggest that Ruth had a critical role in the identification and treatment management of osteoporosis, an increased risk factor for those with rheumatoid arthritis (ACR, 2002; Woolf & Pfleger, 2003).

Dr. Lawson’s conservative approach to nutritional supplements was otherwise evident throughout the Medical Log. For example, during the January 23, 1992 appointment, Dr. Lawson viewed iron supplements as unnecessary. However, as evident in the excerpt below, Ruth subsequently consulted with a pharmacist, and added an iron supplement, given “gaps”; as there was an apparent recognition that Ruth was vulnerable to anaemia. Given conflicting advice, Ruth was left in the position of using her own judgement in determining the appropriate action.

**April 1992**

I went to ... pharmacy & spoke to nice young girl pharmacist re vitamins, etc. I told her that I take: .... She suggested I fill in gaps with Stanley Multivitamins & Iron (8 Vitamins, incl: Vit A 1000 iu; B1 3 mg; B2 2.5 mg; Niacinamide 20 mg; Vit B6 1 mg; Vit B12 3 mcg; Vit C 50 mg; Vit D 400 iu; Iron (ferrous fumerate) 4mg.)

In April. I started taking one Stanley Mitavin per day, as supplement to the Vit. C & Calcium (as well as usual aspirin).
Likewise, Dr. Lawson’s reluctance to consider complementary treatments, apart from standard medical investigations, was evident in his medical management of Ruth’s recurrent diarrhea. The selected excerpts below document Ruth’s interactions with Dr. Lawson regarding diarrhea as a health concern.

1985-86 Winter:

I had a flu shot from Dr. Lawson Oct. 29/85 (after I came back from trip to U.S. to see Bertram, etc.) But had almost continuous trouble with colds or mild ’flu from c. Dec. 1 to March 86. Had frequent diarrhea (esp. thru Jan. – took frequent Mitroilan to control it: I phoned Dr. Lawson in early Jan – he said drink fluids and avoid milk products). Gas (esp. from rear, & rumbling interior); pimples, like a teenager; crick at base of right neck; right ear itching & ringing. I began to wonder if my diet is Ok? Episodes of diarrhea gradually became less frequent thru Mar. & Apr. By May, I still seem gassier & pimplier than I used to be, but I have more energy (felt very limp in winter).

October 22, 1987

2:40 pm – saw Dr. Lawson for regular checkup, and ‘flu shot. Told him retros; he decided I should have bowel test at ... Hospital – barium injected into rump and X-rays taken of bowel.

November 13, 1987

2:30 pm: Saw Dr. Lawson, who told me results of bowel test are OK – no indication of cancer. I recited my various symptoms (!). He doesn’t believe in diet consultants, seeing a dietician, etc. I mentioned that, due to trots, I have not taken much milk lately – have cracking, splitting nails, etc. He decided to send me in for (1) blood tests (to see if I am absorbing calcium vitamins, etc. properly) (2) and stool test (’ova and parasite collection kit’).

November 16, 1987

started stool test (see ‘ova & parasite collex. kit’ sheet in this file). Results were OK – no problem. Also on 16th, Dr. Lawson phoned & said blood tests were normal. He said, if my diarrhea gets worse, tell him.

January 12, 1988

2 pm - I saw Dr. Lawson (made appointment last week). I explained my problem, as above – obvious tendency to have diarrhea at slightest excuse; white furry tongue; loss of appetite; gassy, rumbling stomach; weak & exhausted, no energy; sleep a lot; pm naps; tendency to perspire; cold hands & feet; left eye
trouble. I asked, what can I do for myself? In ... at this point, I would see specialist? Dr. Lawson said, all tests have been done which a specialist wd give, like bowel barium test – no cancer. My blood tests were for a lot of other things such as diabetes, liver disease, calcium absorption, etc. (he named several others.) I said, I have not been eating normally for some time – shd I take vitamins? He said, not at this time. He suggested no more Mitrolan – taking a lot for long period might be harmful (I thot this also). Trimethoprim-Sulfa is for travellers’ diarrhea, which is not the same as mine – he will prescribe it for me if I go on trip. He said good balanced diet is best – OK’d food I ate Monday (tea, chic broth with rice, half banana, scrambled egg). I asked, could he suggest good health book for someone my age, or something on digestive system? ‘Off the top of my head, I can’t think of one’ – most are too general, he said.

September 20, 1993

2pm - saw Dr. Lawson; told him summary of log since trots began c. July 11)93, incl. SEPTRA-DS antibiotic from Sep. 9 to Sept. 17, when I stopped taking it due to red specked rash. I mentioned diet book (recc. by foot dr., tho I didn’t say this; also lady author was on ... show Sept. 17 and at health clinic on weekend): “Food & the Gut Reaction” by Elaine Gottschall. (Her basic idea: too many complex carbohydrates such as starches & many kinds of sugar remain undigested in small intestine, creating ideal environment for too many bacteria, causing gas, diarrhea, etc.)

He didn’t seem much interested in diet. Instead prescribed stool test (take samples & return them to lab ... in ... medic. building, ... at ....) I picked up test kit on my way home.

January 12, 1998

Marion drove me down to see Dr. Lawson. He suspects my diarrhea is a reaction to Claxacillin 250mg (prescribed by Dr. Bridges in Dec. for infected foot) tho it was in early Dec. He also prescribed stool test (pickup & return kit at .....), and lomotil 2.5MG tabs, also another antibiotic: 21 Metronidazole 250 MG, which I shd start to take after stool test. I picked up test kit & 2 prescriptions en route home.

June 25, 1998

TROTS – went to see Dr. Lawson, who gave me prescription for more Lomotil, and requested stool test – gave me a sheet to take to lab in .... Pharmacy Bldg. (2nd floor) – apparently to test for colitis.

While Dr. Lawson viewed a referral to a dietician, or other specialist, as unnecessary, he recommended various dietary strategies, such as the avoidance of milk products (see
1985-86 Winter excerpt) and the maintenance of a balanced diet (see January 12, 1988 excerpt), advice which implied that diet was an important consideration in the treatment of diarrhea. Ruth persistently raised the possibility of a referral to a dietician in 1986, 1987 and 1988.

Dr. Lawson’s apparent reluctance to investigate dietary factors sharply contrasted with Ruth’s detailed and meticulous records of her dietary intake during episodes of diarrhea, as evident in the excerpt below.

**September 01, 1993**

*TROTS ongoing. One or 2 Imodium per day. On Aug 31, gassy pains or discomfort after chicken-rice & gravy dinner & Fr onion soup 1 c downtown; had very loose BM ay c. 2 am Sept. 1. Took 2 Imodium. c 10:30 am, another BM (not as loose – small fragments); took a third Imodium.*

Ruth’s investigative mindset towards both documenting and deciphering possible causes for her diarrhea was clearly evident in the excerpt below.

**Xmas-New year 1997**

*TROTS: (started c Dec. 24/97, continued in spite of careful diet, getting very liquid & frequent over night of Feb. 2-3rd. No cold, fever, strange eating, or blood in stools."

HIST: I have had trots on and off since 1981 (deaf ears also, often with cold or ‘flu). Oct./84 – had test with bowel movement kit; analysis “normal”.

Dec. 1/85-May/86 frequent episodes or diarrhea, with colds.
Oct/86; Sept./87 – same again.
Oct29/87: Barium test of bowel at … (Dr. Lawson ordered). Results OK.
Nov. 16/87: Stool test: “ova & parasite collection kit”. Results OK.
(1987-88 winter bad – bylaws year.)
1989-1990 – winter had many colds, but not trots.
Jan-Feb/93 & July-Sept/93 – trots bad; stool test kit again Sept. 21/93.
Mar/95 –recurrence; then OK until now (Dec/97)
In typical research fashion, Ruth also investigated whether nutritional supplements or prescription drugs were contributing towards her diarrhea. As noted below, Ruth consulted with friends throughout this process and made significant discoveries into possible causation.

**September 8, 1993**

Next day – normal BM! (first for ages.)

I looked up pills I am taking at Library (see list in this file, “Medications being taken as of June/93”) in Can. Medic Assn Guide to Drugs (good book). All seems to be OK, though ASA and alcohol both irritate stomach; also, over 1000 mg of Vit. C per day might cause diarrhea. (I am now taking 1,050 mg daily. Joan Miles suggested cutting down a bit – evening one could be 250 mg pill instead of 500mg? This might be a good idea!)

**January 5, 1998**

After pale-brown violent liquid grunt explosion on bathroom floor Mon. am, I phoned Dr. Lawson. (Phoned twice later in day; he didn’t call back until 6:15pm) I told story, & said Joyce Martin had recommended “Prodiem” a bulk-forming laxative; Dr. L said no, that would cause more diarrhea. I asked for Lomotil; he said, it requires a written perscrip. – he can’t phone it in. Said, try Imodium & Kaopecta together. (I told him, imodium alone has not worked well for me in the past.) Have eaten orange jc only since Sat night.

I’m getting suspicious of the Didrocal white pills I’m taking, tho I didn’t mention them yet; I took the first of the 14 white pills Dec. 22, & last Sun night Jan 4 (c 12 hr before “explosion”). I am to phone Dr. Lawson within 24 hours.

**January 6, 1998**

Joan Miles phoned late pm, & looked up my white Didrocal pill in “Can. Compendium of Pharmaceuticals & Specialties”; I am taking Etidronate Disodium USP 400 mg: Compendium says, if you are taking over 5 mg per kg. of body weight, it is too much”.

My weight, c. 115 lbs (about 52 kg)
Dose I am taking: 400 mg daily (for 14 days)
52 kg (my weight) is: 260 mg
(My dose shd not be higher than 260 mg daily; the 400 mg dose is OK for a 175 lb person.)

Had small dinner of cold sliced turkey, rice & broccoli, with a bit of banana and yoghurt, & went to bed.
January 7, 1998

Backache (Tues also)-rightside, sharp twinges when bending over or extending arms (from frequent stooping to clean up mess?) Took 6 aspirin thru Wed. for this (it helped).

3 loose BM’s today (I have eaten little since Sun.) Got Imodium & Kapectate delivered from ... Pharmacy; 1240pm- 2 Imodium (Noodle soup f 1c) 400pm- 1 Imodium & 2 Kapectate.

5pm – Dr. Lawson called. I told him I was not feeling better after all; I mentioned Dirocal white pills (etidronate disodium USP 400 mg)- suspicious timing (Dec. 22-Jan. 4; trots Dec 24 ff (“explosion” Jan.5) & Joan Miles Compendium (see Jan. 6). He suggested cutting pill in half; I said I was now on blue pills (calcium carbonate) He said, too much calcium can cause diarrhea (and apparently Vit C can too.)

Took no Didrocal pill or any other tonight, except 1 aspirin (for back ache) and 1 thyroid pill (Synthyroid).

On one occasion, after a two month period of persistent diarrhea, Ruth self-medicated with an antibiotic previously prescribed for travel in Chile. According to the log excerpt below, Ruth stopped taking the antibiotic after developing a rash following eight days of self-treatment.

September 18, 1993

(Sat) Loosish, but formed BM in am, then very loose BM a bit later. Pink speckle rash still all over body, and red face, but maybe not quite as red as yesterday. Feeling a bit better No antibiotics taken since rash started Sept.17 (I have 3 left). Usual brek of orange juice, egg & toast, a bit of inst. coffee & 1 aspirin.

Looked up “SEPTRA-DS” antibiotic again at Library in Can., Medical Assn. Guide to Prescription Drugs (1990). Septra is a sulfa drug, combination of (1) Sulfamethoxazole and (2) Trimethoprim. For (1) book mentions aching joints & muscles as possible side effects (“call doctor”), and Rash (“stop taking drug”); For (2) rash is described as ‘common’ side effect (“Discuss with doctor in all cases”).

Hugli “natural: vegt soup for lunch.

Supper: weak gin & tonic, turkey breast, scrambled eggs & bacon, half banana. No pills.

According to the Log excerpt below, Ruth subsequently met with Dr. Lawson who ordered a stool test.
2pm - saw Dr. Lawson; told him summary of log since trots began c. July 11)93, incl. SEPTRA-DS antibiotic from Sep. 9 to Sept. 17, when I stopped taking it due to red specked rash. I mentioned diet book (recc. by foot dr., tho I didn’t say this; also lady author was on ... show Sept. 17 and at health clinic on weekend): “Food & the Gut Reaction” by Elaine Gottschall. (Her basic idea: too many complex carbohydrates such as starches & many kinds of sugar remain undigested in small intestine, creating ideal environment for too many bacteria, causing gas, diarrhea, etc.) He didn’t seem much interested in diet. Instead prescribed stool test (take samples & return them to lab ... in ... medic. building, ... at ....) I picked up test kit on my way home.

Even though diarrhea was a persistent and predominant health concern, there was a marked disjunction between Dr. Lawson’s medical assessment that there were no abnormalities based on laboratory findings and Ruth’s persistent experiential distress. During the January 12, 1988 appointment, apparent interpersonal tension existed during the verbal examination, given Ruth’s need to elaborate experience, in contrast with Dr. Lawson’s need to reiterate negative laboratory findings, a physician-patient dynamic that frequently exists during medical consultation (ten Have, 2002). Given limited medical recommendations for coping, Ruth was left in the untenable position of endurance while drawing on personal resources within her lived experience. While Ruth’s intellectual resources fostered a rapid appraisal of the appropriateness of an attempted strategy, such as self-medication, others engaged in such practices could potentially jeopardize the accurate medical assessment and treatment, particularly if such self-medication remained hidden within the professional relationship. Ongoing medical interventions directed towards mitigating symptomatic distress would have likely constrained such self-directed action, given that continued symptoms would have presumably remained topically relevant within the patient-physician
relationship. There were no other examples of self-medication using prescribed medications for purposes other than originally intended within the Medical Log.

Dr. Lawson’s lack of willingness to support a referral to a medical specialist, or dietician, was surprising, particularly given his observation, when interviewed, that deteriorations in Ruth’s physical status over time included an unexplained weight loss that was thought to be due to an inadequate caloric intake. An apparent reliance on standard medical investigations and pharmaceuticals for symptomatic treatment was also evident with other persistent somatic complaints. In the selected excerpts below, Ruth’s difficulties with unexplained dizziness, urinary frequency and fatigue are chronologically documented below.

April 9, 1990

(Jane Goodall lecture) – small eve. sore throat. Small cold developed. Apr. 12 – lunch at ... with Jessica Lord. Apr. 13 (Good Fri) Lost voice; no voice at all over weekend. For next few weeks, was sick, good & proper – throat, nose, ears, chest – much coughing (almost gagging) with balls of rather solid green phlegm, nose blowing, sinuses full, ear ache, etc. (right ear). No diarrhea or vomiting. Cancelled all appointments, just went out for food, etc. Weak & sleeping a lot. Aching bones-taking 6 asp. per day, nsd of 2.

May 5, 1990

another FOOT appointment, this time with Dr. Winer (Dr. Robertson on vacation). He put pads on toes and ball of right foot, using slightly different type pads from those used by Dr. Robertson. May 7 – went down to see George H. downtown; felt awful on return – total exhaustion.

May 10, 1990

Saw Dr. Lawson. He looked at tongue & throat, & prescribed penicillin (take on empty stomach 1 hour before meals; 4 times a day for 7 days- 28 tabs, 300 mg, lasted 1 week.) I got them at ...Pharmacy in ....) Dr. Lawson also said, drink lots of fluids, and inhale thru steam cloth over nose at bedtime.

May 15, 1990

had dizzy spells, when getting up in am. or lying down.
May 16, 1990

Had dizzy spells in laundry room downstairs, fell down (& had trouble getting up!) I phoned Dr. Lawson & asked if this could be side effect from penicillin; he said, he thinks dizziness is part of the infection. “Let me know early next week if you are still having them”. (Movement of head seems to cause dizzy spells—could it be a problem in my funny-feeling right ear, which aches a bit between aspirins?)

May 19-21, 1990

Still having them, tho maybe not as bad. I move carefully.

May 22, 1990

Woke up extremely stiff (every joint, esp. wrists.) Took 6 aspirin, 3 in morning.

May 23, 1990

Phoned Dr. Lawson; I told him I am still having dizzy spells, esp. when sitting up & lying down, but I think not as bad as last week. Have funny feeling still in right ear; in am (before am. aspirin), have slight ache in head and behind right ear; a bit of coughing, but very little phlegm; throat is better (not sore). Lawson said, he thinks it’s just due to ‘flu, nothing serious; no further antibiotix req’d.

May 23-28, 1990

taking more aspirin than usual, about 5 daily (before this ‘flu, I was taking one or two in am. only.)

June 18, 1990

Better, but not 100%; still taking c. 5 aspirin per day, hobbling around stiffly, legs weak; last week or so had partially white, fuzzy tongue and somewhat upset bowel (2 loose BM’s per day, mild cramps). Very little energy (but better than last month), & still take some pm naps – sleep a lot.

July 17, 1990

1:45 pm TEETH appointment with Dr. White; no holes found, just cleaning & X-ray. I mentioned ear problem & dizziness to him (I’m still dizzy when lying down, or sitting up from lying position). He said, it’s lasted rather a long time, & suggested I see family doctor.
July 19, 1990

Saw Dr. Lawson & told him (1) re dizzy right ear. He tested ear with a sort of tuning rod & said it is “Benign…..(?)” and will wear off – not serious. (2) I mentioned my gradual change in bladder habits – I can’t get thru night now without one or two trips to bathroom. As soon as I wake up, have strong urge to go! (No problem during daytime.) I asked, is it premature old age? He said, ‘you’re too young!’ Sent me down to lab, where I did small urine sample (very small) for test.

July 23, 1990

Dr. Lawson phoned and said all is normal with test (no kidney disease, infection, etc.)

June 25, 1991

- eye floater still there....
My bladder problem continues, esp. at night; I wake up once or twice during night, & have urge to urinate fast, esp. when I bend at waist or move; have to get to john fast, even if bladder not full.

January 23, 1991

Saw Dr. Lawson for medical checkup with cholesterol test (9am; have to fast for 12 hours before test – no food after 9pm on previous night – water only).

He gave me more complete check than usual – stethoscope, pap smear, uterus & ovaries, chest listening, etc etc – “complete physical examination”. Approved of mammogram done last Nov. – “should have it done yearly”. I mentioned dry mouth, dizziness wear off, etc. – recent medic. hist. (recent entries above on this log), and lack of energy (sleeping a lot!) He thinks lack of energy is due to rheumatoid arth – not much can be done about it. Asked if my apt, is dry; I said windows are open, but heat may make it dry. Dr. L thinks I’m healthy and doing OK.

July 05, 1991

fell down in ...; nothing broken; top of left foot swollen.

July 14, 1992

DIZZY SPELLS when sitting or changing position have gone completely since my return from Chile – long plane flights with ups & downs evidently cured it!
Dr. Lawson. I made apptmnt. to see him, as thyroid pills will run out on Sept. 5. (I have noticed no change in symptoms, sleepiness, etc. since I started them in May). I also mentioned my ear test (see Aug 2 above) and also my mild bladder problems; said I was trying Kegel exercises to help bladder problems. He approved. Did not need copy of ear test, but said - the same thing as ear test man said – arthritis can affect 3 small bones in middle ear which are important in hearing process.

