The Development of Illness Narrative in a Structured Cancer Group

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ABSTRACT

How does an illness narrative develop in a structured cancer group? By using narrative analysis, informed by discourse analysis, this qualitative research project illuminated this endeavour by charting the development and evolution of illness narrative in a structured cancer group. What evolved from the participants’ verbal interactions was an overarching narrative of struggle that is primarily moral in nature. This overarching narrative of struggle evolved from the nine themes that emerged from the participants’ verbal interactions. These nine themes are getting “whacked-on-the-side-of-the head”, “information’s power”, “butchers” and “angels”, “the guilt train”, “how a:::re you?”, the “wake-up call”, making a “breakthrough”, the “hard work” of cancer, and the “gift-of-cancer”. The participants co-constructed this narrative by drawing upon a variety of linguistic resources and interpretative practices as they negotiated the moral challenges of their relationships with self and the larger social sphere, brought forth by their status and experiences as individuals with cancer. This study also demonstrated that what are commonly referred to as discourses are used flexibly in the participants’ moral struggles. By examining how group participants use language, perspectives on how coping is accomplished are broadened beyond traditional notions of the acquisition of coping skills.
# Table of Contents

Abstract ......................................................................................................................... ii

Table of Contents .......................................................................................................... iii

Acknowledgements ......................................................................................................... vi

**CHAPTER I** Introduction and General Research Question ............................... 7

Perspectives on Narrative and Discourse Analysis .................................................. 10

Narrative - Conceptual Issues .................................................................................... 11

Illness Narratives .......................................................................................................... 14

Discourse Analysis - Conceptual Issues ..................................................................... 16

Concluding Remarks .................................................................................................... 20

**CHAPTER II** Perspectives From The Research .................................................. 21

Illness as Narrative ....................................................................................................... 22

Narrative about Illness ................................................................................................. 23

Narrative as Illness ........................................................................................................ 26

Groups, and Illness Narratives ..................................................................................... 27

Discursive Approaches to Research ........................................................................... 28

Contributions of Illness Narratives and Discursive Approaches to Research ........... 29

Cancer Psychosocial Interventions ............................................................................ 30

**CHAPTER III** Research Design and Methods ...................................................... 33

Methodological Approaches ......................................................................................... 33

Implementation ............................................................................................................. 36

Participant Criteria and Selection Process ................................................................. 36
<table>
<thead>
<tr>
<th>Chapter IV: Research Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overview of Research Findings</td>
</tr>
<tr>
<td>Themes</td>
</tr>
<tr>
<td>Theme 1: Getting “Whacked-On-The-Side-Of-The-Head”</td>
</tr>
<tr>
<td>Theme 2: “Information’s Power”</td>
</tr>
<tr>
<td>Theme 3: “Butchers” and “Angels”</td>
</tr>
<tr>
<td>Theme 4: “The Guilt Train”</td>
</tr>
<tr>
<td>Theme 5: ‘How Are You”</td>
</tr>
<tr>
<td>Theme 6: The “Wake-Up Call”</td>
</tr>
<tr>
<td>Theme 7: Making a “Breakthrough”</td>
</tr>
<tr>
<td>Theme 8: The “Hard Work” of Cancer</td>
</tr>
<tr>
<td>Theme 9: The “Gift of Cancer”</td>
</tr>
<tr>
<td>Concluding Remarks</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter V: Discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Moral Context of Illness</td>
</tr>
<tr>
<td>Contribution to Knowledge</td>
</tr>
<tr>
<td>Practical Applications</td>
</tr>
<tr>
<td>Policy-Making</td>
</tr>
<tr>
<td>Limitation of this Research Project</td>
</tr>
<tr>
<td>Recommendations for Future Research</td>
</tr>
</tbody>
</table>
Illness Narrative in a Structured Cancer Group

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Reflections</td>
<td>120</td>
</tr>
<tr>
<td>References</td>
<td>121</td>
</tr>
<tr>
<td>Appendix A Format of Structured Cancer Group</td>
<td>131</td>
</tr>
<tr>
<td>Appendix B Participant Consent Form</td>
<td>133</td>
</tr>
<tr>
<td>Appendix C Transcription Notations</td>
<td>135</td>
</tr>
<tr>
<td>Appendix D Hendrika’s Story</td>
<td>136</td>
</tr>
<tr>
<td>Appendix E Theme Transcriptions</td>
<td>140</td>
</tr>
</tbody>
</table>
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CHAPTER I

Introduction and General Research Question

My interest in the illness experiences of people with cancer is based on my professional and personal experiences. I previously worked at an active treatment centre for individuals with cancer. As part of my responsibilities I co-led a weekly support group, and I frequently marvelled at how many individuals overcame great emotional adversity related to the certainties and uncertainties of their physical condition. Before I left this agency I helped form a similar support group for patients with primary brain tumours, which at that time had a prognosis of a 5% two-year survival rate (i.e., 95% of these individuals would die within two years). Once again, I marvelled at how individuals with such a grim future could seemingly find not only solace within a group setting, but could also speak about how they could find meaning and even joy in day-to-day living.

More recently, eight of my colleagues, many of whom had extensive experience caring for individuals with cancer, themselves developed cancer. Three have since died. I had numerous conversations with them about their experiences, including their “insider” (i.e., part of the health care system), now “outsider” (i.e., a patient), observations of the health care system, and they collectively described many failings of the “system”. In describing what experiences were of benefit, two colleagues informed me of positive experiences in group settings. Their descriptions, in light of my earlier professional experiences, rekindled my desire to explore in greater depth how groups can engender these positive experiences. My explorations led me to the writings of Kleinman (1988), a medical anthropologist, who captured aspects of suffering I had observed in my clinical work, but that I did not fully comprehend. From those writings I went on to writings on narrative and illness narratives, which intrigued me because they opened up new areas of understanding about the response of individuals to illness. I next pursued writings on discourse analysis, which provided insights into how discourse was actually accomplished by people. This research project is
therefore an outcome of my desire to learn more about illness narratives, including how they actually came into being, which lead to my research question of "How does an illness narrative develop in a structured cancer group?".

This research is intended to make a contribution to the overall understanding of individuals' experiences within a cancer group intervention program. These programs are one of the most common forms of psychosocial intervention provided to individuals with cancer, and their family members (Cunningham & Edmonds, 1996; Fawzy, Kemeny, Fawzy, Elashoff, Morton, Cousins, and Fahey, 1990; Telch & Telch, 1986). Having cancer can arguably be one of the most challenging experiences for an individual given that "cancer continues to be one of the most feared of all diseases" (Fertsz & Waldman, 1997, p. 245), with anywhere from 25% to 75% of individuals with cancer developing serious emotional problems (Telch & Telch, 1986; Trijsburg, Van Kippenburg & Rijpman, 1992). As well, eventually, three out of four families will have a family member with this illness (Fawzy et al., 1990; Northouse, 1984; Telch & Telch, 1986), which highlights the broad impact cancer has in our society.

A central value of narrative to individuals with cancer is that it gives voice to their suffering (Charmaz, 1999; Good, 1994; Hyden, 1997; Kleinman, Das, & Lock, 1997; Kleinman, 1988). Suffering, in turn, can be ameliorated through the process of finding meaning in one's experiences and incorporating those experiences into one's sense of identity (e.g., Hyden, 1997; Mathieson & Stam, 1995). Medical anthropologists (e.g., Kleinman, 1988) make important distinctions between disease, illness, and suffering. Disease refers to the actual negative physical manifestations that require treatment, and illness "refers to how the sick person and members of the family or wider social network perceive, live with, and respond to symptoms and disability" (Kleinman, 1988, p. 3). Suffering refers to the range of negative emotions and cognitions experienced by the individual with a disease, and is often a manifestation of the meanings attached to one's illness, which in turn is a function of one's relationships with others and the larger social context. Too often traditional Western
health care providers ignore suffering because contributing factors are beyond the physical realm (Conrad, 1990; Gerhardt, 1990; Good, 1994; Kleinman, 1988). Structured cancer groups (e.g., Cunningham & Edmonds, 1996) were developed, in part, to address the unmet needs of individuals suffering with their experiences with cancer.

As well, over the past 10 to 15 years there has been a shift in perceptions of counselling psychologists, health researchers and practitioners, and policy makers that are relevant to research and clinical interventions in cancer-related research. Broadly, there is a growing interest in the context of individuals’ experiences with illnesses, especially chronic illnesses. Gerhardt (1990) notes successful interventions for most secondary infections “which was the most frequent cause of death of the chronically ill until the 1940’s” (p. 1149), along with the improvement of drug and surgical interventions for a variety of illnesses, have lead to a dramatic rise in the prevalence rate of chronic illnesses in most Western countries. In turn, this has lead to an interest in factors other than traditional Western medical interventions to understand and explain the experiences of individuals in whom some aspects of health, and perhaps many aspects of health, are social and behavioural in nature” (Lincoln, 1990, p. 378). These perspectives have become very influential in public and professional domains. For example, health care organizations have been prompted by the Canadian Nurses Association (1997) and the Canadian Council of Health Services Accreditation (1999) to attend to the needs of clients from a holistic perspective. This perspective is core to the practice of counselling psychology (e.g., Egan, 1998).

