

**IN THE COMPANY OF MUSIC AND ILLNESS: THE EXPERIENCE AND MEANING
OF MUSIC LISTENING FOR WOMEN LIVING WITH CHRONIC ILLNESS**

by

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¹*SYNOPSIS OF THE EVENING'S PREMIERE / ABSTRACT*

The purpose of this study was to contribute an experiential understanding of everyday music listening experiences through a text that also conveyed a pathic way of knowing. I studied the phenomenon of music listening in the particular context of women living with chronic illness (i.e., a physical condition that is managed rather than cured), and in keeping with van Manen's (1990, 2000) applied hermeneutic-phenomenological approach. Van Manen's approach to phenomenological inquiry emphasizes implementation of the *reductio* (the reduction), attention to the *vocatio* (the vocative dimension), and the use of empirical and reflective methods to generate and analyze data. The question that guided this study was: What is the lived experience and lived meaning of music listening for women living with chronic illness?

Six women were interviewed in multiple conversations about their music listening experiences. All lived with chronic illness, and identified music listening as important in their lives. Following an initial analysis based on multiple readings from holistic, selective, and detailed perspectives, I used a guided existential reflection based on lived body, lived time, lived space, and lived relation to further understand, organize, and reveal the many ways in which the women listened to music. Writing and rewriting in a reflective and dialogical manner were grounding elements of analysis.

¹ Suggestive terminology is used through the present study in order to create a poetic and vocative text, which is an integral part of van Manen's (1990) applied hermeneutic-phenomenological method. The dissertation is envisioned as a premiere performance of *"A Sonata to Show"* (Chapter IV), framed by a *"Prelude"* (Chapter I) and *"Postlude"* (Chapter V), and accompanied by *"Concert Notes"* (Chapter II) to orient listeners, an *"Eavesdropping Behind the Scenes"* (Chapter III) to overview the technical matters associated with the creation and launch of the work, as well as a *"Programme"* (Table of Contents) and *"Synopsis of the Evening's Premiere"* (Abstract).

Findings contribute in several ways. Most broadly, the final text was constructed to communicate an understanding that is embodied and discursive (i.e., knowledge as participation), and that leads to personal formative knowledge (i.e., knowledge as being). As a phenomenology of music listening, results suggested that to listen to music is to be in the company of music; that is, to be with a longtime companion who ultimately aids in accommodating the unanticipated arrival of chronic illness. Implications include future research to further investigate the complex, relational dynamics associated with music listening experiences, as well as the possibility of the body as a source of knowledge (i.e., mind-body), acting as a musical compass in music listening experiences. Implications for counselling practice are also described.

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Thank you.

OFFERING TO THE MUSES / DEDICATION

I dedicate this work to those who are to either side of me and between whom I live.

For my sons—Keegan James Nicol and Payton James Nicol—who imbue my life with wonder, vitality, and simple pleasures; and whose lives I hope are filled and blessed with the company of music.

And for my parents—Brian Robert James and Mary Jane James—my longstanding anchors.

Give me love

Give me love, give me joy, give me pain, give me life

Give me starting again

Give me hope

Give me hope, give me sun, give me rain, give me up

Give me dancing again

Give me life

Give me life, give me high, give me low, give me truth

Give me something to know

Give me time

Give me time, give me a room, give me a roof, give me a sign

Give me reason to hope

Give me reason to hope

Give me hope, give me hope, give me hope, give me hope

- Roger Hodgson

PRELUDE / INTRODUCTION

prelude; anything played before and as a way of introduction to the main work

Whether listening, playing instruments, moving and dancing, singing, improvising, or composing, people across all cultures are touched by music (e.g., Sachs, 1962). Music is an art form that appeals to our emotional, cognitive, physical, and spiritual senses. Music is unique amongst the arts because it exists in time and fills space, but cannot be touched. In the Western world, music listening is a particularly common and prevalent music experience that requires minimal materials, preparation, or environmental specifications, as well as no special expertise or training.

As a musician, music listener, and music therapist, I wondered what was known about everyday music listening experiences—not music that reflected learning or involved music therapy experiences; and not music studied elementally or philosophically rendered in abstract language. I was curious about everyday music listening experiences that fill people's lives when they awaken to a clock-radio, do chores, drive, exercise, walk, socialize, or just listen. This kind of experience belongs to the lifeworld because it is lived and understood without a "theoretical attitude" (van Manen, 1990, p. 182). Lived experience involves "awareness that is unaware of itself" (p. 35) until intentionally reflected upon; but with reflection, the meaning of lived experience (i.e., lived meaning) can be grasped and illuminated. Lived meaning refers to that which is real and meaningful in how we experience and understand our world (van Manen, 1990), meaning that is immediate, experiential, and largely pre-verbal (van Manen, 1990). Explorations of the lifeworld (i.e., the world of immediate experience) are commonly associated with phenomenological approaches to research—studies of phenomena in order to discern that which is not obvious or apparent.

In turning to the music research, I found a rich but disparate body of knowledge. As noted by one researcher, “experiments and observation have been conducted without any overview or sense of priority” (Swanick, 1988, p. 20). Multiple perspectives and multiple methods convey information on aspects of music that exist independent of each other, separated by the multiple boundaries that delineate aesthetic philosophy, music psychology, music education, and music therapy, for example. I approached the literature by considering the empirical, theoretical, and popular press work on music listening as well as noting general perspectives found in historical and contemporary accounts.

Empirical studies supported a link between music listening and positive outcomes such as reducing anxiety (e.g., Stratton, 1993), increasing attention spans (e.g., Cripe, 1985), and positively altering pain perception (e.g., Schorr, 1993); however, these findings were highly specific. Research occurred in experimental laboratories away from everyday listening, or in clinical settings under non-typical circumstances—for example, dental work (Anderson, Baron, & Logan, 1991); labor (Gonzalez, 1989), and invasive medical procedures (e.g., Barker, 1991; Metzler & Berman, 1991)—in which participants experienced acute stressors or were asked to complete specific tasks. Music also tended to be used as a background experimental condition, usually without consideration of participants’ listening preferences. Participants filled in questionnaires, completed prescribed tasks, and submitted to various physiological measures; but, they were not asked about their personal experiences of music listening.

Theoretical accounts revealed the difficulties of extrapolating beyond the narrow findings of empirical research. Maranto (1993) suggested that distraction was the primary psychological function of music listening in diminishing negative emotions. Fried (1993) focused on breathing and music’s effectiveness in lengthening and deepening breath, which

encourages relaxation. Other authors extrapolated concepts and understandings from broader theoretical frameworks such as behaviorism (e.g., Sears, 1968), psychoanalysis (e.g., Kohut, 1978), Piagetian developmental theory (e.g., Swanick, 1988), and cognitive theory (e.g., Reimer, 1989). Perspectives linked more strongly to lived experience were not specific to music listening. For example, Kenny (1989) conceptualized the process of music therapy improvisation with constructs that grew out of her clinical music therapy work, and Ruud (1998) presented an emerging theory of music identity based on musical autobiographies that reflected individuals' experiences in music over time.

The popular press provided descriptions of lived experiences in music listening, but meaning was typically overlaid rather than anchored in the lifeworld. For example, Joudry (1984) and Campbell (1997) grounded their work in Tomatis' biopsychosocial therapeutic approach to communication, language, and learning; and, Bonny and Savary (1990) used a psychoanalytic perspective to explain their work. Thus, lived experience was described but lived meaning was not.

I concluded that although music listening was generally acknowledged as a significant human experience, little attention had been focused on documenting the lived nature of the phenomenon. Music listening may be such a common and pervasive experience that it is assumed to be understood. For the most part, this is not the case.

Four studies were identified that offered insight into the lived experience and lived meaning of music listening; that is, phenomenological insight that is descriptive and interpretive. Nelson (1994) interviewed 21 university students (14 men, 7 women) about personally meaningful music that they brought in and described to him as it played; and Pederson (1994) had 6 adults (4 women, 2 men) keep audiotaped journals of music listening experiences that

spontaneously occurred over a 7-day period, which she then discussed with them.

Schonhammer (1989) reflected on music listening that occurred with the use of portable cassette players (i.e., Walkmans), and Ihde (1976) considered music listening as part of his interest in the general phenomenon of listening. These authors explored lived experience and meaning, and their works offer a context within which to further elaborate the phenomenon of music listening.

These studies are atypical and stand apart from the rest of the literature. They are also not well positioned to garner attention: two are unpublished dissertations (Nelson, 1994; Pederson, 1994), one appears in a journal of limited circulation (Schonhammer, 1989), and the other is in book format with a title that does not indicate that music listening is part of its topic (Ihde, 1976). I make these points in order to support a conclusion that limited attention has been given to the phenomenon of music listening and its place in the lives of individuals, and further research into the lived experience and meaning of music listening is appropriate in terms of contributing to the extant literature and promoting the value of returning to the phenomenon itself.

As two phenomenological inquiries (Nelson, 1994; Pederson, 1994) had explored music listening in the general life context, I decided to focus on a particular life context. By exploration of the phenomenon within a specific type of lifeworld, music listening examples would emerge that similarly or differently highlighted elements of the phenomenon already identified by Nelson (1994) and Pederson (1994). This parallels the analytic strategy of varying the example in order to uncover further phenomenological understanding (van Manen, 1990).

I chose to concentrate specifically on music listening experienced in the context of women living with chronic illness (i.e., a physical condition that is managed rather than cured). Chronic illness was an obvious choice for study because its impact is significant (e.g., 55% of

Canadians over 14 years of age live with chronic illness according to Statistics Canada, 1995); Western biomedicine has been challenged to meet the needs associated with chronic illness (e.g., Lubkin, 1998); and my personal knowledge of chronic illness led me to anticipate music listening benefits for lives lived with chronic illness. Gender differences have been described in the experience of chronic illness (e.g., Ablon, 1996; Charmaz, 1995) as well as in its incidence (i.e., higher prevalence across most conditions that increases with age), so a focus on women's experiences was appropriate. My interest in pragmatic applications parallels growing precedents for applied applications of phenomenological research (e.g., Caelli, 2000; van Manen, 2000), a trend characterizing the health sciences where concrete (e.g., counselling women with distorted body image, Cairns, 1999) rather than abstract phenomena (e.g., perception, Merleau-Ponty, 1962) are generally studied.

A review of the chronic illness literature revealed a recent surge in chronic illness research by nurse researchers investigating the everyday lived experience and meaning of chronic illness. Research suggested that chronic illness is associated with multiple impacts that bring longstanding and unpredictable disruptions in all aspects of life (e.g., Jensen & Allen, 1994; Morse & Johnson, 1991). Physical symptoms and adjustments are not as challenging as the psychological effects associated with chronic illness (e.g., Gerhardt, 1990; Hwu, 1995). Loss is a pervasive theme (e.g., Schaefer, 1995), especially loss of self (e.g., Charmaz, 1983; Dildy, 1996). Many researchers have identified meaning-making as the necessary counterweight to experiences of loss and ensuing negative meanings (e.g., Gullickson, 1993). The development of meaning is closely aligned with another recurrent theme in the literature—transformation—that involves restructuring the illness experience and restructuring the self (e.g., Paterson, Thorne, Crawford, & Tarko, 1999). Fife (1994) noted that participants who did not experience

transformation (i.e., the development of new positive meaning) felt stigmatized and withdrew socially, or panicked and tried to accomplish as much as possible, or lived with an attitude of passive resignation.

I found three theoretical accounts and one empirical investigation that linked music and/or music listening and chronic illness. Csikszentmihalyi (1990) speculated that “serious” music listening evokes flow experiences—states of concentration in which there is complete absorption in an activity—that are positively related to health and quality of life because of their effects on attention and goal-oriented behavior. Ruud (1997) hypothesized that his research in music and identity also implicates benefits for health and quality of life. Drawing on the stress and coping work of Antonovsky (1987), Rudd posited that music facilitates feelings of life as predictable, manageable, and meaningful, factors associated with health. Sacks (1984) described a music-catalyzed recovery from a neurological injury that he came to believe was associated with musically evoked lived time and space experiences, which generated new action potentials and acted on the body in a transformative manner. Schorr (1993) reported significant findings for women who listened to music and perceived less pain, which she interpreted as supporting a model of health as expanding consciousness (Newman, 1990), a model that also implicates music as an action-provoking medium because of its effect on lived space, time, and body.

Common themes run through the two literatures and suggest potential pairings between the needs associated with chronic illness and the effects associated with music listening. For example, chronic illness evokes unsettling feelings and loss experiences that lead to a preoccupation with life's meaning and value. Music has a strong association with feelings,

conveys experiences of socialization, order, structure, and transcendence, and has been linked with identity formation.

In summary, the present study addressed a general lack of hermeneutic-phenomenological knowledge about everyday music listening experiences. Given the few investigations of music listeners themselves and the potential beneficial implications for those living with chronic illness, I concluded that an applied hermeneutic-phenomenological study, which explicated lived experience as well as lived meaning in terms of practical implications for living, was appropriate. The focus was narrowed to women living with chronic illness given my interest in women's experiences, the prevalence of chronic illness in Canadian women, and precedents that establish chronic illness as an experience affected by gender. Such an investigation was construed as contributing to the research literature by (a) returning attention to understanding the phenomenon as it is lived, a perspective currently not well represented in the literature; (b) using multiple in-depth interviews to further understanding of the experience of chronic illness over time; and (c) possibly implicating therapeutic ramifications of music listening benefits for chronic illness, a topic that remains unexplored in terms everyday life.

CONCERT NOTES / LITERATURE REVIEW

concert notes; familiarize concert listeners with the work(s) to be performed

The research question—what is the lived experience and lived meaning of music listening for women who live with chronic illness?—reflects an intersection of personal, professional, and research interests shaped by the extant research on chronic illness and music, specifically music listening. In this chapter, I include literature that was identified prior to and in the early stages of the inquiry. Pertinent research identified in the later stages of the inquiry as a result of analysis is presented in the discussion chapter. Two phenomenological dissertations on the lived experience of music listening (Nelson, 1994; Pederson, 1994), a phenomenological study of listening and voice (Ihde, 1976), and another focusing on music listening with the use of Walkmans (Shonhammer, 1989) are also discussed in Chapter V because this literature was not reviewed until after analysis ended. This delay is in keeping with the strategic practice of reviewing other pertinent phenomenological studies after results are compiled in order to retain openness to the phenomenon and to minimize the influence of interpretive pre-understandings (van Manen, 2000).

In this chapter, I review research in the two broad areas of chronic illness and music in order to demonstrate the meaningfulness and appropriateness of the research question. In the present study, chronic illness provides the context within which music listening—the phenomenon of primary interest—is explored. The review of the chronic illness literature is meant to (a) establish the current and increasing incidence of chronic illness, yet formative state of understanding in terms of its impact and management, (b) identify themes emerging in human science research about living with and managing chronic illness, and (c) begin to recognize possibilities for the benefits of music listening in lives with chronic illness. The music literature

is reviewed in order to (a) establish the breadth and range of music research, (b) recognize the inattention to music listening experiences as they occur in everyday life, and (c) begin to reflect on how music listening might affect and fit into lives lived with chronic illness.

First, I introduce chronic illness in terms of its definition and incidence, followed by a consideration of the changing medical context where chronic illness is diagnosed, and subsequently treated and managed. I introduce the Western biomedical perspective, identify early sociological and anthropological influences challenging biomedicine, and then describe the field of health psychology and its narrower human science focus, where this inquiry locates itself. Next, I identify a number of conceptual issues that complicate human science research on chronic illness: issues of definition, sampling, representation, and design. Last, I review research that speaks to the personal context of chronic illness. Women and chronic illness, then general models for understanding chronic illness are summarized, followed by findings on the experience of living with chronic illness. I conclude this first part of the chapter with a summary that provides a measure against which to identify general contributions of the study (i.e., its place within the extant chronic illness literature) as well as a place from which to start wondering about what it is that might call for music when one lives with chronic illness?

In the second part of the chapter, I start with the general phenomenon of music and review literature that speaks to the historical and contemporary contexts of music study, a chronicle of explorations of music through time by aesthetic philosophers, music psychologists, music educators, and music therapists. I provide an orientation to the concept of listening as understood from communications and therapeutic perspectives, and then proceed to the specific phenomenon of music listening as presented in empirical, theoretical, and popular press works. Next, I review literature specific to the phenomenon of music listening and chronic illness, and

last, begin to formulate the research question as positioned for relevance, value, and wonderment.

Chronic Illness

For the purposes of this inquiry, chronic illness was defined as a physical condition that is managed rather than cured (Heurtin-Roberts & Becker, 1993). Statistics Canada's most recent health survey (1995) reported that in the year of 1994, 55% of adult Canadians age 15 and over—12.5 million people—lived with diagnosed chronic physical conditions (28% reported one condition; 13% reported two; and 13% reported three or more). The greatest numbers lived with non-food allergies (20% of all adults), then back problems (15%), arthritis and rheumatism (13%), and high blood pressure (9%). Higher prevalence rates were reported by women for most conditions—a difference especially true for migraine headaches, arthritis and rheumatism—and women were also more likely to report multiple conditions. These gender differences became more pronounced with increasing age. Most chronic conditions also increased in prevalence with age. The exceptions were non-food allergies and asthma, which were concentrated in the younger age groups, and migraine headaches, which were most common in the 25-to 44-year-old age group. The only condition evenly distributed across all age groups was food allergies. These data underscore the prevalence of chronic physical illness in Canadian society, and its particular manifestation for Canadian women.

Western Medical Context

Chronic illness brings people into a medical context. Once a person decides that changes in their health status warrant the attention of a medical professional, they enter the world of medicine, receive a diagnosis, become patients, and embark upon a lifetime's participation in professional health care relationships informed and shaped by the biomedical context.

Biomedical perspective. Since the beginning of the nineteenth century, medicine has focused on the biochemical or physical processes of disease, and used a natural science approach to identify causal relationships between variables in order to treat and cure disease (e.g., Lubkin, 1998; Marks, Murray, Evans, & Willig, 2000). Modern medicine represents a major success of science because tremendous gains have been made in terms of treating and curing disease (Lovallo, 1997). Deaths from secondary infections such as pneumonia are more rare (Gerhardt, 1990), and people no longer face immediate death from diseases such as diabetes, high blood pressure, cancer, or HIV/AIDs (Thorne & Paterson, 2000). People now live with disease. But this creates new challenges in a medical system oriented to treatment and cure (Heurtin-Roberts & Becker, 1993). Managing body symptoms is important, but quality of life issues are more pressing over time (Gerhardt, 1990). Medicine's shifting perspective to a more holistic conceptualization that incorporates mind as well as body is, in part, a result of the increased incidence of chronic illness and its poor fit with a biomedical system (e.g., Lubkin, 1998).

Theoretically, there is an inclination to consider the whole of the sick person rather than just the disease (Cassell, 1991). For example, disease is differentiated from illness. Whereas disease specifies a change in function or structure viewed in biological terms, illness refers to the experience of disease and all that this entails (Kleinman, 1988):

By invoking the term illness, I mean to conjure up the innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability. Illness is the lived experience of monitoring bodily processes such as respiratory wheezes, abdominal cramps, stuffed sinuses, or painful joints. Illness involves the appraisal of those processes as expectable, serious or requiring treatment. The illness experience includes categorizing and explaining in commonsense ways accessible to all lay persons in the social group, the forms of distress caused by those pathophysiological processes. And when we speak of illness, we must include the patient's judgments about how best to cope with the distress and with the practical problems in daily living it creates. Illness behavior consists of initiating treatment (e.g.,

changing diet and activities, eating special foods, resting, engaging in exercise, taking over the counter medication or on-hand prescription drugs) and deciding when to seek care from professionals or alternative practitioners. (p. 4)

Similarly, medicine is no longer only defined in terms of disease because an either/or continuum of being sick or not sick leaves people with chronic illnesses "declassified but not reclassified" (Kagawa-Singer, 1993, p. 296), that is, not sick but not well. Health has emerged as a core concept in medicine (Pierret, 1995), which is defined as being "a positive state of being which has physical, cultural, psychosocial, economic, and spiritual dimensions, not simply the absence of illness" (Marks et al., 2000, p. 352). A health-within-illness perspective (Moch, 1989) conceptualizes illness as an experience that expands human potential and is, in fact, an opportunity for health. Rather than being negatively construed as a failure to fully recover, chronic illness is favorably viewed as a condition that can contribute positively to personal growth (Lubkin, 1998). With time, these changes in the biomedical context should be beneficial; but because understandings are still in flux, people presently living with chronic illness face a cacophony of perspectives when they step into the patient role.

Anthropological and sociological perspectives. Challenges to modern medicine's sole biomedical approach initially came from anthropology and sociology. The sociological concept of illness trajectory (Glaser & Strauss, 1968), for example, conceptualized illness as a process catalyzed by physical changes in health status that continue on to a positive or negative resolution. Although general shapes or patterns may be anticipated, illness trajectories can never be predicted with certainty. Some chronic illnesses are characterized by acute phases of illness followed by stable phases of remission or comeback; others involve a steady downward phase over time; and yet others are marked by unstable downward phases interspersed with stable phases. An illness trajectory model also incorporates the perceptions and responses of all

participants who are involved in the illness experience (e.g., the individual, family, friends, neighbors, health professionals), and their contribution and impact on the work carried out in order to shape or manage the illness. From this perspective, physiology and biochemistry of the body are only one aspect of illness.

Kleinman (1980) argued that a health care system—its origin, structure, function, and significance—is fundamentally social and cultural in nature. His model of health care systems identified cultural context as the determinant of: (a) the psychosocial experience of illness; (b) the criteria that guide the health care seeking process and evaluate treatment approaches; (c) the management of particular illness episodes through communicative operations such as labeling and explaining; (d) appropriate healing activities; and (e) the management of treatment outcomes, such as treatment failure, recurrence, chronic illness, impairment, and death. As such, values not "truth" shape beliefs about all aspects of health care, from the causes of illness to norms for choosing and evaluating treatments to the social sanctioning of roles, power relationships, medical settings, and institutions (Kleinman, 1980).

Payer (1988/1996) provided specific evidence and examples to demonstrate that values not science determine medical practice. By comparing medical practices in four countries (USA, Germany, France, Great Britain), Payer illustrated the primacy of culture in determining diagnosis, treatment, and suitable research. She concluded that although empirical studies may identify benefits and risks associated with different treatments, the weighing of those benefits and risks always occurs on a "cultural scale." For example, some of the most commonly prescribed drugs in France are considered ineffective in England and America. German doctors prescribe six to seven times the amount of digitalis-like drugs as do doctors in France and England, but they prescribe fewer antibiotics. The French are seven times more likely than

Americans to get drugs in suppository form, and surgery rates in America are more than twice those of England. A doctor active in international health organizations observed different practices in suturing wounds:

When you see a patient whose wound has been treated by a Spanish doctor, it will have two sutures, since in Spain doctors are paid by treating the wound. An Austrian doctor would have put in six sutures, and the Belgian doctor would have put in as many sutures as he could, as they are paid by the number of sutures. Belgian culture values sutures, so they are put in. It's appreciated, so he gets paid for it.

Furthermore, there is little communication between the countries because they rarely read each other's journals and different terminology undermines translation efforts at conferences (Payer, 1988/1996). This kind of cross-cultural investigation disarms biomedicine as a science of absolute truths, and supports the appropriateness of thoughtful dialogue and reflection when facing matters of health and illness.

Psychological perspectives. Recognition of the importance of psychological processes in the experience of health and illness also led to calls for an expanded medical perspective. Health psychology emerged during the 1980s and 1990s largely in response to disenchantment with biomedical health care, as well as increased awareness about behavior determining significant amounts of illness and mortality (e.g., smoking, poor diet, excessive alcohol, lack of exercise); and increased emphasis of the Western ideology that individuals are responsible for their health (Murray & Chamberlain, 1999). Initially, health psychology was represented by Engel's (1977) biopsychosocial model that attended to the role of physical, psychological, and cultural factors in determining health and illness. The three Ps—people, prevention, psychology—were emphasized instead of the three Ds of biomedicine—diagnosis, disease, drugs. Wellard (1998) identified four major themes in chronic illness biopsychosocial research: manifestations of chronic illness; mapping illness trajectories; evaluating quality of life; and exploring the idea of

compliance. But despite a different content, both the biomedical and biopsychosocial models shared a commitment to natural science methods that was based on experimental designs and "normal" populations as controls (e.g., Murray & Chamberlain, 1999; Wellard, 1998).

More recently, a human science approach to health psychology (Murray & Chamberlain, 1999) has been forwarded as an appropriate way to study individual perspectives about the everyday experience of health and illness. Ogden (1997) concluded that the biopsychosocial model has been a rhetorical challenge to medicine, falling short of its ideals because health psychology continued to promote mind/body separation and interaction rather than the notion of an integrated being; to favor biological rather than psychological etiology; and to separate the physical from the social. Murray and Chamberlain (1999) suggested that modern biomedicine attends to individual bodies, and health psychology just added the mind as defined by psychological variables. Social processes were often ignored or controlled for in statistical analyses meant to produce general laws.

The emergence of human science methods introduces different ways of investigating chronic illness that are based on understanding rather than measurement, meaning rather than causation, and interpretation rather than statistical analyses (Murray & Chamberlain, 1999). Health psychology is currently identified as both a natural science and a human science, with links to health and social sciences such as medical anthropology, medical sociology, medical ethics, social policy, health economics, epidemiology, medicine, surgery, and dentistry (Murray & Chamberlain, 1999). It is defined as "an interdisciplinary field concerned with application of psychological knowledge and techniques to health, illness, and health care" (Marks et al., 2000, p. 8).

In summary, general statistics indicate the far reaching impact of chronic illness in Canadian society, and particularly Canadian women as they age (Statistics Canada, 1995). However, people living with chronic illness are not necessarily well served in a medical system historically focused on diagnosis and cure (e.g., Lubkin, 1998). Voices from anthropology, sociology, and psychology have challenged the exclusive, autocratic rule of biomedicine, and argued for a more holistic conceptualization of disease (i.e., as illness) and an extended understanding of health (e.g., Engel, 1977; Glaser & Strauss, 1968; Kleinman, 1980; Murray & Chamberlain, 1999; Payer, 1988/1996). Currently, the medical context is in flux and multi-interdisciplinary efforts are converging in rich and beneficial ways, although those living with chronic illness right now face a confusing onslaught of ideas (e.g., about medicine, disease/illness, health, treatment) when they encounter and interact with helping professionals, well-intentioned friends, and the media.

In terms of the present study, the implications of change in medicine are positive. It is an opportune time to explore and advance the benefits of counselling and non-verbal therapies (e.g., music therapy), as well as the appropriateness of human science projects that reveal phenomena in their everyday lived complexity.

Research Context

The experiences of people living with chronic illness are studied and represented in the research context. Based on a review of the past 20 years of published research using inductive analytic methods to study aspects of the subjective experience of individuals diagnosed with a disease that is normally considered chronic, Thorne and Paterson (2000) assessed the current status of findings and identified issues that need to be considered in applying findings to practice and in designing future studies.

Defining chronic illness. Despite a growing body of chronic illness research, there is presently no shared understanding of what constitutes a chronic illness experience; rather, most research has been conducted in the context of one or at the most two disease categories, and not with an explicit understanding of chronicity (Thorne & Paterson, 2000). When diseases are studied separately, the intent is to identify experiential features specific to particular chronic diseases. Another approach is to conceptualize different diseases as part of a common chronic illness experience, thereby identifying commonalities across disease categories. Further definitional issues arise when deciding on the criteria that distinguish physical from mental conditions (e.g., schizophrenia, depression), illness from disability (e.g., blindness, cerebral palsy), and acute disease from chronic disease. Holistic approaches to health indicate that the line separating diseases of the mind versus diseases of the body is artificial, although the distinction continues to exist in the literature. Disabilities and chronic illness may share conceptual similarities, however, experiential features appear different. For example, Gordon, Feldman, and Cross (1998) interviewed 40 women (ages 28-79 years) who were diagnosed with either multiple sclerosis, lupus, rheumatoid arthritis, and osteoporosis; yet, the majority did not label themselves disabled. Advances in medical treatment have extended the trajectory of diseases such as cancer and HIV/AIDS; thus, these diseases generally are considered chronic rather than acute although they introduce the spectre of death more pressingly than a diagnosis of osteoporosis, for example. Conrad (1987) differentiated between types of chronic illness as either "lived-with-diseases" (e.g., multiple sclerosis, diabetes, chronic fatigue syndrome) or "mortal illnesses" (e.g., heart attack, cancer, stroke). In sum, chronic illness must be carefully and clearly defined in order to clarify what exactly is being studied and what accompanying

assumptions are held. In the present study, a broad understanding of chronic illness as a single experience was used, and all physical illnesses, but not mental illnesses, were included.

Representation and sampling. Thorne and Paterson (2000) noted that certain diseases are studied more than others—not because of their higher prevalence rate, but because of sampling convenience or theoretical simplicity. For example, people using ambulatory clinics are well researched, as are those with pronounced symptoms. People who are less symptomatic may not participate in research because they do not identify themselves as living with chronic illness. Participants also tend to be those who are educated, reflective, articulate, and open to speaking about their experiences. Although women have typically been under-represented in research, this is not the case in chronic illness. Women have been well-represented and though this may reflect women's higher incidence of chronic illness, Charmaz (1995) speculated that men are less likely to volunteer as participants in studies that focus on the vulnerable and dependent aspects of identity that are at odds with cultural values of male strength, competence, and independence. In general, researchers need to be sensitive and perhaps more intentional about sampling strategies rather than relying on samples of convenience.

Design. Retrospective accounting is most common and, although this gives participants a more distant perspective from which to make sense of an experience, it also conceals aspects of chronic illness experience. Aspects of experiences may be reframed in predictable ways as a result of reflection, which creates imperfect knowledge in terms of apprehending direct, lived experience (Altheide & Johnson, 1994; Sadelowski, 1999). For example, Frank (1995) writes about the incoherence that characterizes narratives obtained during crisis or changes in health status. Lives can have moments of chaos or be in an ongoing state of chaos. In the latter case, there is no past or future time, only present time because when people live in chaos there is only

immediacy. Frank believes there is a moral and clinical need to honor chaos stories by telling them, because no help and caring is possible when this reality is denied. Again, convenience or ease of research implementation may overemphasize certain experiences at the cost of downplaying and overlooking others.

In summary, the subject of chronic illness has received a recent influx of attention and study, particularly from nurse researchers doing human science research. By describing current issues associated with human science research, the present study can be evaluated in terms of how it contributes in terms of its design as well as findings. Based on their review of chronic illness human science research, Thorne and Paterson (2000) called for more longitudinal studies, more thoughtfulness in recruitment and sample inclusion strategies, more reflectiveness in how data is generated, and more critical analyses, so that both “the unique and particular as well as the common and generalizeable” (p. 20) can be understood in as illuminating a manner as possible.

Personal Context

The everydayness of life with a chronic illness—lived experience—occurs in a personal context. There is an increasing body of research focusing on the everyday lived experience of living with chronic illness, especially from nurse researchers.

Women and chronic illness. The past 15 years has witnessed an increased focus on women's health, with scholarship crossing disciplines, content areas, methodologies, and conceptual models (Chesney & Ozer, 1995). Previously, women's health was synonymous with reproductive health; however, women's health now includes various content areas such as societal influences on women's health, violence against women, women and health care policy, and diseases more common in women than men (Chesney & Ozer, 1995). Women's personal,

social, and cultural adjustments are typically understood as different than men's, and increased sensitivity to gender bias in the past few decades has legitimized the claim that different socio-cultural realities impact on health care and that women are disadvantaged in a predominately male health care system. For example, women are under-represented in research (Low, Jolicoeur, Stone, & Fleisher, 1994; Tavris, 1992), receive less aggressive diagnosis and treatment (Ayanian & Epstein, 1991), and receive more "all-in-your-head" diagnoses (Schaefer, 1995; Stern, 1996).

Nevertheless, women have been well represented in human science research investigating chronic illness, and gender differences in the experience of chronic illness have been studied (Thorne & Paterson, 2000). In one study, Ablon (1996) interviewed 14 men and 14 women (ages 20 to 51+ years) with neurofibromatosis, and analyzed gender differences in perceptions of social response to pain and appearance. The disease was equally problematic for men and women; however, they often had different perceptions about the extent to which they were disabled. The men, in keeping with American male stereotypes, talked about their condition in matter-of-fact and practical terms, despite the observation that in this sample, they were more negatively affected (e.g., social withdrawal, poorer economic achievement). The women, on the other hand, were more likely to attend support group meetings, to be partnered rather than single, and to have higher economic achievement.

Charmaz (1995) compared the data of a grounded theory study involving 20 men (ages 21 to 85 years) living with chronic illness (e.g., heart attacks, kidney transplant, diabetes, multiple sclerosis) against data she collected in 80 previous interviews with women living with chronic illness. The men were more reluctant than the women to acknowledge their chronic illness and identity as an ill person, and they struggled with the oppositions of being active

versus passive or independent versus dependent, and between autonomy versus loss of control, public persona versus private self, and domination versus subordination. Charmaz argued that this results from cultural expectations about a man's role in family, and society: vulnerability and weakness are generally not acknowledged, let alone accepted or validated.