As was the case with the medical management of Ruth’s diarrhea, the above excerpts demonstrated the contrast between Dr. Lawson’s medical explanations and the impact of Ruth’s symptoms on her lived experience. For example, according to Dr. Lawson, Ruth’s dizziness was “part of the infection”; “just due to the ‘flu, nothing serious”; and “benign …. (?)”. Likewise, Ruth’s bladder function was assessed to be “normal,” based on standard laboratory tests. In addition, fatigue was attributed to rheumatoid arthritis with the understanding that “not much can be done about it.” As with symptomatic complaints of diarrhea, Dr. Lawson appeared to implicitly convey the message that symptoms, such as dizziness, bladder urgency and fatigue, were to be otherwise endured and self-managed. This finding was consistent with Charmaz’s (1983) critique of western medicine as designed predominantly for acute care, leaving those with chronic illness with inadequate information and while contending with symptoms in relative isolation. In particular, Ruth’s experience appeared to be consistent with critiques of the medical system as lacking with reference to holistic care in the treatment rheumatoid arthritis (Fair, 2003; Iaquinta, Larrabee, 2004; Shaul, 1995).

As was consistent with research by Fair (2003), disparate explanations of the meaning of Ruth’s symptoms appeared to influence the type and effectiveness of clinical interventions. Unfortunately, symptoms that were deemed to be of limited medical concern
created considerable difficulties on Ruth’s ability to function. For example, Ruth experienced dizzy spells when getting up in the morning or when lying down when symptoms were most acute. Dizziness also contributed towards Ruth’s fall in the laundry room, an event that preceded an episode of extreme morning stiffness, signaling the possible exacerbation of an underlying inflammatory process.

In apparent reaction to limited medical recommendations, Ruth subsequently raised concerns regarding dizziness with her dentist. Following Dr. White’s advice, Ruth again raised symptomatic dizziness with Dr. Lawson, who appeared to normalize her concerns. The July 14, 1992 excerpt suggested that Ruth endured residual dizziness for two years, after which she documented a spontaneous resolution of symptoms following air travel.

Likewise, Dr. Lawson responded to Ruth’s report of urinary urgency through standard medical investigations with subsequent findings of normality. Once again, Ruth was apparently left in the position of endurance, in spite of symptoms that were both distressing and presumably predisposed her to a fall, given the assumed need for rapid access to washroom facilities. While Ruth first raised concerns regarding urgency in 1990, Dr. Lawson’s normalizing response, based on laboratory findings, appeared to have a silencing effect in that Ruth did not apparently disclose persistent difficulties until 1995. At that time, Ruth informed Dr. Lawson that she was using Kegel exercises, presumably to strengthen her pelvic floor, to deal with residual symptoms of urinary urgency.

The need for coping strategies to deal with recurrent diarrhea, dizziness and bladder urgency was particularly significant for Ruth given her susceptibility to falling. Woolf and Pfleger (2003) have cited numerous risk factors for the elderly, including general deterioration, balance, gait and mobility problems, visual impairment, as well as extraneous
hazards, factors that were also relevant for Ruth. In addition, osteoporosis, an evident health concern for Ruth, posed a risk factor for fractures in the event of such falls (ACR, 2002; Woolf & Pfleger, 2003). Ross et al. (1990) also found that rheumatoid arthritis was the only chronic illness (other than diabetes, myocardial infarction, stroke and cancer) that was a significant predictor of accidental death in a retirement community, a finding that underlined Ruth’s vulnerability.

There appeared to be a direct association between Ruth’s physical status and four of the six falls documented in the Medical Log. For example, a 1990 fall was associated with dizziness; a 2000 fall was associated with increased foot pain, lessened walking and a presumed decrease in lower extremity strength; a 2002 fall was associated with a debilitated state following treatment for a episode of gastro-intestinal bleeding; and a 2003 fall was associated with a debilitated state coupled with severe and unremitting pain. According to a neighbour, Ruth was frequently falling in her apartment towards the end of her life in 2003.

Dr. Lawson typical non-intervention regarding recurrent complaints of symptomatic fatigue (see January 23, 1991 excerpt) was also consistent with research that has singled out fatigue as a prevalent yet ignored health concern for those with rheumatoid arthritis. (Hewlett et al., 2005). Dr. Lawson’s reported appraisal that Ruth was ‘healthy” and “doing OK,” may have been meant as reassurance, but may also have inadvertently suggested that Ruth’s concerns of fatigue were unwarranted. Bury (1991) has similarly noted that those with chronic illness have difficulties experiencing a sense of legitimization when definitions of the significance of symptoms contrasts with those of the health provider. Shaul (1995), in particular, has noted that the dismissal of symptoms by a physician has a devaluing effect on both the report and the individual patient with rheumatoid arthritis. In general, Ruth found
that medical knowledge was limited and ambiguous in regards to advice for symptom management, a finding that was consistent with research by Bury (1982).

However, according to Dr. J. Cibere (personal communication, August 22, 2006), fatigue may be symptomatic of an underlying inflammatory process or may be related to fibromyalgia (or chronic soft tissue pain) that can accompany rheumatoid arthritis and exert an independent effect. Fatigue was also noted by Dr. J. Cibere to be multi-determined, with potential contributing factors that included poor sleep, pain, depression, and stress. If the disease was controlled, Dr. J. Cibere typically looked to other factors, such as stress and other psychological factors as determinants. As noted previously, Dr. J. Cibere also identified DMARD’s as potentially beneficial in reducing symptoms of fatigue and stiffness, a pharmaceutical benefit that was unavailable to Ruth. Dr. J. Cibere’s observations suggested that Ruth’s disclosures of fatigue warranted additional medical investigation.

Ironically, in spite of a large symptom burden (such as chronic biomechanical foot pain, arthritic pain, intermittent diarrhea, chronic fatigue and functional limitations from deformities) Ruth noted within the April 9, 1990 excerpt that she “was sick, good & proper,” when she developed an upper respiratory infection. In this regard, Ruth’s subjective appraisal suggested that acute symptoms, created by an infectious agent, were regarded as more valid than chronic symptoms, that were frequently managed rather than cured. This finding suggested that the biomedical orientation, as geared towards acute, rather than chronic care (Charmaz, 1983) had an impact on Ruth’s subjectivity in relation to the perceived legitimacy of her health-related concerns.

In spite of this, Ruth generally addressed health-related concerns with Dr. Lawson with apparent self-confidence. However, there was a Log excerpt that suggested that Dr.
Lawson’s dismissal of fatigue, as not amenable to intervention, had a detrimental effect on Ruth’s self-perception. In this regard, Ruth again raised symptomatic fatigue during an annual check-up in 1995, but, as noted in the excerpt below, viewed herself as whining, rather than forwarding a valid health concern.

May 19, 1995

Saw Dr. Lawson for annual checkup. I showed him small skin rashes on hips (from pant elastic?), said I was putting Vaseline on them – he said OK. Also whined about itchy anus area – said I was treating it with Bactroban goo (same as feet). He approved. I asked re Estrogen – if I started it now, would it do any good, or is it too late? He thinks it’s too late – wouldn’t make any diff. now. I whined a bit about lack of energy, & he sent me for blood test at lab on 2nd floor, & he will fone me with results.

Ironically, as noted in the excerpt below, Ruth was subsequently diagnosed with hypothyroidism, a treatable condition that was presumably compounding symptomatic fatigue associated with rheumatoid arthritis.

May 25, 1995

Saw Dr. Lawson again- he sent for me to tell me about result of blood test, which showed him that I have a thyroid problem. My thyroid is not producing enuf of its hormone, so I must take pills for rest of my life, as per his prescription, which I took to ... Pharmacy in .... Young E. Indian (?) gentleman there gave me 100 ELTROXIN 50MCG L-THYROXINE (cost: $7.59); he told me that, if I have any funny side-effects (getting hyper, or change in sleep or appetite, change in normal behaviour, etc) I shd get back to Dr. Lawson – perhaps dose shd be changed. Since I’m going away for weekend (Elizabeth), I will wait a few days before starting these (evidently strong) pills.

There were additional Log entries that suggested an association with self-deprecation and the minimization of persistent symptomatic concerns by health professionals. In the excerpt below, Ruth raised fatigue as a pervasive concern, but again viewed herself as whining.
March 5, 2002

Dr. LAWSON: (12:30 pm-waited until 1pm) Annual Exam. I said I had not had a bad winter – no cold or ‘flu- but had odd reaction to my ‘flu shot (see Dec/01 notes), and whined about slowing down & getting older, need for much rest & sleep (he thot due to my arthritis) gassy fore and aft (too much tonic water? He said no, it does you good) Sore right ear with headache, esp. when I’m tired, neck click when head turned (but not always) little muscle ‘bump’ on right upper leg (not important). Did he say a few mo. ago I am ‘borderline diabetes? He thinks no. He checked back – none moles; skin OK. I shoed him Income Tax Disability form which he filled in last Nov., and he added “SLOW” to description (I will send it in with photos.

I went down for various blood tests; he will phone results.

During the above encounter, Ruth apparently raised a question regarding the effect of her alcohol intake. As with Ruth’s fatigue, the topic was apparently normalized by Dr. Lawson, rather than explored in depth. Likewise, Ruth’s query regarding borderline diabetes was dismissed, in spite of a 1999 log excerpt that identified borderline diabetes as a potential health concern based on laboratory findings. Subsequent laboratory investigations presumably confirmed Dr. Lawson’s impression.

Unfortunately, unexplained gastric symptoms continued to be problematic for Ruth. As was evident symptoms of fatigue, diarrhea, and dizziness, Ruth consulted with two other health professionals, apparently in response to limited recommendations by Dr. Lawson regarding coping strategies (see excerpt below).

Month of April 2002

- Not feeling well, no energy & Indigestion- lots of Gas! on advice of 2 pharmacists, I bot “GAS-X Extra Strong” tablets, about 11 over a few days – very helpful. (It’s Income Tax season!)

  Tried cutting down on aspirin Apr. 15-30 (instead of usual 1 full 325 mg asp. in am. after brek, and 1 in eve after dnr, took ½ a pill only.) This didn’t help, & left toes got swollen & stiff, so went back to usual full pills May 1 (am & pm).
In addition, the above excerpt suggested that Ruth questioned the role of Aspirin in her gastric symptoms, a hypothesis that later proved significant. Ruth was subsequently hospitalized for gastro-intestinal bleeding in June 2002, a potential adverse reaction associated with prolonged use of Aspirin. Following this medical crisis, Ruth was not able to use Aspirin for pain control, a possible factor in Ruth’s inability to manage end-of-life pain, given the previous benefit received.

During the above March 05, 2002 appointment with Dr. Lawson, Ruth’s disclosure of ear and head pain was also deemed to be “not important.” In retrospect, these reported symptoms appeared to herald the arrival of pain that was to become experientially unbearable. As documented in the excerpt below, Dr. Lawson apparently persisted in the minimization of Ruth’s pain even when Ruth’s pain was apparently severe.

**October 08, 2002**

*Saw Dr. Lawson in office; he thinks it's just arthritis (not rheumatoid); warned me re codeine & constipation; doesn't think physiotherapist or acupuncture will help. (Oct. 10 was date of my very bad constipation). Got “Sennosides” laxative pills, & took 2 after dinner, which cleared me out twice Oct. 11.*

According to the October 08, 2002 excerpt, Dr. Lawson dissuaded Ruth from considering acupuncture or physiotherapy for pain management in the months prior to her death. The latter recommendation was surprising given that Ruth had previously received symptomatic relief through physiotherapy in the past. According to Dr. Bridges, other complementary treatments, such as occupational therapy, might have offered Ruth symptomatic relief through structural support, such as a neck brace. Both physiotherapy and occupational therapy are recognized as standard adjunct treatments for rheumatoid arthritis (ACR, 2002).
Elizabeth (the main informant) wondered if the outcome of Ruth’s pain management would have been different if Dr. Lawson had treated Ruth as a co-researcher in the comprehension of her body. Ruth’s relationship with Dr. Lawson was contrasted with Ruth’s stockbroker (and portfolio advisor) in that the latter voiced a deep appreciation for Ruth’s investigative spirit, noting that Ruth frequently had more up-to-date knowledge on the stock market than he could offer. However, Dr. Lawson’s lack of endorsement of acupuncture for pain management was also consistent with the lack of empirical validation reported for its use with rheumatoid arthritis (Casimiro et al., 2005). Such advice by Dr. Lawson may have protected Ruth from being bound to the “endlessly turning wheel of the endlessly failing ‘cure’,” (p. 92) as articulated by Grace Stuart (1953). Likewise, Dr. J. Cibere (personal communication, August 22, 2006) indicated that herbal remedies may be beneficial for symptomatic relief but were not recommended given the lack of research-based efficacy. Unfortunately, the lack of research poses significant risks for those with rheumatoid arthritis given that commonly used supplements, such as Melatonin and Echinacea have potentially adverse effects on an impaired immune system (Taibi & Bourguignon, 2003).

However, the Medical Log suggested that Ruth sought greater dialogue regarding the possible use of complementary (such as a dietary consultation) and alternative therapies (such as herbal and nutritional supplements) with her attending physician. According to Fair (2003) such conversations are typically marginalized by health care providers, even when those with rheumatoid arthritis have expressed a direct interest.

In apparent consequence to the limited dialogue regarding strategies for symptom management, Ruth sought recommendations from other professionals. For example, in the excerpt below, Ruth apparently discussed symptomatic fatigue with her podiatrist.
May 30, 1995

FEET. I told her re Thyroid thing (see above). She recommended “Ginsamax” as good brand of ginseng for energy (her mother likes it).

Ruth’s podiatrist had previously indicated an interest in alternative treatments given a recommendation in 1992 that Ruth consider alfalfa pills in preparation for overseas travel, an apparent preventative measure given Ruth’s recurrent “tourista”. Likewise, Ruth’s podiatrist had recommended a “diet book” (see excerpt September 20, 1993) apparently in response to Ruth’s reported gastro-intestinal concerns.

According to the September 20, 1993 excerpt, Ruth informed Dr. Lawson of the diet book under consideration but did not identify her podiatrist as the source. Ruth’s partial disclosure suggested that she feared “professional umbrage” from a differing second opinion as to the relevance of dietary considerations, as was the case when Ruth sought a second opinion regarding proposed hand surgery. As such, a perceived lack of partnership occasionally led Ruth to acting on her own behalf outside of professional awareness, a lost opportunity for authentic engagement with a woman of considerable intellect. Likewise, Fair (2003) found that professional influence was diminished following patient dissatisfactions with partnership, education and support within the physician-patient relationship, with rheumatoid arthritis patients seeking referrals, stopping prescribed medications or completely withdrawing from traditional treatments. While the unreported use of herbal supplements can create additional health risks for those with rheumatoid arthritis, given possible contraindications with prescribed treatments (Taibi & Bourguignon, 2003), there was no evidence that Ruth used the herbal supplements, as recommended by her podiatrist or otherwise.
As noted previously, Ruth viewed herself as “whining” when raising symptomatic fatigue, following Dr. Lawson’s determination that “nothing could be done” (see January 23, 1991; May 19, 1995; March 5, 2002 excerpts). Likewise, Ruth described herself as complaining when she raised symptomatic pain (that was evidently severe and incapacitating) subsequent to Dr. Lawson’s determination that reported head-related pain was not a problem (see March 5, 2002 excerpt) and that increased pain was “just arthritis” (see October 08, 2002) as evident in the below interactions with Dr. Cook, a locum physician or Dr. Lawson.

**January 08, 2003**

Went to Dr. Lawson’s office: found his replacement Dr. Cook (until the end of April). (Tel. same as Lawson: .....) I complained about various symptoms (see Dec/02 above), esp. right ear (sore & deaf), right side of head & neck; can’t raise head when walking or upright. Is itching due to pss. Tylenol allergy? Dr. Cook doubts this. Should I go back to aspirin for a week or so? He thinks not – might cause bleeding (suspected last summer). He sent me down to Lab. in .... Bldg. for another blood test, also for an X-ray (in adjoining bldg.) Jan. 16 or 17- Lawson office phone me & said Dr. Cook told them results of blood & X-ray were ‘normal’.

I asked him for referral to Dr. Joan Knowles (see Jan 6 above), & gave him info, billing no., etc.

As with Dr. Lawson, Dr. Cook’s medical management was apparently limited to standard medical investigations, as in laboratory results and an x-ray. Likewise, Ruth was informed that investigations were ‘normal,” a stark contrast to her lived reality and growing desperation.

**End of Life Decisions**

The Medical Log contained frequent references to ongoing losses related to physical deterioration, such as overwhelming fatigue, progressive deformities, and, in the later years of her life, a diminished ability to enjoy valued activities, such as travel, coupled with
increased pain that was intermittent and, finally, unremitting. However, there were no documented conversations with primary health providers pertaining to the need for long term planning, particularly with reference to assisted or residential living with increased dependency. Irregardless, Ruth had investigated residential care facilities in the community on behalf of someone else. Offers of home-based assistance were also refused by Ruth during a hospitalization in May-June 2002. Ruth’s preparations for future mental and physical incapacity appeared restricted to the actions described below:

**November 20, 1986**

Saw Dr. Lawson for annual checkup....

I showed him ‘TO MY FAMILY & PHYSICIAN’ form (‘Living will’, not to be kept alive by artificial means, etc.) and he approved – when I get them signed, he will put one in my file.

**January 18, 1993**

Saw Dr. Lawson for annual checkup....
I asked re procedure in real medic. emergency, if one would occur; he said, call 911, & they will take me to hosp. I ask for (if I’m unconscious, they would cart me to nearest hosp – ....)

**September 12, 1997**

Saw Dr. Lawson re Living Will (from “Dying with Dignity” in ... - see my file in “Wood” paper filing cabinet). He agreed with its terms and signed it; witness was girl in his office. I also signed it (see original in file).

**December 7, 1999**

DR. LAWSON – annual exam....
Living Will which he signed Sept. 1997; I made new Will in July/99. Did I give Dr. Lawson names & tel nos. of my cousin, new lawyer and Executor (T-D Trust Co.) for his file? He said no. I should send these.

**September 20, 2000**

Saw Dr. Lawson; told him I am going on trip to Scotland & England Oct. 5 to 19/00, and gave him updated list of addresses (my lawyer, Trust Co.etc.) with cousin Elizabeth’s new address & tel. no.
September 9, 2002

Forgot to tell Dr. Lawson re new Representation Agreement Sep.5. I phoned him & told him about the one I signed recently “for health and personal care”, my cousin Elizabeth Morris to be representative. I said Elizabeth would send him a letter, with Elizabeth’s new address (as of end of Aug.)

Ruth’s Living Will was apparently fashioned from information received from the Die with Dignity Society, of which Ruth had been a member in the 10 years preceding her death. Otherwise, Ruth did not reportedly disclose any thoughts or intentions of suicide to health professionals in spite of contact with a family physician, a podiatrist and a rheumatologist within the month preceding her death. In this regard, Ruth was presumably aware of the legal ramifications of involving a health professional in her decision.

