

# Illness Stories: Themes Emerging Through Narrative

Deborah Docherty, MSW  
Mary Ann McColl, PhD

**ABSTRACT.** The purpose of this study was to explore the use of narrative as a tool to understand the experience of chronic illness. The study is phenomenological in nature, using elements of grounded theory and social constructionism to consider the data collected. As examples of the issues raised using the narrative approach, the paper describes four themes that were pervasive in the first-person accounts of these individuals:

1. Emotional reaction to the diagnosis—Because of both the form and content in the narratives, these are described as ‘peak experiences’;
2. Impact of stress—As a precipitator of symptoms or illness, as an ongoing aggravator of the chronic illness, or as a factor in overall coping with the chronic illness;
3. View of death—Named by all four individuals as it relates to their view of life;
4. Illness meaning—Coined by two of the individuals as ‘philosophy of life.’

These themes were interpreted in terms of their implications for therapeutic relationships with people with disabilities and chronic illnesses. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2003 by The Haworth Press, Inc. All rights reserved.]

---

Deborah Docherty is affiliated with the Hotel Dieu Hospital. Mary Ann McColl is affiliated with Queen’s University.

Address correspondence to: Mary Ann McColl, PhD, Queen’s University, Kingston, ON, Canada, K7L-3N6 (E-mail: mcollm@post.queensu.ca).

Social Work in Health Care, Vol. 37(1) 2003  
<http://www.haworthpress.com/store/product.asp?sku=J010>  
© 2003 by The Haworth Press, Inc. All rights reserved.  
10.1300J010v37n01\_02

**KEYWORDS.** Chronic illness, narrative, diagnosis event, coping, phenomenology, disability, qualitative research, stress, meaning, therapeutic relationship

### *INTRODUCTION*

In the therapeutic alliance, one of the unique contributions that clients bring to the relationship is their experience of the illness or disability—infused with character, embedded in context and enriched by history. While many of the effects of illness and disability can be observed from the outside, the experience cannot be measured or observed by professionals—it can only be shared in the telling. Narrative serves as a way for social workers to attain understanding with their clients. Narrative is the collection of metaphors or stories that individuals build to describe, explain and make sense of their experience. In the context of narrative, the individual attempts to find meaning for both his or her own purposes as well as those of the listener. Rappaport (1993) describes this rather succinctly:

In its simplest form, the narrative approach means understanding life to be experienced as a constructed story. The stories that people tell and are told are powerful forms of communication to both others and one's self. Stories order experience, give coherence and meaning to events and provide a sense of history and of the future. (p. 240)

The reciprocal nature of story-telling meets both internal and social needs, and provides a meaning-making mechanism of benefit to teller and listener. It is this sense of mutual benefit that appeals so powerfully to a group of people who, by virtue of their chronic illness, have felt marginalized, disempowered and stigmatized. Telling their own story and hearing others' stories returns the individual to a place of belonging, even if only to that "fellowship of those who bear the mark of pain" (Schweitzer, 1922, p. 173).

Meichenbaum and Fitzpatrick (1993) postulate that "how individuals and groups engage in narrative construction is critical to their adjustment to stressful events" (p. 712). Diagnosis of a chronic illness or the onset of a disability is indeed a stressful event. The transition from well to ill, able-bodied to disabled, represents a challenge to the beliefs many of us operate under at some level, namely, that we are invulnerable, that

our lives are predictable, that life has meaning, and that we are worthwhile. The onset, sudden or otherwise, of a chronic illness or a disability calls all of those beliefs into question.

A review of the literature reveals an emerging understanding of the power of narrative to uncover meaning associated with illness and disability. Among these, Arthur Kleinman's *The Illness Narratives* (1988) stands out as an example of how one might hear the stories of those living with chronic illness. While chronic illness and disability have many differences, they also raise a number of similar issues, which Kleinman's work helps to illustrate. Directed primarily at physicians, Kleinman speaks to all who would want to better understand the illness experience from the 'insiders' perspective. His most powerful message is that a journey toward understanding of the illness experience requires not only relinquishing traditional medical tools, ideas and treatments; it also requires humility and a sincere desire to learn about, be immersed in, be humbled by the experience of the individual living with the chronic illness. The new equipment required includes a willingness for 'empathic witnessing,' an openness to being taught and an understanding that the affected individual may have a rich repertoire of coping skills, even if these appear unusual or foreign to the outside observer. Foundational to the development of those coping skills is a process of meaning-making. As individuals struggle to make sense of their illness experience, they ascribe meaning to various facets of it.

Harlene Anderson (1995) describes "language and conversation as the central parts of therapy" (Anderson, 1995, p. 27); however, she goes on to elaborate on her careful attention to the way problems are described and by whom. Most striking is her transition from 'expert' or 'therapist' to 'consultant' or 'collaborator' as she relies heavily on the narrative the individuals share with her. Anderson joins her clients in their story and seeks, with them, to discern areas that the individuals deem problematic.