Howell's (1994) grounded theory study of women ($N=19$; age 21-76 years) and pain management generated a gender-sensitive theory for understanding chronic pain that was described as a "subjective, complex phenomenon of inseparable physical, mental, spiritual, and social processes" (p. 94). Whereas women's chronic pain is commonly seen and treated as an expression of depression (Kaplan, 1986), Howell reported that women who learnt to successfully manage pain felt recognized and validated as experiencing physical pain. When pain was viewed as psychological in nature, the women did not successfully learn to manage and live with pain. These three studies offer evidence that chronic illness is an experience affected by gender, so investigations particular to men and women as well as inclusive of both genders are appropriate for furthering understanding. Only women participated in the present study.

Frameworks of illness. Neither Morse and Johnson's (1991) four-stage illness-constellation model or Jensen and Allen's (1994) wellness-illness theory are specific to chronic illness; but, both frameworks are illuminating and useful if chronic illness is viewed as a particular configuration of illness. Morse and Johnson's (1991) practical four-stage illness-constellation model was based on five grounded theory studies (Chasse, 1991; Johnson, 1991; Lorencz, 1991; Norris, 1991; Wilson, 1991). Four stages emerged to describe the illness trajectory: (a) stage of uncertainty; (b) stage of disruption; (c) stage of striving to regain the self; and (d) stage of regaining wellness. The first stage is a time when illness is suspected, severity is uncertain, and discrepancies may exist between the individual's perceptions and those of

significant others. The second stage starts with a precipitating event that catalyzes a search for help, and control is yielded to health professionals and family members. The next stage involves individuals attempting to make sense of the illness, and trying to resume their tasks and responsibilities despite any illness limitations. When the fourth stage is reached, the individual comes to terms with and accepts either recovery or the limitations imposed by the illness.

Wellness is proposed to exist whether limitations are incurred or not.

Aspects of this model are echoed and elaborated with greater detail in the more comprehensive theory of wellness-illness put forward by Jensen and Allen (1994). By incorporating the results of 112 qualitative studies published between 1980 and 1991 that focused on individuals' experiences of health and disease, the researchers described the process, meaning, and context intrinsic to the experience of health-disease, an experience conceptualized as characterizing all human life.

Comprehending, managing, belonging, normalizing, and valuing are the five themes associated with the process of the health-disease experience. Comprehending is when the relationship between health and disease is recognized as disturbed, and people actively seek information and understanding. Managing refers to some restoration of order and control despite nonnegotiable losses. Belonging involves re-establishing connectedness to oneself, others, and the environment in order to regain a sense of wholeness. Normalizing includes acknowledging the changes in the body, self, relationship, and roles as well as developing new priorities and expectations. Valuing is the "guarded optimism" (p. 354) and new hope that occur as people find ways to make sense of their health-disease experiences.

Meaning is characterized by six themes: abiding vitality, transitional harmony, rhythmical connectedness, unfolding fulfillment, active optimism, and reflective transformation.

Each theme incorporates contrasting aspects, which the researchers used to account for the proposed tenuousness of the health-disease balance. For example, vitality is described as vigorous energy versus being drained and run down; harmony implies unity and contentedness, which is contrasted with uncertainty and disintegration; connectedness is experienced through engagement with the world rather than detachment and alienation; fulfilment emerges from purpose and satisfaction which disease impedes by introducing obstacles to achieving goals; optimism is associated with security, hopefulness, and powerfulness but disease triggers doubt, fear, and anger; and reflective transformation acknowledges the possibility of new meanings being found in the experience of health-disease.

Of particular interest to the present study are the four themes identified as comprising the context of health-disease, that is, the existential ground against which illness is experienced or what Jensen and Allen called “being-in-the-world” of health-disease. Being-in-the-world of health-disease involves negotiations of the self as body, in time, in space, and in relation, negotiations of what van Manen (1990) named the lived existentials. Disease brings on an acute awareness of the body, makes time and the future provisional, limits one's relationship to space, and disrupts relationships (Jensen & Allen, 1994). The body is no longer reliable and invisible; and rather than being a body, people experience having a body—a body that demands awareness. Time becomes precious but also seemingly endless given the burdens that must be faced. Space becomes limited, which in turn is limiting, and associated with vulnerability. Relationships diminish, roles change, strengths and limitations are emphasized, and feelings of aloneness increase.

These two frameworks (Jensen & Allen, 1994; Morse & Johnson, 1991) illuminate the profound impact of illness. A disruption of physical well-being agitates all aspects of being,

both intrapersonal and interpersonal. The process of reconciling or adjusting takes place over time, and in the circumstances of chronic illness, is an unpredictable process experienced more frequently and unremittingly than in the circumstances of acute illness.

Themes of loss, meaning, and transformation. Chronic illness is associated with multiple impacts. Unlike acute illness that causes temporary disruptions in the lives of afflicted individuals and their families, chronic illness brings longstanding and often unpredictable disruptions. Unlike biomedicine's focus on biology and physiology, attention to psychological functioning is often most important in terms of helping people live with chronic illness. The impacts of illness are wide-ranging and varied. As described by Kleinman (1988):

Illness problems are the principal difficulties that symptoms and disability create in our lives. For example, we may be unable to walk up our stairs to our bedroom. Or we may experience distracting low back pain while we are at work. Headaches may make it impossible to focus on homework assignments or housework, leading to failure and frustration. Or there may be impotence that leads to divorce. We may feel great anger because no one can see our pain and therefore objectively determine that our disability is real. As a result we sense that our complaints are not believed and experience frustrating pressure to prove we are in constant pain. We may become demoralized and lose our hope of getting better, or we may be depressed by our fear of death or of becoming an invalid. We grieve over lost health, altered body image, and dangerously declining self-esteem. Or we feel shame because of disfigurement. All these are illness problems.

(p. 4)

Hwu (1995) developed a structured questionnaire to assess the impact of chronic illnesses on the physical, psychological, and social functioning, as well as activities of daily living, in 177 patients (84 men; 93 women; $n=39 < 40$ years; $n=78 40 < 60$ years; $n=60$ to 65+ years) hospitalized with chronic illnesses. Correlational analyses indicated that chronic illness had the greatest effect on psychological functioning, followed by physical and social functioning, then activities of daily living. In the area of psychological functioning, 81.4% reported experiencing stressors, 70.6% reported a negative self-concept, and 54.8% reported

changing their philosophy towards life. These men and women were hospitalized, which restricts the generalizeability of these findings when considering non-hospitalized individuals with chronic illness; but, the breadth and pattern of impact are noteworthy.

Psychological functioning is influenced by the many loss experiences that accompany chronic illnesses. LaCroix, Jacquemet, Assal, and Benroubi (1995) collected testimonies, which were solicited on their behalf by general practitioners and lay associations involved with different types of chronic illness. These data were compiled to represent afflicted individuals' voices about the psychological, professional, domestic, social, and financial difficulties associated with chronic illness. A unifying theme of loss characterized the testimonies: loss of previous health, loss of physical integrity, loss of normality, and loss of liberty. Again, the breadth and pattern of impact are broad, and in this case the sample included hospitalized respondents as well as those living in the community.

Loss was also identified as a unifying theme for 6 women (ages 30 to 75 years) living with chronic illness (osteoarthritis, fibromyalgia, multiple sclerosis, coronary heart disease, dermatitis) who participated in a hermeneutic-phenomenological study (Schaefer, 1995). Based on multiple interviews with these women, as well as reflection on previous interviews with 36 women living with fibromyalgia and 3 with cardiovascular disease, Schaefer described specific types of loss. There was loss of health that occurred with diagnosis; loss of support that came in feeling abandoned by friends, family, and medical professionals; loss of function; loss of spontaneity; loss of control; and the loss of truth that happened when they concealed their illness from others. Successful management was equated with experiences in discovery: for example, discovering and knowing the illness; discovering the self; discovering personal strength; and

discovering real friends. These results suggest that it was important that the negative meaning of loss be replaced and understood with positive meaning.

Loss of self is a recurrent theme in the chronic illness literature (e.g., Charmaz, 1983; Dildy, 1996; Kagawa-Singer, 1993). Charmaz (1983) interviewed 53 people (36 women, 17 men; ages 20 to 86 years) with various chronic illnesses (e.g., cardiovascular disease, diabetes, cancer, multiple sclerosis, lupus) with particular attention to their experiences of self that was defined as an organization of attributes that have become consistent over time. Chamaz's analysis concluded that loss of self, not physical discomfort, was the most significant suffering associated with chronic illnesses. Pre-illness self images were described as "crumbling away" (p. 168) without a simultaneous development of new equally esteemed self images to replace them. Unless new self images were generated, self concept progressively deteriorated. With the exception of a few whose physical health improved, participants used a language of loss and grief. The few who experienced improvement in their physical health tended to see earlier difficulties as provoking new knowledge and self-discovery. These results suggest what might happen when positive meanings are not discovered, and loss remains a negative and meaningless experience. The research also points to the influence of retrospection in shaping how experiences are remembered and understood.

Dildy (1996) used grounded theory to identify three phases experienced by 14 people (9 women, 5 men, ages 39-76 years \bar{M} =59.5 years) living with rheumatoid arthritis (6 months to 35 years, \bar{M} =16.75 years). Participants were specifically asked to describe personal suffering in initial interviews that lasted 45 to 90 minutes. Seven participants were involved in second interviews for validation purposes, which lasted 15 to 30 minutes. Transcripts were prepared and analyzed using the constant comparative technique. The process of suffering with

rheumatoid arthritis was described as involving (a) disintegration of self (struggle), (b) the shattered self (loss of dreams), and (c) reconstruction of self (restructuring a future orientation). This process was seen as cyclic and multi-directional, not linear. Given the recurrent nature of the illness, the participants described themselves as moving back and forth between the phases. This investigation corroborates the ever-changing experience of living with chronic illness that causes its impact to be felt more keenly at times. Also, loss is again confirmed as an experience in chronic illness that can be faced and managed with the development of new purpose and goals.

Kagawa-Singer (1993) interviewed Anglo-American (median age of 65 years) and Japanese-American (median age of 66 years) cancer patients ($N=50$; 14 men, 36 women) on two or three occasions in order to illuminate the concepts of health and coping in chronic illness. Transcribed interviews were subjected to content analyses and participants completed visual analog scales to denote their level of activity at different times in their treatment. Although the cultural groups described different coping styles, a common challenge for both groups was a perceived threat to themselves—to the security and predictability of their lives, and to their ability to fulfil role responsibilities. Coping was equated with the ability to maintain a sense of self-integrity, which is the core concept for her theoretical framework of health. In this study, the participants felt like they were losing parts of themselves to illness; but paradoxically, in order to effectively cope with the challenges of their illness, they needed to feel whole and integrated.

Understandably “dramatic changes in biographical course, especially in terms of roles and responsibilities, inevitably challenge identity or self concept” (Thorne & Paterson, 2000, p. 8). Chronicity raises powerful emotions related to accepting a new way of living that may be

much different than that imagined and hoped for prior to diagnosis (Gordon & Benishek, 1996). However, loss experiences do not only reside within the individual. Tang and Anderson (1999) argued that the medical context also contributes to and accentuates loss experiences, particularly the loss of agency. In-depth interviews with 30 Canadian women of Chinese and Anglo-descent living with diabetes, revealed problematic interactions with health care providers that undermined the participants' sense of agency. As described by the researchers: "in chronic illness, the patient's loss of autonomy, and the medicalization of the body are not a temporary phenomena, but are part and parcel of the everyday" (p. 86). An alternate approach to practice that positions health professionals as "reflexive practitioners" rather than "holders of expert knowledge" presents a way to empower women in resisting patienthood and re-acquiring agency. This perspective suggests that being a patient—as experienced in the biomedical context—adds to the losses incurred with chronic illness, and further undermines the sense of agency or self-integrity (e.g., Kagawa-Singer, 1993) that is critical to coping.

Tang and Anderson (1999) acknowledged the similar concerns expressed by Kleinman (1988), who after studying meaning in chronic illness narratives, advocated for a clinical approach that balanced and complemented biomedicine by moving beyond "a language of molecules and drugs to include the language of experience and meanings" (p. 266). Medical practitioners were encouraged to (a) conduct mini-ethnographies (i.e., in order to reconstruct patients' illness narratives and understand the suffering and particular consequences of illness in their lives); (b) obtain brief life histories to identify major life themes that may affect illness over time; (c) elicit personal/family/cultural explanations of the illness; (d) clearly communicate the biomedical understanding; and (e) convey hope. This perspective clearly extends the practice of traditional biomedicine.

The disruption of self that accompanies chronic illness often leads to a search for understanding and meaning, which is considered a central process in learning to adapt to chronic illness (e.g., Fife, 1994; Gullickson, 1993; Robinson, 1993). As noted in earlier studies (e.g., Charmaz, 1983; Dildy, 1996; Schaefer, 1995), the negative meaning of loss experiences was sometimes replaced with a different understanding that was positive or meaningful (i.e., made sense of their circumstance). Meaning is generally understood as reciprocally related to behavior; that is, humans make meaning in their lives and act upon that meaning, as in turn, actions shape and effect the construction of meaning. As such, meaning is a concrete phenomenon with manifest effects.

Gullickson (1993) asked 12 people living with chronic illness (e.g., hypertension, coronary heart disease, renal failure) for more than 2 years to tell her “a story that they will never forget because it best describes what it means to live with a chronic illness” (p. 1387). The resulting verbatim transcripts were analyzed from an Heideggerian phenomenological perspective. The pattern of “my-death-nearing-its-future” (p.1386) was identified, a newly held perspective based on appreciating the nearness of one’s own death versus living in unawareness. Living without a conscious attention to personal mortality is normative; but, in facing this fact, these participants came to a clearer understanding about what was meaningful in their daily lives. They discovered how to live “authentically” because given their illness, death was now a “constitutive part of being” (p. 1389).

Fife (1994) interviewed 38 people (22 women, 16 men; ages 31-74 years) with cancer to study the development of meaning in illness. A mutual relationship was assumed between meaning and behavior, and meaning included self-meaning (individual cognitive responses to particular events) and contextual meaning (perceived responses from others and society in

general). Participants' perceptions of themselves as persons living with cancer influenced their ongoing evaluation of the social world and their roles within this environment (self-meaning), as did responses from the social world about them as people with cancer also influence their feelings of self-worth, competency, and personal power (social meaning). Participants who were able to view illness optimistically experienced fewer difficulties than those who felt either stigmatized by the illness and withdrew socially, or panicked and tried to get as much done as possible, or passively resigned to an altered life. These responses were not considered static. Changed meaning was always possible given the dynamic nature of meaning. Change in circumstances impacts meaning, and unpredictable changes in circumstances are the undercurrent of chronic illnesses.

Robinson (1993) used grounded theory to study 62 accounts based on interviews with 40 individuals (30 women, 10 men), who either had a chronic illness or were a family member of someone with a chronic illness. Various chronic illnesses were represented (e.g., spina bifida, muscular dystrophy, asthma, allergies, multiple sclerosis, arthritis, back problems, heart disease, and inflammatory bowel disease). Meaning was conceptualized as a spontaneously created narrative to bring coherence to lived experiences over time. Unexpectedly, the story of normalization emerged as a significant theme in interviews. At first, families identified with the problem-saturated story generally adopted by society; but with time, families preferred a story of life-as-normal. Strategies such as reframing, covering up, doing normal things, making trade-offs, and desensitization helped families establish a common meaning or story in order to cope with challenging circumstances. Both costs and benefits associated with the normal-life-story are identified, but given the prevalence of this narrative Robinson (1993) concluded that benefits

will commonly outweigh the costs for many families, and helping professionals must consider how they do or do not support families in maintaining stories of normalization.

Another grounded theory study (Baker & Stern, 1993) linked meaning with outcomes for self-care behavior. Self-care is a nursing concept that refers to self-care behaviors that help people live effectively and independently with various chronic illnesses. Findings based on interviews with 12 participants (4 men, 8 women) living with a variety of chronic diseases (e.g., insulin-dependent diabetes, renal failure, cardiovascular diseases, colostomy for bowel cancer) and their nurses revealed that once participants accepted their illnesses and reframed the implications positively (positive meaning), they were able to make sense of self-care teaching and act upon it. They perceived themselves as "self-care agents" (Baker & Stern, 1993, p. 30) exercising control over their illnesses. Successful adoption of self-care behaviors was found in patients who (a) compared themselves favorably to others who were perceived as suffering more because of their illnesses; (b) identified with other similarly effected individuals who were perceived as living meaningful worthwhile lives; and (c) integrated self-care behavior into the routine to their lives. Seeking a cure, scapegoating, and giving up were negatively associated with self-care behavior and positive adjustment. In addition to reiterating the significance of meaning-making, these findings link meaning and behavior in such a way as to explain why providing information in an educational format is not always sufficient, and moreover, why a holistic conceptualization of treatment that includes counselling interventions and perhaps non-verbal experiences, such as music listening, is appropriate.

Transformation is another concept that permeates the chronic illness literature and is closely related to the concept of meaning. Transformation is an idea intuitively grasped but as noted by Paterson, Thorne, Crawford, and Tarko (1999), "transformative processes have not

been described beyond vague generalities, and what has been articulated is not particularly revealing" (p. 786). For example, it remains unclear whether meaning and transformation are independent concepts—Is meaning a catalyst for transformation or an outcome of transformation?

Two themes in the transformation literature are restructuring the illness experience and restructuring of self (Paterson et al., 1999). Restructuring the illness experience refers to philosophical and cognitive shifts in how the illness is perceived—rather than being perceived as a threat and a struggle, illness is viewed as a challenge. Illness is normalized, but illness limitations are also recognized. Restructuring of self refers to a changed understanding of self that permits the maintenance of self-integrity as well as incorporation of illness. The restructuring process often involves body objectification so that the body no longer acts as source of identity.

Paterson et al. (1999) explicated the structures and processes of transformation through a grounded theory research inquiry into the experiences of participants with Type I Diabetes. According to the participants, transformation was an "evolutionary activity" (p. 797) catalyzed by illness challenges. In responding to these challenges, a transformed self emerged that was distinguished from the illness and its site, the body. Transformation served both as an outcome of coping with challenges, and as a strategy to mediate illness impacts. Outcomes such as a heightened sense of self, meaning, and mastery were associated with the process of personal transformation. In concluding, the authors cautioned that individual differences may play a part in the need for some individuals to find meaning. Therefore, transformation and meaning were not to be understood as universal experiences nor prescriptive absolutes for chronic illnesses. As

mentioned earlier for example, Charmaz (1983) found that with few exceptions, participants in her study communicated loss and grief, not the optimism of meaning and transformation.

This admonishment highlights one of the negative outcomes associated with current shifts in medicine. Renaud (1980, cited in Pierret, 1995) remarked: "Whereas previously the 'right to health' referred to the principle that people 'had the right to be ill and receive adequate treatment,' now all of a sudden people have the 'duty to be healthy'" (p.181). This new norm leads easily to "victim blaming," which is invalidating and detrimental. Concepts such as health-in-illness (Moch, 1989), transformation, and meaning are not necessarily universal and absolute standards for successful adaptation to chronic illness. Even the notion of successful adaptation is colored with value judgments (Wright & Kirby, 1999). Although some people describe meaning and experiences of transformation as critical to living effectively with their illnesses; others live with chronic illness, and do not identify with these concepts.

In summary, the general expectation that gender affects experience has been borne out in chronic illness research (e.g., Albon, 1996; Charmaz, 1995), which supports the use of single gender samples. The concept of illness as a trajectory (Glaser & Strauss, 1968) suggests that illness is more than a physiological event that occurs in one body, and therefore research exploring meaning is appropriate. The importance of longitudinal research is indicated by the chronic illness trajectory that is longer and more unpredictable than acute illness, and which is characterized by changing phases of disease and remission, and acuity and stability. This dynamic contributes to what has been called the foreground/background perspective of chronic illness (Thorne & Paterson, 2000):

We have come to the conclusion that living with a chronic illness is typically experienced as an uneven trajectory in which the individual learns to put the disease focus (e.g., burden, loss, unbearable symptoms) into the background of consciousness some of the

time, but also experiences times during which the overwhelming significance of the sickness dominates living with the disease. Shifts from one perspective to the other can be precipitated by personal and sociocultural factors unrelated to the disease. (p. 17)

The impacts of chronic illness are broad and varied, but the significance of psychological impacts is clear (e.g., Hwu, 1995), especially as characterized by feelings and experiences of loss (e.g., Charmaz, 1983; Schaefer, 1995). Personal identity may be experienced as compromised or lost (e.g., Gordon & Benishek, 1996; Kagawa-Singer, 1993), which may lead to a search for meaning and transformation as a way of restructuring identity (e.g., Fife, 1994; Gullickson, 1993). Restructuring identity and restructuring the illness experience are two themes in the transformation literature; however, despite their intuitive appeal, meaning and transformation remain poorly understood constructs (Paterson et al., 1999). Further research on daily lived experience over time may further understanding of these concepts.

Summary of the Chronic Illness Literature

Over the last few decades, social science researchers have challenged the primacy of a biomedical stance, and coupled with changing patient demographics, the current medical paradigm exists in a state of flux. Several new fields offering expertise in aspects of health and illness have emerged, and the knowledge base about chronic illness has grown quickly. Loosening and broadening the boundaries of Western medical practice and research have positively impacted on the generation of models for understanding the lived experience of chronic illness. Researchers and helping professionals have been encouraged to increase their understanding of chronic illness in order to offer more effective care. This has increased receptivity to counselling and non-verbal therapies, such as music therapy, in health care settings as the psychological, social, and relational aspects of chronic illness are considered.

Key characteristics of chronic illness are uncertainty, unpredictability, and change, as well as an implicit movement and progression that can often only be identified with hindsight. Because the chronic illness trajectory is so unpredictable, any period of stabilized health in chronic illness is always more tenuous and uncertain than in acute illness. Whether symptoms are periodic or ongoing, the lived dynamic is one of provisional stability.

A more holistic understanding of chronic illness draws attention to the importance of psychological functioning in terms of successfully managing the challenges of chronic illness. Meaning and transformation appear to be important for many individuals, but not all, as they try to manage the multiple losses associated with chronic illness. Moreover, chronic illness appears more frequently in women, and gender differences have been identified.

In the present study, my intent was to understand the significance of music listening in the context of chronic illness. Given a need for further longitudinal chronic illness research (Thorne & Paterson, 2000), using multiple interviews to study the phenomenon of music listening in chronic illness contributes to further knowledge about the experience of chronic illness. However, it is unclear how music listening might fit into the lives of women living with chronic illness. Moreover, given the themes of loss, meaning making, and transformation, what positive difference might music listening make? As I reviewed the music literature, I kept an ear attuned to possible implications for music listening as suggested in the preceding chronic illness review.

Music

The Phenomenon of Music

I draw on four disciplines (aesthetic philosophy, music psychology, music education, and music therapy) in order to first illuminate the general phenomenon of music, as opposed to the

particular experience of music listening. The four disciplines aspire to different goals—aesthetic philosophers seek to understand the human experience of beauty; music psychologists focus on the cognitive and perceptual processes by which humans experience and organize music; music educators want to impart skills, knowledge, and appreciation; and music therapists wish to draw on the beneficial effects of music in order to facilitate well-being—but cumulatively they provide a broad understanding of music. These understandings inform the present study by helping identify what is known and not known about the phenomenon of music, and what might be overlooked, especially in terms of music listening experiences.

Historical and contemporary perspectives. According to Fiske's (1993) overview of the history of music theories, Pythagoras, Plato, and Aristotle laid the groundwork for long-standing Western beliefs about the “natural interactive mathematical and harmonic order of the heavens, society, and religion” (p. 154). Pythagoras developed a theory of pitch intervals based upon relative lengths of vibrating strings in the sixth century B.C., and declared that music was an expression of universal harmony, something that also characterized astronomy and mathematics. His work introduced a general opinion, which continues to this day, about the “natural” order of Western musical modes, scales, and intervals. One hundred years later, Plato contended that specific musical modes led to specific thoughts and emotions. Similarly, Aristotle hypothesized that music imitated human moods and emotions, and thus “bad” music could evoke harmful emotions. Ethics, morality, behavior, and the laws of music were linked. Eight hundred years later, Augustine drew on the writings of Pythagoras, Plato, and Aristotle, and developed a theory of musical meaning based upon theology (Fiske, 1993). He identified preferred ratios and suggested that they imbued music with religious significance. Music was understood as a medium that acted on listeners, dancers, and performers of music.

During the Middle Ages, when religiosity was believed to restore well-being, and during the Renaissance, when balance between music and medicine was considered the key to health, there was a very close alliance between music and medicine (Weldin & Eagle, 1991). People believed that music was a powerful healing force that could be employed to achieve either of these ends, and presumably, this belief arose because of intensely felt music experiences. Though music continued to be held in high esteem, the disciplines of music and medicine diverged during the Baroque-Classical and Romantic periods when medicine became more a science than an art form. As a science, Western medicine was shaped by the empirical tradition of positivism, and “disease-theory” emerged with its attention on identifying diseases, treating symptoms, and ideally producing cures (Cassell, 1991). The physical body became the focus of medicine, and aspects of humanness such as meaning and emotions were excluded.

Music as an art, on the other hand, became the subject of aesthetic inquiry, a field primarily concerned with contemplating the experience of beauty and considering the nature and value of the arts (i.e., their meaning). There was general agreement that music had an important association with feelings, although the nature of this relationship was disputed. Initial inquiries in the mid-1700s were framed by formalism (also called absolutism) (Fiske, 1993). Human responsiveness to music was believed to originate in the music itself, so attention focused on identifying the formal aspects of objects that were perceived as sources of aesthetic responses. Friedrich Vischer published an important book, Aesthetics (1840, cited in Fiske, 1993), that reflected this thinking. He argued that specific emotions were communicated through musical forms such as tonality, rhythm, and structure. This perspective was in keeping with the earlier views posited by Pythagorus, Plato, Aristotle, and Augustine that intervals, modes, and scales acted on listeners and communicated particular messages.

This view was challenged by those who advocated referentialism, a more psychological perspective in which aesthetic responses were believed to emerge from the life that the viewer projected onto the art object. The significance of music was considered to be extra-musical. Edward Hanslick's book, The Beautiful in Music (1854, cited in Fiske, 1993), introduced the idea that the association between the emotional content of music and its form was analogous in nature; that is, form suggested general not specific emotions. Hanslick's ideas about musical structures serving as analogues for human feelings were later extrapolated by Langer (1942) who developed a detailed theory of signs and symbols. Signs represented the existence of something; symbols evoked their concept. Langer reasoned that music forms and structures acted as symbols of particular human responses that resulted in particular types of meaning. From this perspective, musical elements were understood as influencing general meaning, but this general meaning was superseded by meaning that came from the listener.

The influences of English empiricist philosophies, development of inferential statistics, evolution of the hypothesis-based scientific method, and physiological discoveries such as nerve structure and conduction of nerve impulses, led to a rejection of aesthetic inquiries as forwarding subjective, informal, and untested assertions (Fiske, 1993). The new experimental psychologists sought to correct this situation, and audition was one of the first areas of perception to be formally investigated. An early figure who catalyzed this type of research was Herman von Helmholtz, a physicist and physiologist. He used his experimental laboratory work to generate a theory that attempted to integrate acoustics, psychoacoustics, music theory, and philosophical aesthetics. His book, On the Sensations of Tone (1863, as cited in Fiske, 1993), addressed the physical laws of vibration, the effects of vibration on the auditory nervous system, and the proposed impact of vibration on auditory sensation and perception. Two kinds of research

emerged from Helmholtz's work: theories of psychoacoustics and theories of musical experience. The former tried to explicate the neurophysiology of musical experiences; the latter was founded in the work of Carl Seashore, a psychologist who established the first laboratory of experimental research in music psychology (Fiske, 1993). Seashore produced an influential theory derived from systematic, laboratory-controlled observation of musical listening and performance behavior, as well as the Seashore Measures of Music Talents, the first set of measures intended to assess children's musical aptitude. His work concentrated on linking musical experience to the neurophysiology of sensory stimulation.

Although the methods and data collected by Seashore and Helmholtz continue to be significant in current research, their theoretical perspectives have generally been dismissed (Fiske, 1993). To adequately explain musical experience in terms of neurobiological responses appeared simplistic as attention turned to new and burgeoning interests in cognitive processes.

Meyer (1956) advanced an influential theory that bridged cognition and perception. As a composer, he was interested in explaining how a composer's intent might be comprehended by listeners. By studying musical scores and observing how musical elements set up expectations and aroused various types of resolution and expectation satisfaction, Meyer proposed that these musical tensions and resolutions produced tensions and resolutions in the listener that were analogous to feelings and therefore significant. His theory incorporated elemental musical analysis, and then applied it to the holistic experience of listening. From this perspective, the listener attributes particular meaning, but the music instigates and shapes that meaning.

Educators developed theories emphasizing cognitive processes. Reimer (1989) drew on the concept of cognition as a diverse rather than unitary phenomenon and suggested that creating and experiencing music educated feeling in the same way that reading and writing educated

reasoning. Reimer (1989) further exhorted that music provided “meaningful cognitive experience unavailable in any other way and such experience is necessary if essential humanness is to be realized” (p. 34). Referred to as absolute expressionism, this position integrated both referentialist and formalist ideas and proposed that the special relationship between feelings and music permeates all cultures. Reimer identified listening as the most fundamental, if not most important musical behavior in music education and stated that listening to music was “among the most demanding mental-emotional tasks the human species is capable of...the perceiver actively and creatively engages himself or herself in the expressive unfolding of the work” (p. 70). His ideas are premised on the primacy of feelings in music experiences, but he also suggests a reciprocity between music and listeners, that the music and listener are mutually involved in the listening experience.

Another music educator, Swanick, observed children's composing and performances at different ages (Swanick & Tillman, 1986) and drew on the work of Piaget to posit a relationship between cognitive growth and creative expression. By replacing the concepts of mastery, imitation, and imaginary play with the analogous musical concepts of control of sound materials, expressive character, and structure, Swanick (1988) conceptualized music as imaginative rather than physical play; that is, “play without action” (Vygotsky, 1976 as cited in Swanwick, 1988, p. 38). Musical compositions of children seemed to follow a developmental sequence based on these elements. Swanick (1988) observed a fourth level of development in children over 15 years, metacognition, which he described as being self-aware of thoughts and feelings that generate a valuing of music such that “music has meaning for an individual at a high level of personal significance” (p. 74). Again, the notion of reciprocity between the listener and the music is understood in the description of music as imaginative play. For example, play exists in

the interaction between toys and children, and by extension between music and listeners.

Toys/musical works are created with a general intention that can only be realized in a child's/listener's particular play with that object; thus, each child/listener experiences the toy/musical work uniquely.

Psychologists and music therapists offer further perspectives on the significance of music. Kohut (1978) drew on psychoanalytic principles to expound a theoretical perspective of music as an art form that simultaneously satisfies the id, ego, and superego. The id is satisfied by the vicarious release of tensions through musical emotions (e.g., dancing to angry rap tunes); the ego is appeased by the mastery component of music (e.g., analyzing the structural components of a piano sonata); and the superego is gratified by the aesthetic codes regulating music (e.g., performing choral harmony). Kohut used a psychoanalytic framework to make sense of the multiple ways in which music appeals to us and affects us.

Storr (1992), a psychiatrist and music lover, argued that because music is such a deeply felt and significant experience, it serves to justify existence for many people. Based on a comprehensive review of theoretical, empirical, biographical, fictional, and poetic texts, Storr hypothesized that music allows us to experience ourselves in wholeness, with emotions and thought integrated rather than separate as is more usual. The inherent elements and patterns of music are believed to give structure and coherence to feelings and emotions such that inner experience acquires a manifest form. Storr integrates familiar themes of music study (e.g., feelings, structure, order) in order to assert and explain the profound existential impact of music in some lives.

Sears (1968), a music educator and music therapy pioneer influenced by behavioral theory, proposed a theoretical perspective of music as associated with three conditions: (a)

experience within structure, (b) experience in self-organization, and (c) experience in relating to others. From this perspective, music provides a framework that organizes experience at temporal, affective, and sensory levels; music requires self-organization of individuals if they are to coherently and successfully express themselves in music; and group experiences in music (e.g., choir, band) lead to positive experiences in feeling needed, appreciated, and recognized by others. A behavioral framework of music emphasizes the organizing and reinforcing effects of music.

Kenny's Field of Play (1989)—a transpersonal understanding of music, specific to the practice of improvisational (spontaneous music making) music therapy—was influenced by Sears's (1968) constructs (e.g., process, experience, environment, relationships) and her Native American cultural roots. Kenny (1982) observed that during music therapy sessions, hospitalized psychiatric patients spontaneously drew on mythological themes that elaborated themes of loss and death. Field of Play (Kenny, 1989) developed with continued study of these themes and belief that music carried “implicit healing patterns for human development” (p. 3). Improvisational music therapy was conceptualized as a dynamic interplay of seven elements or fields: the aesthetic, the musical space, the field of play, ritual, particular state of consciousness, power, and creative process. The aesthetics are the music therapist and client who “contain conditions for the creation of beauty” (Kenny, 1996, p. 67), and musical space is the relational field of their therapeutic relationship. Together, the aesthetics and musical space create an experimental and innovative field characterized by repeatable forms of ritual, a particular state of consciousness, and energy and inner motivation. Creative process ensues with the interplay of all fields and is both a process and result of this interaction. Kenny (1996) wrote that the direct experience of music therapy is “an experience of intense beauty in a heightened state of

awareness ... and each person is a whole and complete form of beauty.” (p. 56). This understanding of music improvisation in therapy draws on relational concepts (e.g., fields) as well as the linkages between beauty, perfection, and transcendence that echo earlier ideas of Pythagoras, Plato, and Aristotle later developed in aesthetic theory (Fiske, 1993).

