WOMEN CONFRONTING THE REALITY OF MULTIPLE SCLEROSIS:

A QUALITATIVE MODEL OF SELF-HEALING

by

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ABSTRACT

Multiple sclerosis (MS) is a chronic debilitating disease that has an uncertain course. Although uncertainty is a universal experience in chronic illness, uncertainty in MS is especially threatening to psychological well-being. Chronic illness, including conditions of disability, is one of our greatest health care problems as society ages. Never completely cured, chronic illness forces people to adapt in order to cope with their new health status. Given these conditions, health educators will need to direct more attention to tertiary prevention and rehabilitation in health promotion and education. To help people cope effectively, educators will need to understand how people attempt to manage their lives with chronic illness.

Chronic illness is the human experience of suffering symptoms and distress. Healing is a personal experiential process of the transcendence of suffering. People transcend or move beyond suffering and integrate uncertainty into their lives by revising their life narratives to find new purpose, meaning, and acceptance of illness and the self with illness. In this context, self-healing is the tendency of human beings to bounce back from adversity through a desire to be effective in coping with their world even in the continuing presence of disease.

The purpose of this study was to explore the question: How do women with the chronic illness multiple sclerosis cope with the distress of MS and move through and beyond suffering into a proactive process of self-healing? This qualitative study

explored the phenomenon of self-healing and used grounded theory principles and methods to develop a theoretical model that provides an understanding of how the women coped with their illness and moved into a proactive coping and self-healing process.  Coding and analysis of the participants' interviews found that they employed strategies of living one day at a time, focusing on positive aspects of the experience, and redefining values.  Their efforts to change manifested in a need for autonomy, social support, and competence.  Stories and metaphors from participants' interviews can help health educators understand the meaning of their self-healing.  Health education approaches that use story and metaphor to facilitate and support individual self-healing are suggested.

To my beloved nephew
Matthew John Carl
1971-1994
In gratitude for your insight and wisdom

"What is the purpose of these too—few—many years if life?"

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ACKNOWLEDGMENTS

INTRODUCTION

Multiple sclerosis (MS) is a chronic, debilitating disease of the central nervous system that is thought to be autoimmune in nature. From the earliest recognition of MS, treatments have tried to work in three ways: (a) to reduce the seriousness of attacks, (b) to relieve symptoms, and/or (c) to try to change the disease process itself (Murray, 2005). Although no specific stimulus or agent has been identified, it is currently thought that MS is triggered by one or more viruses or bacteria in people with a genetic predisposition (Kalb, 2004). Even though great advances have been made in the treatment of MS, there is still no cure for the disease. The course of MS is unpredictable and uncertain. As compared to other chronic illnesses, MS is considered to be especially threatening to psychological well-being, with uncertainty being one of the most difficult aspects of the disease (Rao, Huber, & Bornstein, 1992; Reynolds & Prior, 2003; Rudick, Miller, Clough, Gragg, & Farmer, 1992).

In common usage, the concepts of disease, illness, curing, and healing tend to be merged into dyads that assume disease and illness are synonymous as are curing and healing. However, medical anthropologists make distinctions between the concepts (Swinton, 2001) and these distinctions are vital to understanding the concepts of healing and self-healing. *Disease* is the physical manifestation of a condition that includes symptoms and disability which is most often viewed by the medical practitioner using a pathophysiological model (Larsen, 2006; Swinton). In contrast to disease, *illness* is the

subjective, individual human experience of symptoms and suffering which includes how the disease is perceived, lived with, and responded to by individuals, their families, and society (Larsen).  In light of viewing disease versus illness, *curing* focuses on the eradication of physical disease processes, while *healing* distinguishes between disease and illness by focusing on the illness experience to provide personal and social meaning for problems caused by the disease (Swinton).  *Healing* views the illness experience as a person's ongoing life journey in which the person looks for ways to find enough meaning to maintain a sense of self, purpose, and direction, "irrespective of the presence or absence of distress and illness" (Swinton, p.57).  Healing has been defined simply as the personal experience of the transcendence of suffering (Egnew, 2005).  *Transcendence* is then the process of moving beyond the illness by accepting what is happening and finding new meaning and purpose in one's life (Egnew).

*Chronic illness,* by its very nature is never completely cured, therefore, people are forced to adapt to their new health status.  *Coping* is an adaptive process involving what a person thinks and does to try to manage the internal and external demands of an emotional encounter through the appraisal or evaluation of the encounter as personally significant and stressful (Folkman & Lazarus, 1980; Folkman & Moskowitz, 2004; Lazarus, 1991; Lazarus & Folkman, 1984).  Coping is a complex, multidimensional process because it is sensitive to the environment and its demands and resources, and to the personality disposition of the individual that influences the appraisal of stress and the resources for coping.  In this context, *self-healing* is a self-righting process that includes both the tendency of human beings to bounce back from adversity and a desire to be

effective in coping with their world even in the continuing presence of disease (Bohart & Tallman, 1999).

Diverse practices, as forms of healing, are recognized by their common concern to alleviate suffering, prolong life, and reduce disability (Kirmayer, 2004). Suffering involves more than coping because it asks for attempts to control one's life as well as to cope with it (Morse & Carter, 1996). Suffering is an unpleasant experience reflecting a sense of helplessness (Chapman & Gavrin, 1993) that results from a loss of certainty and loss of control which may include the loss of bodily control and personal autonomy (Charmaz, 1999). The loss of certainty encompasses the loss of a "taken-for-granted future" and the "personal belief in sustained health" (Charmaz, p. 366). While suffering may begin in the body, it also affects the social sphere. Chronically ill individuals may not be aware of how much they suffer while they attend to other pressing needs and obligations, and let other people take priority in their lives (Charmaz, 1999; Morse & Carter, 1996).

Being diagnosed with a chronic disease influences the current roles of the person who may now need to incorporate new knowledge and alter behavior in order to define the self in a new social context (Larsen, Lewis, & Lubkin, 2006). Therefore, when people receive a chronic illness diagnosis, they and their families often need information, understanding, and competent intervention to successfully adapt to the life changes imposed by their illnesses (Sullivan-Bolyai, Sadler, Knaffl, Gillis & Ahmann, 2003). Successful adaptation to chronic illness "includes the conviction that a meaningful quality of life is worth the struggle" (Larsen, 2006, p. 9).

When individuals are confronted by a stressful event, such as a diagnosis of having a chronic illness, they begin a coping process that is a response to an appraisal that important life goals have been threatened, harmed, or lost through the effects of this stressful life event (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). Coping occurs within a complex, dynamic stress process that involves the person, their environment, and the relationship or transaction between them. Therefore, context must be taken into consideration when examining coping. A contextual approach guides much coping research which holds that various coping processes are inherently neither good nor bad. Rather, the adaptive role of the coping process needs to be assessed within the specific context of stress in which it is being used (Folkman & Moskowitz).

In the past, coping was seen mainly as a *reactive* strategy to deal with the pathology of stress produced by something that had already occurred (Folkman & Moskowitz, 2004; Greenglass, 2002). Reactive coping is directed at compensating for a loss or alleviating harm done by something that has already taken place. More recently, a type of coping, seen as *proactive*, is viewed as something an individual can do even before stress occurs (Folkman & Moskowitz; Greenglass). *Proactive coping* is a forward-looking, multidimensional positive approach to dealing with stress. Proactive coping is more future-oriented and as such is an effort to build up resources that help promote the creation of challenging goals and personal growth.

In confronting a stressor such as a chronic illness, people engage in processes of coping that often involve meaning-making and, in fact, coping is increasingly seen as having multiple positive functions, paralleling the recent interest in positive psychology and the relationship between health and the life well-lived (Greenglass, 2002; Keyes &

Haidt, 2003).  The expanding field of coping includes positive striving, emotions, and the search for meaning (Folkman & Moskowitz, 2004; Keyes & Haidt; Park & Folkman, 1997).  In the illness experience, finding a new sense of meaning and purpose in their lives helps people move beyond or transcend their distress and suffering by no longer opposing it and accepting what is happening (Charmaz, 1991; Egnew, 2005).  Healing becomes a person's journey to find enough meaning to maintain a sense of self, purpose, and direction even in the presence illness (Swinton, 2001).

Healing reconciles the meaning an individual gives to distressing events with his or her own perception of wholeness as a person (Egnew, 2005).  In the present study, *healing* is defined as a dynamic personal experiential process of moving beyond the suffering and distress caused by the chronic illness multiple sclerosis and achieving some level of wholeness as a person.  *Wholeness* lies in the coherence of the physical, emotional, intellectual, social, spiritual, and environmental elements of the person and their human experience (Egnew; Quinn, 2000).  Healing is then seen as the emergence of right relationship or coherence among the parts, the way in which the parts are in relationship to each other, that increases energy and creativity (Quinn, 1997).  Overall, the healing and coping processes appear to relate to each other.  Then *self-healing* may be seen as a positive mode of coping because self-healing implies that when there is some disruption in the integrity of the life process, individuals begin a process of restoring that integrity by confronting and mastering problems even when they involve pain, rather than engage in defensive, avoidant methods of adaptation (Bohart &  Tallman, 1999).

The basic question that health educators need to ask is: "What experiences contribute to positive life satisfaction in illness?"  (Reynolds & Prior, 2003, p.  1226).

Pinzon-Perez (2005) suggests that professional development agendas for health education need to address holistic health and integrative healing. In both the general population and people with MS, studies have shown that the most important motivation for using integrative therapies is people's desire to participate actively as partners in their own healing process (Carlson & Krahn, 2006; Winterholler, 1997).

Chronically ill individuals are beginning to be viewed as the "experts" on their illnesses as people are coming to see themselves as partners in their own healthcare and become more vocal and participative in their treatment (Larsen, Lewis, & Lubkin, 2006, p. 32). By acquiring knowledge of the chronic illness experience through interaction with chronically ill individuals, health professionals can help clients cope and adapt more effectively to the effects of the disease. Health educators can help individuals to cope and adapt by not only providing knowledge, experience, and skills, but also by assuming the role of advocate for the individual's autonomy and freedom to exercise self-determination (Curtin, 1979; Gadow, 1990; Hummel, 2006). With knowledge and advocacy providing the possibility for choice and control in their self-care, people are empowered to make informed decisions affecting their health and other needs (Zerwekh, 2000).

Even though the self-healing process begins with the individual, the health educator's ultimate role is to provide the proper environment for supporting the individual's efforts because every healing effort and intention in an optimal healing environment starts with the health professional (Schmidt, 2004). As our society ages and chronic illnesses, including disabling conditions, increase in prevalence, attention in the health field is more often directed to rehabilitation and health promotion (Stuifbergen,

Seraphine, & Roberts, 2000).  While there is much nursing literature on the concept and process of healing, it has continued to focus primarily on the professional as the healer rather than on the healee's or patient's role (Zahourek, 2005) as a proactive participant and self-healer.  In an effort to define the ill person's role in healing, the purpose of this qualitative study was to understand how the women with multiple sclerosis coped everyday with the distress imposed by chronic illness and moved through suffering to a proactive and positive self-healing process.

The first chapter is a qualitative study that used grounded theory principles to develop a theoretical model to describe the phenomenon of the self-healing process in women with multiple sclerosis.  The women were found to be using proactive coping strategies to confront the reality of living with their MS on a daily basis as they struggled with acceptance of the illness and the image of self with illness.  This model provides a framework for integrating healing and self-healing into the practice of health promotion and education.  The framework can be used as a basis for developing health education interventions to facilitate the individual coping and self-healing process.

The second chapter identifies and explores the metaphors that emerged from the participants stories in the qualitative interviews from chapter one.  Because metaphors convey meaning, motives, and understanding and can play a role in facilitating developmental change, the women's metaphors are analyzed for underlying themes and meanings.  Due to the loss of body function and self-concept, people with chronic illness suffer (Charmaz, 1991, 1999).  However, many talk about their pain and problems while limiting their stories to specific events and situations without using the word suffering.  To tell one's story in one's own voice has a healing power (Braud, 1998) that is evident

in the metaphors of the women who achieved varying levels of self-healing in their proactive coping efforts. Interviews and narratives about one's own life obtained from individuals with MS have located positive turning points in the process of reconstructing their identity are associated with finding new purpose and meaning in life (Monks & Frankenberg, 1995). Therefore, it would be beneficial to develop health education interventions that encourage people to tell their stories, to identify metaphors, and to explore their metaphors for meaning.

The third chapter presents an application suggestion for health educators and other health care professionals in facilitating the process of proactive coping and self-healing in people with chronic illness. Because chronic illnesses such as MS create disorganization in people's lives, they are forced to adapt to an altered body and life (Paterson, 2001). People use metaphors when they tell personal stories to create meaning, purpose, and coherence for disruptive experiences (Baumeister, 1991; Charmaz, 1995, 1999; McAdams, 1993). The metaphors examined emerged from stories in qualitative interviews with women who have MS and were identified in the study in Chapter 2. A model of the women's coping and healing process that incorporates their metaphors and meanings was developed. To help facilitate, nurture, and support individual coping and integrative self-healing, a dialogical and collaborative health education approach that encourages the use, identification, and exploration of metaphor and story is suggested.

Health educators need to ask what experiences and environments they can create to facilitate a positive coping and healing process. Specifically, we need to ask ourselves what the individuals need from health educators and other health professionals. What do

the individuals themselves bring to the coping and healing process in adapting to MS? What is their process? Before we can answer these questions, we need to understand how these individuals engage in the coping and healing processes. In order to understand the relationship of social, emotional, and mental events and physical behavior to healing, we need to identify patterns of involvement or engagement in individuals (Cunningham, 2001) who are coping with chronic illness.

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CHAPTER 1. WOMEN CONFRONTING THE REALITY OF MULTIPLE

SCLEROSIS: A QUALITATIVE MODEL OF SELF-HEALING

Abstract

This qualitative study investigated how women with multiple sclerosis (MS)
coped proactively with the limitations imposed by their chronic illness and moved into a
self-healing process. Three coping strategies of living one day at a time, focusing on
positive aspects of the experience, and redefining values emerged from the coding and
analysis of semistructured interviews with eight women. The women's responses and
stories offer a picture of how the women played an active role in their own healing
process as they coped day to day with their illness. A theoretical model emerged that can
inform the creation of interventions by health professionals for the facilitation of the
individual proactive coping and self-healing process.

Multiple sclerosis (MS) is a debilitating disease of unknown cause that affects
the central nervous system and that is, at present, incurable (Murray, 2005). The
deterioration and loss of mobility, visual acuity, cognitive functioning, continence, and
energy levels that characterize MS often follow an uncertain and unpredictable course
(Reynolds & Prior, 2003). The uncertain and the unpredictable course of MS that is
marked by remissions, exacerbations, and increasing disability contribute to a level of
emotional distress that is higher in MS than in other chronic illnesses (Gulick, 2001).

Although uncertainty has been described as a universal experience in chronic illness (Mast, 1995; Mishel, 1999), uncertainty becomes a "constant companion" (Mishel, 1999, p. 269) in MS and the higher levels of depression as compared to other chronic illnesses leads to uncertainty being one of its most difficult aspects (Miller, 1997; Stuifbergen & Rogers, 1997). Therefore, the uncertainty of MS is especially threatening to a sense of well-being and psychological health (Rao, Huber, & Bornstein, 1992; Reynolds & Prior; Rudick, Miller, Clough, Gragg, & Farmer, 1992).

Uncertainty creates a period of great disorganization in which a person's view of self and reality falls apart (Mishel, 1999). With each new bodily impairment, people repeatedly experience losses of control, certainty, identity, and future expectations that result in a loss of unity of body and self, leading to distress and suffering (Charmaz, 1995, 1999). Adapting successfully to an impaired body means living with illness without living solely for it. Earlier theories focused on the management and elimination of uncertainty in chronic illness (Mishel). However, successful adaptation means defining integration and wholeness of being while simultaneously experiencing loss and suffering. When Mishel (1990, 1999) reconceptualized the theory to focus on how the integration of uncertainty can occur in one's life, uncertainty then became a force leading to a new life perspective through a gradual, nonlinear process to personal growth.

Although there is a body of literature that focuses on the physical impact of MS and how various psychosocial factors interact with depression and disability in people with MS, research studies focusing on the strengths and competencies of MS patients, and on how coping promotes positive psychological states is lacking (Kirkpatrick Pinson, Ottens, & Fisher, 2009; Pakenham, 2006). Few studies seek to determine whether there

are commonalities in the coping experience of various individuals with MS (Kirkpatrick Pinson et al.). Regarding healing, the focus in the literature is mainly from the field of nursing and has been on the role of the health professional as healer (Zahourek, 2005) rather than on the role of the ill person as a proactive agent in a self-healing process. This study sought to explore and explain how the women played an active role in their own healing process by identifying their strengths and competencies and their common coping strategies that promoted positive psychological perspectives.

*The Chronic Illness Experience*

Living with chronic illness has often been described as a phased process with a predictable trajectory. However, the overall perspective of chronic illness contains elements of both wellness and illness. In the Shifting Perspectives Model of Chronic Illness (Paterson, 2001), the experience of chronic illness is portrayed as an ever-changing perspective of wellness-in-the-foreground or illness-in-the-foreground. Both perspectives have specific functions in the person's world and enable people to make sense of the experience.

A perspective represents experience, beliefs, perceptions, expectations, and attitudes about what it means to be a person with an illness in a specific context (Paterson, 2001). Perspectives of chronic illness determine how people respond to the disease, themselves, other people, and situations that are affected by their illness, such as a job or a career path. Whether or not illness is as significant and present as perceived by the individual is irrelevant. What matters most in determining how people interpret and respond to illness is the individual's perception of reality, not the reality itself.

Illness in the foreground has a protective and utilitarian function (Paterson, 2001) because it helps a person learn about, reflect upon, and come to terms with the disease, especially, early in the overall experience. Paradoxically, it may be necessary to keep illness in the foreground to get medical attention and to manage the disease so that it may be kept in the background. The person must recognize the disease as a fact of life while at the same time rejecting its limitations and significance. Although the disease recedes to the background, the wellness in the foreground perspective creates a major paradox for the individual because the management of the disease must still be foremost in the person's mind (Paterson).

The wellness in the foreground perspective allows people a means for reconciling themselves to the physical effects of their disease (Paterson, 2001). Being positive is essential to the wellness perspective. However, people with chronic illness often must face overwhelming losses or suffering. The shift to wellness occurs in the individual's thinking which allows the individual to focus away from the disease. This shift makes it possible for the individual to appraise the illness as an opportunity for meaningful change in relation to self-identity and their identity shaped by the illness, as well as in the individual's relationships with environment and other people. The self rather than the body with disease becomes the source of identity. This perspective is not a distortion of reality but allows the person to see what is possible. Then the person learns to live with the disease and its effects by becoming a "creator of circumstances" instead of a victim (Barroso, 1995, p. 44).

Learning to live with chronic illness in both social and personal contexts unfolds as people develop and accumulate strategies "to get through the day" (Charmaz, 1991,

p. 136).  As illness progresses, people's conditions change and they need to constantly revise their strategies.  Progression is not always linear but consists of both smooth and rough stretches, good days and bad days (Charmaz; Paterson, 2001).  Illness remains in the background during smooth stretches and moves into the foreground during rough times such as exacerbations (Charmaz; Paterson).

Chronic illness becomes intrusive when symptoms interfere with daily routines and activities (Charmaz, 1991).  Symptoms or exacerbations can increase self-awareness allowing people to make some sense of the intrusive illness.  This, in turn, may allow them to be successful in minimizing the effects of the intrusion of illness upon their lives so that they can function more effectively.  Therefore, even though exacerbations remain unpredictable, the illness overall becomes predictable because people learn to expect their symptoms, to accommodate them, and to plan their days around them.

Success in accommodating and minimizing intrusion depends on managing stress by managing the illness and the regimen it imposes (Charmaz, 1991).  Coping by living one day at a time provides a way for managing oneself while facing uncertainty because it helps alleviate negative emotions and the sense of being overwhelmed by the illness because it brings some sense of control over the day, over the situation, and over one's actions.  People may then feel they have made some improvement and are successful in their struggle against illness.  Individuals must deal with things each day to control them as best they can by concentrating on the present while often letting go of rigid plans involving activities, goals, and obligations.  For health professionals to better understand chronic illness and how people cope successfully with it, it is important to distinguish illness from the physical disease that produces the illness experience.

*Disease, Illness, and Self-Healing*

In common usage, the concepts of disease, illness, curing, and healing tend to be merged into dyads that assume disease and illness are synonymous as are curing and healing. However, medical anthropologists make distinctions between the concepts (Swinton, 2001) and these distinctions are vital to understanding the concepts of healing and self-healing. *Disease* is the physical manifestation of a condition that includes symptoms and disability. *Illness* is the subjective, individual human experience of symptoms and suffering that consists of the social and personal consequences that emerge from the presence of the physical disease (Swinton), including stigmatization by others, loss of one's former identity and sense of self, and a sense of diminished self-worth (Charmaz, 1991, 1995). In this context, *self* is synonymous with self-concept (Charmaz, 1991). A *self-concept* means the relatively stable, coherent organization of characteristics, attributes, attitudes, feelings, and opinions that a person holds about herself (Charmaz; Gecas, 1982; Turner, 1976).

The commonly used medical model focuses on curing and control in the eradication of physical disease processes leading to a compartmentalization of the individual rather than on exploring ways to restore the person to wholeness (Larsen, 2006; Swinton, 2001). In contrast, *heal* means "to make whole" from the root, *haelan*, the condition or state of being whole (*Webster's Encyclopedic Dictionary*, 1994). *Healing* distinguishes between the physical disease and the personal experience of illness by focusing on the illness experience to provide personal and social meaning for problems caused by the disease (Swinton). Healing views the illness experience as a person's ongoing life journey in which the person looks for ways to find enough meaning

to maintain a sense of self, purpose, and direction, "irrespective of the presence or absence of distress and illness" (Swinton, p.57). Healing has been defined simply as the personal experience of the transcendence of suffering (Egnew, 2005). *Transcendence* is then the process of moving beyond the illness by accepting what is happening and finding new meaning and purpose in one's life (Egnew).

*Self-healing* is a self-righting process that includes both the tendency of human beings to bounce back from adversity and a desire to be effective in coping with their world (Bohart & Tallman, 1999). Self-healing refers to the human capacity to recover from emotionally injurious experiences and to change dysfunctional life pathways by changing ways of being, behaving, and experiencing so that a person moves toward greater functionality and coherence or wholeness. However, not all people will automatically move toward more wholeness and personal growth. If their lives are reasonably functional from their point of view, they may solve the small immediate problems but not make any major changes in who they are or how they live and cope with life (Bohart & Tallman).