A key feature of this joining entails adopting a 'not-knowing' stance by which one genuinely abandons the power implicit in the traditional social worker's position. One moves to a place of sincerely seeking to understand by engaging in what Anderson terms "a manner and attitude [which is] respectful and humble" (Anderson, 1995, p. 29). She advocates allowing the individual to describe the meaning they have attributed to their lives in general and their problems in the specific.

This stance of 'not-knowing' is more than a therapeutic technique or trick. It involves a commitment to values that place the individual as the author of his or her own story. As the author/narrator, the individual be-

gins to share the essence of that which troubles him or her. The 'therapy' becomes "generative conversation" (Anderson, 1995, p. 34) and the individual begins to consider alternate interpretations of events and reactions. This process of coexploring the familiar (i.e., the client's story, view of the problem, and meanings) and codeveloping the new (i.e., meanings, realities, and narratives), marks a shift away from problem definition and a move toward new ways of making sense of behaviour, feelings and events.

Anderson (1995) comments on helping individuals find 'space' in their self-story that creates the possibility of a different or alternate interpretation. Rather than the social worker imposing the alternate interpretation (such as 'correcting faulty thinking'), the individual is encouraged to explore, within his or her own story, places that may hold a different significance or meaning. It is only with respectful listening, a not-knowing stance and a willingness to consider the client as the author/expert of his or her own narrative, that the social worker can be most helpful.

The individual living with a chronic illness and struggling with the negative relational impact of that experience, desperately wants to be heard, to be understood and to have his or her interpretation of the illness experience validated. Anderson's position is radically different from the modern medical discourse that offers/prescribes advice, treatment, intervention and expects compliance. Anderson, conversely, suggests the answer lies within the individual. It is the individual's interpretation of the illness experience and the significance given to it that shapes his or her feelings, reactions and behaviour. This position does not refute the physiology or biology of the disease process but it offers an alternate response to the illness experience, one that changes the meaning-making process and opens up new possibilities.

Clayton and colleagues (Clayton, Rogers & Stuijbergen, 1999) use another metaphor to highlight the importance of information generated through narrative. They liken it to the writing found in the margins of structured assessment forms that attempt to fit the client's experience to the professional's expectations. They suggest that the writing in the margins is often more important than that found in the body of the form for achieving understanding.

Arthur Frank (1995) offers his own illness narrative as a 'call to action,' an invitation to those learning the hard way, what it is to live with a chronic illness. Because of the exclusivity of this club, the members have not simply a right but an obligation to help non-members better

understand what membership in this club is all about. Charter membership brings with it not simply the camaraderie of fellow sufferers. It also implies a duty to inform/instruct/enlighten those who do not yet belong. Helpers of those living with a chronic illness are invited to listen in a new way, to accept the expertise of the narrator of his or her own story, to engage with that person in a dialogue that has the potential of untangling an illness narrative as well as enlightening both helper and recipient of help.

More recently, Loewe and colleagues (Loewe, Schwartzman, Freeman, Quinn & Zuckerman, 1998) observe that the illness narrative has become a popular literary form. A number of authors have used narrative as a means to explore particular aspects of the disability experience. Themes explored in this literature include: reappraisal and redefinition of the self (Fitzgerald & Paterson, 1995); awareness of embodiment, and the relationship between body and mind (Ekman, Ehnfors & Norberg, 2000; Dacher, 1997; Garro, 1994); and, issues around diagnosis (Knafl, Ayres, Gallo, Zoeller & Brietmayer, 1995). In addition, special populations have been studied, including women with disabilities (Thorne, McCormick & Carty, 1997; Tompkins, 1995), and people with addictions (Rae Davis & Jansen, 1998; Steffen, 1997), and chronic pain (Kelley & Clifford, 1997). These studies consider the usefulness of narrative in addressing the unique needs of a specific population.

Those living with chronic illness define the journey they will embark on. They come to the departure point with diverse luggage and equipment for the voyage. They select very different paths along which to travel. They come to see themselves as changed by the journey in very different ways. This may be the most relevant conclusion, at least as far as this study is concerned, that all of the voices heard have been altered by the illness experience. All are different for the journey. None have remained unaffected.

The purpose of this study was to explore the use of narrative as a means to elicit the experience of chronic illness, and as a means to permit social workers to hear about personal and existential issues associated with chronic illnesses. The paper describes four themes that were pervasive in the first-person accounts of four individuals, and that are pertinent to social work practice. These themes are not new to the literature on chronic illness, but they are offered here as examples of issues that can be successfully uncovered through the use of narrative. In other words, they are described here to allow us to hear them in a new way.

## **METHODOLOGY**

### ***Design***

The study is phenomenological in nature, using elements of grounded theory and social constructionism to understand the data collected.