However, disclosure of an overwhelming state of hopelessness may have not prevented Ruth’s resolve to commit suicide. As noted by Hauerwas (1990), “the physician may be able to help the patient cope with her pain, but if the patient lacks any substantive narrative, the physician cannot provide a meaning for ineliminable pain” (p. 125).

Psychological References

Within the Medical Log, explicit psychological references were typically absent, both in regard to interactions with medical professionals and general self-reflection. However, Ruth’s emotional state may be implied throughout numerous Log excerpts, albeit in a speculative fashion. For example, Ruth’s occasional use of exclamation marks appeared to signal the indirect expression of an emotional state. While analysis was not exhaustive, speculated emotional states may be implied within various Log excerpts in the following manner.
Satisfaction with medical professionals on intake:

**c. April 26 or 27, 1980**

He’s another ... grad! Gave me a good eye exam, prescribed “Blephamide”, & I got it filled at pharmacy in same bldg.

**Feb. 12, 1980**

3pm – saw my first actual Dr. Charles Lawson (recommended by Dr. Woodward) ....Office:.... just opposite .... Hospital. Tel: .... (day & nite). Paid $12.50, got receipt. He is a young ... grad (not long in practise, said Woodward’s nurse). – looks good.

**April 23, 1980**

2 pm: Saw Dr. Weiss (3rd floor, ... Bldg. adjoining .... Hospital). He is a nice youngish man (in late 30’s or 40’s?) and we had a very good interview & examination.

**c. April 26 or 27, 1980**

He’s another ... grad! Gave me a good eye exam, prescribed “Blephamide”, & I got it filled at pharmacy in same bldg.

Amusement with treatment recommendations and impressions of health professional:

**July 19, 1990**

Saw Dr. Lawson .... I mentioned my gradual change in bladder habits – I can’t get thru night now without one or two trips to bathroom. As soon as I wake up, have strong urge to go! (No problem during daytime.) I asked, is it premature old age? He said, ‘you’re too young!’

**July 27, 1990**

She put on a bandage on each toe with lift-off brown tape for bathing, etc. Getting it dry is important – sjj hair blower-drier or space heater!

**September 11, 1996**

EYES. Saw Dr. Graham for annual checkup; (he was more communicative than usual!)
Enthusiasm regarding treatment recommendations/advice:

April 23, 1980

Dr. Weiss said swimming is OK (I told him re plan to swim!) and has a mild exercise program in mind!

February 26, 1981

1:00 pm – saw Dr. Weiss. Told him about my dilapidated condition, due to ‘flu, successive colds, etc. Feeling weak, sleepy, hungry etc. A bit stiffer than previously, prob. due to ‘flu. I told him that pharmacist had recommended 3 grams of Vitamin C daily while one has a cold (Dr. Lawson said 1 gram daily all the time – he takes it himself). Dr. Weiss said, a lot of people do this – it might be a good idea. Also vitamins and Halibut Liver Oil pills (which were previously recommended by pharmacist). Told him I will be seeing Dr. McFee at the Arthritis Centre in (exactly) a month, and I saw Dr. Lawson on Monday last….He said rest is good for recovery from colds, etc. (‘your body is trying to tell you something’). I asked him also about riding a bike – he didn’t recommend it. Not a good idea!

He also said, Coricidin is good for post-nasal drip, etc. to help dry up sinuses, if necc.

March 25, 1982

I told her that Dr. Weiss feels my legs could use some exercises (I agree!)

September 8, 1993

Next day – normal BM! (first for ages.)
I looked up pills I am taking at Library (see list in this file, “Medications being taken as of June/93”) in Can. Medic Assn Guide to Drugs (good book). All seems to be OK, though ASA and alcohol both irritate stomach; also, over 1000 mg of Vit. C per day might cause diarrhea. (I am now taking 1,050 mg daily. Joan Miles suggested cutting down a bit – evening one could be 250 mg pill instead of 500mg? This might be a good idea!)

Ambivalence regarding surgery:

December 1972

Had hand X-rays done & saw Dr. Brown. He said, change in hands since last year “barely perceptible”.

Some joints (i.e., base of little finger on right hand) are “sub-lex”. He suggested physical implants, to be done by Dr. Lapierre. (I stalled on this, as
hands had been doing well & did not hurt.) He looked at feet. It was agreed to put off hand operation.

Anxiety regarding surgical decision-making process:

**November 18, 1981**

*NB in …. – saw Dr. Wolfe (I arranged this by telephone in advance). I told him that Dr. McFee is willing to operate, but wants me to say when I want operation (I don’t feel qualified to judge when it should be done.) Dr. Wolfe looked at my right hand (didn’t examine it closely), and said, it is worse than when I saw it last – suggested that ‘something be done about it soon’.*

*Interview was brief and friendly.*

**May 20, 1982**

3:30 pm – saw Dr. McFee in his office. *(This was much better, I thought, than at Combined Clinic – more time, & fewer people around.) I said, I would love to find out & would like to ask him if there was some solid medical reason why something should be done with hands this year, or if I could safely postpone until next year or future. *(Said, if something should be done soon, I’m quite happy to have it done, but otherwise feel I am getting along quite well, and if nothing drastic is impending, would postpone it further – but don’t want to postpone to the point of foolishness).*

*I also mentioned idea of time on my side (?) – getting benefit of new research!*

*He said he never talked people into having operations; said nothing drastic was going to occur if I didn’t have one now; but felt something could be done to open hands up further, make them able to do more things, etc. *(He examined hands & dictated a few notes to Sec’y.) He had gotten new hand assessment (commented on Arth Cntr efficiency, looking at date!) I told him about my trip to US last Nov as example of ‘getting along OK’.*

*He said that he would like me to meet a Miss Walton, one of his post-operative hand patients, now staying at the …Inn (nr Arth. Center). *(This is the lady who was written up in the Feb issue of …Hosp. magazine…on Orthopaedics (the same one I had my hand photo in). He gave me note: “I would like Miss Williams to meet Miss Walton who is post-op hand surg. Please check with Miss Walton first”. *(signed Dr. W.M. McFee, May 20, 1982). I took this note to “Martha” at front desk of Arth Cntr, and will also show it to Francis Henry (O.T.) when I see her for follow-up appointment on Wednesday May 26 (1 pm)*


Surprise at estimated dental costs, with dread of treatment:

November 5, 1980

I have 6 fillings to be done, at estimated cost of $202.00! Need 2 appointments of ¾ hr ea. and one of half an hour (Horrid thot). I said OK.

Impatience with service delivery:

March 25, 1982

Arthritis Centre finally called – had space for appointment with physiotherapist “Rose” for a reassessment, 1245 pm Fri. March 26/82. Rose is a very nice, older Swiss lady – I told her a bit about my case, we chatted about the possibility of a hand operation, etc. I told her that Dr. Weiss feels my legs could use some exercises (I agree!)

May 11, 1982

Arthritis Center at last called re appointment for hand assessment. May 19, 1982 – hand assessment was done by Francis Henry (nice young Irish girl). She got it done just in time for my apptment with surgeon, Dr. McFee, on May 20 (had made this apptment on April 16)

October 8, 1996

Dr. Johnson called back. I told her the above, & why I couldn’t get down to see her. She said 222’s (no prescription req’d) might be better than aspirin. I mentioned thyroid pills – she told me to phone... pharmacy; they will phone doc., who will OK them & pharmacy will send them to me (they did, 6pm Wed. 9th) I mentioned osteoporosis test (I have weak bones). She said, if I can walk on it, it isn’t a fracture.

She was annoyed by my 10-min phone consultation. “If you’re going to talk for 20 min, you might at least come into office and at least I’d get paid”.

January 5, 1998

After pale-brown violent liquid grunt explosion on bathroom floor Mon. am, I phoned Dr. Lawson. (Phoned twice later in day; he didn’t call back until 6:15pm)

December 7, 1999

DR.LAWSON – annual exam, 8:30 am. No food since 8:30 pm night before (blood lab people asked me this; Dr. Lawson said exam doesn’t have to be at
8:30, “can be any time” (tho his nurse when I made apptmt said it had to be 8 or 8:30.

Pride in self-management:

**June 16, 1980**

Ankles are OK, but feet..! She wondered how I walk on them (I once again mentioned Tender Tootsies and Metropolitan Museum!) and if I have a lot of resistance to pain.

**July 11, 1980**

1 pm appointment at Arthritis Clinic, occupation therapy dep’t., for Hand Assessment. Nice young German (?) occupation therapist, (Heidi Schultz), and another girl (assistant?) spent about 1 hour and a half doing outlines of my hands in various positions, measuring fingers here & there, and giving me various little tests of things to do with hands, such as turning keys, opening doors, cutting ‘meat’, picking up coins, pouring water from measuring cups into bowls, lifting various weights with luggage-type handle, etc. – assorted everyday-type skills. I showed them my Swiss jar opener and screwdriver, and answered various questions about how I do things (incl. writing - my writing ability has declined noticeably in past year, I have problem controlling my signature at bank, etc. – use typewriter a lot, with 2-finger method). The examined hands and the way they do things thoroughly, made notes, etc.

She would like to see my ‘joint log’ (and I also might bring them pliers I use next time – my idea.)

**July 21, 1980**

I gave glowing account of my new Tender Tootsies shoes, bot c. April, worn c. 6 hrs on marble floors of Met. Museum in N.Y. without ill effect, etc. – due to soft uppers, no blister on 2nd toe!

**Winter ’84-’85**

I bot sheepskin for bed, under bottom sheet, & removed mohair. Sheepskin helps somewhat – a bit lumpy, but softer. Winter was OK without any bad ‘flu or cold; occasional ‘turista’ (loose bowel movements) for no apparent reason, but no fever, etc. I try to do gentle exercises every night, & swim once a week (more or less) at warm pool at ... Hospital on .... Have little energy, get stiff easily & seem to require a lot of sleep & rest. Stiff knees – going up & down stairs not easy.
Oozing right ear problem is now OK – it responded well to Polysporin ointment (‘sterile Ophthalmic’) which I got awhile back for small eyelid infection. (Self-medication!)

Disappointment with treatment results:

**October 1972**

Had some physiotherapy sessions at Dr. Brown’s office (exercise, heat, etc.) Felt good, but didn’t seem to make much change. Hand had been feeling well, no pain, working well, etc.

**June 13, 1980**

2:00 pm – my second physiotherapy session with Joan at Clinic. (Arth. Centre). I gave her a copy of my Joint Log, also showed her exercise program man in ...had done for me 2 years ago. She completed my hand assessment (separate one for each hand) – angles of each finger, joint facility, web width, etc! Thot hands not in good shape – she probably can’t do much for me with exercises etc.

Relief regarding symptom significance:

**September 11, 1996**

EYES. Saw Dr. Graham for annual checkup; (he was more communicative than usual!) He said eyes are in good shape – I don’t need cataract operation yet. Small area of dark color on right eye near nose isn’t serious – just means eye surface there is getting thinner. I also told him about “double” vision effect – if I watch an object (say, door handle) and don’t blink or squint, a 2\textsuperscript{nd} handle appears and moves slowly up and to right of first one, at an angle. He said, this isn’t serious or unusual (apparently just feature of ageing eye). I should see him next Sept.

Exasperation with symptoms and dissatisfaction with medical advice:

**January 12, 1988**

2 pm - I saw Dr. Lawson (made appointment last week). I explained my problem, as above – obvious tendency to have diarrhea at slightest excuse; white furry tongue; loss of appetite; gassy, rumbling stomach; weak & exhausted, no energy; sleep a lot; pm naps; tendency to perspire; cold hands & feet; left eye trouble. I asked, what can I do for myself? In ... at this point, I would see specialist? Dr. Lawson said, all tests have been done which a specialist wd give, like bowel barium test – no cancer. My blood tests were for a lot of other things such as diabetes, liver disease, calcium absorption, etc. (he
named several others.) I said, I have not been eating normally for some time – shd I take vitamins? He said, not at this time. He suggested no more Mitrolan – taking a lot for long period might be harmful (I thot this also). Trimethoprim-Sulfa is for travellers’ diarrhea, which is not the same as mine – he will prescribe it for me if I go on trip. He said good balanced diet is best – OK’d food I ate Monday (tea, chic’ broth with rice, half banana, scrambled egg). I asked, could he suggest good health book for someone my age, or something on digestive system? ‘Off the top of my head, I can’t think of one’ – most are too general, he said.

November 4, 1988

2:40 pm – I saw Dr. Lawson & was given flu shot (they arrived a bit late this year). I told him about recent stiffness (& wrist decay), and my increase in aspirin intake to 5 or 6 per 24-hour period; he asked if aspirin upset my stomach, and I said no. I said I felt much better than at this time last year, and loose bowel problem has stopped – everything seems to be normal. He asked about blood or leaks from anywhere, & I said no....I asked him if he believed in mammograms; he said, ‘we do use them’; but he thinks best way is self-examination. I said I wondered how good a job I can do with these hands; he thus examined them for me, and found all OK. I asked re bone densitometer exam, saying I think I’ll be a prime candidate for osteoporosis; he didn’t think necessary (I think they concentrate on younger people) but said – eat high-calcium diet, milk, etc. I asked him if he believed in calcium supplements, and this time he said yes – any kind will do – but ‘if you drink 3 glasses of milk a day, you don’t need them’ (no mention of ‘predisposes to kidney stones’ this time, unlike last time I asked him.) I asked re hormone therapy (‘still controversial??’) and he said, if I were 50 he’d put me on them, abut now it’s too long after menopause....

September 20, 1993

2pm - saw Dr. Lawson; told him summary of log since trots began c. July 11)93, incl. SEPTRA-DS antibiotic from Sep. 9 to Sept. 17, when I stopped taking it due to red specked rash. I mentioned diet book (recc. by foot dr., tho I didn’t say this; also lady author was on ... show Sept. 17 and at health clinic on weekend): “Food & the Gut Reaction” by Elaine Gottschall. (Her basic idea: too many complex carbohydrates such as starches & many kinds of sugar remain undigested in small intestine, creating ideal environment for too many bacteria, causing gas, diarrhea, etc.)

He didn’t seem much interested in diet. Instead prescribed stool test (take samples & return them to lab ... in ... medic. building, ... at ....) I picked up test kit on my way home.
Exasperation with symptoms:

1985-86 Winter:

I had a flu shot from Dr. Lawson Oct. 29/85 (after I came back from trip to U.S. to see Bertram, etc.) But had almost continuous trouble with colds or mild flu from c. Dec. 1 to March 86. Had frequent diarrhea (esp. thru Jan. – took frequent Mitrolan to control it: I phoned Dr. Lawson in early Jan – he said drink fluids and avoid milk products). Gas (esp. from rear, & rumbling interior); pimples, like a teenager; crick at base of right neck; right ear itching & ringing. I began to wonder if my diet is Ok? Episodes of diarrhea gradually became less frequent thru Mar. & Apr. By May, I still seem gassier & pimplier than I used to be, but I have more energy (felt very limp in winter).

November 13, 1987

2:30 pm: Saw Dr. Lawson, who told me results of bowel test are OK – no indication of cancer. I recited my various symptoms (!). He doesn’t believe in diet consultants, seeing a dietician, etc. I mentioned that, due to trots, I have not taken much milk lately – have cracking, splitting nails, etc. He decided to send me in for (1) blood tests (to see if I am absorbing calcium vitamins, etc. properly) (2) and stool test (‘ova and parasite collection kit’).


Flu gradually tapered off c.Jan 22, tho still felt weak c. Feb. 2. (But no upset bowels!)

May 16, 1990

Had dizzy spells in laundry room downstairs, fell down (& had trouble getting up!) I phoned Dr. Lawson & asked if this could be side effect from penicillin; he said, he thinks dizziness is part of the infection. “Let me know early next week if you are still having them”. (Movement of head seems to cause dizzy spells–could it be a problem in my funny-feeling right ear, which aches a bit between aspirins?)

July 17, 1990

1:45 pm TEETH appointment with Dr. White; no holes found, just cleaning & X-ray. I mentioned ear problem & dizziness to him (I’m still dizzy when lying down, or sitting up from lying position). He said, it’s lasted rather a long time, & suggested I see family doctor.
January 23, 1991

Saw Dr. Lawson for medical checkup with cholesterol test (9am; have to fast for 12 hours before test – no food after 9pm on previous night – water only). He gave me more complete check than usual – stethoscope, pap smear, uterus & ovaries, chest listening, etc etc – “complete physical examination”. Approved of mammogram done last Nov. – “should have it done yearly”. I mentioned dry mouth, dizziness wear off, etc. – recent medic. hist. (recent entries above on this log), and lack of energy (sleeping a lot!) He thinks lack of energy is due to rheumatoid arth – not much can be done about it. Asked if my apt, is dry; I said windows are open, but heat may make it dry. Dr. L thinks I’m healthy and doing OK.

September 8, 1993

Next day – normal BM! (first for ages.) I looked up pills I am taking at Library (see list in this file, “Medications being taken as of June/93”) in Can. Medic Assn Guide to Drugs (good book). All seems to be OK, though ASA and alcohol both irritate stomach; also, over 1000 mg of Vit. C per day might cause diarrhea. (I am now taking 1,050 mg daily. Joan Miles suggested cutting down a bit – evening one could be 250 mg pill instead of 500mg? This might be a good idea!)

December 1, 1998

ANNUAL CHECKUP with Dr. Lawson, and flu shot. He said my bones were thinning (osteoporosis) & recommended Vit D (“take code liver oil”). I had to remind him that I’m taking Didrocal already.) I told him about normal BM’s – no more turista, (thank goodness). I bot cod liver oil.

December 7, 1999

DR.LAWSON – annual exam, 8:30 am... I said I still get sleepy fast; in Newf. “falling asleep in mid-sentence!”

Month of April 2002

Not feeling too well, no energy, & Indigestion- lots of Gas! on advice of 2 pharmacists, I bot “GAS-X Extra Strong” tablets, about 11 over a few days – very helpful. (It’s Income Tax season!)

September 05, 2002

Saw Dr. Lawson. Described period since I got out of hosp.: .... Little energy; can sleep anywhere, at once!
Suspiciousness regarding vitamin product claims and the side effects of pharmaceuticals:

**August 22, 1996**

In Aug., I also phoned ....Rec Centre for personalized fitness counselling, in my case, exercises for leg muscle strengthening. Joan Peary, one of their fitness people, phoned me & made a house call. I bought plastic exercise ball from her & she gave me a set of exercises to do on it – see file under “Exercises, Nutrition, etc.” She also sells Shaklee vitamin products, & I bot some (see file “Shaklee”). As Aug. 23, I am using up old vitamin pills and taking some “Shaklee” as well- phasing in supposedly purer S. Pills as old ones get used up.

**January 5, 1998**

After pale-brown violent liquid grunt explosion on bathroom floor Mon. am, I phoned Dr. Lawson. (Phoned twice later in day; he didn’t call back until 6:15pm) I told story, & said Joyce Martin had recommended “Prodiem” a bulk-forming laxative; Dr. L said no, that would cause more diarrhea. I asked for Lomotil; he said, it requires a written perscrip. – he can’t phone it in. Said, try Imodium & Kaopectate together. (I told him, Imodium alone has not worked well for me in the past.) Have eaten orange jc only since Sat night.