A chronic illness such as MS causes people to experience a major change and disruption in their sense of wholeness of body and self characterized by great loss and feelings of isolation (Charmaz, 1995, Egnew, 2005). A sense of *wholeness* in human experience lies in the coherence of people's physical, emotional, intellectual, social, environmental, and spiritual elements (Egnew; Quinn, 2000). To be whole again means to be in relationship to your body, to your culture, and to others, rather than being isolated or separated from self, society, and others (Egnew).

In this study, *self-healing* is a dynamic and proactive experiential process that is driven by the chronically ill individual. The process allows the individual to transcend or move beyond suffering and distress caused by the illness and involves movement toward wholeness as a person (Egnew, 2005). Wholeness in self-healing is then seen as the emergence of right relationship or coherence among the parts that leads to an increase of energy and creativity (Quinn, 1997). The human capacity for self-healing arises from a capacity for change when needed by developing new ways of being and behaving through creative and productive thinking (Bohart & Tallman, 1999). The human capacity for self-healing arises from a overall desire to be effective in coping with the world.

*Coping*

*Coping* involves what a person thinks and does to try to manage the internal and external demands of a stressful emotional event (Folkman & Lazarus, 1980; Folkman & Moskowitz, 2004; Lazarus, 1991; Lazarus & Folkman, 1984). The transactional theory of stress views a stressful event or situation as a *transaction* by emphasizing the continuous, reciprocal nature of the interaction between the person and the environment (Lazarus; Schwarzer & Taubert, 2002). Lazarus distinguished between *problem-focused* and *emotion-focused* coping. The former involves addressing the problem causing stress, such as making a plan of action (Folkman & Moskowitz). The latter aims at relieving negative emotions associated with the problem by engaging in distracting activities that may be either negative or positive, such as using drugs or alcohol, or seeking social support. More recently, Park and Folkman (1997) have identified *meaning-focused* coping as distinct from problem- and emotion-focused coping and emphasize the role of meaning-making processes in the individual's interaction with the environment.

Although coping research is very complex, it holds "great promise for explaining who thrives under stress and who does not . . . and for informing effective interventions to help people better handle both acute and chronic stress" (Folkman & Moskowitz, p. 768).

Because MS as a chronic illness is never completely cured, people are forced to change or adapt previous roles to accommodate their new health status and social expectations (Larsen, 2006). When individuals are confronted with a chronic illness diagnosis, they begin a coping process that is an adaptive response to their appraisal or evaluation that important life goals have been threatened, harmed, or lost through the effects of this stressful, emotional event (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). Successful coping implies that the individual acknowledges impairment or loss of bodily function and alters life and self to accommodate to physical losses and to reunify body and self. Successful coping also "includes the conviction that a meaningful quality of life is worth the struggle" (Charmaz, 1995, p. 9).

Seen as a transaction between the person and the environment, coping is affected by the personality disposition of the individual that influences the appraisal of stress and the resources for coping meaning that a stressful event or situation may be perceived in different ways by different individuals (Lazarus, 1966). These subjective perceptions are considered to be the main determining factor that affects the subsequent behaviors and health status of the individual. The appraisal determines the quality of the individual's emotional response and the ways in which the individual copes after making an appraisal. The overall impact of the stressful event is mediated by the person's appraisal of the stressor and the psychological, social, and cultural resources that the person is able to call upon in the coping process (Lazarus, 1991).

Previously seen as a *reactive* strategy to compensate for a loss or to alleviate harm that has already taken place, coping is now seen as *proactive* or as something an individual can do before stress occurs (Folkman & Moskowitz, 2004; Greenglass, 2002). *Proactive coping* is a forward-looking, multidimensional positive approach to dealing with stress that is an effort to build up resources and to help promote the creation of challenging goals and personal growth. Although different people have different ways of being, living, and healing, what proactive self-healing people have in common is that they are agents in their own change and they take deliberate steps in a struggle to make their lives better (Bohart & Tallman, 1999).

Using the precursors of change model (Hanna, 2002), Kirkpatrick Pinson et al. (2009) showed that an individual can have a positive experience with MS when they examined how women coped successfully with primary progressive MS. Their findings confirmed that three precursors, including confronting the problem, effort or will toward change, and awareness, seem to be very powerful in creating favorable conditions for helping individuals cope successfully with MS. In the coping process, self-healing people are capable of choosing their own goals, of planning and initiating action to accomplish those goals, and generally prefer the behavioral freedom associated with a proactive, positive approach rather than rely on defensive, avoidant solutions (Bohart & Tallman, 1999; Hanna).

*Proactive Coping as Acceptance and Transcendence*

For most people the effects of chronic illness fall somewhere between loss of self and transcendence of self that includes small victories, major comebacks, and repeated tests of self (Charmaz, 1973, 1983; Denzin, 1986). Both loss and transcendence emerge

from the experience of illness and the respective meanings that people give to illness. In fact, people may experience both loss and transcendence, although at different points in their illness (Charmaz, 1991). Loss of self means losing one's self-definitions (Charmaz) or losing "what it means to be yourself" (Egnew, 2005, p. 257). However, suffering a series of physical, psychological, and social losses, while at the same time facing them head on, often gives ill people a sense of having faced the worst and transcended it (Charmaz). Transcendence then means moving beyond the illness by accepting one's status without struggling, envy, sorrow, or anger (Charmaz; Kubler-Ross, 1969), by accepting what is happening now, and finding new meaning and purpose in one's life (Egnew).

Transcendence includes the acceptance of illness and self with illness, both now and in the future, with the definition of self depending on more than the body and the illness (Charmaz, 1991). Transcendence contrasts with reconciling oneself to illness only to the extent possible in the present but never really accepting it as part of the future. When people adapt by trying to accommodate and flow with the experience of illness, "adapting shades into acceptance" (Charmaz, 1995, p. 657). Although people suffer bodily losses, they gain a new definition of self through a deeper level of awareness. Through transcendence, paradoxically, "the self is of the body yet beyond it" (p. 675). In an examination of stress and coping antecedents in MS, Pakenham (2006) found acceptance to be the strongest and most consistent predictor of positive outcomes and levels of distress.

People have different styles of dealing with chronic intrusive illness, such as MS, which emerges from their degree of acceptance of the illness and the meanings that they

attach to illness regarding self and identity (Charmaz, 1991). Rather than make illness their reason for living, people who incorporate or integrate illness recognize its presence, take it into account, and live *with* illness as they work around it (Charmaz) which is a sign of self-healing (Bohart & Tallman, 1999). Others work at keeping illness contained by "packaging" or treating illness as if it is controlled, delimited, and confined to specific circumstances (Charmaz, p. 66). They may question whether their physical condition is an illness at all, thereby trying to separate it from their lives and to detach it from self-concepts. Keeping illness tightly packaged relieves a person of the necessity of facing illness directly.

The strategy of containing illness may be effective for a person as long as they experience no exacerbations. However, acceptance and moving beyond or transcending the distress caused by illness in the process of self-healing becomes possible only when people reflect upon and confront the reality of their problems (Bohart & Tallman, 1999; Charmaz, 1991). Furthermore, people are capable of retaining a sense of transcendence or having moved beyond their illness even after great or repeated loss when they believe that they can still make autonomous choices despite diminished possibilities and when they can retain or create self-respect (Charmaz).

*Transcendence and Autonomy*

The struggle for control of self in illness is a struggle for balance and against loss, and, sometimes, for transcendence (Charmaz, 1991). Others can support transcendence by encouraging ill people to reflect and to define a valued self beyond the debilitated body. Others can foster self-respect in ill people by supporting their choices and demonstrating respect towards them. However, relative loss and transcendence of self

also depend on autonomy. The self-respect and autonomy in transcendence represent a trust in oneself and in one's sense of internal and external realities.

Transcendence through acceptance includes a process of reevaluation and depends on autonomy that means making independent choices and taking actions based upon reason (Charmaz, 1991). Voluntarily relinquishing control in certain areas to preserve autonomy can help ill people maintain valued aspects of self, create new meaning, and produce a deepened sense of self-knowledge. Through the experience of struggling for control of self-defining images and then abandoning conventional symbols of control and success, ill people may gain autonomy. Then the stories of their illness may shift from stories of loss to stories of transcendence.

People who can transcend their environment are able to rise above other people's opinions as they listen to their inner voices (Maslow, 1968). Therefore, transcendence often requires the rejection of the traditional symbols of productivity, accomplishment, and success held by society (Charmaz, 1991) while looking within oneself for guiding rules and values to live by (Maslow). Transcendence is not a rejection of prior experience but is founded upon and integrates all that came before (Maslow).

Overall, humans are inclined to integrate their experiences and to internalize within themselves the regulation of activities that were initially prompted by external factors in an effort to move toward a relative personal and interpersonal coherence or sense of wholeness (Deci & Ryan, 2000, 2008a). Integration is the transformation through which extrinsically motivated behaviors become truly autonomous or self-determined. In Self-Determination Theory (SDT), autonomy, competence, and relatedness are postulated to be three innate psychological needs necessary for the

effective functioning and ongoing psychological growth and well-being in human beings as they proactively interact with their environments (Deci & Ryan, 2000). *Competence* relates to people's feelings of curiosity, challenge, and sense of personal efficacy (La Guardia, Ryan, Couchman, & Deci, 2000). *Relatedness* concerns feeling connected with and cared for by another person in a relationship marked by stability and positive or pleasant personal interactions (Baumeister & Leary, 1995; La Guardia, et al.; Ryan, 1993). *Autonomy* is related to feelings of agency and volition (La Guardia, et al.) and consists of people's striving to feel that they are the origin of their own actions and that they have input into determining their own behavior (Deci & Ryan, 1991). Contexts

The essence of autonomy in SDT concerns the experience of integration and freedom but it is often incorrectly equated with the ideas of independence or individualism (Deci & Ryan, 2000). However, autonomy, unlike independence, does not equate with "being subject to no external influences" (La Guardia, Ryan, Couchman, & Deci, 2000; Ryan, 1993, p. 10). Within SDT, people may choose to exercise *autonomous interdependence* or *autonomous dependence* by freely choosing to depend on others or to be independent of them (Deci, La Guardia, Moller, Scheiner, & Ryan, 2006).

However, autonomy that is defined by *rigid* separation between self and others reflects an insecurity in one's own identity so that a person fears losing oneself and cannot risk entering into another person's reality (Keller, 1985). This *reactive autonomy* is the tendency to be reactively opposed to any outside influence on one's behavior even if it is positive. Keller's concept of dynamic autonomy means a person is secure and able

to be both with and apart from others with equal comfort and security in one's own selfhood.

Reactive autonomy contrasts with the reflective autonomy of SDT in which autonomous behaviors are those that are initiated and regulated by choices based on an awareness and reflective evaluation of one's needs, interests, feelings, and integrated goals in light of possible options (Koestner & Losier, 1996). Within SDT, people may choose to be autonomously dependent or interdependent. They may freely choose to depend on others or to be independent of them (Deci, La Guardia, Moller, Scheiner, & Ryan, 2006). Research has shown that persons high in reflective autonomy were willing to follow expert advice, whereas those high in reactive autonomy moved away from others' influences, even to their detriment (Koestner et al., 1999).

Furthermore, SDT distinguishes between autonomous motivation and controlled motivation (Deci & Ryan, 2008b). Autonomous motivation includes intrinsic motivation and well-internalized extrinsic motivation, in which people have identified with the inherent value of an activity and ideally have integrated it into their sense of self. Controlled motivation and control-determined behaviors are initiated and regulated by controls in the environment, such as rewards, or by internally controlling imperatives of how one "should" or "must" behave and involve contingent self-esteem and/or avoidance of shame (Koestner & Losier, 1996). In studies, autonomous motivation or regulation has consistently been associated with greater persistence, more positive affect, healthier lifestyles and behaviors, and higher levels of psychological well-being (Deci & Ryan, 2008a).

As health educators, we need to ask why some people can transcend the loss of bodily function through impairment and the accompanying loss of identity and self associated with chronic illness (Charmaz, 1991)? Also, how can we facilitate proactive coping that leads to acceptance, autonomy, and transcendence? The overall purpose of this exploratory study was to make a beginning by answering the question: How do women with the chronic illness multiple sclerosis cope everyday with the distress of MS and move through suffering into a proactive process of self-healing?

## Methods

A qualitative method of inquiry was chosen for this study because qualitative research focuses on what people experience and how they interpret the world (Polkinghorne, 1983). Qualitative strategies are also especially appropriate to address the meanings and perspectives of the participants and offer access to human process (Hoshmand, 1989). A constructivist approach assured that priority was placed on a phenomenon of interest, i.e., coping as self-healing. The approach views data and analysis as created from shared experiences and relationships with participants and other sources of data (Charmaz, 2006).

Some grounded theory concepts and strategies were used to develop an emergent theory and conceptual model to describe the phenomenon of the self-healing process in the women with MS. The model allowed me to better understand participants' experiences by placing emphasis on examining processes, making action central to the study, and creating abstract interpretive understandings of the data to explain the actions that people take in response to their environment and situation (Charmaz; Strauss & Corbin, 1990). The emergent theory and model can provide a framework for action

(Strauss & Corbin) in helping health educators and other health care professionals develop interventions that facilitate and support the proactive coping and self-healing processes of individuals with chronic illness.

*Participants*

The study participants were seven Euro American women and one African American woman, ages 30 to 66 years, time since MS diagnosis 5 to 36 years, and length of time waiting for diagnosis less than 1 month to 20 years.  Inclusion criteria included a limit on time since diagnosis to at least 2 years because the diagnosis of a chronic disease or the onset of new symptoms "forces" a person to focus on the illness, learn about it, and come to terms with it, only later being able to focus also on healing through coping (Paterson, 2001, p. 23).  Participants also had interactions with a neurologist and were actively involved in at least one social or professional activity, e.g., an exercise program, working in a job, volunteering with an organization or group, and/or taking a class. Seven of the women had the relapsing-remitting form of multiple sclerosis.  One woman, the complementary case discussed below, had suffered only one significant exacerbation and was not definitively diagnosed with relapsing-remitting MS.

*Researcher as Instrument*

The heart of qualitative research is to develop an understanding of people's actions within a sociocultural context (Morrow & Smith, 2000; Charmaz, 2006).  The researcher becomes a part of the world she studies and the data she collects.  Theories are constructed through past and present involvement and interaction with research practices people, and perspectives (Charmaz).  Theoretical sensitivity is a researcher attribute that

brings together interpersonal perceptiveness and conceptual thinking exhibited in an

overall posture of *reflexivity* or self-reflection on the part of the researcher (Fassinger,

2005). A vital aspect of the reflexivity process is that I, as the researcher, make clear my

biases (Morrow, 2005).

*Immersion in the setting.* Entering into the participants' social worlds made it

possible for me to form relationships with participants which helped me formulate

interview questions that were relevant (Morrow & Smith, 2000). It also provided a

background for viewing the data that adds to the complexity of understanding of the

phenomenon of interest. Establishing rapport with participants and respecting their

perspectives and practices (Charmaz, 2006) increases trust and openness which elicits

better data (Morrow & Smith). Such intimacy with the world of the participants may lead

to bias.

*Personal background and interests of the researcher.* In qualitative research, bias

is seen as an inevitable, positive aspect of the process (Morrow, 2005). However,

identification of biases and assumptions plays a critical role in lending credibility to

qualitative methodology (Morrow & Smith, 2000). In fall 2005, I took part in a pilot

study in which Tai Chi was taught to people with MS who participate in an exercise

program in Physical Therapy (PT) at the University of Utah (DeMille, Gappmaier,

Trunnell, & Romagosa, 2007; Trunnell, Romagosa, DeMille, & Gappmaier, 2007). I

interviewed nine participants and transcribed eight interviews. In fall 2006, I conducted

an independent study with members of this group to observe their casual social behavior.

I attended some monthly lunches of the exercise group and met informally with several of

the participants, one of whom became my gatekeeper to this MS community. Already

interested in the idea of "healing" as opposed to "curing" because of involvement in an Integrative Health Network, I believed that this population would be excellent for examining the phenomenon of healing.

*Managing bias and subjectivity.* To manage my bias, I kept analytic and self-reflective notebooks which allowed me to examine my biases and put them aside or consciously incorporate them into the analysis (Morrow, 2005). The practice of self-awareness and self-reflection ensured that the meanings reported are those of the participants and not mine (Morrow & Smith, 2000). *Participant checks*, intended to establish trustworthiness, were conducted after analysis of data was begun and ensured that my interpretations reflected the participants' meanings and not my own (Lincoln & Guba, 1985).

*Trustworthiness.* Trustworthiness, which is compared to the traditional validity applied to quantitative studies, is the conceptual and analytical soundness of a qualitative study (Fassinger, 2005). To ensure trustworthiness, five participants did follow-up interviews to clarify and confirm data from earlier interviews and to critique and confirm my interpretations. Participant checks allow the researcher to share categories and to seek feedback and confirmation on the accuracy of researcher interpretation of the data for results (Charmaz, 2006; Morrow & Smith, 2000; Patton, 1990). All participants were sent an interpretive summary of their overall process in coping with MS along with a request to critique the summary. Additionally, I met with two other student researchers as a peer debriefing team to review and analyze data as well as to critique and corroborate codes and categories (Lincoln & Guba, 1985). They read transcripts and reviewed

interpretations, including the various iterations of the emerging model of the participants' coping and healing process.

*Procedure*

*Sampling and recruitment.* I gained entry into the MS community during participation as a research assistant the MS Tai Chi study described above. Participants were first selected using purposeful sampling to find people who could provide the researcher with rich information about the central research interest (Charmaz, 2006). Two participants from the Tai Chi study volunteered for the present study and were the purposeful sample. Two additional participants from this group were identified through snowball sampling (Patton, 1990). One participant was a personal friend of mine and three participants were referred by people who knew others with MS who met the inclusion criteria. Possible participants were recruited through an introduction letter describing the study, which included informed consent forms that had been reviewed by the University of Utah IRB. Consent forms were either mailed to me or signed at the initial interview session. In order to protect confidentiality, participants were identified in the research records using numbers, e.g., Participant 1 or P1. Pseudonyms were used in the final reports.

*Theoretical sufficiency and constructing theory.* Participant recruitment in this study was stopped after interviewing eight women because I believed that theoretical sufficiency had been reached. Dey (1999) prefers the term *theoretical sufficiency* as opposed to "saturation" to denote the appropriate point at which partial coding and participant recruitment can be stopped because it better fits how researchers use grounded theory methods. He points out that grounded theorists produce categories through partial,

not exhaustive, coding. Therefore, the decision to no longer collect data is a judgment that the investment of time will no longer produce a "likely (theoretical) reward" (p. 117) and that this not the final word but only "a pause in the never-ending process of generating theory" (Glaser & Strauss, 1967, p. 40).

Generating and constructing theory is not a mechanical process (Charmaz, 2006). Theorizing requires seeing possibilities and establishing connections as the researcher questions the data and her own research process and analysis. Categories result from the participants' objectives and actions rather than being attributed to certain individuals. Therefore, theorizing places emphasis on actions and processes rather than on individuals as a strategy in constructing theory in order to move beyond categorizing types of individuals.

*Participant interviews and data collection.* Grounded theory principles focus on the interpretation of a phenomenon as process and action (Charmaz, 2006). Therefore, the researcher relies on the participants' words to examine their actions and processes. The primary source of data was one-on-one digitally recorded, semistructured interviews that were conducted and transcribed by me (see Appendix for the interview protocol). The semistructured questions were designed to focus on certain aspects of the individual's experience while being sufficiently open-ended and nonjudgmental which encourages unanticipated statements and stories to emerge (Charmaz). The participant can then take whatever direction and use whatever words they want to represent what they have to say (Patton, 1990).

Initial interviews were about one hour long. Follow-up interviews with five participants were used to collect more data, to clarify data from the earlier interviews, and

to provide participant checks of the interpretation of data (Charmaz, 2006; Morrow & Smith, 1995; Paterson, 2001). While providing an opportunity to check interpretations of data, the questions for the follow-up interviews were also tailored to the particular participant and her responses to original interview protocol questions. These interviews varied in length from ½ to 2 hours.

Congruent with the constructivist approach, any analysis is contextually situated in a time, place, culture, and situation (Charmaz, 2006). A secondary source of data was *observation*, which allowed me to immerse myself in the research context (Morrow & Smith, 1995). Observation was carried out in some of the participants' settings and yielded general information in regard to social interactions and processes that helped to interpret data rather than yielding information specific to any individual. This contextual information helped me to develop a theory that represents a composite of the participants' experience rather than focusing on any individual experience.

*Data analysis.* Using grounded theory methods, data were examined to make analytic interpretations and to develop an emergent theory that is grounded in and explains the particular data. The data were analyzed in a two phased coding process of initial coding and focused coding (Charmaz, 2006). *Initial coding* involved naming segments of data and examining the data for analytic ideas which could be used to pursue ideas for further data collection and analysis. *Focused coding* was more selective and conceptual and involved choosing the most frequent or significant initial codes to help sort, synthesize, organize, and integrate the large amount of data most effectively (Charmaz). Follow-up interviews were conducted after the identification of potential

focused codes to check the accuracy of interpretations. Overall, codes were assessed for which ones best represented what was happening in the data.

A *constant comparative method* (Glaser & Strauss, 1967) was used to organize, compare, and contrast codes, categories, and subcategories. I used *memo-writing* to analyze data and codes in order to develop theoretical categories and subcategories, and to define and conceptualize relationships between categories, experiences, and events (Charmaz, 2006). Categories explain ideas, events, and processes in the data and may subsume common themes and patterns in several codes. This comparative process leads to the construction of a theory and a theoretical model (see Figure 1). For example, in the model of self-healing that was developed, the category Waking Up was defined by the three initial experiences of Diagnosis, Denial, and Wake-Up Call.

*Disconfirming data.* Qualitative researchers often use negative cases to find new variables or to provide alternative explanations for their emerging theory (Charmaz, 2006). These cases can arise from the data or be imported into the research to generate disconfirming data that offer alternatives (Patton, 1990) or complementary explanations (Charmaz). Where patterns and trends have been identified in the data a so-called "negative" case can increase an understanding of those patterns (Patton). If the cases arise in the data, they may indicate the need to refine one's emerging theory (Charmaz). In this study, one complementary case emerged from the data that complemented the study and led to a refinement of the emerging theory. Such cases are considered to be another mode for ensuring the trustworthiness or integrity of the research (Patton). This case is discussed in more detail throughout the Results section.

**CONFRONTING REALITY**
Uncertainty day-to-day
Unknown future
Impairment

**Waking Up**
Diagnosis - **Event**
Denial – **Reactive coping**
Wake-up call

Precursors of Change
Awareness – Effort – Hope

**Balancing Act**
**Coping strategies**
Living one day at a time
Focusing on positive
Redefining values

**Proactive coping**
Competence –capacity
to act and change

**Transcendence
as Self-Healing**
Reflective autonomy
Autonomous motivation
Autonomous interdependence

**Ongoing Struggle
with Acceptance of**
Illness
Self with illness
Autonomous self

**Acceptance
as Self-Healing**
Intuition
Reflection
Perseverance

**RELATEDNESS**
Giving and Receiving Social Support

*Figure 1.* Theoretical model for self-healing in women with multiple sclerosis.