Having the disease of cancer, which either directly or indirectly affects a large portion of society, results in a range of negative emotional reactions and adjustment issues, and is therefore of direct concern to the practice of counselling psychology. According to the mission statement of the Department of Educational and Counselling Psychology, and Special Education at the University of British Columbia, counselling psychology aims “to understand how people overcome problems and accomplish life tasks, and to design effective ways to help live more productive, fulfilling and meaningful lives”. Furthermore, the
Illness Narrative in a Structured Cancer Group

American Psychological Association’s Division of Counselling Psychology includes as part of counselling psychology’s mandate, a focus on clients’ health issues (Altmaier, Johnson, & Paulsen, 1998). One broad area of concern for counselling psychologists, therefore, is to understand how individuals might better manage living with serious illnesses such as cancer. Counselling psychology shares this concern with other professions such as nurses and physicians, thus the purpose of this study is well situated within the domains of counselling psychology and those of other health care practitioners (e.g., Corney, 1996; Mellor-Clark, 2000; Taylor, 1999; Roth-Roemer, Robinson Kurpius, & Carmin, 1998).

Perspectives on Narrative and Discourse Analysis

This study is broadly situated within the epistemological perspective of social constructionism, “which assumes that, in the sphere of social and psychological inquiry, there is no fixed external reality to be “objectively” known but a fluid “social reality” which is co-constructed” (Corney, 1996, p. 60). As well, Gergen (1985) argues that many research approaches applied to interactions of individuals are inherently limited because they ignore individual differences and contextual factors without which human interactions cannot be fully understood. A core factor in understanding individuals’ behaviours is the interactive effects of relationships whereby one cannot completely separate the actions of individuals within a relationship, what Lyddon (1995) refers to as the “primacy of the relationship” (p. 591).

As stated above, the aim of this study is to examine the development of an illness narrative in a structured cancer group. With qualitative narrative studies, however, defining narrative becomes problematic given the variety of definitions given by different researchers in this area (e.g., Mathieson & Stam, 1995; Mishler, 1995; Riessman, 1993), as described in the following section. Similarly, there is no uniform consensus as to definitions of discourse analysis (e.g., Potter & Wetherell, 1990; 1996; Stubbs, 1983; Van Dijk, 1997), which is included for discussion in this section because discourse analysis as method cannot be easily separated from its various conceptual bases, including its relationship to narrative.
Conceptual issues and related methodological issues are described in the following section. The concepts that form the basis for the actual approaches taken in this study are highlighted, and are described in greater detail in Chapter III.

**Narrative - Conceptual Issues**

Bruner (1986; 1987) is cited by Kenyon and Randall (1997) as a central figure in generating interest in the notion of narrative in the realm of psychology. His basic premise is that humans are capable of two modes of thought, logical and narrative. Bruner (1987) argues that so basic is the narrative form of thought to human existence that the living of life cannot be separated from the stories we tell about our lives. Bruner’s work signalled a departure from cognitive psychology, which had emphasized a singular perspective on logical thought, and from the larger social scientific community, in which earlier generations viewed narrative merely as a form of representation (Hyden, 1997). Hyden notes that narrative-related research now “is being focused on how people talk about and present events, and not only on what is said” because “the form of the narrative, its presentation and organization, also conveys something of the self-image that the narrator hopes to convey to others” (p. 50).

Narrative, in essence, is viewed as the means by which an individual mediates between “self and world, either evoking or simply creating order and meaning” (Hinchman & Hinchman, 1997, p. xvi). According to Mattingly and Garro (1994), this evoking or creation of order and meaning more specifically relates to how one creates meaning of real life events “that require relating to an outer world of observable actions and states of affairs” (p. 771). Time then becomes a defining feature of narrative as one experiences “events” in life, and makes sense of them, in part, by making reference to past events to explain the present and project into the future. Mattingly (1994) quotes the work of Ricoeur (1980), who argues for the close relation of narrative and temporality, in that “I take temporality to be that structure of existence that reaches language in narrativity and narrativity to be the language structure that has temporality as its ultimate referent” (p. 812). Mattingly further cites Ricoeur as postulating that plot is the narrative structure “most associated with temporality” (p. 812), and uses the
concept of emplotment to delineate the process by which a series of events are structured (i.e., "configured") in some meaningful and coherent fashion into a whole story or narrative. Mishler (1995) notes that researchers of narrative with this perspective commonly refer to stories having a beginning, middle, and an end, where the relationship between these events are more than chronological, that is: “They refer to cultural, meaningful, and recognizable boundaries of passage ... that give a stretch of talk or text a unity and coherence” (p. 91).

The construction of narratives is inherently social in nature, in that language is a symbolic meaning system that is negotiated and validated, or not, through interactions with others (Gergen & Gergen, 1997). Great emphasis is placed on the role of language in influencing human behaviour given the assumption that language is the basic medium by which individuals interact and that language imparts symbolic meaning through interactions with others and society at large. The basic structure of language is that of stories, or narratives, such that:

Narratives are a language-based explanation of phenomena that occur within the individual (by way of talking to one’s self), in relationships with others (by way of conversation), and among members of cultures (by way of mores, myths, and cultural values). Once developed and internalised, narratives become the basis of knowing regarding self and the world ... Because the narratives serve as the basis of our knowledge of the world, they promote behaviours that are congruent with the narrative and discourage behaviours that are not. (Sexton & Whiston, 1994, p. 64)

It is in this sense that certain authors (e.g., Gergen & Gergen, 1997; Harre & Gillett, 1994; Hinchman & Hinchman, 1997) argue that an individual’s identity, or ‘self’, is in fact constructed through narrative.
Personal identity, the answer to the riddle of “who” people are, takes shape in the stories we tell about ourselves. Such stories may not necessarily be the ones we tell to others or to the public at large; they are the narratives that we construct as we orient our present choices and actions in light of our imagined futures and the version of our own pasts that fits with these projects.

(Hinchman & Hinchman, 1997, p. xvii)

While there is a consensus as to the importance of narrative, there is little consensus as to its definition. Mishler (1995), for example, notes that with the marked increase in narrative studies, there has been a concurrent increase in different perspectives as to what actually constitutes narratives, or what he refers to as “the current state of near-anarchy in the field” (p. 88). Mishler views this situation optimistically as he argues against conceptualising narrative as a separate discipline of study, but rather as a “problem-focused area of inquiry” so that the study of narrative warrants a variety of approaches, and that each approach can learn from the other. The variety of perspectives on narrative are understandable given that, as Riessman (1993) notes in her text on narrative analysis, “the study of narrative does not fit neatly within the boundaries of any single scholarly field” and is “inherently interdisciplinary” (p. 1). She argues that, broadly speaking, narrative is viewed across disciplines as an organizing principle for human action, and that an individual’s story becomes the focus of study, to be analysed as to how it is put together and the resources one draws upon in its telling. She further notes that a defining characteristic of any narrative is that it must have a ‘point” to ensure that what is spoken is accepted by the listener (see also Wilensky, 1983, cited in Mishler, 1995).

For Mathieson and Stam (1995) the issue about how to constitute lived experience in narrative comes down to opposing, yet related, perspectives. They note the use of the term narrative in the social sciences is “frequently confused on this count; referring sometimes to ‘stories’ with ‘plots’ or underlying ‘schemas’ and sometimes to the lived experience which
are themselves the subject of a narrative" (p. 283).

Thus, narrative can be viewed as having multiple definitions depending on the context or perspective one wishes to take. In one sense it is a meta-theoretical construct, and in another, it is the simple telling of a story, and in yet another, it is the retelling of that same story (e.g., Mishler, 1995). For the purposes of this dissertation, narrative is principally viewed as the story, or stories, one tells of one’s experience, organized by a plot, and with temporality as a major referent point, as described above.

Illness Narratives

It has become axiomatic in the illness narrative literature that a major illness is a disruptive force in an individual’s life (Bury, 1982; Good, 1994; Hyden, 1997). Bury refers to this situation as “biographical disruption” because the condition imposed by an illness “creates new and qualitatively different life conditions” (Hyden, p. 57), which forces one to re-examine one’s life. Cancer can arguably be one of the most disruptive of diseases given that it not only threatens death, but also creates uncertainty about whether or not their disease will be successfully treated, or if dormant, whether it will return with all its attendant adversities. As noted by Samarel, Fawcett, and Tulman (1997) “cancer survival is an ongoing process that begins on the day of diagnosis and continues for the remainder of the person’s life” (p. 25). Given that temporality is inherent to life, an unexpected illness disrupts one’s life narrative, resulting in a profound loss of orientation such that “the fabric of our lives may be ripped to shreds” (Hyden, 1997, p. 53). One is faced with the dilemma of how to answer core existential and moral questions (Hyden, 1995; Kleinman, 1988). For example, Hyden, in his study of the narratives of psychiatric patients noted that individuals not only ask what happened, but “also why it has happened and what constitutes the unity of that life” (p. 69). The question of why it happened becomes a moral question because one examines one’s own, and others, contributions to one’s predicament. “The central moral quest is to find out to what extent the illness event is a result of the kind of life the person has led” (Hyden, 1995, p. 83). By answering these and other questions related to how and who one will be in
the world, one begins to ‘reconstitute’ one’s life narrative.