Ruud (1998), a Norwegian music therapist, linked music and identity. He initially started researching the topic by asking his music therapy students to compile musical autobiographies (self-compiled audiotapes of 10 to 15 songs identified as biographically important) and then talk with him about them. Later, more students submitted tapes along with a typed commentary about the selected music. An ongoing analysis and engagement with the topic led Ruud (1998) to hypothesize that memories of significant life events experienced through music organize a coherent narrative of a music-based identity. Furthermore, involvement with music was posited to be not so much a reflection of identity as much as it was a way of performing or enacting identity. More specifically, there are four categories believed to encompass all aspects of music and identity: personal space, social space, the space of time and place, and the transpersonal space (Ruud, 1998). Personal space includes experiences such as (a) being fully attended to and “seen” by adults as a result of music-making activities in childhood; (b) becoming musically educated in experiencing, identifying, and managing feelings; (c) discovering a private and genuine sense of self that is defined musically (e.g., with the “right” instrument, the “right” genre); and (d) experiencing mastery and recognition. Social space refers to musically communicated understandings of the self as belonging and separate from groups, a contextual placement (e.g., historical, cultural, social, and gendered location). The space of time and place includes experiences that connect people to geographical space and chronological time, and transpersonal space evokes music experiences that are beyond the

ordinary and everyday musical experiences that connect people to a larger sense of what life is. Individual themes of music such as feelings, order, structure, and transcendence reappear in Ruud's (1998) work, and are merged into the concept of music identity.

In summary, music has remained a source of study and wonder through time, recognized as a powerful medium of alluring charms and enchantments that is equally capable of igniting virtuousness or debauchery. Music seems to embrace all aspects of humanness—feelings, cognition, behavior, and beyond the tangible to the spiritual—which is perhaps why it has been studied across disciplines and framed with various theoretical constructs. Music offers evidence that supports or accommodates the tenets of behaviorism (e.g., Sears, 1968), psychoanalytic thought (e.g., Kohut, 1978), the transpersonal and mythological (e.g., Kenny, 1982, 1989), narrative perspectives (Ruud, 1998), neurophysiology (e.g., Helmholtz, 1963 as cited in Fiske, 1993), and pedagogy (e.g., Reimer, 1989). Presumably, each perspective offers a truth about music, one piece of a bigger puzzle. The focus of the present study is in the section of the puzzle that illuminates the phenomenon of music listening.

The Phenomenon of Listening

Communication perspectives. Listening is generally acknowledged as the most common communications activity that humans engage in; however, it is only in the last 15 to 20 years that listening has been studied in any depth by communication researchers (Bostrom, 1990).

Processing spoken verbal messages involves good listening behavior, which was first operationalized in terms of factual recall (Nichols, 1947). This spawned a succession of similar studies that revealed a broad range of individual differences in listening abilities, although the reason for these differences was unclear. Various listening ability measures were developed and listening was understood as a unique skill unrelated to other cognitive skills. This view was later

challenged by Kelly (1965) who demonstrated that listening tests correlated highly with other measures of cognitive abilities, though intelligence did not fully account for listening ability. Consequently, an attitudinal dimension was introduced whereby the notions of willingness or motivation on the part of the listener were included (Weaver, 1972). This is illustrated in the following commonplace dictionary definition of listening: "to make an effort to hear; to pay attention" (Oxford Dictionary, 1991, p. 299). More recently, Bostrom (1990) emphasized the importance of studying the specific functions of listening and developing a listening typology instead of assuming that receiving behavior or listening is alike across all circumstances. For example, he differentiated between short-term listening, short-term listening with rehearsal, interpretive listening, lecture listening, and selective listening.

Wolvin and Coakley (1993) developed a listening taxonomy based on five general purposes of listeners: discriminative, comprehensive, therapeutic, critical, and appreciative listening. Discriminative listening is used to distinguish auditory and/or visual stimuli; comprehensive listening focuses on understanding a message; therapeutic listening incorporates empathy in order to facilitate problem solving for the speaker; critical listening is based on the evaluation and judgement of what is said; and appreciative listening attends to achieving a sensory stimulation or enjoyment of sounds, such as those in music, poetry, or the natural environment. Given their relevance to the present study, appreciative and therapeutic listening are discussed in more detail.

Therapeutic perspectives. Sharing information and telling seem to be inherent conditions of being human that bring relief. According to Ruesch (1961), thoughts were long ago viewed as foreign entities that required release in religious and medical procedures. This led to practices of decontamination, which later developed into the religious ritual of confession, and still later,

into the psychoanalytic notion of cathartic listening—the belief that disclosing unexpressed emotions to an analyst who listened in a non-critical, non-judgmental fashion, maintaining an air of benign curiosity was therapeutically beneficial (Freud, 1895, as cited in Corsini & Wedding, 1989).

In counselling, listening is considered the basis of counsellor competence (Gibson & Mitchell, 1999). Attending (e.g., posture, gestures, facial expressions, voice) and listening (e.g., for feelings, emotions, experience, behaviors, and point of view) are the first communication skills taught to student helpers (e.g., Egan, 1994). Good listening skills anchor verbal counselling skills. Effective listening is important in all counselling theories, although, client-centered counselling incorporates listening most explicitly as a key therapeutic condition (Rogers, 1958/1989). Rather than understanding listening as a set of techniques or skills, Rogers proposed the development of listening as a way of being, a receptive, responsive, and thoughtful way of being in the world.

Because of an inclination to focus on elements of music performance, therapeutic aspects of listening have not always been considered in music therapy. Recently however, some attention has turned to the role of listening in music therapy practice (Amir, 1995; McMaster, 1998). Amir (1995) identified listening as a main factor in music therapy stating that music therapists listen to clients and themselves, as well as encourage clients to listen to inner sounds before expressing them vocally and instrumentally. Listening was construed as a transcendent activity in that listening goes “beyond the personal into the transpersonal” (p. 55). McMaster (1998) developed an understanding of life as a musical work with implications for listening. Based on this metaphor, life is an experience marked with places of consonance and dissonance, melody and atonality, and so on. When sounds of apparent chaos are listened to with care, the

larger musical structure can be heard, which in its entirety is always cohesive and meaningful. McMaster (1998) speaks to general structural, cohesive, and holistic associations with music, whereas Amir (1995) focuses on the specific relational aspects of listening that are part of music therapy practice.

Entrainment and Iso Principle are two concepts used by music therapists to grasp the relationship between a listener and music. The Iso Principle (Gatewood, 1921 as cited in Hanser, 1999) refers to the idea that gradual changes in the mood of music similarly change the listener's mood, as long as the initial music is matched to the initial mood of the listener. Entrainment provides a slightly different view of the relationship between listener and music. According to Goldman (1988 as cited in Amir, 1995) all vibrating things tend to harmonize or vibrate together, and entrainment is "a phenomenon of sounds in which the powerful rhythmic vibrations of one object will cause the less powerful vibrations of another object to lock in step with the rhythms of the more powerful object and oscillate at this rate" (p. 54). These concepts focus on how music acts on listeners.

A unique biopsychosocial, therapeutic approach to communication, language, and learning processes based on listening was developed by Alfred Tomatis, a French physician, psychologist, and ear specialist. His method of auditory stimulation is based on the premise that the development of communication skills, language acquisition, learning ability, and social adjustment are highly dependent upon the quality of early listening experiences, which begin in utero at 4 1/2 months when the sense of hearing first develops (Gilmor, Madaule, & Thompson, 1989). According to Tomatis, the fluid environment creates a high frequency for all sounds but especially the mother's voice, which the fetus starts to attend to in a cycle of waiting for the voice, being fulfilled when it is heard, then waiting again, and so on. The belief is that the

process of listening begins in this fetal world and continues on through childhood and adulthood. The ear is emphasized as the most important body organ, and is neurally connected to all the major organs of the body. According to Tomatis (as cited in Campbell, 1997): "The ear if not a differentiated piece of skin. The skin is a differentiated piece of ear." (p. 54).

If listening has been detrimentally affected, a device called the Electronic Ear is used to provide auditory training that incorporates a range of physical, social, and psychological factors (Gilmor et al., 1989). The Electronic Ear delivers modified higher frequency sounds that, after 60 to 100 hours of listening and self-listening exercises, are believed to establish proper listening abilities. This method has been promoted in approximately 30 treatment facilities throughout the world, including one in Toronto, Canada. Supportive evidence has been demonstrated primarily through case histories, anecdotes, and observations from parents, teachers, and clinicians.

In summary, listening is a process of attention—an attending to sound. Humans listen in a variety of ways based upon particular behaviors, skills, and intentions. Communication perspectives have tended to focus on listening as a receiving behavior (Bostrom, 1990) and auditory stimuli as contained and constant entities, a perspective also reflected in some music therapy concepts (e.g., Iso Principle, Entrainment). Conversely, therapeutic perspectives have typically focused on the other direction of listening interactions, that is, on the cathartic value for those who are heard by professional listeners (e.g., Corsini & Wedding, 1989; Egan, 1994). The tendency to consider listening uni-directionally goes back to the earlier mentioned controversy between formalism and referentialism in aesthetics (i.e., does music act on the listener or does the listener act on the music?). On the other hand, Tomatis's (as cited in Gilmor et al., 1989) description of listening as a interactive process that facilitates learning conceptualizes listening as a reciprocal process, and is in keeping with the work of Meyer

(1956), Reimer (1989), and Swanick (1988), for example. In the present study, the phenomenon of music listening is considered with a sensitivity to its emergence as either a uni-directional or bi-directional experience.

The Phenomenon of Music Listening

As noted earlier, music listening is a type of appreciative listening because the intent is to enjoy and/or experience sensory stimulation. Appreciative listening evokes emotional responses based on personal processes of listening that are shaped by a listener's perception, experience, background, mental set, understanding of the presentation, expectations, motivation, interest, and previous knowledge (Wolvin & Coakley, 1993). Musicians and music educators emphasize music listening as an art to be acquired with practice and application (e.g., Copeland, 1957; Machlis, 1977). Copeland (1957), a composer, distinguished between music listening on a sensuous plane, expressive plane, or sheerly musical plane, and similar classifications were made by Cziksentmihalyi (1990) when he described sensory, analogic, and analytic modes of music listening. Cook (1990) categorized two types of music listening—musical and musicological—by collapsing sensuous/sensory and expressive/analogic modes together and maintaining the category of analytic or sheerly musical type of listening. Musical listening involves pleasure and gratification, whereas musicological listening involves analytical listening in order to identify aspects of style, structure, or technique, for example. Generally, music therapists have emphasized the sensual and emotional aspects of music listening, and music educators have attended to analytic listening. Analytic listening has been considered a more sophisticated and “proper” way to listen, as illustrated in the following comment from the composer Aaron Copeland (1957):

The surprising thing is that many people who consider themselves qualified music lovers abuse that plane [sensual] in listening. They go to concerts in order to lose themselves. They use music as a consolation or an escape. They enter an ideal world where one doesn't have to think of the realities of everyday life. Of course they aren't thinking about the music either. Music allows them to leave it, and they go off to a place to dream, dreaming because of and apropos of the music, yet never quite listening. Yes, the sound appeal of music is a potent and primitive force, but you must not allow it to usurp a disproportionate share of your interest. The sensuous plane is an important one in music, a very important one, but it does not constitute the whole story. (p. 18-19)

A less admonishing account about the varied nature of music listening experiences is conveyed by Machlis, a musicologist (1977):

We vary greatly in our way of responding to music. During the playing of the Triumphal March from Aida, one listener will summon up a vision of ancient tombs and Pharaohs. Another floats off in a daydream equally far removed from the music and the world. A third is filled with a strange sense of power at the ringing tone of the trumpets. His neighbor for no apparent reason recalls the half-hour he spent in the dentist's chair. This one is pleased with himself for having noticed the reappearance of a theme. That one has decided that the conductor is a shoemaker and wonders how he ever managed to get an orchestra. The musicologist reflects upon the contribution of Verdi to grand opera style. The critic polishes a phrase for his next review. The budding composer is oppressed by a suspicion that he was born too late. (p. 5-6)

When music listeners hear music, too much is happening to attend to everything.

Musical and non-musical elements vie for attention. Music psychologists empirically investigate perceptual and cognitive experiencing of music elements (e.g., melody, rhythm, pitch), often comparing the data of musicians (i.e., trained listeners) and non-musicians (untrained listeners). In general, music listeners focus their attention on melody and rhythm, and only skilled musicians, for example, perceive complex harmony (Orbach, 1999). Each listening may also be heard or attended to differently:

The truth is we are notoriously fickle about what we perceive. Sometimes we hear a piece of music in great detail; sometimes it passes us by and we aren't even aware of it. Sometimes it is masked; and sometimes we just don't pay any attention to it. Sometimes it grips us and we experience an emotional charge; at other times it seems banal and flat, without a spark of feeling. Sometimes it appears full of meaning and, at other time it seems utterly meaningless. Sometimes we organize it one way and, at other times in a

totally different way. Sometimes we like it; sometimes we don't. In short, we vary greatly in the way we respond to the same music, the very same pattern of sounds. Also we differ among ourselves in the way we respond to music. (Orbach, 1999, p. 267)

In sum, music is a complex entity comprised of multiple elements that move us to feel and/or to think. Consequently, there are endless possibilities for particular experiences and meanings in music listening that must be held in tension with elements of the phenomenon that supercede the individual.

Empirical research. The empirical literature appears to have established three undisputed facts about the phenomenon of music listening. First, listener characteristics such as gender, age, musical training, personality traits, and education are not associated with significant differences in the reported enjoyment of music (e.g., Madsen & Byrnes, 1993; Sloboda, 1991; Wheeler, 1985). Second, there are undoubtedly positive responses associated with listening to music. Music listening is most commonly understood as a coping strategy for managing stress. For example, Lehrer and Woolfolk (1993) noted that listening to music "may be one of the oldest informal techniques of stress reduction" (p. 9). A survey of almost 4,000 Americans (Golin & Hanlon, 1995) reported that 41% of respondents intentionally listened to music in order to relieve stress, and similar survey findings were reported by Fellows and Jones (1994). Avants, Margolin, and Salovey (1990-91) found that when used as a stress management technique by undergraduate students, music listening was more effective than progressive muscle relaxation or focused imagery and as equally effective as distracting imagery. Music listening's effectiveness as a coping strategy has also been evaluated by manipulating experimental conditions in order to create stressed participants. Stratton (1993) found general support for using background music to reduce emotional responses produced in a mildly stressful situation, as did Hatta and Nakamura (1991) who used waiting as a stress-inducing stimulus. Quasi-experimental studies in

stress management have examined the use of music listening to reduce the acute anxiety often evoked in medical settings during debridement for burn treatment (Barker, 1991), bronchoscopy procedures to examine the airway (Metzler & Berman, 1991), dental work (Anderson, Baron, & Logan, 1991), Caesarean births (Stein, 1991), and labor and delivery (Gonzalez, 1989). These researchers reported positive relationships between listening to music and reduced anxiety as measured in self-report psychological data; but, inconclusive results were obtained when physiological measures of blood pressure, heart rate, skin temperature, and galvanic skin response were used.

Research investigating music's apparent influence in increasing secretory IgA, a substance that helps to kill bacteria and strengthen the immune system, seems more conclusive. Rider, Achterburg, Lawlis, Goven, Toledo, and Butler (1988 as cited in Tsao, Gordon, Maranto, Lerman, & Murasko, 1991) reported that listening to music produced statistically significant increases in IgA production when compared to the control condition. Other researchers (Tsao et al., 1991) found that when university students spent 20 minutes listening to music, there were significant increases in their secretory IgA.

Further positive associations between music listening and other desirable outcomes have been established outside a stress and coping framework. Cripe (1985) found that listening to rock music decreased activity levels and increased attention spans in young boys with attention-deficit disorder. Morton and Kershner (1990) reported that background music increased memory capacity on a verbal dichotic listening task.

Third, there are also negative consequences associated with music listening. Martin and Clarke (1993) reported that music preference in adolescents was linked with vulnerability to suicide ideation, depression, delinquency, and deliberate self-harm. Feeling sadder after

listening to preferred types of music distinguished the most vulnerable group of adolescents. However, Kim, Kwak, Chang, and Yang (1998) identified sensation-seeking motivation as a mediating factor in the positive relationship between rock music preference and antisocial behavior demonstrated in Korean adolescents.

In sum, the empirical research supports the present study's premise that music listening is a commonly experienced, often positive activity for human beings (e.g., Golin & Hanlon, 1995). Music listening has been implicated as a coping strategy for managing distressing feelings such as anxiety (e.g., Metzler & Berman, 1991), as well as positively affecting attention (e.g., Cripe, 1985) and memory (e.g., Morton & Kershner, 1990). Empirical research also warns of potential negative effects of music listening (e.g., Martin & Clarke, 1993), which also is important to explore in the present study. The methodological restrictions associated with empirical research of music listening support the present study's use of a different method since music listening has been restricted to paper and pencil tests, in a clinical or experimental setting, and usually without consideration for individual music preferences. The subject of everyday music listening has not been captured in these empirical studies.

Theoretical research. Different ideas have been put forward to try and explain our responsiveness to music listening. Because only self-report data and not physiological data support an association between music listening and decreased anxiety, Maranto (1993) suggested that the primary effect of music in reducing stress may be distraction. She interpreted the evidence as suggesting that music listening involves benefits based on cognitive psychological processes rather than physiological processes.

Conversely, Fried (1993) proposed that stress responses were hypoxic phenomena; that is, responses generated by a lack of oxygen. His clinical observations led him to believe that

music positively influences breathing. Pieces such as Pachelbel's Canon in D and the Minuet from the Boccherini String Quintet in E appeared to facilitate deep-diaphragmatic breathing. Tempos less than the heart rate (72 beats per minute), triple meter, slow sustained melodies, slow drones, softer timbre (flutes, strings, voice), and gradual dynamic changes were musical characteristics associated with deeper breathing (McClelland, 1988).

Supporting neither physical or cognitive/psychological arguments, Thaut (1989) concluded that hopes of establishing causal relationships and general principles are unrealistic because "physiological responses to music are the product of each individual's unique, idiosyncratic physiological make-up, which is further influenced by the individualized psychological experience of music" (p. 60). Osborne (1989) reached a similar conclusion. He wanted to know the extent to which music could represent the narrative contained in the same scenes without listeners having the benefit of the program. Four female graduate students listened to Strauss' Alpine Symphony over several weeks and wrote descriptions of their experience. Although Strauss' work was programmatic and meant to communicate specific images, the data demonstrated that individual thoughts and feelings transcended the particular program of the Alpine Symphony. The students' experiences were diverse in terms of content and imagery although similar emotions were described. For example, a participant who was a dancer used imagery associated with movement and dance, whereas another who enjoyed gardening relied on gardening and plant images. Osborne (1989) concluded that it might be futile to establish or make meaningful distinctions in aesthetic experience.

The theoretical research illuminates the difficulties of extrapolating beyond the particular findings of empirical studies. General cause and effect principles fail to reflect the complexity of the phenomenon of music listening, and instead, have led researchers to focus on particular

aspects of music listening: for example, breathing (Fried, 1993) and distraction (Maranto, 1993). The inadequacy of theory to explain the impact of music listening suggests the appropriateness of returning to the phenomenon itself in order to establish a ground from which to anchor the particular findings of empirical and theoretical work.

Popular press. Much information on the therapeutic benefits of music listening as well as music listening descriptions appear outside of refereed academic journals and peer-reviewed books. These popular press books and articles target the general public often with the purpose of offering self-help. Many of these texts include descriptions of lived music listening experience as well as exploration exercises and suggestions for readers. I briefly summarize a few representative books.

Moss (1977), a doctor who left his medical practice to incorporate a transformative perspective into his work, provided a perspective that construes medical crises as opportunities for personal growth. Moss posited that the rational elements of human consciousness manifested in mainstream medicine are best partnered with a transformational perspective, a perspective that “encourages patients to acknowledge the limits of conscious effort in illness and move from a problem-oriented consciousness to a healing consciousness” (p. 23). A healing consciousness is described as an ego-less state in which wholeness rather than separateness exists and a different kind of healing energy is accessed, a transpersonal healing energy. One chapter of this book focuses on music listening as one way of “surrendering” (p. 89) into this state of consciousness. Readers are instructed to select a piece of music intuitively by going to their music collection and when they “feel a sense of connectedness” (p. 84), choose the selection, prepare to listen by deep breathing, and then “let go into the music and become lost in it” (p. 84). “Dissolving into the music” (p. 88) is hypothesized to encourage feelings of unity and ease, and importantly,

“create space within consciousness” (p. 88) for a different experience of self such that “the music is unified—there is no music, there is no listener” (p. 89), and a natural wholeness occurs.

Coinciding with the introduction of Sony Walkmans in 1979, Joudry (1984)—a novelist and playwright—promoted the Tomatis method as a “listening technique using high frequency music for beneficially recharging the cortex of the brain” (p. i) with a vitalizing, harmonizing, and healing effect that results in benefits such as more efficient sleep; fresh vitality and sense of well-being; deep relaxation and relief of anxiety; improved hearing; balancing of the inner ear fluid; alleviation of stammering; help for children's behavioral and learning problems; slowed metabolism; and increased creativity and mental capacity. Readers are encouraged to listen at least 3 hours a day to specially recorded cassettes of classical music using a portable cassette player as they carry on with their usual daily activities. A lack of conscious attention is advocated with the implication that benefits are incurred neurologically and independent of listeners' intent. Approximately 12 case histories, including the author's, are included in the book as well as a rationale based on Tomatis' understanding of ear and brain functioning.

Mathieu (1991), a musician, composer, and teacher, wrote about the power of listening as an instrument of self-discovery and personal transformation. His book is comprised of 70 short essays, musings, and anecdotes meant to heighten awareness of listening, listening to music, and making music. Exercises designed to link sound, music, and everyday life are included and readers are encouraged to listen with their “whole self” (p. 36) by solely focusing on the music. Similar to the intent of a phenomenological text, Mathieu's book serves to remind and reveal an experience he believes has been forgotten or overlooked because music has become “devalued currency, ubiquitous and banal” (p. 37). Readers are invited to recognize and discover listening to music afresh.

Bonny and Savary (1990) provide a music therapy perspective on listening and imagery. Drawing on psychoanalytic concepts, they describe techniques for listening to suggested music in an altered state of consciousness. Exercises for both individual and group music listening are presented with the intention of helping readers experience new levels of consciousness in order to “develop self-awareness, clarify personal values, release blocked-up psychic energy sources, enrich group spirit, bring about deep relaxation, and foster religious experience” (p. 15). The steps of guided imagery include induction, the listening experience in an altered state of consciousness, then return to normal consciousness, followed by reflection. The induction incorporates deep relaxation, concentration, and a count-down (e.g., descending 10 stairs); and the return to normal consciousness involves a count-out (e.g., ascending 10 stairs). Reflection is encouraged through activities such as drawing, writing, moving, or quiet meditation. The exercises for individual listeners involve several choices of music to play as well as an image and/or narrative (e.g., exploring a meadow while listening to selections of Beethoven's Pastoral Symphony). The authors emphasize the diversity of listening experiences: some listeners see vivid images whereas others may experience colours, sensations, or moods and feelings.

A recent and well-received book is by Campbell (1997), a musician and educator on music and healing, who coined the phrase “Mozart Effect” to convey the benefits of music. Research, anecdotes, observation, case histories, and various concepts, models, and theories are detailed in this comprehensive book. The ideas of Alfred Tomatis figure prominently. Listening exercises are described with the intent of having readers enter into lived musical experiences ranging from listening, to humming, to moving. Eighteen potential benefits of music listening are listed: Music (a) masks unpleasant sounds and feelings; (b) slows down and equalizes brain waves; (c) affects respiration; (d) affects heartbeat, pulse rate, and blood pressure; (e) reduces

muscle tension and improves body movement and coordination; (f) affects body temperature; (g) increases endorphin levels; (h) regulates stress-related hormones; (i) boosts immune function; (j) changes perception of space; (k) changes perception of time; (l) strengthens memory and learning; (m) boosts productivity; (n) enhances romance and sexuality; (o) stimulates digestion; (p) fosters endurance; (q) enhances unconscious receptivity to symbolism; and (r) generates a sense of safety and well-being.

The popular press provides a rich source of writing that underscores the powerful and appealing effects of music; however, its contributions must also be tempered by the realization that authors writing for the mass media may simplify or overstate facts because of various influences and pressures. For example, prescriptive suggestions for music model a biomedical approach to diagnosis and treatment that serves to (a) enhance credibility, and (b) create financial benefits through the sales of tapes and CDs. A general desire to see music valued in society (e.g., music included in school curricula; music therapy positions included in hospital settings) may also encourage unfounded assertions or sweeping generalization. Both Summer (1995) and Ruud (1998) voiced concern and caution about these contemporary trends to promote music. Descriptions of everyday music listening experiences without the overlay of theory or prescription are needed in order to see and understand the phenomenon “as it is in itself” (Ray, 1994, p. 120).

The Phenomenon of Music Listening in the Context of Chronic Illness

In this section, I review three theoretical accounts and one empirical investigation that are directly related to the phenomenon of music listening in the context of chronic illness. The first theoretical framework is that of Csikszentmihalyi (1990) who introduced the concept of flow experiences as “states of concentration so focused that there is an absolute absorption in an

activity that seems to make time and emotional problems disappear” (p. 109). When listeners “seriously attend” (p. 109) to music, music listening becomes an activity that can induce flow experiences. Csikszentmihalyi speculated that flow experiences are positively related to health and quality of life because music listening helps to organize the listeners’ minds and keeps boredom and anxiety at bay by filtering out random and distracting information that undermine goal achievement.

Frank (1995) retold the story of Oliver Sacks, a neurologist, who injured his leg and following its treatment, was unable to experience sensation in the leg, and more disturbing, no sense of his leg being part of him. Frank used Sacks’ disturbing surreal experience to exemplify the moments of chaos that often accompany illness. In this particular example of chaos, music led Sacks back from the surreal because Sacks recovered by listening to Mendelssohn. The following excerpt is from Sacks book (1984) in which he described first listening to the piece.

I yearned for music but was frustrated in my efforts to obtain it. By mid-week I was sick of my impossible radio, and asked a friend if he would bring a tape-recorder and music....he brought along his recorder with a single cassette, saying he was sorry, this was the only one he could find. It was Mendelssohn’s Violin Concerto. I had never been a special Mendelssohn lover, although I had always enjoyed the liveliness and exquisite lightness of his music. It was (and remains) a matter of amazement to me that this charming, trifling piece of music should have had such a profound, and, as it turned out, decisive effect on me. From the moment the tape started, from the first bars of the concerto, something happened, something of the sort I had been panting and thirsting for, something that I had been seeking more and more frenziedly with each passing day, but which had eluded me. Suddenly, wonderfully, I was moved by the music. The music seemed passionately, wonderfully, quiveringly alive—and conveyed to me a sweet feeling of life. I felt, with the first bars of the music, a hope and intimation that life would return to my leg—that it would be stirred, and stir, with original movement, and recollect or recreate its forgotten motor melody....I played the Concerto again and again. I didn’t tire of it: I desired nothing else. Every playing was a refreshment and renewal of my spirit. Every playing seemed to open new vistas. Was music, I wondered, the very score of life—the key, the promise, of renewed action and life. (p. 86-87)

In this second excerpt, Sack (1984) described the moment of transformation in which he

suddenly walked and sensed himself whole again:

And suddenly—into the silence, the silent twittering of motional frozen images—came music, glorious music, Mendelssohn, fortissimo! Life, intoxicating moment! And, as suddenly, without thinking, without intending whatever, I found myself walking, easily, with the music. And, as suddenly in the moment that this inner music started, the Mendelssohn which had been summoned and hallucinated by my soul, and in the very moment that my ‘motor’ music, my kinetic melody, my walking, came back—in this self-same moment the leg came back. Suddenly, with no warning, no transition whatever, the leg felt alive, and real, and mine, its moment of actualisation precisely consonant with the spontaneous quickening, walking and music....I remembered walking’s natural, unconscious rhythm and melody; it came to me suddenly like remembering a once-familiar but long-forgotten tune, and it came hand-in-hand with the Mendelssohn rhythm and tune. There was an abrupt and absolute leap at this moment...from the awkward, artificial mechanical walking of which every step had to consciously counted, project, and undertaken—to an unconscious natural-graceful musical movement. (p. 108-109)

Both excerpts provide lived descriptions of music listening experience in the context of an acute injury. Sacks experienced music as catalyzing him into movement and an integrated sense of self. As a neurologist, Sacks was greatly troubled because his subjective experience of his leg contradicted the neurophysiological truth that his leg was there and it was repaired. Following his recovery and return to work, he started to have patients use their own words to describe their experiences. He discovered that his experience was commonplace when there was neurological damage to a body part. Many of his patients described the affected body parts as “missing or alien objects stuck on” (p.158). Nevertheless, this phenomenon was not understood or explained in the literature of neurology. It involved the notion of a self, which was theoretically incongruent with the assumptions of neurology (i.e., that humans are a neurological system).

Compelled to understand this phenomenon, Sacks read Kant (1781 as cited in Sacks, 1984) and discovered the concept of self described as “synthetic a priori intuitions which allowed, organized and made sense of experience: the a priori intuitions of space and time, which could structure experience and support an experiencing ego or self” (p. 166). In human

experience, there is usually a congruency between the outer and inner states based on a unity of space and time. When there is a disruption between the inner and outer states (e.g., absence of nerve-impulse), a “sort of intermediate state” (p. 166) is entered into in which the outer appearance is disconnected from an accompanying inwardness. In order to leave this intermediate state and recover, action is necessary to re-create space and time. Sacks speculated that music is the prototype of inwardness and inner being since it has no outer appearance, and is a “seamless flow of inner states, of indivisible, interpenetrating” (p. 167) inner time; therefore music is able to catalyze the necessary action. Sacks (1984) described music as “this living stream, this kinetic melody and utterance” (p. 167) that is capable of igniting action. Without action, the body part is perceived as lifeless and dead. Franks (1995) summarized this process of transformation as, “Music allows a direct connection to his body that speech can no longer provide. As he learns to turn musical rhythms into movement, Sacks begins to rediscover the use of this body ... and thus reintegrate himself” (p. 109). Sacks (1984) believed that music listening animated him in some transformative way as a result of experiences of lived time and space in music.

Ruud (1997) theoretically extended his work on music identity to suggest implications for health or a positive quality of life. Music identity was understood as a factor of lifestyle and culture that maintains a positive quality of life. Involvement with music (e.g., listening, performing, composing) was hypothesized to contribute to health because (a) music may increase feelings of vitality and awareness of feelings; (b) music provides opportunity for an increased sense of agency; (c) music-making provides a sense of belonging and communality; and (d) experiences of music create a sense of meaning and coherence in life. These four elements of music were conceptually linked to health through the work of Antonovsky (1987),

an Israeli medical sociologist who has researched associations between health and coping.

According to Antonovsky, there are three main resources that help mobilize against disease: (a) life feels comprehensible (predictable); (b) life feels manageable (conceivable); and (c) life feels meaningful. Ruud speculated that involvement in music fosters the development of a “strong, flexible, differentiated, and coherent identity” (p. 86) that is a further resource in achieving quality of life.

In Schorr's (1993) study of music listening, a repeated measures design was used to assess the impact of music listening on 30 women's perception of their chronic pain related to rheumatoid arthritis. They completed the McGill Pain Questionnaire (prior, during, and 1 to 2 hours after listening to music of their choice. Findings indicated that pain threshold increased while the women listened to music and for a period of time following the listening. ANOVA, based on subscales of the pain measure demonstrated significant results for both Number of Words chosen, $F(3, 26)=18.23$, $p<.001$ and the Pain Rating Index-Rank, $F(3, 26)=32.67$, $p<.001$. Schorr suggested that these findings offered preliminary support for Newman's (1990) model of health as expanding consciousness. Consciousness was conceptualized as a manifestation of the underlying pattern of the human field, which arises from patterning between time, space, and motion. Music was posited to be a patterned environmental resonance (ordered sound) that, by changing time-space-motion patterns, can precipitate a transformation or shift in consciousness that is understood as uncovering new action potential. Conceptually, music is linked to increased pain tolerance through changes in the human field that reveal possibilities for action that are transforming.

In sum, little attention has been given specifically to the experience and meaning of music listening for individuals living with chronic illness. Based on the four works reviewed,

beneficial links between music listening and chronic illness may be based on music-evoked time and space experiences that catalyze action (Sacks, 1984; Schorr, 1990) and/or attention that is goal-oriented and purposeful (Cziksentmihalyi, 1990), or reflect music's capacity to enhance identity by encouraging vitality, awareness of feelings, agency, community, and meaning that are conceptually congruent with a positive quality of life (Ruud, 1997).