- Grounded theory, as outlined by Glaser and Strauss (1967), encourages the emergence and development of theory from the data received rather than the starting point being theory and the selection of data serving to 'prove' theory. The narrative approach to the collection of data is an element of grounded theory.
- A social construction approach reflects the view that both illness and involvement with health care professionals are socially constructed.

### ***Participants***

The study involved four participants, all of whom had a chronic illness of at least two years' duration. Pseudonyms have been assigned to all of the individuals interviewed for the present study to preserve their confidentiality.

1. Doug is a 74 year old man, a white retired academic who has been dealing with the consequences of severe cardiac disease. His cardiac condition led to complex open-heart surgery approximately 17 years ago, forced him to retire early from a very senior position and has had a significant impact on his life since that time.
2. Bill is a 59 year old black man who was diagnosed with Multiple Sclerosis approximately 10 years ago after living with undiagnosed symptoms for approximately 15 years. He retired six months ago, having served as a senior correctional officer and a member of the Armed Forces. He grew up in Southern Ontario as part of the only black family in a small town. Both of his sisters have also been diagnosed with Multiple Sclerosis.
3. Ann is a 52 year old white woman. She was told in January, 1998 that she has a degenerative brain disease; however, there seems to be some disagreement among the neurologists about this diagnosis. Ann is currently unemployed, living at the poverty level but, as yet, not eligible for provincial disability benefits. She completed an undergraduate degree in history and several diploma courses in the visual arts.

4. Nancy is a 29 year old white woman. She was diagnosed two years ago with Multiple Sclerosis after a sudden onset of optic neuritis. She is currently in receipt of provincial disability benefits and is pursuing her interests as a visual artist.

### ***Data Collection***

Qualitative data were collected by the first author through semi-structured interviews with four individuals. Each of the four participants was invited to participate via a letter outlining the nature of the study. Once they agreed to participate, a mutually-agreeable time and place was established for the interview. The interviews ranged from 1.5 to 2 hours. An interview guide was prepared (see Table 1), although once the interview began, participants narrated their own illness stories as they felt appropriate. Individuals determined the emphasis they would place on different aspects of their story, and they were given the freedom to describe the meaning they had given to their own experience. The interviews were audio-taped, transcribed, reviewed and coded to identify themes emerging.

TABLE 1. Interview Guide

---

1.	What was the process of adaptation to chronic illness
	– when did it begin?
	– immediately after diagnosis?
	– after a gap in time?
2.	Are there coping strategies that have emerged from the process? What are they?
3.	Have some proven to be more useful over time than others? What are they?
4.	In retrospect, do you think there were identifiable contributing factors that lead to your diagnosis? What were they? How do you deal with those factors now?
5.	In general terms, what do you think the overall impact of your illness has been on your life? e.g., Your relationships with family and friends? Your relationship with yourself? Your relationship with your community?
6.	How do you think your illness has changed you?
7.	What does a bad day look like for you? What does a good day look like for you?

---

After reviewing the individual transcripts and highlighting themes, the data were categorized according to Riessman's (1994) components of a personal narrative: content, form and omissions. This approach to narrative analysis considers the depth of meaning in the participants' stories using a number of mechanisms, such as parsing and line-by-line coding, which invite a deeper understanding of what is said and what is not said. The participants of the current study had much to say about their illness experience (content), they expressed it in their own idiosyncratic ways (form), and they chose to leave out significant details from their story (omissions). The review and analysis of these three components revealed not only important themes but also painted a rich picture of four individuals living full and reflective lives, a part of which included a chronic illness.

### *FINDINGS*

Four themes were present in all four interviews, as follows:

1. emotional reaction to the diagnosis—because of both the form and content in the narratives, these are described as 'peak experiences';
2. impact of stress—as a precipitator of symptoms or illness, as an ongoing aggravator of the chronic illness, or as a factor in overall coping with the chronic illness;
3. view of death—named by all four individuals as it relates to their view of life;
4. illness meaning—coined by two of the individuals as 'philosophy of life.'

#### *Emotional Reaction to Diagnosis: 'Peak Experiences'*

In the context of this study, all four participants recounted, with amazing detail, their response to the transition from a state of health to a state of illness. Doug's recall of practical detail was matched by his tentative exploration of the emotional impact of this new health challenge. While he would acknowledge his first heart attack was a primary pivotal event, a secondary pivotal event was his decision to retire from a very senior academic position of considerable responsibility. He recalled an epiphany of understanding when he said to his wife "everything is different now," in reference to the impact of his changed health



status on his life. Hindsight over the last seventeen years has afforded Doug perspective but it has not diminished his recall of his own emotional reaction to the onset of his new health status. As Doug crossed the threshold from healthy, active, busy and needed, to very ill and requiring lots of rest and no stress, he took stock of his relationships with others but also his inner reaction to the identity he was giving up and the identity he was taking on.