I’m getting suspicious of the Didrocal white pills I’m taking, tho I didn’t mention them yet; I took the first of the 14 white pills Dec. 22, & last Sun night Jan 4 (c 12 hr before “explosion”). I am to phone Dr. Lawson within 24 hours.

Disappointment and/or relief regarding the presence or absence of symptoms during valued activities:

**July 20, 1980**

another all-too-normal period, almost on time (c. 2 days starting July 28th, right at start of Seattle Opera Tour, Lasted several days (not bad – I didn’t eat much), and then faded away.

**April 11th to May 20th, 1983.**

All went well except ‘turista’ in Paris (prob from drinking tap water) & same with nausea in Seville (prob. exhaustion & strange food). Didn’t catch cold, tho.
February 24-March 17, 1992

trip to Chile. Went OK, except for c. 48 hrs of “turista” which meant
cancellation of trip to La Serena (N. of Santiago). I did much more walking &
climbing than usual, esp. in Chiloe, in old running shoes (very comfy) but bald
toes – seemed to work OK.

July 14, 1992

DIZZY SPELLS when sitting or changing position have gone completely since
my return from Chile – long plane flights with ups & downs evidently cured it!

December 3, 1996

-small shopping walk in ... (to ...). Wore new shoes, & for 1st time, heel didn’t
hurt (left one) – even occasionally!

May 22, 1997

FEET: (Dr. Bridges)....He did regular foot job, scraped toe, etc. – said all
looks well. I told him about trip to Seattle with no bandage or
“wondercircle” toe protector on either foot, but shoes were comfortable &
feet OK! (Maybe shoes have gotten softer, or some slight change in foot?)....

Discouragement with health status:

February 27, 1990

(Gen note on winter 1989-1990): Not a good winter- NB weak, sleeping a
lot, afternoon naps, no longer staying up late, often too tired to take evening
bath; not sleeping thru night, getting up once or twice to urinate, etc. (Never
did this 2 or 3 years ago.) No energy at all, and even routine jobs take much
time & leave me very tired.

May 24-June 18, 2001

- it has taken a long time to “recover: from trip to .... More arthritic aches,
esp. in right upper arm & shoulder (due to being pulled up into vans?) Very
sleepy, little energy, & taking extra aspirin.

Anxiety regarding health status:

March 5, 2002

Dr. Lawson: (12:30 pm-waited until 1 pm) Annual Exam. I said I had not
had a bad winter – no cold or ‘flu- but had odd reaction to my ‘flu shot (see
Dec ’01 notes), and whined about slowing down & getting older, need for much rest & sleep (he thot due to my arthritis) gassy fore and aft (too much tonic water? He said no, it does you good) Sore right ear with headache, esp. when I’m tired, neck click when head turned (but not always) little muscle ‘bump’ on right upper leg (not important). Did he say a few mo. ago I am ‘borderline diabetes?’ He thinks no. He checked back – no moles; skin OK. I showed him Income Tax Disability form which he filled in last Nov., and he added “SLOW” to description (I will send it in with photos.

I went down for various blood tests; he will phone with results.

September 05, 2002

Saw Dr. Lawson. Described period since I got out of hosp.: I have been thin, weak & wobbly, eating carefully & resting a lot. Osteoporosis getting a bit worse? Stiff creaky neck clicks, right ear slightly deaf and makes occasional typewriter “clicking” noises – worse when tired, but Tylenol helps. Little energy; can sleep anywhere, at once! Fell down gently on Marion’s steps Sept. 1 – nothing broken. Left bruise on tail.

I asked for a follow-up blood test to see if slow interior blood leak is still going on. (In Spring, when leak was occurring I couldn’t tell-no evidence until black stools appeared.

Sept. 6 Dr. Lawson phoned: results of blood test on 5th all OK (Sept. 5 cont’d) I told Dr. Lawson my Didrocal prescription and Synthyroid will run out soon (Sep. 14 & 17). He gave me percrip for both. I told him & gave him list of pills I take daily (2 or 3 reg. Tylenol, no aspirin, 1 Synthyroid, 1 Didrocal, & Vitamins. Should I take a bit of aspirin daily, for non-arthritis reasons? He said YES, take one 80 mg ASA (kid size) daily.

I asked re Folic acid 1 mg. & Iron pills brot from hospital (expire 2004). Dr. Lawson said, take folic acid; keep iron pill (Iron is 300 mg) Present Synthyroid dose, 125 mcg, is OK.

December 2002

Not feeling well. Take fairly frequent Tylenol regular (325 mg, not with codeine); no constipation, but headaches, ear aches, head aches, back of neck stiff, “prickling” feeling at right back of head, itchy, etc. Had to opt out of 2 Yule parties, and was uncomfortable at dinner on Christmas Day (Marion & Lee). Sleeping a lot: hot sweaty spells; very cold-sensitive, esp right ear & neck

January 08, 2003

Went to Dr. Lawson’s office: found his replacement Dr. Cook (until the end of April). (Tel. same as Lawson: ....) I complained about various symptoms (see Dec/02 above), esp. right ear (sore & deaf), right side of head & neck; can’t raise head when walking or upright. Is itching due to pss. Tylenol
allergy? Dr. Cook doubts this. Should I go back to aspirin for a week or so? He thinks not – might cause bleeding (suspected last summer). He sent me down to Lab. in .... Bldg. for another blood test, also for an X-ray (in adjoining bldg.) Jan. 16 or 17- Lawson office phone me & said Dr. Cook told them results of blood & X-ray were ‘normal’.

I asked him for referral to Dr. Joan Knowles (see Jan 6 above), & gave him info, billing no., etc.

While relatively hidden, speculated implicit psychological states appeared to exert a significant influence on Ruth’s behaviour and relationships with health care providers. For example, Ruth’s typical satisfaction with health providers appeared to underline her trust in the medical system and her desire to be collaborative within the treatment process. However, instances of anxiety and dissatisfaction served to erode the transparency that appeared to otherwise exist within Ruth’s professional relationships. Examples include Ruth’s seeking second (and third) opinions regarding proposed hand surgery when anxious within the decision-making process as well as Ruth consulting with third parties regarding persistent symptoms, such as dizziness, diarrhea and fatigue given limited recommendations regarding treatment or coping strategies.

While relationship issues were essential towards maintaining collaboration, there were no apparent instances of the use of immediacy (Egan, 1990), whereby the nature of the professional relationship itself was explored. Likewise, there were no apparent instances of Ruth’s emotional state being queried, reflected or explored by a health professional. This absence may have conveyed the implicit message that issues related to trust and emotional safety within the professional relationship were irrelevant to discussions at hand. However, Ruth’s emotional reticence and attitudes of self sufficiency presumably hindered dialogue regarding psychological processing. Ruth also typically directed attention to health-related
symptoms and concerns, thereby colluding with the implicit biomedical agenda during consultations.

While explicit psychological references are rare within the log, there are three exceptions. The first psychological reference occurs in the following excerpt, written after Ruth’s initial hand surgery, a joint fusion, in 1973.

December 1973

Operation done by Dr. Brown at ... Hosp. Thumb bone fused at base. In right hand, a few changes were noticed after operation, & slight loss of mobility, position of a couple of fingers changed a bit, etc. (Reaction to operation, or bandage, or natural progression of disease? Not sure.)

The second psychological reference occurs within a description of ongoing flu-like symptoms:

end of September- early October/84-

had ‘flu. Crept around with no fever, but very tired, loose bowels, weird symptoms & depressed – ringing oozing right ear, poor reflexes, addled brain, etc. Recovered slowly, and went to Harrison Hot Springs with Eileen Walton in rented car weekend Oct. 19-21.

The last reference occurs approximately one month before Ruth’s death.

December 18, 2002 ff:

(All those Yule cards!) Dark, gloomy weather – feeling worse (is this psychology, or weather?) Taking c. 6 to 8 Tylenol Regular (no codeine) per day, with a Ty. Extra Strength” now and then. Quite Weak, very sleepy, esp. after bath or BM; better (as usual) in pm than am. (esp 10 am) Taking occasional lax (Phillips) (1 or 2 chewed pills) esp. after Extra-Strength Tylenol with codeine.

The first explicit psychological reference (December 1973) and last (December 18, 2002) suggested psychological uncertainty at two significant points in Ruth’s life, subsequent to hand surgery in 1973, approximately two years following diagnosis, and a month prior to her death in January 2003. Archival records suggested that while Ruth had retired in 1969 to care for her bedridden mother, she had continued to be paid for part-time work until
approximately January 1973. Ruth’s first hand surgery occurred in December 1973, shortly before Ruth completely withdrew from the workforce. Presumably, the loss of a vocational identity, a source of personal worth and existential meaning, as identified by Iaquinta and Larrabee (2004), coupled with surgical intervention for progressive and painful deterioration in her hands, sparked Ruth’s questioning of her reaction to surgery and the disease process. This finding was consistent with Charmaz’s (1983) observation that the loss of self, a fundamental form of suffering for the chronically ill, was “most marked at the onset of a serious, debilitating illness or at points when ill persons define former actions, lives and selves as now precluded by illness” (p.168). In this regard, the psychological reference of December 1973 appeared to be an example of a “moral” illness narrative, defined by Bury (2001) as a narrative of shifting social status. While the “contingent” illness narrative, or narratives of the cause and effect of symptoms, was frequently represented within Ruth’s documentation, “core” illness narratives, or those illness connecting experience to deeper cultural meanings (Bury, 2001) were explicitly absent within the Medical Log. During the last months of life, Medical Log excerpts suggested an implicit shift from a heroic core narrative (of exemplary resilience in the face of adversity) to that of progressive deterioration and ultimate tragedy. However, numerous informants endorsed Ruth’s suicide, as a triumph of personal choice, an exercise in the right to choose a “hastened death” (Humphry, 1991) over unremitting suffering and dependency. Therefore, the interpretation of Ruth’s end-of-life illness narrative depends on the philosophical lens employed (Maris et al., 2000; Kleespies et al., 2000).

The December 18, 2002 excerpt suggested a life preoccupied with pain and symptom management. While Charmaz (1995) has defined successful adaptation to chronic illness as
“living with illness without living solely for it,” (p.658) the presence of severe pain created a
dilemma for Ruth as pain was overtaking consciousness and existence. Ruth appeared to
lack a philosophical framework through which a meaningful life could be created with the
loss of independence, privacy and autonomy that was presumably forecast by the presence of
severe and unremitting pain. While Charmaz (1995) has defined the last stage of adaptation
to chronic illness as a process of surrender or “the end of the quest for control over illness,”
(p. 659) for Ruth, such surrender brought forward notions of suicide.

The December 2002 entry also suggested that Ruth’s self-presentation, as engaged
with life and generally optimistic, was congruent with her typical internal psychological
state. In this regard, Ruth documented feeling “worse” but noted that an apparently
depressed affect could have been attributed to the gloomy weather rather than “psychology;”
an entry that occurred approximately one and a half months prior to Ruth’s suicide. The
Medical Log contained no excerpts that suggested the presence of undue anxiety or
intermittent depression throughout her life. However, given extensive research documenting
the reciprocal relationship between negative affect and pain (Gatchel et al., 2007; Huyser &
Parker, 1999; Keefe, Lumley, Anderson, Lynch & Carson, 2001), Ruth’s progressive and
severe pain may have created vulnerability towards a depressive state. In addition, numerous
variables were present that have been found to be independently predictive of depression,
including fatigue, pain, disability, lack of control over pain control and the perception that
medications were ineffective (Covic et al., 2006). Research has suggested that an affective
disorder, typically the first episode of unipolar depression, as the mediator between physical
illness, functional impairment and elderly suicide (Conwell & Brent, 1995; Conwell,
Duberstein & Caine, 2002).
However, the contents of Ruth’s suicide note and her disclosures to extended family and friends suggested that hopelessness regarding pain remediation, rather than depression, was at the forefront of experience at the end of her life. Extensive research has underlined the role of hopelessness as a predictor of suicidal ideation and completed suicide in adult psychiatric populations (Beck et al., 1989; Beck et al., 1975; Beck et al., 1993; Beck et al., 1985) as well as suicidal ideation and completed suicide in the elderly (Hill, et al., 1988; Rifai, et al., 1994; Ross et al., 1990). Findings within the Medical Log generally supported informant impressions that Ruth had coped with health challenges with remarkable psychological stamina and resilience until the last weeks of her life.

Within the Medical Log, there was a noticeable four week record-keeping gap surrounding Ruth’s experience as an inpatient from May 26, 2002 to June 01, 2002. Documentation during this time period was restricted to a discharge summary provided by the attending physician. This finding suggested that Ruth may have lacked the motivation, concentration or stamina to actively monitor her health status, (and, thereby, serve as her own advocate) given a debilitated state. Most significantly, there was no documentation of Ruth’s psychological reaction to the inpatient experience, an experience met with feelings of anger and degradation. Likewise, there were no explicit excerpts within the Medical Log that indicated a growing sense of hopelessness in regards to end-of-life pain management. However, the absence of psychological references does not imply that such processing was absent or irrelevant. Indeed, one explicit psychological reference (dated September- early October/84) suggested that Ruth was cognizant of the depressive effect of illness. According to Bury (2001), context and motive shape recounted illness narratives, as does the presence
and behaviour of the listener. Ruth presumably regarded psychological processing to be unnecessary or irrelevant for the purposes of medical care.

**Last Six Months of Life**

There are two significant events that occurred prior to the last six months of Ruth’s life. As noted in the excerpt below, Ruth apparently first reported right ear and head pain to Dr. Lawson in March 2002.

**March 5, 2002**

*Dr. Lawson: (12:30 pm-waited until 1 pm) Annual Exam. I said I had not had a bad winter – no cold or ‘flu- but had odd reaction to my ‘flu shot (see Dec /01 notes), and whined about slowing down & getting older, need for much rest & sleep (he thot due to my arthritis) gassy fore and aft (too much tonic water ? He said no, it does you good) Sore right ear with headache, esp. when I’m tired, neck click when head turned (but not always) little muscle ‘bump’ on right upper leg (not important). Did he say a few mo. ago I am ‘borderline diabetes? He thinks no. He checked back – no moles; skin OK. I showed him Income Tax Disability form which he filled in last Nov., and he added “SLOW” to description (I will send it in with photos ). I went down for various blood tests; he will phone with results.*

Secondly, Ruth was hospitalized for gastro-intestinal bleeding in May-June 2002, presumably an adverse reaction associated with a prolonged use of Aspirin. As noted previously, Ruth was no longer able to use Aspirin as an analgesic, a medication that had typically provided sufficient pain relief throughout her life. The May-June 2002 hospitalization was also significant in that Ruth appeared angered by her hospital experience and informed significant others that she preferred suicide to such perceived degradation in the future.

The following Medical Log excerpts detailing the last six months of Ruth’s life are provided below in chronological order (beginning of August 2002 to the end of January 2003).
August 19, 2002

Had Mammogram at ....Hospital. Got usual letter a week or so later, saying all OK.

August 21, 2002

FEET: Dr. Bridges did usual job, cut nails, replaced horseshoe bandage on right big toe, etc. All OK
Since my small tube of “Bactroban” is getting thin, Dr. Bridges gave me a new prescription, which I filled at ... Pharmacy (15 g tube, contains 20 mg mupirocin/g; antibiotic ointment).

September 03, 2002

TEETH: Regular 6 month appointment at Dr. Farley (Irish opera-loving dentist at ....Nice technician “Donna Lee” inspected, cleaned & polished my fangs, and Dr. Farley examined – found them in OK shape. No fluoride wash given, since I said I could do it at home (“Oral-B Anti-bacterial with fluoride & no alcohol”) (It costs more when done at office.) Total Cost: $100.80 (Pd by cheque)
Dr. Farley also signed “Declaration” rec’d today from Govt of ...financial office – every 2 years they want one to prove recipient of pension is still alive, etc. It was mailed back to ....today (3rd Sept).

September 05, 2002

Saw Dr. Lawson. Described period since I got out of hosp.: I have been thin, weak & wobbly, eating carefully & resting a lot. Osteoporosis getting a bit worse? Stiff creaky neck clicks, right ear slightly deaf and makes occasional typewriter “clicking” noises – worse when tired, but Tylenol helps. Little energy; can sleep anywhere, at once! Fell down gently on Marion’s steps Sept. 1 – nothing broken. Left bruise on tail.
I asked for a follow-up blood test to see if slow interior blood leak is still going on. (In Spring, when leak was occurring I couldn’t tell-no evidence until black stools appeared.

Sept. 6 Dr. Lawson phoned: results of blood test on 5th all OK (Sept. 5 cont’d) I told Dr. Lawson my Didrocal prescription and Synthyroid will run out soon (Sep. 14 & 17). He gave me percrip for both. I told him & gave him list of pills I take daily (2 or 3 reg. Tylenol, no aspirin, 1 Synthyroid, 1 Didrocal, & Vitamins. Should I take a bit of aspirin daily, for non-arthritic reasons? He said YES, take one 80 mg ASA (kid size) daily.
I asked re Folic acid 1 mg, & Iron pills brot from hospital (expire 2004). Dr. Lawson said, take folic acid; keep iron pill (Iron is 300 mg) Present Synthyroid dose, 125 mcg, is OK.
September 09, 2002

Forgot to tell Dr. Lawson re new Representation Agreement Sept. 5. I phoned him & told him about the one I signed recently “for health and personal care”, my cousin Elizabeth Morris to be representative. I said Elizabeth would send him a letter, with Elizabeth’s new address (as of end of Aug.)

September 11, 2002

TEETH: “Barnacles” removed from tips of front teeth, and edges smoothed over. These hard, (calcium?) scratchy edges have been there for years, tearing at inside of upper lip which gets sore; not as bad in last two years or so, perhaps due to change in placement of front teeth (moving out a bit, “buck” teeth). Have caused a bit of trouble for last few months.

September 18, 2002

FEET. All OK – Dr. Bridges did usual job. A bit of gore from right big toe during scraping, but not bad. Usual horseshoe pad with “wondertape” put on toe, as usual, but this time in vertical position (opening at top), which works better.

October 02 to 04, 2002 (weekend) ff:

Problems. Increased pain in right neck & ear; hard to turn over, esp. on right side. Woke up at night, felt cold (heat helped) – better when sitting up.

October 05, 2002

Phoned Dr. Lawson’s office & reached Dr. Stevens, who recommended Tylenol with some caffeine & codeine, but didn’t mention that codeine was constipating (it is! after taking it for several days)

October 08, 2002

Saw Dr. Lawson in office; he thinks it’s just arthritis (not rheumatoid); warned me re codeine & constipation; doesn’t think physiotherapist or acupuncture will help. (Oct. 10 was date of my very bad constipation). Got “Sennosides” laxative pills, & took 2 after dinner, which cleared me out twice Oct. 11.
until c. October 24, 2002

Some boiled prunes every morning (brek). Lots of Tylenol Regular (no codeine); and occasional old Winthrop suppository helpful; occasional arth. twinges in right hip & thigh; weak & wobbly, & very sleepy.