The importance of the personal experiences of the research participants in relation to the study's findings cannot be overemphasized. Reality is subjective in that it is influenced by the individual's social context of experience and resulting perceptions (Morrow & Smith, 2000; Ponterotto, 2005). Providing a "distinctively human method of inquiry to investigate human behavior and meaning" (Morrow & Smith, p. 224), the qualitative process allowed the participants and I together to reveal their personal experiences with MS and gave me an exploratory glimpse into the commonalities of their coping and healing experience.

<div align="center">Results</div>

The overarching core category *Confronting Reality* emerged from the data analysis. The *core category* is the main conceptual theme of the research and is a latent pattern based on incidents in the data (Strauss & Corbin, 1998) that subsumes and pulls together other categories, summarizes the data obtained from participants' perspectives, and provides an integrative framework around which the ongoing analysis develops (Dey, 1999). Under the central or core category Confronting Reality, there were five main categories that subsume other subcategories or properties: (a) *Waking Up*, (b) *Balancing Act*, (c) *Ongoing Struggle with Acceptance,* (d) *Acceptance as Self-Healing*, and (e) *Transcendence as Self-Healing*.

After the initial confrontation with reality represented in Waking Up, the categories and subcategories may connect, overlap, and reemerge in a nonlinear, circular or spiral process. The circular nature of the participants' ongoing process, as shown in Figure 1, is represented by the bidirectional arrows, indicating that the processes of self-healing and maintaining a self-healing attitude co-occur in an iterative process of

confronting reality. The process may move forward or backward, depending on the person's fluctuating symptoms which are perceived as either good days or bad days (Charmaz, 1991). As a spiral, the process represents successive levels of ongoing growth achieved by an individual.

Although participants may achieve levels of transcendence that make proactive coping easier and more effective, because of the possibility of future exacerbations and increasing debilitation, it cannot be assumed that they reach an endpoint in their process. Confronting Reality describes participants' experience of needing to confront the physical, psychological, and social realities of MS on a never ending basis. Even though participants were autonomous agents in their proactive confrontation with reality, *Relatedness* in the form of Giving and Receiving Social Support emerged as an underpinning participants needed to support their process.

*Confronting Reality*

The core category of Confronting Reality is like a pattern in a tapestry and is the main story (Glaser & Strauss, 1967) that connects all the categories and subcategories in the model. Confronting reality from moment to moment on a daily basis was the catalyst that drove participants' ongoing process of coping and healing. In MS, this means continuously confronting uncertainty, not only in not knowing how the body will function on a given day but also on what the unknown future may hold (Charmaz, 1991, 1999). Confronting reality means having to adapt to and live with impairment that may not always be apparent to others. Self-healing means directly experiencing MS and allowing one's self to feel strong emotions (Bohart & Tallman, 1999). Emily addressed this problem most directly:

The most important thing for understanding what it feels like is that whole uncertainty thing. The biggest negative is the unknown. You just don't know. I could have a fine future but I don't know! It changes day to day.

Barb, a participant who had waited 20 years for her diagnosis, viewed the challenge of MS as an "impasse" in her life that would require her to learn new things because she was "confronted with something" that she had not expected. To her this impasse meant:

The things a lot of people think about when they're much older in life, you get confronted with much earlier. You just have to think about those things much earlier in life knowing that your ability could be gone.

In everyday life, confronting the reality of uncertainty was represented by the need to confront the impairment caused by overwhelming fatigue, discomfort or pain, and difficulty with mobility, problems mentioned or implied by all participants. After commenting that only others with MS could understand what living with MS was like, Barb described specific problems:

When the world's spinning on the days when you're dizzy, it takes longer to get from here to there. Some days everything's like walking on a tight rope. For some people just to walk into a grocery store, if you can just imagine doing it all on a balance beam, you're pretty tired by the time you get to that point, by the time you get out, that's a day of mental work.

Impairment is not always apparent or obvious to others, especially earlier in the day or before a shopping expedition. Pat described an unpleasant and hurtful confrontation she had when parking in a handicapped spot at a big box store:

After I do what I'm doing in those big stores that require a lot of walking, I can't get back to the car. I've had to have people help me get back to the car. But I've had people, as I'm walking gingerly into Home Depot, say to me, "Oh, you look real disabled!" or "What are you doing parking there?" It is hurtful and I cry [or] get very defensive.

Jodie, who emerged as a complementary case, spoke of her diagnosis as "devastating" and was not in denial. She spoke at length about her symptoms and what she did to live with them. However, when asked questions that might involve confronting emotions, thoughts, and feelings, a necessary action for self-healing (Bohart & Tallman, 1999), Jodie quickly directed the answer away from herself to others or other topics. Jodie emerged from the data as a complementary case because she was doing some of the things that self-healers do, such as finding ways to adapt to and live around the symptoms that bothered her. However, when specifically asked how her thoughts and feelings about MS had changed over time, she began a rather lengthy reply about others and other diseases in this manner: "Well, you certainly become aware of the number of people that have it and when I tell people I have it, they *always* know someone that has it." This is one example of how she continuously avoided confronting her MS through emotional engagement which is considered to be one of the most important aspects of self-healing (Bohart & Tallman, 1999).

*Waking Up*

Under the core category, the first main category in the model is Waking Up, an overall experience that seemed to serve as a call to action. Waking Up is defined by the three initial experiences of *Diagnosis*, *Denial,* and *Wake-up call.*

*Diagnosis.* Diagnosis is the initial event in confronting reality when the involuntary present and future experience of living with MS and its implications is recognized by the individual. Even though they never used the word per se, some participants' words implied suffering or experiencing great distress. Emily said, "I went where I thought I could change nothing, do nothing, control nothing, everything was

being done to me. Your dreams are gone." This suffering arose from both body and

emotions due to loss of identity, physical ability and functionality, loss of control, loss of

certainty, and loss of an anticipated future (Charmaz, 1999).

The participants in this study responded to their diagnoses in different ways that

seemed to depend, in part, on their age or maturity at the time of diagnosis, on their

experience, and how long unexplained symptoms had been endured. Emily, a

30-year-old woman who was diagnosed in less than a month at 16, said:

> I didn't even have an identity yet. I wasn't a person yet. I wasn't even on a path,
> that's not fair. I want to see what I could have been, what I would have been. It's
> so unclear and nobody has any answers for me. That's so hard. Since I've been
> having to deal with the disability stuff, I'm finding myself scared.

On the other hand, receiving a diagnosis often elicited a sense of relief, especially

in those who were older and had experienced unexplained symptoms for an extended

period. Having an explanation for symptoms provided some sense of control and a sense

of legitimacy or validation (Charmaz, 1991) as expressed by Camie who was 66:

> I had been symptomatic for so long and had experienced the fatigue particularly
> that was debilitating. It was a relief just to have some kind of definite parameter
> to hold what was happening and that I knew [it] was not psychosomatic. Because
> of your symptoms and you don't know what's going on, this is anxiety provoking.

Early responses to a diagnosis often included taking some action that varied from

dramatic to simple and straight forward. Joan explained simply that "I got home and I

took my parents to dinner and I said, 'This is what [the doctor] said.'"

Pat, who had a more dramatic response, talked about believing that she was going

to be in a wheelchair in a year and took action, which turned out to be positive for her,

even though based on a lack of accurate information about the disease:

> I decided I'm going to move to a place where I can snow ski and mountain bike
> which I love. I'm going to live out my last active days just doing that. I divorced

my husband, put everything I cared about in my car and I drove from the Midwest to Utah. I did what I had to do and I'm glad I did because I can't do either of those things now.

Even though the participants responded in different ways to a diagnosis of MS, most of them seemed to experience some degree of relief at knowing what was causing their symptoms. The diagnosis was a catalyst for beginning some type of coping process. The nature of the coping appears to depend on the individual's life experience, with some individuals directly confronting the reality and others needing a period of denial.

*Denial.* Following the diagnosis, there was frequently, but not always, a period often seen as denial by the person with the illness. In experiencing denial, there again seemed to be a contrast between those who were older at the time of diagnosis and how long unexplained symptoms had been endured. The participants who had waited the longest for a diagnosis did not appear to experience denial. Camie said that upon her diagnosis she had "a willingness to change my ways" and "I knew I had to change certain dynamics in my household. I recognized that immediately because by that time my energy was seriously limited." Emily, the youngest woman who had the shortest wait for a diagnosis, said: "I totally ignored it for a good long time, four years. For a long time I kept [my MS] a secret, in my denial stage. I just didn't know what to do with it."

The course of MS with symptoms and exacerbations followed by a sometimes extended remission seemed to create an ambiguity which led some women, relatively early in their experience after diagnosis, to have mixed responses. Some women took what for them was considered a positive action while hiding the illness from others. Paradoxically, some expressed an awareness of the illness, took positive action, and later described themselves as being in denial at the same time. Pat who divorced, packed up,

and moved to Utah to do what she loved said: "Oh, [it was] denial! I medicated with Bud Light. That's how I coped with the news of MS. Definitely, my first response was to just numb it and not deal with it."

Not disclosing one's illness, which may appear to be denial, may be an attempt to avoid stigmatization by hiding the illness from others. Kate responded in this way while taking positive action and showing awareness and insight:

> I knew it was there. I'm sure it was denial. I just avoided the situation. I didn't tell anybody for 15 years because it was embarrassing to have. I read everything I could find, mostly diet and some exercise. I started exercising even though they said, "Don't do it." I thought, "Well, that's really stupid."

Although occurring relatively early in the process, denial is not necessarily an immediate response that follows diagnosis and the process was not always linear, as exemplified in Joan's response:

> I was tired of the side effects, I stopped that [medication]. I did the whole denial routine 3 or 4 years after I was diagnosed. I got the "wake-up call" going into a full relapse where I had probably been in remission for 4 years. No denying it. I've got MS.

What looks like denial to an outsider is frequently a result of the reality of the individual's experience. In MS, this occurs because there is a remission period that is free of serious symptoms or impairment. Joan's experience showed that she needed a "wake-up call" to bring her out of denial.

*Wake-up call.* Although the women may seeming to have used denial relatively early in their process of dealing with chronic illness, they eventually experienced a wake-up call that also may have served as a call to take action or pay attention. This experience was frequently an exacerbation of their MS that served to counteract denial

and make denial all but impossible.  Joan described a specific moment as being especially

defining for her:

> A defining point for me [was] changing medication, where I started having my
> body function properly for the first time in years, all of a sudden having the wake-
> up call that my hip said, "Pay attention." So I've been doing a lot more.

Although an exacerbation often brings an awakening, several women described

other types of specific experiences that were wake-up calls for them.  Pat described what

brought her to Alcoholics Anonymous:

> From the time I was diagnosed definitely that was my first response to just numb
> it and not deal with it.  It'll be 5 years but prior to that I medicated with Bud
> Light.  What got me to go--and I did this a handful of times--I would wake up in
> the morning and I did not know where my kids were.  They were in their beds
> asleep but I didn't remember putting them to bed.  It just scared me!

When asked to identify her defining moment, Kate described an experience that

occurred several years before her diagnosis:

> I can tell you exactly when it happened.  When I was about 15 years old, [I went
> to someone's home].  This very large, monumental woman sitting in the corner in
> an easy chair that reeked of urine said, "I have MS.  I can't do anything." Then I
> was diagnosed and that was my image.  I thought, "I won't be that! I will not go
> there.  That will not happen to me."

Two properties of the subcategory Wake-up call emerged, *Awareness* and *Hope*.

Awareness is a sign of personal growth that was evident in the participants' responses.

Joan saw her increased awareness in terms of consciousness: "I make a more conscious

effort to be more conscious.  I will make conscious choices about when and where I go to

do things." The words of Emily showed an increased awareness of both self and others:

> It has definitely increased my awareness of others and others' struggles because
> we all have an issue.  For a long time after diagnosis I felt like, everything is
> MS's fault.  I've had to learn that's not the case.  One of the biggest things that
> I've learned from my disease is we are all capable of a lot more than we think.

Pat who had been a confident, assertive, and successful business woman before her MS diagnosis had apparently gone through a loss of identity and now expressed an increasing sense of self-awareness and new self-confidence:

> After 5 years of sobriety, I have become more self-confident and [I] have more awareness and acceptance. It's acceptance that I'm not in control. In the beginning I thought it was immediate. You got it and you were in a wheelchair. I have friends who are 20 years diagnosed and you see that they just go on living.

Hope emerged after the women recognized that their futures had irrevocably changed and they expressed or implied realistic hope for the future. Hope often involved acknowledging that their new medications have given them more hope for a better future than older medications. Like others, Emily expressed her intention to participate in making her future a good one. She also expressed hope for her future that was realistically tempered by the need for patience:

> I changed medications 3 months ago. Hoping for a miracle. No miracle but still hopeful. Don't lose patience. It takes time, so I'm giving it time. I have every intention of doing my part to make [the future] as great as it could possibly be. So I feel good about that in the future. I don't know. I hope good things.

Kate who was more debilitated than all the others implied a realistic hope for her future based on new medications, technology, and her own efforts: "I really think that I will stay the way I am. I will continue to have some good days, some bad days but I'm doing everything I can do to maintain my life as it is."

Having dealt with a diagnosis of having to live with an incurable chronic illness and having awakened to an increased awareness of themselves, the women in this study engaged in strategies to proactively cope and confront the reality of life with MS. When asked what was happening in her life today, Barb characterized her life as "the balancing

act which basically has been there forever, what I prioritize to get done versus what needs to get done and what I'd like to get done.  It's very frustrating."

*Balancing Act*

The category Balancing Act is an overall process of prioritizing activities to control how a woman uses her energy and time.  It means learning to live with and around the illness through self-care and management of physical symptoms.  Prioritizing is necessary because the ever present and overwhelming fatigue of MS places limits on energy, meaning that choices have to be made regarding what needs to be done as opposed to what women want to get done.  As Barb described it: "You can't do everything you wish you could do or be the person you might have been with a little more energy."

In an effort to change their behavior and to maintain the Balancing Act in order to preserve energy, the women employed three strategies for moving through the process of confronting life with MS: (a) *Living one day at a time*, (b) *Focusing on the positive*, and (c) *Redefining values*.

*Living one day at a time*.  Living one day at a time arose out of suffering and the recognition of the loss of future possibilities as expressed by Emily: "My biggest thing that has been at my core for a long time [is that] I have to do everything right now because I don't know what I'm going to be able to do in a year or two."  Living one day at a time was also necessitated by the need for self-care.  However, it was hard work for some to not worry about the future as expressed by Barb: "I have to focus on taking care of myself, really not think of future things.  I have to give that up.  I work hard on not worrying about that." Not thinking about the future was also a way to avoid stress as

described by Susan: "I don't think about the future. I think about one day at a time. I think once you start thinking about your future is when you start to stress." Coping by living one day at a time helps people alleviate negative emotions which may, in turn, help them identify positive benefits that come out of their experience with illness.

*Focusing on the positive*. Finding something positive in the problem situation involves reframing the situation, which may lead to a new appreciation for life. The women were able to identify positive outcomes from their experience with MS, even though it was not always an easy task. Pat was still struggling with identifying the positive aspects of her experience, but upon reflection, she did find some:

> I'm trying to find a positive. The only thing I can think is that it might make [my boys] more tolerant. There are days when Mommy can't walk and so hopefully it will help them. And you could say it's slowed me down. It's made me more reflective on life. You know what? It's made me more tolerant. I will say that. So I'm a less judgmental person and more tolerant. That would be a positive**.**

Barb said that, "The positive has allowed me to focus on what's important. Things the world cares about that truly aren't that important. To put my faith in something much bigger than myself. Those are the positive things." Joan was aware of a positive impact that MS had on her life: "I will make conscious choices which I think is positive because if I make the effort, I can appreciate it more. There are things I do that are smarter choices, because of the MS."

When asked if any positive things had come out of her experience with MS, the complementary case Jodie responded: "I can't think of *anything* positive but it's not direly negative either because mine isn't so bad. I don't walk around with this cloud over my head all the time but I really couldn't think of one positive thing."

*Redefining values*.  Redefining life values encompassed a process of reassessing

what is most important in life now that participants are living with an incurable disease.

Barb expressed a new appreciation for life, taking new pathways, shifting attention and

perspectives, and her ability to change beliefs:

> Certain things that I used to think were important, I just don't think are important
> at all anymore, things that the world cares about that truly aren't that important.
> There is a much bigger picture than our bank accounts, our work, the cars we
> drive, the clothes we wear.  To think people make it when they are experiencing
> life differently, a different path and still defining life.  That's what interests me
> more now than the career path and getting things done.  So you have to find a
> different way to give credence to who you are and what you do.  I mean there are
> choices we have to make, where our values are.

For a number of the women, reassessing what they valued most in life seemed to

lead to the rediscovery of a part of themselves they had been ignoring.  Barb described

her return to drawing which she had done before giving it up to help others who did not

seem to appreciate it:

> I started drawing and painting and then I gave that up to do all the help here and
> help there.  I'm finally back on track with that and was really regretting that I
> gave up those eight years running around and doing things for other people,
> because that's where [drawing] I really feel my heart needs to be.

Showing a need for competence, the women explicitly believed that they could

change things in their lives.  Barb said, "I might not be able to change my health but I can

definitely change my outlook." Kate said, "Absolutely, I can change things in my life and

I believe it because I have done it." The women recognized that they were capable of

changing and engaged in strategies that supported their own change.  However,

acceptance which is one of the most important characteristics of the overall process of

change, transcendence, and self-healing (Bohart & Tallman, 1999; Charmaz, 1991;

Egnew, 2005; Kirkpatrick Pinson, Ottens, & Fisher, 2009), seemed more elusive for

them.  At this point, participants' overall process and efforts to change could be characterized as an ongoing struggle with acceptance.

*Ongoing Struggle with Acceptance*

Although at varying levels, the ongoing struggle with acceptance was expressed or implied by all participants but especially by the complementary case who resisted emotionally confronting the illness.  One of the reasons that learning acceptance may be so difficult is because accepting the illness alone is not enough.  For self-healing to occur, acceptance on three levels seemed necessary: (a) Acceptance of the illness; (b) Acceptance of the self with illness or the changed self; and (c) Acceptance of the autonomous self or acceptance of the self as a woman who feels justified in taking time for herself versus the self-sacrificing "selfless" woman that the culture expects.

*Acceptance of the illness.*  Accepting a chronic illness means acknowledging or recognizing its presence now as well as in one's future.  Although recognizing her ability to change things and identifying positive outcomes from her experiences with MS, Emily expressed most directly her ongoing 14-year struggle for acceptance of the illness:

> I ended up going to some counseling about this thing that I had been denying for so long.  It was terrifying and I didn't want to think about it.  I didn't know *how* to think about it.  So that was my start to my acceptance. . . .  I only started getting really debilitated with my disease in January so I was fine for a long time but since then that's been a whole other level of acceptance: What am I gonna do now? What's happening to me? I'm not there yet this time, but I'm working on it.

To move beyond illness, people need to accept not only the presence of the illness, they also need to accept whom they have become because of the presence of the illness, i.e.  they need to accept the self with the illness (Charmaz, 1991).

*Acceptance of the self with illness.* Emily explained her struggle to accept herself with the illness: "I thought for a long time that by doing everything right, I would be fine. That's been a giant realization. I'm doing everything right but I'm not fine. What do you do with that? I'm still figuring that out." When people like Emily struggle with their illness rather than against it, they do not give up instead they struggle to keep their bodies functioning as well as possible. Emily exemplified this when she said, "I'm a big believer in exercise for stress reduction and 'use it or lose it.' I want to maintain everything I possibly can." As well as not giving up, Emily seemed to have little trouble with accepting her autonomous self when she exercised agency in making her own choice to take action in spite of her mother's fears and doubts.

*Acceptance of the autonomous self.* Emily explained that when she wanted to take yet another extensive bike ride, her mother expressed fears about it. However, she exercised autonomy and agency in her response to her mother: "I'm going to do this and your fear and worry and stuff is not helping. You're really taking away from me. And what . . . you want me to be scared? Because I'm doing it."

Barb expressed her own struggle for her autonomous self in order to answer the need to take time for herself as opposed to always sacrificing self to others, a struggle made more difficult by the changes imposed by MS:

> I do always feel like I wish I could do more for family and friends and I have to realize I can't. So to set priorities is very hard at times. Usually you cut back on yourself and that's probably the last place you should cut back on. I've had to learn to accept just what I can do, not what I wish I could do. And I still try to take on too much which I've always done. But it's probably not to please myself, it's to please others. They probably could care less anyway.

Even though people have different ways of coping and healing, all the participants except the complementary case Jodie seemed to have achieved some level of acceptance

on all three levels. Although Jodie attempted to package or contain her illness as a means

of controlling it and maintaining emotional distance from it, her words and behavior

showed that she, too, was struggling with acceptance when she started to choke up and

cry:

> Even with this mild case as I have, I really can't stop it. I mean this makes me think about it much more than I've thought about it probably all together in the how many years--except in the beginning--it is difficult to think it's never going away.

People do not just decide to accept their illness and their new identity as self with

illness. As seen in these women, acceptance requires time and effort because acceptance

is a process as well as an outcome of self-healing.

*Acceptance as Self-Healing*

In spite of their struggles with acceptance, a majority of the participants seemed to

intuitively recognize what was needed to cope successfully with their illness. Three

important properties of self-healing as acceptance emerged: (a) *Intuition*, (b) *Reflection*,

and (c) *Perseverance*.

*Intuition.* The women showed intuition concerning their physical illness as

exemplified by Kate who, at the time of diagnosis, decided to exercise even though

"they" told her not to: "I thought, 'Well that's really stupid. If you don't move a

muscle, it will stagnate. It won't work any more.'" In addition to the intuition

concerning their physical condition, the women seemed to intuitively understand what it

meant to psychologically heal. When asked what they thought psychological healing is,

many of the participants either directly identified "acceptance" or implied it in their

responses or actions. Their acceptance was associated with both their situation or life as

it is and with self as Barb expressed it: "I think healing means acceptance, acceptance of who we are and connect to who we were born to be and where we're at [in life]."

*Reflection.* The women's responses also indicated reflective thought in recognizing what acceptance is and is not as in the case of Emily: "If you are a healed person, if you're comfortable with who you are and your situation in the world then you are healed equals acceptance—peace. Stress is *not* healing. Anger is *not* healing." Pat demonstrated inner reflection in terms of how she accepted herself, how she was changing, and how she related to others:

> Acceptance, love of yourself, but I think healing is meant to love yourself on a different level of love. I have something to offer. I'm not going to force it on you. I'm going to be kind about it. I guess maybe I've discovered I'm becoming kind. I love myself when I'm kind. That's all part of the very important healing.