This period of critical reflection on a significant transition in health status was also engaged in by Bill as he came to terms with the sudden attack that led to his diagnosis of Multiple Sclerosis. He described a single event as “major, very traumatic” that precipitated the diagnosis. Like Doug, Bill could remember vividly the episode that led to this. He recalled being out for a walk with his wife and suddenly losing mobility in one leg and having to drag the leg in order to get home. What was remarkable about Bill’s description of the episode was the phenomenal detail included. It was as though Bill were retracing his steps on that walk, seeing the same sights, and feeling the same incomprehensible sensations all over again. While there was not a lot of emotion included in Bill’s recitation of the event, it clearly stands out in his memory as a “very traumatic event.”

A number of factors contributed to an unusual emotional reaction for Ann, but it was no less intense than for the other three individuals. The commonality was the vivid recitation of details. The fact that the diagnosis was disputed by her neurologist has compounded Ann’s confusion over what she must deal with. It remains unclear whether Ann’s different emotional reaction to the diagnosis was due to the cognitive changes of the brain damage itself. While Ann’s affect was somewhat different, her precise recounting of details surrounding this period was the same as the other three individuals interviewed.

Nancy remembered an acute sense of fear and loneliness at the point of diagnosis. Unlike Bill’s fifteen years of unusual, undiagnosed symptoms preceding confirmation of his diagnosis, (i.e., time to contemplate what may be awry in his body), Nancy was diagnosed immediately after the sudden onset of optic neuritis (a visual disturbance that is often an indicator of M.S.). With considerable passion in her voice, as though the sensations she described were occurring in the present, Nancy identified both the range of emotion she grappled with and also the seeds of her own coping. Like Bill’s positive attitude, Nancy seemed to deal with the intense emotions evoked by her diagnosis with a sense of competence and openness.

The deep emotion Nancy felt in reaction to her diagnosis, was mirrored in her response to ongoing challenges. However she seemed to be crossing thresholds, facing transitions, moving forward. In a most powerful series of metaphors Nancy stated:

It's all just fear and it's totally faceable. . . . but I describe it to my friends as feeling like the Hounds of Hell at my heels and a gaping maw of fear at my face. . . . and I just allowed myself to be eaten through by that, just to see where that was taking me . . . Do I want to be sunk in the fear, and the poverty and the victim? Do I want fear, to be sunk there or do I dare face what's ahead of me with courage and grace? Well, I guess I dare. But I'm still afraid, you know.

No attempt was made in any of the four interviews to interpret the content or even the relevance of the specific emotional reactions of the individuals. Instead the issues of diagnosis have been highlighted in the precise and vivid recollection of the event itself. Much flowed from the diagnosis event, and the narratives took shape and texture as individuals described how they came to view themselves in their new state of being 'chronically ill.' The intensity of the experience was etched indelibly on the psyche—sights, sounds, smells, sensations and feelings that are not replicated easily in day-to-day living. There appears to be a human need to anchor oneself at critical stages of one's life in milestones (good and bad) that mark a passage from one state of being to another.

### *Impact of Stress*

This particular theme revealed some interesting differences in gender and socioeconomic status of the four individuals interviewed. Both males clearly identified stress (occupational and relational) as an antecedent to their chronic illness. Doug used words like "wrought up," "churned up," "stirred up," or "tear you apart" to describe his response to his occupational stress. In his position of responsibility he was required to deal with a multitude of problems on a daily basis. His temperament and strong sense of a moral code would not allow him to dismiss issues or permit a less than perfect solution to be employed. He frequently took on extra tasks to ensure they were completed to his standards. With retrospective insight, Doug considers the interplay between the effect of stress on his health and his strong sense of responsibility and he continues to face this as an ongoing dilemma.

Bill reviewed in considerable detail the stress he was under at work (Armed Forces) and at home (in his first marriage) during the fifteen years preceding the confirmation of his diagnosis of M.S. Throughout this period he was experiencing troubling but undiagnosed physical symptoms. Like Doug, Bill acquired insight the hard way and used it as he reviewed his past, as well as in his day-to-day living: "Any time I had a peak period of stress [referring to his work] then I'd also start feeling increased symptoms." In the present, Bill notes: "If I get to a very stressful period then my symptoms increase."

Bill attributes the dissolution of his first marriage to the stress of military life. He does see the combination of his occupational stress and marital stress as having a significant impact on his lived experience with a chronic illness. However, both Doug and Bill differ from Ann and Nancy in their response to stress. Both males described a rather pragmatic action-oriented reaction to the stress they experienced. Further, both males enjoy considerable economic comfort (largely due to financial investments and work place pensions).