Summary of the Music Literature

Music listening has been classified in terms of thinking or feeling (e.g., Cook, 1990; Copeland, 1957) and also investigated in terms of perceptual processes (e.g., Orbach, 1999). Empirical research has supported links between music listening and positive outcomes such as reduced anxiety (e.g., Barker, 1991; Stratton, 1993), increased attention span (Cripe, 1985), and better memory recall (Morton & Kershner, 1990), and is commonly construed as a coping strategy that either acts on the body in favorable ways or provides psychological relief through distraction and mood management. Potentially negative associations with music listening are also recognized (e.g., Martin & Clarke, 1993).

The findings of empirical research are far removed from the lived experience and lived meaning of everyday music listening. Investigations have occurred in experimental laboratories or in clinical settings under non-typical circumstances (e.g., dental work, labor and delivery, invasive medical treatments). Research designs have been time-limited investigations in which music often provides a background experimental condition against which participants experience an acute stressor or must complete a specific task. Music preferences have not typically been considered. Participants have completed surveys, prescribed tasks, and a variety of physiological measures, but, they have rarely been asked about their personal experiences in music listening.

Clinical work published in the popular press seems to use a different language, repeatedly referring to themes of consciousness, transformation, energy, and wholeness. Descriptive accounts of music listening appear, but they are explained with theory and suggested implications rather than explored in terms of lived meaning. By imposing theoretical concepts or responding to a political or financial purpose, the lived meaning of everyday music listening remains unrevealed.

Specific to music listening in the context of chronic illness, Cziksentialyi (1990) has conceptually linked music listening and a positive quality of life, and Ruud (1998) has linked music in all its varied forms with a positive quality of life and music. In addition, Sacks (1984) has provided phenomenological insights specific to an acute neurological illness and implicated the lived existentials of time and space; and Schorr (1993) has linked empirical findings with a theoretical framework (Newman, 1990) that incorporates the lived existentials of time, space, and body. These works suggest the promising nature of further investigation into music listening as experienced and understood in the context of chronic illness.

Formulating the Research Question

There is currently no single paradigm that explains human responsiveness to music (Maranto, 1993). Similar to Golan's (1963) description of the literature on creativity, a striking feature of music research literature is the "diversity of interests, motives, and approaches characteristic of many investigators" (p. 548). There is an assortment of theories, models, and ideas, and the rationale adopted likely reflects researchers' interests, expertise, and/or best theory-practice fit. Although, the concepts may be premised on aspects of lived experience of music, imposed theoretical terms obscure and distort lived experience and meaning.

Although it is confusing and challenging to find the research literature so scattered and fragmented, it is also a tribute to the complexity, significance, and appeal of the phenomenon. Longstanding themes have influenced and informed investigations of music across time—music's ability to appeal and to physically, emotionally, intellectually, and spiritually stir its participants; to convey wholeness, structure, and order; and to endlessly fascinate and hold interest. These themes resurface in work that focuses on identity development (e.g., Ruud, 1997), interpersonal experiences (e.g., Sears, 1968), management of feelings (e.g., Stratton, 1993), enhanced attention and goal-oriented behavior (e.g., Cripe, 1985; Csikszentmihalyi, 1990), beneficial neurological activity (e.g., Tsao et al., 1991); and triggered relaxation responses (e.g., Fried, 1993). Some of these ideas are specific to music listening and others are based on a general concept of music that includes music listening as one of several ways that music is experienced (e.g., performance, improvisation, composition).

In turning to the chronic illness literature, there are many psychological and physical impacts associated with chronic illness. Themes of loss (e.g., Charmaz, 1983; LaCroix et al., 1995), meaning (e.g., Dildy, 1996; Schaefer, 1995), and transformation (e.g., Fife, 1994; Paterson et al., 1999) have been particularly emphasized in human science research. Uncertainty, unpredictability, and continuous change characterize the course of chronic illness as individuals face changed bodies, relationships, and roles (e.g., Jensen & Allen, 1994).

The two literatures suggest many possible links between music listening and chronic illness, given the experiences and needs associated with chronic illness and the experiences and affects associated with music listening that are documented in the research literature. From them, several questions emerge: How might the fragmentation wreaked by illness be effected by musically evoked sensations of wholeness and order? How might loss of identity in illness be

impacted by identity formation in music? Are relationships based on music disrupted as are other relationships disrupted by illness? Can the distressing feelings and thoughts evoked by illness be managed with the relaxation and soothing responses brought by music? These questions point to places of overlap in the research literature, findings that dovetail in ways supportive of a belief that music listening might benefit individuals living with illness.

Further evidence arises in my own experiences. Since the onset of a chronic illness 9 years ago, I have become increasingly aware of the significance of music listening—rather than music performance—in my life. Prior to the present study, this was a “felt knowing”, largely unarticulated and unexplored. A personal connection to the phenomenon being investigated in a hermeneutic-phenomenological inquiry is not unusual because such research always starts as “a project of someone; a real person, who in the context of particular, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence” (van Manen, 1984, p. 40).

Music listening is a commonplace activity enjoyed by many people. I was curious to know more deeply what experiential meaningfulness occurs in music listening. I wanted to dwell on the phenomenon of music listening in order to uncover its lived nature, to reveal an experiential knowing of music listening. I also wanted to communicate this experience to others, and hermeneutic-phenomenological writing aims to involve readers and catalyze personal knowing. A hermeneutic-phenomenological text allows readers to know both pathically and intellectually that which was previously obscured, and this leaves readers able to act more tactfully and intentionally (van Manen, 1990).

And so the research question formulated for consideration and reflection in the present study was: What is the lived experience and lived meaning of music listening for women living with chronic illness?

EAVESDROPPING BEHIND THE SCENES / METHODOLOGY

eavesdrop; to listen in on

eavesdropping behind the scenes; the opportunity to find out what goes into creating, launching, and performing a new work or production

In this chapter, I position the inquiry, outline the guiding tenets of the present study's applied hermeneutic-phenomenological method, and identify the strategies used to generate, analyze, and transform data into a final text communicating the lived experience and lived meaning of music listening experiences for women living with chronic illness. I also discuss ethical considerations and then epistemic criteria associated with this type of phenomenological study.

Situating the Inquiry

The present study exemplifies the human science model (Howard, 1986), one that "focuses on subjectivity and stresses the achievement of understanding as opposed to the demonstration of truth; stresses collaboration with participants rather than a subject-object dualism; and emphasizes holism in contrast with fragmentation" (Rennie, 1994, p. 235). These attributes reflect the subject matter of human science inquiries, questions, and topics that explore what it is to be human. Phenomenological investigations are well-suited to human science research because all phenomenological research shares an interest in the inner perceptual world of human beings; in the world of everyday experiences (i.e., the lifeworld); and in descriptions that depict these experiences without the distortion of conceptualized, theorized, or categorized pre-understandings (Schwandt, 1997). Phenomenological inquiries aim to understand and

articulate phenomena in such a way that everyday lived experiences are recognized in a deeper, more profound manner.

Phenomenological Philosophy

Phenomenological research is founded on and best understood vis a vis phenomenological philosophy. Key themes of the phenomenological movement were established in the influential works of two German philosophers, Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976). Descriptive phenomenology, also referred to as eidetic or transcendental phenomenology, is associated with Husserl. Interpretive, or hermeneutic, phenomenology is associated with Heidegger.

Husserl's purpose was to develop a philosophy that allowed science to address meaningful and complex human concerns in a rigorous way (Spiegelberg, 1982). He strove to develop phenomenology as a "science of origins" (Husserl, 1971/1980, p. 69, as cited in Cohen & Omery, 1994), seeking to identify and describe essential, a priori structures that constituted human experience. Such descriptions were called eidetic. Eidetic descriptions were considered fundamental, free of bias and interpretation, and only attainable through phenomenological reduction (also identified as epoche), a process based on "suspending prejudgements, bracketing assumptions, deconstructing claims, and restoring openness" (van Manen, 2000, website) as well as carefully considering representative examples to intuit and describe (Cohen & Omery, 1994). Husserl held that the reduction was necessary because he believed that human consciousness rather than objective facts shaped experience and understanding of the world. The reduction circumvented interpretation—human consciousness—and allowed phenomena to be seen naively and without bias.

When Heidegger came to work with Husserl, Heidegger was already an established scholar interested in illuminating the “beyond ordinary” meaning of humanness—what is called Being or Sein (*presence*)—as opposed to the everyday meaning of humanness—what is called being or Dasein (*to be there*). Husserl’s ideas offered a way to stand back from typical everyday meaning of life and transcend to its larger meaning (Cohen & Omery, 1994). The men came to share a commitment to the phenomenological motto, “Zu den Sachen” or “To the Things Themselves” (Speigelberg, 1982) as well as a belief that the lifeworld (i.e., being-in-the-world) could not be known unless studied phenomenologically; however ultimately, their paths diverged. Heidegger rejected the notion that phenomenon can be known free of bias or interpretation—eidetic description—and identified hermeneutics (i.e., the theory and practice of interpretation) as a basic characteristic of human existence (Schwandt, 1997). Whereas Husserl believed that truth was revealed through the phenomenological reduction, Heidegger believed that truth was revealed through the world hermeneutically interpreted (Cohen & Omery, 1994).

Phenomenological Methods of Inquiry

Because phenomenology is a multi-faceted philosophy that has changed over time, both across and within different philosophers, there is not a singular phenomenological method (Cohen & Omery, 1994). For example, participants at a recent American conference identified 18 different forms of phenomenological research (Caelli, 2000). There are no unanimous criteria used to discriminate between different phenomenological methods because different disciplines (e.g., nursing, psychology, education, counselling psychology) have forwarded different typologies, and at this moment in time, the development of phenomenological approaches to research is an “ongoing, unfinished project” (Hein & Austin, 2001, p. 5).

A broadly conceived understanding attends to the philosophical commitments that anchor descriptive and interpretive phenomenology. Descriptive phenomenology, which is linked with Husserl's work, is based on the premise that researchers can transcend bias and engage with phenomena free of presuppositions and identify eidetic structure. Giorgi (1970; 1985), and his colleagues at Duquesne University—now recognized internationally for its contributions to phenomenological research in psychology—systematized an influential descriptive phenomenological method of inquiry predicated on this assumption. Similarly, the methods of van Kaan (1966), Colaizzi (1978), Karlsson (1993), and Moustakas (1994) focus on identifying eidetic structure. There are differences in the particulars of the methods. For example, van Kaam used a large number of participants, independent judges to establish intersubjective consistency at different stages of the analysis, and basic statistics to identify themes (e.g., frequencies); whereas Giorgi and Colaizzi used a smaller number of participants and did not incorporate intersubjective checks or statistical calculations (Hein & Austin, 2001); and Karlsson (1993) included hermeneutical elements. What is common across descriptive phenomenological research is an emphasis on the phenomenon's general structure and an explicitness of design and analysis (e.g., steps for analysis, tabular presentations of data analysis at different stages; use of direct quotes from participants), which is why this approach is sometimes described as empirical phenomenology (Hein & Austin, 2001).

Unlike descriptive phenomenology, interpretive phenomenology—linked with Heidegger—is not based on analytic steps nor an aspiration to identify general eidetic structures. Instead,

Results are offered as insights, not as replicable results of a structural analyses. The researcher aims to create a rich, deep account of a particular phenomenon, an uncovering rather than an accurate analysis of participants' descriptions (Hein & Austin, 2001, p. 7)

The methodological implications of Heidegger's work were explicated by Gadamer (1976) who emphasized the centrality of language and dialogue in understanding, and concluded that it is ultimately impossible for phenomenological research to bypass interpretation because language (i.e., talking and writing) is central to the phenomenological project, and language is always interpretive. Hermeneutics—the art, theory, philosophy, and practice of interpreting the meaning of objects (Schwandt, 1997)—was deemed a necessary and integral part of phenomenological methods. Interpretation was not judged as distortion or inadequate intuiting, but embraced as desirable. The hermeneutic practice of dialogical reflection on wholes and parts has become a purposeful strategy in contemporary interpretive phenomenology that is used to interpret phenomena and bring out tacit meanings. Heidegger's attention on the ontological understanding of Being/Sein has been replaced by a focus on understanding the *Verfallen* world of being, the everyday world that humans gravitate to (Cohen & Omery, 1994).

Paradoxically, differing philosophical commitments may generate similar findings. When two researchers independently analyzed an interview transcript—one from the perspective of van Manen's (1990) interpretive phenomenology, and one from the perspectives of Colaizzi (1978) and Osborne's (1990) descriptive phenomenology—their findings were remarkably similar (Hein & Austin, 2001). The authors argued that this convergence in analyses points to "human capacities for reflection and intuition, and the presence of intersubjective meanings" (p. 1) and is actually a positive statement about researchers' ability to reveal meaning, despite the challenges of interpreting meaning and despite using different methods.

Commenting as a nurse-researcher, Caelli (2000) distinguished between European and American phenomenology, contending that American phenomenology has extended phenomenological research in valuable ways that are particularly appropriate for the health sciences. Caelli observed that European phenomenology has investigated abstract phenomena such as consciousness, being, and perception. American phenomenology, on the other hand, has been used in the health sciences where practice rather than theory is apt to be emphasized; and thus, more concrete phenomena have been studied. Paralleling this difference in focus, American phenomenology has tended to (a) describe participants' lived experience within the context of culture rather than searching for universal or unchanging meaning of it, and (b) include rather than exclude thoughts and interpretations of the phenomena as part of data collection and analysis.

Van Manen (2000), an educational researcher, classified phenomenological research on the basis of different philosophical orientations (e.g., transcendental, existential, hermeneutic, historical, ethical, and linguistical phenomenologies) that have emerged from or with the influence of phenomenology. Practice based or applied phenomenology—what Caelli calls American phenomenology—supercedes specific orientations because theoretical commitments are subsidiary to an interest in the practice and application of phenomenological principles. Van Manen identified his own approach, and that of Giorgi (1970, 1985), Moustakas (1994), and Benner (1994) as all representing an eclectic applied phenomenology, which is studied in terms of practical consequences for living.

Van Manen's applied hermeneutic-phenomenological approach to research. Van Manen's (1990) approach to phenomenology seeks to be simultaneously descriptive and

interpretive, integrating the traditions of both phenomenology and hermeneutics, and representing the influences of Dutch scholars (e.g., Buytendijk, Linschoten, and Langeveld as cited in van Manen, 1990). A Canadian educator and researcher, van Manen's approach was formulated with a pedagogical focus; however, his method is widely known and has been utilized in similar practice-based disciplines such as nursing (e.g., Bergum, 1989; Bottorff, 1991; Madjar & Walton, 1999; Schaefer, Ladd, Lammers, & Echenberg, 1999), and to a lesser extent, counselling psychology (e.g., Cairns, 1999; Ferch, 1996; Massing, 1999; Starko, 1999).

Six research activities comprise the structure of his approach: (a) turning to a phenomenon that seriously interests and commits us to the world; (b) investigating experience as we live it rather than as we conceptualize it; (c) reflecting on the essential themes that characterize the phenomenon; (d) describing the phenomenon through the art of writing and rewriting; (e) maintaining a strong and oriented relation to the phenomenon; and (f) balancing the research context by considering parts and whole (van Manen, 1990). However, the implicit spirit of this kind of inquiry, a "carefully cultivated thoughtfulness" (p. 8), is more important than any of the six practical steps. Critical moments of such inquiry are considered to be ultimately elusive to systematic explication and more dependent upon the "interpretive sensitivity, inventive thoughtfulness, scholarly tact, and writing talent" of the inquirer (van Manen, 1990, p. 34), not a "mindless, slavish, or mechanistic" (p. 172) adherence to van Manen's ideas. A more recent articulation of his research approach (van Manen, 2000) described it as a method of reflection based upon implementation of the *reductio* (the reduction), attention to the *vocatio* (the vocative dimension), and use of empirical and reflective methods to generate and analyze data.

Summary of the Present Study's Method

Phenomenology is an influential and complex philosophy that has been used in a variety of methodological applications to research. There remains an ongoing tension between efforts to describe ways of generating and analyzing data (e.g., Giorgi, 1985; van Manen, 1990) and a criticism that methodological preconceptions lead towards a phenomenological positivism (Bolton, 1987). Nonetheless, the congruent thread that runs through phenomenological research is a desire to understand phenomenon in naïve, unfettered ways—that is, going to the “things themselves” (Cohen & Omery, 1994, p. 141)—which requires a methodological attitude acquired with the engagement in phenomenological reduction.

The purpose of the present study was to consider the lived experience of music listening for women with chronic illness, a research question that reflected a wondering about the nature and the meaning of an everyday experience within a particular set of life circumstances. In keeping with van Manen's (1990) approach, the intent was to describe and to interpret. Congruent with contemporary research applications in health sciences, a pragmatic orientation colored the study. A specific rather than universal context was considered, and reflective as well as pre-reflective material included. In keeping with the non-linear nature of phenomenological inquiry, the six research activities were worked at intermittently, simultaneously, and with a continuing return to see afresh and anew.

Data Generation

Turning to the Nature of Lived Experience

This inquiry was catalyzed by a convergence of my musical world, my world of health and illness, my world as a professional helper, and my world as a researcher. Logically, my own life experiences were immediately accessible to me in a way that no one else's could be, and provided an initial place to orient to the phenomenon and consider assumptions and pre-understandings that I brought to the study.

At the start of the present study, I knew that music listening was important in my life—more important since the onset of chronic inflammatory arthritis and iritis 9 years ago—and that vivid, easily recalled “music-marked” moments dotted the landscape of my life. Music and chronic illness were deeply felt, but generally unarticulated experiences. I have played the piano for more than 30 years and grew up in a home filled with an appreciation of music and the playing of recorded music. I completed a 4-year Bachelor of Music degree—studies in music theory; music history; music acoustics; conducting; orchestration; piano, guitar, choral, and Chinese ensemble performance—while supporting myself financially as a piano teacher; ballet accompanist; keyboard demonstrator; and children's special needs worker. I completed another undergraduate degree in music therapy that coupled studies in psychology with those exploring the therapeutic applications of music; and, after working for 2 years as a music therapist with older adults and adults with dementia, and institutionalized developmentally delayed adults, I started graduate studies in counselling psychology with a specific interest in counselling women, exploring feminist scholarship, and furthering my understanding of music as therapy. I completed research under the supervision of a faculty member with expertise in the stress and

coping process, and used multiple regression analysis in my Master's research to explore the relationship between creativity and perceived stress levels in music hobbyists and music therapists. During this time, I was diagnosed with chronic inflammatory arthritis and shortly thereafter, iritis, a chronic inflammatory condition of the iris. Not surprisingly, I found myself drawn to topics of health and illness with particular attention to stress and coping implications. Doctoral studies in counselling psychology granted me the opportunity to further specialize in counselling women and increase my familiarity with literature in the areas of music, health and illness, and stress and coping, as well as introduce me to the epistemological and ontological controversies in research. These methodological dilemmas were further appreciated as a result of working on two interdisciplinary research teams involving collaborations between faculty in counselling psychology, nursing, sociology, health and epidemiology, and medicine. One study used standardized measures and interviews to investigate applications to stress and coping principles for dual-income families becoming first-time parents; and the other used interviews and focus groups to re-conceptualize student mothers' experiences of stress.

My own lived experiences in music listening, performance, improvisation, and orchestration; in living with a chronic illness that has active and inactive phases; and in witnessing the complexity of humanness as revealed through professional and personal interactions with many different kinds of people, were all valuable sources of data. Including my theoretical and empirical understandings of these phenomena, and current personal demographics as a married 38-year-old Caucasian woman of British/Canadian heritage with 2 children, I had a jumble of rich personal knowledge from which to consider the lived experience and lived meaning of music listening for women living with chronic illness.

My initial and simplest anticipation was that the phenomenon of music listening in the context of chronic illness had a lot to do with emotions—both in the music and in the listener. More speculatively, I wondered what unique aspects of musical structure facilitated the expression and experiencing of emotions; that this was particularly pertinent in the circumstances of chronic illness; and that perhaps music listening acted as a coping strategy for managing the emotional impacts of chronic illness. I was also cognizant of the themes emerging in the literature review and summarized in my formulation of the research question.

Techniques of phenomenological reduction. Five techniques of phenomenological reduction—heuristic reduction, hermeneutic reduction, phenomenological reduction, eidetic reduction, methodological reduction (van Manen, 2000)—helped me use these personal experiences and understandings in a way that enhanced rather than hindered the research process of generating and analyzing data, and of creating a text that represented the phenomenon in a recognizable and feeling way. With the heuristic reduction, I bracketed (i.e., set aside) an attitude of taken-for-grantedness in order to approach the music listening phenomenon with wonder and naïveté. The hermeneutic reduction of bracketing interpretation and assumptions encouraged me to remain open to the phenomenon, and guard against pre-maturely understanding the phenomenon on the basis of personal preferences, inclinations, expectations, or wishful thinking (van Manen, 2000). The phenomenological reduction meant bracketing theoretical knowledge in order to elucidate concreteness, thus making the phenomenon clear in its experiential reality. Rather than ignoring theory, I considered theory in terms of the phenomenological insights it might hold. The eidetic reduction served to make the particular and concrete nature of lived experience more universal by revealing meaning and themes, which I understood as possible representations of human experience and not absolute universals of humanness. My aim was to

identify “iconic images of the phenomenon—intimations of meaningfulness” (van Manen, 2000, website), which involved among other things, using free imaginative variation—a comparison process of imaginatively changing, eliminating, or varying themes. For example, I compared the phenomenon of music listening with similar but different phenomena (e.g., television or reading); I reflected on how the phenomenon of music listening in chronic illness might differ from listening in health. The methodological reduction gave me permission to bracket methodological practices in order to prioritize faithfulness to the phenomenon rather than techniques. I approached the phenomenon with guidelines, not rules. My overriding concern was to represent the phenomenon in a text that was strong and insightful, rather than impose techniques on the phenomenon.

Although these reductions sound like discrete and contained activities, they were, in fact, aspects of a singular fluid process that continued throughout the research—an ongoing dialogue I held with myself and with others, and which took place both inside and outside the research environment. In keeping with Ahern’s (1999) description of bracketing and reflexivity as “fruit from the same tree” (p. 410), bracketing and reflection occurred interdependently. In order to maintain and reflect this fluid process, my voice is interspersed throughout the present study, rather than isolated in one place as is a more common practice.

Investigating Experience as We Live It

Personal experiences, interests, education, and training provided an initial impetus and source of data for the present study. Further data were generated primarily through the participants’ experiences as revealed to me in conversation and journal entries.

Participants. Following a pilot interview (see Appendix A), 6 women were interviewed on multiple occasions about their music listening experiences. Advertisements were first posted specifying the inquiry's purpose and criteria for participation (see Appendix B); however, a lack of response led me to seek a purposive sample by word-of-mouth. I distributed the advertisements to friends and colleagues for them to pass onto their own contacts and 6 women ended up participating in the present study, who all met the requisite criteria as determined in telephone interviews (see Appendix C). They had lived at least 2 years with a physical chronic illness, which was defined as any physical condition that could be treated but not cured (see Appendix D); they considered music listening to be an important part of their lives; and they spoke, read, and wrote enough English to participate fully in the research.

Meetings were scheduled at the women's convenience and took place over a 3-year period. Each woman met with me in her home on two occasions, with the exception of one participant who met with me in a university office both times. Our audiotaped conversations ranged from 1 to 2 ½ hours, were transcribed by either myself or a professional transcriber, and later edited for consistency and maintenance of confidentiality.

All conversations were conceptualized and introduced to the women as knowledge-generating endeavors in which the women and I were motivated by a common curiosity and intellectual wondering about the phenomenon of music listening. The emphasis and focus was placed on the participants' lived experiences, and the interviews were open-ended and largely unstructured. There were a few questions that I asked of each woman (see Appendix E), but my general task was to keep us attuned to the phenomenon of listening to music and continuously encourage them to tell me, especially through the use of examples and anecdotes, what listening

to music was like for them in their lives. I drew on my skills as a trained counsellor, which were useful because I immediately felt at ease in the conversational setting. I was also practised in establishing rapport and common purpose; attuned to the impact of posing questions in different ways; aware of non-verbal behavior; familiar with the processes of self-reflection and collaborative reflection; and used to being engaged in the moment while simultaneously attending to myself, the participant, the conversation, and the environment.

The initial interviews started with a review of the consent form (see Appendix F) and an orientation to purpose. Then each woman was asked, "Tell me how listening to music is part of your life and how this relates to your chronic illness? Subsequent queries included questions such as: Can you remember when you first became aware of the importance of listening to music in your life? Can you tell me that story? Can you give me an example? Can you think of a different kind of music listening experience? Although anecdotes were encouraged in all the conversations, this was especially true of first meetings where the primary purpose was to establish a common rapport and understanding of purpose, and gather detailed descriptions of specific music listening experiences. The women were encouraged to describe rather than explain their experiences.

Second interviews focused on exploring preliminary interpretations and meanings, as well as soliciting further stories. Themes that I identified from earlier conversations were discussed in light of the question, "Is this what this experience is really like?"

A third contact was made when I sent a copy of the results chapter to each participant. One participant received the printed text as well as an audiotape of the chapter because of her limited vision. Some of the women responded spontaneously by e-mail, phone, or letter, which

was incorporated into the present study as evidence supporting the representation and legitimization claims of the present study.

Texts. All the women were given a journal at the end of the first interview, and invited to note or elaborate on any insights, experiences, or thoughts pertinent to music listening that occurred between the first and second interviews. The journals were private and optional. If they wrote in them, the women were free to share the material in whatever manner they chose (e.g., allowing me to read directly, reading to me, summarizing parts) as well as free to not share material. Three of the 6 women kept journals. Two gave me their written material, and another read from it during her second interview.

In addition to the women's journals and transcripts, I read autobiographies written by women living with chronic illness (see Appendix G). Additional sources of data that informed the present study were poetry, quotes, and texts that spoke to music and/or to illness; music, etymological, and standard dictionaries; and a series of six concerts I went to with the express purpose of attending to my experience of the music (see Appendix H). Less tangible, but nonetheless important, were the unexpected sources of insight that arose from ordinary moments in my life—movies, theatre, newspaper articles, radio shows, daily interactions—as I lived with a curiosity and wonder about the phenomena of music listening and chronic illness, and their intersection.

Data Analysis

Data analysis was undertaken to identify what constituted the experience and meaning of lived music listening experiences for women with chronic illness. Hermeneutic phenomenological reflection and writing, the “reflective activity of textual labor” (van Manen,

1990, p. 78), helped discern beyond the phenomenon's immediate appearance and to its multi-dimensional and multi-layered meaning.

Hermeneutic Phenomenological Reflection and Writing

Initially, I read the women's transcripts and journals a few times for familiarity; then I started to identify anecdotes and shorter quotations that seemed especially notable in their clarity, appeal, and revelatory nature (van Manen, 1989). Next, I analyzed the documents using a selective or highlighting approach; a holistic or sententious approach; and a detailed or line-by-line approach (van Manen, 1990). The three levels of analysis involved (a) using a pen to highlight thematic phrases that stood out in the transcripts (i.e., ideas that were emphasized or repeated); (b) generating statements that conveyed the main significance of each woman's overall story, as well as (c) generating thematic statements or phrases that captured each sentence or sentence cluster. Each reading led to further thoughtfulness and meditation on particulars of the lived experiences and emerging broader themes.

Guided existential reflection. A guided existential reflection based on the four lifeworld existentials—lived body, lived time, lived space, and lived relation—continued the process of phenomenological questioning, reflecting, and writing (van Manen, 1990). Because humans always exist in body, time, space, and relationship, the lifeworld existentials help reveal how we live and experience ourselves as human beings. These existential themes are found in the phenomenological literature and are generally believed to characterize the lifeworld of all human beings (Merleau-Ponty, 1962; van Manen, 1990). For example, (a) we are always bodily in the world, so the lived body always informs or is part of experience; (b) we experience subjective time, which is how time feels rather than how it is marked in minutes and hours and live with a

felt sense of the past, present, and future; (c) we experience the dimensions of our world in terms of felt space; and (d) we live in relation, communing with people and also in terms of a spiritual otherness. Van Manen (1990) called them lived existentials in order to differentiate them from the kinds of themes that characterize the human phenomena studied in human science research, and to emphasize their pre-reflective nature (i.e., they tend to be experienced pre-verbally). The lived existentials are interdependent concepts, but for pragmatic purposes are considered individually.

I used the lived existentials to reflect more deeply on the data. For example, I wondered about how music listening affected space and about what meaning there was in a musically changed space. I sorted the data by existential groupings, and considered the data against the more substantial questions such as “What qualities make this phenomenon what it is and without which it could not be?” and “What does this reveal about the experience of music listening in illness?”

Writing as analysis. To deepen my understanding of the data, I wrote freely around specific anecdotes, quotes, and words. I varied the example by imaginatively changing aspects of the phenomenon in order to identify the broader themes illuminating the lived experience and meaning of music listening in illness (van Manen, 1990). I contemplated other creative arts and activities that were like but unlike music. I wondered about reading and visual art, how were they like and unlike music listening? I reflected on the music filled space, and how a space with musical sounds was like or unlike a space with television sounds? What was it to listen? What was it to hear?

I wrote and rewrote, drawing on additional sources of data—quotes about music, etymological meanings, personal experience, autobiographies of illness—and always moving between the particulars and the general, always coming back to the lived experiences found in the participants' data and my own history. Writing around anecdotes was useful because they provided analytic anchors of lived experience. The best anecdotes incorporated concrete particular details that simultaneously suggested more general principles. The continued movement between the particulars of data and broader questions—for example, what does this reveal about the experience of listening to music? What further meaning might this have within a life characterized by chronic illness?—as well as shifting between lived experience and interpreted, linguistically represented experience led to a “rigorous interrogation of the phenomenon” (van Manen, 1990, p. 131).

Writing for a vocative text. Final linguistic transformations involve clarifying key themes and translating them into a text that is vocative (van Manen, 1996) and aesthetic (Todres, 1998), a text that speaks to and addresses its readers. Such texts are thoughtful and suggestive rather than definitive, showing experientially (expressive meaning) rather than telling rationally (designative meaning) (van Manen, 1996). These texts use language to encourage knowing through the senses, knowing that is felt and that has texture (Todres, 1998). In this way, readers are touched and led to engage personally with the text. Without textual tension, the writing is flat and superficial (van Manen, 1990). The stronger the vocative text, the more embedded the meaning, and the more difficult it is to paraphrase or summarize the text (van Manen, 1996).

In order to accomplish this kind of poetic writing, I attended to the textual features of concreteness, evocation, intensification, tone, and epiphany (van Manen, 1996). I achieved concreteness by using specific and particular descriptions written in the present tense to place

the phenomenon concretely in the lifeworld. I also introduced each woman in sufficient detail to reveal her more fully and concretely. I created an evocative text by seeking words that evoked and vividly revealed the phenomenon, and I intensified the text by trying to maximize the full poetic value of words. I chose words that kindled sensory knowing (especially of the ear), interlaced the text with music terminology in order to enrich meaning, and thoughtfully attended to the arrangements of words. The inclusion and elaboration of metaphor were used to further these efforts. Various metaphors were incorporated in the final text, as well as one extended metaphor meant to further elaborate on the phenomenon as well as reveal it differently by drawing on a parallel yet contrasting experience. I strove to imbue the text with a tone that addressed readers in a feeling and stirring manner, and furthermore, to create an evocative text that would leave readers feeling changed by what they read.

Parts and Whole, and Maintaining Relation to the Phenomenon

Hermeneutic-phenomenological inquiries produce texts that aim for a certain effect based on their “dialogical structure and argumentative organization” (van Manen, 1990, p. 33), an effect that is more than a descriptive explication of “whatness.” The overall design was repeatedly assessed with attention to the important contribution of the parts to the “total textual structure” (p. 33). Considering the parts and wholes meant moving back and forth between the particular and the general as in reflective analysis, but also in terms of the final text. I tried to step back and look at the total, as well as immerse in the specifics in order to compose a text that incorporated a tension between what is unique and what is shared; between particular meaning and transcendent meaning; between the reflective and the pre-reflective.

I remained mindful of the original question and thus continuously connected to lived experience throughout the stages of generating, analyzing, and writing the data. Allowing the phenomenon to fully “animate” me was one safeguard against the possible “superficialities and falsities” of an inadequate understanding (van Manen, 1990, p. 33). As an educator, van Manen’s pedagogic focus has repeatedly returned him to the question, “And what does this tell me about the nature of pedagogy?” As a professional helper, my recurrent and grounding question has always been, “And what does this reveal to me about human psychology and the nature of helping?”

Ethical Considerations

This inquiry shared ethical concerns common to all research endeavors as well as some specific to human science research. General considerations involved obtaining informed consent prior to audiotaping; declaring participants’ right to withdraw at any time; identifying possible consequences of participating in the study; and stating measures taken to maintain confidentiality (see Appendix F). On the basis of these criteria, the study was approved by the Clinical and Behavioral Sciences Research Ethics Board at the University of British Columbia (see Appendix I).