October 17-18, 2002

took more codeine tabs (Tylenol 325 with 8 mg codeine) for head, neck and right ear pain, & 1 Sennosides lax tab.

October 19, 2002

Tried stool softener for 1st time; it worked well. More codeine pills & 2 Senno lax pills (result- too much loose BM on 20th) BM’s & baths very weakening; mornings bad, eves much better.

October 21, 2002

I switched my pill timing to taking almost all pills in am, with brek. Eased up on no. of Tylenols after Oct. 24/02.

See separate yellow page “Notes re Tylenol: for more info re Tylenol varieties, lax, stool softener, etc. Oct. 21 – was able to see “AIDA”.

October 13, 2002 (separate sheet)

Notes re Tylenol (Acetaminophen)

-From Compendium of Pharmaceuticals and Specialties in .... Library (Can. Drug Reference Year 2002), white page 1758 (#R 615.11 COM)

“The recommended dose for codeine for children is 0.5 mg/kg of (My body weight in kg is 50; suitable codeine 25 mg /body weight.” Advise not to take with any ASA (aspirin) “Overdose is in excess of 150 mg/kg.” Tylenol can produce side-effects, and has to be watched; if you get a rash, that’s bad. Light-headedness, dizziness, sleepiness (like a sedation); does not go well with alcohol, or kidney or liver disease.

6 different kinds were listed in Compendium:

- Tylenol “Elixir” with codeine; cherry flavour (perhaps a liquid?) meas. in mL – children over 2 yrs can take it.

- Tylenol #1 “Forte”. Contains: Acetaminophen 500 mg
  Caffeine 15 mg
  Codeine 8 mg
(These disc pills made my head ring) (1 to 2 tabs every 4 hrs; don’t exceed 8 per day. Read box – (not much info on bottle re contents) Bot at ….

- Tylenol #1 (not “Forte”).
  - Acetaminophen 300 mg
  - Caffeine USP 15 mg
  - Codeine Phosphate USP 8

“Forte” and
(This are the ones I took in early Oct., which gave me bad constipation. I took child’s dose (1 pill) of pms-SENNOSIDES laxative (12 mg) (“6 to 12 yrs, 1 tab at bedtime”

(adults get

Tylenol #1: “Adults & children 12 years & older: take two tabs every 4 hrs. Max. daily dose, 12 caps.” No mention on bottle that it shd be taken with laxative, & Dr. Stevens (Dr. Lawson’s weekend sub.) didn’t mention this.) I phoned Dr. Lawson, who said Sennosides was “good choice”. Mrs. Chalmers uses 2 tabs. Phillips Lax (Magnesia) chewable with antiacid at bedtime; they work well. Docusate is “stool softener” which can be taken daily, unlike others

- Tylenol #2
  - Contains: Acet. 300 mg
  - Caffeine 15 mg
  - Codeine 15 mg

( Didn’t get this)

- Tylenol #3 same as #2, except has codeine 30 mg, not 15.
  (Didn’t get it)

- Tylenol #4 Same as #2, “ “ “ 60 mg. (Didn’t get)

October 09, 2002

FEET. All OK – Dr. Bridges did usual job. “Used, older” black & beige stretchy-top shoes had orthotic insoles switched.

November 04, 2002

EYES. Dr. Graham found “little change from last year”. No new prescript. necc.

November 07, 2002

FEET. Dr. Bridges found build-up of dead skin on right big toe “a bit gummy”. Applied Bactroban, bandage, etc.
November 13, 2002

**FEET.** again, at Dr. Bridges request (no “user fee” for this) Big right toe has improved.

November 25, 2002

**Dr. Lawson** – went to his office to get ‘flu shot and ask 11 questions: (1) Folic Acid: I’m now taking folic supplement of 1 mg daily, & also get 0.6 mg from Centrum & 0.1 mg from B50 complex - is this too much? Ans. – he thot not necc to take 1 mg supplement, but I can finish bottle. (Don’t reorder – stay with the 0.7 from other pills)

(2) Do I need another blood test? He thinks no.

(3) Itchy right head behind ear – Could I be allergic to something put on hair? Ans. Maybe – hard to tell.

The remainder of this entry is apparently incomplete, given the recording of three questions, rather than the 11 that Ruth intended to ask.

December 03, 2002

**FEET** Dr. Bridges did usual job & said feet in good condition. (Forgot to put on horseshoe pad & wondertape; I did it later) I showed him “new” black stretchy-top shoes, bot at ...just before it closed; I can’t get foot into them, even with non-new orthotic insoles (older, worn-in ones) rather than new stiff ones (which are OK in beige shoes). Has there been a slight change in design? Dr. B. will try to find out; he thinks they are a bit smaller.

December 23, 2002

**FEET** Dr. Bridges did usual job; all OK. We talked about “new” black shoes; he says mfr. was changed (or changed factories); slight change in size has changed shoe fit – he will try to get more info. Next time I se him, I shd bring box they came in.

December 2002

Not feeling well. Take fairly frequent Tylenol regular (325 mg, not with codeine); no constipation, but headaches, ear aches, head aches, back of neck stiff, “prickling” feeling at right back of head, itchy, etc. Had to opt out of 2 Yule parties, and was uncomfortable at dinner on Christmas Day (Marion & Lee). Sleeping a lot; hot sweaty spells; very cold-sensitive, esp. right ear & neck.

(Was also taking white Didrocal pills (c60% of ea Dec. 16 to 28)
December 18, 2002 ff

(All those Yule cards!) Dark, gloomy weather – feeling worse (is this psychology, or weather?) Taking c. 6 to 8 Tylenol Regular (no codeine) per day, with a Ty. Extra Strength” now and then. Quite Weak, very sleepy, esp. after bath or BM; better (as usual) in pm than am. (esp 10 am) Taking occasional lax (Phillips) (1 or 2 chewed pills) esp. after Extra-Strength Tylenol with codeine.

January 06, 2003

Spoke with Dr. Joan Knowles on phone: she is arthritis specialist in new medic. office bldg. at .... Tel: .... (Recc. b Mrs. Chalmers & Marion Black (her friend Janice) You have to be referred by your Family Doctor: she gave me her Billing Number: .... Dr Knowles works Mon, Tues, Wed only.

January 08, 2003

Went to Dr. Lawson’s office: found his replacement Dr. Cook (until the end of April). (Tel. same as Lawson: ....) I complained about various symptoms (see Dec/02 above), esp. right ear (sore & deaf), right side of head & neck; can’t raise head when walking or upright. Is itching due to pss. Tylenol allergy? Dr. Cook doubts this. Should I go back to aspirin for a week or so? He thinks not – might cause bleeding (suspected last summer). He sent me down to Lab. in .... Bldg. for another blood test, also for an X-ray (in adjoining bldg.) Jan. 16 or 17- Lawson office phone me & said Dr. Cook told them results of blood & X-ray were ‘normal’.

I asked him for referral to Dr. Joan Knowles (see Jan 6 above), & gave him info, billing no., etc.

January 15, 2003

I phoned Dr. Knowles (....) & spoke to Lynn Jessop (sp?). I mentioned Dr. Cook referral, blood tests, & spine Xray. (She will get them). She gave me an appointment with Dr. Knowles for Monday Jan. 27/03 at 11:30 am; she works only Mon., Tues., and Wed.

January 13, 2003

FEET: Dr. Bridges did usual job – found feet OK. As he asked, I took him the shoe box for most recent pair of black stretchy-top shoes, which I bot at ... before they closed last year; he thinks mfr. has made change in size (they switched to another factory), which is why I find them unwearable, even with the softest and oldest of his orth. liners.
January 24, 2003

**FELL DOWN** c. 4am at entrance to bathroom; hit head on corner of German stool, with some gore (blotted with Kleenex), then small Elastoplasts. Weak, wobbly & stiff (esp. left side of groin, hip, shoulder; heat helps.)

Very quiet day-rested a lot. No B.M. in morning or later (in spite of good dinner night before – Thurs Jan. 23) Took (between 6:30 am & midnight on Friday) 4 “Regular” Acetaminophen and 6 Extra Strength (Acet. 200mg, with caffeine 15 mg and codeine 8mg).

Since codeine gives me constipation, I took at bedtime 4 Phillips Lax tablets, & 1 “stool softener” pill.

January 25, 2003

No BM. Very quiet day: ate little; took 8 “Regular” Acet. At bedtime, took 1 “Sennosides” lax pill & 1 stool softener.

January 26, 2003

At last had good solid (lumpy) BM at noon. Very quiet day weak & wobbly, left side still stiff & sore from fall (hard to reach shoes, etc.)

The above excerpts documented Ruth’s progressive physical decline during the last six months of her life. According to the September 05, 2002 excerpts, Ruth had been in a debilitated state since her hospitalization in May-June 2002 for gastro-intestinal bleeding. Ruth’s reported symptoms included generalized weakness, fatigue and an unsteadiness that apparently contributed towards a fall. In addition, Ruth appeared concerned about possible degenerative changes from osteoporosis, given unusual clicking sounds in her right ear and neck. In spite of this large symptom burden, medical follow-up was not documented in the Medical Log until approximately three months post-discharge, although the hospital discharge summary noted a follow-up appointment with Dr. Lawson scheduled in the week after discharge.

During the above interactions with Dr. Lawson, Ruth actively co-managed her medical care, in spite of her debilitated state. For example, Ruth requested screening to rule
out a persistent slow interior haemorrhage, given the lack of warning prior to gastro-intestinal bleeding in May-June 2002. While the request for screening appeared preventative in nature, Ruth may also have been concerned about the reasons underlying her persistent debilitated state. In addition, Ruth initiated a post-discharge medication review and alerted Dr. Lawson to the need for prescription renewals. Ruth also initiated discussion regarding the use of Aspirin for prophylactic reasons, a previously beneficial analgesic but apparently suddenly discontinued given the potential for adverse effects, such as gastro-intestinal bleeding. While Dr. Lawson recommended the use of lose dose Aspirin, Ruth later noted that Aspirin was contraindicated with prescribed Tylenol (see October 13, 2002 excerpt).

On September 09, 2002, Ruth also informed Dr. Lawson that her cousin, Elizabeth, had been made her legal health representative. While such decision-making appeared to stem from a rational appraisal of potential need for the future, Elizabeth (the main informant) also questioned if such actions were initiated by Ruth to provide safeguards in case her suicide attempt was non-lethal. While such information provided an opportune time for long health care planning, Ruth would presumably have deflected such queries from Dr. Lawson as unnecessary given her recent refusal of home based assistance during discharge planning as an inpatient.

While Ruth first reported right ear and head pain to Dr. Lawson in March 2002, her pain appeared to suddenly worsen, given the October 02 to 04, 2002 excerpt. Tylenol with codeine was eventually recommended, given that regular Tylenol was insufficient for pain relief. However, Ruth documented additional discomfort caused by constipation, a side effect of codeine, a symptom that presumably accentuated body discomfort, surveillance and concern.
During the October 08, 2002 appointment, Dr. Lawson diagnosed Ruth’s pain as “just arthritis,” or osteoarthritis, rather than rheumatoid arthritis, an explanation that was presumably offered as reassurance. While Dr. Lawson followed up Ruth’s complaints with laboratory investigations, results may have consolidated the understanding that Ruth’s rheumatoid arthritis was inactive and that her physical status was “okay.” In consequence, a possible inflammatory process was ruled out and Ruth’s pain experience apparently minimized.

Dr. Lawson also appeared to convey the message to Ruth that complementary treatments, such as physiotherapy, would lack benefit in her pursuit of pain management. This advice appeared surprising given that Ruth had apparently experienced physiotherapy as beneficial for the treatment of pain in the past. As such, the implicit message inadvertently conveyed was that Ruth’s treatment options were pharmaceutical in nature, with endurance as the default coping strategy, a message that may have fostered desperation.

During a subsequent medical appointment with Dr. Lawson’s replacement physician, Dr. Cook, on January 08, 2002, Ruth described herself as “complaining,” in spite of severe and incapacitating pain. As previously noted, Dr. Cook’s response was similar to Dr. Lawson in the marked disjuncture between explanations of normality, in this case, via laboratory and X-ray findings, and Ruth’s lived experience.

In spite of severe pain, the above excerpts suggested that Ruth continued to have a will to live, given her persistent involvement in routine health care. For example, Ruth attended appointments with both her ophthalmologist and her podiatrist. During the November 25, 2002 appointment with Dr. Lawson, she obtained a flu shot for the coming winter and arrived with 11 health-related questions for discussion. In addition, Ruth
researched various kinds of Tylenol, noting contraindications and side effects. Ruth also appeared to experiment with both the timing and types of analgesics used in her efforts at pain control. During the January 08, 2003 medical appointment, Ruth also raised queries regarding the temporary use of Aspirin as an option, given unmitigated pain. Ruth also initiated a self-referral to a rheumatologist, expediting the referral through the provision of relevant information at both Dr. Cook’s and Dr. Knowles’ offices. Interestingly, Ruth’s entries in the Medical Log on November 25, 2002 were uncharacteristically incomplete. This information gap suggested a diminished ability to monitor and record relevant information, perhaps symbolic of the diminished voice that Scarry (1985) has associated with the experiential world of those in severe pain.

During the October 21, 2002 excerpt, Ruth noted that she “was able” to see an opera, a comment that alluded to the effort entailed. However, by Christmas 2002, Ruth was unable to attend two Yule parties and was uncomfortable during Christmas dinner with friends. In addition, the December 18, 2002 excerpt suggested that Ruth experienced Christmas rituals, such as Christmas cards, as an experiential burden. As such, while Ruth appeared motivated to remain socially engaged, she also appeared increasingly unable to enjoy or pursue valued activities, given the presence of severe pain.

Ruth’s recognition of a possible depressive state, within the December 18, 2002 excerpt, was not surprising given research linking pain with negative affective states (Gatchel et al., 2007; Huyser & Parker, 1999; Keefe et al., 2001) and the loss of valued activities to the onset of depression (Katz & Yelin, 2001). However, Ruth also thought her depressed affect could be as easily attributed to extraneous factors, such as the effect of dark and gloomy winter weather.
During the last two weeks of Ruth’s life, additional unforeseen difficulties arose that presumably created additional experiential burdens. In this regard, Ruth had difficulties with the fitting of her orthopaedic shoes (which was attributed to a change in manufacturer). Most significantly, Ruth had a fall, which further compounded Ruth’s experience of severe and unremitting pain.

In general, Medical Log excerpts chronicling the last six months of life, appeared to confirm the impression of numerous informants; that hopelessness, rather than depression, was the primary psychological state that mediated between pain and suicide. Research has highlighted the significance of hopelessness, as a construct associated with and distinct from depression, as a predictor of adult suicidal ideation and completed suicide (Beck et al., 1989; Beck et al., 1975; Beck et al., 1993; Beck et al., 1985) as well as suicidal ideation and completed suicide in the elderly (Hill, et al., 1988; Rifai, et al., 1994; Ross et al., 1990).

During the last month of life, Ruth had contact with three physicians, Dr. Cook, a locum physician for Dr. Lawson, Dr. Bridges, a podiatrist, and Dr. Knowles, a rheumatologist, with the latter consulted on one occasion. This finding was consistent with research that has investigated primary physician contact rates prior to elderly suicide, with 62% of patients having contact in the month preceding suicide, with a 36% contact rate reported within the preceding week (Conwell, 1997). Ruth’s lack of disclosure regarding her suicidal intention, her meticulous avoidance of detection and use of violent means was also consistent with reported characteristics of elderly suicides in general (Conwell et al., 2002).

According to information provided by informants, Dr. Knowles had told Ruth that she could pursue acupuncture, for pain management, if she desired. In addition, a referral note
signed by Dr. Knowles and dated January 27, 2003, contained the following recommendations and follow-up requests:

1. Please get labs

2. For osteoporosis, please make sure calcium 1500 mg/d and Vit D 800 iu /d Continue Didrocal

3. For arthritis, take 2 Tylenol per day and begin one Plaquenil per day
   Use Glucosamine Sulfate 750mg twice daily
   Menthacin cream, apply with glove one to three times daily on painful areas

The above referral note suggested that Dr. Knowles was considering further medical investigation and pharmaceutical treatments. It was also noteworthy that Dr. Knowles recommended the use of Plaquenil, a DMARD, contrary to Dr. Lawson’s opinion that such medications were an inappropriate choice for Ruth’s medical treatment.

However, the absence of Medical Log entries following this appointment appeared to confirm the reported impression of numerous informants that the meeting had been significant in Ruth’s decision to end her life. Following consultation, Ruth informed others that nothing more could be done for her pain and that it would only worsen. Whether or not Dr. Knowles actually conveyed or intended to convey such information, Ruth’s interpretation proved critical to subsequent events, given her suicide within days of the appointment.

As noted with interactions between Ruth and Dr. Lawson and Dr. Cook, the disjuncture between Dr. Knowles physical appraisal and Ruth’s experiential reality of life as unendurable, inadvertently appeared to have negative consequences. Dr. Knowles treatment recommendations apparently failed to bolster Ruth’s resolve to live. Even if Ruth had continued with Dr. Knowles, there was no guarantee that suggested treatments would have
been effective given the presence of numerous variables associated with lessened treatment
effect, including Ruth’s gender, higher disease functional class (presumed on deformities)
and the presence of a disease process of long duration (Anderson et al., 2000). However, the
identification of a possible inflammatory process might have reframed symptoms as a
temporary exacerbation in disease activity, rather than a sign of unremitting pain that would
only worsen over time.

Unfortunately, the biomedical orientation of Ruth’s primary health providers colluded
with the constricting experiential lens of pain, a contracted body focus that marginalized
interpersonal engagement. At this time, Ruth was in need of an advocate, or, at least, an
empathetic witness, to her suffering. In the words of Scarry (1985), such “worldly self-
extension,” (p.50) critically maintains hope for those in severe pain. According to Scarry
(1985) “the success of the physician’s work will often depend on the acuity with which he or
she can hear the fragmentary language of pain, coax it into clarity, and interpret it” (p. 6).
Unfortunately, the experience of many patients “would bear out the opposite conclusion, the
conclusion that physicians do not trust (hence, hear) the human voice, that they in effect
perceive the voice of the patient as an ‘unreliable narrator’ of bodily events, a voice which
must be bypassed as quickly as possible so that they can get around and behind it to the
physical events themselves” (Scarry, 1985, p.6). Likewise, Groopman (2004) identified
physicians as having a seminal role in maintaining hope within the experience of a severe
chronic illness, while noting a typical lack of prerequisite understanding and training.

In this regard, Dr. Lawson appeared to marginalize Ruth’s experience of pain towards
the end of her life, remaining convinced that the disease process was inactive and that Ruth’s
pain experience was minimal. However, Ruth’s physical deterioration also appeared marked
during the month of December 2002, the period of Dr. Lawson’s absence. If Dr. Lawson had been in attendance, rather than a locum physician, perhaps the extent of Ruth’s deterioration would have been more evident, given a baseline comparison.