Ann stated a number of times that one of her greatest difficulties was stress; the stress she experienced during the protracted diagnostic period and the concomitant medical confusion; the stress of the symptoms of her illness (fatigue, thought disorder, memory lapses); the stress of poverty; and the overall stress on her ability to cope. Referring to the brain disorder, Ann stated:

What gets worse is, because there are areas in the brain that are damaged there can be . . . deficiencies . . . and when I can say it's worse, it's worse because of the stresses of poverty and 'How am I going to pay this bill?' There's all this stress and it makes me worse, my brain will just shut off. . . .

At this point Ann turned the discussion of the stress in a different direction. She described the social isolation she feels as a result of her illness. In describing why she turns down invitations to go out with friends for dinner, she stated:

They're going to find out there's something wrong with me. I don't want to be stupid or seem stupid. I say the wrong words or lose a thought. That's distressing. It's an ongoing stress. Sometimes it's just stuck in there and it doesn't come out and there gets to be more confusion . . . very stressful.

The ability to reject the social discourse and hang onto a positive self-image was a constant struggle, but one that Ann engaged in with courage and humour. Like Ann, Nancy tended to describe her reaction to the stress of her illness by discussing the social discourses that she felt constrained her. Like Ann, she felt the sting of poverty as a considerable source of stress. The 'inner work' as Nancy referred to it, seemed to be her attempt to put the stress surrounding her illness experience in perspective.

For Nancy, the stress that was most often mentioned was fear—fear of what has happened in terms of her illness, fear of what is to come, and fear of her potential to 'succeed.' In response to the stress and fear she felt around choosing a suitable career path, Nancy recognized the source of her fear as being external; that is, the expectation to succeed in a career. Nancy grappled with a lived illness experience that prevented the realization of those expectations. On the one hand she dismissed the social discourse of what she 'should be' achieving, given her age. On the other hand she had emerging goals of her own.

Nancy struggled with the stress created by the external social discourse of expectations and her internal narrative that was filled with messages of self-doubt. It is ironic that it is in response to her illness, Nancy began unravelling this dilemma that clearly predates her diagnosis. What she couldn't come to terms with when she was feeling healthy she is now dealing with when she is plagued by fatigue.

All four individuals identified stress as a factor that has had a significant impact on their illness experience in the past and continues to in the present. They have responded to stress in unique ways. They have developed coping strategies for different reasons and for different purposes. None claim to be experts at mastering or overcoming stress.

### *View of Death*

This theme was consistent across all four interviews. Doug experienced what has been described in the lay literature as a 'near-death experience.' As a physicist by training, Doug entered into his health care crisis and hospitalizations with unique understandings. He described with amazingly clear recall

I do remember, being a physicist, that with numbers always goes a graph in my mind and I could remember listening to them, at this big heart attack, hollering out the blood pressure numbers, the high and the low, and I could see the two points on a graph converging

and I thought ‘That’s interesting. I know what that means. The pump isn’t doing anything.’ And just as I figured that out, that was my last sort of sane, conscious thought because then I was gone and the next thing I remember was . . . actually I wasn’t concerned then at all. It was very peaceful, but I could hear this voice from far away, the nurse hollering in my ear, ‘Doug, you come back, you can do it’ and I remember thinking ‘Yah, maybe I can, but there’s nothing to worry about, should I bother’ . . . But I did. I sort of said, ‘Okay, there are people who depend on me. I better get back.’ And I sort of forced myself back.

Implicit in this excerpt was Doug’s clear understanding of his own death, an experience few of us have the privilege/burden of recounting. However there was also a keen sense of ambivalence between staying in that ‘peaceful’ place where he was free of concerns, and returning to a state of responsibility, where others depended on him.

For Doug, the cardiac arrest left him more acutely aware of the fragility of his health and indeed life itself. He continued to have regular reminders of his tenuous relationship with life, and they have shaped both his philosophy of life and his coping mechanisms. It was clear that his experience of ‘dying’ had deeply affected his subsequent living.

While Doug was the only one to actually experience death and being revived, he was not alone in having thought about death in relation to living with a chronic illness. Bill reflected on a period in his life after his diagnosis of M.S., when having a sense of control over his death was very important to him.

At one time I thought I could even have some control over that [death] ’cause with euthanasia, if things get too tough—I’m gone! (laugh) I don’t need to put up with this.

By exploring these ideas, Bill came to develop a renewed but enriched sense of purpose for his life, one that respected his own temperament and allowed him to feel fully invested in living.

Ann expressed thoughts similar to Bill in terms of contemplating her death. Immediately after learning her diagnosis (despite the confusion over the accuracy of that diagnosis), Ann began worrying about what was to come.

. . . then I was panicking about hospital. Nobody to look after me and I’d end up in hospitals and I didn’t want to do that. Maybe I should kill myself, but not when you’re well and sometimes when

you get sick you're too sick to kill yourself and I said maybe I should take all my money and spend it and go on a big trip but then what if I didn't die?