Further ethical considerations focused primarily on the relationship between myself and the participants. Kvale (1996) referred to interview inquiries as moral enterprises for which explicit rules or clear solutions cannot be stated. Ethical principles and obligations are generally less clear within the parameters of human science inquiries because interview-based investigations involve topics of lived experience that are necessarily intimate and sensitive despite being cloaked with the impersonal label of science or research. Sustained interpersonal

contact between the participants and myself; high personal interest on my part; and a focus on often unvoiced private realms of personal experience created a simultaneously intimate yet oddly formal relationship as well. As a graduate student, an important purpose was to generate an academic document that met the university's criteria, and I arrived at the women's doorstep as a researcher. And although I was motivated by a desire to contribute beneficently to the women immediately and others more generally; there was always the risk that whether intended or not, participants could end up feeling compromised, silenced, misrepresented, or unfairly treated. Paradoxically, although the inquirer/participant relationship is the predominant site of ethical difficulty, it is also the place to offset or rectify ethical issues. I strove to be open, genuine, and reflective in my interactions with the participants, and was continuously attentive to their welfare as effected by their participation in the research.

Epistemic Criteria

Epistemic criteria are those used to establish the veracity or truthfulness of an inquiry. They provide a means for assessing the credibility of an investigation, a basis for evaluating claims to knowledge and ascertaining confidence in findings. The general concepts of representation and legitimation address the two related issues of (a) how and with what evidence are participants represented through the inquiry's data and interpretations; and (b) by what criteria are legitimacy claimed for the inquiry? In short, how are data and interpretations justified as trustworthy (Palys, 1997; Schwandt, 1997)?

Representation

Representation attends to how participants' voices are represented and how readers are informed about these strategies of representation so that the data's credibility can be

substantiated. Because the data are generated in conversation, credibility started with the relationship between the participants and myself. The extent to which our conversations were based on a common desire to seek understanding and reveal aspects of music listening experiences is associated with greater credibility of the data. All the women appeared to engage openly and responsively in interviews. Eagerness, thoughtfulness, puzzlement, delight, and quiet pondering were displayed as we grappled to articulate the felt experience of music listening. Further evidence of a shared responsibility and commitment in the project was demonstrated by 3 of the women who mailed me magazine articles on the topic of music, shared personal pieces of music with me during our meetings, lent me a favorite relaxation tape so that I could make a copy for myself, and kept journals between meetings. These actions exceeded the stated obligations for participation in the study, and demonstrate their investment in the research and its findings.

I started the inquiry quite concerned about differentiating between the research context and the more familiar therapeutic context because I feared that my training as a counsellor might undermine or conflict with my "scientific responsibility" (Kvale, 1996, p. 118). I took care in framing the research question, the purpose of our conversations, and our respective roles; I carefully reviewed the pilot interview; and I monitored and ruminated on my feelings and thoughts during and after conversations. These actions strengthen the credibility of the present study's findings.

The strength of an interpretation as premised on faithful representation is evaluated by the readers who come to their own conclusions about the apparent integrity and cohesiveness of the text. Sufficient details need to be included so that readers feel informed to reach a

judgement. Because the fidelity in hermeneutic-phenomenology is not so much to exact words but to a revealing or insightful rendering of participant descriptions—what Caelli (2001) refers to as interpreted narratives—readers are capable of assessing the text. As the researcher, my autobiographical particulars, motivations, and relationship with the participants must also be visible because of their significant influence on the generation and analysis of data (e.g., Rew, Betchel, & Sapp, 1993; Sword, 1999). As I made my voice heard and present throughout the text, readers acquire necessary information because, as an hermeneutic-phenomenological researcher, I was a conduit for experiential descriptions that were melded in a revelatory, meaningful way (van Manen, 1990).

Legitimation

Legitimation in human science research is a process negotiated through the implementation of an investigation and its later dissemination (e.g., Angen, 2000; Gullickson, 1993). Human science research rests on “a form of truth that is negotiated through dialogue and considered socially constructed through intersubjective experiences we have in the world” (Angen, 2000, p. 386). The phenomenological text is always open and never ended because the conversation to understand and reveal meaning is perpetual. A “final, complete interpretation” is not the purpose (Schwandt, 1997, p. 115). The purpose is to show something that was previously unshown, to show something that speaks to experiential meaningfulness.

As noted, readers evaluate the legitimacy of the present study. One type of judgement about the value of hermeneutic-phenomenological inquiries arises in what is called the “validating circle of inquiry” or the “phenomenological nod” (van Manen, 1990). Readers of the research text actively participate in the validation process when they become involved with the

hermeneutic circle—moving between data, analysis of data, and theme patterns from data—and determine for themselves if the presented interpretations are convincing (Gullickson, 1993). A good hermeneutic-phenomenological text elucidates an aspect of the life world such that the text resonates with readers and is recognized as an experience that has been had or could have been had, and sufficient information is provided to render the author credible and trustworthy. Initial drafts of the present study's findings (Nicol, 1998; Nicol, 1999) were positively received by both academic colleagues as well as audience members who lived with chronic illness. In both cases, conversations with interested parties generated validating circles of inquiry as they experienced recognition of phenomenological insight as well as pushed me to discern further.

The phenomenological nod describes the symbolic act of nodding in recognition when reading a phenomenologically sensitive text that reveals something as new and wondrous, yet familiar. In its simplest terms, hermeneutic-phenomenological value is determined when readers are re-awakened to lived meaning and significance. When this occurs, then the nature of a phenomenon has been adequately described, and the more foundational grounds of the experience uncovered (van Manen, 1990). During the second interview when we discussed meaning, the women "nodded" in response to emerging understandings of lived relationship in music listening. And later, after reading the results chapter that was sent to each participant at the end of the research, some of the women responded with comments that exemplify the phenomenological nod. Jean, for example, wrote to tell me how insightful the chapter was, but also, that she felt a renewed appreciation for music despite having always recognized its importance in her life.

Consequently, lived experience becomes a criterion for assessing lived experience: “a good phenomenological description is collected by lived experience and recollects lived experience, is validated by lived experience and it validates lived experience” (van Manen, 1990, p. 27). This is the validating circle of inquiry. Good hermeneutic-phenomenology uncovers shared practices and common meanings of lived experiences (Gullickson, 1993) such that we can live in a more tactful manner with opportunities for more thoughtful and intentional action: Phenomenology “allows us to belong to our experience again, but hopefully in a more profound way” (Ihde, 1976, p. 18).

Moral and Pragmatic Criteria

The moral and pragmatic implications of a study are additional criteria for judging the worth of human science research. According to Angen (2000),

When we pay attention to the realm of everyday experience, we discover the myriad influences that impinge on human thought, speech, and action, and see that we can no longer strive for some unitary truth of human behavior using exclusively reductive, positivist procedures. Instead what we require is an interpretive approach to social inquiry that will enlarge and deepen our understanding of what it means to be human in this more-than-human realm. To do this is to risk certainty, but this loss is mitigated by what we stand to gain in moral and practical relevance. As researchers, we remain ethically culpable, both for doing justice to the topics we take up and for choosing topics that have something meaningful to say about how we carry on from here. (p. 380)

Important criteria for assessing human science research involve considering how carefully the research question was pondered and framed; how respectfully the research was carried out; how persuasive arguments were developed in the written account; and how widely the results were disseminated (Angen, 2000). Angen (2000) suggested that these criteria were more important than epistemological criteria.

I concur that these criteria are important, and prefer to believe that moral, pragmatic, and epistemic criteria can co-exist. At the start of the present study, I was concerned about my stance as researcher versus counsellor, but, I discovered that helping and research-oriented interviews seemed to exist in continuum rather than dichotomously. The research orientation was grounding, but therapeutic benefits were undeniable.

Simply having an opportunity to talk was helpful for the women, as was the validation experienced from me and through the other women's stories. Their roles as active contributors to the knowledge-making process was esteem-enhancing as well. These benefits occurred spontaneously and were inherent in the structure of the research. There were also other occasions when I purposefully acted with both an academic and therapeutic intent. For example, on one beautiful sunny day I met with a participant who within the space of 10 minutes expressed both the delight of anticipating a first great-grand child's arrival and the despair of possibly losing bladder and bowel control. She said she would rather die than live with that. I later asked her what was most terrible in facing this possible outcome; this was a question that helped to clarify meaning (research-oriented) but also challenged the woman to articulate her fear rather than just be paralyzed by it (therapeutically-oriented). She responded rhetorically by saying, "well, would you want to live like that?" to which I paused, shrugged and said lightly with a rueful smile, "well, it's a beautiful day and a great-grandchild is on the way." This short exchange exemplifies the fleeting and contained ways in which therapeutic seeds could be dispersed and considered. My training as a counsellor benefited both epistemic and moral concerns.

Despite my keen awareness of professional training, the women did not seem to respond to this aspect of my identity. My personal rather than professional qualifications were most important to the participants. They appeared to primarily engage with me as another woman similarly situated in terms of enjoying music and living with a chronic illness, which I think was facilitative in terms of the inquiry's purpose.

To the best of my ability, I acted with high regard for the well-being of the participants and beyond the usual measures taken to ensure confidentiality and informed consent. I relied heavily on rapport and dialogue in order to ensure that participants felt justly treated and fairly represented. Nonetheless, I am mindful that no efforts could completely eradicate the implicit power imbalance between researcher and participant, which ultimately is a limitation to both the inquiry's ethical integrity and authoritative credibility.

PREMIERE OF “A SONATA TO SHOW” / RESULTS

premiere; the first performance or showing of a work

sonata; a piece of music having 3 or 4 movements to show; cause to be seen

Composer's Notes / Logistical Considerations

composer; one who puts together in a form, usually musical works

In this chapter, I have created a text of sounds and silences that point to and show the lived experience and lived meaning of music listening experiences for women with chronic illness. My goal is to help you hear the phenomenon in your own life, encourage you to listen, and leave you to continue in the company of its echoes.

Following an initial orienting to the concepts of music, listening, and hearing in a section entitled *Orchestral Tuning*, I begin the *Exposition* with a personal reflection on what it is to "live in the company of music and illness." Then, I introduce the 6 women and consider their stories by way of my music and illness story, as well as contrasted with each other's. After reflecting upon their differences, a guided existential reflection—based on the four lived existentials of body, time, space, relation—is used to identify commonalities in their lives with chronic illness. This understanding of life with chronic illness foreshadows and provides a framework for the next section—the *Development*—where I continue with a guided existential reflection to tease out significant aspects of the 6 women's music listening experiences, and intensify meaningfulness. Next, the *Recapitulation* section restates earlier material in different forms with the intent of providing additional phenomenological insight. By writing from a more general perspective, and then from a stance of metaphorical reflection, I continue to elaborate the lived experience and meaning of the inquiry's phenomenon. Finally, the last section is the *Coda*, which marks a place of ending and renewed wondering.

Certain conventions are utilized in the work. Ages given for the women are accurate to the first interview. Further details of their illnesses appear in Appendix D. Quotes have been edited to clarify the participants' meanings in the following ways: Three consecutive periods indicate the deletion of conversation that was irrelevant to the passage's significance and/or weakened comprehension; rounded brackets identify non-verbal body language or clarify what is being referred to although not explicitly identified in the excerpt; and square brackets identify my participation in the conversations. Definitions appearing in italics are drawn from several sources: The Oxford Concise Dictionary of English Etymology (1996), The Oxford Concise Dictionary of Music (1977), and Webster's New Dictionary and Thesaurus (1990).

Orchestral Tuning / Phenomenon Attunement: Listening and Hearing Music

tuning; during the warm-up that precedes a performance, musicians prepare their instruments for playing after an initial pitch is sounded by the First Violinist to introduce and establish harmonic agreement amongst orchestral members

listen; to try to hear, to pay attention hear; to perceive by the ear

Hermeneutic-phenomenological research requires a wondering and questioning attitude of both its composer and its audience (van Manen, 2000). By starting with some preliminary reflections on the lived experience of listening and hearing—both in a general sense as well as specific to music—I want to establish a common reflective tone so that the phenomenon can be approached with a shared orientation.

What is it to listen? What is it to hear? The women in the present study listen to music, but what do they hear when they listen? The obvious answer is music, sounds organized and combined in a manner meant to provide aesthetic pleasure. This is the organic, fundamental offering of all art forms: a pleasuring of the senses. Melodic shape, chordal resonance, rhythmic momentum and pulse, instrumental timbre, phrasing: these are just a few of the

musical elements endlessly combined to create pieces of music that delight, horrify, or sometimes even bore. When audible sounds of music reach our ears and travel our auditory brain pathways, we hear, and then depending upon whether the music pleases or displeases, we decide to listen or not. Given music's inherent capacity to provide pleasure, it is perhaps not surprising that music listening experiences are important to the women participants who live with chronic physical illnesses and more limited pleasures.

There is some truth in this logic; but, the lifeworld, the world of lived experience, remains unconsidered. Understood semantically, hearing is the physiological process that takes place in the ear and discerns the presence or absence of auditory stimuli, which is sound. Listening, on the other hand, is a psychological process characterized by the intentional seeking of and/or attending to sound. But what is it to listen and hear as we live the phenomena of listening and hearing? Consider the following description:

I sit at my desk writing. I hear the fan whir, the computer keys click, and music play quietly; but, do I listen to them? No. I hear them but I do not listen, or at least not until these written words direct my attention to them. What I actually am listening to is silent to the observer though loud to me. I am listening to the words and sentences appearing on the computer screen in front of me. I hear the words in silent sound and listen for their effect: How does that sound? Is that what I want? How does this sound now? It is hard work and, as I reach points of frustration and fatigue, I stop listening and attending to the words. I am ready to be distracted. My ears scan the environment, listening for diversion, settling in with the voices outside the door, moving on, finding the fan (which another sensory modality notices as cooling), pausing, and then perking up. Hark! I hear music! Music moves to the foreground, absorbing me and all my exasperation as I start to listen. Everything ceases as I listen to the music, heeding its call and lost in its offering. I am absent to the office and captivated in rhythmic play. My toes tap, shoulders swing, and I start humming. What a short but invigorating sojourn! I hear words again; they start back into my head; and the music recedes. I am back listening to the words on the computer screen and sorting out how it all sounds.

This short excerpt of personal lived experience quickly demonstrates the constraints of semantic meaning. Hearing is more than a physiological process that occurs in the mechanisms

of the ear because hearing involves sounded sound as well as unsounded sound, sounds we hear despite silence or sounded sounds. For example, a musician scans the score before her recital, listening for mastery as she silently hears the score loud with the sounds of a run-through performance. Or what of the child who races into the street, and then abruptly pulls up short as the often-heard parental cry "stop, look, and listen" intrudes suddenly, loudly—and silently—into his consciousness? He hears a command, listens to it, and acts.

Do music listeners hear more than the music itself when they listen? Beyond the apparent and audible music that the women of this inquiry hear, what else might be sounding as they listen? What unsounded sounds are present for women who live in the company of music and illness?

Exposition/ In the Company of Music and Illness

exposition; first section of a sonata in which basic material is presented or exposed

Like the women of this inquiry and many others, I live in the company of music and illness, a seeming and oftentimes odd duo: the beauty of music, the beast of illness. Music is the long time companion, met early in life, and intertwined through all its facets. Chronic illness, on the other hand, arrived unexpectedly, abrupt and rude, although I know it sometimes arrives quiet and sneaky. Chronic illness is a wily companion, doing as it pleases, never mastered nor wholly appeased.

Music and illness—one invited, the other not; both shaping and coloring, framing and elaborating lives; amenable and bullheaded; with pleasant and unpleasant surprises. Mostly I keep an ear to one or the other, an uneasy union. I am lucky because I do not really pay that much attention to illness. I might be startled first thing in the morning; but soon enough, chronic

illness is just a faint echo receding to the background; overlooked, ignored. In fact, sometimes I almost wonder if I imagine this companion. Am I really living in the company of illness?

Music and illness—they are familiars and they are present: music more enchanted given the stamp of illness, and illness more coherent given ordered, expressive music; music construed ugly although still beautiful; illness occasioned lovely although always terrible. Together their bittersweet harmony draws and repels, aching of life. I know what it is like for me to live in the company of music and illness. Six women told me what it is like for them.

Six Voices A Cappella / The Women's Stories

voice; a melodic line a cappella; unaccompanied singing

Laurie. Laurie is 41 years old, and lives with her cat in the top floor of an older character house. After 31 years of "always being healthy and able to do whatever I want whenever I want," her life became characterized by a variety of physical problems. What started with "a complaint of sore hands in 1990," was followed by "difficulty with sleep," "a car accident," "lots of pain," and then another car accident. Laurie was initially diagnosed with Carpal Tunnel Syndrome, then Diabetes, and finally, after debilitating pain in her hands and neck caused her to "cut back on work," Laurie saw a rheumatologist who "determined that I fit all the criteria for Fibromyalgia." A good friend with the disease had not worked for almost 8 years, so Laurie's first reaction was "I'm not sick like her!" Although Laurie continues to work at two part-time jobs as a music therapist, she struggles with fatigue; poor sleep; pain in her hands, head, shoulders, neck, and lower back; a distressing inability to concentrate on occasion; and intermittent problems with short-term memory. Laurie describes her symptoms as variable so the ordinary activities of her life have to be negotiated with planning and foresight.

When I can rest and get away from the world as far as possible—I get overstimulated quite easily—then I seem to have better days. But activity just takes it right out the window, going to work or vacuuming or whatever.

Music has always been important in Laurie's life. As a young adolescent she traveled alone to see the her city's symphony perform and she "just couldn't get enough of it." She described herself as having a "wide-eyed child's" appreciation and "sense of magicalness," which made it seem "like a fantasy to play on stage in an orchestra." But Laurie went on to become a talented musician herself; performing on stage and working in the field of music therapy.

Fibromyalgia makes it painful for Laurie to play her instrument and losing her ability to play freely and skillfully is difficult. In practical terms, this constrains Laurie's work as a music therapist because she cannot always play instruments with clients. But the impact is more than pragmatic given Laurie's statement that "the thought of not being able to play music again really really scares me." Nonetheless, Laurie later says:

It seemed that when we talked about it (loss of musicianship) last year, there was a release in some way. And I noticed that afterwards I didn't feel as emotionally connected in the same way. Even though I am experiencing more pain, my first thought isn't "oh, how about my music?" I've moved a little bit past that.

When asked to identify the biggest challenge of her illness, Laurie replies:

Well, I don't want people to know. I think that by not wanting other people to know I'm not accepting it. I think I should just adjust and cope and be different in the world. But I'm finding it really difficult to be clear on my needs and let other people know about it. So including people in it—I'd always rather just do what I do and have others not know. And not being the same as I was—that I have to say "no."

Just as playing her instrument hurts Laurie, she can also experience pain when listening to music. Some music and sounds "hurt" her. As a result of increased sensory sensitivity because of the fibromyalgia, Laurie is "particular about quality" and very careful about what

music she listens to. With the onset of her illness, Laurie started listening to different music, discovering an enjoyment and immense attraction to the music of female folk artists. She finds herself listening to lyrics rather than listening for the musician(s)'s technical prowess. Laurie talks about finding "comfort" in music, and clearly seeks and discovers much solace in all her music. For example, certain songs are not used in her music therapy work because "they just seem like mine." When I comment that meaningful listening experiences seem to occur when she was alone, she concurs:

Yes. I have played some of my songs for people but not very many. Because they don't necessarily understand. I mean you could take the words as they are. That's not all it is though; but, it is a big part.

On one occasion when Laurie took in a song to share with a therapist, it ended up being a very dissatisfying experience.

I was actually seeing somebody for awhile and I brought her the song and I couldn't really say anything about it. It was very weird...because of course someone's going to say, 'what does this music mean to you' right? And it's like, 'well, don't you get it?' [So the music speaks for itself?] Yeah, for me. And to articulate that doesn't work.

Laurie responds thoughtfully and often takes short moments to silently consider my questions and comments. She describes herself as a private person, with "a lot of difficulty expressing emotion," although music helps her to access and experience her feelings. She oftentimes seems surprised by our conversation and her thoughts as she articulates them. She exclaims, "I haven't consciously thought about any of this" and "you're making me think! I don't usually think this much."

Jean. Jean is 64 years old and lives with her husband in a recently purchased suburban condominium where they moved after selling their Vancouver home. She started having health

problems about 4 years ago, and recently had a name to put to her difficulties—fibromyalgia. It has been a hard few years and Jean says that now:

I think I've gotten to the stage where there's no role playing. I went through this stage where I thought everyone would think I was neurotic and then I thought I was neurotic. But when I accepted that it was real and discovered a friend who has it—that's been a great help. In talking with her, I realized I wasn't making these things up. You're not going mad.

Jean experiences pain throughout her body, as well as fatigue and depression. Her illness is significantly debilitating, intrusive, and restrictive.

So my brain gets 'fibroblock' and all I want to do is go to sleep. I had a day like that a few days ago. And there's really nothing you can do to alleviate that. NOTHING. And I get quite a few of those days. I probably get more bad days than good days. I just want to escape on those days.

Music has always been part of Jean's life. She told me that she grew up playing the piano and listening to music and then in her teens, "suddenly felt that there was this music—this beautiful music." This revelation coincided with her father's heart attack and "in those days when you had a heart attack you didn't do anything, you just had to rest." So her father sold his business, and "developed a great liking for classical music." During this time Jean started seeing a man who according to Jean "introduced me to the art of music." He later became her first husband and when this marriage ended, a shared love of opera led to a second marriage with her current husband. Music is also at the heart of an intimate relationship Jean now shares with her grand-daughter who is a talented young musician.

Although music has always been a source of pleasure and basis for meaningful relationships, music listening is now more important than ever. Music literally has become the organizing construct of Jean's life. Several times Jean refers to music as a "lifesaver" because fibromyalgia interrupts her life so much. Jean explains:

Music was the one thing I still had and during this last year there were times when you get a depression with fibromyalgia and I'd think, "what's the point of life if I can't do anything at all?" And I'd try to do things and I'd just become ill and be ill for several days and eventually my husband said to me, "Well Jean, there's still a lot left in life for you. There's a lot we can do with your love of music. Let's just more or less plan our lives around that"...so really, I think it's probably saved me because I really have come to a point where I get up in the morning and think, "well, what will we listen to today?", "what will we start off the morning with?" It was a turning point for me because I thought, "he's quite right." There's still a lot out there that I can do and it really helped the depressed feeling I felt of being worthless and not being able to do very much. It makes me realize there's still a lot of pleasure there. So certainly music has really been a lifesaver.

Jean and her husband review upcoming national and international opera performances, plan an itinerary, purchase CDs and librettos in preparation, and then travel around the world to attend operas. Listening to music, especially operas, gives Jean a "high" in which she is "hypnotized by the music and everything else disappears." This includes the physical tension and pain associated with her illness: "Once the music starts, I just find that my muscles relax and I just sit back and let the music flow, so to speak."

Of all the women, Jean is the most explicit in identifying her passion for music, and the importance of music listening. Jean clearly articulates its place in her life, "I think music is one of the most moving things that one can experience...It's the greatest joy that I have."

Storm. Storm is 68 years old, a widow of 10 years, and lives in an elegantly furnished apartment located in the downtown city core, within walking distance of the theatres, shops, ocean, and the seawall boardwalk. Upon meeting her, I immediately notice the signs of osteoarthritis in her gnarled, misshapen fingers. Storm explains that it started almost 20 years ago when her fingers seemed somewhat swollen and her wedding ring would not come off; but, she thought "oh well, it's probably in my head." Although diagnosed by a rheumatologist a few years later, Storm continued to lead a very active life playing golf, going ballroom dancing, and

visiting her daughters and their families. At the time of our first meeting, she was in the midst of planning an extended solo summer trip back to her hometown of Amsterdam and on through Europe.

Neither she nor her parents played musical instruments, but Storm recollects that "music filled the house" she grew up in. Nowadays, music is turned on first thing in the morning and she sings and dances her way through daily routines and chores, until she falls asleep listening to Chopin and "floats up to the clouds." Storm said "I love to dance and I sing, just love to, if I know the words. My daughters too, they don't play instruments but love listening to music." Her eyes well up when she mentions how music evokes memories of her father and she explains that her feelings are "not sad, not depressed. It (music) just takes me there. I cry easy and I laugh easy."

For a long time, Storm's biggest illness-related challenge was coping with the pain in her fingers. She refused pain medication and specifically used music at night-time when the throbbing was the worst. However, at our second meeting 10 months later, Storm's circumstances were very different. The osteoarthritis, which started around 1980 in her fingers, progresses suddenly and rapidly until one day she can not "go up the stairs anymore." X-rays reveal "a narrowing on both hips" and several spurs along her lower spine:

My legs are so painful, especially at night. I can't lay on this side. I can't lay on that side. I can't lay on my back. On my stomach my neck starts hurting. And so my sleep isn't very good. And I haven't been able to play golf or do ballroom dancing which I used to do like three times a week. So I'm getting to be pretty depressed. Walking is very difficult. A kilometer, and then I've had it.

Storm's shock and distress are clear:

It's gone through my whole body but I never thought it would really happen to me. When I went to this clinic and saw all these people there, I felt sorry for them. I thought that's not going to happen to me.

But it did and Storm is clearly in the midst of much personal turmoil and crisis when we met for a second interview: seeking information and advice; hoping for relief; torn by conflicting feelings; uncertain that she could adjust; and fearful about the future.

Is it going to get worse? I made a joke about it. I said to my daughter "Perhaps you'll have to buy me an electric cart someday." Then I thought "oh, how did I say this?" I mean, I'd rather die than do that. [So your biggest fear is that it will get worse?] Absolutely. Because I've seen it get worse in NO time. In March I was still exercising three times a week and all of a sudden I couldn't do it anymore. I don't want to sit here and feel sorry for myself because that's the worse thing that can happen. I go to the library and read up on it as much as I can, if there is anything like a cure. But I know there isn't anything. But you know there should be something so that I don't have so much pain. There should be. I don't know what.

When asked what the hardest thing is about her illness, Storm replies:

I can't do what I used to do. That really bothers me. I used to walk with my friends and now I have to say, 'well let's go for a walk but yah, I can't go too far.' So they go by themselves because they like to go for a good walk. Dancing. I love ballroom dancing. I can't make these turns anymore. I mean it really bothers my hips. And golf. I tried it but because of the movement you make again with your hips - it didn't work out at all. It was painful because I like walking on the course and pulling the cart was painful. And then it's the nights that I can't stand. That's what really bothers me... My whole lifestyle has changed (tears welling up) (silence). It's also the feeling of am I getting old? All these things are happening to me now. And that's a thought that really bothers me too. Probably because I always have been so active. And now all of a sudden, you can't do anything. Here's this old lady and she can't do this and she can't do that. That's really awful. I mean even my granddaughter said to me "can you carry me upstairs Nana?" and I thought this is terrible, I can't do this. I can't do these things anymore. (eyes fill) I've always been proud that nothing happened to me in my life. I never had surgery. Appendix taken out but that's about all I've had in my life. No high blood pressure, no drugs or taking anything so this is really something.

When our conversation turns to music, Storm's emotional tone eases and she appears calmer and less troubled. She continues to rely on music and tells me that she has the "radio going all day," in part because "it does help get your mind off things." However, she does not go to concerts anymore because it is too painful to sit for more than an hour and she does not want

to "walk out in the middle of the concert and bother people." In closing, I ask Storm what listening to music means to her. She answers:

What does music mean to me? It is my savior. Yah. It keeps me sane. Definitely. It's the first thing I turn on and the last thing I turn off. It is something you can't take away from a person and that's what's nice. It will always be there.

Celia. Celia is 50 years old and lives half the year in the city with four house mates in a co-op house arrangement. The warmer half of the year is spent in the countryside. Celia was 36 years old, and working as a massage therapist when she got ill. The last 12 years have been "a long haul." Celia explains:

It's hard for me to think about specific things in those first 6 years because I was so confused and foggy. I just needed as much peace and quiet and as much tranquillity as I could get. If I could have lived in a cocoon and slept for 3-4 years, that would have been the best thing. So I don't actually remember much about the first 6 years other than that I felt miserable and tortured most of the time.

It took several years before Celia's condition was diagnosed as Chronic Fatigue Syndrome. Celia says:

Chronic Fatigue Syndrome wasn't even around for the first few years. And then a lot of people were diagnosed with this host of symptoms. And they still don't know exactly what it is. It's all at the theory level. So what people do basically is manage their symptoms. [And have you found your own way to do this?] Yes, I've experimented. I had a list of about 25 various things I've tried from non-western medicine and none of them made an appreciable difference. But something has and I attribute it to what I call excessive moderation. So it's not what I've done, but what I've actually not done. Still seems to be, much to my frustration, the thing that's been most successful.

Adhering to excessive moderation means that Celia spends much time alone and music often keeps her company and keeps her mind stimulated.

I listen to the music on the radio a lot. I usually just stick it on CBC AM so you end up hearing a lot of music just accidentally because you switch the radio on. The nature of my illness is that I need lots of alone time, not doing much of anything. That's changed over the years but it's still a big part of it. I spend a lot time alone. So I listen to the radio, kind of, for company and information and a sense of comfort.

Celia's life has always been filled with music, singing, and dancing:

I think much of it (enjoyment of music) comes from my childhood. Although I come from a constrained very conservative family in some ways, both my parents were terrific dancers. My dad used to sing and he put on lots of different music. And he would sit and listen to music as opposed to sit, listen, and read his newspaper. Sometimes he'd get me to sing the melody and he'd do the harmony. And I used to dance around a lot. As he listened to music I would just start to dance and eventually I took ballet classes. So for me, music and physical movement became married in some way. So I did ballet, modern jazz, expressive dance and got as serious as you can get in a small town. Sometimes I think that given a different circumstance I would have loved to be a choreographer.

Though not a choreographer, Celia does sing gospel music, which is music embracing the union of movement and song. When she was still very unwell, Celia attended a concert by the gospel choir and was so moved by the experience that she auditioned and was accepted. Despite being a "fairly strong non-Christian, almost anti-Christian," she has sung with the choir for the last 6 years

The music was so celebratory, it felt at that time that it kind of lifted me out of myself. And I was really looking for escape....I could hardly hear the words and it didn't matter, which is one of the reasons I decided I could sing in that choir and get over the words without stumbling on them or having all sorts of judgments in my head or re-translating every time I sang something.

Celia attends practices every Monday and participates in various performances. She has a "sneaking suspicion" that singing in the choir has probably been good for her health and describes the choir as one of the "major things that happened in my health and what I consider to be my healing."

Celia talks about the importance of listening in general. She finds that when she is in the countryside, she often does not listen to recorded music.

Living in the country I just consider the sounds around me to be their own kind of music, like the creek. Sometimes I'll go by the creek and I'll just listen, and again I don't have the words for this, but I know there are chords or I think they're called harmonics. Picking out the song of the creek, and which are the sounds of the trees and other things around? I think I come from a family that does that kind of thing. They would never

talk about it, but they are very much natural naturalists. That's also part of my training. To listen, to watch. We'd be in a very different soundscape in the city if people actually did listen and hear and register.

Like Laurie, Celia is wary about the music she listens to because her nervous system is "so affected by chronic fatigue" that heavy guitar or overly loud percussion, for example, can feel "wearing, as though it was wearing me out in some way." Although Celia's health has improved, she still has "a certain caution about what I expose myself to."

Iris. Iris is a 50-year-old woman of Japanese heritage who lives with her twin sister in a suburb apartment, and works in a university library. A little over 2 years ago, Iris experienced the sudden onset of acute transverse myelitis and was hospitalized to manage the swelling of her spine. As a result of this first occurrence, she had to relearn how to walk and continues to have numbness, tingling, and dysfunction in her legs. Our first interview came just 3 weeks after a second sudden onset that hospitalized her for 9 weeks. Iris explains that, "It's because of the spinal cord that it can affect the nerves. So it is not always the same. This time I got it in my right arm. It just depends on which nerves get affected."

She uses a cane, cannot manage stairs, and is one of the most visibly disabled participants; yet, despite what appears to be a dramatic and debilitating illness, Iris presents generally unperturbed and quite accepting of her situation. When asked what the hardest thing was about her disease, Iris replies:

The hardest thing? Uhm. I haven't thought about that. I guess that I have some limitations now. That's probably the hardest thing. Not being able to do things I was able to do before. Because of my leg problem I can't play tennis. But apart from that, most of the things I used to do before I can still do. I can still do my craft work. I can still go bowling. So that's one thing that's good about it; but, I guess not being able to move the way I want to. Like certain days I can't move as well as other days. So that's one of the worst things that's happened. [How does that make you feel? Is it hard to accept that you can't do some things?] No. I accept it. It's just that the funny thing is that I'll be walking fine and then all of sudden my legs don't work properly. So it's just

something that I have to put up with. I'm getting used to it. It doesn't bother me really. Now that I'm aware of what limitations I have, I just sort of cope you know, work around it. And it seems fine.

Listening to music has always been part of her life, although Iris reiterates several times that music listening was "just for pleasure, it's just a habit." As a child, Iris took music electives in school and sang in a choir. As an adult, she later took organ and guitar lessons. She cannot remember a time when music was not in her life.

My family, there was always music. Japanese music. We still have some of the 78s. Like my mom used to have a turntable and we'd listen to music a lot of the time. I remember my dad used to buy records for us. We'd listen all the time and my dad would say "that record's going to wear out" because we'd play it over and over! We just listened to music a lot.

Iris still enjoys listening to Japanese music, especially when she is doing her physiotherapy:

I like to listen to Japanese music, a lot. I listen to it while I cycle. It's more fun and makes the time go fast...I don't understand it, so I don't feel anything really. It's just listening to the music. How do I say it? There's no real feeling. I think if I understood the language I'd have more of a feel for it, for what it is. [So it's the sounds of the instruments and the voice?] Yes. So I like it.