A key aspect of this reconstitution concerns itself with problems of identity (Hyden, 1997). “Narrative ... is one of the inescapable structural requirements of identity” and “narratives are not just vehicles for collecting personal information; they are the very process of identity construction (Mathieson & Stam, 1995, p. 288). These authors base their claim on their interviews of individuals with cancer. They delineated three elements to the process by which individuals re-establish a new, cohesive identity: disrupted feelings of fit, which describes how individuals reacted to the initial signals of threat; renegotiating identity, which includes managing issues of stigmatisation, and giving voice to their experiences; and biographical work, a life long endeavour, which in the context of the cancer experience, incorporates “the major biography-altering facts of cancer: altered relationships, a curtailed sense of agency, and a changed vision of the future” (p. 300). The therapeutic value of narrative, therefore, is its ability to “provide a context that encompasses both the illness and surrounding life events and recreates a state of interrelatedness” (Hyden, 1997, p. 50). Thus, while narratives in general are thought to develop on an on-going, interactive basis, this dynamic takes on greater meaning with illness narratives given that affected individuals are commonly engaged in an active struggle for coherence and meaning-making in their lives, an activity which often becomes a singular focus in their lives.

Given this dynamic, this study draws upon the literary-based notions of plot and emplotment (e.g., Good, 1994; Good, Munakata, Kobayish, Mattingly, & Good, 1994, Mattingly, 1994) to provide perspectives on narrative and methodology. “Plot provides the underlying structure of narrative” (Good et al, 1994), giving it both structure and meaning, especially in the context of temporality. “Emplotment”, in turn, is the activity whereby a succession of events are configured in time to make a greater whole, or ‘story’ (Mattingly, 1994). In this endeavour, emplotment takes a central role. “The activity of emplotting, thus has a special affinity to the experience of persons with debilitating chronic illness” (Good, 1994, p. 145), as one must actively re-emplot a self-narrative to regain a sense of coherence
in one’s life. As well, in many instances, given the uncertainty of the progression of an illness like cancer, one will necessarily be continually emplotting one’s self-narrative as one struggles to deal with the ongoing disruptions engendered by the disease. “With few exceptions, the narratives are not complete, the stories not finished” (Good, 1994, p. 146). Thus, illness narratives have a characteristic quality of ambiguity, as the narrator continuously struggles to find meaning in his or her life situation (Hyden, 1997).

Mattingly (1994) and Mishler (1995) note that the concept of emplotment was originally developed by Northrop Frye, a literary critic, who set forth four archetypal plot structures, or genres (i.e., romance, tragedy, comedy, and satire), which were argued to set the structure for all narratives. As noted above, this notion was further developed by the philosopher Ricoeur, who argued that the foundation of all narratives is temporality and that plot is the narrative structure that is most closely associated with temporality (Mattingly, 1994). Mattingly develops this notion even further, to encompass emplotment as something that actively occurs between a therapist and a patient, based on her study of how occupational therapists work with brain injured patients to develop a more temporarily coherent story.

While this ongoing search for coherence and meaning is viewed as typifying illness narratives, Mathieson and Stam (1995) and Bloom (1997) note that some individuals reach a point where the experience no longer dominates their lives. “Cancer survivors in the study often reported a sense that they had reached a point where ‘cancer no longer encircles’ their lives. In effect, the illness experience moved from the foreground into the background as one became ‘well’ again” (Mathieson & Stam, 1995, p. 300). Thus the frequency, intensity, and meaningfulness of the vicissitudes of one’s ongoing experiences can be viewed as mediating the experience of disruption and its attendant demands to reconstitute one’s life narrative.

Discourse Analysis - Conceptual Issues

Just as writers have struggled with the variety of different and often contradictory perspectives on narrative, so to do writers on discourse analysis. For example, in Stubbs (1983) writings on sociolinguistic perspectives he states that, “No one is in a position to write
a comprehensive account of discourse analysis. The subject is at once too vast, and too lacking in focus and consensus” (p. 12). Potter and Wetherell (1990; 1996) note that this situation is due to at least four distinct strands of work laying claim to the title discourse analysis. “The terms ‘discourse’ and ‘discourse analysis’ can be part of contrasting theoretical and disciplinary debates and can come to mean quite different things” (Potter & Wetherell, 1990, p. 2). In Potter and Wetherell’s (e.g.1996) later work they attempt “to forge a coherent theoretical and analytic programme of discourse-orientated research” (p. 80). The authors note that a central theme of discourse analysis is a dual focus on individuals’ ‘discourse practices’ and ‘discourse resources’. Discourse practices refers to “what people do with their talk and writing” and discourse resources refers to “the sorts of resources that people draw on in the course of those practices...which provide a machinery for social life.” (p. 81). The authors then note that despite this distinction, discourse analysis research typically must draw upon both perspectives, although the emphasis tends to be weighted towards a psychological and/or sociological perspective, and less to a purely linguistic perspective. “The goal is to make a contribution to our understanding of issues of identity, the nature of mind, constructions of self, other and the world and the conceptualization of social action and interaction” (p. 81).

Potter and Wetherall’s work can be seen as part of a new paradigm in psychology developed during the 1990’s, known as discursive psychology (e.g., Harre & Gillett, 1994). Discursive psychology challenges traditional cognitive psychology’s perspective on the inner, contained, workings of the mind, to a perspective based initially on the work of Wittgenstein (1953), who argued that language is action orientated, and constructed through interaction with others. It is this aspect of joint construction that takes the mind out of the sole purvey of the individual. “We must learn to see the mind as the meeting place of a wide range of structuring influences whose nature can only be painted on a broader canvas than that provided by the study of individual organisms” (Harre & Gillett, 1994, p. 23).

Of particular interest to both discourse analysis and discursive psychology is the
influence of social discourses and rhetoric that individuals' draw upon in their speech activities. The perspective is of direct relevance to the study of illness narratives given that individuals with illnesses such as cancer are viewed as drawing upon moral, cultural, and rhetorical perspectives to make sense of their experiences (Hyden, 1997). For example, Frank (1993) argues that a particular North American genre of illness narrative has arisen, with the rhetorical structure of self-as-project-for-change, and often in dramatic form (i.e., 'phoenix rising from the ashes'). He further argues that “At the core of any illness narrative is an epiphany” (p. 41), so that an individual’s “fundamental meaning structures” are altered. From this perspective, Frank (1993; 1995) developed what he refers to as three “storylines” that influence how illness narratives (i.e., ‘restitution, ‘chaos’, and ‘quest’) are presented.

Rhetorical structures not only influence how individuals understand and experience their illness, but also can structure the actual practice of oncologists. For example, Good, Good, Schaffer, and Lind (1990) argue that in comparison to other cultures such as Japan and Italy “American oncology appears as a unique variant of international biomedical culture” (p. 59). From this perspective “hope” is viewed as a “dominant symbol” grounded in American cultural notions of individuality and the mobilization of hope and personal willpower to surmount adversity. In a related study, Good et al. (1994) argue that this discourse on hope has generated a public mandate whereby oncologists are expected to “instil hope in the therapeutic narratives they create for and with patients” (p. 856). They interviewed oncologists and observed how their mandate has led to narrative strategies such that the oncologists engage their patients in a way that keeps a focus on the immediate occurrences (i.e., on “highly foreshortened [time] horizons”) and away from what could be unhopeful narrative endings. The topic of how physicians structure their conversations with patients has been of great interest to medical anthropologists (e.g., see Todd & Fisher, 1993), especially as those structures are seen to prevent patients from expressing their often profound suffering (e.g., Conrad, 1990; Good, 1994; Gerhardt, 1990; Kleinman, 1988).

Thus, from certain perspectives of narrative and discourse analysis, social discourses
and rhetoric are seen to strongly influence both the structure and content of discourse between individuals, and individuals' narratives. This is not seen to be deterministic as such, but rather sets up what Potter and Wetherell (1990) refer to as a rhetorical struggle, given that one rhetorically based discourse can be countered by another. For example, Wilkinson and Kitzinger (2000) used what they described as a discursive approach to study how cancer patients actually incorporated the use of “thinking positive” into their discourse. The authors noted that “thinking positive” is a central construct in the stress and coping literature, but the results of their study indicated that “thinking positive” was in fact used as an idiom of speech, and was not reflective of internal cognitive processes. Relevant to a discussion of rhetoric and discourse analysis, one part of this study revealed that while “thinking positive” was used in some instances as a moral injunction, some participants resisted this injunction. As Potter and Wetherell (1990) argue, “In part, a study of discourse is an analysis of this rhetorical struggle” (p. 8).

Thus rhetoric gives rise to certain genres of speech acts, which “typify the intricate cultural and linguistic codes underlying the most simple utterance” (Kleinman, Das, & Lock, 1997, p. 33). Discourse between individuals, therefore, takes on certain forms that the speaker assumes will be understood by those listening, and these forms develop from various social discourses (e.g., the rhetoric of “thinking positive”, or of “hope”), as well as typical story structures (e.g., Frank’s (1993) “story lines”).

Discourse analysis proves difficult to define. Like narrative, it draws upon a variety of perspectives that are not easily synthesised, however, narrative is more easily situated within certain perspectives, and typologies have been developed (e.g., Mishler, 1995). As yet no typologies have been developed for discourse analysis, and debates ensue as to its definition and related criteria (see Abrams & Hogg, 1990; Parker, 1990a; Parker, 1990b; Potter & Wetherell, 1990). This study does not attempt to settle opposing viewpoints, but rather simply acknowledges that discourse is more than what people simply say or write. As described above, this study adopts the perspective of Potter and Wetherell (1996) that
discourse is both what people do with their talk, and the resources they draw upon to “do”
their talk. In this sense, discourse is much broader than narrative, although they have much in
common conceptually. Potter and Wetherell (1990) describe the relationship between
discourse practice and discourse resources, in that “There is a clear tension between seeing
people as active users on the one hand, and seeing discourses as generating, enabling and
constraining on the other. Put simply, discourse analysis studies how people use discourse
and discourse uses people” (p. 12).