Like Bill, Ann expressed a sense of relief when she learned the diagnosis: "not the devastation of having a degenerative disease but at least it was a label on what I had." The prognosis of an early death was used by Ann in an interesting way. She took the diagnosis, learned a great deal about the disease from the Internet and then engaged in a comprehensive life review. Rather than becoming mired in what might lie ahead, she used the life-altering news to affirm her accomplishments and efforts. Like Bill, she found new meaning in her life and developed a sense of spirituality that helped her cope with her experience of today and her sense of tomorrow.

Ann expressed not only her ambivalence about suicide, but she seems to have settled on a positive reframing of this stage of her life as an opportunity for reflection. Her very telling comment about now knowing that she is 'okay,' reflects a great deal of hard work on her part to refute the many discourses (social, medical, academic) that have told her otherwise. She has rejected those negative descriptions of her imposed by outsiders and she has settled on a more positive story about herself.

Nancy, like the other three individuals interviewed, has contemplated her own death. In struggling to understand her fears, Nancy explored her view of death.

I thought I was afraid of death but I spent two weeks being utterly sure that all I wanted to do was die and I realized that that was not at all where my fear was. I looked at life and realized that I was so petrified of what possibilities there are out there, what I can do, what might be, I don't know, just everything. That's really what it is, right there. . . .

Nancy felt she had confronted the worst possibility, suicide, during a period of depression, and rejected that option. Having demonstrated to herself the capacity to come up against that choice and reject it, Nancy was, in essence, writing an alternative chapter in her own narrative.

### *Illness Meaning: 'Philosophy of Life'*

In very different ways (with some difference along gender lines), all four interviewees described how they had come to make sense of their

illness experience. Three of the four spontaneously used the phrase ‘philosophy of life’ to describe this process. Doug, the oldest of the four, felt this keenly as he reflected on a gift given to him upon retirement (due to illness).

. . . when I left work, all the secretaries on our floor gave me this key chain and it says ‘One day at a time’ and so this is the philosophy I try to adopt and what I do realize is that I always have to be ready to say good-bye, that’s it . . . you know, if you have another day, that’s great and if you don’t . . .”

Doug acknowledged that his background and childhood had been formative in his adoption of a moral code that emphasized ‘doing what is right,’ accepting responsibility and working hard. These elements, among others, came together with the sudden heart attacks and forced him to rethink how to live his life. The pre-illness attitude of taking on more work and responsibility to ensure the job was done right, was no longer a sustainable approach to living. It is worthy of note that Doug used the technique of distancing himself from topics of intense emotion (such as death) by switching from the first person (“the philosophy I try to adopt”) to the more impersonal second person (“if you have another day . . .”). This technique of emotional distancing was present at critical points of discussion in all of the interviews and may reflect a significant opening in the individuals’ narrative for exploration.

Bill shared a sense of being different that he traced to his earliest memory in childhood, perhaps as a result of growing up black in a white Southern Ontario town. Bill’s comments in fact described a more elemental process than reacting to racial difference—that of meaning-making. He was sorting out, even as a child, who he was and how he would navigate through his life from his own unique perspective, a perspective that did not seem to be shared by others. His separateness led him later in life to wonder why he had survived and his fellow paratroopers had not; to wonder as a Corrections Officer why there were so many non-whites in the prison system but so few non-whites guarding them; and eventually, to wonder what the point of his life was.

I’ve come to the conclusion that the purpose of my life, the purpose for everyone, is to develop their spiritual being, not so much their physical being. There’s a reason for being here. That’s the way I look at it. When you help someone you’re helping yourself, you’re developing your spiritual being.

Bill's view of himself as a child persisted into adulthood and he has used it to help him cope with many challenges including his chronic illness. Like many facing such challenges, Bill views his illness in a positive way.

So looking at it from that point of view, it was a blessing that I was born black in a white country. It's a blessing. I look at M.S. as a blessing 'cause you know what it's done for me? It's made me a much better person than I would have been if I hadn't had it.' 'Cause it's forced me to look at what I'm doing here.

Such positive reframing is not possible for everyone living with a chronic illness, but Bill seemed to have been able to script his own narrative, of which his illness was but a part, in a manner that gave his life meaning. He summed up our interview by saying "It's the journey to Mecca that counts, not the end result."

Ann revealed her sense of a philosophy of life early in our interview. She mentioned some of the negative descriptions about herself that she had absorbed early in her life and how she had come, more recently, to remind herself of a more positive central core. As Ann explained how she had come to rediscover the essence of herself, she used words such as "contemplation," "introspection," and the phrase: "I spend a lot of time alone thinking. . . . thinking about things, about my being okay. . . ." This process seemed to lead to a greater degree of self-acceptance which continued to snowball as she validated herself. She reflected back on this incremental self-discovery and self-affirmation process by saying;

Once you come to the part about whatever you understand the meaning of life, why we're here. Once you've got that, you get the whole picture, Universe-wide, then . . . the other stuff is small stuff. . . . But the actual meaning of life. Well, you go round and round. But then I figured out it's so basic! It's why we're here. It's to create love and to look after each other and to look after the planet . . .