In addition to Japanese music, Iris and her sister share a preference for "soothing and calming music, nothing really wild!" There is one radio station, which her alarm clock radio is tuned to as well as the radios in the kitchen and den:

My radio comes on so I have that on while I make my bed, while I'm getting dressed. And when I go to the kitchen, the kitchen's got the same radio station turned on, so I turn that on. And I listen to that while I'm eating breakfast. So that's what I do, on a daily basis.

Iris listens to QM-FM because "I don't like shows where they do a lot of talking" whereas her sister's preferred station is KISS-FM. Iris tells me about how their different station preferences play out in their lives:

So what happens in our car is we have one button for her and one button for mine. It's really funny. People might think it's kind of silly but what we do is, say we're going out,

so we put her radio station on. And then on the way back, we'll put my radio station on. Or sometimes one of us will say, "oh I really want to listen to mine today" so I'll put mine on and then hers on the other way. So we always do that! And it works out. Quite often in the evening, her show is talk and she doesn't care for that either. So she'll switch to mine, my radio station. Even if we listened to mine on the way, we'll listen again if hers is too talky. There's more music on mine.

Doing craftwork is another important "habit" in Iris's life. When asked if her crafts bring her the same kind of pleasure as listening to music, Iris answers: "Oh yes. Well I just like doing all kinds of crafts, trying different things. I guess because I grew up doing different kinds of crafts. It's a pastime."

In Iris's life, listening to music is often associated with doing things; for example, music listening accompanies craft work, chores, driving, and conversation. Despite using the phrase "background noise" to describe the music listening, it is clear that Iris experiences the activities in a qualitatively different way when they are paired with music:

Sometimes I do just listen to music, but usually I put it on as background noise. [So let's say you're doing a craft and you put music on. How is that different than not having music on?] Uhm, I don't know how to explain it. It's just like having some kind of background noise on, you know instead of just having it plain, with no noise. I don't know how to say it. It kinds of helps with the flow of things...the music somehow makes me get with it.

I also ask Iris how watching television was different than music listening as they sound like somewhat interchangeable activities in her life.

Well I think music is more enjoyable. Sometimes tv is distracting. Whereas I don't find music distracting. I find it more pleasant...music is more enjoyable and more soothing. I enjoy it more. So most times I do have the music on.

Later when asked if there was a time or moment when she became aware that listening to music was important to her, she replies:

No, not really. I just use it for enjoyment. I've never thought of it that way. I just enjoy music. I never really give it a thought when I listen to music. I just listen to music.

Iris is clear about not overstating the place of music listening in her life; however, at the end of our first interview as she reiterates the "pastime" nature of music listening she says:

Yes, just for enjoyment. Sometimes you just feel like you need ...(silence) Well, say there's nothing on tv or sometimes tv is depressing and just horrible. And we'll say "let's go and listen to some music." So we do. And it kind of gets you away from that bad stuff, unpleasant stuff. It brings you back to being more happy. Or sometimes we get bored and say "let's listen to some music."

May. May is 78 years old and lives with her second husband, who she married more than 20 years ago after being widowed with three daughters. They live in their family home located in a Vancouver suburb. Our first interview focuses almost exclusively on music with little mention of her physical status. I know that she has age-related macular degeneration in both eyes as well as a spinal condition, spinal stenosis, that impede her mobility; however, May does not want to dwell on her "troubles," and strikes me as lively, bright, and interested in the research. She is keen to show me some favored CDs and tapes, and expresses much appreciation about the range of music available nowadays because "there used to be just one radio station and that was it, that's what you listened to." May grew up singing around the piano and fondly recollects town dances "where you dressed up and swept around the floor." Much of May's music collection is light classical, romantic, and dance music. She experiences a lot of vivid imagery when listening to the dance music:

I just close my eyes and I'm right back there. The people, the clothes, the sounds. It was such a civil time. Takes me right back to happier times and helps me forget my troubles.

May also invites me into her bedroom to point out the tape recorder at her bedside table. She and her husband keep separate bedrooms so there is no worry about disturbing his sleep.

I keep it there all the time so when I wake up stressed and overwhelmed, I just reach over and play my relaxation tape. It's always there ready to go. My daughter taped it for me. It calms me, relieves the pain and stress in my life.

The "pain and stress" in her life are further explained in our next visit because initially it seems that progressive loss of vision is of foremost concern. But as with Storm, our next meeting coincides with a marked change in circumstances. We meet the day before May goes for a second consultation to decide whether or not to pursue corrective back surgery, a surgery that involves a long recovery period with uncertain benefits and possible risks. May explains:

I had back surgery about 6 years ago and I had 2 or 3 good years. Then things started going downhill. Now I'm into a walker and a lot of other things are showing up. I'm going to see a specialist tomorrow. He gave me 6 weeks to think about this surgery and I really haven't been able to think about it. I'm so panic-stricken. My legs are so numb, I can kick you and not know it. And one of the worst things that can happen is you can lose bowel and bladder control.

Despite philosophically commenting that "you have to take what life gives you and this is not a good deck of cards this time" and later suggesting that "there's a lot going on in a lot of people's lives that's probably a lot worse than mine," May is distressed:

It's not that I didn't know this was going to happen. I mean I knew I had problems and I was prepared to deal with it. But when this diagnosis came up with the back; I just turned right completely around. I've been in panic for 6 weeks. I haven't made any decisions. As I said I haven't been able to. I seem to be in a melancholy state. Like I don't have as much pain; more numbness and weakness.

She expresses both frustration because "organically, I'm so healthy," and fatalism as she anticipates certain outcomes:

If it evolves to like the bladder going, I'd just rather die. If that's what's going to happen, let me die now. That's just the way I feel. I said to the kids, 'if this happens, don't feel sorry. I'm 78.'

Although May still makes a point of listening to music, she does not find the same respite as she had previously.

I can't turn my mind off. Before I listened to music and you could sort of turn your mind off. But now I can't. I mean where am I going? What's going to happen? You know? Am I going to be in a wheelchair? Like I was using the walker just on the street before but now, my balance is terrible. I can't stand.

As May talks further about the ineffectiveness of music, it becomes clear that her relationship with her husband is actually causing equal if not more distress than her physical deterioration.

Music doesn't seem to be helping as much. I'm happy to have it on in the background but I just feel so tense and so panic stricken. I'm not dealing with my problem. [You're putting it off because it's too painful?] Yes and I've put it off too long. I've put off leaving too long. And then when he got sick with cancer, I thought I couldn't. But financially, I still don't know if I can do it...And I've felt this way for years and here I still am. It's stupid. Never had the guts to do it.

In this exchange, I assume the "problem" is deciding whether to go ahead with surgery or not.

But May actually refers to the "problem" of a longstanding unhappiness with her marriage that now seems to be preventing her from actively seeking solutions, specifically selling the home and moving into a residential facility. When asked what was hardest about her illness, May says: "I just feel like I don't have a happy safe environment now. My daughters say I need to be where there's more social activity for me and safety too." However May's husband does not want to move from the house. May, on the other hand, yearns for company and conversation, and misses many of the activities she used to do. She talks about being "cut off from reading my paper, doing the crosswords, doing the crafts I used to do, gardening" and later comments:

I don't see as many people. I quit my bridge club this year. I only went once every 2 weeks but I was so afraid of the stairs and I was so wobbly. And it meant they picked me up and somebody had to take that thing (points to walker) with me and I don't think that's fair to ask these women to lug these darn things in the trunks of their cars because they're in their sixties too you know. [So you've become more isolated?] Yes, very actually. About the only thing I get out to is the Council of the Blind club and we meet every Thursday afternoon. I get phone calls from people but not too many visitors. No. My daughters are very good to me. I used to walk a lot; we'd go out; people would stay; we'd have a lot of company; all that stuff. But now, I don't even want to cook a meal. This is sad. I've sort of lost interest in everything and I know this isn't a good sign...I'm trying not to take medications. Maybe this sounds selfish or silly. But (pause) there's no (pause) relief you know. Nothing. Watch this stupid tv and there's nothing on there very challenging.

Isolation from people as well as activities makes for long days. May said, "I really don't want to be with a lot of people but I like to have someone to talk to." Her husband drives her to the mall or out for walks; but, May describes it as "a sort of duty, you know." As her physical limitations increase, the relationship strain increases because "when I was independent I could go and it really didn't matter much."

Working around the dissatisfactory marital relationship is harder now and May seems to be blocked from making some decisions or seeking information that might help her better cope with her changing circumstances. Feeling so paralyzed and depressed is not familiar for May. Near the end of our interview, May comments:

The other day my daughter said to me, "Mom what's happened to you? You were the strongest woman I ever knew and now you're just like a bowl of jelly." She wasn't being nasty, the three of them just don't like to see me this way. They're there for me whatever I do. I know I have that support. I have to be ME too, you know. There it is. But music. I know music is probably going to play a bigger part in my life than it ever has. Not that I know a lot about it. I just love music.

Vibrato / A Seventh Woman

Vibrato; a slight fluctuation of pitch used by singers to make the tone more expressive

I am the seventh woman participating in these conversations, and each woman effects me uniquely. The women's stories resonate with different aspects of my own life experiences, sometimes in provoking and uncomfortable ways.

Laurie resonates with the musician in me and names my own secret and unvoiced fear of losing "my music" when my finger joints are eventually effected with arthritic inflammation. The possibility of no longer freely playing the piano is a future reality too easily imagined with its accompanying implications of loss: losing a long-lived way of self-expression and self-

soothing; a way of being, sharing, and interacting with family and friends; a source of esteem and accomplishment.

Jean opens me to my own passion for music. Her direct and clear statements articulating a profound cherishing of music stir me, and free me to recognize and more fully acknowledge my own deeply felt responsiveness to music. I find myself able to speak more candidly about music without feeling encumbered by vague embarrassment.

Storm humbles me. Her sudden decline takes me aback and jars my own complacency that evolves unnoticed with each passing year in which my own illness remains stable and managed. I suddenly remember the first 2 years when every visit to the rheumatologist seemed to mark still another change as the inflammation moved from a toe, to a knee, to a hip, and then an eye. Each change brought tears and abrupt feelings of panic and fear, which then subsided as life continued on. Storm reminds me that upheaval is always imminently present.

Celia impresses me with her ability to live richly within the confines of her illness. She inspires me with her evocative turns of phrase, thoughtful words, and provocative ideas. She also models good self-care by appropriately and assertively rebuking me for rescheduling a meeting at short notice, without considering the reality of living with chronic fatigue and having to carefully allocate one's energy. Celia demonstrates that "health-within-illness" is not just a fanciful idea, but a possible reality.

Iris reminds me of the importance of doing and being, and of keeping an eye to the simple and uncomplicated. She nudges me into standing back and re-noticing the always looming possibility of distant and inconsequential scholarship. Appearing to live unhampered by earnest deliberation or stultifying intellectual rumination, Iris reminds me of pleasure and immediacy, and not looking too hard to understand.

May rekindles a fresh cognizance of my own pleasure in helping and being of service, while simultaneously demonstrating people's great capacity to solve their own problems given appropriate support and dialogue. May personifies a capable person not being adequately served by the health care system. I leave May's house with a strong sense of personal satisfaction that I have identified the kind of work I want to do, and May joins the ranks of many other elderly people who have entered my life and left a lasting positive impression.

Contrary and Parallel Motion in Chronic Illness / Stories of Contrast and Commonality

motion; the combining of voices in a composition--parallel motion is when voices proceed in the same direction; contrary motion is when they proceed in the opposite direction

Laurie, Jean, Storm, Celia, Iris, and May have lived with chronic illness for differing periods of time, in differing life circumstances, with differing ages of onset, and differing strengths, challenges, and needs. Their differences are immediately apparent, perhaps more so than their commonalities.

Contrary motion / Stories of contrast. Quiet and private, Laurie seems to feel things deeply but does not always have an avenue for sharing or discussing these emotions. She struggles with chronic illness and the problem of how to live her life under new circumstances. Music listening ministers to her inner feeling world. Celia, on the other hand, appears to accept however unenthusiastically a life of "excessive moderation" to accommodate the demands of her illness. She creates a world that fits her needs, and either developed new skills to accomplish this or fell back on a longstanding assertiveness and confidence. Music listening offers Celia a range of experiences, including music for intellectual stimulation, for physical pleasure (i.e., the experience of her body as healthy and responsive), for companionship, and for an intimate communion with the world and its inhabitants.

Iris's nature is steady, pragmatic, and understated. She appears to matter-of-factly accept the limitations resulting from her illness and integrates music listening into her life in a seeming chance and not fully intentional manner. Music simply feels "good" and is "pleasant." Iris does not cognitively or explicitly acknowledge music listening as an important activity in her life, despite her stories giving evidence that it is. Conversely, Jean is derailed by fibromyalgia, to the extent that she questions the value and purpose of her life with this illness. As a result of this existential crisis and subsequent introspection, Jean creates a life that specifically and intentionally puts music center-stage.

Both May and Storm suffer unanticipated, debilitating, and upsetting declines during the present study; however, the meaning of their difficulties differs as do their music listening experiences. Storm seems most taken aback by the loss of her physical freedoms and capabilities, the abrupt awareness of an uncooperative body. Her sense of self has been securely anchored in a strong physical identity of ability and independence, and she is torn between hope that things will change and despair that they will not. Fortunately, listening to her music through the day continues to provide Storm with great joy and comfort. May, however, finds no respite in her music despite efforts to calm herself by listening to favored recordings. Unlike Storm's abrupt decline, May's deterioration has been slow and progressive. May expresses panic and shock at the uncertainty of her future physical status, but she is more perturbed and distracted by the accompanying and distressing awareness of a long-standing strained marital relationship. May seems unable to sufficiently quiet her mind in order to make important decisions about her future.

Parallel motion / Stories of commonality. Each story is individual and personal; yet, similarities exist across the common existential ground of chronic illness as revealed in the lived

existentials of body, time, space, and relationship. Most obvious is the existential of lived body, the site of disruption. These women's bodies move to the foreground, no longer silent or known with "unaware awareness" (van Manen, 1998, p. 13). When Laurie laments that prior to 31 years of age she did whatever she wanted whenever she wanted, she recalls a healthy body that has been taken for granted and relied upon. Now her body is no longer trustworthy. Similarly, Iris's leg can midstep, suddenly become uncooperative and disobedient; Storm no longer golfs, goes to the exercise center, or falls asleep with ease; May no longer walks through the neighborhood or does needlepoint and crosswords; and Celia, Jean, and Laurie carefully choreograph their days and energy demands in order to appease their vulnerable bodies. Rather than being bodies, the women are confronted with having bodies and face the challenge of "recovering a livable relation with their bodies" (van Manen, 1998, p. 9).

The women are more cognizant of time, both its provisional nature and its slow passing. May practically spits out the words when she talks about how long her days are. Decreased eye sight and mobility confine her physical world, restrict her leisure activities, and slow the march of time. Jean experiences time as unbearable when she is in pain, times when she just wants "to escape." How to pass time when activities are restricted or one's body is so uncomfortable? Orienting to the future can be equally discouraging. May wonders, "Where am I going? What's going to happen?" and Storm worries, "Is it going to get worse?" What lies ahead feels uncertain and frightening. Also alarming is the realization that a more accurate depiction of chronic illness is actually captured in the question, "when will it happen?"

The women experience their environments differently because space is increasingly limited and restricted. More time is spent at home where the environment can be controlled and predicted, which means safe and secure. May, however, no longer even experiences her home as

"happy and safe." Instead, she feels vulnerable because her private home space is now becoming unmanageable and threatening, qualities more commonly associated with public spaces. Celia, Laurie, and Jean all express a wariness of public spaces and unknown and unpredictable intimidations (e.g., large jostling crowds, chaotic assaults of noise, or unexpected broken escalators). Anticipation alone leaves their bodies taut with vigilance.

Relationships are altered and disrupted. Laurie, Jean, and Celia need much quiet time alone, which means saying "no," turning down invitations, and being less available socially. Iris withdraws from her walking group and must establish new relationships with health care providers during each hospital stay. Jean perceives herself as judged negatively by others in terms of the legitimacy of her physical suffering. May cringes at having her bridge partners "lug along her walker." Storm avoids concerts rather than risk disrupting the experience of other audience members, and she encourages friends to go ahead without her rather than limit their walking time. And although none of the women dwells on it, their family members and partners also share in, and are effected by, the experience of illness. These moments in their stories reveal the women's heightened sensitivity to both themselves as well as the perceived reactions of others.

Collectively, the four lived existentials of body, time, space, and relation reveal how the "unity of existence in the world" (p.12) and the "smoothness of forgetfulness" (p.13) are lost in chronic illness (van Manen, 1998). Chronic illness stops them from "engaging in the world in habitual ways" (Toombs, 1992, p. 62). This is the landscape of chronic illness where Laurie, Jean, Storm, Celia, Iris, and May listen to music.

Development / Listening and Hearing Music in Illness

development; section of a sonata that develops earlier themes and motives by breaking them up, recombining, extending, and generally showing them in unexpected and often exciting new contexts, commonly with much use made of counterpoint

Ensemble for Voices in Counterpoint / Six Stories Merged

ensemble; musical work in an opera, cantata or oratorio for two or more performers

counterpoint; the combination of simultaneous voices, with or without additional material, such that a coherent musical texture results

What happens to the landscape of chronic illness when it is visited with music? Music listening is another lived experience that is understood more richly when the existential ground of lived body, time, space, and relation is considered.

Music embodied: A musical compass. The centrality of the body in music listening experiences is readily apparent to most, if not all of us, because physicality permeates music listening, both immediate and recalled music listening experiences. Sitting with the women, I see eyes sparkle, eyes mist over, lips tremble, fingers snap, legs bounce, arms float, faces glow, and faces grimace as the women recollected experiences of music listening. Energy resonates from the story tellers and reverberates with me. I observe embodied music in each woman, their bodies infiltrated with remembered music.

Verbal descriptions about the varied impacts brought by music into their bodies accompany these spontaneous non-verbal communications. Celia says:

Even when I'm just listening, doing nothing but lying there on the couch listening to music, there will be some part of my body that's moving in some way. I can feel my muscles shifting around in my body...As I get more physical health and energy, it feels like the music comes through my body. It's not like I necessarily move all the time. But I'll notice there's a foot tapping, a head nodding, or I'm humming along.

Jean's body tends to relax and release tension, as does Laurie's. Laurie actively seeks music as a "release kind of thing" because "a lot of my pain is from holding [tension in the muscles] so in listening to the music, I'm trying to let go."

Their bodies often release tears when listening to music. Storm speaks of crying easily, and Jean talks about the music "being so moving that I can cry easily and be totally involved in it I guess." May describes her tears in a journal entry:

The other evening I had had a very stressful weekend and was depressed. I turned the tv on to "Let's Sing Again." It restored my soul. I had a cry and felt better. Life is very stressful at the moment and I am turning to music more and more for solace.

In describing her tears, Celia hazards an explanation:

Tears are some kind of release or relief. It's almost like building up an emotional charge in your body in response to something and it's useful to have some way to express that. Sometimes we laugh, sometimes we cry, sometimes we move our arms. But especially if you're in an audience and you're supposed to be sitting there and not getting up to holler or dance or something—in some way it's almost like letting a little emotional pressure off, letting that charge dissipate a bit. I think that's what it is.

Music moves us, with emotion and motion. Jean, in particular, often uses the word "moving" to convey the emotional arousal she experiences in listening to music. But might it be more accurate to identify her body as being moved by or even moved into music? One of her journal entry reads:

P & J visiting. They brought Bach's Cello Suites as a gift. Find they [the suites] make me relax, even as I'm doing other things, especially in the shoulders. The cello almost becomes part of my body. My body is the cello.

On this occasion, Jean's body and the music are experienced as one entity, her body's boundaries and tensions dissolve and ease into the sweet rolling cello line. Similarly, Celia experiences her body as a conduit reaping benefits by transmitting music:

It feels like listening to music allows energy to move through my body in some way. In a complete cycle. I have this sensation of my body being a set of electrical circuits and the

energy in the music passes right through my body and it feels like a cleansing or an undoing of kinks.

Does listening change when the body is the site of not only music, but also illness? What is it like to be in the company of both music and illness? Celia recalls when she was most ill:

I remember really missing the sense of music being in my body. It was so unresponsive that I didn't even have that internal "twinkle" response I guess you'd call it. I just didn't want to move anything. I'd lie there like a dead weight. The music would go but it just felt like it was floating in my ears, once through my head and then it was gone. In some way it almost made me feel more deadened because of the lack of response in my body.

Laurie remembers how she started listening to different types of music with the onset of her illness:

I think at first I really stayed away from music I knew well or had played or studied or analyzed to death. And I really started listening to, for some reason, female singer songwriters. And I started listening more to words and I started looking for songs that seemed to connect with me. [And how did you find the songs?] I think just by listening to things. It needs to resonate with me somehow and I couldn't tell you what that is.

Jean comments that although she used to enjoy chamber music and the piano, nowadays they "still give me enjoyment to listen, but don't move me the way opera does."

Could it be that different music is chosen or wanted by a body that is changed? Might the body actually be judging a music's agreeableness, or lack thereof? Celia observes:

The music I've listened to over the years has changed and its paralleled the ups and downs of my condition. And I think it's because my nervous system registers music so strongly and has been so affected by the chronic fatigue...I mean any kind of stimulation on my body for the first 6 or 7 years was experienced as stress. Music as a certain kind of stress ... any sound that was louder than my voice is right now would be startling and my body would go on stress alert ... I mostly listened to quiet gentle music, more classical, and an alto flute. The flute didn't have such a jarring irritation. And I didn't listen to much back then that had words in it. I think it would have overtaxed my brain.

Iris and Storm do not describe changes in their musical tastes but, for the others, it seems that they have needed and enjoyed different types of music over time. Perhaps this reflects the status of their changed bodies, bodies now living with chronic illness.

Music preference is conceptualized by the women as a cognitive act, a rational decision of liking or not. Storm plays ballroom music in the morning to get her going and often Chopin at night to send her off to sleep. Laurie listens to her female folk singers for comfort. Celia has “car music” for driving around town. Each woman has specific preferences and types of music that they can describe. Sometimes the choice of music is prescriptive, set by day, season, holiday, or activity (e.g., Mass every Sunday morning or reggae for housecleaning). On other occasions, the choice is not predicated on time or activity, but rather is responsive to something in the moment: a mood or a thought to which the women match music. Despite each women’s ability to rattle off their listening preferences, I wonder about the body’s contribution. Perhaps sensory processes of the body precede cognizant recognition of musical preferences? Maybe initial body responses identify or discover the “right” music, which is then cognitively known and named? Is the body in fact a musical guide that provides a way of knowing, an instrument able to show the way? A compass always shows the way when handled by a skilled and trusting orienteer. Is the body an equally trustworthy and knowing compass?

A last point of wondering involves notions of reciprocity because a compass is bi-directional. The north end of the compass’s magnetic needle always points to the magnetic north pole, pulled yet also reaching. Are music and the body reciprocally allied? Pulling and pulled; reached and reaching; beckoning and beckoned? Or conversely, repelled and repelling? Like magnetic forces, a reciprocal relationship exists as music calls the body, and the receptive body returns the call or reaches out to hear the call, a responsiveness perhaps heightened in the presence of chronic illness?

Music time: Time-less, time-full, time-encored, time-tabled. The experience of lived body changes in music listening as music occupies the body (e.g., experiencing a loss of

embodiment or conversely, a heightened sense of embodiment). Lived time also changes in the presence of music, generally in concert with the body but sometimes independently. Being time-less involves loss of objective time, a complete immersion in the moment. Some of the women experience time-less time when listening to music with full attention, whereas others experience it when doing something with the accompaniment of music.

The experience of being time-less when music accompanies activity is discerned most readily when considered alongside things similar yet different—by varying the example. Listen to the following excerpt in which Iris and I ponder how doing crafts with silence is different than doing crafts with music.

... the music somehow makes me get with it. [So it kind of effects how you experience time?] Yes, yes. How do I say? You get the urge to keep going. Cause I don't get like bored. Like if I'm just sitting here doing crochet or something with no music, no nothing. I tend to (pause) I don't know. I just don't tend to keep going as well. Like I'm not purely concentrating on what I'm doing because I have the music in the background. [So part of your attention is on the music even though it's background, and the activity you're doing kind of moves into this flowing state? Whereas if all your attention is on the activity?] Then you're almost too concentrated. It's being concentrated to a certain degree that's best.

We return to the subject later, attempting to fine-tune our understanding. This time the example is varied by recalling times when television accompanies the craft activity rather than music:

Well, it is very hard to explain because when I've got the music, I don't really notice the time. Whereas with the tv, you'll see one show finish; the next show will finish; all that kind of stuff. When we have the music, it's just continuous music. And it just seems that time isn't going by fast and it feels more relaxed. [So it's nice not keeping track of time?] Yes. I don't keep track of time at all when I listen to music. Seems to me to be quite good. I like it.

Similar experiences are conveyed by May when she laments the slowed passage of time in her life with illness. She spontaneously offers anecdotes that point to the experience of being time-less, what she calls “losing herself.”

Well if you've a really good book you're reading and interested in, then you can really lose yourself in reading the book. You're really in another time-frame. You forget what's going on. If I could read now, then I could probably sit here and enjoy an hour and a half reading a book. Get my mind off things. [So music does the same thing? It allows you to lose yourself?] Right. And particularly if I could sit and knit and listen to music, using my hands in some way which I used to do a lot. Years ago I used to do needlepoint. I had it set up in the den and I'd sit there for a couple of hours doing my needlepoint and listening to my music. And it was great. However (sighs then is silent)

May yearns for some freedom from the time that marks her daily life, time marked in deliberate seconds and minutes. Previously, music listening in accompaniment with other activities offered that freedom, but, failing eyesight leaves her reliant on only the music as a means for escape, and this is not always successful for her, much as she may seek it.

Others readily slip into unmarked time when they listen and only listen to music. Jean notes in her journal:

Watched Samson and Dalila on the tv from the Met. Superb singing. Felt completely absorbed and forgot all pain and tiredness. Music seems the only panacea. Keep listening!

Laurie, Storm, and Celia's quotes further illustrate this time-less time: "I can lose myself;" "I'm unaware of anything else, just completely into the music;" and "I'm oblivious, even those people in front of me don't matter." These time-less moments are marked in music rather than measurable units of time. The women feel suspended or absent in time; swept away, caught up, and transfixed by the music; all turns of phrase that suggest an unrecognized or differently marked passing of time. The timekeeper is music rather than a clock.

Time-full is another music-evoked experience of lived time. The term conveys fluid time travelling, with its planned and unplanned stopovers in the past, present, and future. Time-full experiences often animate the body, which is what helped me identify this aspect of the music listening phenomenon.

For example, Celia tells me about Kev Mole, an exciting musician she has discovered, and as she talks, her body transforms before me:

[Just looking at you, you're getting animated. You're almost responding as if the music was playing right now]. Yup. I can hear it in the back of my head. I can hear the tone of his voice. It's very rich and it's just exciting to hear somebody that good at what they're doing. It's kind of like listening to something that is perfectly itself. And within its genre, within what he does, it's just perfect.

A similar thing happens when Laurie recalls the purchase of her first record following a particularly impressive and stirring performance of Rachmaninoff's Second Piano Concerto:

[As I sit here and I listen to you and I watch you, it's like you can remember what it was like. Like you just tap right into that feeling of listening to that music?] Yeah, yeah. It blows me away that I'm actually remembering these things. It just takes me right back. As soon as I talk about the Rachmaninoff record, I can see that album - in fact, I still have it somewhere - and how innocent and naive I was. I really wasn't very experienced at life and this record cover was sort of impressionistic. Like two bodies lying down together. My brother says to me, "what are you doing with a picture like that?" I didn't see it.

Laurie feels the flush of youthful passion as the rush of the concert returns to her via the remembered Rachmaninoff record. She remembers the cover, is surprised by the intensity of her memories, and actually blushes as she loses herself in a past that unexpectedly surges into the present. She laughs girlishly. She is more than a fragmented partial person defined by illness. By recalling parts of who she was and still is, perhaps it is easier to imagine a future.

Celia recalls the delight of discovery, which gives her experiential knowledge that delight can still be had, and might still be had in times ahead. Celia's excitement in discovering the musician Kev Mole is accentuated by the bluesy and rousing nature of his music, and further amplified by her sense of witnessing and participating in something that is "perfect onto itself." Not many things are perfect in this world, least of all her body with its illness; but, music can be most perfect and most exquisite. Perhaps being in the presence of such beauty resonates with

particular acuity in illness? As perfect music animates the body, a flawed and damaged body is transformed beautiful, and with this comes a realization that perhaps, each and every body is ultimately "perfect onto itself."

These two examples illustrate the kind of unexpected time-full experiences that happen when a life has been rich with music. There are many music-marked moments to run into, moments to be re-experienced with the help of what Celia calls "musical memory hooks." Listening to music hooks the women into the past, which allows the past to move into the present and the present into the past; a musically induced re-collecting (written this way to more fully evoke the word's meaning; i.e., *to collect or assemble again*) of the past that increases today's coherence and helps generate tomorrow's possibilities.

Musical memory hooks are also approached intentionally. Storm deliberately listens to a particular radio station so that she can re-member (*go back to constituent parts*).

Music connects me to the past mostly. Because I listen to a certain station most of the time and music from the days that I danced a lot and I guess it reminds me of it. It calms me. Listening to music makes me feel good, yah. Music. I don't know, if I didn't have music I would be miserable.

Similarly, May fondly re-lives (*to have life again*) town dances and happy moments; Jean revisits (*to see with friendly intent again*) other occasions of music listening; Celia re-covers (*to bring back again*) memories of her father listening to music as she danced around with abandon; Iris re-calls (*to summon again*) the old record player and records she listened to with her siblings; and Laurie re-turns (*to come again*) to moments shared with friends. Time-full listening re-vives (*to live again*) personal histories and affords opportunities for the women to re-claim (*to call back*) and re-cognize (*resume possession of*) themselves more fully.

Time-encored refers to the unique opportunity that music listeners have to listen tirelessly, endlessly, and unceasingly. This call for more performances is often loud and insistent, not a polite request, a need for musical fulfilment that is compelling, urgent, and immediate. For example, Laurie finds a certain song that “seems to connect” with her and then plays “the same song...over and over and over and over again.” The CD is in her house and a copied tape is in her car; so if she needs the song, it is there. She repeatedly rewinds the cassette, repetitiously listening because “I had to listen to the song of the time.” On another occasion, Laurie hears the singer, Shari Ulrick, sing at a benefit concert and just has to buy the CD: “I had to have it, I had to have it...and I never buy CDs at concerts, but I bought it.” Hungering with pure desire for the music, and consumed by urge, Laurie is overcome. She must act.

Jeans talks of wallowing in Wagner’s Tristan und Isolde until she feels absolutely “saturated.” Saturate means “*to combine with the utmost quantity of another substance*” and is derived from “satur,” meaning full or satiated. What is it to be saturated until engorged with music? To be fully filled with music? To listen until want is completely absorbed into stasis?

The women have no answer. They perceive want and are able to satisfy it, so they do. The body’s physical hungering and the music’s lure eventually subside, replaced with new hungers for new objects of musical desire. Former loves collect on the CD rack and are returned to with fond nostalgia because unlike human relationships that change, music stays friendly and makes no demands. Music is a constant, steady, and reliable companion. This is valued by the women, particularly given the constant, disruptive and unpredictable presence of chronic illness.

Storm confides that music “is something that you can’t take away from a person and that’s what’s nice. It will always be there.” Laurie concludes that “If I can’t ever play music again, would it be that bad? No, because I can always listen to music.” Similarly, May depends

on and cherishes her bedside tape recorder and relaxation tape: "Whatever happens, I know that if I wake up I can turn on my tape and listen."

Musical time-tables are temporal experiences that occur independent of the body.

Whereas being time-less frees music listeners from objective time, time-tables anchor music listeners in objective time. This is the prescriptive nature of music, that is, its ability to establish ritual in the daily, weekly, monthly, and annual rhythms of life. Holidays call for special seasonal music, birthdays call for the birthday song, sporting events call for national anthems and team cheers. Outside the public realm, we cultivate private music time-tables. As a younger woman, Jean could not go to work in the morning without listening to Rachmaninoff's Piano Concertos: "I used to put them on at 8 in the morning. I can still hear it when we talk about it now. And it set me on track for the day." Years ago, a ritual in music started the day "right," and now many years later, rituals in music listening make her life "right" once again. Music aesthetically accentuates the cycles of time, rendering time predictable, as well as something to be anticipated with pleasure, which is comforting given the unpredictable eruptions of chronic illness and the unknown future cast in its shadow.

Musical spaces: Places to listen, be music-held, and music-freed. Both the tangible physical space and the intangible psychological space are part of the music listening phenomenon. The women listen to music in a variety of settings, both public and private: in the home, the concert hall, the car, and both with and without headphones. With the advent of portable cassette CD players, there is greater freedom to listen to music where we wish; although constraints still exist. Physical space effects the way we listen to music and the way we "answer" music. During the day, for example, Storm feels free to play her stereo out loud through the speakers, but she uses headphones at night time so as to not musically intrude on her

neighbors. Spontaneous movement, singing, and other responses possible in private or solitary spaces, are inhibited in public space. As Celia notes, we are unlikely to "holler" or jump around at the opera, although this might be okay at the folk festival, rock concert, or bar. Space implicates certain cultural codes for musical decorum.