In contrast to these two women, when asked what psychological healing is, Jodie the complementary case, who had only suffered one exacerbation, responded in a manner which indicated that her acceptance amounted to containing or packaging her illness in an attempt to delimit and control it (Charmaz, 1991):

> I don't know if I've ever experienced . . . psychological healing but I don't know that I haven't either. I've never been really sick. I don't know that MS is really a quote "illness." It's a state. I don't know if you categorize it as an illness.

*Perseverance.* The women also realized that healing was not easy and demanded perseverance as Barb indicated: "Healing comes from within and to get totally healed takes a lot of inner work." Joan saw acceptance as "probably the most difficult thing for anyone to make." Although still struggling in varying degrees with acceptance, Camie at the same time exhibited signs of transcending the distress of her situation:

> Acceptance is for me, in more of a Zen context, being fully present to what is going on and not resisting what's going on, just being with it. Interestingly

enough, if you do that, sometimes some of the symptoms and the struggles just vanish in a sense.

The participants engaged in reflective thinking about the meaning of acceptance. They trusted intuition as they patiently persevered by staying with the process. As natural self-healing processes, these properties helped the women progress toward transcending or moving beyond their illness rather than let it take over their lives

*Transcendence as Self-Healing*

Transcendence of illness and self through acceptance depends on autonomy (Charmaz, 1991). People are capable of retaining a sense of transcendent self even after great loss when they believe that they can still make autonomous choices despite their diminished possibilities and when they can retain or create self-respect. Three properties of self-healing as transcendence that emerged were: (a) *Reflective autonomy*, (b) *Autonomous motivation,* and (c) *Autonomous interdependence.*

*Reflective autonomy.* The women appeared to extend their reflective thought processes in the exercise of reflective autonomy represented by autonomous behaviors that were initiated and regulated by choices based on an awareness and reflective evaluation of possible options in light of their needs and interests (Koestner & Losier, 1996). They recognized this in their ability to change the way they thought about their illness as when Barb said, "I might not be able to change my health but I can definitely change my outlook." Kate also recognized from past experience that she could do something about it: "Absolutely, I can change things in my life and I believe it because I have done it." Pat saw it in terms of control: "I do believe that I can control *me*. I can control my attitude, I can control my response to this whole thing."

Barb demonstrated reflective autonomy in recognizing the need for letting go of

the culture's standards for success (Charmaz, 1991) and for validating herself while also

acknowledging the inner voices (Maslow, 1968) from which she sought guidance:

> I have faith that there is a much bigger picture. There are so many other options out there and MS has allowed me to see all those other options. If you do value yourself on [what] most of the world values, you'd get a pretty low rating. [I] listen to those hidden voices that there's so much more than the material world that we see, see it as more of a spiritual existence. So I try to listen to that more. It's more of finding your own way.

Contrasting Jodie, the complementary case, to these women highlights her lack of

belief in her ability to change things in her life:

> You can change things if everything that has happened in your life leads you to do that. I think when you think you have a choice in life, you *don't*. Everything that you will choose to do is predetermined by other things that have happened.

*Autonomous motivation and Autonomous interdependence.* With *autonomous*

*motivation*, the individual is intrinsically motivated by identifying with the inherent value

of an activity and ideally integrating it into their sense of self (Deci & Ryan, 2008a).

*Autonomous interdependence* indicates that the individual is freely choosing to depend on

others or to be independent of them depending on the situation (Deci, La Guardia,

Moller, Scheiner, & Ryan, 2006). The most dramatic example of transcendence can be

found in these words from Kate, the most debilitated participant, who exhibited both

autonomous motivation and autonomous interdependence:

> I will never accept that I am disabled as in "unable to do anything." There's always something--some way I can find to do something. I may have to do it differently. I still ski, but I ski on a bi-ski and I love to paraglide and I tandem paraglide with another pilot because I am afraid I don't have the strength to do it myself. But I will never give those things up. I want that opportunity to see.

Kate's words indicate that she inherently valued and enjoyed these activities. She also could freely choose to be dependent on the outside necessary support in order to participate in such activities. Her words show how vital relatedness and support can be for people with the debilitation of a chronic illness. In comparison, the complementary case, Jodie, showed clear signs of reactive autonomy and independence, as opposed to a willingness to let others help her: "I don't want *anybody* taking care of me. I don't want to be on the end of that. Nor do I want to take care of somebody else."

*Relatedness*

*Relatedness* in the form of giving and receiving social support was a theme that threaded throughout the categories and subcategories that connect and overlap in the nonlinear process of self-healing. Emily offered this general assessment of the need for support: "Support helps. That's the big thing I've learned from my MS, you need people. You need that support and it's silly to keep it a secret because people are so ready to help." As may be expected, one of the most important sources of giving and receiving support was participants' families when Kate explained:

> The most important things are my family, having my regular contact with my husband and my children and my siblings, staying current with what's going on in their life. Being involved and knowing that if one of them needs me, they know I'm there. They can call me and it's okay. That's very *vital.*

Friends who stuck with participants were also important to them. However, Kate believed that friends who can understand what it is like living with MS were an especially important source of giving and receiving support:

> Friends I had before disappeared, but my MS friends are always there and they always know whether I'm having a low energy day or a day with a lot of spasms, a lot of pain. They know. I can talk on the phone and I know by the tone in [my friend's] voice if she's having a hard [day].

Pat, in demonstrating autonomous interdependence, was glad to have friends who were happy to see her when she was able to go exercise and who gave her moral support at the gym:

> When I go to exercise class, just being involved with . . . my friends there who are able-bodied [and] go get my bench for me. They are so nice. So that helps me cope because they cheer me up and they get me going.

The participants' overall process, as shown in Figure 1, was circular indicating that self-healing and maintaining a self-healing attitude co-occured in a continuous iterative process that required the participants to constantly confront the physical, psychological, and social realities of their MS experience that began with their diagnoses. The process moved forward or backward depending on the person's symptoms which create periods of time that are perceived as either good or bad (Charmaz, 1991). Seen as a spiral, the process represents varying levels of ongoing growth that an individual may achieve. The growth process included five steps represented by the five main categories of Waking Up, Balancing Act, Ongoing Struggle with Acceptance, Acceptance as Self-Healing, and Transcendence as Self-Healing. Even though it is the individual that creates their own healing through proactive coping, the participants needed support for their ongoing process in the form of Relatedness as both Giving and Receiving Social Support.

## Discussion

Although there is a body of literature focused on the impact of the physical and psychosocial factors of multiple sclerosis on coping, this exploratory study is distinctive in examining the commonalities in coping strengths and competencies of various individuals with MS as they move toward self-healing. The research question of how women with the chronic illness multiple sclerosis cope everyday with the distress caused

by MS and move into a proactive coping and self-healing process was answered by analyzing the words and experiences of the participants.  A theoretical model of the participant's coping strategies and self-healing processes emerged from the analysis.

From their own point of view, all participants in the present study, including the complementary case who was the least successful in terms of self-healing, were actively trying to: (a) adjust as best they can to their situation; (b) to preserve their autonomy; and (c) to maintain their connectedness, goals, power, pride, and maneuverability (Bohart & Tallman, 1999).  Kirkpatrick Pinson et al. (2009) showed that women can have a positive experience while living with the multiple sclerosis.  Their findings confirmed that three precursors of change (Hanna, 2002) also found in the present study, i.e., confronting the problem, effort toward change, and awareness, seem to be very  powerful in creating favorable conditions for successful coping in individuals with MS.

Even though this study's participants appeared to be at different points on a continuum, manifesting varying levels of self-healing, they continued to proactively cope with the reality of their illness.  Analogous to "confronting the problem" (Hanna, 2002), the overarching core category of Confronting Reality that emerged from the data in this study describes participants' experience of needing to confront the realities of MS on a never ending basis that begins at diagnosis.  In self-healing, confronting the problem means exposing oneself to the situation and directly experiencing one's problem while allowing oneself to feel strong emotions in order to make discoveries and master fears (Bohart & Tallman, 1999).

The reality of living with MS means confronting the continuous uncertainty of the physical disease which threatens psychological well-being (Rao, Huber, & Bornstein,

1992; Reynolds & Prior, 2003; Rudick, Miller, Clough, Gragg, & Farmer, 1992). The proactive self-healing participants were capable of tolerating uncertainty and ambiguity with both patience and a creative perseverance that allowed them to stay with their problem of living with MS until they found ways to live with it and around it (Bohart & Tallman, 1999) in order to integrate or incorporate it into their lives (Charmaz, 1991).

For these women, denial seemed to be dependent on maturity, experience, and how long the person had endured undiagnosed symptoms suggesting that self-healing may be influenced by one's developmental growth level. The women who waited longer for a diagnosis expressed relief at finally having an answer that legitimized their suffering, a finding congruent with the chronic illness experience described by Charmaz (1991). Eventually, all the women who experienced denial received a wake-up call, which was often an exacerbation that made it impossible to ignore the illness. As a result of their waking up experiences, the women recognized that they had developed a sense of awareness, which makes change possible (Hanna, 2002) and appears to be a "critical step on the way to facing life with MS" (Kirkpatrick Pinson et al., 2009, p. 187).

Awareness gives rise to what Hanna (2002) contends may be the core activity for change, "confronting the problem" (p. 71), represented in this study by confronting the reality of MS. The process is characterized by active engagement with and movement through a problem, instead of dancing around it. In a study of women with primary progressive MS, participants identified a great need for confronting their problem or MS (Kirkpatrick Pinson et al., 2009). Additionally, over the course of living with MS, there was a need to develop and enhance this precursor of change in order to cope with the demands of the disease. The women in the present study displayed the capability to

confront their problem in an ongoing intentional and deliberate act of directing attention toward a painful, intimidating experience in spite of their fears, confusion over uncertainty, or a tendency toward avoidance (Hanna). A second property of the waking up experience was a sense of hope with which the women considered what they could realistically achieve and expect despite obstacles (Hanna). Hope has been found to be a resource for those individuals who fare better long term with MS (Samuel & Cavallo, 1999) and has provided a means for dealing with the characteristic uncertainty of MS (Miller, 1997).

In agreement with the precursors of change (Hanna, 2002) and self-healing characteristics (Bohart and Tallman, 1999), this study's participants recognized that they had the capacity to make changes in their lives and made an effort to do so. These self-healing women confirm what Charmaz (1991) describes as learning to live with chronic illness in an ongoing process of developing strategies to get through each day. Labeled by one of the women as a balancing act, they engaged in an overall coping process of learning to live with and around the illness by prioritizing activities to control how they used their energy and time. In their effort to maintain this balancing act, they used three strategies: (a) living one day at a time, (b) focusing on the positive outcomes of their experience with MS, and (c) redefining values or what was most important in life. Characteristic of active self-healers and the self-healing process, these strategies encompassed positive outcomes that are characteristic of self-healing, such as a new appreciation for life, shifts in attention, exploring new pathways, a change in perspective, and an ability to change beliefs and behaviors (Bohart & Tallman, 1999).

For these women with MS, the crux of their self-healing process was an ongoing struggle with acceptance. Struggling to achieve acceptance was important for them because a lack of self-acceptance, or of one's whole self including self with illness, can block more effective proactive coping (Bohart & Tallman, 1999). These women accepted the presence of the illness and continued to cope, an effort that led to self-healing as acceptance. Acceptance occurred on three levels: acceptance of the illness, of the self with illness or the self changed by illness (Charmaz, 1991), and of the autonomous self who feels justified in taking care of herself and comfortable with not being the selfless, self-sacrificing woman that the culture expects (Wood, 1994).

In their struggle with acceptance, the women called upon intuition, reflection, and perseverance, all characteristic of the self-healing individual (Bohart & Tallman, 1999). The women showed a trust in intuition in that they understood what was going wrong and had a sense of a healing direction. However, their process did not consist of merely automatically following intuition or feelings, which can be wrong (Bohart & Tallman). Their problem solving involved reflection and logical, thoughtful analysis which from their point of view made sense as a proactive effort to find a livable life in their world. People cannot just "decide" to accept their illness (p. 70); acceptance comes only with time, as demonstrated by participants' struggle and process. As proactive self-healers, they persevered in trying to find the best workable accommodations given the constraints of their situation (Bohart & Tallman). In this manner, they found ways to accept and live with and around their illness and its effects.

Acceptance is both an outcome and process of coping and moving toward self-healing (Bohart & Tallman, 1999) and, in combination with autonomy, is required for

self-healing as transcendence (Charmaz, 1991).  Transcendence not only depends on autonomy but also requires reevaluation, renewal, making choices, and taking action (Charmaz), all of which were evident in the lives of these women as reflective autonomy, autonomous motivation, and autonomous interdependence (Deci & Ryan, 2008b).

In contrast, the complementary case was coping and struggling with both illness and her changed self by finding ways to live around the physical symptoms.  While she was not in denial, she was avoiding the vital processes or actions required for self-healing.  Transcendence is not a rejection of prior experience but is founded upon and integrates all that came before (Maslow, 1968) including the acceptance of the illness and the self with illness (Charmaz, 1991).  Rather than integrating her MS into her life, Jodie was containing or packaging her illness, i.e., "treating illness as if it is controlled, delimited, and confined" to specific areas of her life (Charmaz, p. 66).  Questioning whether it was even called an illness, her responses to interview questions indicated that she was avoiding emotional engagement with the illness.  Emotional suffering, a very distressed state in which emotions are released, is a healing agent (Morse, 2001).  People who are enduring their illness do not move to this release until they are tentatively ready to accept the losses imposed by their illness.  Additionally, Jodie said she was a "determinist" and expressed doubt that people could in fact change much at all.

The other participants illustrated reflective autonomy as seen in their autonomous behaviors that arose from a reflective evaluation of possible options in light of their needs and interests, as opposed to a reactive opposition to any outside influence that was seen in the reactive autonomy of Jodie (Koestner & Losier, 1996).  The women also acted from autonomous motivation as either intrinsic or well-internalized extrinsic motivation in that

they seemed to identify with the inherent value of an activity or process and to have

integrated it into their sense of self (Deci & Ryan, 2008a). Jodie seemed to act from

controlled motivation and introjected regulation, in which the regulation of her actions

were energized by contingent self-esteem, ego-involvements, and, perhaps, avoidance of

shame (Deci & Ryan).

Autonomy, unlike independence, does not equate with "being subject to no

external influences" (La Guardia, Ryan, Couchman, & Deci, 2000; Ryan, 1993, p. 10).

The self-healing women in this study chose to be autonomously interdependent, that is,

they freely chose to depend on others or to be independent of them (Deci, La Guardia,

Moller, Scheiner, & Ryan, 2006). Although showing a need for the presence of friends in

her life, Jodie adamantly refused to be taken care of or to be dependent upon others and,

furthermore, did not want someone else to be dependent on her. This attitude contrasts

with dynamic autonomy (Keller, 1985) that is fluid, secure, and able to be both with and

apart from others with equal comfort and equal security in one's own selfhood. Keller

contrasts this with an autonomy or independence that is defined by a rigid separation

between self and others, which reflects an insecurity in one's own identity and a fear of

losing self in entering into another's reality.

Underpinning the individual processes of self-healing was a great need for

relatedness, in the form of giving and receiving social support (Deci & Ryan, 2000,

2008b). The self-healing women in this study felt a need for both receiving and giving

support to others. Social support from others has been found to be an important precursor

for change in women with MS (Kirkpatrick Pinson et al., 2009). The desire for

interpersonal attachments in the form of mutuality in relationships fulfills an innate need

to belong (Baumeister & Leary, 1995). The mutuality of support for autonomy has been shown to predict psychological well-being (Deci, La Guardia, Moller, Scheiner, & Ryan, 2006).

*Limitations and Implications for Future Research*

It is the nature of qualitative methodology to use purposeful and snowball sampling to examine a population for a specific phenomenon. In this study that phenomenon is self-healing and the population was limited to eight women with multiple sclerosis from the Intermountain West of the United States. Seven of the women were Caucasian and one was African American, ages 30 to 66 years and time since diagnosis 5 to 36 years. Future researchers may want to examine the process of self-healing in men or in different races or cultures, to compare the process in men and women, or to limit their research to certain age ranges.

The findings also suggest that the strategies used by the women in this study may be less relevant at symptom onset and diagnosis and may be more applicable after people have had time to make sense of their illness and to accept its presence and it effects on their lives (Pakenham, 2005; Paterson, 2001). Therefore, researchers may want to examine and compare different lengths of time waiting for a diagnosis or different lengths of time since diagnosis. Definitions and theories must always be considered to be provisional (Egnew, 2005). However, the definition and theory of self-healing presented in this article provides a starting point for discussion and further study, extending the definition and model of self-healing beyond psychotherapy. It may be possible to develop quantitative instruments to measure or evaluate self-healing based on the categories, subcategories, and outcomes found in the present study.

*Implications for Practice*

Although qualitative findings are not generalizable, *transferability* may be thought of as being analogous to the external validity or generalizability of traditional quantitative methods (Lincoln & Guba, 1985). The qualitative researcher provides the necessary database but readers must make transferability judgments and decisions regarding whether or not the model of self-healing presented here may be applicable to their particular situation. This theoretical model can provide a framework for integrating healing and self-healing into the practice of health promotion and education by serving as a basis for developing interventions that facilitate the individual's process.

Moving beyond or transcending the distress of illness while living with it is possible when people have time for reflection and the skills that allow them to define qualities of self as distinct from the body (Charmaz, 1991). Reflection creates awareness (Koch & Kralik, 2001) and taking time for reflection can facilitate the transcendence process (Charmaz). The process requires making choices and taking action that arise from a reevaluation and reframing of experience.

The participants, when asked what advice they would give to health professionals, expressed a need to be heard, understood, and respected. Camie said: "Listen and be open. Empowerment. Freedom to make the choice." Joan liked the fact that the person administering her medicine engaged in reflective listening and "tells me back what she thinks she heard [me say]." Kate wanted professionals to "be open to us, listen to us. You have to listen to me to hear what I have to say."

The self-healing process is unique to each person (Bohart & Tallman, 1999; Quinn, 2001). Every healing effort and intention that creates an optimal healing

environment starts within the health educator or health care professional (Schmidt, 2004).

Profound healing can occur in other health dimensions even if there is no change in a

treated physical condition. However, we cannot cause healing to occur because it

emerges from within the individual (Quinn). It is the body, mind, and spirit of the person

that is the true healer.

The vital task of the health educator is to create the container for learning and

healing by creating a safe and supportive environment. We must be reflective learners as

we encourage our students to be reflective. Therefore, health educators need to respect

the autonomy of our students, clients, or patients by listening to what they want to tell us

and have a need to tell us. We can offer our participants opportunities for diverse

experiences and then we can respect their autonomy by giving them choices about which

interventions or methods work best for them.

*Conclusions*

Self-healing is a process told as a life story. If health educators and other health

professionals can understand the process that facilitates people to move through having

MS and its effects on their life situation in order to employ a positive, proactive coping

approach, we can help people accept and integrate the limits imposed by their illnesses,

enhance positive psychological attitudes, and promote positive outcomes (Pakenham,

2006). As health educators or other health professionals, one of our most important tasks

is to listen to our patients, clients, and/or students. In so doing, we can nurture the self-

respect of those with chronic illnesses by seeing them as the experts on their own illness

experiences. We should support their personal strengths as we do our best to increase

their knowledge levels and enhance their positive behaviors and practices.

Appendix

Interview Questions for Healing in Women with Multiple Sclerosis

How old are you now?

How old were you when you were diagnosed with MS?

How long did it take for you to be diagnosed?

1. PAST –Could you briefly tell me what your reaction was when you received your diagnosis of MS?
    A. Do you think that you had a period of denial? What happened?
    B. Do you think you've had "aha" moments in your experience with MS?

2. PRESENT –What's are you doing in your life today?
    A. Do you believe that *you* can change things in your life and why?
    B. How has having MS changed what you believe and do?
    C. What are the most important things in your life?
    D. What helped you to manage or cope with your MS?

3. CONSEQUENCES –
    A. What are the most positive things in having MS? Has anything positive come out of your experience with MS?
    B. What are the most important lessons you learned through experiencing MS?
    C. Did you discover strengths or weaknesses you didn't know you had?
    D. What goals have you set, if any?
    E. What do you think psychological healing is? (i.e., as opposed to physical healing)
    F. What do you think acceptance is? What is self-acceptance?

4. OTHERS IN YOUR LIFE –
    A. How have others affected the way you deal with MS?
    B. What advice would you give to someone who has just discovered that he or she has MS?
    C. What advice would you give to health educators and other health professionals who work with people who have MS?

5. FUTURE –What do you think may happen in the future?

6. Is there anything else you think I should know to better understand what it's like living with MS?

7. Is there anything you would like to ask me about that we haven't already talked about?

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CHAPTER 2. METAPHORS AND MEANINGS OF SELF-HEALING

IN WOMEN WITH MUTIPLE SCLEROSIS

Abstract

Human beings use metaphors in telling their stories to create a sense of coherence, unity, meaning, and purpose in their confusing life experiences.  Metaphors that emerged from qualitative interviews with women who have multiple sclerosis were identified and examined to uncover themes and their meanings.  Metaphors convey meaning, motives, and understanding and can play a role in facilitating developmental change.  To tell one's story in one's own voice has a healing power that was seen in the metaphors of the women who achieved varying levels of self-healing in their proactive coping efforts. Health educators and other health professionals can gain a greater understanding of the individual self-healing process by exploring the metaphors that arise in the stories of their students, clients, or patients.

Human beings are storytellers who use metaphorical language and embed metaphorical images within their stories (Coffey & Atkinson, 1996).  In narrative thought and stories, "we seek to explain events in terms of *human actors striving to do things over time"* (McAdams, 1993, p. 30).  As social actors, we retell and organize our experiences and lives in terms of events, influences, and decisions in order to make sense of them and to provide our confusing experiences with a sense of coherence (McAdams,

1993).  Stories are more about meaning than about conveying fact (McAdams) and we expect our lives overall to be meaningful (Baumeister, 1991).  In order to live well with unity and purpose, we compose and convey narratives of the self to discover and illustrate what is true and meaningful in our lives (McAdams).

Within our stories, we use metaphors to convey meaning and motives (Coffey & Atkinson) and to construct and reconstruct personal meaning for our experiences (Carlsen, 1996).  The use of metaphor can help expand emotional awareness (Fox, 1989) and help a person translate "the intangibles of emotion into some sort of verbal expression" (Carlsen, 1996, p. 350).  In some instances, the opportunity and the experience of telling one's story in one's own voice can prove to be an experience of healing power and personal growth (Braud, 1998; McAdams).  In fact, metaphors are found across all domains of human thought, whether philosophical, scientific, personal, or psychological (Lakoff & Johnson; Leary, 1990; Lyddon, 1989).