In explaining the impact her illness has had on her overall philosophy of life, Ann summed up by saying:

It [her illness] has been a profound difference in my life upon reflection. Peace . . . in spite of the earthly crap! Just be good to your-



self. But I don't think everybody can do that and I don't know exactly how it [her positive attitude] came. I guess it just evolved, a lot of it was precipitated by the stamp of death for a while. Marked."

Whether it was being marked by the stamp of death as a result of her illness or by some other means, Ann has arrived at an understanding of what her life is all about. Like Bill, her illness narrative has informed her larger narrative and given her life a sense of purpose.

Nancy employed language similar to Ann's when she described her journey of self-discovery as "inner work," and "really going within myself to try to figure out what I want." As Nancy struggled to express herself, she said:

. . . I don't know how to describe it, but it's all just so incredibly simple. We create what we have. We are responsible for everything in our Universe, and we have the power to change anything in our Universe. Anything and everything that we have is our own doing, so if you are unhappy with something in your life, you absolutely just have to change that!

This was a very intense portion of our interview as Nancy seemed to relive the intensity of her recent period of uncovering these insights. The excerpt above is certainly reminiscent of Ann's views about the meaning of life. These two women seemed to have gone through similar journeys of self-discovery and arrived at echoing philosophies of life. They also reflected the same sense of self-acceptance and arrival at an inner peace after rather different inner struggles.

Nancy seemed to be sharing a number of discoveries or epiphanies as she put words to her recent period of reflection; the subtle yet profound rewriting of her narrative. She incorporated the reality of her illness experience into that narrative, but did not allow herself to script an altered narrative that limited her.

I'm just asking, instead of saying I can't, I'm asking the Universe for 'this is what I need' . . . and if I really *believe* in M.S. as a partnership within myself, then I really, I really can achieve anything because it's not a limiting factor. It's just a factor.

This revealing of an altered narrative continued without interruption for several minutes as Nancy appeared to be opening doors for herself.

Her metaphor of M.S. as a 'partnership within' seemed to be one that was increasingly comfortable for her as she used phrases such as "understanding and compassion for those around me, for my life, for my own self, for everything." Her level of animation and intensity increased as she spoke, as she warmed to her topic and as she heard what her inner story sounded like:

So it's just, it's all so clear and M.S. to me, at this point, feels like just the hugest gift, you know. It's hard, but, just the hugest gift. There's really no other way to describe it. I wouldn't be here now if I hadn't had to go through this path and I'm so grateful and I wouldn't trade it for a million dollars, even though I don't want to be poor . . . It's the best thing that ever happened to me!

Nancy describes her journey of self-discovery alternately as a pilgrimage and as a quarantine. Either descriptor implies a sense of separateness, a uniqueness of the experience.

### *DISCUSSION*

In summary, this study has identified four themes in the illness narratives of four individuals living with chronic illness and disability: the emotional impact of the diagnosis; the compounding impact of stress; an altered view of death; and, the illness as a determinant of one's philosophy of life. One remarkable finding of this study was the almost limitless capacity of the individual to craft an illness narrative that contained themes that transcended the illness experience, and resonated for both the listener and the narrator. As a social worker, one is left to reflect on the extent to which these themes are consistent with those typically addressed in social work. Is any discrepancy between these and typical social work issues simply a function of communication styles and patterns? Is it a result of the socially constructed ideas about chronic illness? Is it related to the stage of the illness experience at which individuals are when interviewed? Or is it simply reflective of the temperament of the individual living with the chronic illness? Are these the types of issues social workers are prepared in their education and training to deal with effectively? Are they sometimes avoided because they touch a chord that is personal rather than professional for social workers?

What was not surprising about the data elicited by this study was the power of the vehicle, namely the depth of the stories gathered using a narrative approach. The interviews followed the direction determined by the participants. Their choices of what to include, what to exclude, what to elaborate on, what to emphasize, what to minimize, what to complain about, what to celebrate in themselves or others, all had relevance to them at that point in time. Several of the participants described feeling pleased and surprised with the interview process, noting that they found themselves re-visiting topics and events that they had thought were long forgotten and of no current relevance. All four participants seemed to understand and comfortably embrace the narrative approach, making few apologies for the direction the interviews took. They seemed to appreciate both the open-ended opportunity to explore their own illness experience and the validity of their own inclusions and omissions.

The most powerful mechanism available to the individual living with a chronic illness is the narrative they are living. The self-story, for all of its origins and influences outside of the individual, remains the closest rendition of the authentic self. Coming to understand one's own story is the process of self-enlightenment revealed most particularly by the two female interviewees of this study. The illness may have been the catalyst, but these women opted to explore their own story in a vigorous, searching way. They mined their own experience and were rewarded with rich insights about themselves. These epiphanies prompted self-acceptance and a retrieval of self-identity unlike the 'loss of self' referred to by Charmaz (1983).