Concluding Comments

As described above, the terms “narrative” and “discourse analysis” are both
represented by numerous perspectives that defy simple definition. The nature of the study
environment lends itself to a perspective of narrative that incorporates certain notions of plot,
emplotment, rhetoric, and genre as key devices worthy of study. These in turn are compatible
with Potter and Wetherell’s (1996) and Stubbs (1983) perspectives on discourse analysis,
especially in regards to an action-orientated perspective on speech. Furthermore, the
aforementioned perspectives acknowledge the influence of context on narrative and
discourse, which is of primary concern to this research study.
CHAPTER II

Perspectives From The Research

In Hyden's (1997) review of illness narratives published over the previous 10 years, he noted that there have been thematic, theoretical, and methodological shifts. There has been a shift towards patients' experiences and perspectives of suffering, and away from physician perspectives and their influences on patients' experiences. Research has focused on how patients manage their situations, especially issues of identity. The narrative, previously viewed as background, now has taken a pivotal position in research, on par with identity. Furthermore, there is a movement towards studying situational factors in how narratives are continuously being constructed, and away from the notion of identity constructed as a singular life history.

Presently there is no consensus as to what typology best fits illness narratives. For example, Mishler (1995) termed his typology as 'fuzzy categories'. Similarly, Hyden (1997) argued that various typologies (e.g., Frank, 1993; Robinson, 1990) had limited ranges. Hyden (1997), therefore, developed a typology, which is adopted for this section on perspectives from the research, based on what he refers to as the formal interrelational aspects of illness narratives, "namely the relationship between narrator, illness, and narrative...resulting in three types of illness narratives: illness as narrative, narrative about illness, and narrative as illness" (p. 54).

Illness as narrative refers primarily to the telling of the illness experience by that affected individual and significant others. Hyden uses this term because he argues that the narrator’s telling of his or her illness experience is so intimately interwoven with the illness itself that they cannot be separated. Therefore they serve a variety of functions, such as giving voice to the experience, and as a vehicle by which one can integrate the experience into one’s life.

Narratives about illness refers to narratives that are primarily told by another, and
concern themselves with conveying "knowledge and ideas about the illness" (Hyden, 1997, p. 54). Typically these narratives focus on how physicians and other health care professionals talk about an illness (e.g., to form a clinical profile), and research in this area has historically examined "how the communication between doctor and patient develops...and how the patient experiences the information conveyed by the doctor" (Hyden, 1997, pp. 54-55). As presented below, other researchers from a variety of disciplines and perspectives have also examined the illness experience of others (e.g., to enhance participation in medical screening programs).

Narrative as illness refers to those situations when the narrative is insufficient to the degree that it generates the illness. For example, in Mattingly's (1994) study, the brain-injured patient lacked the capacity to form a cohesive narrative without the intervention of the occupational therapist. Therefore, one's inability to construct a self-narrative becomes the illness as one cannot make sense of who one is, nor can one put together a coherent life story.

**Illness as Narrative**

The influence of medical anthropologists such as Kleinman (1988) and Good (1994), dissatisfied with the dominance and restrictiveness of medical discourse, sought to give voice to the suffering of patients. Giving voice to suffering not only allows for a better understanding of the totality of the sufferer's experience, but is an integral component to the renegotiating of identity (e.g., Mathieson & Stam). The necessity to express one's suffering perhaps explains the pervasiveness of first-hand narratives about individuals' experiences with cancer. The popular media is saturated with personal stories about illness, and by one estimate there are approximately 2000 biographical or autobiographical books on this topic (personal communication, Richard Gwyn). Frank (1995) asserts that the majority of published illness narratives are about what he terms individual quests. His notion of quest is one of three available storylines that can be used as a resource by individuals to give shape to their story or self-narrative. In a similar perspective, Hawkins (1999) uses the term "pathographies" to denote personal illness narratives and the struggle to overcome them.
Two books titled 'Cancer Stories' highlight the interest in personal cancer stories and their meaningfulness. Dreifus-Katton (1990) used different story tellers to illuminate reactions to typical episodes and phases of the cancer experience, as well as certain psychoanalytic perspectives on interventions (e.g., art psychotherapy). The author uses "personal accounts of cancer authors" to provide "moving depictions of illness, dying, and creativity" and to demonstrate "how we are all interconnected, the sick and the healthy, and how losses bind and embrace us all" (p. 7). Thus, not only do we gain insight to individual personal experiences, but these experiences have meaning for the reader in the larger context of human existence.

Nine years later, Gregory and Russell (1999) also compiled personal cancer narratives to highlight the issues of suffering, and as well to identify 'gifts' from the individuals' experiences (i.e., the learning that comes from the generation of knowledge embedded in experience). The core learning is that it is the love from others, and our meaningful relationships that "enable us to live with or transcend intractable suffering" (Gregory & Russell, 1999, p. 183). Once again, the experiences of a small number of diverse individuals have something of importance to offer the larger community.

**Narrative about Illness**

As noted above, narrative about illness refers primarily to someone other than the ill person telling the illness narrative. Such narratives traditionally reflected physicians' perspectives and/or the influence of the physician on an ill person telling his narrative (e.g., see Todd & Fisher, 1993). This category also includes attempts to broaden clinical understanding of ill persons' perspectives to better meet their medical/physical needs, and to identify and better understand their psychosocial needs. In relation to the former, one common strategy to the use of illness narratives is to identify the informants' perspectives on certain health issues. This approach by researchers seeks to highlight the necessity of care providers to better understand those perspectives so that they might better meet their health needs. Examples of this approach are provided in the following review of four research
articles. Three of these articles focus on individuals with breast cancer, and the fourth concerns itself with individuals with metastatic bone pain.

Lawson (1998), Facione and Giancarlo (1998), and Matthews, Lanin, and Mitchell (1994) are concerned with how the belief systems of women with breast cancer affected their help-seeking behaviours. Lawson (1998) was concerned with the narratives of black women, given that as a group they seek diagnostic intervention less frequently than white women, which in part may explain their higher diagnostic rate of advanced breast cancer. Using a case study approach, the author performed content analysis on the clinical life history narratives of 20 black women diagnosed with chronic or life-threatening cancer. The author demonstrated how their previous life experiences resulted in a perception of risk that tended to keep them from seeking medical assessment and intervention (e.g., a belief that cancer results from “bad luck” or “fate”).

Facione and Giancarlo (1998) take a similar tack, although their concern is focused on the issue of the decision-making process of women in regards to seeking mammography. Using focus groups taken from a total number of 80 women of mixed ethnicity, and presumably free of cancer, they analysed elicited narratives using a structured components framework (i.e., abstract, orientation, plot, evaluation, resolution, and code). The authors ascertained that certain beliefs and concerns contributed to the participants not seeking testing, for example, concerns about overwhelming family resources, and concerns about a personal sense of extreme modesty.

In an earlier study, Matthews, Lanin, and Mitchell (1994) were also interested in why black women delayed seeking treatment for cancer. Twenty-six black women, who were part of a larger quantitative study of factors related to delayed treatment seeking behaviour were interviewed. A two-fold analysis was performed. First, the overall structure of the narratives was examined, looking for the types, and sequencing, of topics. Next, the researcher delineated the ways informants conceptualised and understood breast cancer. These were validated by testing initial metaphors and propositions on later interviewees, and “where
possible” to reinterview informants (20 of 26). A variety of beliefs and concerns that impacted on seeking treatment were identified. Most notable for many informants, was the belief that linked breast cancer symptoms to a belief in “bad blood”.

Coward and Wilkie (2000) were concerned with the communication behaviours of informants regarding their pain, which is a potential indicator of metastatic bone cancer. Using narrative data from semistructured interviews, the authors’ descriptive sought to investigate gender differences (10 women and 10 men) in reporting pain symptoms, but none were found. Of interest is that the majority of the informants preferred not to tell others of their pain, and more than half did not take medication as scheduled due to their fears that the pain did in fact mean their cancer was recurring.

A second broad area of research concerns the exploration of the various aspects and dimensions of illness in order to better understand ill persons’ experiences and psychosocial needs. As noted in Chapter I, medical anthropologists (e.g., Kleinman, 1988; Good, 1994) and sociologists (e.g., Bury, 1982) identified the dimension of suffering to illness and its’ disruptive impact on the afflicted individual. The study of illness spans many disciplines, such as nursing (e.g., Carpenter, Brockopp, & Andrykowski, 1999), psychology (e.g., Mathieson & Stam, 1995), and occupational therapists (e.g., Mattingly, 1994), and these disciplines take a variety of approaches.

For example, Carpenter, Brockopp, and Andrykowski’s (1999) research concerned itself with how women with breast cancer reconstructed or ‘transformed’ themselves in the context of their illness experiences, and the relationship of self-transformation to a sense of self-esteem and well-being. They studied 60 women with breast cancer, using structured interviews and questionnaires, and age-matched them to women without cancer. Compatible with Gergen and Gergen’s (1997) rudimentary types of narratives, the authors identified three categories of transformation among the informants: positive, minimal, and stuck. The author found evidence to support a relationship between self-transformation, and self-esteem and well being (i.e., those categorised as positively transformed had higher levels of self-
illness narrative in a structured cancer group

esteem and well being than the stuck group and the age-matched comparison group). Thus there is some suggestion that the construct self-transformation is somehow linked to self-esteem and well being.