Likewise, Dr. Bridges recalled Ruth’s disclosure of upper body pain, during the last weeks of her life, only through direct questioning. As a specialist, Dr. Bridge’s medical domain centered on the biomechanical management of Ruth’s feet. Dr. Bridge’s deferral of Ruth’s generalized care to Dr. Lawson presumably contributed towards his relative inattention to her disclosure of pain. Unfortunately, Ruth’s experience of severe and remitting pain remained relatively invisible to her primary medical providers in the last months of life.

Rich (1997) has identified numerous ethical issues related to the prevalent under treatment of pain by physicians, including unwarranted fears regarding opioid addiction, fears of legal prosecution, and cultural values that regard individual suffering to be not only unavoidable, but laudatory. However, these research findings suggested that other dynamics may be relevant to discussions, including the effect of role divisions and the reliance on laboratory investigations that do not capture clinical complexity. According to Engel (1977), successful physician query rests not just on a comprehension of clinical data but on an understanding of the psychological, social and cultural influences that may be influencing the patient’s account.

In addition, as noted by Scarry (1985), the attributes of severe pain, such as its private nature and general inexpressibility, contribute towards the lack of comprehension and compassionate action by others, whether within and outside the medical context. According to Scarry (1985), the reality of disease “may be believed-in but the accompanying pain
disbelieved and the pain medication under-prescribed. Medical contexts, like all other contexts of human experience, provide instances of the alarming phenomenon noted earlier: "to have great pain is to have certainty; to hear that another person has pain is to have doubt” (p. 7).

However, Ruth also appeared to further render pain invisible through her self-presentation with primary health care providers. For example, Ruth did not directly voice anxiety or desperation regarding her pain experience to either Dr. Lawson or Dr. Bridges during the last months and weeks of her life. In particular, Dr. Bridges described Ruth’s manner as almost jovial during their last appointment, which occurred approximately two weeks before her death. Likewise, hospital health care providers were not privy to the anger and humiliation Ruth felt towards her hospital experience, but rather responded to an apparent pleasant and appreciative manner. As Dr. Bridges astutely recognized, patients are far more complex than what is known, a relevant observation within discussions of ethics and pain management.

While an understanding of illness narratives fosters emotional resonance and empathetic engagement (Bury, 2001; Frank, 1995; Hauerwas, 1990; Kleinman, 1988), such understanding by physicians remains predicated on a patient’s desire and willingness to be transparent about their lived experience. In this regard, Ruth preferred a separation between her medical, personal and social worlds, a compartmentalization that colluded with the biomedical agenda while also preserving definitions of dignity and respect. While Ruth’s coping style typically promoted resilience and functionality, implicit values, such as privacy, independence and autonomy, also constrained understanding in the last months of life. While dialogic interactions during medical consultations were shaped by a biomedical
agenda (ten Have, 2002); Waitzkin & Britt, 1989), research findings also illuminated Ruth’s influence in shaping interactions and understandings.

While hopelessness is generally viewed as a distorted cognitive construct (Beck et al., 1975), the present research illuminated hopeless as dialogically co-constructed state, which was partially constructed through conversational realities (Shotter, 1993) with Ruth’s health professionals. Dialogue with health professionals appeared to consolidate definitions of Ruth’s pain as “hopeless,” while constraining further actions towards pain remediation. Given Ruth’s scientific mindset and philosophical endorsement of “rational suicide” (Humphry, 1991; Maris et al., 2000), a negative medical prognosis, while not deterministic, opened the horizon to suicide as a rational option, given the presence of unremitting suffering.

As noted by Hauerwas (1990), western society lacks a grand narrative through which suffering and death are experienced at a communal, rather than individual level. In consequence, each individual faces suffering and death through a privately determined meaning. In this regard, Ruth faced her death alone, without the presence of human solace, which presumably accentuated her suffering. However, Ruth’s final actions were also in accordance with the principles of rationality that had consistently guided her living, as expressed through self determined choice and control.

Likewise, the space created by Ruth’s physical absence invited a rational search for the “reasons” in order to “solve the puzzle” as to “why” Ruth chose suicide as an option. The puzzle metaphor potentially invited a response of judgement, given the certainty that frequently accompanies the determination of the “right” answers. However, instead of reasoned “absolute truths,” partial, and, frequently, ambiguous truths have surfaced within
the present research. In this regard, while Ruth actively shaped her preferred way of being with others, she was also shaped by surrounding cultural discourses. As such, Ruth’s experience of pain, and chronic illness, in general, existed within the intersection of self, body and culture (Morris, 1991; Scarry, 1985; Williams, 1999; Willig, 2000; Yardley, 1996).

Morris (1991) has likened the understanding of pain to the comprehension of a mystery, rather than a puzzle, an apt guiding metaphor when confronting Ruth’s experience of pain. Contrary to the “puzzle” metaphor, the metaphor of mystery creates an ongoing space for curiosity, given the certainty of “unknowing” within the context of multiple truths that unfold with ever increasing complexity.
CHAPTER 5: DISCUSSION

This chapter will provide a summary of the critical analysis of research findings as provided in Chapter 4. Theoretical implications of the research findings will be integrated within the analysis and discussion, as recommended by Willig (2001). Clinical implications and limitations of the research findings will be followed by recommendations for future research.

Summary of Research Findings and Theoretical Implications

As initially stated, the purpose of the present research was to investigate the various cultural discourses that constituted the identity, subjectivity and agency of Ruth, a woman who had lived with rheumatoid arthritis over a 40 year time period. In particular, the research question sought to understand how the main archive, a 40 year Medical Log illuminated constitutive discourses, using a critical discourse analytic methodology informed by Parker (1992) and Willig (2001).

A comprehensive analysis and discussion of research findings, as provided in Chapter 4, clearly demonstrated the complexity and the interdependent relationships between various discourses, primarily biomedical, psychological and socio-cultural, which constituted Ruth’s identity, subjectivity and agency, both within immediate dialogic interactions and overtime. In turn, Ruth’s lived experience illuminated constitutive discourses as to their effect, while also identifying inherent gaps, inconsistencies and areas of ambiguity. In summary, the research findings offered a unique glimpse into the interrelationships between discourses, embodiment, identity, subjectivity, and agency, as reflected through lived experience over
time, a theoretical expansion to standard discourse analytic investigations of health and illness (Willig, 2000).

Ruth’s scientific training and mindset perfectly matched the requirements of an explicit biomedical orientation, a biophysical lens predominantly focused on pathology and symptom presentation (Foucault, 1963/2003; Walker et al., 2004). As was consistent with DiGiacomo’s (1992) observations, such objectification intersected with western individualism, situating Ruth’s body as “a project for the self to work on.” (Gordon, 1988, as cited in DiGiacomo, 1992, p.122.) The organization of the main archive, the Medical Log, reflected such objectification, with excerpts typically divided by body parts, (e.g. eyes, teeth, and feet) which were occasionally referenced in the third person as part of Ruth’s meticulous observations.

Ruth’s diligent monitoring of health-related issues, her conscientious practice of recommended treatments and self-directed research in regards to symptom management also exemplified a strong Protestant work ethic, a cultural value which frequently pervades the experience of chronic illness (Charmaz, 1983). Within the context of medical care, Ruth sought up-to-date knowledge, actively co-managed symptoms, and implicitly sought involvement in decision-making processes, all ways of being identified as common within the process of adaptation to rheumatoid arthritis ((Iaquinta & Larrabee, 2004; Shaul, 1995).

Excerpts within the Medical Log also illuminated the centrality of lived experience in providing the context of meaning for health-related concerns. In this regard, Ruth frequently employed contingent narratives (Bury, 2001) within the Medical Log, noting the suspected causes of symptoms as well as the impact on lived experience. As was consistent with research (Katz and Yalin, 2001; Neugebauer, Katz, & Pasch, 2003) Ruth frequently
referenced her ability to engage in valued activities as a means of determining symptom significance.

In general, Ruth maintained functionality and symptom management through a coping style that was marked by rationality, an internal locus of control, optimism, a strong sense of self-efficacy, and an active problem-oriented approach that was also appropriately flexible and context-driven, attributes and strategies endorsed as beneficial within the experience of rheumatoid arthritis (Affleck et al., 1987; Flor & Turk, 1988; Keefe et al., 1989; Nagyova et al., 2005; Smith et al., 1994; Treharne et al., 2005; van Lankeveld et al., 1994; Walker et al., 2004; Zautra & Manne, 1992). Ruth’s active coping style presumably protected her from greater functional disability, depression and pain given research findings that have associated such adverse effects with a more passive coping style (Brown & Nicassio, 1987; Flor & Turk, 1988; Covic et al., 2003; Covic et al., 2006; Keefe et al., 1989; Smith & Wallston, 1992; van Lankveld et al., 1994). Likewise, Ruth’s life passions (or aesthetic spirituality) fostered a positive life engagement while presumably marginalizing the effect of functional disabilities and health-related concerns, given research linking measures of spiritual transcendence to positive affect and enhanced health perceptions (Bartlett et al., 2003). In spite of a large symptom burden and significant physical limitations, Ruth tenaciously pursued valued activities, such as travel, music-related activities and socializing through perseverance, a coping strategy found to maintain optimal functionality over time (Katz, 2005).

Implicit Anglo-Saxon cultural values, such as those which privilege privacy, independence, family autonomy (Charmaz, 1983), were powerfully constitutive of Ruth. The attitude of self-sufficiency was perhaps crystallized in the statement “I must do it myself,” given in response to persistent offers of assistance from an extended family member. Ruth’s adamant deflection of assistance reflected a central core-ordering process (Mahoney, 1991)
through which meaning was constructed within the lived experience of rheumatoid arthritis. While central to Ruth’s coping style, these values were also constitutive of relationships in that such coping was viewed as exemplary, whether by professionals or otherwise.

While Ruth relished life, there were also patterns of ongoing relinquishment, as evidenced in the loss of a vocational identity, the bequeathing of possessions, a gradual constriction in the pursuit of valued activities, such as overseas travel and visitation, and a trend towards a minimalist lifestyle. Such findings concurred with Charmaz’s (1983) observations of the centrality of loss within the experience of a debilitating chronic illness. However, Ruth’s tenacious pursuit of valued activities also presumably buffered the psychological impact of such loss, given research findings linking depression with the loss of activities that are replete with meaning (Katz & Yalin, 2001; Neugebauer et al., 2003).

Ruth frequently deferred to medical opinion, particularly in regards to the assessment that her rheumatoid arthritis was inactive, in spite of many indicators, such as ongoing fatigue, progressive deformities and episodic inflammatory pain, as identified by American College of Rheumatology treatment guidelines (ACR, 2002), which suggested otherwise. The appraisal of Ruth’s rheumatoid arthritis as inactive was apparently based on the interpretation of laboratory findings, minimal pain reports (until the last months of life) and a lack of overt inflammatory disease activity. Clinical decision-making appeared to be complicated by an inconsistent disease presentation that existed from the time of formal diagnosis in 1971, given Ruth’s observations (as contained within the Medical Log) that “some joints swollen, but don’t hurt; others look OK but do hurt,” and a subsequent disclosure that severe hand deformities were associated with minimal pain. A lack of correlation between measures of disease activity and laboratory investigations is reportedly
not uncommon (Mooreland et al., 2001; Newman & Revenson, 1993) with rheumatoid arthritis also marked by ongoing remissions and exacerbations of inflammatory activity (ACR, 2002).

The understanding that Ruth’s rheumatoid arthritis was inactive appeared to have a significant impact on the nature and degree of ongoing medical diligence in regards to treatment management, particularly in regards to pharmaceutical treatments and the ongoing expertise of a rheumatologist. Likewise, the interpretation of various laboratory tests and physiological markers occasionally over-rode Ruth’s experiential reality, given the assumed expertise of biomedicine in defining reality and truth (Berger & Luckmann, 1966/1967; Foucault, 1963/2003; 1980). In consequence, Ruth appeared to have a distorted clinical lens through which to decipher symptoms and associated experiences, a source of disempowerment and a barrier to informed consent within clinical decision-making. For example, from 1982 to 2002 (non-inclusive), Ruth was not under the ongoing care of a rheumatologist as she understood that there was no need, eventually initiating a referral at the recommendation of friends, given severe and unremitting pain in the later weeks of her life.

The frequent marginalization of Ruth’s lived experience also appeared to limit the effectiveness of general medical care, as was consistent with research investigating the chronic illness experience, in general, and rheumatoid arthritis, in particular (Bury, 1988; Charmaz, 1983; Fair, 2003). Such marginalization appeared to contribute towards the minimization of symptomatic concerns, including that of recurrent diarrhea, dizziness, bladder urgency and fatigue, the latter symptom commonly neglected by health providers within the experience of rheumatoid arthritis (Hewlett et al., 2005). All of these symptoms, when present, significantly increased Ruth’s vulnerability to injury from falls, given a
weakened and debilitated state coupled with the risk factors associated with osteoporosis (Woolf & Pfleger, 2003). In this regard, four of the six reported falls within the Medical Log were associated with additional symptomatic concerns (other than the biomechanical instability associated with foot deformities), including dizziness, increased foot pain, debilitation following a hospitalization for gastro-intestinal bleeding and debilitation associated with severe and unremitting pain.

Likewise, the marginalization of lived experience appeared to influence decision-making regarding the need for ongoing physiotherapy. In this regard, Ruth was typically implicitly made responsible for maintaining lower extremity strength and function through self-directed exercise programs, in spite of numerous functional difficulties which impeded accurate self-appraisal, including chronic foot pain, progressive deformities in her hands and feet and recurrent skin infections on her feet that were difficult to visualize. The last documented physiotherapy treatment occurred approximately two and a half years prior to Ruth’s death, initiated through self-referral, following the painful aftermath of a fall. Unfortunately, Ruth also fell during the last week of her life, evidently compounding pre-existent severe pain. According to an informant, Ruth was frequently falling in her condominium in the later weeks of her life, a sobering disclosure given that rheumatoid arthritis was found by Ross et al. (1990) to be the only chronic illness (other than diabetes, myocardial infarction, stroke and cancer) predictive of traumatic accidental death in a retirement community.

The marginalization of experiential reality also contributed to the lack of legitimization of complaints during physician-patient interactions, a dynamic identified by Bury (1991) as common within the chronic illness experience. The devaluing effect of this
process, as articulated by Shaul (1995), was perhaps most acute when Ruth presented with increasing pain towards the later months of her life, which was defined as “not a problem” and “just arthritis,” with blood and spinal x-ray findings defined as “normal” in the weeks preceding her death. While Ruth’s physical status was viewed as normal, her experiential reality was increasingly intolerable given the presence of severe, progressive and unremitting pain. This finding was consistent with Bury (1991) who described the sharp disjunction between definitions of symptoms that are held by self and others in the face of deterioration without a sufficient explanation.

The Medical Log also suggested occasional, yet infrequent, shifts in Ruth’s self-perceptions as a patient that was associated with the presence of an ongoing and increasing symptom burden. In this regard, Ruth referred to herself as complaining or whining during medical interactions, particularly when requests for assistance persisted following ineffective medical interventions for symptom management. Likewise, in spite of a large ongoing symptom burden, Ruth wrote that she “was sick, good & proper,” when she developed an upper respiratory infection. Ruth’s subjective appraisal implicitly suggested that acute symptoms, created by an infectious agent, were regarded as more valid than chronic symptoms, that are frequently managed rather than cured. Such self-depreciation suggested that Ruth occasionally personalized inadequacies within medical care, a system critiqued by Charmaz (1983) as geared towards the treatment of acute, rather than chronic illness.

While nursing scholars have provided significant insights into the needs and lived experience of those with rheumatoid arthritis (Brown & Williams, 1995; Dildy, 1996; Edwards et al., 2007; Fair, 2003; Hewlett et al., 2005; Iaquinta & Larrabee, 2004; Melanson & Downe-Wamboldt, 2003; Plach et al., 2004; Shaul, 1995), the lack of nursing involvement
in Ruth’s ongoing medical care was consistent with the reported experience of other research participants with rheumatoid arthritis (Iaquinta & Larrabee, 2004). The absence of nurses within the offices of primary care physicians illuminated a health-care delivery gap given that the nursing roles of case management, education and compassionate support and understanding, as identified by Iaquinta & Larrabee (2004) may not otherwise be realized. While such absence was presumably driven by cultural shifts towards a cost-cutting business orientation in health care delivery (Bury, 1991), Shaul (1995) identified professional supportive assistance as important to the process of adaptation to rheumatoid arthritis, a service that benefits both health-related outcomes and, ironically, costs.

The marginalization of lived experience within health care was also associated with the relative exclusion of Ruth’s extensive social network. While relatively invisible during interactions with health care professionals, friends and extended family members offered significant emotional and instrumental support, whether through compassionate concern and regard or through shared interests and activities, unobtrusive practical assistance, occasional transportation, shared research and indirect advocacy through referral. As such, Ruth’s extensive social network was a resource that remained relatively unknown and untapped by health care professionals. However, Ruth’s preference for autonomy, privacy and independence would presumably have hindered both the identification and engagement of significant others within health care.

The lack of knowledge of Ruth’s extensive social network also prevented the identification and remediation of potential sources of psychosocial stress that were potentially impacting disease activity. In this regard, extensive research has documented the adverse effect of minor life stressors (Potter & Zautra, 1997; Zautra et al., 1989) and
interpersonal stressors, in particular (Zautra et al., 1994; Zautra et al., 1998; Zautra et al., 1997) given heightened markers of immune response and disease activity. For example, the Medical Log suggested a heightened inflammatory disease process following Ruth’s travel to the United States (see excerpt May 24-June 18, 2001), the last trip taken to oversee her brother’s residential care. According to informants, this trip was particularly stressful for Ruth as she was under pressure to take on the fulltime care of her brother and felt obligated to provide evidence of her physical limitations in order to justify her refusal. Any unrealistic expectations on the part of Harold’s health care providers might have been effectively addressed through clarifying correspondence with Ruth’s primary health care providers. Likewise, the engagement of significant others by health professionals during times of interpersonal stress might have provided some benefit to Ruth, given research has identified support as buffering consequent negative affect (Affleck et al., 1994; Zautra et al., 1998) and markers of heightened immune and disease activity (Zautra et al., 1998).

Direct interactions with medical practitioners, particularly during times of conflict and ambivalence, also illuminated the influence of predominant discourses regarding the construction of the physician-patient relationship, with the patient viewed either as an empowered consumer or as inexpert and deferent (Dixon-Woods, 2001; ten Have, 2002). In this regard, conflict, while infrequent, typically remained hidden within physician-patient relationships, lessening the influential power of the physician while limiting Ruth’s investigative spirit and mind as a resource. For example, when dissatisfied with original recommendations in regards to preventative screening tests, such as ongoing mammograms or bone density scans, Ruth repeatedly raised the issue during subsequent medical appointments or, in the latter case, self-referred to a testing program rather than directly
challenging medical opinion. In addition, when Ruth did not receive sufficient recommendations for coping with various symptoms, such as gastric complaints, fatigue, intermittent diarrhea and dizziness, third parties outside of the primary care relationship were consulted. Likewise, when Ruth was undecided regarding the advisability of hand surgery in the 1970’s, second and third opinions were sought outside of the attending surgeon, given Ruth’s fears of creating professional umbrage.