Psychological space is the felt space of our experiences, and this is the space the women allude to most when they talk about space. The musical space of listening is important. Just as colors, lines, and arrangements of furniture and objects create a spatial feel, so does music. A dinner party is ideally supported by a warm, comfortable musical space; a dental office hopes for a pleasant, nonthreatening musical space; the fitness club wants a motivating, happy musical space; and the romantic café seeks an intimate, discreet musical space. We might not notice when the musical space is right, but wrong music or an absence of music sets us on edge.

Music imbues space and marks space. The boundaries of a listening space may be inviting or they may be excluding and protective of the listener. When Jean shares a personal piece of music with me in our first meeting, a private listening space opens to me. Her music suddenly suffuses our now shared listening space. There is immediate intimacy and my body tingles at the surprising and unexpected heightening of the moment. We both feel the intensified charge in our shared space; we are both surprised.

Conversely, when Storm suddenly discovers music allows her to escape pain and find sleep, she discovers a listening space that excludes.

I'd been out one day, playing golf all day. It was a bad day, bad golf. So frustrated with my hands, with my self. My hands were cold and aching. I rubbed them together, tried to warm them but it made no difference. I came home angry, irritated and these throbbing hands. In bed I wondered how to make this go away. I got angry, telling those little demons to get out! Nothing helped. Hot water, massage, and suddenly I thought - music. And it worked, the pain disappeared. I put on some Chopin piano. Light fingers, and just floated off and away. Light and up to the clouds.

This listening space allows no pain, no frustration, and no tears because only good things are received here. Storm's music space encloses her and keeps her safe from intrusive pain and negative feelings.

Music takes the women into different spaces, spaces transformed with music. Music listening spaces usurp physical space, often embodied space as well, and encourage freeing flights of travel and whimsy. Sometimes a space is close and intimate, the women held quietly in music. Other times a space is expansive and open, the women wildly freed in music. Jean talks of being "taken out of myself...almost an orgasmic feeling." Communicating a similar sense of freedom from worldly constraints, Storm says: "I'm light, free, and floating."

Why is this important in their lives with chronic illness? What do music listening spaces offer? Celia articulates its significance for her: "I actually do use music as an escape...when I need a break from being in my body and being so conscious of my condition." Celia needs a break, which literally means "*severed into parts*." Sometimes music listening makes her whole, but it also enables her to separate—from body, from time, from tangible space, from all that is of the concrete world. When Laurie talks about her songs allowing her to "go into a place of helplessness" and stay there, she also moves into a space that gives her a break: a break from managing and coping, a concession to the limits of conscious effort.

In these moments, the women appear to experience an unawareness of the concrete physical space around them, and instead experience a felt space of being what I call music-held and music-freed. The music holds and supports them in such a way that they are free to be without care and in escape. In their music listening breaks, the women are held in the music,

supported in the music, and freed as they wish in the music. They experience respite and immersion in spaces of musical sanctuary and refuge.

Musically related: With others, with self, with music. Music listening encompasses multi-faceted experiences of connectedness: the women connecting with others, with themselves, and with the music. Lived relation is pervasive and complexly manifested in the phenomenon of music listening.

The most easily understood experience of lived relation is music as a shared interest or hobby. Listening to music is a way to be together because the music provides a focus for conversation, activity, and planning. Music is the object of common interest. For example, music is a shared project for Jean and her husband:

We plan our trips around going to places that have different operas and become interested in unusual operas. So it becomes a project that we set out to do....If we're going to an opera that we don't know, we go through the libretto several times and listen to it at the same time.

When Iris or her sister feels bored, one says "let's listen to some music" and this becomes their shared project. Celia and her friends engage in a common project of sharing music and inexpensively expanding Celia's music collection. Her friends compile and send tapes to her, which is how she gets "turned onto" new musicians and sounds.

But shared projects in music listening are sometimes more than just activities of doing.

When Storm talks about music linking the generations in her family, the listening is more:

I've always had music in my life. My mother, my father. There was always music in the house. My daughters too. They don't play instruments either but they love listening to music too.

Listening to music conveys a felt meaning of her family, a place of belonging. Music is a place where she and intimates gather. Similarly, Jean tells me that her father “also had it,” a love of music, and furthermore:

I have always said I couldn't live with a man that didn't love classical music...And of course it's a great joy that a grand-daughter is following and she knows that she has my wholehearted approval and support in this. She phones me up to tell me what she's done. We discuss our feelings about things too.

Music exposes us and reveals us. We are made visible in music: visible to ourselves, visible to others. In listening to music, we can be known and we can know others. This forges special bonds of alliance and relationship. Celia's friends are in fact doing more than expanding her collection of music by compiling and forwarding tapes. Her friends meaningfully share themselves in music with her, as well as demonstrate their intuitive understanding of Celia in music—what she might like or not like.

Iris's relationship with her sister also plays out in music, the music of favored songs and radio stations.

We'll take turns. After we listen to her radio station, we'll listen to mine. So it works out pretty good. I mean we have similar tastes. Sometimes it's funny because we'll choose the same tape. She'll say 'let's play that' and then I'll say 'I was just going to say that too!' So it's pretty good because our lives are close, pretty similar.

If her sister likes Iris's song when they listen to it, or if they both choose the same song to listen to, Iris is delighted. She offers herself in song and her sister accepts. She knows who she is by the music she likes; she knows who her sister is by the music she likes; and she knows the strength of their relationship by the music they share. Chronic illness has not changed this.

When music listening brings us in to relationship with our inner private world and its many facets, we become visible to ourselves in music. We are visible in all of our history, which includes our history in illness but is not limited to that. Laurie says:

In some ways the music brought me inside myself because I tend to really dissociate with pain and I think it [the music] does bring me in. In some way I am more inside my body. And being able to be there more...and to experience emotions that most likely are similar to what I'm feeling but I'm not acknowledging. It's almost like having a block of not identifying what these emotions are but recognizing them at a different level and I hear them, so I can relate to them. But I can't necessarily tell you what it is.

Celia listens and remembers passion, a feeling she knows but that is normally obscured by illness and fatigue:

It's very sensual music. Lots of people would call it sexual but I call it sensual. It's quite romantic in its own way and I think what it does is that it reminds me or brings out those aspects of myself in my own personality.

The music itself is imbued with qualities of affiliation and relationship. The lyrics, instruments, musician(s), and composer(s) initiate musical communion. This is revealed in small words and turns of phrase as well as in the more detailed anecdotes. Laurie talks of having music "with me in the bath" or how a song is "just mine." May speaks about "listening to my music." Jean describes how music "reaches in and takes you out," how the "voice really seemed to reach me," and how "opera is my big love." Music is able to offer a companionship and a presence that is perhaps difficult or impossible for family and friends to provide.

When listening to the singer Shari Ulrich sing about her experiences, Laurie acknowledges that Ulrich's experiences might not be "the same as mine, but I can feel for her and in that way, be more emotional [for myself]." Through her relationship with music, Laurie finds validation for her experiences at a time when she may not have access to other sources of validation.

She also finds herself feeling connected or disconnected by what she hears in a musician's playing:

When I listen to people is when I hear them. If I can hear them in the music, it's coming from what I call true musicality. It's not always the technique, it's the intent of it. If I

hear a recording of this wonderfully played Bach piece, it doesn't do it for me. I feel no connection with the music person. They are just playing notes. And I seem to be able to tell that.

Whether this is true or not is unimportant. What is important is Laurie's perception of being in relationship, of being played for, and of recognizing this musician's gift offered in music.

Celia gives another example that also illustrates the feeling of being brought in and included in the music:

Listening experiences kind of accordion themselves, they build on themselves. So if I listen to a lot of Celtic music, my ear will fine tune itself so that I know what I'm listening for. And if there's a little musical joke then I can pick up on it. Like if they play 2 bars of Mary Had A Little Lamb on the bagpipe? I can hear it and then it's gone, like a musical gesture. And it's like being included in some way in what they're doing. Like the music reaches out and encompasses me in some way. So I'm a participant as opposed to a monitor.

Celia is participating in the musicians' music making. In her solitude, sitting on her couch, alone in the living room, separate from a world of bustling people with places to go and work to do, she listens to music and feels part of something beyond her immediate self. The accordion image speaks to the uncommon ability of music to offer more and more. As Jeans says, "It opens all sorts of other doors as well." Listening to music means endless stimulation, delight, and solace.

In chorus: Body, time, space, relation. As lived, the music listening phenomenon of this inquiry is a rich, multilateral, multifarious experiencing of music, illness, and self against the existential ground of body, time, space, and relation. As is likely apparent in the illustrative quotes and anecdotes of this work, the four lived existentials do not exist independently. They actually are in a state of co-existence, moving fluidly in and out of proximity. It is impossible to discuss one without invoking another. For example, when Laurie listens to her favorite female folk songwriter, she moves into a listening space filled with the companionship of the artist's

music, music conveying recognizable feelings that make Laurie feel known and understood, as well as knowing and understanding of the singer/songwriter. Laurie describes this as, "somebody else knows that space too and to be there with them." Reciprocal relationship is being experienced spatially, and likely supported with changed body and temporal experiences. Another time Laurie talks about listening to music in such a way that "I don't forget about who I am, or who I was, and who is still part of me." This is a relational and temporal experiencing of music. Can time-full experiences in music listening ever occur without an emphasis of lived relation? Can spatial experiences of being music-held and music-freed ever occur without being time-less? The most memorable music listening experiences seem to highlight a harmonious convergence across all four life existentials.

Chorus out: Unwelcome music. There is also unwelcome music. Music is unwelcome when the women's bodies resist it, either successfully rejecting its company or unhappily biding its presence. In these cases, there is no fluidity or harmony amongst the lived existentials. For example, when Storm attends the recital of a highly lauded pianist, who nonetheless performs poorly:

Terrible. I even heard bad notes! Tense body, tight shoulders, hands clutching. I kept telling myself to relax but no good. I would have left but my friend took me. I was so mad when I got home. At home, I can turn it off.

Her body does not animate with the music; rather, her body tenses to keep the music out.

Celia disparages Muzak, which is the trade name for recorded music meant to be innocuous and benign. Early in her illness and feeling that "it was supposed to be good for me in some way," Celia listens to relaxation and healing tapes accompanied by Muzak. But if she had had the energy, Celia says "I would have been grinding my teeth."

More recently, she walks into an elevator with Muzak and immediately has a sensation of "kind of curling up as though I've been singed." Jazz puts May "on edge;" Jean finds modern music "jarring;" and Laurie finds herself needing to "get out and away" from certain music. All these words and images divulge the disembodied nature of music when unwelcomed, when the music does not fit. Listeners veer away, intuitively led by the musical compass that resides in their bodies.

If there is no escape, then time seems to stop, the body's discomfort is loud, the space is unsuitable, and no kindred feelings exist or are possible for anyone or anything. At its worst, there is the lived experience of enforced music listening; listening to music that does not absorb or sweep away its listeners because they do not hear what they need or want. Perhaps this happens at an otherwise all Beethoven concert that opens with a specially commissioned new 21st century work for the orchestra. The music starts. Shortly, the seat is uncomfortable, the body fidgets, perhaps the throat feels dry and constricted, there is a cool draft whistling by the legs or a flush high on the cheeks; and the mind darts between the whispering duo ahead and worrisome details about tomorrow's plans. The person behind hacks uncontrollably for a few seconds, blows their nose wetly, and then fumbles with the noisy candy wrapper. It is unbearable. When will this end? Time seems to barely move, and the listener is held captive in music misery, a state that ironically highlights and parallels the extreme scenario of chronic illness: bed-bound, in pain, subject to an environment and people who cannot be removed, and listening to time crawl.

Recapitulation / Lived Experience and Lived Meaning

recapitulation - section of a sonata where with relief or resolution, the themes and other elements of the exposition are heard again in their original order with everything in the same key

Da Capo / Starting Again

da capo - from the beginning

This work points to lived experience and lived meaning by selectively directing and attuning our ears to noteworthy moments and places in the music listening experiences of 6 women who live with chronic illness. Re-casting these moments makes the phenomenon newly audible. First, I describe a more sweeping and general understanding that focuses on ways of listening. I follow this by a metaphorical account meant to amplify as well as further disclose the phenomenon of music listening in illness.

Ways of listening “for” music in illness. It is apparent that the women seek music. They listen for music, open, ready, and receptive to hearing and finding “something” in their listening experiences. Sometimes the music listening is very purposeful and other times it is less purposeful; but, is it ever truly accidental?

When Laurie finds herself listening to the same songs over and over again, intent is there. She responds to some need that is fulfilled by listening to particular songs. Laurie recognizes her need, as well as recognizes and acts upon opportunities for music listening. When Celia listens to two particular radio stations, she tells me that she ends up “hearing a lot of music just accidentally because you switch the radio on;” yet a purposeful orientation to music listening is retained because like Laurie, she recognizes and acts upon opportunities to turn on the radio, as well as maximizes her chances of finding engaging music because she chooses one of two radio stations that she likes. Similarly, Iris has one preferred radio station, and although she cannot predict the specific music she will hear, she knows the type of music she will hear. Like

Celia and Laurie, Iris listens for something particular in the music, and recognizes moments to seek out and realize music listening experiences.

However, intentions are not always sufficient to achieve a desired music listening experience. For example, May speaks of being unable to find her accustomed musical solace: "At the moment, even music is not easing the stress. I play CDs, tapes, and radio but feel nothing, even though I know the sounds are beautiful." Cognitively she recognizes something that gave her pleasure previously, but, in these particular times, she does not find what she seeks. Similarly, Jean writes in her journal:

Have had a few bad days. A lot of pain in shoulder, up neck to head. Everything seems a tremendous effort. And I find it difficult to concentrate. Depressed. Listened to Lucia. Music seemed to lift me, but only temporarily.

Yet despite these times when music listening is not helpful or of benefit, May and Jean retain hope for future positive occasions. A fidelity to music remains, and they continue listening for music. In listening for music, all the women are receptive and oriented to finding, perhaps receiving, the "right" music. What is the "right" music? What is being sought?

Ways of listening "to" music in illness. In seeking certain types or specific selections of music, the women seem to pursue definite ways of listening to music. Said differently, particular ways of listening are supported by the music that is heard. For example, Jean tells me, "If I'm feeling low then I need something that will rouse me out of it. Something that's got a lot of life to it. And if I'm feeling mellow, we put on something that's a little bit more subdued." The nuances of Jean's sensitivity to her feelings and consequent musical need are notable. "Feeling mellow" is different than "feeling low;" "Feeling mellow" calls for different music than "feeling low."

What are some of the ways of listening to music in illness? And what is it about chronic illness that calls for such ways of listening? Iris tends to listen in background, accompanying ways as she does her crafts and exercises, a seemingly absentminded way of listening. Although music is experienced as background, it simultaneously enhances the foreground activity so the experience of activity and music is fluid, flowing, and comfortable. Somehow the music helps establish an equilibrium that maximizes pleasure and minimizes intrusions such as the clock, body discomfort, or distracting thoughts.

Laurie likes to listen in remembering ways—"So if I'm thinking about somebody or what not, I'll put that kind of music on"—and in consoling ways—"I still go back to some of the old favorite tunes when I need comforting or whatever." Listening to remember reminds Laurie of who she is and who is with her. She is not alone nor without. The physical and psychological fragmentation wreaked by chronic illness seems repaired in music. Past and present integrate, catalyzing momentum towards the future. Re-membering (*going back to constituent parts*) strengthens Laurie from within by solidifying her knowledge of self, and this certainty of self mitigates the distressing uncertainty of body and its future. When courage and hope do falter, there is the comfort and solace found as music gently and familiarly holds its listeners. Consoling ways of listening offer no surprises, no questions, and no judgements—just compassion.

Other times, the animating force of music compels the body into action. The body assumes full reign. Visibly the toes tap, hips sway, voices hum, and torsos rock, or maybe the animation is not outwardly demonstrated but inwardly felt. Celia talks of "almost feeling like I'm doing what they're doing. I can feel in my body what it feels like to blow that flute to make that sound." Similarly, Storm's housecleaning tasks are animated with waltz: she feels "as if"

she is gracefully dancing from room to room, and from task to task. Whether the ill body actually acts with grace does not matter. It is the feeling of being animated with musical grace.

Listenings in surrendered ways are the times when the women abandon themselves to the music, letting themselves be taken and transported with music. They step away from themselves in order to live more fully in the music. Jean surrenders herself to following the soprano's voice; Celia abandons Christian skepticism to travel with songs of the Gospel; and May relinquishes distress to voyage with happy choruses. Being lost in the music means being lost to the ordinary world yet unworried, because music is a trusted companion who will return them safely.

The women listen to music in ways that touch and nourish them. Sometimes the music is anchored in a singular way of listening; other times, the women might listen in multiple ways.

The following anecdote conveys a listening experience that evoked many kinds of listening for Celia:

At a performance the other day, The Spanish Flamenco Troupe did Carmen and I'm familiar with the music of Carmen and the story. But for me the music is always heightened if I can move or I'm watching somebody move to the music. So, this was an all encompassing experience for me. It brought all the components together for me. The visuals, the music, the music that I'm familiar with and could hum along to even as a kid, and also the Flamenco dancing and the percussive use of their bodies. Not just the clapping but they also pounded the tables. And the sound of their heels, it feels like it sweeps me away when that happens. I don't play music to deliberately take me back to a certain era in my life. But it is very pleasant when I'm reminded. I mean that music (Celia starts to sing the chorus of Carmen) reminded me of what it was like to be a kid and the freedom I felt to thoroughly enjoy that music. And also the connection I had with my father during that time because he was always playing that music and he would sing along. And there's a certain carried awayness. I love that feeling. And when you're doing it with other people, feeling connected and commonality. It breaks down social barriers more easily. Like I went to Carmen by myself and I turned to the people next to me who were very obviously, from how they were dressed, very different people from myself. But I just started to chat to them about their response because I'd noticed their response during the performance. So I think there's a group pulse or something that can take over and be very positive.

Celia's experience of this concert was not anticipated, but she was open and receptive to the music's offering. She let the music carry her away and enjoyed the unexpected delights of being animated with vigor, remembering, camaraderie, and good will. This experience was complete in its moment and although now past, is readily available to be in the present—re-called, re-lived, and re-membered.

Hearing differently to hear anew. Recurrent sensations and images of water came to me throughout the inquiry, both as I read and reflected, and as I listened. On different occasions of music listening, I felt "bathed in sound" as if waves washed over me, or "buoyed with sound" as if floating on lapping ocean waves. Other times I felt like the water itself. I was the river current coursing forwards, the swirling, churning whirlpool, or the dropping, weightless rain drops.

Water takes on many forms and incorporates many experiences. We surrender with giddy laughter and shouts as a pounding surf picks us up and tosses us around; we become entranced by the steady crunch of the snow under our feet as we hike the long trail home; we stroll carefree along the beach as the water laps coolly at our ankles; we invigorate our body with the blast of a cold shower. A damp trickling stream, a relentless pounding rain, an ethereal morning dew—these are just a few of water's many manifestations and properties.

Some enjoy water in all its states; others are well acquainted with just a few of its manifestations; and others fear or even dislike it. Or perhaps water is not thought of; or not until drought-plagued lands are visited and the changed environment changes what is noticed. Some like the water at a distance and as part of the view; walking, reading, and napping by the water. Some like being right in the water, swimming, diving, and bubbling like water itself. Others stay close, though separate, with canoeing and sailing. If a vessel is strong, boaters feel safe to

enjoy and partake in all types of water; but if a vessel suffers damage or has repairs, the water's conditions are observed and experienced with more careful attention.

Some are experts about water: scientists who study its elements for new knowledge, fishers who attend to its rhythms for setting and gathering their nets, or map-makers who plot its journey for directions. But expertise is not necessary for enjoyment or appreciation. Those who are non-experts can still know water well and know its many pleasures.

Like water that remains water despite its many manifestations and properties, so too does music remain music despite its many forms and qualities. Just as surfers, kayakers, and swimmers know different things of water but share experiences of its sensations, so do rappers, classicists, and jazz affectionados know different things of music but share in its sensations. Just as the women listen to music in multiple ways, so water is experienced in multiple ways; and just as some favor particular ways of listening to music, so others enjoy the water in particular ways. There are unlimited ways of being with water—or music—and so the possibility for unending discoveries and possibilities exists. Increasing experience and knowledge generate a sensitivity and receptiveness that is enacted without the intentional formation of thought. The fisher feels something shift in the air, even though the rain is unseen; the listener feels some rhythm start in her body, even though its source is unheard.

Earlier I wondered about what the women hear, what unsounded sounds play to their ears. I now think that they hear offerings and possibilities. Music sets the stage for an interaction and extends an invitation. The women listen to know what “gift” is there, and decide whether to accept it or not. Music is sought, perhaps music seeks them—because of their long standing relationship and involvement it is difficult to tease out the beginnings and endings of interactions.

What is clear is that the women of this inquiry have lived in the company of music through most of their lives, and in the company of illness for the more recent parts of their lives. Illness has changed their relationship with music by making its presence, invitations, and offerings more audible, and music has changed their relationship with illness by making its dissonant harmonies more sonorous and even permissible. And now they live in the company of music and illness.

Coda / A Place to Cadence

coda; concluding remarks, usually brief and subsidiary, on movement's subject matter

cadence; melodies or chords associated with the end of a phrase, section, movement, or piece

Make a large place in your life for music and it will give you a priceless reward. All desires of your heart will come closer as you become attuned to the rhythm and harmony of life.

In the hour of rest, music will uplift your spirit and give refreshment to every faculty of your being.

In the hour of work, you will rejoice in the strength and energy which music has given you.

In the hour of jubilee, music will bring you the thrills of delight that compensate for all that is dull and commonplace.

In the hour of prayer, music will quicken your soul and perfume your life with the breath of heaven.

In the hour of fellowship, music will blend your spirit with others in unity and understanding.

In the hour of love, music will enrich your heart with the feelings that magnify the meaning of existence.

In the hour of memory, music will unseal the treasure of the past and bring a sacred glory to the present.

In the hour of death, music will speak to you of a life filled with an eternity of song.

In the hour of vision, music will give power and scope to your inquisition and bring into reality the things that were not.

In the hour of high purpose, music will summon the potentialities of your soul and urge them forward to great and glorious achievement.

Such is the power of music ... to this power open the doors of your soul and there will enter into your life a greater fullness for all that makes for progress and joy

The Power of Music by Waldo Warren

And if your life has been rich with music, there is assurance that in the hours of illness, music will come and music will offer.

POSTLUDE / DISCUSSION

postlude; anything played as an after piece

In this chapter, I briefly summarize the study and its findings, and then identify its limitations. Next I discuss the results in terms of their contribution as a particular way of knowing (van Manen, 2000), as a phenomenology of music listening (Ihde, 1976; Nelson, 1994; Pederson, 1994; Schonhammer, 1989), and as part of the extant literature. The latter focuses primarily on implications for two unanticipated areas of research: the construct of mind-body and the construct of social support as a coping resource. New literature is introduced in this part of this discussion because it was identified later in the research as a result of the analysis. The four phenomenologies of music listening are also reviewed here for the first time, which is in keeping with the strategic practice of delaying the review of pertinent phenomenological research until after analysis (van Manen, 2000). Last, I suggest implications for future research and for counselling practice, before concluding with *The Last Note*.

Summary of the Inquiry

This applied hermeneutic-phenomenological inquiry involved multiple interviews with 6 women living with chronic illness—Laurie, Jean, Storm, Celia, Iris, and May—who identified music listening as important in their lives. The purpose of this inquiry was to reveal the phenomenon of music listening as lived by these women. Word-of-mouth was used to solicit participants living independently in the community. Because pre-existing personal relationships accompanied the request, participants volunteered who might otherwise not have come forward because of either isolation, shyness, wariness, or a disbelief about their ability to contribute. This is a strength of the present study because the participants represented a unique group not normally recruited through academic or community postings, and a group who did not all fit the

description of being “articulate, reflective, and readily able to talk about their experiences” (Thorne & Paterson, 2000, p. 10).

Another strength of the present study was the multiple interviews with each participant. Because there was a 2- to 12-month interval between first and second interviews, the changing experience of chronic illness was captured and evidence offered in support of the foreground/background perspective of chronic illness (Thorne & Paterson, 2001), as well as the concept of chaos narratives (Frank, 1995). Both Storm and May experienced unexpected declines between the first and second interviews, which brought their illness and bodies to the foreground, and catalyzed chaos moments in their stories.

The women had been medically diagnosed with different illnesses. Storm and Iris’s illnesses (i.e., osteoarthritis, macular degeneration, spinal stenosis) are considered illnesses of aging, and along with Iris’s illness (acute transverse myelitis) are assumed to have a physiological etiology; on the other hand, Celia, Jean, and Laurie’s poorly understood illnesses (i.e., chronic fatigue syndrome, fibromyalgia) appear more frequently in women, and are commonly suspected of having a psychological etiology. But rather than focus on the unique features of particular illnesses, I followed the lead of researchers who conceptualize chronic illness as a singular experience distinguished by general characteristics that are shared across different types of illness (e.g., Charmaz, 1983; Gullickson, 1993).

Although there was some diversity across individual characteristics (e.g., socioeconomic status ranged from low to higher income; cultural/racial heritage included North American, European, Asian; ages ranged from 41 to 78 years; years living with illness ranged from 2 to 20 years), this was not intentional in terms of the study design nor significant vis a vis the study’s results and purpose. These demographics are offered for descriptive purposes only.

Significant to the study was my stance of continued wondering and questioning in order to understand more profoundly what lived meaning and experience was obscured by the everyday and habitual nature of this phenomenon. I started from a perspective informed by the obvious pleasure associated with music listening as well as a recognition of its role in helping to express and manage feelings, in perhaps acting to distract, as well as in accompanying or catalyzing feelings of being transcended beyond ordinary life. These characteristics seemed potentially significant in terms of living with chronic illness because of the themes identified in the chronic illness literature (i.e., themes of loss, meaning, and transformation). These thoughts were put aside with bracketing and reduction processes, and I moved more deeply into the phenomenon by engaging in conversation, reflection, reading, and writing; and, by using a guided existential reflection based on lived body, time, space, and relation to keep me closely attuned to the everyday unarticulated and lived aspects of music listening in chronic illness. Importantly and unexpectedly, I discovered that music was a long standing part of each participant's lives and that music was experienced as a companion—a trusted, loyal, and intimate companion—who ultimately aided in accommodating the later arrival of an uninvited, unfamiliar, and unpredictable chronic illness.

Limitations of the Inquiry

The limitations of the present study can be clarified by understanding what hermeneutic-phenomenological findings do and do not offer. The direct purpose of phenomenological research is not to provide theoretical abstraction, solutions, causal relationships, or a basis for later empirical analysis. Rather, the purpose of hermeneutic-phenomenology is to “uncover shared practices and common meanings of our lived experiences” (Gullickson, 1993, p. 1390). New understanding and insights are revealed by uncovering the hidden meaning of everyday

ordinary life. Because hermeneutic-phenomenological questions are always questions of meaning, they necessarily remain “open and anticipatory” because a “final complete interpretation” can never be realized (Schwandt, 1997, p. 115). A cautionary note from van Manen (1990) warned,

To do hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspects of the lifeworld, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal. The phenomenological reduction teaches us that complete reduction is impossible and that full or final descriptions are unattainable. (p. 19)

The goal of the present study was to render visible the lived experience and meaning of music listening for women living with chronic illness. The text was written with the intent of making the reader see something specific, with the modest hope that readers would (a) acquire a deepened understanding of the experiential meaningfulness of this phenomenon; (b) grasp more fully what it means to be human; and (c) potentially act in more thoughtful and intentional ways.

Because the inquiry sprung forth from lived experience and incorporated accounts of lived experience, the inquiry is not anchored in a foundation of speculation, hypotheses, or theories. Speculation, hypothesizing, and theoretical wondering always arose from and in conjunction with examples of lived experience (e.g., anecdotes). Anecdotes provide a “tangible counterweight to abstract theoretical thought” (van Manen, 1989, p. 247) and connect life and theory. Anecdotes allow us to dwell in a experiential knowing that is lost in theory. As such, the present study anchored itself in the lifeworld, and not the mind.

The use of a guided existential reflection to analyze and frame the results is a heuristic strategy forwarded in van Manen’s work (1990, 2000). It is based upon a recognition that these four concepts weave through phenomenological literature, and are believed to reveal how humans live and experience themselves. On the other hand, these may not be the only ways that

humans experience themselves. Furthermore, the use of a guided existential reflection raises epistemological questions related to phenomenology's status as an unencumbered, theory- and method-free way of knowing. The guided existential reflection was helpful in the analysis and organization of findings; however, its usage necessarily shaped and thus limited the findings as well.

The findings are limited to the lives of 6 particular women and to the extent that they were able to provide me with anecdotes of the phenomenon, and the extent to which I was able to engage in hermeneutic-phenomenological analysis and writing. Nonetheless, the findings are believed to reflect an experiential meaning of chronic illness and music listening that can speak to shared understandings:

By attending to the experience and meaning of the everyday lived world is to offer plausible insights that ultimately bring us into more direct contact with the world, making us thoughtfully aware of the consequential in the inconsequential; the significant in the insignificant. (van Manen, 1990, p. 8)

Phenomenology as Practice

My broadest intention in this phenomenological research was to produce a text that revealed a particular way of knowing, a way of knowing that informed and animated action by illuminating practices and experiences of everyday thinking and acting (van Manen, 1999). Like other written knowledge, the end product of the present study was a text; however, unlike other texts, this one was constructed so that its meaning was embedded, which makes findings difficult to summarize and isolate from the text. Such a text communicates understanding that is embodied and discursive (i.e., knowledge as participation), and that leads to personal formative knowledge (i.e., knowledge as being). This kind of knowledge is not a theoretical or technical problem-solving knowing. Rather, phenomenological information contains cognitive and pathic,

conceptual and poetic, informative and formative elements that "enhance our perceptiveness, contribute to our sense of tact in human relations, and give us pathic forms of understanding that are embodied, situational, relational and enactive" (van Manen, 2000).

Phenomenology as Pathic Knowing

I intended for readers of the present study to experience a pathic way of knowing, that is, a felt sense of being and knowing. More specifically, van Manen (1999) described pathic knowing as embodied, enactive, situated, and relational knowing rather than gnostic, cognitive, intellectual, and technical knowing. Embodied knowledge is when the body knows how to do things (e.g., routines, habits, conventions, and rules). Actional knowledge is based on what we do, how we act, and is generally a silent, nondiscursive knowing. Situational knowledge arises in the environment such that we know how to act in different kinds of environments (e.g., how to ask a question when at home, in the workplace, or at a public meeting). Relational knowledge exists or is found in relationships with others (e.g., with one person we experience ourselves as funny and relaxed, yet with another we feel unfunny and awkward). By reading, reflecting upon, and thus participating in the present study, readers are exposed to a pathic way of knowing and being in the world.

Phenomenology as Tact

Tact that relates to phenomenological perspectives is defined as "a particular sensitivity and subtle awareness to situations and how to behave although this is not based on knowledge from general principles" (van Manen, 2000). Tact is not an intellectual knowledge nor a set of skills that mediates between theory and practice. Tact is conceptualized as a separate entity, that manifests itself as a certain kind of acting, "an active intentional consciousness of thoughtful

human interaction" (van Manen, 2000). I hope that because of the insights gleaned and uncovered in this study, more intentional and tactful actions ensue in the lives of readers.

The Inquiry as a Phenomenology of Music Listening

The present study can be further understood in terms of other phenomenological studies that reveal something about the phenomenon of music listening. Although it is impossible for me to do full justice to the following phenomenological works given their richness and density—Ihde (1976), Nelson (1994), Pederson (1994), and Schonhammer (1989)—I present them by conveying a general impression of each work, and then reflecting on particular questions evoked by the texts. I conclude by identifying the unique contributions of the present study.

Music Listening with a Walkman

Schonhammer (1989) wrote about the music listening experiences of individuals using portable cassette players with headphones (i.e., Walkmans). He realized that he felt extremely critical of these listeners, so he decided to explore the meaning of his irritation and investigate the acoustic environment of the Walkman. Data were generated in a variety of ways (e.g., self-reflection, interviews and surveys of Walkman users, having people walk with and without earphones and then describe their experiences) and analyzed by considering the constituents of the phenomenon. Insights were forwarded about the lived experience of space and time, which was described as becoming split when using headphones in public places. For example, the world's noises are silenced and replaced with music, which then renders the world in terms of musical rhythm and melodies. Music severs usual contact with the world and re-establishes it in music. When listeners live in musical relationship with the world, time becomes the time of music itself, and this causes listeners to "forget about the distance between 'now' and 'then'" (p. 141), which characterizes a goal-oriented attitude. Objective time is suspended and time seems

to pass unnoticed. Schonhammer also pointed to the incongruency that occurs in the body's inclination to move and break into dance that is constrained by the public space of walking or busing, for example. By suppressing the motivation to move freely, "Walkman users bodily experience the splitting of lived space and time: they themselves are walking, moving goal-directedly, but feel, at the same time, driven to give up goal-directedness...thus they...find in one way or another a compromise between walking and dancing on their stroll between two worlds" (p. 142). In this place between worlds, listeners experience the environment more intensely. One participant said,

The world again looks magnificent, much more colorful, much more varied, much freer...When I wear this instrument I feel splendid, as if I were in a concert. No disturbance detracts from one's personal concert situation. The concert takes place in one's head; I am not feeling totally isolated. I can make contact with other people at any time, and yet I can shield myself against them also at any time. (p. 134)

In reading Schonhammer's (1989) work I was re-struck by the question, "what is it about the world lived in music that is desirable for a woman whose world is also lived in chronic illness?" His description of a world being lost and re-established in music especially spoke to me, making me think of the individual worlds changed with chronic illness and which must be re-established in a way that accommodates illness. Somehow music eases this shift, maybe softening the edges of reality when it seems too harsh. A world experienced in music is a great gift when otherwise, the world is experienced in pain and upheaval, or lethargy and dullness.