<div align="center">Metaphor</div>

Substantial linguistic evidence supports the metaphorical quality of human thought processes (Lakoff & Johnson, 1980).  Metaphor is a fundamental and indispensable structure of human understanding, a basic unit of mental functioning (Modell, 1997).  Through metaphor, we generate new perceptions of the world, we organize and make sense out of experience, and we connect the known and the unknown because metaphor allows us to find the familiar in the unfamiliar (Edelman, 1989; Modell).  Incomplete, disorderly, and chaotic experiences and feelings that are cognitively undefined or delineated require metaphors (Modell).  Cognitive scientists and linguists engage in research on metaphor because metaphor plays a role in human

thought, understanding, and reasoning, and extends to the creation of our social, cultural, and psychological reality (Kövecses, 2002).

*Metaphor in Theory*

Metaphor has traditionally been viewed as a characteristic of language and as a matter involving the conscious and deliberate use of words by certain people with special talents, such as great speakers and writers.  This traditional view has been challenged by the cognitive linguistic theory of metaphor (Lakoff & Johnson, 1980) in which "the essence of metaphor is understanding and experiencing one kind of thing in terms of another" (p. 5) and metaphor is seen to be a property of concepts and not of words.   In formulating their theory, Lakoff and Johnson were primarily concerned with how people understand their experiences in the everyday world.  Metaphor is seen to be used in everyday life by ordinary people as an inevitable process of human thought and reasoning because human thought processes are primarily metaphorical.

Linguistic evidence shows that our ordinary conceptual system, fundamental to thought and thinking, is metaphorical in nature (Kövecses, 2002).  Many concepts that are important to us are abstract or not clearly delineated in our experience (Lakoff and Johnson, 1980). The language of conceptual metaphors is "the stuff of thought" that offers humans a means to transcend our cognitive and emotional limitations (Pinker, 2007, 435).  People use metaphors to reason.  Humans take their concepts of space, time, causality, and substance, and create a framework to apply to more abstract matters by stripping away the physical contents for which the concepts were originally designed. We, therefore, gain understanding of abstract concepts by means of other concepts that

we understand more clearly.  Metaphors matter in the scheme of human experience because they offer a mechanism that the mind uses to understand otherwise inaccessible concepts.

*Conceptual Metaphor*

In cognitive linguistic theory (Lakoff & Johnson, 1980), metaphor is defined as *conceptual metaphor* in which one conceptual domain is understood in terms of another conceptual domain (Kövecses, 2002).  A *conceptual domain* is defined as any coherent organization of experience.  A convenient way for representing a conceptual metaphor is: CONCEPTUAL DOMAIN (A) IS CONCEPTUAL DOMAIN (B) for example, LIFE IS A JOURNEY.  The capital letters indicate that these particular words may not be used in the language spoken by an individual but that they conceptually underlie what is being expressed (Kövecses, 2002).  When speaking, we use *metaphorical linguistic expressions* or ways of talking to express or demonstrate conceptual metaphors or ways of thinking. For example, the conceptual metaphor above may underlay and be expressed in speaking as "She's young and she has a long road ahead of her."

Conceptual metaphors point to an obvious way in which people can learn to reason about new, abstract concepts by recognizing or having pointed out to them a parallel between a physical realm they already understand and a conceptual realm they do not yet understand (Pinker, 2007).  If we want to better understand a concept, our subjective experiences in the physical world offer us a natural and logical basis for understanding a more abstract domain or *target domain* by using a *source domain* or a concept that is more concrete, physical, or tangible in some way (Kövecses, 2002).   In the conceptual metaphor LIFE IS A JOURNEY, we try to understand the abstract target

domain A "life" in terms of the concrete source domain B "a journey."  Simply put,

metaphor offers human beings a way to make sense of our experiences by using a more

concrete experience to understand a more abstract and, perhaps, confusing experience.

*Metaphor in Human Experience*

With a recent convergence of interest in the concept of metaphor in the disciplines

of neurobiology, linguistics, and cognitive science, metaphor is viewed as being rooted in

the body.  The interaction of our bodies and selves with the physical world gives rise to

root or generic metaphors.  The embodiment of metaphor means that metaphors have

their origin in bodily sensations and metaphor is used to organize bodily sensation

cognitively, especially in regard to emotions (Lakoff & Johnson, 1980; Modell, 1997).

Beginning at infancy, humans need to categorize experience (Modell) and

sensorimotor experiences arising from the body's interaction with the world determine

how we categorize that world (Johnson, 1987; Lakoff, 1987).  Schemas that have a basic

logic preconceptually structure our bodily experiences and give rise to metaphors that

project logic onto abstract domains (Lakoff).  Our need to categorize applies to both our

internal and external worlds.  Our internal experiences are projected outward as

metaphoric categories applied to the physical world.  At the same time, our interaction

with the external physical world can be categorized metaphorically (Modell, 1997).

Psychoanalysts have known for a long time that emotional experiences emerging

from within the body are transformed into metaphors (Modell, 1997) and have

recognized that emotions and memory are inseparable (LeDoux, 1996).  Metaphors allow

us to form bridges between the past and the present (Modell).  Emotions, memory, and

metaphor form a synergistic unified system (Modell) in which affective experiences cannot be separated from the context in which they occur and are perceived (Stern, 1985).

Emotional experience and exploration often play a pivotal role in the change process by organizing a person's self-experience and establishing connections between self and environment (Greenberg, Rice, & Elliott, 1993). Metaphors and metaphorical knowing may play a significant role in accessing and symbolizing emotions, in uncovering and challenging tacit assumptions, and in introducing new frames of reference (Lyddon, Clay, & Sparks, 2001). Metaphors may be useful tools for helping people access and represent emotions that may have been previously unexpressed, unexplored, or unrecognized (Fox, 1989).

Intense positive and negative emotions may be experienced as if they arise from a source outside the self and hence are believed to be uncontrollable (Modell, 1997). Metaphor provides a schema that allows for some degree of organization and control over the disorganizing effects of emotional experiences so that experiences can be brought within the agency of the self. Modell identifies two types of metaphors that arise when counseling clients, foreclosed or fixed metaphors and generative metaphors.

*Foreclosed metaphors* that are fixed, unambiguous, and unchanging can be found operating in traumatic memories and inhibitions (Modell, 1997). Intense negative emotions and traumatic experiences that are not recontextualized or reframed can continue to exert a negative influence as expressed in a compulsion to repeatedly refer to painful experiences. From the standpoint of adaptation, foreclosed or fixed metaphor allows the memory system to actively scan the environment for metaphoric similarity and to ignore differences between past and present contexts in an effort to avoid ambiguity.

However, if people cannot eventually reframe the experience, they are unable to move beyond the negative influence of the experience.

On the other hand, *generative metaphors* transform and enlarge our understanding through the generation of new meanings that promote reframing or recontextualizing of emotional experiences (Modell, 1997). The capacity to perceive generative metaphors that are not foreclosed but are open and flexible allows for the play of imagination. With generative metaphors, the fluidity and flexibility of metaphoric relationship between past and present contributes to an individual's ability to bounce back from trauma.

<div align="center">Stories, Metaphors, and Meaning in Chronic Illness</div>

Uncertainty has been described as a universal experience in chronic illness (Mast, 1995; Mishel, 1999). Uncertainty creates a period of great disorganization in which a person's conceptions of reality and what it means to be one's self fall apart (Egnew, 2005; Mishel, 1999). Having a chronic illness means not only learning to live with it, but also struggling to maintain control over the defining images of self and over one's life (Charmaz, 1991). In this context, *self* is synonymous with self-concept (Charmaz, 1991). A *self-concept* means the relatively stable, coherent organization of characteristics, attributes, attitudes, feelings, and opinions that a person holds about herself (Charmaz; Gecas, 1982; Turner, 1976).

Losses in physical capacity and functionality mean that a person cannot do what they were used to doing. "Not being the persons they have known themselves to be, they suffer" (Egnew, p. 257). People examine and question their sufferings far more than their joys because the world in some vitally important way no longer makes sense (Baumeister, 1991). Therefore, suffering creates a need for new meaning.

Telling a story of suffering can be a way to create continuity and wholeness in the face of disruption and a way of coming to terms with a changed life (Charmaz, 1999). Life is a series of efforts to adapt to the environment (Baumeister, 1991) and adaptation as "healing is a lifelong journey toward wholeness" (Achterberg, 1990, p. 194). Even though having some incompleteness and uncertainty in our lives is probably inevitable, on the healing journey, coherence or wholeness is the assumption that everything makes sense and is related to our human need for higher meaning (Baumeister, 1991).

The constructing then telling and retelling of a story may yield hidden benefits because the storyteller may learn new ways of managing life that transcend immediate suffering (Charmaz, 1999). A lack or loss of meaning is often the central issue in suffering and unhappiness (Barrett, 1999; Baumeister, 1991). The subjective stories of chronically ill people have meaning and offer them ways of seeing themselves and their situations from new and fresh perspectives (Charmaz). The stories contain wisdom and provide life lessons because the telling evokes reflection and reevaluation, and leads the person toward resolution of loss. "Suffering ceases to be suffering in some way" (Frankl, 1963, p. 179) and may be transcended when invested with meaning congruent with a new sense of personal wholeness (Egnew, 2005).

When people lose their integrative understanding of self and the world that had previously structured their normal everyday life, they often begin an active search for new, higher meaning as they attempt to reintegrate their experiences and make sense of them so as to be able to resume a more normal life (Baumeister, 1991). Cognitive reappraisals continuously mediate the coping process (Lazarus & Folkman, 1984). These

reappraisals transform people's appraised situational meanings and global meanings or valued goals and enduring beliefs about life and the world (Park & Folkman, 1997). Reappraisal can decrease the threatening and harmful aspects of the appraised meaning of an event and, sometimes, even increase its positive aspects. In a similar way, metaphorical language can play a role in facilitating key developmental change by helping people become more aware of their emotions and helping them construct new personal meanings of their experiences (Lyddon, Clay, & Sparks, 2001). Significant change often involves a shift in a person's frame of reference that is organized around a new metaphor. As a result of this reframing, the person has an opportunity to explore alternative perspectives and new possibilities.

In this process, life transitions can be periods of heightened self-reflection involving attempts at meaning-making (Cantor & Kihlstrom, 1987) and offering opportunities for psychological development (Bauer & Bonnano, 2001). When using interactive qualitative research with participant interviews, "the conventional boundaries between research, practical application, personal growth, and transformation can melt away" (Braud, 1998, p. 43). This is true because there can be healing power in the interview process in which the participants may learn more about themselves, more fully integrate and assimilate experience, and work through issues more thoroughly than before. Interviews and autobiographical narratives of individuals with MS have found that positive "turning points" in the process of reconstructing their identity are associated with finding new purpose and meaning in life (Monks & Frankenberg, 1995). The purpose of this article is to explore the metaphors that emerged in the women's stories concerning their struggles with the realities of MS as they transitioned to a more positive

journey of self-healing. Their metaphors may be used as examples of how others can proactively and successfully cope with the realities of their life situations.

## Methods

A qualitative study that combined metaphoric and narrative methods was used to explore the participants' experiences by examining processes and making actions central to the study, and creating abstract interpretive understandings of the data represented by the participants' words (Charmaz, 2006; Strauss & Corbin, 1990). A constructivist approach that viewed data and analysis as created from shared experiences and relationships with participants and other sources of data placed priority on the phenomenon of interest, i.e., coping as self-healing (Charmaz). Some grounded theory concepts and strategies were also used to develop an emergent theory and conceptual model that allowed me to explain the actions that people take in response to their environment and situation (Charmaz; Strauss & Corbin). The emergent model can provide a framework for action (Strauss & Corbin) in helping health educators and other health care professionals develop interventions that facilitate and support the proactive coping and self-healing processes of individuals with chronic illness.

*Participants*

The study participants were seven Caucasian women and one African American woman, ages 30 to 66 years, time since MS diagnosis 5 to 36 years, and length of time waiting for diagnosis less than 1 month to 20 years. Inclusion criteria included a limit on time since diagnosis to at least 2 years because the diagnosis of a chronic disease or the onset of new symptoms "forces" a person to focus on the illness, learn about it, and come

to terms with it, only later being able to focus also on healing through coping (Paterson, 2001, p. 23).  Participants also had interactions with a neurologist and were actively involved in at least one social or professional activity, e.g., an exercise program, working in a job, volunteering with an organization or group, and/or taking a class.  Seven of the women had the relapsing-remitting form of multiple sclerosis.  One woman had suffered only one significant exacerbation and had not been definitively diagnosed with relapsing-remitting MS.

*Researcher as Instrument*

The heart of qualitative research is to develop an understanding of people's actions within a sociocultural context (Morrow & Smith, 2000; Charmaz, 2006).  The researcher becomes a part of the world she studies and the data she collects.  Theories are constructed through past and present involvement and interaction with research practices, people, and perspectives (Charmaz, 2006).  *Theoretical sensitivity* is a researcher attribute that brings together interpersonal perceptiveness and conceptual thinking exhibited in an overall posture of *reflexivity* or self-reflection on the part of the researcher (Fassinger, 2005).  A vital aspect of the reflexivity process is that I, as the researcher, make clear my background and biases (Morrow, 2005).

*Immersion in the setting.*  Entering into the participants' social worlds made it possible for me to form relationships with participants which helped me formulate interview questions that were relevant (Morrow & Smith, 2000).  It also provided a background for viewing the data that adds to the complexity of understanding of the phenomenon of interest.  Establishing rapport with participants and respecting their perspectives and practices (Charmaz, 2006)  increases trust and openness which elicits

better data (Morrow & Smith, 2000).  Such intimacy with the world of the participants

may lead to bias. In qualitative research, bias is seen as an inevitable, positive aspect of

the process (Morrow, 2005).  However, identification of biases and assumptions plays a

critical role in lending credibility to qualitative methodology (Morrow & Smith, 2000).

   *Personal background and interests of the researcher.*  In fall 2005, I took part in a

pilot study in which Tai Chi was taught to people with MS who participate in an exercise

program in Physical Therapy (PT) at the University of Utah (DeMille, Gappmaier,

Trunnell, & Romagosa, 2007; Trunnell, Romagosa, DeMille, & Gappmaier, 2007).  I

interviewed nine participants and transcribed eight interviews.  In fall 2006, I conducted

an independent study with members of this group to observe their casual social behavior.

I attended some monthly lunches of the exercise group and met informally with several of

the participants, one of whom became my gatekeeper to this MS community.  Already

interested in the idea of "healing" as opposed to "curing" because of involvement in an

Integrative Health Network, I believed that this population would be excellent for

examining the phenomenon of healing.

   *Managing bias and subjectivity.*  To manage my bias, I kept analytic and

self-reflective notebooks which allowed me to examine my biases and put them aside or

consciously incorporate them into the analysis (Morrow, 2005).  The practice of self-

awareness and self-reflection ensured that the meanings reported are those of the

participants and not mine (Morrow & Smith, 2000).  *Participant checks*, intended to

establish trustworthiness, were conducted after analysis of data was begun and ensured

that my interpretations reflected the participants' meanings and not my own (Lincoln &

Guba, 1985).

*Trustworthiness.* Trustworthiness, which is compared to the traditional validity applied to quantitative studies, is the conceptual and analytical soundness of a qualitative study (Fassinger, 2005). To ensure trustworthiness, five participants did follow-up interviews to clarify and confirm data from earlier interviews and to critique and confirm my interpretations. Participant checks allow the researcher to share categories and to seek feedback and confirmation on the accuracy of researcher interpretation of the data for results (Charmaz, 2006; Morrow & Smith, 2000; Patton, 1990). All participants were sent an interpretive summary of their overall process in coping with MS along with a request to critique the summary. Additionally, I met with two other student researchers as a peer debriefing team to review and analyze data as well as to critique and corroborate codes and categories (Lincoln & Guba, 1985). They read transcripts and reviewed interpretations, including the successive iterations of the emerging model of the participants' coping and healing process.

*Procedure*

*Sampling and recruitment.* I gained entry into the MS community during participation as a research assistant the MS Tai Chi study described above. Participants were first selected using purposeful sampling to find people who could provide the researcher with rich information about the central research interest (Charmaz, 2006). Two participants from the Tai Chi study volunteered for the present study and were the purposeful sample. Two additional participants from this group were identified through snowball sampling (Patton, 1990). One participant was a personal friend of mine and three participants were referred by people who knew others with MS who met the inclusion criteria. Possible participants were recruited through an introduction letter

describing the study, which included informed consent forms that had been reviewed by the University of Utah IRB.  Consent forms were either mailed to me or signed at the initial interview session.  In order to protect confidentiality, participants were identified in the research records using numbers, e.g.,  Participant 1 or P1.  Pseudonyms were used in the final reports.

*Participant interviews and data collection.*  Grounded theory principles focus on the interpretation of a phenomenon as process and action so that the researcher relies on the participants' words to examine their actions and processes (Charmaz, 2006).  For this reason, the primary source of data was one-on-one digitally recorded, semistructured interviews in which the questions are designed to focus on certain aspects of the individual's experience while being open-ended and nonjudgmental.  Such questions encouraged unanticipated statements and stories to emerge (Charmaz) so that the participant could then take whatever direction and use whatever words they wanted to represent what they had to say (Patton, 1990).

*Data analysis.*  Using grounded theory strategies, data were examined to make analytic interpretations and to develop an emergent theory that was grounded in and explains the particular data.  The data were analyzed in a two phased coding process of initial coding and focused coding (Charmaz, 2006).  *Initial coding* involved naming segments of data and examining the data for analytic ideas which could be used to pursue ideas for further data collection and analysis.  *Focused coding* was more selective and conceptual and involved choosing the most frequent or significant initial codes to help sort, synthesize, organize, and integrate the large amount of data most effectively (Charmaz).  Follow-up interviews were conducted after the identification of potential

focused codes to check the accuracy of interpretations. Overall, codes were assessed for which ones best represented what was happening in the data.

A *constant comparative method* (Glaser & Strauss, 1967) was used to organize, compare, and contrast codes, categories, and subcategories. I used *memo-writing* to analyze data and codes in order to develop categories and subcategories, and to define and conceptualize relationships between categories, experiences, and events (Charmaz, 2006). Categories explain ideas, events, and processes in the data and may subsume common themes and patterns in several codes. This comparative process leads to the construction of a conceptual model.

*Metaphorical and narrative analysis.* The storied qualities of qualitative data derived from interviews represent and contextualize the experiences and personal knowledge of our research participants (Coffey & Atkinson, 1996). People recall and order memories as a series of stories marked by key happenings. Thinking about stories in our data enables us to think creatively about how we interpret data. Exploring stories can alert us to themes that coding may not reveal and can shed light on how participants use language to convey meanings and experiences.

Research is a product of the interaction between the observer and the observed that deals with creating and compiling data and, finally, conferring meaning upon it (Charmaz, 1991; Davis, 1974). Metaphors as a mode of expression provide possibilities for the communication of nuance and completeness of experience that ordinary descriptive language does not (Braud, 1998). Metaphorical imagery that is constructed through the stories in spoken interaction provides a useful way of interpreting textual data (Coffey & Atkinson, 1996). Metaphors are rhetorical devices that serve a particular

purpose for the speaker. Analytical questions then may focus what the person is trying to express, what information she is trying to impart, or how her interests are being served by the use of the metaphor. Analytically, we are interested in the outcome of metaphor in terms of function and in the meaning imparted by the metaphor. In their stories of living with multiple sclerosis, participants in this study used metaphors that demonstrated the self-healing characteristics of confronting the reality of their problem or situation (Bohart & Tallman, 1999; Hanna, 1996, 2002).

## Results

The main story line or core category (Glaser & Strauss, 1967) that emerged from the data was *Confronting Reality*. The need to confront reality everyday was the catalyst that drove the ongoing process of coping and healing. The reality of chronic illness creates great uncertainty that results from "losing the collective myth of a taken-for-granted future as well as the personal belief in sustained health" (Charmaz, 1999, p. 366). In MS, the reality is that people subjectively experience a loss in their sense of having control because they never know how the body will function on a given day and what the future may hold (Charmaz, 1991, 1995). In this study, *self-healing* is a dynamic and proactive experiential process that is driven by the agency and autonomy of the chronically ill individual.

Self-healing in general means confronting and directly experiencing one's problem or situation and allowing oneself to feel strong emotions surrounding that experience (Bohart & Tallman, 1999). Metaphorical language and metaphorical knowing offer people access to their emotions and a means for expressing emotional understandings that may be difficult to express in more literal terms (Lyddon, Clay, &

Sparks, 2001). Metaphors can help in revealing previously held assumptions and in finding new frames of reference. Just as each person has a different way of healing that may be unique to that individual (Bohart & Tallman, 1999; Quinn, 2000), each participant created her own metaphors based on her personal experience with chronic illness. However, in spite of the differences, many of the themes and meanings of the women's metaphors overlapped and corresponded to each other.

*Loss of Control*

The physical losses and impairment of chronic illness intrude upon a person's daily life (Charmaz, 1991, 1995, 1999; Kestenbaum, 1982). In so doing, they undermine and disrupt the person's sense of unity between body, self-identity, and the world by challenging previous assumptions about the relationship among them. Several of the participants used metaphors that suggested their sense of having lost control over what was happening in their lives.

Pat described her early experience of confronting the reality of MS with words that directly expressed this meaning. Her metaphor, "this *low, dark place*" meant "I thought I could change nothing, do nothing, control nothing, everything was being done to me." This "metaphor of opposition" represents an attitude of the self versus body and struggling against rather than with the illness (Charmaz, 1995, p. 658).

If people have previously based their identity and self-respect on being able to exercise control and autonomy as this woman had, losing them creates a sense of a "diminished self," which leads to suffering (Charmaz, 1999, p. 370). Autonomy of self then becomes tied to keeping control of the body. Even though people talk about experiences of suffering, they seldom use the word "suffering" to describe their

experiences and the language of suffering remains implicit (Charmaz). Pat was able to

express her emotional understanding of suffering as a metaphor rather than in literal

terms (Lyddon, Clay, & Sparks, 2001).

When another participant, Barb, was asked to recall specific feelings she first

experienced at diagnosis, she replied that it seemed "like an *impasse* in my life, that I

would have to learn new things, that I was confronted with something that I hadn't

expected." She saw the disease as "a position from which there is no escape" (*Webster's*

*Encyclopedic Dictionary*, 1994, p. 713) implying a loss of control over removing herself

from the situation. However, at the same time, Barb seemed to realize that there was

something she could do by learning "new things" about her situation. With the wisdom

of intuition, she was apparently confronting the reality of her problem, multiple sclerosis.