As well, Mathieson and Stam (1995), as described above, sought to delineate cogent aspects of the influence of cancer experiences on identity, and how identity issues were subsequently addressed. They challenged traditional measures of psychosocial sequelae as labelling individuals with cancer as pathological (e.g., depressed and anxious). They also took issue with common notions of 'adjustment' and its connection to the cognitive adaptation model, which the authors deemed as inadequate to account for the social and institutional contexts of individual experiences. Using Glass and Strauss's (1967) grounded theory approach they interviewed 37 informants based on open-ended questions related to identity. Categories of response were delineated through three stages, into three categories: disrupted feelings of fit, renegotiating identity, and biographical work. This study not only gave voice to the issues of identity for the informants, it validated previous work done by others on the disruptive effects of cancer (e.g., Bury, 1982), and illuminated a core process by which those with cancer navigate their experiences.

**Narrative as Illness**

Narrative as illness refers to the condition whereby the individual is incapacitated to the degree that he or she cannot form a substantive self-narrative. The work of Mattingly (e.g., 1994) speaks to this concern, as noted in Chapter I, in her research that demonstrated therapeutic interventions of assisting the affected individual to connect one’s daily activities into a coherent self-narrative (i.e., emplotment). To date, there are no cancer illness narratives in this category. There is, however, one article (Nochi, 1998), which investigated the experiences of individuals from a support group, each of whom had traumatic brain injury (TBI). His findings are directly relevant to the area of cancer given that some individuals experience primary brain tumours, and many others experience metastatic brain lesions.
The author notes that an important focus of counselling individuals with TBI is the common occurrence of "loss of self". He quotes Pollack's (1994) assertion that "the primary goal of psychological intervention for TBI patients is to enable the injured person to re-establish, or in the case of minor brain injury, to confirm the sense of self" (Pollack, 1994, p. 674).

Nochi (1998) interviewed four women and six men of various ages, and identified three forms of loss of self. He referred to the first form of loss as the opaque self, where loss of self is related to emotional and cognitive changes, which are "opaque" to the individual in that they do not know how or why these changes came about. The second form of loss is referred to as loss of self by comparison, where the individual compares the "new" self to the "old" self, and in some cases, to the future that they imagine they would have had. Two strategies employed by participants to minimize this loss, are to either maintain hope for future recovery, or to discount the past (e.g., by stating present life is better because one no longer drinks or consumes drugs). The third form of loss is loss of self in the eyes of others, which for some occurred when they experienced certain labels as pathologizing (e.g., the term TBI). Informants spoke of other, less offensive terms. Ironically, some who were mildly injured found being labelled as "normal" lead others to underestimate their real limitations and denied them medical attention for their legitimate health problems.

The author's work expanded the range of categories of "loss of self". In concert with other authors, Nochi (1998) concluded that health care providers need to better understand their clients' perspectives in order to better meet their needs.

Groups, and Illness Narratives

Even though a group format is the most common structure for cancer psychosocial intervention, as noted above, there has been virtually no narrative-related research in this area. One study of interest by Allen (1999) explored the issue of "survivorship" of 30 informants who were, or had been, members of a support group. She used support group membership as a criterion for "survivorship". Using grounded theory methodology (Glass &
Strauss, 1967), she analysed the informants’ responses to questions regarding feelings about living with cancer, the impact of cancer on social relationships, self, and spirituality, and a description of a typical day. From her analysis she was able to integrate two other models of sickness and chronic illness, and developed six survivorship profiles based on this integration. Thus, this study contributed to the conceptual understanding of issues of survivorship and identity.

Relevant to this research proposal, Allen (1998) recommends that given the inherent limitations of her retrospective research, “A full-blown ethnography of the cancer support group experience” (p. 446) is warranted, as well as an investigation into spirituality issues, which was an important issue for many of her study participants. Also of interest, Dean (1998) writes on the theoretical utility of a narrative approach to groups. She notes that storytelling in self-help groups plays a key role in their functioning, for example, in Alcoholics Anonymous groups, which are based on sharing one’s story and finding acceptance among the membership. Many self-help groups emphasize the roles of social and emotional support, and these activities are key to structured cancer support groups as noted in a following section on cancer psychosocial interventions.

Discursive Approaches to Research

Similar to cancer-related illness narrative research, cancer-related discourse analysis research has not generated a significant body of literature. One relevant exception, however, is the work of Wilkinson and Kitzinger (2000), as noted above. They examined the use of the expression ‘think positive’, and concluded that it was used as an idiom for social discourse, rather than being a direct representation of internal cognitive processes, which is a key concept in the stress and coping literature. Notions on coping are relevant to the traditional study of cancer psychosocial interventions, as described below.

Discourse analysis, as well as illness narrative research, is also concerned with issues of identity (e.g., Potter & Wetherall, 1996). At least one author (e.g., Horton-Salway, 2001) took a discursive approach to demonstrate the rhetorical underpinnings to identity formation
in an illness narrative case study. Furthermore, researchers such as Edwards (1999; 2000) and Kitzinger (2000) demonstrate the rhetorical nature of verbal interactions, and how individuals can utilise a variety of resources and strategies to negotiate social situations. These and other readings in discourse analysis assist one to discern how individual accounts are constructed, and from these accounts, illness narratives can be discerned.

**Contributions of Illness Narratives and Discursive Approaches to Research**

Collectively these illness narratives gave voice to the experiences of the informants, to the benefit of the informants, that is ‘to be heard’, and to those in the counselling and health care arena. By listening to and comprehending these narratives, counsellors and other health care professionals are better equipped to target interventions for those in need. Examples are found in Lawson’s (1998), Facione and Giancarlo’s (1998), and Matthews, Lanin, and Mitchell’s (1994) works in eliciting narratives of women with breast cancer. The illumination of the participants’ perspectives offer counsellors and health care providers an opportunity to devise better early diagnostic interventions for a serious and life-threatening illness.

Illness narrative research can contribute to the refinement and development of conceptual frameworks, as did Mathieson and Stam (1995), who further developed Bury’s (1982) notion of biographical disruption by illuminating the process of identity change one undergoes with cancer. Similarly, the work of Frank (e.g., 1995) and Nelson (2001) help articulate the nature of self and the role of narrative and storytelling when the self is challenged by serious illness. Furthermore, Nochi (1998) expanded the range of conceptual categories of “loss of self”, a key feature of impaired cognitive functioning.

These research projects contribute to the promise of narrative research by demonstrating the impact, and therefore the importance, of narrative in human lives. As Mattingly and Garro (1994) point out, one of the defining features of narrative is “its image-rich quality, its capacity to describe a world through the evocation of sensory images” (p. 771). It is this richness of the language of illness narratives that has the power to connect
the individual readers into a shared sense of collective humanity (e.g., Dreifus-Kattan, 1990; Gregory & Russell, 1999).

**Cancer Psychosocial Interventions**

This section reviews traditional psychological perspectives on cancer psychosocial interventions. This review, in part, gives the reader a perspective by which to evaluate the results of this research project. In particular, this research project argues that the usefulness of the results of this study is that the usefulness of a structured cancer group extends beyond learning coping skills.

Anderson (1992) has provided one of the most thorough reviews of cancer intervention research to date. Later reviews, (e.g., Fawzy & Fawzy, 1998; Poslusny, Hyman, & Baum, 1998), reviewed much of the same research related to groups. Anderson (1992) noted that the research has generally demonstrated a correlation between the magnitude of the disease and related treatment, and the degree of psychological distress (e.g., Cella, Orofiamma, Holland, Silberfarb, Tross, Feldstein, Perry, Maurer, Comis, & Oraz, 1987). Anderson therefore structured her review into categories of low, moderate, and high morbidity risk.

Across all levels of risk groups, Anderson (1992) identified five mechanisms for intervention effectiveness: an emotionally supportive environment; information about the disease and treatment; behavioural and cognitive coping strategies; and relaxation training. To a large measure these interventions can be viewed as effective coping strategies, which have been demonstrated to be effective when coping with other stressors:

- learning more about a stressor, confronting it with positive cognitive states,
- active behavioural strategies, and eventually, reduced emotional distress may provide realistic appraisals of current or impending stresses of the disease or treatment process and enhance one’s sense of self-efficacy or feelings of control early in the adjustment process. (p. 562)
Furthermore, these interventions may enable later mechanisms to emerge, for example, effective coping may lead one to adopt further positive behaviours that influence one's future health status as an individual with cancer (e.g., maintain optimum diet).

Another mechanism that has received attention in both the professional and lay communities (e.g., Anderson, 1992; Cunningham, 1992) is the notion of immune system enhancement, which refers to stimulating the immune system in a manner that would enhance its ability to kill cancer cells. This is thought to occur by either stimulating it directly with certain agents, or via what is commonly referred to as the ‘mind-body connection’ (e.g., Cunningham, 1992). For example, Fawzy et al. (1990) implemented a structured, cancer group intervention research study, using a randomised treatment-control format with patients from a low morbidity risk group. Not only did the treatment group demonstrate significant improvement on emotional and behavioural measures, but as well, six months later the treatment group had a significant elevation in natural ‘killer’ cells associated with an enhanced immunity system. At six year follow-up, the treatment group had a significantly higher survival rate (10 of 34) then a control group (3 of 34). While these results are both significant and intriguing, the sample size was small (34 for both groups), and further research is warranted.