Additionally, Schonhammer's (1989) understanding of changed lived time as an interruption of a goal-oriented attitude fits with Laurie's description of listening in order to let herself feel helpless within the music (i.e., abandoning a goal-oriented attitude), and Moss's (1977) belief that people with illness should surrender into music listening in order to relinquish a problem-solving approach (i.e., goal-oriented attitude) and move into a "healing

consciousness" (p. 23) that concedes the limits of conscious effort. Csikszentmihalyi's (1990) notion of flow also incorporates this changed experience of time that paradoxically interrupts intentional goal seeking but is beneficial. Laurie felt freer to go about her day after music listening; Moss (1977) suggested that a "transpersonal healing energy" (p.24) is accessed; and Csikszentmihalyi (1990) argued that goals are attained because distracting information is eliminated. Musically lived time benefits listeners, and perhaps especially those whose goals and actions are constrained by chronic illness.

Music Listening and Voice

Ihde (1976) reflected on the phenomenon of listening and voice over a 7-year period in which he studied physiology of hearing, acoustics, and music theory, observed classroom activities with his students, and implemented intersubjective research, whereby all examples were cross-checked with other persons' experiences. Several insights about music emerged because music was considered as one type of sound. In contrast with other sounds, music was described as sound that draws attention to itself by referencing the body rather than things. Music listening motivates the body to dance, which Ihde distinguished as either an observable outward dancing or an inward dancing based on the internal rhythms and movements felt in the body. Because the body is engaged musically, music listening was posited to unite the body and mind. Ihde also commented on musically experienced lived space and time. Music seems to fill auditory space, creating a sensation of openness. The term *timeful* was used to capture the ability of sound—all sound, not just music—to reveal time, as in "sound dances timefully within experience" (p. 84). For example, the sounds of city traffic and a country chorus of birds provide auditory stability by establishing rhythmic temporal cycles. Ihde associated music in

particular with the possibility of experiencing lived spatiality and temporality that are "full" (p. 102).

Ihde's (1976) attention to temporal and spatial experiences of fullness in music listening resonated with my own description of music listening—as time-encored, time-tabled, time-full, and time-less, and as being music-held and music-freed—and emphasized the significance of music's association with changed spatial experiences, an observation noted by several authors. Sacks (1984) and Schorr (1993) identified the lived experience of space as a unique and catalyzing aspect of music listening. Kenny (1989) used the term musical space to refer to a "contained...intimate and private field" (p. 79) that exists between the music therapist and client in the context of music therapy improvisation; and Ruud (1998) referred to music associations with space in describing music and identity (e.g., personal and social space; the space of time and place; and transpersonal space).

I find myself wondering, in particular, about what it means to feel satiated with music. Sometimes music listening evokes something so whole, so complete, and so full, that it seems impossible to be in want of anything else. Perhaps, when a moment is so complete and right and the listener feels so complete and right, then the listener must concede that, ultimately, there is a completeness and rightness in themselves?

Phenomenological Dissertations on Music Listening

Two dissertations (Nelson, 1994; Pederson, 1994) were completed based on phenomenological investigations of music listening with participants who had varied musical histories, although all had been involved in some way with music from a young age. Both researchers used unique methods to generate data.

Spontaneous music listening over a week. Pederson (1994) had 6 adults (4 women, 2 men) verbally record journal entries onto audiotape after each incident of music listening that occurred spontaneously in their everyday lives over a 7-day period. Once the journal entries were transcribed, the participants discussed them with the researcher. The audio-taped journal entries were analyzed based on the 4-step method of Giorgi (1985), and results indicated that music listening experience related to four areas of human existence: mental functions, interpersonal growth, intrapersonal growth, and transcendence. Mental functions involved processes of the human mind (e.g., initiation of physical activity and effects of music listening on perception, attention, cognitive activity, creativity, levels of arousal, emotions, and mood). Interpersonal growth pertained to the development of relatedness with oneself and others, and learning to balance them. Intrapersonal growth referred to music listening experiences that prompted either insight into past and present situations, or an evaluation of personal characteristics through introspection and/or the psychological resolution of issues. Transcendence included experiences that seemed to take the listeners beyond ordinary or material existence (e.g., a metaphysical event; the experience of perfect beauty or pleasure).

As a result of explicating the psychological meanings of the self-initiated music listening experience occurring naturally within lives of listeners, Pederson (1994) concluded that music listening seemed to play an important role in terms of overall life struggles and themes being experienced by the listeners. Music was described as being used intentionally and sometimes in response to unrecognized goals or need; moreover, listeners sometimes felt as though a unrecognized, spontaneous motivation led them to music. These occasions of music listening moved listeners toward psychological growth, resolution of emotional pain, or awareness of a metaphysical connectedness to something beyond themselves. This led Paterson to speculate

that listeners are capable of "metaphorically inducing a subconsciously needed psychological state" (p. 126).

In commenting on the varied influences of music listening experiences, Pederson (1994) suggested that music listening is a malleable phenomenon influenced by the "initiatory context and needs of the individuals" (p. 126). Music listening seemed to be a highly individualistic experience that was apparently influenced by contextual conditions such as the particular affective, psychological, and need state of the listener. As a result of keeping and discussing the audio-journals, participants became newly aware of recurrent themes in their music listening over time. One listener found a repetitious use of music to seek and experience order in life; another used music listening to manage stress and affect; and yet another experienced music-evoked fantasy that offered an escape from day-to-day life.

Pederson's work spoke to many things (e.g., multiple ways of listening, feeling transcended, experiencing time-encored); but, I particularly noticed the description of what seemed to be intentional listening experiences that nonetheless did not seem to start with a cognitive intent. I reflected again on how it is that listeners find the right music or know what way of listening to seek. I again found myself pondering the possibility of highly attuned entities, an interchangeable compass and magnet. In the present study, the women's bodies clearly told them which music was unwelcome. Does it similarly guide them to the right music?

Listening to personally meaningful music. Nelson (1994) focused specifically on listening that involved personally meaningful music and then discussed consequent methodological, clinical, and practical implications. Similar to Ruud's (1998) approach to generating data, Nelson (1994) asked 21 participants (14 men, 7 women) from a university student population to select 2 to 5 personally meaningful musical selections to share with the

researcher. During the interviews, the personal selections of music were played and participants asked to describe aloud their on-going experience of listening, to "describe thoughts, feelings, emotions, ages, sensations, fantasies, or any related experiences that occurred to them" (p. 90). Data were analyzed by first identifying statements that matched a priori categories identified by Howes (1970)—feeling, memory, cognition, imagery, relational, and physical sensations—and then by identifying "common sense understandings" as described by Kvale (1983). Results were classified according to the different meanings ascribed to the music.

Music was described as standing for and being associated with (a) a person's self-view or belief structure (e.g., "this music tells me I believe in myself," "it's self-esteem, being proud of who you are"); (b) relationships and different developmental stages (e.g., "it means how I feel about my girlfriend and our relationship," "represents nostalgia, reminiscence of childhood, there's a tranquility to it," "it means me changing, it described a time period of my life that I left behind, yet it's still a part of me"); (c) coping and adaptive thinking processes (e.g., "helps me keep going," "gives me confidence," "it brings out a sense of hope, strength, it helps me not get discouraged"); and (d) self expression (e.g., "I love to feel emotion, I express myself through both of these songs," "I can feel through music the way I can't even feel with another person," "people can have profound experiences to music, I guess it brings out yourself"). During the interview process, Nelson observed body swaying, foot tapping, head nodding, mouthing words, smiling, crying, and tearfulness. Discussing their music listening experiences was intimate, personal, and something most participants had never done before, and all acknowledged an increased awareness about the effect of music listening on their emotional, cognitive, and relational experiences as a result of participating in the research.

I found that two things particularly stood out in Nelson's work. First, I recognized anew the irresistible nature of music. During interviews, participants not only moved to the music, they also became tearful and/or wept in their first meeting with a stranger to whom they were describing a piece of music. Music has a remarkable immediacy and potency that addresses listeners directly, in feeling, sensing ways that are of the body. Second, Nelson noted the obvious as well as less obvious kinds of relational experiencing evoked in music listening. Similar to the women in the present study, a male participant in Nelson's study said, "It's (music) always there whenever you want it, it gives you everything without wanting anything back. I could say music is the perfect spouse, the perfect thing you can be with all your life, with no problems, no conflicts" (p. 126).

The companionship attributed to music is striking; yet, this understanding of music as friend and companion surprised me despite now recognizing its lived truth in my life. Ruud's (1998) work, for example, addressed the related ideas of music and identity, music and reminiscence or remembering, and music and feelings; but the particular relational experience of music as companion has not been developed in his work nor any others that I can locate.

Conclusion

Together, the four phenomenological studies reveal varied insights about the lived experience and meaning of music listening. They also offer evidence of the always incomplete nature of a phenomenological investigation since continued reflection inevitably suggests further questions and further insights (van Manen, 1990). The present study extends the phenomenological understanding of music listening in two significant ways. First, the phenomenon is placed within the life context of women who live with chronic illness. This focuses attention on particular aspects of the phenomenon and reflects an interest in pragmatic

applications. The consideration of a specific lifeworld can be conceptualized as a varying of the example, an analytic strategy that furthers the broader efforts of identifying common elements across music listening experiences; that is, "what qualities make this phenomenon what it is and without which it could not be?"

Second, I strove to create a vocative text as an effective way of communicating and revealing the phenomenon. Nelson (1994) and Pederson (1994), for example, identified participants by number or letter, and listed categories of meaning illustrated with representative quotes. This style of writing reflects a logical, linear, and cognitive text. Conversely, in the present study, participants' lives are detailed and the phenomenon of music listening is described and understood within these personal contexts; creative devices are used, such as metaphor and the inclusion of musical terminology to organize the study; and words are carefully chosen for their qualities of concreteness, evocation, intensification, tone, and epiphany (van Manen, 1997). By attending to the pathic qualities of the present study's text, I meant to prompt readers to actively engage in the reflective process, and become more fully immersed in and affected by the research findings. This engagement with the text augments pathic knowing and the possibility of future tactful actions.

The Inquiry as a Contributor to the Extant Literature

The findings of this phenomenological study were relevant to many of the varied theories and concepts in the extant literature. This supports van Manen's (2000) statement that theory should not be ignored but considered thoughtfully because it often simplifies or covers over phenomenological truths. For example, Maranto (1993) concluded that distraction might be the primary impact of music listening in reducing stress. Distract means to "draw away in different directions," which could be one way of interpreting the present study's findings. However, the

term fails to adequately convey the depth of music listening experiences—the manner in which music compels and engages listeners, and the rich content with which listeners are distracted. Phenomenology reminds and reawakens us to the complexity and vitality of lived experience.

Similarly, listening to music may relieve tension with its harmonic resolutions (e.g., Meyer, 1956), please with its aesthetic perfection (e.g., Kenny, 1989), and challenge with its analytical elements (e.g., Swanick & Tillman, 1986); but what is gained and what is lost by identifying this as a reflection of id, super ego, and ego functioning (e.g., Kohut, 1978)? Listeners may listen repeatedly to a musical selection (Sears, 1968), but is this a sole function of positive reinforcement? Music listening might facilitate deep breathing and relaxation (Fried, 1993), but is this the only therapeutic way to listen? Imposing terminology, suggesting prescriptive solutions, or prematurely reaching conclusions robs listeners of their experience and the phenomenon of its subtleties. Phenomenology restores a lived truth that reflects experience and meaning as unencumbered as possible. Phenomenology provides one type of finding against which findings generated by different types of research can be considered in an ongoing thoughtful and questioning dialogue.

Unanticipated Findings

Two findings in the present study were unanticipated and directed me to unconsidered areas of the literature—the concepts of mind-body and social support. I focus on these results because somatic awareness and relational aspects in music listening have not been adequately recognized and developed in the research literature.

The concept of somatic awareness/mind-body. The notion of the body as a musical compass attends to the attracting and repelling nature of magnetic properties, a reciprocal relationship between the compass magnet and the earth's poles, or by extension, between the

women and music. Music listening seemed to involve a reciprocal relationship in which there was a readiness for music as well as a knowingness about what music to seek. Laurie talked about happenstance discoveries of music that were immediately recognized as special and "just right." A participant in Nelson's (1994) research used the metaphor of "music dials" to describe how he instinctively found the "right music" by moving the dial to a particular setting. Pederson (1994) commented on participants who felt "prompted toward music listening by an internal force which prior to listening was beneath their level of conscious awareness" (p. 125). I too have experienced seemingly chance findings of immediately meaningful music and intuitive realizations of what music to put on. Moss (1977) seemed to refer to this latter sensation when he talked about intuitively choosing a music selection by standing in front of a music collection and waiting for a "sense of connectedness" (p. 84) that would direct the listener to a particular selection.

Perhaps these are coincidental occurrences, or perhaps personal projections onto sufficiently ambiguous music, but, I am now more inclined to believe these experiences might reflect the existence of an "articulate mind-body rather than a mindless biological mind-body" (Foss, 1996, p. 46). The possibility of a "thinking" mind-body was more clearly evidenced in the present study by the women's descriptions of unwelcome music. This music "jarred," set them "on edge," "singled," and made them want to "get away"—language that references the body by conveying information as bodily sensations. Changed music preferences over time and following the arrival of chronic illness also provoked a wondering about the body as a site of knowing. Bakal (1999) used the concept of somatic awareness to implicate an innate wisdom about personal psychobiological health that is a source of information and direction. Benner and Wrubel (1989) described the body as an embodied intelligence that has "the capacity to respond

to and act in meaningful situations without conscious reflection" (p. 407). Price (1993) coined the term "body listening" to refer to being aware, and able to understand and interpret one's body. Amir (1995) talked about encouraging music therapy clients listening to "inner sounds" (p. 53). Is there a knowing body that guides and informs behavior?

The concept of social support as a stress and coping resource. The relational aspects of music listening were more surprising than the indications for somatic awareness in music listening, if only because the physical behaviors incited by music are so apparent. But the relational experiences associated with music listening quickly emerged in the data analysis and were augmented by reflection upon a quote from Robert Browning, "Who hears music feels their solitude peopled at once" (as cited in Wallace & McKowen, 1996, p. 92). I wondered about how music can people us when we listen alone? I understood that reminiscence of others, of self, and of various memories were evoked in music listening (e.g., remembering ways of music listening) but the pervasiveness of relationship through all aspects of music listening was startling. For example, listeners experienced felt relationships with the music itself, as well as with its players and its creators. This kind of relational experience was always new and of the "now." Whereas tangible relationships recovered from memory helped the women re-member themselves so they could feel whole and not only illness-defined, newly felt music relationships helped the women with immediate feelings and experiences not yet integrated as part of their self-identity. Relationship through re-membering and relationship through immediate listening peopled the participants' solitary music listening experiences. Most broadly, lived relation existed in each listening experience simply because to listen is to engage and to accept the offering of music. Based on bodily sensations perhaps below cognizant awareness, the decision is made to listen

and, in that decision, we move into relationship with the music. Over years and years of listening, music can become not just as a pleasurable art form, but a companion and an intimate.

These lived meanings confirm and reiterate Ruud's (1998) work on music and identity, as specific to music listening, and provide some detail about how music listening might act as a resource in stress and coping processes, as well as a coping strategy (e.g., Barker, 1991; Hatta & Nakamura, 1991; Stratton, 1993). Coping strategies are behaviors that either manage emotional distress (i.e., emotion-focused) or alter the source of stress (i.e., problem-focused); whereas resources are antecedent conditions that reduce vulnerability to stressors (Lazarus & Folkman, 1983). Social support is a resource associated with psychological and physiological benefits that is broadly understood as "all those forms of support provided by other individuals and groups that help an individual cope with life" (Reber, 1995, p. 734). I believe that this common understanding of support as something occurring through interactions with tangible beings must be extended and elaborated to include other kinds of relational sensation such as those illuminated in the present study. Ruud (1997) hypothesized that involvement with music might encourage a positive quality of life by enhancing life's predictability, conceivability, and meaningfulness, three factors identified by Antonovsky (1987) that help mobilize against disease. The relational experiences and meaning of music listening suggest possible implications for music as a personal resource closely linked to the concept of social support because with music, you are known, understood, and recognized—and you are not alone.

Implications for Future Research

Further phenomenological investigation is always called for, and therefore continued hermeneutic-phenomenological inquiry of the music listening phenomenon is warranted. The example may be varied by considering different lifeworld contexts against which to orient to

music listening. For example, I am curious to speak with men about their music listening experiences as well as individuals characterizing different developmental stages (e.g., childhood, adolescence). I also would like to elaborate more fully the particular themes of the present study. Research might focus on a particular way of listening (e.g., remembering ways, surrendered ways) or particular experiential qualities of music listening (e.g., time-less, music-held, time-encored).

The unanticipated subjects of relational experiences in music listening, and the body as a source of knowledge also invite further research. I would like to understand relational dynamics in music more fully (e.g., further description) as well as to explore links with social support as a personal resource. I do not know whether the experiential meaning that emerged of music as a companion or friend developed as a function of time, or because of individual differences perhaps related to emotional expressiveness. Exploring the lived experience and meaning of music listening for those who feel indifferent to music may shed insight. Moreover, the concept of a thinking mind-body raises many questions specific to its role in music listening and finding the "right" music, as well as implications for those living with chronic illness.

Implications for Counselling Practice

General implications for counselling practice arise from the possibilities for more tactful actions as a result of reading and engaging with the present study. Based on a heightened awareness of everyday music listening experiences, counsellors may act more intentionally in considering the significance of everyday music listening for their clients, whether living with chronic illness or not. Findings of this present study as well as those of Nelson (1994) and Pederson (1994) suggest that, although individuals may be cognizant of music pleasure, they may be unaware of music's personal meaningfulness. Therefore, music may not spontaneously

be forwarded for discussion by clients or counsellors. In recognizing music as a fertile potential source of meaning, counsellors can enrich their clinical interactions, as well as sensitivity to the office's auditory environment and client preferences.

There are endless possibilities for professional helpers who are not music therapists to incorporate music into their practices, and these have been described in the literature (e.g., Gladding, 1992). The present study provides an experiential knowing of the phenomenon that allows counselling practitioners to grasp more perceptively the significance of music listening, thereby deepening the sensitivity and tactfulness of music use in their counselling practice, as well as receptivity to collaborations with music therapists and other creative art therapists.

The methodology also presents implications for counselling practice. Phenomenological strategies are highly congruent with the goals of counselling practice—for example, suspending pre-judgements so that clients can be approached with wonderment, and therefore known and understood as individuals. Theory and past counselling experiences are integral to successful counselling practice, but, counsellors must also guard against their damaging effects. Pre-conceptions based on theory and past experience can cover and conceal each client's uniqueness. The ability to stay fresh, alive, and responsive to each client is an ongoing challenge for counselling practice, and the present study's methodology offers a solution. If the phenomenon of study is understood as the client, then the activities associated with bracketing and reduction (e.g., writing and dialoguing to explicate assumptions) are appropriate strategic practices for counsellors to use in their clinical work. For example, the heuristic reduction allows the phenomenon/client to be approached with wonder and naïveté; the hermeneutic reduction encourages openness to the phenomenon/client; and the phenomenological reduction elucidates the phenomenon/client's experiential reality.

Last, the strategies associated with creating a vocative text—using anecdotes and words to create a text that shows and suggests—provide writing guidelines that are useful for counsellors wanting to share their work (e.g., at team meetings, conferences, or in publications). Hermeneutic phenomenological writing implicates ways of writing for maintaining experiential truth in a text rather than relying on theoretical terms that silence lived experience. For counselling practitioners, it is important to uncover the meanings that individuals hold relative to their lives, as well as to share this in a meaningful way with others such that they are touched in the same way that client and counsellor are touched as they work together.

The Last Note

The present study involved me in a personal and meaningful experience that ultimately brings me back again to my first intimations that there was something important and consequential in my music listening experiences as I also lived with chronic illness. I have moved forward in terms of grasping the lived meaning of these experiences, but also come to rest knowing that there is yet more to understand and more to write. Thus, it seems most fitting to end with words penned by T.S Eliot that Sacks (1984) also used in ending his book: “And the end of all our exploring, will be to arrive where we started, and know the place for the first time.” (p. 168).

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SCORES / APPENDICES

Appendix A

Pilot Interview

In order to gain some experience in phenomenological interviewing as well as guidance in the process of generating data, I had a 2-hour interview with Ginette, a 27 year old woman living with fibromyalgia. Her illness was debilitating, and she had been living with it for over 10 years. Nonetheless, she was working, studying, and was raising a child on her own. Ginette was also an accomplished musician, and she described music as a longstanding "accompaniment" to her life. For example, her parents' participation in choirs was something she had always "taken for granted." She described herself as using music to affect her mood, but not to relax—usually to "get a charge." Music listening was a "direct route to a soulful place" and when I asked for more description about this place, Ginette explained that the "music pulls me into interacting with it and just listening." She talked about the importance of experiencing the beauty of music when she wasn't feeling well and was in a "dark place," and said that music listening was "an experience that you can have in the face of awfulness that is beautiful and that you can count on." Ginette also said that, "music seems to accompany the passage of time really well."

The pilot interview with Ginette influenced my approach to interviews in several ways. First, I discovered that it was very easy to stray into theoretical, explanatory discussion. Ginette's interview generated important material, however, there was also a lot of irrelevant talk pertinent to the present study's purpose. Furthermore, I realized that I needed to emphasize the music listening focus, rather than the illness focus. In the pilot interview, for example, a significant amount of time attended to Ginette's experience of illness, which generated

interesting yet not specifically helpful information.

As a result of the pilot interview, I had a clearer understanding of my purpose in speaking with the women. I wanted to obtain lived descriptions of music listening experiences. This helped me focus our conversation with specific questions such as, “what is a recent experience of music listening that stands out in your memory?” or “tell me about a different kind of music listening experience?” In my conversations with the 6 participants of the present study, information and discussion about illness occurred within a music listening context. For example, in the pilot interview, I asked Ginette to tell me about her life with illness, which led to a long and detailed chronology of its onset, diagnosis, and impact. Conversely, the 6 women of the present study were asked to tell me about how music listening was part of their lives and how this related to their chronic illness.

The pilot interview also confirmed the richness of the research question posed in the present study, and removed any doubts I had about participants being unable to speak to the question. This enhanced my confidence as a researcher.

Appendix C

Telephone Screening Protocol

Thank you for contacting me about the research project on music listening experiences in the lives of women with chronic illnesses. I'd like to get a little information from you and then explain what the project is about and what's involved for you if you decide to participate in it.

Name:

Phone number:

Where or how did you hear about the project?:

Do you speak, read, and write enough English to participate fully?:

Do you self-identify music as important in your life?:

What type of physical chronic illness do you have?:

How has it been since you were diagnosed?:

The purpose of this research project is for me to gain some insight into your experiences of listening to music. I'm going to be doing this by meeting with you twice; once to talk about your actual experiences of listening to music and another time to focus more on the meaning. At the end of the first interview I will give you a journal which you can use between the first and second interview to write any ideas or impressions etc. The journal will be yours to keep and you can choose whether you'd like to share any of it with me or not at the second interview. The interviews will be audiotaped and then transcribed. I will keep all materials confidential and in a locked file during the project. The tapes will be destroyed at the end of the project. You are also free to withdraw from the research at anytime. If you're still interested and able to participate, let's arrange a convenient meeting time.

Appendix D

Description of Participants' Illnesses

The women's illnesses included Acute Transverse Myelitis, Chronic Fatigue Syndrome, Fibromyalgia, Macular Degeneration, Osteoarthritis, and Spinal Stenosis. Each is briefly described in order to provide a general understanding of the disease processes involved. Information was gathered from two medical texts (Ambrose, Angone, Eckman, & Johnson, 1996; Tierney, McPhee, & Papadakis, 2000).

Acute Transverse Myelitis has a variety of causes (e.g., infection, virus, toxic agents) and refers to an inflammation of the spinal cord that causes motor and sensory dysfunction dependent upon which level of the spinal cord is affected. This particular form of myelitis has a rapid onset with impairment appearing in 1 or 2 days. Residual neurological deficits usually continue after recovery. Treatment involves reducing the inflammation; however, no effective treatment exists for preventing occurrences.

Chronic Fatigue Syndrome, also known as Chronic Epstein-Barr Virus or Myalgic Encephalomyelitis, is a disease characterized by debilitating fatigue, neurological abnormalities, and continuing symptoms, such as muscle weakness and discomfort, sleep disturbances, low grade fever, painful lymph nodes, headaches, forgetfulness, difficulty thinking, confusion, depression, and inability to concentrate. It occurs primarily in women under 45 years. There is no known cause, no effective treatment, and no diagnostic tests.

Fibromyalgia is a chronic widespread musculoskeletal arthritic pain syndrome characterized by fatigue, chronic headaches, sleep disorders, and numbness. Similar to Chronic Fatigue Syndrome, Fibromyalgia is more common in women aged 20-50 years, and has no known cause, no single effective treatment, nor diagnostic tests. The distinguishing feature is that pain dominates in Fibromyalgia rather than fatigue, which dominates in Chronic Fatigue Syndrome.

Macular Degeneration is the main cause of severe irreversible loss of central vision in the elderly. The macular disk degenerates and a change in central vision is noticed. Visual loss is gradual and progressive. The cause is unknown but its incidence increases with each decade over age 50. There is no specific treatment and the degeneration cannot be stopped. Low-vision optical aids can be helpful when there is good peripheral vision, and in some cases, laser treatment appears helpful in reducing severe visual loss.

Osteoarthritis is the most common of arthritic conditions with an incidence that increases with age. It is a degenerative joint disease in which cartilage wears down and bone spurs develop. Symptoms include localized pain, stiffness, and limited motion in the affected joints, which are typically the hands, spine, knees, and hips. Osteoarthritis progresses slowly and symptoms are uneven: for example, periods of worsening can be followed by stabilization and comeback. Treatment, such as exercise, weight loss, analgesic/anti-inflammatory drugs, or surgery to replace joints, may relieve symptoms and improve function.

Spinal Stenosis mostly occurs in people over 60 years and involves a narrowing of the spinal canal. Symptoms involve difficulty walking and/or back pain. There is a gradual onset of pain, weakness, or unsteadiness in both legs. Surgery may provide short-term relief, and weight loss as well as specific exercises may slow the decline.

Appendix E

Interview Questions

First Interview

Following an orienting statement in which I introduced the purpose and anticipated format of the interview, all participants were asked the first question:

Tell me how listening to music is part of your life and how this relates to your chronic illness?

After this question was discussed, I posed the following question:

Take a moment to think of any strong recollections and memories you have of listening to music since your illness began. Choose one and tell me about it, describing it so that I can experience it as though I was there myself: e.g., how the experience started, what you did, how you felt, what you saw, what you heard, and so on.

Then I asked for another example, one that was perhaps different than this one. I asked if they could tell me about a negative music listening experience. At some point in our conversations, I also asked all participants:

Do you remember when you first became aware of the importance of music listening in your life? Can you tell me about that experience?

I concluded our conversations with the following question:

Is there anything else you'd like to say about your experiences of music listening?

Second Interview

I initially presented my preliminary understandings of our first conversation and asked for clarification of any material that was unclear. I inquired about any thoughts that had arisen between interviews or as part of their journal writing. Then I initiated a discussion of emerging themes that were discussed in terms of the question: Is this what the experience of music listening is really like?

Appendix F

Informed Consent Form

Music Listening Experiences in the Lives of Women with Chronic Illnesses

Purpose of this study:

Jennifer James Nicol, PhD Candidate, under the supervision of Dr. Bonita Long, PhD, is conducting a research-interview study focusing on experiences of music listening in the lives of women with chronic illnesses. The research is part of the requirements for the PhD degree.

Procedures:

As a participant in this study, I will be asked to:

- 1) participate in an initial interview lasting approximately 90 minutes. During this interview I will be asked questions about experiences and perceptions of music listening in my life;
- 2) participate in a second interview lasting approximately 90 minutes. During this interview I will be asked to provide further clarification, and to discuss themes and ideas about listening to music with the researcher. The maximum amount of time that may be requested of me is 4 hours. I understand that I may decline to participate in these interviews at any time. I may be contacted to clarify information from the interviews.
- 3) keep a journal about any insights or experiences occurring between the first and second interview that are related to my experiences of music listening. I understand that this is an activity I can decline to do at any time. I also can decide whether or not to share this material with the researcher. The journal will remain in my possession.
- 4) agree to having all interviews audiotape recorded. I will receive a summary of the interview and have the option of reviewing the audiotapes for editing purposes. All meetings will be conducted at my convenience by pre-arranged appointments to meet at the University or at a field location more convenient for me.

Confidentiality:

I understand that portions of my interviews may be included in the final write-up of the study and I know that in this, or any other possible future use of the interview material, I will not be identified. All information I give will remain anonymous and confidential. I will be identified by a pseudonym that I may choose. Interviews will be audiotaped and transcribed. These transcriptions and tapes will be kept in a locked file at all times. Only the investigator and her supervisor will have access to these materials. The transcripts without any identifying information may be seen by research assistants for the purposes of analysis. After the study has been completed, the audiotapes will be destroyed. I also understand that my participation in this study is entirely voluntary and that I may refuse to participate and may withdraw at any time.

Appendix G

Illness Autobiographies

Crawford, J. (1991). Art and healing: An artist's journey through cancer. Vancouver, BC, Canada: Gallerie Publications.

A personal account of the author's experience with cancer and her use of painting during her treatment.

Frank, A. (1991). At the will of the body: Reflections on illness. Boston: Houghton Mifflin.

The author's reflections on his experience with chronic illness, following a heart attack and subsequent diagnosis of cancer.

Giroux, L. (1998). Taking the lead: Dancing with chronic illness. Kelowna, BC, Canada: Northstone.

A recounting of Louise Giroux's life with multiple sclerosis as revealed through the metaphor of dance.

Klein, B.S. (1997). Slow dance: A story of stroke, love, and disability. Toronto, ON, Canada: Alfred A. Knopf.

A personal account by filmmaker, Bonnie Klein, about her experience with a stroke that paralyzed her and left her to adapt to life with a disability.

McPhee, R. (1994). Picasso's woman: A breast cancer story. Vancouver, BC, Canada: Douglas & McIntyre.

A personal narrative about Rosalind McPhee's experience with breast cancer.

Olson, C.T. (1993). The life of illness: One woman's journey. New York: State University of New York.

A phenomenological work detailing the author's experience of life with kidney disease.

Register, C. (1987). Living with chronic illness: Days of patience and passion. New York: Free Press.

Based on her personal experience with Caroli's Disease (congenital defect of the liver), Cherie Register writes about how illness shaped her life and those of other people living with invisible chronic illnesses who she interviewed.

Wells, S.M. (1988). A delicate balance: Living Successfully with chronic illness. New York: Plenum Press

A personal account about living with multiple illnesses and the challenge of finding a balance. The perspectives of those touched by chronic illness are also included.

Appendix H

Other Sources of Data

Dictionaries:

- 1) Oxford concise dictionary of english etymology. (1996). England: Oxford University Press.
- 2) Oxford concise dictionary of music. (1977). England: Oxford University Press.
- 3) Oxford mini-dictionary. (1991). Oxford, England: Clarendon.
- 4) Websters's new dictionary and thesaurus. (1990). New Lanark, Scotland: Geddy & Gromet.

Books (Fiction, Quotations):

- 1) Exley, H. (1991). Music lovers quotations. New York: Exley Publications
- 2) Findley, T. (1995). The piano man's daughter. Toronto, ON, Canada: Harper Collins.
The protagonist is a young piano tuner who recounts the stories of his mother, his childhood, and his now pending fatherhood.
- 3) Seth, V. (1999). An unequal music. Toronto, ON, Canada: McArthur and Company.
The romance between two musicians—a violinist and a pianist—that involves an English quartet and its performance of a particularly difficult piece.
- 4) Wallace, S., & McKowen, S. (1996). A music lover's diary. Willowdale, ON, Canada: Firefly Books

Concert Series: 1999-2000 Fall Season of "Wednesday Noon Hours," UBC School of Music.

- 1) September 29, 1999—Rita Costanzi (harp) and Andrew Dawes (violin).
- 2) October 6, 1999—Silk Road Music with World Musical Guests, Celso Machado and Laurence Mollerup.
- 3) October 13, 1999—Vilma Vitols (Mezzo-Soprano) with Tara Morton (piano).
- 4) October 20, 1999—Vancouver Chamber Choir.
- 5) October 27, 1999—Continuum (Contemporary Chamber Music).
- 6) November 3, 1999—The Burney Ensemble.