As much as Frank (1995) implores the 'wounded' to tell their stories, the journey to self-discovery can be more than simply painful. As Nancy described it, it can be alternately a 'pilgrimage' or a 'quarantine,' a time of lonely searching and social exclusion. However, all four interviewees described in slightly different ways the 'gift' their illness had been. All four appeared to have transcended, at least in intermittent ways, the confining, limiting aspects of their illnesses.

This study has everything to do with metaphors, those employed by the interviewees and those used in the interpretation. Metaphors can be altered, enhanced, manipulated and rejected. They provide a framework for understanding chaos and attributing meaning. They can be rich with complexity, or superficial in their simplicity. They are accessible to all. Learning to hear the metaphors of another, learning to listen carefully as the metaphors are revealed, witnessing as the narrator discovers for him

or herself the metaphors within the narrative, and helping to make the desired changes are all potentially part of the role of the social worker. It is far from a passive abandonment to story telling; rather it invites immersion in the narrator's story. The benefit of such immersion accrues to both the narrator and the listener.

Manuscript Received: 11/30/01

Accepted for Publication: 05/09/02

## REFERENCES

- Anderson, H. (1995). Collaborative Language Systems: Toward a Postmodern Therapy. In R. Mikesell, D-D. Lusterman and S. McDaniel (Eds.), *Integrating Family Therapy: A Handbook of Family Psychology and Systems Theory* (pp. 27-44). Washington, D.C.: American Psychological Association.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), 168-197.
- Clark, F. (1993). Occupation embedded in real life: Interweaving occupational science and occupational therapy. *American Journal of Occupational Therapy*, 47(12), 1067-78.
- Clayton, D.K., Rogers, S. & Stuijbergen, A. (1999). Answers to unasked questions: Writing in the margins. *Research in Nursing & Health*, 22(6), 512-22.
- Dacher, J.E. (1997). Older womens' narratives of aging, disability and participation in a rehabilitation program. A phenomenological study of lived experience. PhD. Dissertation. State University of New York at Albany.
- Ekman, I. Ehnfors, M. & Norberg, A. (2000). The meaning of living with severe chronic heart failure as narrated by elderly people. *Scandinavian Journal of Caring Sciences*, 14(2), 130-36.
- Fitzgerald, M.H. & Paterson, K.A. (1995). The hidden disability dilemma for the preservation of the self. *Journal of Occupational Science (Australia)*, 2(1), 13-21.
- Frank, A. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago: University of Chicago Press.
- Garro, L.C. (1994). Narrative representations of chronic illness experience: Cultural models of illness, mind and body in stories concerning the TMJ. *Social Science & Medicine*, 38(6), 775-88.
- Glaser, B.A. & Strauss, A.L. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Kelley, P. & Clifford, P. (1997). Coping with chronic pain: Assessing narrative approaches. *Social Work*, 42(3), 266-277.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Knafl, K.A., Ayres, L., Gallo, A.M., Zoeller, L.H. & Brietmayer, B.J. (1995). Learning from stories: Patients' accounts of pathways to diagnosis. *Paediatric Nursing*, 21(5), 411-5, 432-3.

- Loewe, R., Schwartzman, J., Freemand, J., Quinn, L. & Zuckerman, S. (1998). Doctor talk and diabetes: Toward an analysis of the clinical construction of chronic illness. *Social Science & Medicine*, 47(9), 1267-76.
- Meichenbaum, D. & Fitzpatrick, D. (1993). A constructivist narrative perspective on stress and coping: Stress inoculation applications. In L. Goldberger & S. Breznitz (Eds.), *Handbook of stress: Theoretical and clinical aspects* (2nd ed.) (pp. 706-723). New York: Macmillan.
- Rae Davis, D. & Jansen, G.G. (1998). Making meaning of Alcoholics Anonymous for Social Workers: Myths, metaphors and realities. *Social Work*, 43(2), 169-181.
- Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in the mutual help context. *Journal of Applied Behavioural Science*, 29(2), 239-256.
- Riessman, C.K. (1993). *Narrative analysis*. Newbury Park, CA: Sage.
- Riessman, C.K. (Ed.). (1994). *Qualitative studies in social work research*. London: Sage.
- Schweitzer, A. (1922). *On the edge of the primeval forest: The experiences and observations of a doctor in equatorial Africa*. London: A. & C. Black.
- Steffen, V. (1997). Life stories and shared experiences. *Social Science & Medicine*, 45(1), 99-111.
- Thorne, S., McCormick, J. & Carty, E. (1997). Deconstructing the gender neutrality of chronic illness and disability. *Health Care for Women International*, 18(1), 1-16.
- Tompkins, C.H. (1995). A critical ethnography of disability in women's lives. PhD Dissertation. University of California, San Francisco.