Pat eventually seemed to have uncovered and challenged her earlier assumptions

(Lyddon, Clay, & Sparks, 2001) when she said that she had come to believe that she

could control herself and her attitude. However, she still seemed to be struggling with

seeing MS in a more positive light when she said she would give the following advice to

someone who had just been diagnosed with MS:

> Even if you're not having symptoms, you need to be on [medication] because it's
> going on, it's bubbling, the *lava is bubbling under the volcano*. Just because
> there's nothing coming out, it's bubbling and you've got to pour some ice cubes
> or whatever on it. You've got to be on something.

In spite of this personal change and growth, Pat was not yet ready to shift to a

generative metaphor (Modell, 1997) for MS. She was still using negative interpretations

of the illness that seemed to emphasize its uncertainty and unpredictability. Even though

she referred negatively to MS as a volcano with lava bubbling underneath, she appears to

be confronting reality and tolerating the uncertainty and ambiguity of her situation with

patience which are indications of her self-healing process (Bohart & Tallman, 1999).

Additionally, the fact that Pat uncovered and challenged her earlier assumptions that she

could do nothing about her situation seems to point to an increasing awareness as she

moved toward proactive coping and self-healing.

*Increasing Awareness for Transformation*

The women's early confrontation with MS was an overall experience of Waking

Up, defined by three initial experiences of Diagnosis, Denial, and Wake-up call.  The

initial confrontation with the illness was receiving a diagnosis of having to live with an

incurable chronic illness, an experience that resulted in a denial period for many of the

women.  Those participants who went through a period of denial early in their

confrontation with MS eventually experienced what Joan called the wake-up call, which

was often an exacerbation of symptoms.  As a disruption in the process, the wake-up

experience meant confronting reality or the problem of living with MS and produced an

increased sense of awareness and hope, both of which are precursors of change (Hanna,

1996, 2002).

Joan talked of her experience of getting "the *wake-up call* going into a full relapse

where I had probably been in remission for 4 years."  She spoke of her increased

awareness as  "a very clear point where I can say the *light bulb clicked* where I [started]

feeling a lot happier, a lot more effective, a lot more capable.  I make a more conscious

effort to be more conscious."  Her metaphors suggested that she saw her process as one

of change and transformation when she likened it to having been "in a *cocoon* for several

years" and "while I wouldn't necessarily call myself *a little caterpillar turning into a*

*butterfly*, I would say that I have woken up."

Joan's metaphors of transformation showed that she experienced creative insight. Rather than being trapped in foreclosed metaphors, she was able to use generative metaphors that allowed her to recontextualize her emotions and to generate new meanings and possibilities (Modell, 1997). Healing has been defined as "the process of bringing together aspects of one's self, body-mind-spirit, at deeper levels of inner knowing, leading toward integration and balance with each aspect having importance and value" (Egnew, 2005, p. 256). With their deeper levels of knowing as evidenced in increased awareness and insight, the women overall recognized that they were capable of changing and engaged in strategies that supported their own change and integration.

*The Drive for Integration*

Having dealt with their diagnoses and achieved some level of increased awareness, the women used certain strategies to proactively cope each day with their illness. When asked what was happening in her life today, Barb who saw her MS as an impasse characterized her life as "*the balancing act*," a metaphor for the "very frustrating" process of "what I prioritize to get done versus what needs to get done and what I'd like to get done." Choices had to be made regarding what needed to be done or what was most important to do because "you can't do everything you wish you could do or be the person you might have been with a little more energy." In using this metaphor, she was adapting to chronic illness by altering her way of living and accommodating herself to physical losses to reunify body and self (Charmaz, 1995). Her adaptation implied that she acknowledged her impairment and represented successful adaptation which meant living with the illness rather than solely for it by engaging in effective self-care and management of physical symptoms (Charmaz, 1991).

To maintain the balancing act, the women employed strategies of Living one day at a time, Focusing on the positive aspects of the experience, and Redefining values or what is most important in life. The women's strategies were employed in what became an Ongoing Struggle with Acceptance. When people struggle *with* illness, they struggle to keep their bodies functioning and their lives as "normal" as possible meaning that they do not give up (Charmaz, 1995, p. 663). Through struggling with illness, they eventually integrate new facts regarding their bodies into their lives and self-concepts (Charmaz, 1991).

Metaphors arose from the women's experiences in struggling to live with the illness rather than struggling against it. Joan who had made arrangements at her job to make it easier to work around her illness was able to describe her balancing act strategy as "*going with the flow* right now and just enjoying everything." Her adaptation became acceptance when she decided to try to flow with the experience of illness rather than struggle against it (Charmaz, 1995). When people cease to struggle *against* illness, they no longer seek to control it and their willingness to surrender and to flow with bodily experience increases. They then view illness as integral to their subjective experiences and as integrated with self-concepts. However silently or tacitly it may occur, surrender is an active, intentional process that leads to acceptance and a new unity between body and self-concept.

These women displayed an understanding that acceptance was necessary when, in Chapter 1, they defined psychological healing as acceptance or some form of acceptance. In learning to accommodate to and live with their illness with acceptance, the women exhibited healing because both are important characteristics in the overall process of

change, transcendence, and self-healing (Bohart & Tallman, 1999; Charmaz, 1991; Egnew, 2005; Kirkpatrick Pinson, Ottens, & Fisher, 2009). People can experience healing and transcend suffering when they reconstruct their identity, reevaluate and find new purpose in life, and revise their life stories to accept and find meaning (Egnew, 2005).

*An Opportunity for Learning*

Four women in this study used various metaphors to imply, in positive terms, that their experience with MS was an opportunity for learning. The search for meaning often includes *benefit-finding,* a process in which people identify positives benefits or positive outcomes as personal growth that has resulted from their stressful experience (Schwarzer & Taubert, 2002). Benefit-finding in terms of coping with stress is a positive reappraisal that involves reinterpreting the stressful event in terms of benefits to one's values, beliefs, and goals (Folkman & Moskowitz, 2004).

*MS as a teacher.* When asked what advice she would give to someone who has just discovered that she has MS, Barb who saw her MS as an impasse told a story of having recently done just that. In her story, she is reframing MS from a negative to a positive, from the enemy to a teacher or mentor while, at the same time, confronting the reality of the chronic illness which, in fact, "you don't get rid of":

> I did meet with someone . . . I did tell her that I saw MS not as a negative thing but as more of what do we have *to learn from it.* So it can be a very positive thing if you take it as more of a *teacher* or a *mentor* who's guiding you down *a new path* to learn new things about life. She actually really liked that because she said that's how she was thinking about doing it, more as a *faith journey* versus something to get rid of because the reality is you don't get rid of it, so to see it as a *teacher* more than your *enemy*.

Barb showed evidence of significant personal change when she revealed a shift in metaphors and an apparent shift in her frame of reference when she spoke of the advice she had given to someone who was recently diagnosed with MS (Carlsen, 1996).  This shift in her frame of reference that was organized around a new metaphor gave her an opportunity to explore alternative perspectives and new possibilities for seeing her situation (Lyddon, Clay, & Sparks, 2001).  Her actions in looking for other paths, modeling behavior, and providing helpful advice are characteristic of transcendence and self-healing (Bohart & Tallman, 1999; Charmaz, 1991). Two other women showed evidence of self-healing in their ongoing struggles with reality and acceptance when they used similar generative metaphors (Modell, 1997) to describe different aspects of MS as a teacher or as being something from which they could learn.

*Listening to the body.*   Camie used teaching metaphors in regard to her values and what MS meant for her in her life.  She talked of MS as a teacher but from the perspective of being an embodied experience:

> It's been my *teacher*.  When you have an illness like that, you pay attention, your illness, your body, to how you're feeling, what's the level of fatigue.  Part of the *teaching of your body* is that if you rest a day or two and just kind of clear your mind so you can be present.  Listen, listen, listen to your body because your body is going to tell you if *you're in tune*.

Camie's embodied experience for her meant paying attention and listening to her body and the teaching of her body because she believed that it could tell her what she needed to do on a day-to-day basis.

*A learning process.*  Kate, when asked how her thoughts and feelings about MS had changed over time, said:

> I watched my mother go through and die of ALS and I thought I'm dealing with a *piece of cake* here.  It's really not *the end of the world*.  I can continue to live a

normal lifespan and there are worse things that could happen to me. My best friend died of cancer. So you watch other things that happen in the world and you realize how fortunate you really are and I view this as more of *a learning proce*ss.

Kate saw her experiences with MS as a learning process, implying that she, too, saw MS as a teacher. She used metaphors to reframe her attitude toward MS and expressed hope for the future after going through the experience of seeing her mother die of ALS. She felt that dealing with MS was a piece of cake and really not the end of the world which made her feel fortunate that she could live a normal lifespan. In feeling fortunate as compared to others, Kate expressed a sentiment similar to all the participants in the study who felt relieved that they were better off than others or that circumstances were not as bad as they could be.

*Learning to appreciate life.* Joan who seemed to be at a different level of self-healing, but was moving successfully through the process, saw her experience with multiple sclerosis as just another aspect or "facet of life" and related MS to a process of learning to appreciate things when life is seen as "a precious gem":

> *The whole thing* is just all about life. It's just another *facet of life* when you look at *life as a precious gem.* This is just a different side, it's not that this one's at all bad, it's still beautiful, it's still pretty but so is this. It's just what I'm *learning*, that you can appreciate a lot of different things, *learning* to appreciate that appreciation.

People such as Joan who have experienced severe stressful events and report that they have gained something positive from the experience often report having a greater appreciation for life (Folkman & Moskowitz, 2004). In spite of being at an earlier level of self-healing, Joan displayed signs of acceptance when she related MS to a learning process in which she was learning to appreciate many different things and even learning to appreciate that appreciation. Joan showed signs of self-healing in her new appreciation

for life (Bohart & Tallman, 1999) when she realized that looking at life as a precious gem meant that her experience with multiple sclerosis was just another facet of life and the whole thing is just all about life.

*Life as a Spiritual Journey*

Camie who seemed to have achieved a relatively high level of self-healing held a broader perspective on her life with MS, using a generative metaphor (Modell, 1997) to describe it as a journey defined by spiritual characteristics:

> The *big picture* is healing for me. Joseph Campbell in the Power of Myth showed that the psyche is not just your individual little *journey* but it's also connected to a *larger view.* I've had a lot of healing in that sense of the deep connectedness and interconnectedness of all beings. Even my own illness, for example, what's going on with our dear Mother Earth, our planet, right now, she is very sick.

Barb, who saw her life as a balancing act and MS as her teacher, also seemed to be engaged in an active search for new, higher meaning in an attempt to reintegrate her experiences and make sense of them (Baumeister, 1991). She talked about the need for living one day at a time, not worrying about the future, and focusing on the positive. The self-healing women used these strategies to varying degrees, depending on where they were in their personal process. For Barb, finding positive aspects in the situation involved the use of the generative metaphor (Modell, 1997) of having faith that there is a much bigger picture. She was, at the same time, reframing her perspective and reevaluating what was most important in her life. Believing that there is a "bigger picture" seemed to lead her to a new appreciation for life:

> I just have to focus on me, on taking care of myself, really not think of future things. I have to give that up and I work hard on not worrying about that because I think by taking care of myself, by taking my meds, and exercising, that's all I can really focus on. The positive has allowed me to focus on what's important. Friends, reading and looking for beauty in the world, focusing on those positive

things. I know that my family support system truly helps. To put my faith in something much bigger than myself. Those are the positive things. I have faith that there is a much *bigger picture*.

As well as focusing on these positive aspects of life, her process also included

redefining life values or what is really most important in life which, in turn, defined "the

bigger picture" for her:

> Certain things that I used to think were important, I just don't think are important at all anymore, those things that the world cares about that truly aren't that important. There is a much *bigger picture* than our bank accounts, our work and the cars we drive and the clothes we wear. To think people make it when they are experiencing life differently, *a different path* and still defining life. That's what interests me more now than the career path and getting things done. So you have to find a different way to give credence to who you are and what you do. I mean there are choices we have to make, where our values are.

Even though she was still struggling with aspects of acceptance, Barb had come to

realize that in chronic illness, you have to find a different way to define your self-worth

and self-respect. Exercising reflective autonomy, Barb knew that she had to make

choices about what she valued most. Her new appreciation for life, taking new pathways,

shifting attention and perspectives, and her ability to change beliefs are all signs of self-

healing (Bohart & Tallman, 1999). She also showed evidence of the transcendence of

illness and the body in separating herself from the symbols of success productivity, and

accomplishment held by society (Charmaz, 1991).

When asked to describe what the bigger things are that she put her faith and

thought into, Barb spoke of the need to listen to those voices and messages that are not

so clear in our culture and:

> I always like the *great voice* here I've listened to or hope to follow or always tended to put off. So I try to listen to that more. I read the Bible a lot and I have faith that there is a much *bigger picture* than the certain things that I used to think were important and I just don't think are important at all anymore. So to listen to

those life messages like the *hidden voices*, the hidden messages of life, that there's so much more than the material world that we see.  To see it as more of a spiritual existence.

Barb, as a self-actualizing person who could transcend her environment, had the ability to turn away from the outer world in order to listen to her inner or hidden voices (Maslow, 1968).  These women with multiple sclerosis answered the research questions by telling their personal stories about how they live with chronic illness and what is has meant for them.  In telling stories, they spontaneously used metaphors and metaphorical concepts.  This use of metaphors in the stories of our students, clients, or patients has important implications for health educators.

Discussion

This chapter explored the metaphors that the women used in their stories of  living and struggling with the realities of MS as they transitioned to a more positive journey of self-healing.  The participants experienced an increased sense of awareness and hope, important precursors of change (Hanna, 1996, 2002).  The women then recognized that they could initiate change and made an effort to find ways to change (Hanna) and cope with their chronic illness.  They were successful in their proactive coping and self-healing process as seen in their use of metaphors and in their behaviors and approaches to living with MS.

Their metaphors told us how they proactively and successfully coped with the realities of their life situations.  Rather than being trapped in foreclosed metaphors, they achieved personal change and growth evidenced in their ability to use generative metaphors that were indicative of transformation (Modell, 1997).  They were able to express their emotional understanding of their experiences with multiple sclerosis in

terms of metaphors rather than in literal terms (Lyddon, Clay, & Sparks, 2001). Shifts in frames of reference were organized around new metaphors that allowed them to place emotions into new contexts and to generate new meanings which in turn provided opportunities to explore alternative perspectives and new possibilities for seeing their situation (Lyddon, Clay, & Sparks, 2001).

Their successful adaptation meant living with the illness rather than solely for it by engaging in effective self-care and management of physical symptoms on a day-to-day basis (Charmaz, 1991, 1995). Furthermore, the participants were self-healing in their learning to accommodate the illness in order to live with and around it (Bohart & Tallman, 1999). Their behaviors of confronting reality and tolerating the uncertainty and ambiguity of their situation with patience were indications of their self-healing process (Bohart & Tallman, 1999). Their adaptation became acceptance when they tried to flow with the illness experience (Charmaz, 1995). This is important because acceptance is one of the most important characteristics of the overall process of change, transcendence, and self-healing (Bohart & Tallman, 1999; Charmaz, 1991; Egnew, 2005; Kirkpatrick Pinson, Ottens, & Fisher, 2009).

*Implications for Practice*

In order to understand how loss and recovery of the body-self unity occurs, we need to understand people's meanings of their bodily experiences which are mediated by their interpretations of ongoing experience that they relate in their narratives (Charmaz, 1995). The participants in this study told stories about the distressing events in their lives that contained wisdom and provided lessons for living (Charmaz, 1999). Their stories enabled them to reflect, reevaluate, and to redirect their thinking. Their use of metaphor

and metaphorical knowing was fundamental to the interpretations that they constructed about their lives, personal challenges, and relationships with others (Lyddon, Clay, & Sparks, 2001).

The meaning and significance of the experiences of chronically ill people extends beyond chronic illness (Charmz, 1991). Other adults who experience crisis and loss will find strong parallels with the experience of ill people. Following disruptions caused by divorce, acute grief, job loss, or substance abuse, people struggle to put their lives back together. The metaphors that people use in telling personal stories offer health educators the possibility of facilitating a significant change process for our students, patients, or clients. By encouraging people to actively explore their metaphors and the meanings of their metaphors, we can help them uncover beliefs and assumptions they hold about their self-concepts, their lives, and the world. Exploration of beliefs provides people with insight and the opportunity to change beliefs that are no longer helpful or productive. They then may be able to discover alternative life metaphors that serve as a bridge to positive change and personal growth (Goncalves, 1994; Lyddon et al.).

Exhibiting the creative perseverance of self-healing by staying with a problem until finding some way to master it (Bohart & Tallman, 1999), one woman said that she would never accept that I am "unable to do anything" and said that there's some way she could find to do something even though she may have to do it differently. She still skis and tandem paraglides with another pilot but would never give those things up because she wanted "that opportunity to see." Overall, health educators can offer people that opportunity to see and empower them to critically examine their metaphorical

experiences and to change their metaphors and interpretations, if necessary, through a process of dialogical interaction with self and others in which new meanings can be constructed.

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CHAPTER 3.  METAPHORICAL SELF-HEALING LESSONS FROM WOMEN WITH

MULTIPLE SCLEROSIS: COPING AND INTEGRATIVE

HEALING IN HEALTH EDUCATION

Abstract

People living with chronic conditions is the greatest health concern for the 21st century.  Chronic illnesses such as multiple sclerosis (MS) create disorganization in people's lives and force them to adapt to an altered body and life.  People use metaphors when they tell personal stories to create meaning, purpose, and coherence for disruptive experiences.  The metaphors examined emerged from stories in qualitative interviews with women who have MS.  A model of the women's coping and healing process which incorporates their metaphors and meanings was developed.  To help facilitate and support individual coping and integrative self-healing, a dialogical health education approach that encourages the use of metaphor and story while nurturing transformative learning is suggested.

"Just be open to us, listen to us.  I think maybe instead of telling so much, they need to hear.  The [health] community needs to just hear.  You have to listen to me to hear what I have to say."  A woman with the incurable chronic illness multiple sclerosis (MS) responded with these words when asked what health professionals should know to better understand what it is like living with MS.  As health educators, we need to honor and to learn about the experiences of people with chronic illness as well as to see them as

the "experts" on living with their illness (Larsen, Lewis, & Lubkin, 2006, p. 32).

People with a chronic illness such as MS repeatedly experience losses of control, identity, and future expectations that create great uncertainty leading to distress and suffering (Charmaz, 1995, 1999). Uncertainty at first creates great disorganization in which a person's sense of unity and conceptions of reality as well as what it means to be one's self fall apart so that they have to reassess who they are and who they can now become (Egnew, 2005; Mishel, 1999). In this context, *self* is synonymous with self-concept (Charmaz, 1991). A *self-concept* means the relatively stable, coherent organization of characteristics, attributes, attitudes, feelings, and opinions that a person holds about herself (Charmaz; Gecas, 1982; Turner, 1976).

People can transcend or move beyond their illness and suffering when they accept their sense of self with illness in the present and the future (Charmaz, 1991, 1995). Through acceptance, uncertainty can be integrated into one's life to become a force that leads to a new life perspective and personal growth through a gradual, nonlinear process of coping and healing. For example, Pakenham (2006) found acceptance to be the strongest and most consistent predictor of positive outcomes and levels of distress when he examined stress and coping antecedents in MS.

Success in coping with MS requires people to acknowledge loss of bodily function and depends on managing stress by managing the illness and the routines it imposes by altering their lives and self to accommodate to physical losses (Charmaz, 1991, 1995). They adapt by trying to accommodate and flow with their experience of illness on a daily basis. Then their identity is not based on the body with disease (Paterson, 2001) and the person learns to live with and around the disease in a process of

self-healing (Bohart & Tallman, 1999).  Self-healing arises from a desire to be effective

in coping with the world and from a capacity for change when needed by developing new

ways of being and behaving through creative and productive thinking (Bohart &

Tallman).

The perception or appraisal of a stressful situation such as living with a chronic

illness is unique to the individual (Folkman & Moskowitz, 2004; Lazarus, 1966; Lazarus

& Folkman, 1984).  The person's subjective perceptions are considered to be the main

factors that determine the quality of the individual's emotional response and the

subsequent coping behaviors and health status of the individual (Lazarus, 1991).  In

emotion-focused coping, the individual attempts to relieve negative emotions associated

with the problem by engaging in distracting activities that may be either negative or

positive, such as using drugs or alcohol versus seeking positive social support (Folkman

& Moskowitz, 2004).

Successful adaptation involves first trying to make sense of a traumatic event and

then finding some benefit in the experience (Janoff-Bulman & Frantz, 1997; Pakenham,

2005).  The meaning-based coping strategy of benefit-finding or trying to find something

positive in the illness experience relates to positive emotions and outcomes (Pakenham).

Being positive is essential to a wellness perspective that includes an appraisal of the

illness as an opportunity for meaningful change in the person's relationship with their

environment and other people (Paterson, 2001).

People tell stories to draw meaning from their sufferings because their world no

longer makes sense and suffering creates a need for new meaning (Baumeister, 1991).

Telling a story of suffering can be a way to create continuity in the face of disruption and

a way of coming to terms with a changed life (Charmaz, 1995) by discovering and illustrating what is true and meaningful for us in our lives (McAdams, 1993). The constructing then telling and retelling of a story may yield hidden benefits because the storyteller may learn new ways of managing life that transcend immediate suffering (Charmaz, 1999).

Although different people have different ways of being, living, and healing, what proactive self-healing people have in common is that they are active creators of circumstances in their own change (Barroso, 1995; Bohart & Tallman, 1999). They take deliberate steps in a struggle to make their lives better. People create change during extraordinary experiences, such as living with MS, using the normal processes by which they change in everyday life (Bohart & Tallman). The processes are three interrelated learning activities of thinking, experiencing, and behaving that feed into each other in a cyclical manner (Kolb, 1984). Thinking, experiencing, and behaving lead to certain outcomes that, in turn, can lead to problem resolution and personal change (Bohart & Tallman).

*Thinking* begins with the articulation of experience into words and symbols as people try to fit concepts and words to their experiences, many of which are nonverbal (Lakoff, 1987; Pennebaker, 1995). Human beings understand the world through two modes of thought, paradigmatic and narrative (Bruner, 1990). Paradigmatic thinking uses reason, logic, and empirical observation to understand experience, but it is not able to make sense of human desire, goals, social conduct, and the ambiguity of human events (Bruner; McAdams, 1993). On the other hand, narrative thinking, which is the mode of stories, deals with human wants, needs, intentions, and goals. Stories are not only

constructed to make sense of disruptive experiences (Bruner; Bohart & Tallman, 1999),

they may also "mend us when we are broken, heal us when we are sick, and even move

us toward psychological fulfillment and maturity" (McAdams, p. 31).