Anderson (1992) notes that there are differences on the focus of treatment for the low risk morbidity group and the high-risk morbidity group. For the low risk group, the emphasis is towards a crisis intervention format, given the immediacy and intensity of initial reactions typically experienced by both client and family members.

For the high risk morbidity group, there tends to be a shift towards death and related quality of life issues. Anderson (1992) speculates that these individuals may benefit as well from a significant therapeutic relationship with a therapist, where the therapists’ qualities of empathy, warmth, and genuineness would be “pivotal”. She further speculates that these qualities could be “transferred” to a group, as demonstrated in an earlier study by Speigal,

Whereas the available research provides evidence for the effectiveness of structured cancer group intervention (for reviews see Anderson, 1992; Cunningham & Edmonds, 1996; Fawzy et al, 1990; Fawzy & Fawzy, 1998; Fawzy et al., 1995; Posluszny et al, 1998; and Trijsburg et al., 1992), Posluszny et al. (1998) note that there are significant confounding variables and methodological concerns in this research. For example, whereas Cunningham et al.’s (1993) study demonstrated that a structured cancer group format is effective across diverse client variables (e.g., gender; age; diagnostic site), the authors noted that the results were only exploratory given that the participants were self-referred, and the study had no control group, thus limiting the generalizability of the results.

In contrast to the preceding study, Posluszny et al. (1998) note that most participants in the studies are white, middle-class women, and that studies have high refusal rates, sometimes greater than 70%. “These sources of bias...must be addressed as potential mechanisms mediating the effectiveness of these interventions” (Posluszny et al., 1998). Despite these limitations and shortcomings of the available research, the authors conclude that “the findings from this growing literature are fairly consistent: group interventions among cancer patients are beneficial” (p. 102).

Both Anderson (1992) and Posluszny et al. (1998) note that the available research does not support either individual intervention or group intervention as superior to the other. Fawzy (e.g., Fawzy & Fawzy, 1998) and Cunningham (e.g., Cunningham & Edmonds, 1996) make a favourable argument for the use of group intervention, not only for its demonstrated effectiveness, but as well, that it is a more economical format, of benefit in the present climate of health care cost-containment and financial accountability.
CHAPTER III

Research Design and Methods

This section describes the practical steps and the methodological strategies to successfully answer the research question of “How does an illness narrative develop in a structured cancer group?” Denzin and Lincoln (1994) use the term “bricoleur” (i.e., “constructor of knowledge”) to describe the role of a qualitative researcher. This role requires that the researcher be skilled in a large number of diverse tasks “ranging from interviewing to observing, to interpreting personal and historical documents, to intensive self-reflection and introspection. The bricoleur reads widely and is knowledgeable about the many interpretative paradigms...that can be brought to any particular problem” (Denzin & Lincoln, 1994, p. 2). A key skill of a bricoleur is that of reflexivity, which at a basic level is the capacity for self-awareness on one’s world-view influences the research process and outcome. Given that reflexivity is a key issue for validity in qualitative studies, it is described in greater detail in the following section on validity. Given these two perspectives on bricoleur and reflexivity, this section gives space to the personal voice of the researcher.

Methodological Approaches

The following section first provides an overview of the methodological approaches taken. Next, the reader is provided a description of how the study was implemented, how participants were selected, and how ethical issues were identified and dealt with. One is then provided a description of how the data were analysed and how issues of validity are addressed. The last section provides a profile of the individual participants.

As described in the Chapter I, narrative analysis, informed by perspectives on discourse analysis, are the methods that were used in this project. These approaches are assumed to complement each other given that this research project is concerned with both the illness narratives that developed in the structured cancer group, and how they are produced. The reader is therefore directed to the Appendix A, which outlines the format of the ten-
session structured cancer group. Note that each session is structured in two parts, with the first part given to learning a specific activity (e.g., performing progressive muscle relaxation; "dialoguing with your inner healer"), and the second part given for group discussion and processing of that activity. An initial assumption of this research project was that, given this group design, the meaningfulness of the participants' activities could be more than simple skill acquisition. Therefore, it was assumed that this meaningfulness would be captured, in part, by observing their verbal interactions and the resulting development of their narratives.

Discourse analysis, as put forward by Potter and Wetherall (e.g., 1994; 1996), is therefore employed to inform the analysis. Gubrium and Holstein (2000) give support for this approach in their chapter on current perspectives for doing qualitative research. They note that discourse analysis is well situated within current perspectives on qualitative research that is "interested in the social accomplishments of meaning and order" (p. 487). The authors state that interest in this area has broadened into an interest in "interpretative practices", "the constellation of procedures, conditions, and resources through which reality is apprehended, understood, organised, and conveyed in everyday life" (p. 488). This "ethnomethodological turn" assumes that individuals actively use social values and mores to give order to their world. From this perspective speech and social interaction are of primary interest to researchers, as these constitute the "doing" of social life. Different directions to performing research are available to the researcher depending on the particular emphasis of the research (i.e., non-Foucauldian discourse analysis, conversational analysis, and Foucauldian discourse analysis). Given that this research project is concerned with the production of illness narratives, and that a basic assumption in narrative research is that they are produced through interaction with others, non-Foucauldian discourse analysis, as put forward by Potter and Wetherall (1994, 1996), lends itself well to this endeavour (Gubrium & Holstein, 2000).

This research project adopts the perspective of Mishler (1995) that narrative research is best viewed as a problem-focused area of inquiry given the variety of approaches taken by different disciplines. Therefore, perspectives on narrative analysis, illness narrative, and
discourse analysis, as described above, guided the analysis of the data. This research project also utilised the self-confrontation technique (see Pristang, Barker, & Rutter, 1997; Tannen & Wallat, 1993; Valach, Young, & Lynam 2002; Wiseman, 1992), however, as discussed below, it was deemed to be of limited success. This technique involves asking participants to review selected videotaped portions of the previous session, immediately following that session. The use of this technique was deemed to be of interest given a perspective among some researchers that speech acts are not representations of internal cognitive processes (e.g., Drew, 1996; Potter & Wetherall, 1996). Therefore, the question arose as to what is occurring in the participants’ inner landscape (i.e., thoughts and feelings), and how might their perspectives illuminate an understanding of such acts, for example, by providing a perspective on contextual aspects of the group that impacted the participant’s verbal interactions.

At the first session I asked for a volunteer from the group to engage in the self-confrontation activity at the end of the second session. In each subsequent session a research participant was to be asked to volunteer for the following session. I deemed it too demanding on both the participants and the resources of the research project to review the whole session, so I therefore made an arbitrary decision that the review activity would last a maximum of one hour. I further decided that the portion of the videotaped selected for review would start at the beginning of the recorded session, which is structured for the participants to “check-in” about any specific issues or concerns that have arisen during the previous week. One-minute segments of the tape were played back to the participant volunteer, who was then asked to recollect his or her thoughts and feelings at the time.

Unfortunately, several difficulties arose that limited the amount of material obtained using this technique. Skytrain services to the hospital recently became available and therefore off-site parking became more restrictive and fines for overtime parking increased significantly. Therefore participants were concerned with leaving quickly at the end of each session, especially given that street parking was limited to 2 hours, which is the time allotted
for the group sessions. As well, this project ran over the late fall and early winter months, and so the weather also became an issue, as participants were concerned with leaving before the weather worsened. The impact of these situations was that participants did not readily volunteer for the post-group activity even though they had all expressed willingness to do so prior to starting the research project. I then devised a new strategy of soliciting volunteers by approaching an individual participant rather than asking the group as a whole, and then negotiating how I could address their specific issue, for example, by offering to pay for parking.

A second, more serious problem arose, in that of the six post-group self-confrontation sessions, technical difficulties in recording the sessions made three of the six unusable. I did keep field notes of each session, but these were kept to a minimum, as I had not anticipated technical failure. Although these difficulties limited the amount of usable information, they still provided some useful information, which is described in the following chapter.

Implementation

Participant Criteria and Selection Process

For the purposes of this study I selected the structured cancer group format sponsored by the BC Society for Psychosocial Oncology (see Appendix A). Based on my experience and my review of the literature, I thought this model would provide the best group program for individuals with cancer, without requiring professional resources. It incorporates in one program the hierarchy of programs developed by Cunningham and Edmonds (1996), with the exception of actual psychotherapy, which is beyond the mandate of a non-professional community-based program. As well, it is more sophisticated and comprehensive than the basic model proposed by such authors as Fawzy and Fawzy (1998), and lends itself to adaptation within a wide number of settings.

I solicited the participation of two staff members to facilitate the research group, both of whom had personal and professional experience with cancer. They obtained permission from their employer to run this group and received group facilitator training through the BC
Society for Psychosocial Oncology. As well, the staff's employer provided the services of an audio-visual technician, and a room in which to conduct the study.

Participation in this research project was open to anyone with a history of cancer regardless of site or treatment history. As well, one "significant other" per participant could also attend. The only exception to these criteria were if a potential participant had a degree of cognitive or physical impairment that would significantly impair their ability to actively participate in the group activities. Participants must also be able to speak English well enough to engage in group discussions. From 5 to 8 participants were to be selected, as less than 5 was deemed to be too few for appropriate group process, and more than 8 was initially considered too unmanageable for this research project. Up to 9 participants attended the group, but given the anticipated variability in attendance, this was deemed a reasonable number to facilitate the group process.