In general, physician-patient interactions regarding surgical decision-making in the 1970’s and 1980’s illuminated the implicit ambiguities and contradictions embedded within expert medical opinion, given the varying opinions offered in regards to the advisability of surgery as well as to the preferred surgical technique. In addition, the marginalization of Ruth’s lived experience appeared to negatively impact decision-making, given the predominant medical focus on what could be done, rather than “the context of meaning for medical interventions,” a context that could have provided an appreciation of Ruth’s “values and hopes” as well as her “reservoirs of agency and strength” (Barnard, 1985, as cited in Hauerwas, 1990, p. 66). Ruth eventually decided against a third hand surgery in the 1980’s as she reportedly obtained no significant functional improvement from prior surgery in the 1970’s, and had experienced severe pain in the process.

Considerable time and energy was expended by Ruth in the surgical decision-making process, given the differing expert opinions forwarded, with expense accrued to the medical system during the consultation process. This finding was consistent with Bury’s (1982) astute observation that medicine provides “an objective fixed point on a terrain of uncertainty” (p.179) for those with rheumatoid arthritis but that such knowledge frequently becomes both “ambiguous and limited” (p.179) within lived experience.
In general, Ruth was appreciated and respected within relationships with health-care providers, particularly for her investigative spirit and symptom co-management. However, when Ruth avoided direct confrontation of differences or unease within a professional relationship, she gave the impression of a silent partnership, rather than co-management. In this regard, Ruth appeared constrained by the “subject position” (Davies & Harré, 1990) of patient, lacking a sufficient, or perhaps, conflicted “interpretive repertoire” (Potter & Wetherell, 1987) through which the practice of mutual co-management could be realized. As a woman born in 1929, Ruth appeared constrained by modern biomedical constructions of the physician-patient relationship which had predated recent cultural shifts towards greater egalitarianism (Bury, 2001).

Notions of patient “co-management,” (Iaquinta & Larrabee, 2004), “partnership” (Affleck et al., 1987), “self-management,” (Katz, 2005) or “mastery” (Shaul, 1995) within the field of rheumatoid arthritis paradoxically suggest personal responsibility for health care without typically acknowledging the implicit power differential between patient and professional which influences the field of practice. As noted by ten Have (2002), the biomedical discourse shapes the patient as a guest and the physician as host, during patient-physician consultations thereby implicitly underlining the power hierarchy. According to Bury (1991), a traditional biomedical agenda has assumed that the provision of information will be met with compliance, an expectation that fails to acknowledge the limitations of existent knowledge as well as the need for negotiation around treatment regimens within the experience of chronic illness. Fair (2003) found that patients with rheumatoid arthritis typically desired a partnership with their health care provider, as well as ongoing support and education, but frequently felt dissatisfied and undermined by the implicit power imbalance.
While numerous researchers have critiqued the biomedical model for the relative exclusion of lived experience and social-cultural context, whether for reasons of effective health-care delivery (Bury, 1988, 1991; Charmaz, 1983; Fair, 2003), socio-political change (Waitzkin & Britt, 1989) or empathetic engagement (Scarry, 1985; Hauerwas, 1990; Kleinman, 1988), the explicit biomedical orientation also reflects a reification of western values and practices (Berger & Luckmann, 1966/1967; Charmaz, 1983; Hauerwas, 1990), an orientation that was also consistent with Ruth’s preferred ways of being. For example, while there were no documented instances of Ruth’s emotional state being queried, reflected or explored directly within the Medical Log, Ruth’s characteristic emotional containment and attitudes of self-sufficiency also directed attention to physical symptoms and concerns. This was particularly evident during Ruth’s last conversation with Dr. Bridges, her podiatrist, in the weeks preceding her death. In spite of severe and unremitting pain, Ruth was reportedly almost jocular in manner during the appointment. Likewise, Ruth had earlier maintained an appreciative and upbeat manner with health care providers while hospitalized in 2002, only to angrily inform Elizabeth, the main informant, on discharge, that she preferred suicide to such perceived humiliation in the future. As noted by Bury (2001), the understanding of illness narratives requires the inclusion of both context and motive as well as the influence of the presence, questions and comments of the witness. Ruth’s illness narrative shifted significantly based on contextual expectations and the degree of intimacy within dialogic interactions. For hospital professionals, Ruth enacted the role of appreciative patient reserving feelings of victimization and moral outrage for intimate friends.

While Ruth was shaped by the predominant biomedical discourse, both as a cultural resource (Foucault, 1963/2003; Bury, 1982) and through specific discursive practices
(Anspach, 1988; ten Have, 2002; Waitzkin & Britt, 1989), Ruth also co-constructed professional relationships, creating a conversational reality (Shotter, 1993) that directed fields of practice. In this manner, Ruth colluded with the biomedical agenda, marginalizing experiences that might have otherwise opened avenues for empathetic engagement. Underlying definitions of respect and dignity that were implicitly forwarded by Ruth typically remained unquestioned by health professionals, given implicitly shared values (Berger & Luckmann, 1966/1967; Charmaz, 1983) that defined Ruth’s coping style as exemplary.

The co-constructive nature of physician-patient interactions has been largely theoretically neglected, with critiques directed towards biomedical models of care for the neglect of the cultural and social-political context (Lorber, 1997; Turner, 1987; Waitzki & Britt, 1989), or the meanings subscribed to symptoms (Fair, 2003; Hewlett, 2003) or to the chronic illness experience, in general (Charmaz, 1983; Bury, 1982; 1991; Kleinman, 1988; Walker et al., 2004). As was consistent with research by ten Have (2002), reciprocal dialogic influences existed between Ruth and health care providers, interactions that co-constructed medical understanding and responses as well as Ruth’s lived experience.

Likewise, Ruth’s social world was co-constructed through the mutual acceptance of privacy, independence, and family autonomy as guiding life values, whether within interactions or as expressed in attitudes towards external support. While significant others occasionally expressed frustration with Ruth’s “fierce independence,” given a thwarted desire to assist Ruth in various ways, the typical refusal by Ruth also preserved definitions of dignity and self-respect within relationships given shared Anglo-Saxon values. As with medical providers, Ruth’s coping style was viewed as exemplary and courageous, an attitude
that was presumably co-constructive of Ruth’s preferred lived narrative (Burr, 1995; Polkinghorne, 1988), particularly within the process of meaning-making associated with her chronic illness experience (Bury, 2001).

Ruth’s characteristic privacy regarding symptomatic concerns and her preference for perseverence, accommodation and active remediation as coping strategies, was similar to the experience of others with rheumatoid arthritis (Hewlett et al., 2005; Iaquinta & Larrabee, 2004; Katz, 2005; Melanson & Downe-Wamboldt, 2003; Plach et al., 2004). As found by nursing researchers (Iaquinta & Larrabee, 2004; Plach et al., 2004), the experience of embodiment underlined Ruth’s desire to appear “normal,” with efforts directed towards the concealment of discomfort, deformities and physical limitations.

While Bury (1982; 1988) has underlined the ambiguities implicit within the legitimization and negotiation of support within the experience of rheumatoid arthritis, Ruth’s experience illuminated the need to understand support within the context of the individual’s core processes of meaning-making (Mahoney, 1991). While shared sentience provides the impetus for a compassionate response by others (Scarry, 1985), the interpretation of the act, as to whether or not assistance was desired or intrusive, depended on the meaning ascribed by Ruth within the relationship. Otherwise, social support was interpreted as a form of benevolent control, rather than empathetic in nature.

Towards the end of Ruth’s life, proven coping strategies were rendered ineffective in the presence of severe and unremitting pain. Contrary to her characteristic reserve, Ruth disclosed the severity of her pain and perceived hopelessness regarding pain remediation to significant others. While the relinquishment of control over severe pain has been identified as likely adaptive for those with rheumatoid arthritis (Schiaffino et al., 1991; Treharne et al.,
2005), and as a last stage in adaptation to chronic illness, in general, (Charmaz, 1995) this mindset apparently brought forward Ruth’s belief in suicide, particularly given the philosophical endorsement of suicide as rational in the presence of unremitting pain and suffering.

Given observations by Gatchel et al. (2007), the relinquishment of control and acceptance of suffering may also have inadvertently created vulnerability towards a depressive state. Likewise, Ruth’s difficulties in maintaining valued activities may have had a detrimental psychological effect, given research by Katz and Yalin (2001) linking such losses with the onset depression. A persistent downward health trajectory presumably had a compounding effect on both physical and psychological health, as was consistent with research by Erdal and Zautra (1995).

Unfortunately, while Ruth’s self and world was collapsing, pain was filling the vacuum left within consciousness (Scarry, 1985). Given extensive research linking the reciprocal nature of anxiety, depression and pain (Gatchel et al., 2007; Huyser & Parker, 1999; Keefe et al., 2001) a depressive state may have accompanied Ruth’s decision to commit suicide, or to “die with dignity,” depending on the perspective and philosophical lens employed (Kleespies et al., 2000; Maris et al., 2000). At the end of Ruth’s life, numerous conditions were present that have been found to be independently predictive of depression, including fatigue, pain, disability, lack of pain control and the perception that medications were ineffective (Covic et al., 2006). In this regard, Ruth may have experienced the first episode of a unipolar depression, an affective disorder that has been identified as the possible mediator between physical illness, functional impairment and elderly suicide (Conwell & Brent, 1995; Conwell, Duberstein & Caine, 2002).
Ruth’s experience, at the end of her life, was consistent with the chaos illness narrative, as identified by Frank (1995), an incoherent narrative also marked by despair and potential for suicide (Corbin & Strauss, 1987). Such longing for escape through death has been similarly reported by Shaul (1995), particularly for those with rheumatoid arthritis who are suffering with symptoms associated with an active disease process. As found by Dildy (1996), the presence of unmitigated pain hindered transformative meaning-making through which Ruth could reconstruct meaning for continued existence. Likewise, Ruth’s experience mirrored the findings of Charmaz (1983), in that a lack of physical improvement and stabilization prevented the finding of any benefits within the experiences of loss associated with debilitation. According to Melanson and Downe-Wamboldt (2003), very few older adults with established rheumatoid arthritis report any benefit from the stressors associated with rheumatoid arthritis.

Predominant psychological and biomedical and socio-cultural discourses within the field of rheumatoid arthritis offered relative silence in regards to the creation of a meaningful future in the presence of progressive pain, disability and presumed dependency. For example, biopsychosocial models of adaptation to rheumatoid arthritis have neglected existential issues related to meaning, suffering and inter-relatedness (Walker et al., 2004). In addition, the predominant biomedical discourse, focused on rational bio-physical appraisal, offered silence in regards to the reconstruction of meaning, a silence which suggested that endurance and pharmaceuticals were the only perceived alternatives.

Likewise, Ruth’s suicide reference material, a video based on the work of Humphry (1991), presented suicide within technological terms, effectively excluding the familial-social context as a resource for the restructuring of meaning. And, lastly, Ruth’s socio-cultural
context respected and typically philosophically endorsed a rational right to self-determination through suicide, particularly in the presence of unremitting suffering. Given the social construction of reality, and the self, in particular (Burr; 1995; Polkinghorne, 1988; Gergen, 1999; 2001), suicide, as defined as a valid “horizon of action” (Shotter, 1993), existed within Ruth as a dialogically co-constructed state. In this regard, Ruth was, in part, constituted by a community of internalized others (Tomm et al., 1998) who implicitly, and occasionally explicitly, endorsed her philosophical views regarding assisted suicide and euthanasia, particularly within the context of unremitting suffering. Such social endorsement would presumably have led Ruth to believe that significant others would understand her decision, even while she enacted her suicide, thereby mediating concerns of a painful, social aftermath.

Ruth’s last words to others, as represented by a suicide note, was attuned to the distress that would result from her death, yet directly expressed the reason for her act, without apparent ambivalence or redirected aggression, as was characteristic of elderly suicide notes in general (Leenaars, 2003). Likewise, the direct reference to unbearable suffering and instructions intended to protect others were also consistent with typical elderly suicide notes (Lester & Tallmer, 1994).

In addition, the violent nature of Ruth’s suicide methods (including wrist slashing, overdose and possible drowning) was consistent with the violent method chosen by 90% of women with rheumatoid arthritis who have committed suicide (Timonen e al., 2003). While also similar in regards to age and disease duration, Ruth varied from other women with rheumatoid arthritis who have committed suicide in that 90% had a comorbid diagnosis of depression, with 50% also having a history of a previous suicide attempt (Timonen et al., 2003), characteristics that were absent in Ruth’s case.
The theoretical question remains as to whether or not Ruth would have committed suicide if she had been aware that, one, her rheumatoid arthritis was, presumably active and, secondly, whether or not such knowledge could have led to more effective pain management overtime. Certainly, the interpretation of severe pain as stemming from a possible flare-up in disease activity varies from an interpretation of severe pain that is indefinite and progressively worsening. The former raises hope that a remission may still occur whereas the latter offers nothing but endurance as to what is. Research by Ganzini et al. (2000) in particular, underlined this unresolved question given the finding that 46% of patients withdrew requests for physician-assisted suicide following substantial medical interventions, whether symptomatic or psychosocial in nature, in contrast with 15% of patients who received no intervention. Unfortunately, given findings by Anderson et al. (2000), available treatments may have been less effective for Ruth given her gender, the presence of a disease process of long duration and a higher disease functional status (as presumed from deformities and associated disability).

Groopman (2004) has underlined the physicians’ seminal role in fostering hope, particularly within the experience of a severe chronic illness, also noting that physicians are generally ill-equipped through existent training. During the last month of life, Ruth had contact with three physicians, a locum physician, a podiatrist and a consulting rheumatologist, consistent with research findings that 62% of elderly adults had contact with a primary care provider within 1 month of suicide, with 35.3% having contact within a week of death (Conwell, 1997). Ruth’s lack of disclosure of suicidal intent, as well as the meticulous steps taken to avoid detection, was consistent with the reported characteristics of
elderly suicide in general, a determination that constrains the identification of suicidal intent and crisis intervention (Conwell et al., 2002).

Ironically, the legalization of physician-assisted suicide might have facilitated a disclosure of Ruth’s suicidal intentions and the nature of her pain experience. In this regard, numerous inter-related dynamics contributed towards the apparent under estimation and under treatment of Ruth’s pain, particularly towards the end of her life. These included the influence of specialization with the biomedical model of health care, with deferral of pain management to the general practitioner, the temporary absence of Ruth’s attending physician, who might have noticed Ruth’s marked physical deterioration, apparent cognitive constriction on the part of medical providers, with decisions based on laboratory and x-ray findings, the apparent sudden cessation of Aspirin in May-June 2002 (given potential adverse effects, such as gastro-intestinal bleeding), Ruth’s self-presentation during medical appointments, described as emotionally reticent yet upbeat, a fall, which compounded her pain experience in the days before her death, as well as the inherent challenges with the external representation and comprehension of pain by others, as articulated by Scarry (1985). These research findings offered additional insights into systemic, personal and interpersonal dynamics which may contribute towards the persistent under treatment of non-cancer pain within western systems of health care (Boulanger, et al., 2007; Rich, 1997).

The absence of a formal process whereby professionals were notified of Ruth’s death also suggested that health care providers may be hindered from reflecting on critical issues related to service delivery, including the possible iatrogenic effects of their practice, insights that might be otherwise gained through a case review. Such notification would have also
denoted significance to Ruth’s life as having truly mattered both within and apart from the context of professional care.

As was consistent with research investigating suicidal ideation and completed suicide in adult psychiatric populations (Beck et al., 1989; Beck et al., 1975; Beck et al., 1993; Beck et al., 1985) as well as suicidal ideation and completed suicide in the elderly (Hill, et al., 1988; Rifai, et al., 1994; Ross et al., 1990), research findings underlined the role of hopelessness as a significant influence in Ruth’s decision to commit suicide, a state that was implicit in end-of-life disclosures to significant others as well as the contents of her suicide note. While hopelessness is typically conceptualized as an intra-psychic construct, or cognitive distortion of future negative expectancies (Beck et al., 1975), the present research illuminated hopelessness as a dialogically co-constructed state (Shotter 1993) that was partly constructed through interactions with health professionals. As medicine offered the most influential empirical voice at hand, negative predictions regarding pain management and prognosis were viewed by Ruth to be rational in their appraisal. In this regard, rather than simply an individual intention, actions towards suicide were, in part, guided through conversational realities (Shotter, 1993) that constrained actions towards the further remediation of pain. While not deterministic, these conversations appeared to consolidate internal and external influences that expounded the rational right to self-determination through suicide, given the presence of unremitting suffering. In this regard, Ruth’s suicide physically substantiated a co-constructed state of hopelessness, an act that also unveiled the extent to which pain had overwhelmed experiential reality, given the totalizing effect of severe pain, as described by Scarry (1985).
Given that Ruth’s experiential world was collapsing, the power differential between Ruth and health professionals presumably expanded, magnifying their influence during dialogic interactions. While significant others were attempting to advocate indirectly on Ruth’s behalf through referral, the reported words and perceived cursory manner of the locum physician and consulting rheumatologist presumably reinforced both a state of hopelessness in Ruth, while also conveying the message that Ruth was a burden, a state that Ruth had avoided at all costs throughout her life. Given theorizing by Scarry (1985), this was precisely at the moment when Ruth required an advocate, or “worldly self-extension,” (p. 50) by another, in order to remain secure in the knowledge that hope was maintained in the midst of her collapsing world, that a meaningful life would eventually be restored, within a committed community of care.

Ruth’s diminishment by pain underlined the need for the body to be incorporated as an essential reality within the theoretical underpinnings of health related research, as advocated by numerous researchers (Williams; 1999; Willig; 2000; Yardley; 1996). As evident within Ruth’s experience, the extent of her pain, particularly at the end of her life, remained relatively invisible to others, while also remaining resistant to accessibility through dialogic means (Scarry, 1985). To otherwise neglect the impact of physical deterioration and pain, risks a lack of understanding of the disempowered person, increasing the potential for acts which may be lacking in both compassion and ethics. In particular, the present research illuminated the moral responsibility of others, to serve as advocates or, at least, empathetic witnesses, in order to sustain hope within the experience of severe and unremitting pain.
Clinical Implications

There were numerous research findings with clinical implications for various disciplines, including nursing, physiotherapy, psychology and medicine. For purposes of the present research, clinical implications specific to counselling psychology will be explicated.

Given the understanding that discourses are constitutive of identity, subjectivity and agency, the present research reinforced the need for the counselling psychologist to understand the individual at the intersection of self and culture (Gergen, 1999; 2001; Parker, 1992; 2002; Willig, 2001) and the body (Scarry, 1985; Williams, 1999; Willig, 2000; Yardley, 1996).

Narrative therapists, in particular, have demonstrated that attending to the adverse effects of dominant discourses in an individual’s life frequently facilitates therapeutic movement towards a preferred way of being (Freedman & Combs, 1996; White, 1991; White & Epston, 1990). According to Gergen (1999; 2001), all therapeutic practices are inherently value-laden in their effect, in either challenging or sustaining constituting discourses. For example, dialogic interactions with an individual with rheumatoid arthritis will inevitably sustain or challenge various constructions of the physician-patient role, as identified by Dixon-Woods (2001), thereby empowering or disempowering a client to identify the preferred subjectivities through which to live (Willig, 2000).