Cognitive scientists believe that experiencing is grounded in perception and that

conceptualizing or thinking comes later (Barsalou & Prinz, 1997).  Thinking that results

from direct encounter and observation of experience seems to be particularly important

(Bohart & Tallman, 1999).  Therefore, thinking seems to be most productive when there

is a dialogue between thinking and experience or between thinking and behaving (Bohart

& Tallman).

*Experiencing* is our most basic mode of knowing the world and comes through

direct interaction and encounter with the world (Bohart & Tallman, 1999; Lakoff, 1987).

Experiencing and experiential knowing possesses bodily, emotional, and perceptual

components.  Experience is grounded in perception which is more direct and immediate

than thought (Bohart & Tallman).  Through perception people recognize or actually "see"

how to do something, which is a more powerful learning experience than merely

acquiring a concept about something.

People know things through experiences that are not thought by intuitively

sensing patterns from their direct experiential encounters and interactions (Bohart &

Tallman, 1999).  Although this knowing is nonconceptual in nature, concepts are derived

from experience when people attempt to articulate their experience in words and try to

understand their experience (Bohart & Tallman; Lakoff, 1987).  Change occurs when a

person reaches an experiential recognition of meanings because true insight is based

primarily in perception and recognition, and only secondarily in conceptualization

(Bohart & Associates, 1996; Schooler, Fallshore, & Fiore, 1995). When people are actively trying to change themselves, they need to be able to explore both experientially and conceptually, using both the internal and external dimensions of experiencing (Bohart & Tallman).

The external involves having both extraordinary and everyday experiences in the outside world (Bohart & Tallman, 1999). Internal experiencing occurs when people track their own life experiences in talking or writing about them). Tracking can also include vicariously experiencing through imagination. What is common in both instances is a move into a mental state of observing and listening to oneself, rather than engaging in an intellectualized self-analysis. In tracking and following internal experience, allowing and experiencing of emotion appears to be an important component (Greenberg & Paivio, 1997). To be really exploring and confronting a problem means also to be open to experiencing emotion (Bohart & Tallman). The experiencing of emotions is part of accessing the meaning of experience and people learn directly and change by trying out new behaviors and facing fears.

*Behaving* means trying out new behaviors in the outside world as well as practicing and learning new skills for self-management and for coping with the environment (Bohart & Tallman, 1999). Behavioral experimentation in the real world opens up new possibilities and has a much more potent experiential effect on a person than does cognitive insight or explanation. Behavioral experiences of efficacy and skills training are ways of exploring one's ability to master and have some control over one's life (Bandura, 1997).

The purpose of this article is to suggest health education methods and techniques that involve thinking, experiencing, and behaving to explore people's stories and metaphors about living with chronic illness. The suggestions were generated from the results of two studies and are based on lessons learned from women with multiple sclerosis. The qualitative study used one-on-one interviews and grounded theory principles to derive a model of the women's proactive coping and self-healing. The second study was a qualitative analysis that specifically examined the women's metaphors about living with the realities of MS and their transitions to a positive journey of integration and self-healing. In this study, *self-healing* is a dynamic and proactive experiential process that is driven by the chronically ill individual. The following section discusses methods that can be adapted by health educators in developing interventions that facilitate and support personal growth, change, and self-healing.

<div align="center">Facilitating Personal Growth and Change</div>

Interviews and autobiographical narratives of individuals with MS have found that positive "turning points" in the process of reconstructing their identity are associated with finding new purpose and meaning in life (Monks & Frankenberg, 1995). In this process, life transitions can be periods of heightened self-reflection involving attempts at meaning making (Cantor & Kihlstrom, 1987) and offering opportunities for development (Bauer & Bonnano, 2001). In some instances, the opportunity and the experience of telling one's story in one's own voice can prove to be an experience of healing power and personal growth (Braud, 1998; McAdams, 1993). At critical transition points when the status quo is challenged, interventions are believed to be the most effective for enhancing

optimal growth and coping (Arnold & Breen, 2006; Cowan & Cowan, 2003). Support in this process increases the effectiveness of the individual's experiences.

*Telling Stories and Using Metaphors*

When people lose their integrative understanding of self and the world that previously structured their normal everyday life, they often begin an active search for new, higher meaning as they try to reintegrate their experiences and make sense of them so that they are able to resume a more normal life (Baumeister, 1991). People shape their autobiographical narratives or stories to maximize their own sense of control and efficacy (Baumeister & Newman, 1994). Using stories as a means of interpretation may contribute to a sense of control because understanding something gives people a sense of control over it, even if there is nothing they can do to alter it (Rothbaum, Weisz, & Snyder, 1982). This may in some ways allow them to retain their faith in being able to control the future (Baumeister & Newman).

Analysis of narrative data has revealed that women with MS appear to move through a phase of turmoil and distress when first confronted with the chronic illness (Koch & Kralik, 2001). However, overtime many women make a transition toward incorporating the illness into their lives. Telling their story may be the turning point that enhances the participants' lives because stories are more about meaning than about conveying fact (McAdams, 1993). In a stressful situation such as degenerative MS when the possibility of control is low, the negative effects of stress may be buffered by responses that control the meaning of the situation (Park & Folkman, 1997). The stories that chronically ill people tell have meaning, contain wisdom, provide life lessons, and offer them ways of seeing themselves and their situations from new perspectives

(Charmaz, 1999). Furthermore, the telling of stories facilitates reflection and reevaluation that leads the person toward resolution of loss.

Within our stories, we use metaphors to convey meaning and motives (Coffey & Atkinson, 1996) and to construct and reconstruct personal meaning for our experiences (Carlsen, 1996). When we allow ourselves to write spontaneously, unexpected associations and connections occur (Metzger, 1992). The core of these connections is metaphor. Metaphors and metaphorical knowing can play a significant role in accessing and symbolizing emotions, in uncovering and challenging tacit assumptions, and in introducing new frames of reference (Lyddon, Clay, & Sparks, 2001). Metaphors may be useful tools for helping people access and represent emotions that may have been previously unexpressed, unexplored, or unrecognized (Fox, 1989). Through the use of metaphor, we generate new perceptions of the world and we organize and make sense out of experience (Modell, 1997).

Therapists have found that two types of metaphors arise when counseling clients, foreclosed metaphors and generative metaphors (Modell, 1997). *Foreclosed metaphors* are fixed, unambiguous, unchanging, and can be found operating in traumatic memories with intense negative emotions. However, when traumatic experiences remained fixed are not put into a new context or reframed they can continue to exert a negative influence as when someone repeatedly refers to painful experiences. On the other hand, *generative metaphors* transform and enlarge our understanding through the generation of new meanings that promote reframing of emotional experiences (Modell). The capacity to perceive generative metaphors allows for the use of flexibility and imagination which contributes to an individual's ability to bounce back from trauma.

Because many concepts that are important to us are abstract or not clearly delineated in our experience, we gain understanding of them by means of other concepts that we understand more clearly (Lakoff & Johnson, 1980). Metaphor may be seen as a means by which people understand an abstract domain of experience in terms of a more concrete domain of experience (Kövecses, 2002). For example, the metaphorical idea that LIFE IS A JOURNEY uses the concrete concept of "a journey" to better understand the abstract concept "life." One way that health educators can help people explore their metaphorical experiences and learn from them is through writing assignments.

*Expressive Writing and Disclosure*

Emotional writing reveals people's natural abilities to construct stories and there is little doubt that writing stories about emotional upheavals result in improved physical and mental health (Ramírez-Esparza & Pennebaker, 2006). Expressive writing in which people disclose stories of personal traumatic experiences has been shown to have a positive influence on health, biological activity, emotions, and behaviors. Three linguistic features in stories predict health improvements. First, the more people use positive-emotion words and moderate levels of negative-emotion words, the more health improves (Pennebaker, Mayne, & Francis, 1997). Even people who write about horrible experiences but still use words like love, care, and happy are better off than those who do not use positive emotion words, suggesting that the person is thinking along an overall positive line reflecting a process of optimism. Second, evidence from multiple studies suggests that the use of cognitive words that are associated with *causality*, such as because or reason, and *insight*, such as understand or realize, are linked to improved health (Ramírez-Esparza & Pennebaker). Lastly, as time progresses, people who switch

pronouns from first person to third person, indicating that they are becoming more aware of others and less focused on self, are more likely to subsequently have better health reflecting the changing perspective of the writers.

*Using Dialogue to Create Meaning*

When we provide our participants with the opportunity to describe their life experiences, the interaction becomes a learning process for both the health educator and the participant (Braud, 1998). Health educators, like therapists, can participate in co-constructive dialogue with patients, students, or clients (Bohart & Tallman, 1999). The opportunity offered to people to speak with their own voices has a healing power (Braud). This is especially true when a relevant and important topic offers people the opportunity to learn more about themselves so that they may more fully integrate their experiences and work through important issues more thoroughly than before. Researchers have used a dialogical interpretive approach to collaborative inquiry that focuses on meaning-making to understand what is important to women living with MS and how they live well with the chronic illness (Koch & Kralik, 2001). The use of dialogue offers health educators an opportunity to create a culture of healing.

Learning as an adult is closely related to the context and experience of adult life (Merriam, 1994). Learning from life experience means giving attention to and reflecting upon experience for purposes of meaning-making and to satisfy the need to make sense of our life events. If an experience is unsettling or incongruous to our current meaning structure and we choose to work or struggle with it, learning results (Mezirow, 1991). The only expert on the participant and her experience is the participant herself (Bohart & Tallman, 1999; Larsen, Lewis, & Lubkin, 2006). The expertise of the health educator

consists of (a) helping people identify and clarify their problems, (b) helping them define potential solutions and pathways for change, and (c) helping them find ways of accomplishing change.

Ideally, teaching adult learners should be a democratic, dialogic process (Lee, 1994). *Dialogue*, which is more than conversation, occurs when two or more speakers engage in an exploratory activity directed toward new understanding of the world, self, and others, and toward the acquisition of knowledge, insight, and sensitivity. In *external dialogue*, teachers and learners cooperate as partners in creating and sharing knowledge and the teacher's responsibility is to ensure that everyone has a voice in the dialogical process. The teacher-of-the-students emerges as a "teacher-student" while the student-of-the-teacher become "students-teachers" (Freire, 1971). Their interactions lead to mutual respect, trust, and concern as a community of learners (Miller, 1999; Burbules, 1993).

The heart of holistic education is dialogue, connection, and mutual creation of meaning (Miller, 1999) with knowledge as "a medium evoking the critical reflection of both teacher and students" (Freire, 1971, p. 67). As opposed to didactic talk, where is no attempt by participants to come together to share and to arrive at a new understanding, the ideal conditions for reflective discourse and dialogue are the *real talk* of *connected knowing* characterized by careful and attentive listening, exploration, questioning, speculation, and sharing (Belenky, Clinchy, Goldberger, & Tarule, 1986, p. 144; Mezirow, 2000). Using dialogue and connected knowing, health educators can create the environment for *transformative learning* founded upon reflection and interpretation of experiences, ideas, and assumptions based on prior learning (Mezirow).

The foundation for transformative learning is a change process of meaning-making where taken-for-granted frames of references, i.e. meaning perspectives, mind-sets, and habits of thinking, are transformed and made more open, inclusive, discriminating, reflective, and "emotionally capable of change" (Mezirow, 2000, p. 8). Individuals become more aware of their own purposes, values, feelings, and meanings, as opposed to what they have acquired from other individuals and society in general. They gain greater control over their lives as clear-thinking decision makers.

When using dialogue in teaching, we do not change other people, they change or transform themselves (Burbules, 1993). Teachers can facilitate the process by setting the stage to start and encourage dialogue, but participants construct their own meanings, not only in external dialogue but also in internal dialogue. *Internal dialogue* occurs when individuals think by themselves about another person's advice, opinion, or knowledge (Staudinger & Baltes, 1996). However, the more dynamic dialogical self also has the capacity to place itself in multiple positions for thinking thus creating a potential for self-change, self-innovation, and self-renewal (Hermans, 1996). This internal *positioning* and *repositioning* offers the possibility for an emergence of new knowledge resulting from an internal dialogical interchange (p. 43).

In transformative learning, roles shift back and forth and there is a potential for all participants to learn from the process (Burbules, 1993). Although a cognitive interest in knowing is essential, participants also share feelings toward one another. Then concern and commitment draw them into the dialogue and hold them there. To use dialogue effectively, teachers must be willing to take risks and to be as vulnerable as they encourage their students to be vulnerable (Tassoni & Tayko, 1997).

Ultimately, the learning that occurs is a collaborative product of the active and creative efforts of the participants, students, or clients, supported by a facilitator, be that a therapist or a health educator (Bohart & Tallman, 1999). The single best thing we as health educators can do to establish a collaborative environment for self-healing is to engage in respectful listening. Respectful listening means we take participants' ideas seriously, as if they are worthy of consideration and thought. Being interviewed begins a dialogue. The following section presents and explores metaphors that emerged from listening to qualitative research participants as they told their stories of living with and coping with multiple sclerosis.

<div align="center">Lessons Learned from Women with Multiple Sclerosis</div>

The main story line or core category (Glaser & Strauss, 1967) that emerged from the data was *Confronting Reality*. In their stories of living with multiple sclerosis, the women used metaphors that demonstrated the self-healing characteristics of confronting the reality of their problem or situation (Bohart & Tallman, 1999; Hanna, 2002). The need to confront reality everyday was the catalyst that drove the ongoing process of coping and healing. In this study, *self-healing* is a dynamic and proactive experiential process that is driven by the agency and autonomy of the chronically ill individual. The reality of chronic illness creates great uncertainty that results from "losing the collective myth of a taken-for-granted future as well as the personal belief in sustained health" (Charmaz, 1999, p. 366). In MS, the reality is that people subjectively experience a loss in their sense of having control because they never know how the body will function on a given day and what the future may hold (Charmaz, 1991, 1995).

Self-healing in general means confronting and directly experiencing one's problem or situation and allowing oneself to feel strong emotions surrounding that experience (Bohart & Tallman, 1999). Metaphorical language and metaphorical knowing offer people access to their emotions and a means for expressing emotional understandings that may be difficult to express in more literal terms (Lyddon, Clay, & Sparks, 2001). Metaphors can help in revealing previously held assumptions and in finding new frames of reference. Just as each person has a different way of healing that may be unique to that individual (Bohart & Tallman; Quinn, 2000), each participant came up with her own metaphors based on her personal experience with chronic illness. However, in spite of the differences, many of the themes and meanings of the women's metaphors overlapped and corresponded to each other. Figure 2 presents a model of the women's process with their metaphors appearing in italics and the themes or meanings of the metaphors in bold italics. The nonitalicized words are findings from the qualitative study in chapter one.

*Loss of Control*

The women's early confrontation with MS consisted of receiving a diagnosis, sometimes followed by a period of denial. The threat or presence of physical losses and impairment from MS intrude upon a person's daily life (Charmaz, 1991, 1995, 1999). In so doing, they undermine and disrupt the person's sense of unity between body, self-identity, and the world by challenging previous assumptions about the relationship among them. Several of the participants used metaphors that suggested their sense of having lost control over what was happening in their lives.

**CONFRONTING REALITY**

**Loss of Control**
Diagnosis – Denial
*Low, dark place*
*Impasse*
Uncertainty
*Lava is bubbling under the volcano*

**Increasing Awareness for Transformation**
Wake-up Call
*The light bulb clicked*
*A caterpillar in a cocoon turning into a butterfly*

**The Drive for Integration**
Living in present
Focusing on positive
Redefining values
*Balancing Act*
*Going with the flow*

**Life as a Spiritual Journey**
Transcendence as Self-Healing
Reflective autonomy
Reframing perspective
*The bigger picture*

**An Opportunity for Learning**
Struggle with Acceptance
Acceptance as Self-Healing
*MS as a teacher*
*A learning process*

**RELATEDNESS**
Giving and Receiving Social Support
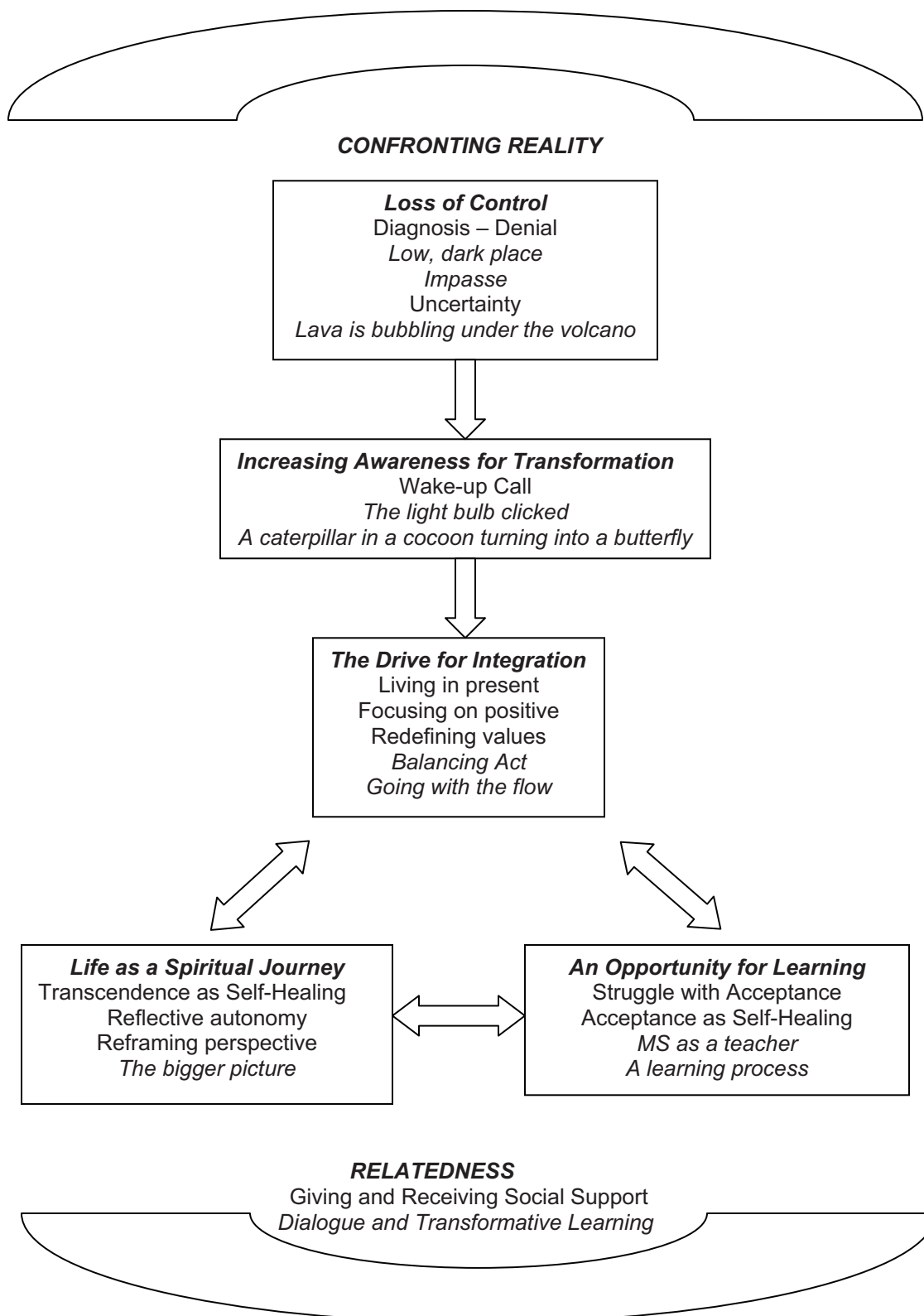*Dialogue and Transformative Learning*

*Figure 2.* Metaphors, themes, and meaning of self-healing in women with MS

Pat described her early experience of confronting the reality of MS with words that directly expressed this meaning. Her metaphor, "this *low, dark place*" meant "I thought I could change nothing, do nothing, control nothing, everything was being done to me." This "metaphor of opposition" represents an attitude of the self versus body and struggling against rather than with the illness (Charmaz, 1995, p. 658).

If people have previously based their identity and self-respect on being able to exercise control and autonomy as this woman had, losing them creates a sense of a "diminished self" which leads to suffering (Charmaz, 1999, p. 370). Autonomy of self then becomes tied to keeping control of the body. Even though people talk about experiences of suffering, they seldom use the word "suffering" to describe their experiences and the language of suffering remains implicit (Charmaz). Pat was able to express her emotional understanding of suffering as a metaphor rather than in literal terms (Lyddon, Clay, & Sparks, 2001).

When another participant, Barb, was asked to recall specific feelings she first experienced at diagnosis, she replied that it seemed "like an *impasse* in my life, that I would have to learn new things, that I was confronted with something that I hadn't expected." She saw the disease as "a position from which there is no escape" (*Webster's Encyclopedic Dictionary*, 1994, p. 713) implying a loss of control over removing herself from the situation. However, at the same time, Barb seemed to realize that there was something she could do by learning "new things" about her situation. With the wisdom of intuition, she was apparently confronting the reality of her problem, multiple sclerosis.

Pat eventually seemed to have uncovered and challenged her earlier assumptions (Lyddon, Clay, & Sparks, 2001) when she said that she had come to believe that she

could control herself and her attitude. However, she still seemed to be struggling with

seeing MS in a more positive light when she said she would give the following advice to

someone who had just been diagnosed with MS:

> Even if you're not having symptoms, you need to be on [medication] because it's going on, it's bubbling, the *lava is bubbling under the volcano*. Just because there's nothing coming out, it's bubbling and you've got to pour some ice cubes or whatever on it. You've got to be on something.

In spite of this personal change and growth, Pat was not yet ready to shift to a

generative metaphor (Modell, 1997) for MS. She was still using negative interpretations

of the illness that seemed to emphasize its uncertainty and unpredictability. Even though

she referred to MS as a volcano with lava bubbling underneath, she appears to be

confronting reality and tolerating the uncertainty and ambiguity of her situation with

patience which are indications of her self-healing process (Bohart & Tallman, 1999).

Additionally, the fact that Pat uncovered and challenged her earlier assumptions that she

could do nothing about her situation seems to point to an increasing awareness as she

moved toward proactive coping and self-healing.

*Increasing Awareness for Transformation*

The initial confrontation with the illness was receiving a diagnosis of having to

live with an incurable chronic illness, an experience that resulted in a denial period for

many of the women. Those participants who went through a period of denial early in

their confrontation with MS eventually experienced what Joan called the wake-up call.

The wake-up call was often an exacerbation of symptoms. As a disruption in the process,

The wake-up experience meant confronting reality or the problem of living with MS and

produced an increased sense of awareness and hope, both of which are precursors of change (Hanna, 2002).