Potential participants were solicited via a number of avenues, primarily within what was then the Simon Fraser Health Region. Representatives from the Ambulatory Care Department, Royal Columbian Hospital, including the attending medical oncologist, agreed to actively promote this project to their cancer patients. As well, a recruitment pamphlet was inserted into the information packages given to newly diagnosed patients. Furthermore, as a long-term employee in the Simon Fraser Health Region, I had many contacts that agreed to actively assist me in promoting my research project throughout the health region. I also made presentations to several cancer-related support groups. Interestingly, I received only one participant through a contact, and all the others came from my presentations at the support groups.

In the fall and winter of 2001-2002 the group met weekly for 10 weekly sessions, with a 2-week hiatus over the Christmas holidays. The number of group participants varied from session to session, up to a maximum of 11, including the 2 group facilitators. The variability in attendance was due to several reasons. Some had scheduling conflicts, for example, to attend a doctor's appointments. One participant attended 2 sessions, but stated
she felt too emotionally fragile to continue given that her disease was progressing. Another participant became physically incapacitated and could not continue. Yet another had not initially realised that her vacation plans would interrupt her participation and therefore missed the last 2 sessions, however, she did attend a second group upon her return. Profiles of the individual participants and the co-facilitators are provided in the final section of this chapter.

The role of the co-facilitators, Mia and Lil, was to assist and support group interaction, and to instruct about and coach, specific skill development. In cancer groups facilitators typically also have personal experiences with cancer, which is deemed an asset in that they can better appreciate what the participants “are going through”. Thus, facilitators may become personally involved in the group’s sharing of personal experiences and related perspectives, as well as attending to the role of group facilitator. For example, in this study Mia often shared her personal perspectives on having cancer, while Lil occasionally shared her personal perspectives, but more consistently functioned in the facilitator role. Because the co-facilitators shared their personal perspectives, their verbal interactions are included in some of the transcripts.

The group sessions were structured around a different learning activity each week and related topics were presented by the facilitators. Each session was designed to include a learning activity and an opportunity for discussion. Several participants in the first session expressed their desire to have the group emphasise group discussion, and this request was accommodated by the facilitators, even though all participants had initially expressed an understanding of the group activities and a willingness to participate. As well, one participant stated she did not want to engage in the activity of journaling, as she had tried this before without benefit, while another stated he would journal once a week rather than daily as requested. The activity of maintaining a journal was considered a private activity for the benefit of the participant, and it was at their discretion whether they shared this information with the group. Thus, from the first session an emphasis was placed on the value of group
Each session began with a “check-in”, where the participants shared their thoughts and feelings about significant events of the week. Often this was in relation to the various prior learning activities, including their challenges and successes. Overall, this “check-in” was loosely structured, and the discussions were wide-ranging.

After the check-in, a facilitator would lead the group in an activity or discussion on a specific topic. At the end of the session, the participants were given an assignment to practice daily at home. Although the expectation of daily practice was explicated in the informed consent, there was a range of compliance with the request for various reasons. The most common reason given was that many participants felt challenged to discipline themselves to do daily practice, given the demands of work and family life, plus the physical limits imposed by their disease. A potential drawback to the emphasis placed on group discussion and the limited daily practice essential to skill development was that I was less able to study the effect of successful skill development on the development of illness narrative.

Ethical Issues

Ethical concerns are always a central issue with any human research, but it takes on even greater significance with chronic illness research. Informed consent is a key aspect of any study, however, Estroff (1995) argues that in chronic illness narrative research, obtaining signed consent is only the beginning of informed consent, in that consent is an on-going process, never complete and seldom “truly informed”, but a helpful framework and goal to keep in mind. Consent and collaboration are negotiated in ongoing, complicated relationships with our informants, relationships which sometimes generate conflicts with our tasks and roles as researchers (pp. 89-90).
My initial concern was that I exercise due diligence and not to coerce participation in some way. I do have a heightened sense around issues of informed consent given my professional experiences in an active cancer treatment centre. I was involved in experimental treatments, for example, the initial Interferon studies, and part of my responsibility was to obtain written consent. I learned that potential participants may in fact desire to participate in a project without adequately considering its demands or risks. Subsequent to that research I published an article that, in part, addressed ethical issues for obtaining consent for experimental treatments (Wade, 1983). Also, in my later work experience, I was directly involved in risk management issues, and took courses that covered legal and ethical issues regarding informed consent. I am therefore well versed in the basic principles of informed consent, and used this knowledge to guide my actions throughout the research project and beyond.

One concern I had was in regards to the potential for a negative reaction by potential participants to being videotaped. In a discussion with a colleague who facilitated a documentary of children with cancer, I was encouraged to stress the benefits of this research, that is, that their experiences would assist caregivers to better understand the cancer group process, and to guide providers of cancer groups with important information about how to enhance such groups in the future. To this I would add that the experience of participating in this research could be a powerful form of giving voice, a testimony, to their experiences, thereby making a direct contribution to their own developing narratives. A strategy that I used to minimize any sense of coercion was to offer potential participants the option of attending a second structured group, which would follow the first group and would not be videotaped. To my surprise not one potential participant expressed a concern about being videotaped. The only concern expressed to me was by those who could not attend during the daytime and therefore wanted to attend an evening program, which I did provide.

The second main ethical concern was to balance my need to complete a research project with the participants' sense of well being and autonomy. For example, as noted
above, the group strayed somewhat from the group design, which emphasized more balance between group discussion and skill acquisition with daily between session practice. This was, however, within the bounds of operating a group such as this, as participants are encouraged to set parameters around the group activities, and as well, the research consent form did make explicit that participants could choose how much they participated.

Analysis

Analysis was performed by using narrative analysis (e.g., Riessman, 1993), informed by discourse analysis (Potter & Wetherell, 1990; 1994; 1996) as well as relevant perspectives from the literature on illness narrative, as described in Chapter I and Chapter II. Narrative analysis and discourse analysis are primarily inductive approaches in that “narrative analysis is rather loosely formulated, almost intuitive” and “conclusions are often...quite context bound” (Manning & Cullum-Swan, 1994, p. 465), and discourse analysis has no prescribed methods of analysis, only “considerations” (Potter & Wetherell, 1994). Drawing upon these perspectives, the steps of analysis were as follows.

During the group sessions I began to observe the use of language and ways of discussing certain topics, some of which were familiar to me from my previous experiences with cancer groups, for example, certain notions of the relationship of stress to cancer. One of the initial challenges is to pay attention to the many aspects of speech that can be found in a single utterance, for example, as found in the following transcription.

“We know that the mind-body interaction, what we tell ourselves is happening – if we tell ourselves we are bad and we are doing something wrong, and that will affect our immune system if we keep worrying about these things”.

One could examine this piece of transcript from various perspectives such as viewing it as the “taking up” of a mind-body discourse, a manifestation of the moral context of illness, and/or a literal representation of the impact of a negative thinking style on the
functioning of the one’s body. It is this multiplicity of perspectives on language, all of which could be deemed appropriate, that presents the challenge to find a coherent narrative that can be said to be a fair representation of the participants’ verbal interactions. What I did, therefore, was to be mindful of the multiplicity of potential perspectives by which the participants’ use of speech and verbal interactions could be apprehended, when I made my initial notations of interest. The perspectives that guided my initial identification of interactions of interest are described in greater detail below. I used this initial organisation as a starting point of my review of the transcriptions. I examined sections of the transcriptions before and after the identified interactions of interest, to get a better sense of the context that they were produced and the related meanings.

Transcripts of the tapes were made, using a modified version of Jefferson’s (1979) transcription method (Appendix C). The transcriptions were of 20 hours of videotaped sessions that resulted in almost 700 pages of double-spaced typed pages. Also, I had attended every session but one, and made notes of the groups’ verbal interactions. While there are no clear-cut expectations as to what constitutes features of interest, various perspectives on narrative and discourse analysis guided this pursuit. For example, Stubbs (1983) details a variety of approaches to guide “listening closely” such as how speakers take turns in speaking, and various linguistic signposts to this ebb and flow of speech. My attention was also guided by my counselling skills, for example, by noting non-verbal behaviours such as extended pauses or changes in voice tone. (e.g., Egan, 1996). Key to these perspectives is an appreciation that language is polysystemic (i.e., is organised and made coherent by different types of mechanisms), any and all of which could be of interest to the researcher. Potter and Wetherell (1994) take this same perspective, what they refer to as “reading-the-detail” in analysis, the doing of which is seen as a craft of the researcher rather then a specific technique.

Given that this research project seeks to track the development of narratives in a structured cancer group, I paid close attention to participants’ talk that was seemingly
narrative-related. I was guided by Riessman’s (1993) perspective that the researcher should listen for evaluative clauses, which are “the soul of the narrative” as these clauses tell how narrators “want to be understood and what the point is [to the narrative]” (p. 20). Concurrent with a focus on evaluative clauses, I also listened for talk related to identity and identity-formation.

I also paid close attention to what Potter and Wetherall (1996) refer to as variability, either within an individual’s discourse or between speakers, which can lead the researcher to identify features of how an account is constructed. “Variability is important because it marks the action orientation of discourse” and “helps the analyst map out the pattern of interpretative repertoires that the participants are drawing upon” (Potter & Wetherell, 1996, p. 87). Interpretative repertoires, as noted above, are of central interest to discourse analysis as they are viewed as a principal resource for the doing of discourse practices. They are identified as “broadly discernible clusters of terms, descriptions, and figures of speech often assembled around metaphors or visual images” (Potter & Wetherall, 1996, p. 89). Thus, I paid special attention to participants’ use of metaphors and visual images, especially those that might arguably be related to narrative development.