Counselling psychologists are also well positioned to serve as client advocates, particularly in facilitating understanding of the experience of a painful and progressive chronic illness within medical contexts or otherwise. Such practices resist the effects of disciplinary divisions that are inherent within the standard biopsychosocial models of care (Yardley, 1996) while also potentially facilitating understanding of the effect of constitutive
discourses. In particular, professionals and non-professionals alike are under a moral imperative to advocate for those who are in severe pain and otherwise disempowered (Scarry, 1985), a salient cultural issue given the persistent under treatment of non-cancer pain within western culture (Boulanger et al., 2007; Rich, 1997).

In addition, the therapeutic context may provide an opportunity for the exploration of existential issues, such as the meaning of suffering or definitions of respect and dignity within the chronic illness experience, conversations which may be otherwise absent within medical or social contexts. The need for such dialogue is particularly important within the experience of a deteriorative, painful, and disabling chronic illness, given both the centrality of loss (Charmaz, 1983) and the marginalization of existential issues, within predominant psychological (Walker et al., 2004) and biomedical (Charmaz, 1983; Kleinman, 1981) discourses. Such dialogue may assist in the reconstruction of meaning within the experience of ongoing loss (Neimeyer, 2001), assisting individuals to identify a preferred way of being for the present and future. As noted by Kleespies et al. (2000), with appropriate training, psychologists may also have a significant role in addressing end-of-life issues, promoting communication and decision-making, albeit within existing legal parameters. The pervasive endorsement of suicide as potentially rational among mental health professionals (Ogden & Young, 1998; Werth & Corbia, 1995) underlines the ethical imperative for professional consultation and supervision, particularly if the rationality of suicide is explored within therapeutic conversations.

The present research also highlighted the need to attend to discourses which are both explicit and implicit within lived experience, given that the latter may have a powerful, yet unacknowledged constitutive effect. For example, the present research illuminated the way
in which the expert/power differential (Foucault, 1963/2003; 1980) was heightened during times of conflict, ambiguity or unease within a professional relationship. The present research clearly demonstrated that conflict will exert an influence within a professional relationship but remain relatively hidden if not openly acknowledged as inevitably present. Such findings underlined White’s (1991) recommendation that mental health professionals openly acknowledge the effects of the power differential within the therapeutic relationship with their clients. The professional owns the ongoing responsibility to be reflexively aware of their co-constructive role within the therapeutic process (Gergen, 1999), particularly during times of conflict, ambiguity or unease as such processes may signal contested constructions of meaning. Otherwise, the professional remains responsible for actively addressing the client’s experience of the power imbalance throughout the relationship through skills such as immediacy (Egan, 1990), with a goal towards enhanced understanding and mutuality.

Most significantly, the present research illuminated the influence of professionals, as well as significant others, in the dialogic co-construction of meaning, intentions and emotional states (Shotter, 1993), both within immediate interactions and as enduring internalized others (Tomm et al., 1998). As Gergen (1999) has succinctly stated, “we are made up of each other,” (p. 138), existing primarily as “relational selves,” in that emotions, thoughts and intensions are inseparable from processes of social interaction, whether verbal or symbolic in nature.

While research has repeatedly underlined the need to assess hopelessness in determining suicide potential (Beck et al., 1989; Beck et al., 1975; Beck et al., 1993; Beck et al., 1985), the present research also illuminated the need to attend to the dialogic co-
construction of hope, or despair, within the professional relationship. For example, a suicidal client might be queried as to what, within the therapeutic relational context, fosters hope for a better future or consolidates despair within present life circumstances. As such, research findings suggest an additional clinical strategy that may be used in conjunction with recommended cognitive-behavioural interventions for the care of suicidal individuals in general (Jobes, Rudd, Overholser, & Joiner, 2008).

Ruth’s lived experience with rheumatoid arthritis also illuminated the loss of hope that may be particularly marked during times of illness downturns that are painful and devoid of sustained improvement (Charmaz, 1983; Corbin & Strauss, 1987; Dildy, 1996). Such periods call for particular professional vigilance in regards to dialogic influences, whether within a therapeutic context or otherwise, as self-representation and hope may increasingly depend on empathetic representation by another (Scarry, 1985). As noted by Corbin and Strauss (1987), without hope, there is no incentive for embracing the future and shifting towards a state of acceptance within given life circumstances.

**Limitations of the Present Research**

The present research focused on an exploration of the discourses constitutive of the lived experience of a particular woman, situated within a unique personal and socio-cultural matrix. While providing a narrative that informed the understanding of the intersection between self, body and culture, Ruth’s experience was unique and cannot be extrapolated to others. In this regard, the influence of race, age, sex, marital status, education and socio-cultural context will inevitable intersect in a unique fashion within the experience of a chronic deteriorative and painful illness, or otherwise. As such, research findings cannot be generalized to the experience of others.
Given the retrospective self-report of informants, verbal archival material was potentially influenced by subjective interpretation and selection bias. Given a desire on the part of several informants to engage in the research project as a means of honouring Ruth, this bias may have a positive trend, particularly given shared values regarding privacy, independence and family autonomy. In addition, as the majority of informants viewed Ruth’s suicide as rational, there may be an under-reporting of depressive symptoms, particularly towards the end of her life. The provision of written archival material, such as letters, documents and photographs, in particular, may have been similarly affected.

The use of written archival material, such as the Medical Log, also contained the inherent risk of a bias through the omission of significant information. There were numerous significant events and interactions, as disclosed by informants, which were not contained within the Medical Log, given that Ruth’s reasons for documentation were presumably at variance with research purposes. For example, there was no reference of Ruth’s refusal of home-based assistance that was considered as part of discharge planning during an inpatient hospitalization in May-June 2002. Likewise, there was no documentation of Ruth’s anger and feelings of degradations voiced in response to an inpatient hospital experience, a state that remained both undocumented and unknown to health care providers. Most significantly, at the end of her life, there were no explicit references to Ruth’s state of hopelessness and desperation regarding adequate pain management, nor to her suicidal resolve.

The research analysis and discussion of constitutive biomedical, psychological and socio-cultural discourses also occurred through the interpretative bias and subjectivity of the researcher, and, as such, do not represent truth claims. The findings are far from exhaustive and are limited by various constraints. Another researcher might also have highlighted
different aspects of Ruth’s experience, or might have focused on different constitutive discourses that were not the present focus, such as age, and gender. In this regard, the act of writing solidified a representation that inevitably could not contain the complexity of lived experience (Josselson, 1996), but instead offered a simulacra or a verisimilitude of Ruth’s lived experience through multiple lenses.

**Future Research**

The present research has demonstrated the utility of a discourse analytic approach in understanding the constitutive effects of discourse on identity, subjectivity and agency within the lived experience of a chronic painful illness. In turn, the investigation of unique experience within the intersection of self, body and culture has illuminated constituting discourses in novel ways. An investigation into the lives of other individuals with rheumatoid arthritis, including those who differ in respect to age, gender, race, marital status or socio-economic backgrounds, would provide further understanding as to the constitutive effect of discourses within the lived experience of a chronic painful illness, such as rheumatoid arthritis. Each investigation has the potential to illuminate embodied experience in a unique fashion, given the distinctness of individual experience as an archive of cultural practices (Foucault, 1976/1990; Scarry, 1985; Willig, 2000). Such research would privilege lived experience as a source of enlightenment as to the constitutive effects of expert knowledge/power (Foucault, 1963/2003; 1980; Parker 1992; 2002; Willig, 2001) and provide insight into avenues of empowerment within the embodied experience of health and illness (Willig, 2000).

Given the effects of severe pain on the person, there exists a moral imperative for continued research in order to externally substantiate an otherwise private experience within
the public domain (Scarry, 1985). As noted by Scarry (1985), such substantiation fosters social legitimization and the consequent allocation of cultural resources. Such research activity would also potentially further understanding into existent cultural practices which foster the under treatment of noncancer pain (Boulanger et al., 2007; Rich, 1997).

As a discipline, counselling psychology is well situated to understand the constitutive effect of discourse on lived experience, whether within a painful and deteriorative illness, such as rheumatoid arthritis, or otherwise. Such an approach could be used to investigate the constituting effect of discourse in a broad range of issues and contexts, including that of health, education, mental health and social services, using spoken or written narratives as archival material for investigation.

While a psychological autopsy approach is typically used to investigate the multi-determined nature of suicide (Cronwell et al., 2002; Pearson, 2000), a discourse analytic approach broadens the research field to include complex dialogic influences, thereby encompassing the socio-cultural, as well as, the intrapersonal context. In particular, the present research underlined the need to investigate the dialogic co-construction of hopeless as an influence in suicide, a construct identified as predictive of suicidal ideation and completed suicide in adults (Beck et al., 1989; Beck et al., 1975; Beck et al., 1993; Beck et al., 1985) and the elderly (Hill et al., 1988; Rifai et al., 1994; Ross et al., 1990). In particular, research investigation of dialogic processes with health professionals, which precede the act of suicide, may foster recognition of conversational realities (Shotter, 1993) which may have an iatrogenic effect, albeit unintentionally. Such research could potentially foster the identification of attitudes, words and behaviours, which could facilitate the relational existence of hope, particularly for those who are disempowered or otherwise disheartened.
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APPENDICES

Appendix A: Certificate of Approval

The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

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<th>DEPARTMENT</th>
<th>NUMBER</th>
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<td>Educ &amp; Couns Psych &amp; Spec Educ</td>
<td>B04-0586</td>
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<td>Friesen, Heather, Counselling Psychology</td>
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<td>1 year</td>
<td>July 26, 2004, Contact letter / Consent form</td>
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**CERTIFICATION:**

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of the following:

- Dr. James Frankish, Chair,
- Dr. Cay Holbrook, Associate Chair,
- Dr. Susan Rowley, Associate Chair
- Dr. Anita Hubley, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.

*Information has been masked throughout the appendices in order to maintain confidentiality and privacy when appropriate.*
Appendix B: Consent for Research Use of Diary

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational and Counselling Psychology, and Special Education
Faculty of Education
2125 Main Mall
Vancouver, B.C. Canada V6T 1Z4

CONSENT FOR RESEARCH USE OF DIARY

Title: Illuminating Discourse Through Lived Experience With Rheumatoid Arthritis

Principal Investigator: Dr. Marla Arvay, Department of Educational and Counselling Psychology and Special Education, University of British Columbia. Telephone: (604) 822-4625.

Co-Investigator: Heather Friesen, BScN, MA, PhD Candidate; Department of Educational and Special Education, University of British Columbia. Telephone: (604)

I...........................................hereby grant Heather Friesen permission to use the diary of ....................................for research purposes solely related to her doctoral dissertation. I understand that the diary may be duplicated to protect against damage or loss and that it will be stored in a locked filing cabinet. I understand that specific segments of the diary may be disclosed for research purposes but that steps will be taken to maintain anonymity and confidentiality for the author and any third parties. I understand that the original and complete diary will be returned to my possession when the study is completed.

Date:__________________________

Signature of Informant:__________________________

Signature of Researcher:__________________________

version: July 26, 2004
Appendix C: Letter of Introduction by Main Informant

January 03, 2006

Dear friends and relatives of [Name],

I am writing this letter to introduce Heather Friesen, a doctoral student at UBC. Heather's dissertation is titled *Illuminating Discourse through Lived Experience with Rheumatoid Arthritis*.

I have been acquainted with Heather for several years. She is highly respected both as a therapist and as a researcher. Heather is a very sensitive person and has the utmost respect for the diary that she left which details her medical experience of living with rheumatoid arthritis. The research proposal has met the stringent requirements of the UBC ethics committee.

It is my hope that you will be able to provide background information regarding [Name]'s life.

... had such an inquiring mind and was fascinated by research. I think she would have been pleased that her experience might in some way benefit others suffering from the same crippling disease.

Sincerely,
Appendix D: Invitation to Participate in a Research Study

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational and Counselling Psychology, and Special Education
Faculty of Education
2154 Main Mall
Vancouver, B.C. Canada V6T 1Z4

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Principle Investigator: Dr. Maria Arvay, Department of Educational and Counselling Psychology and Special Education, University of British Columbia. Telephone: (604) 822-4625

Co-Investigator: Heather Friesen, BScN, MA, PhD Candidate, Department of Educational and Counselling Psychology and Special Education, University of British Columbia. Telephone: (604)

Title: Illuminating Discourse Through Lived Experience with Rheumatoid Arthritis

Date:

Dear ........,

I have been given your name by ........................................ as I understand that you were acquainted with........................................
I am presently involved in a doctoral research project in which I am studying a 40 year diary kept by........................................given that ........................................ has granted permission for the use of the diary for research purposes. The purpose of the research is to gain a better understanding of rheumatoid arthritis from the life of someone who experienced such a painful chronic illness first hand.

I am contacting you as I am seeking background information regarding ........................................ to better understand her diary and life circumstances. I believe you would make a valuable contribution to this research given the nature of your relationship with........................................

If you are interested in participating, please sign the enclosed consent form and mail to the address provided below. Please indicate your
telephone number and times that you may be reached at the bottom of the consent form so we can arrange for an interview at our mutual convenience. If you have any questions regarding the research study or your participation, I may be reached at (604) or by email at hfriesen@shaw.ca

Mailing Address: Heather Friesen

Yours Sincerely,

Heather Friesen, BScN, MA, PhD Candidate
Appendix E: Consent Form for Research Participation

THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational and Counselling Psychology, and Special Education
Faculty of Education
2125 Main Mall
Vancouver, B.C., Canada V6T 1Z4

CONSENT FORM FOR RESEARCH PARTICIPATION

Title: Illuminating Discourse Through Lived Experience With Rheumatoid Arthritis

Principal Investigator: Dr. Marina Arvay, Department of Educational and Counselling Psychology and Special Education, University of British Columbia. Telephone: (604) 822-4625

Co-Investigator: Heather Friesen, BScN, MA, PhD Candidate, Department of Educational and Counselling Psychology and Special Education, University of British Columbia. Telephone: (604)

Purpose: The purpose of the study is to understand rheumatoid arthritis from the life of someone who experienced such a painful chronic illness first hand. This research study is for the dissertation of Heather Friesen.

Procedures: You will be asked to provide background information regarding..............................in order that I may better understand her diary and life circumstances. Participation would involve being interviewed for approximately 1 to 3 hours on 1 or 2 separate occasions. The interview will be recorded manually. You will not be audiotaped. A summary of the research results will be available on request.

If, at any point in the interview, you wish to withdraw your participation from this research study, please inform me and your request will be honoured.

Confidentiality:

Your identity will be kept strictly confidential. Other informants will
CONSENT FOR RESEARCH PARTICIPATION (continued)

not be aware of your participation nor will your comments be directly shared with other informants, even if other informants have provided contact information. Steps will be taken to protect your identity should your information be used in the research project, either published or unpublished. For example, your name, age and relationship with the diarist will be altered or remain anonymous. Permission will be sought for the use of direct quotes. The following steps will also be taken to ensure that your confidentiality is maintained.

1. All information obtained in this research study will be stored in a locked filing cabinet.

2. All computer files will be locked with a password.

3. The locked filing cabinet containing the research information will only be directly accessible by Heather Friesen.

As per university policy, all information obtained in this research study cannot be destroyed until at least five years after presentation or publication of the research findings in a refereed academic journal. If we become interested in using your information in a new research study, you will be re-contacted for consent. After the five year period, all information obtained in this research study will be manually shredded.

Potential for Risk: We are aware that ........................................ended her life after suffering much pain and disability from rheumatoid arthritis. Please inform Heather Friesen if you are experiencing any emotional distress during the research interview. A list of affordable counselling and related services will be made available to you prior to the interview should you desire follow-up assistance.

Compensation:

There is no financial compensation should you choose to participate. The research study is not under a funding agreement with any agency or institution.

Contact:

If you have any questions or desire further information with respect to the study, please contact Heather Friesen at (604) or Dr. Marla Arvay at (604) 822-4625.

If you have any concern about your treatment or rights as a research participant, you may contact the Director of Research Services at the University of British Columbia at (604) 822-8598.

2
CONSENT FORM FOR RESEARCH PARTICIPATION (continued)

Consent:

If you have any questions about the research study or your participation in it, please address these with Heather Friesen before signing the consent form.

I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time.

I have a duplicate of the consent form for my own records.

My signature below indicates that I consent to participate in this study:

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<th>Name (please print)</th>
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Please indicate your telephone number and times that you are available below so that an interview can be arranged at a mutually convenient time and place.

Phone number...........................................Times available...........................................

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version: July 26, 2004
Appendix F: Semi-Structured Interview Questions

Questions for the main informant:

- What was the nature of your relationship with ___? How long have you had a relationship with ___?

- I am interested in understanding ___’s family and cultural heritage. Please describe ___’s ethnic and cultural background and her immediate family (i.e., how many siblings, nature of relationships, etc.)

- Please describe ___’s childhood and significant events that occurred during this time period (i.e., accidents, traumatic incidents, etc.) that you are aware of.

- Is there a family history of any significant medical or mental illness?

- Please describe how the family would typically respond to physical and emotional stress.

- Please describe ___’s personal, social and work-related history as an adult (i.e., What was ___’s marital status? Did she have any children? How would you describe her social network? What was ___’s education background? How was she employed throughout adulthood?)

- Are you aware of any significant events that occurred during ___’s adulthood (i.e., accidents, traumatic incidents, etc.)? How would ___ typically respond to physical and emotional stress?

- Please describe ___’s medical history. What medical and complementary/alternative resources would ___ typically utilize? Are you aware of any history of mental illness?

- Did ___ ever access counselling/psychological resources?

- Please describe ___’s religious/spiritual practices and beliefs.

- Given that you have read ___’s diary, what were your general impressions?

Questions listed on the next page for informants in general were also included for the main informant, with medical informants asked questions from either source when appropriate.
Questions for informants in general:

- What was the nature of your relationship with ___? How long have you had a relationship with ___?
- What impact did chronic illness (rheumatoid arthritis) and pain have on ___’s life?
- How did ___ cope with rheumatoid arthritis? How did she cope with pain? What resources did ___ use in grappling with rheumatoid arthritis and pain? Did ___ discuss the benefits and difficulties associated with these resources?
- How did the experience of chronic illness and pain effect ___’s identity (or sense of herself)? How did the experience of a chronic illness and pain effect how ___ experienced life in general? How did the experience of chronic illness and pain effect ___’s sense of agency (her ability to act and shape her life as she preferred)?
- What meaning did ___ give to having rheumatoid arthritis (i.e., why she had the disease while others did not)?
- Have you any information that would suggest that ___ was grappling with depression?
- Was ___ grappling with any other mental illnesses that you are aware of?
- Are you aware of any major traumatic event in ___’s life (both during childhood and adulthood)?
- In your opinion, what led to ___’s decision to take her own life? How have you been effected by ___’s decision to end her own life?
- What do you hope will be accomplished through your decision to be involved in this research project (for yourself, for ___, for others)?