Joan talked of her experience of getting "the *wake-up call* going into a full relapse where I had probably been in remission for 4 years." She spoke of her increased awareness as "a very clear point where I can say the *light bulb clicked* where I [started] feeling a lot happier, a lot more effective, a lot more capable. I make a more conscious effort to be more conscious." Her metaphors suggested that she saw her process as one of change and transformation when she likened it to having been "in a *cocoon* for several years" and "while I wouldn't necessarily call myself *a little caterpillar turning into a butterfly*, I would say that I have woken up."

Joan's metaphors of transformation showed her to be more insightful. Rather than being trapped in foreclosed metaphors, she was able to use generative metaphors that allowed her to recontextualize her emotions and to generate new meanings and possibilities (Modell, 1997). Healing has been defined as "the process of bringing together aspects of one's self, body-mind-spirit, at deeper levels of inner knowing, leading toward integration and balance with each aspect having importance and value" (Egnew, 2005, p. 256). With their deeper levels of knowing as evidenced in increased awareness and insight, the women overall recognized that they were capable of changing and engaged in strategies that supported their own change and integration.

*The Drive for Integration*

Having dealt with their diagnoses and, perhaps, denial, the women achieved some level of increased awareness and used certain strategies to proactively cope each day with their illness. When asked what was happening in her life today, Barb who saw her MS as

an impasse characterized her life as "*the balancing act*," a metaphor for the "very frustrating" process of "what I prioritize to get done versus what needs to get done and what I'd like to get done." Choices had to be made regarding what needed to be done or what was most important to do because "you can't do everything you wish you could do or be the person you might have been with a little more energy." In using this metaphor, she was adapting to chronic illness by altering her way of living and accommodating herself to physical losses to reunify body and self (Charmaz, 1995). Her adaptation implied that she acknowledged her impairment and represents successful adaptation which means living with the illness rather than solely for it by engaging in effective self-care and management of physical symptoms (Charmaz, 1991).

To maintain the balancing act, the women employed strategies of Living one day at a time, Focusing on the positive aspects of the experience, and Redefining values or what is most important in life. The women's strategies were employed in what became an Ongoing Struggle with Acceptance. When people struggle *with* illness, they struggle to keep their bodies functioning and their lives as "normal" as possible meaning that they do not give up (Charmaz, 1995, p. 663). Through struggling with illness, they eventually integrate new facts regarding their bodies into their lives and self-concepts (Charmaz, 1991).

Metaphors arose from the women's experiences in struggling to live with the illness rather than struggling against it. Joan who had made arrangements at her job to make it easier to work around her illness was able to describe her balancing act strategy as "*going with the flow* right now and just enjoying everything." Her adaptation became acceptance when she decided to try to flow with the experience of illness rather than

struggle against it (Charmaz, 1995). When people cease to struggle *against* illness, they no longer seek to control it and their willingness to surrender and to flow with bodily experience increases. They then view illness as integral to their subjective experiences and as integrated with self-concepts. However silently or tacitly it may occur, surrender is an active, intentional process that leads to acceptance and a new unity between body and self-concept.

These women displayed an understanding that acceptance was necessary when, in Chapter 1, they defined psychological healing as acceptance or some form of acceptance. In learning to accommodate to and to live with their illness with acceptance, the women exhibited healing because both are important characteristics in the overall process of change, transcendence, and self-healing (Bohart & Tallman, 1999; Charmaz, 1991; Egnew, 2005; Kirkpatrick Pinson, Ottens, & Fisher, 2009). People can experience healing and transcend suffering when they reconstruct their identity, reevaluate and find new purpose in life, and revise their life stories to accept and find meaning (Egnew).

*An Opportunity for Learning*

Four women in this study used various metaphors to imply, in positive terms, that their experience with MS was an opportunity for learning. The search for meaning often includes *benefit-finding,* a process in which people identify positives benefits or positive outcomes as personal growth that has resulted from their stressful experience (Schwarzer & Taubert, 2002). Benefit-finding in terms of coping with stress is a positive reappraisal that involves reinterpreting the stressful event in terms of benefits to one's values, beliefs, and goals (Folkman & Moskowitz, 2004).

*MS as a teacher and listening to the body.* When asked what advice she would give to someone who has just discovered that he or she has MS, Barb who saw her MS as an impasse told a story of having recently done just that. In her story, she is reframing MS from a negative to a positive, from the enemy to a teacher or mentor while, at the same time, confronting the reality of the chronic illness which, in fact, "you don't get rid of":

> I did meet with someone . . . I did tell her that I saw MS not as a negative thing but as more of what do we have *to learn from it*. So it can be a very positive thing if you take it as more of a *teacher* or a *mentor* who's guiding you down *a new path* to learn new things about life. She actually really liked that because she said that's how she was thinking about doing it, more as a *faith journey* versus something to get rid of because the reality is you don't get rid of it, so to see it as a *teacher* more than your *enemy*.

Barb showed evidence of significant personal change when she revealed a shift in metaphors and an apparent shift in her frame of reference when she spoke of the advice she had given to someone who was recently diagnosed with MS (Carlsen, 1996). This shift in her frame of reference that was organized around a new metaphor gave her an opportunity to explore alternative perspectives and new possibilities for seeing her situation (Lyddon, Clay, & Sparks, 2001). Her actions in looking for other paths, modeling behavior, and providing helpful advice are characteristic of transcendence and self-healing (Bohart & Tallman, 1999; Charmaz, 1991).

In order to understand how loss and recovery of the body-self unity occurs, we need to understand people's meanings of their bodily experiences which are mediated by their interpretations of ongoing experience that they relate in their narratives (Charmz, 1995). Camie expressed ideas similar to Barb's regarding her values and what MS meant

for her in her life when she talked of MS as a teacher but from the perspective of being an

embodied experience:

> It's been my *teacher*.  When you have an illness like that, you pay attention, your illness, your body, to how you're feeling, what's the level of fatigue.  Part of the *teaching of your body* is that if you rest a day or two and just kind of clear your mind so you can be present.  Listen, listen, listen to your body because your body is going to tell you if *you're in tune*.

Camie's embodied experience for her meant paying attention and listening to her

body and the teaching of her body because she believed that it could tell her what she

needed to do on a day-to-day basis.  Other particpants showed evidence of self-healing in

their ongoing struggles with reality and acceptance when they used generative metaphors

(Modell, 1997) in viewing different aspects of MS as a teacher or as being something

from which they could learn.

*A learning process and learning to appreciate life.*  Kate, when asked how her

thoughts and feelings about MS had changed over time, said:

> I watched my mother go through and die of ALS and I thought I'm dealing with a *piece of cake* here.  It's really not *the end of the world*.  I can continue to live a normal lifespan and there are worse things that could happen to me.  My best friend died of cancer.  So you watch other things that happen in the world and you realize how fortunate you really are and I view this as more of *a learning proce*ss.

Kate saw her experiences with MS as a learning process, implying that she, too,

saw MS as a teacher.  She used metaphors to reframe her attitude toward MS and

expressed hope for the future after seeing her mother die of ALS.  In comparison, Kate

felt that dealing with MS was a piece of cake and not the end of the world which made

her feel fortunate that she could live a normal lifespan.  She also felt fortunate as

compared to others, a response similar to all the participants in the study who felt relieved

that they were better off than others or that their circumstances were not as bad as they could be.

Joan who seemed to be at a different level of self-healing, but was moving successfully through the process, saw her experience with multiple sclerosis as just another aspect or "facet of life" and related MS to a process of learning to appreciate things when life is seen as "a precious gem":

> *The whole thing* is just all about life. It's just another *facet of life* when you look at *life as a precious gem.* This is just a different side, it's not that this one's at all bad, it's still beautiful, it's still pretty but so is this. It's just what I'm *learning*, that you can appreciate a lot of different things, *learning* to appreciate that appreciation.

People such as Joan who have experienced severe stressful events and report that they have gained something positive from the experience often report having a greater appreciation for life (Folkman & Moskowitz, 2004). Joan displayed signs of acceptance and self-healing when she related MS to a learning process in which she was learning to appreciate many different things (Bohart & Tallman, 1999). In her new appreciation for life, she realized that looking at life as a precious gem meant that her experience with multiple sclerosis was just another facet of that life. Overall, in learning acceptance, the participants trusted in their intuition and persevered in their reflective process of self-healing (Bohart & Tallman).

*Life as a Spiritual Journey*

Camie who seemed to have achieved a relatively high level of self-healing held a broader perspective on her life with MS, using a generative metaphor (Modell, 1997) to describe it as a journey defined by spiritual characteristics:

The *big picture* is healing for me. Joseph Campbell in the Power of Myth showed that the psyche is not just your individual little *journey* but it's also connected to a *larger view*. I've had a lot of healing in that sense of the deep connectedness and interconnectedness of all beings. Even my own illness, for example, what's going on with our dear Mother Earth, our planet, right now, she is very sick.

Barb, who saw her life as a balancing act and MS as her teacher, also seemed to be engaged in an active search for new, higher meaning in an attempt to reintegrate her experiences and make sense of them (Baumeister, 1991). For Barb, finding positive aspects in the situation involved the use of the generative metaphor (Modell, 1997) of having faith that there is a much bigger picture. While reframing her perspective and reevaluating what was most important in her life, her process seemed to lead her to a new appreciation for life:

> I just have to focus on me, on taking care of myself, really not think of future things. I have to give that up and I work hard on not worrying about that because I think by taking care of myself, by taking my meds, and exercising, that's all I can really focus on. The positive has allowed me to focus on what's important. Friends, reading and looking for beauty in the world, focusing on those positive things. I know that my family support system truly helps. To put my faith in something much bigger than myself. Those are the positive things. I have faith that there is a much *bigger picture*.

Focusing on these positive aspects of life and redefining what was really most important in life defined "the bigger picture" for her:

> Certain things that I used to think were important, I just don't think are important at all anymore, those things that the world cares about that truly aren't that important. There is a much *bigger picture* than our bank accounts, our work and the cars we drive and the clothes we wear. To think people make it when they are experiencing life differently, *a different path* and still defining life. That's what interests me more now than the career path and getting things done. So you have to find a different way to give credence to who you are and what you do. I mean there are choices we have to make, where our values are.

Even though she was still struggling with aspects of acceptance, Barb had come to realize that in chronic illness, you have to find a different way to define your self-worth and self-respect. She knew that she had to make choices about what she valued most.

Her new appreciation for life, taking new pathways, shifting attention and perspectives, and her ability to change beliefs are all signs of self-healing (Bohart & Tallman, 1999). She also showed evidence of reflective autonomy and transcendence of illness and body in separating herself from the symbols of success productivity, and accomplishment held by society (Charmaz, 1991).

When asked to describe what the bigger things are that she put her faith and thought into, Barb appeared to be reintegrating her experience when she spoke of the need to listen to those voices and messages that are not so clear in our culture:

> I always like the *great voice* here I've listened to or hope to follow or always tended to put off. So I try to listen to that more. I have faith that there is a much *bigger picture* than the certain things that I used to think were important and I just don't think are important at all anymore. So to listen to those life messages like the *hidden voices*, the hidden messages of life, that there's so much more than the material world that we see. To see it as more of a spiritual existence.

These women with multiple sclerosis answered the research questions by telling their personal stories about how they live with chronic illness and what is has meant for them. In telling stories, they spontaneously used metaphors and metaphorical concepts to create meaning. Although they had different ways of being, living, and healing, as proactive self-healing people they were all creators of circumstances for change and agents of change in their own lives (Barroso, 1995; Bohart & Tallman, 1999). The women's interviews suggest that using stories and metaphor can have important implications for health educators in developing interventions to support individual coping and healing processes. The next section suggests a three-step dialogical approach that health educators may adapt for teaching by having participants write stories and then identify and explore metaphors.

An Application for Health Education Practice

The objective of using stories, metaphors, and dialogue in interventions for people with chronic conditions is to help them become aware of how they view and feel about their illness and how that subsequently can affect their behavior.  With support from health educators, individuals can develop skills for more effective coping strategies so that they can become agents of change and creators of positive circumstances in their own lives.  A three-step approach is suggested based on a dialogic interpretive approach to meaning-making that has been effectively used by Koch & Kralik (2001) to examine how women live well with MS.  This application is operationalized in three steps known as looking, thinking, and acting (Koch & Kralik, 2001; Stringer, 1996) which are directly related to the three cyclical learning activities of thinking, experiencing, and behaving (Bohart & Tallman, 1999; Kolb, 1984).

*Looking* entails gathering information to define and describe the situation to be explored to acquire a preliminary understanding of the individual's chronic illness experience (Koch & Kralik, 2001).  After presenting didactic information on stories and storytelling, health educators can encourage the telling of participants' personal stories beginning with writing exercises.  Looking involves the everyday learning activity of internal experiencing when, through talking and writing, the individual tracks their own experiences with chronic illness.  This first step of looking can be a preassessment exercise to find out if and how the participants use metaphor in telling stories about their experiences.

Writing can be prompted by a series of guiding questions relevant to their experience that encourage them to describe in detail what their day-to-day life is like.

For example, one participant was asked: What is happening in your life today and what experiences are you having at the present time?  What are the most negative and positive things in living with MS?  She responded with her story about needing to maintain "the balancing act" by prioritizing what she needed to get done as opposed to what she would like to do.  This balancing act is necessary, she explained, because people with MS have problems with overwhelming fatigue.

*Thinking* involves exploring, reflecting, interpreting, and explaining (Koch & Kralik, 2001).  The learning activity of thinking begins with the articulation of experience into words as stories that are embedded with metaphors and symbols (Lakoff, 1987; Pennebaker, 1995).  In this application, the thinking step consists of participants' sharing stories by reading them aloud and exploring their meanings in a group format.  The educator should present material on dialogue and the definition and use of metaphor before the group begins sharing their stories.

Metaphors can be identified and interpreted during a sharing process in which the teacher encourages participants to discuss and dialogue about their experiences and explore the meanings of their metaphors.  For example, when Barb was asked what advice she would give to someone newly diagnosed with MS, she said that she saw MS as a "teacher" or "mentor" that is "guiding you down a new path" rather than an "enemy" that "you want to get rid of."  When she answered, she used metaphors and described what they meant.   When teaching about story and metaphor, Barb could be asked: Could you explain how you see MS as a teacher or mentor?  What does that mean for you? What is your new path?

If participants do not use metaphors or use negative metaphors, they can be encouraged to consciously select positive metaphors for their illness and their process of living and coping with MS. They should be encouraged to think about and to reflect upon why they chose the metaphors they did, what they mean to them, and eventually what healing may mean for them personally. This process may help participants shift to more positive metaphors and perspectives. In this manner, they may be able to reframe in positive manner what they have previously seen to be a negative experience.

The third step is *acting* which parallels the learning activity of behaving or trying out new behaviors in the outside world by learning and practicing new skills for coping with everyday life (Bohart & Tallman, 1999). In the group setting, the health educator can create and process experiences involving various coping skills. By asking participants what they can do each day to cope proactively, they can be encouraged to develop plans for taking action to effect change in their everyday lives using some of the coping strategies that they have experienced in class. This process may involve redefining values and deciding what is most important in life and where is it most beneficial to put their time and energy.

The possibilities generated by thinking and reflecting in a classroom setting need to "fleshed out" and "made real" through experiential encounter (Bohart & Tallman, 1999, p. 205). Health educators can provide experiential opportunities to make this possible. Overall, we can help people extend the use of their skills in a generative manner by asking them to improvise and vary the skills and by encouraging their use in new situations external to the classroom. The importance of experiencing to the

individual as an active self-healer is that change ultimately takes place through the individual's own confrontation with experiences and own experiential self-discoveries.

## Discussion

The participants in this qualitative study told the researcher that they want health professionals to listen to what they have to say about their illness. The self-healing process is unique to each person (Bohart & Tallman, 1999; Quinn, 2001). Regarding an optimal healing environment, Schmidt (2004) offers a core thesis that every healing effort and every healing intention starts within the health educator or health care professional. Healing is not caused in people but emerges from within them (Quinn, 2001). Even if there is no change in a treated physical condition, profound healing can occur in the other health dimensions of the individual. It is the body, mind, and spirit of the person that is the true healer.

As health educators, we need to honor the autonomy of our students, clients, or patients by listening to what they want to tell us and have a need to tell us. We must be reflective learners as we encourage our students to be reflective. After offering them opportunities for diverse experiences, we can respect their autonomy by giving them choices about which interventions or methods work best for them.

People can transcend or move beyond their illness in order to define themselves as more than the illness itself (Charmaz, 1991). This transcendence implies reevaluation, renewal, and a reframing of experience. It means making choices and taking action. Reflection creates awareness (Koch & Kralik) and taking time for reflection can facilitate the transcendence of suffering and distress by helping people with chronic illness define qualities of self that are distinct from their bodies (Charmaz, 1991). Moving beyond

illness while still living with it is possible if people have time for reflection, acquire the tools to do it, and define qualities of self as distinct from the body.  Encouragement from others to reflect and to define a valued self beyond the body with illness supports transcendence and healing.

Integrative healing as health practices is based on the understanding that individuals have internal self-healing mechanisms, and that nature, time, and patience are the best healers (Pinzon-Perez, 2005).  Health educators need to generate knowledge on the application of integrative healing to the practice of health education because, although there is much information on complementary alternative medicine, there is very little on integrative health applied to the health education profession (Pinzon-Perez). The vital task of the health educator as a facilitator is to create the container for learning and healing by creating a safe and supportive environment.

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SUMMARY AND CONCLUSIONS

Summary

The qualitative study in chapter one examined how women with multiple sclerosis (MS) coped proactively with the limitations imposed by their chronic illness and moved into a self-healing process. The findings emerged from the coding and analysis of semi-structured interviews with eight women and showed that they used coping strategies of living one day at a time, focusing on positive aspects of the experience, and redefining values. These strategies allowed them to make choices regarding what was most important to do in an effort to conserve their energy resources which are sorely tested by the overwhelming and always present fatigue of MS. The women's responses in the form of stories with embedded metaphors offered a picture of how the women played an active role in their own healing process as they confronted and coped with their illness. Using grounded theory principles, a model was developed for the phenomenon of the self-healing process.

In chapter two, the metaphors that emerged from the qualitative interviews with the women having multiple sclerosis were examined to find themes and their deeper meanings that underlie their responses to the research questions. The participants' stories about the distressing events in their lives contained wisdom, provided lessons for living, and enabled them to reflect, to reevaluate, and to redirect their thinking into more positive

channels (Charmaz, 1999). The metaphors and metaphorical knowing which they used supplied the foundation for the interpretations and meanings that they created about their lives, personal challenges, and relationships with others (Lyddon, Clay, & Sparks, 2001). These findings have implications for health educators because people can transcend or move beyond their illness in order to define themselves as more than the illness while still living with it. This is possible if they have the opportunity of time for reflection, acquire the tools or skills to do it, and define qualities of self as distinct from the body (Charmaz, 1991). Using metaphor and story in teaching offers health educators the possibility of facilitating the means by which our students, patients, or clients may transcend illness and move toward self-healing.

In chapter three, a model of the women's coping and healing process that incorporates their metaphors and meanings was developed. suggests a dialogical and collaborative health education approach that encourages the use of story, metaphor, and dialogue to help facilitate, nurture, and support significant change for our students, patients, or clients through a proactive coping and integrative self-healing process. By encouraging people to use dialogical methods to actively examine their metaphors and meanings through sharing their stories, we can help them explore the beliefs they hold about themselves and their lives which can provide them with the insight and the opportunity to change beliefs that are no longer helpful or productive (Lyddon, et al., 2001). They then may be able to discover alternative life metaphors that serve as a bridge to positive change and personal growth (Goncalves, 1994).

Conclusions

More than ever before, the aging population and the increasing presence of chronic illness, including debilitating conditions, present health educators and other health care professionals with many challenges (Arnold & Breen, 2006).  Individuals, families, and communities need assistance not only in the prevention of chronic illness and the management of the everyday work of living with chronic illness, but also in maintaining optimal function and quality of life over time (Germino, 2006).  Research on chronic illness focuses on two major categories of either prevention or management. Qualitative research, as descriptive research, has been one of the richest resources for information on the management of chronic illness from the perspective of the ill person or the "insider" perspective (p. 409).

*Implications for Health Education Practice*

Self-healing is a process told as a life story.  If health educators and other health professionals can understand the process that facilitates people to move through having MS and its effects on their life situation in order to employ a positive, proactive coping approach, we can help people accept and integrate the limits imposed by their illnesses, enhance positive psychological attitudes, and promote positive outcomes (Pakenham, 2006).  As health educators or other health professionals, one of our most important tasks is to listen to our patients, clients, and/or students.  In so doing, we can nurture the self-respect of people with chronic illnesses by seeing them as the experts on their own illness experiences.  We should support their personal strengths as we do our best to increase their knowledge levels and enhance their positive behaviors and practices.

As people with chronic illness live longer, health educators will be working with older populations in which developmental changes and other transitions will influence and reshape not only the chronic illness experience but also the strategies of self-management and self-care that people use (Germino, 2006). Adult learners are self-directed rather than dependent and come into the learning situation with a problem-centered, present-oriented focus to learning (Knowles, 1970). They are ready to learn based on a need to know or to do something in order to perform more effectively in their lives. Adult learners bring much experience to the learning situation which serves as a rich resource for learning.

The characteristics attributed to adult learners (Kicklighter, 1991; Knowles, 1970) are congruent with signs of self-healing (Bohart & Tallman, 1999). Proactive self-healing people, as problem-centered, present-oriented adult learners, are struggling to make their lives better and take active, deliberate steps to seek help or learning in order to do so. These qualitative studies offer health educators a framework and foundation for supporting the desire of adult learners to participate as active partners in their self-healing process (Engel & Strauss, 2002). As exemplified by the women who experienced an awakening awareness and behavior change after suffering exacerbations, self-healers as adult learners are capable of learning and capable of changing their beliefs, ideas, emotional reactions, and behaviors in response to encounters with new input (Bohart & Tallman, 1999). As health educators, we need to support the individual's unique self-healing process by allowing them to be a part of their own process by offering them choices and allowing them to make choices that work best for them.

*Implications for Future Research*

Glover (2004) suggests that "the brain and behavior appear to be the new landscape for health education" (p. 267). He believes that the future of health education lies in emotions, personality, and behavior research. Health educators need to learn more about mental health and interventions to improve mental health that lead to the mind-body connection for overall health status improvements in the people we work with as partners (Huebner et al., 2004). The future of health education lays not only in partnering with our students, clients, or patients, but also in health behavior research. Definitions and theories must always be considered to be provisional (Egnew, 2005). The definition and model of self-healing presented here provides an overview of a complicated process as a starting point for discussion and further study in extending the concept of self-healing beyond psychotherapy.

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