Furthermore, I paid attention to how participants organised their discourse rhetorically from both narrative and discourse analysis perspectives. Rhetoric, however, is a term upon which there is no consensus as to its meaning. It broadly refers to the use of language to in some fashion influence others, often in a socio-political context. “It is, in one way or another, a vehicle for responding to, reinforcing, or altering the understandings of an audience or the social fabric of the community” (Gill & Whedbee, 1996, p. 157) and can take many forms. From narrative perspectives I considered rhetorical structuring devices such as Frank’s (1993) notion of self-as-project-for change. From discourse analysis perspectives, I considered Potter and Wetherall’s notion of rhetoric, which view verbal interactions as naturally reflecting forms and styles of argument. They also include notions of accountability to these verbal interactions in that they view individuals’ account giving to others as
constructed in some fashion to make them difficult to rebut or undermine. Rhetoric and accountability constructions are what Potter and Wetherall (1994) refer to as “two sides of the same coin” (p. 60). Rhetoric, a special form of variation, is a device whereby one makes an argument for one’s point of view, often in contrast to an implied alternative point of view. Accountability refers to how one presents one’s point of view as fair and objective typically through the devices of justification or excuses. For example, it is common for participants in cancer groups to be critical of traditional medical care, and to draw upon certain discourses (e.g., stress) to argue against that form of care and justify non-traditional approaches.

Thus, for the purposes of this research project, rhetoric is considered as a resource to be drawn upon (e.g., Frank’s (1995) storylines), a structuring device (e.g., Frank’s self-as-project-for-change), and a form of action (e.g., to resist a dominant or challenging perspectives, see Kitzinger, 2000). These forms of rhetoric are deemed to be manifested in some way in the verbal interactions of the research participants, and therefore are looked for in the analysis of the group session transcripts.

I found that a useful strategy was to compile what I deemed to be major categories of talk being expressed by the various participants, while attempting to maintain an awareness of overlapping and/or multiple categories at the same time. As I combed through the transcripts I continued to look for potential quotations or sections of transcripts based on the various perspectives described above. I then attached Post-It Notes with abbreviated quotations and tentative category or categories of interest.

My next research strategy was to refine my collection of compilations into narrative related themes, while keeping what I deemed to be relevant from a perspective of discourse analysis. Thus, as the narrative-related themes evolved, I examined them from an ongoing discourse analysis perspective to illuminate their construction.

To sum, metaphorically I “cast a wide net” in my analysis without preconceived notions as to what factors or aspects of the participants’ use of speech and their verbal interactions, would emerge to be of the greatest interest. This approach is compatible with the
“loosely formulated, almost intuitive” perspectives of both narrative and discourse analysis, as noted above. From a narrative perspective, what emerged as most salient in illuminating the development of the illness narrative were the contextual influence of the moral environment of illness on the participants’ use of speech and their verbal interactions, and the use of metaphors as a pervasive form of speech among the participants. From a discourse analysis perspective, what emerged as most salient in illuminating the development of the illness narrative is the manifestation of rhetorical forms of verbal interactions. Other salient aspects related to various perspectives of narrative, illness narrative, and discourse analysis were also evident, and are discussed in Chapter IV and Chapter V.

Validity

Gergen and Gergen (2000) cite Denzin and Lincoln’s (1994) assertion that there is a “crisis of validity” in qualitative research, primarily because language does not directly represent an objective reality, and that social reality is by its very nature interpretative, with multiple possible meanings. Gergen and Gergen (2000), after reviewing several qualitative methodological approaches, further note that “the debate on validity has reached an impasse” (p. 1031). Thus, there is yet no definitive approaches or guidelines that can be said with absolute confidence to ensure that a qualitative research project is valid. Certain approaches, however, can be taken to increase the trustworthiness, and therefore, the persuasiveness of a researcher’s account (i.e., Altheide & Johnson, 1994; Gergen & Gergen, 2000; Potter & Wetherall, 1994; Riessman, 1993; Stubbs, 1983), and these approaches will guide the construction of this research project.

Altheide and Johnson (1994) describe a researcher’s use of reflexivity as a major method to make accounts more trustworthy. This perspective arose from a concern among ethnographers during the 1960’s and 1970’s about how the researcher shapes “reality” in giving an account of their experiences and observations. Based on the assumption that “the observer is part and parcel of the setting, context, and culture he or she is trying to understand and represent” (Altheide & Johnson, 1994, p. 486), researchers attempt to account
for the various influences within the research environment on the final research product. Reflexivity becomes a key indicator of validity given a related assumption that researchers with different perspectives would produce different research products. Given this relativistic perspective on “reality” a reflexive accounting allows the readers to discern for themselves whether this accounting is appropriate and believable for the given circumstances. Reflexivity implies that the researcher clearly articulates the process of the research, including accounts of “the interactions that have occurred among context, researcher, methods, setting, and actors” (Altheide & Johnson, 1994, p. 489). Key issues to be addressed about these interactions are: how various research problems are addressed; the presence of multiple voices, including the researcher’s; and the identification of the multiplicity of meanings and perspectives in relation to various (often hidden) contextual factors.

One method to access other voices, meanings and perspectives is to ask those most intimately involved in the study, in this case the participants and the facilitators. I therefore made a group presentation on the themes I had identified and the quotes and stretches of transcriptions from which the themes arose. All the participants were at this presentation, except for Carol, who had attended only two sessions and had subsequently died, and Gwen, with whom no one was able to make contact even though she had verbalised at strong desire to attend. As to their pragmatic value, one participant stated that the findings should be published, as they were a coherent representation of their experiences, which she found personally meaningful. As well, during this presentation several comments were made about the accuracy of the findings in terms of individual experiences. Overall, the results were received warmly and enthusiastically and no dissenting views were expressed. As several participants did not offer any comments I asked if anyone had any disagreement or different perspective on what I presented. One participant responded with the comment that “it would be hard to argue with our own words”. In a follow-up conversation with a group co-facilitator who had been present at the presentation, she commented on how meaningful and “great” my findings were. When I shared my observation that several participants did not offer
comments, she responded that my presentation was so logically presented that the other participants did not have anything to add.

My second approach to validity follows the advice of Riessman (1993) and Stubbs (1983), who recommend that one should give clear descriptions as to how interpretations were made, and to make the “data visible” to the reader, by including detailed quotations in the research document. I have therefore made extensive use of direct quotes and transcriptions of the participants’ verbal interactions in my findings, as described in more detail in Chapter IV.

My final approach to validity, that of reflexivity, in part is addressed by the preceding strategy of using extensive quotes. The reader can therefore evaluate whether my use of these quotes show the findings fits with the data. Similarly, I have attempted to clearly describe the steps I have taken in this research project and my rationale for doing so, thereby assisting the reader to ascertain the validity of my efforts.

**Participant Profiles**

In this section the reader is introduced to the participants. I have used direct quotes to give the reader a better sense of the participants’ use of language, which is developed more fully in the following chapter. Included are profiles of the two group co-facilitators as they too have direct experience with cancer, and often shared their experiences with the group. Six of the participants are in their sixties, three are in their forties, and one age is unknown, but assumed to be at least in her fifties. The co-facilitators are in their forties. As well, two of the participants came as a married couple, the wife cancer-free and attending to “support” her husband. The group started with five participants and the two co-facilitators. Two participants started in the third session and the final participant started in the fourth session. This last participant attended the next cancer group to ‘make up’ for the missed sessions in the research group. The participants are as follows (n.b., pseudonyms are used).

**Arnold and Eva**

Arnold and Eva are the aforementioned couple, both in their sixties. Arnold, a retired
engineer, was diagnosed with prostate cancer in 1999, and was treated with surgery, radiation, and ongoing hormone therapy. He presumes his cancer is under control, and has regular blood tests to monitor the status of his cancer. He states that he attends this group to learn more about what might help him ("I would - I’m open for anything more or less and like - to find out what other people do and if it would help me I would like to do it too."). Eva typically describes herself in relation to her husband ("I am the other half wherever he goes more or less I follow behind you know what I mean"), and that she shares in Arnold’s treatment decisions ("So I am involved more or less from the beginning on and the decisions we make more or less"). Eva tended to talk more than her husband in the sessions, sometimes speaking on his behalf.

Debbie

Debbie is in her forties and was diagnosed with an advanced form of breast cancer in 2000. She was treated with surgery, chemotherapy, and radiation, and had only recently returned to work. She describes herself as not yet fully recovered in that she lacks the "energy" she had prior to her treatment. She is a manager of a department that provides technical services to a health care organisation and has considerable ‘expert’ knowledge related to disease processes such as cancer. She initially identifies a desire to learn relaxation skills given that she views herself as typically actively goal-orientated, but that this approach no longer proved effective when she’s emotionally challenged ("Yah see before if I was upset about something I’d just uh do more things...because then you accomplish something an-a-an-I don’t know it uh levelled out or something...but uhm you ca- there’s no more you can do so just learn to pause"). Debbie offers some direct comments to the group discussions, but generally speaks less then the other participants.

Paul

Paul is in his sixties and was diagnosed with prostate cancer in 1995. A retired teacher and now a part-time businessman, he elected to not undergo surgery due to concerns about impotence as a possible side effect ("I was willing to have surgery but I decided
against it-I had just been remarried [to] a young wife-I said I didn’t want to be impotent”). He was treated with hormone therapy and also avidly pursued alternative treatment approaches.

Throughout the group sessions Paul makes frequent contributions to the group discussions, for example, by citing numerous research references he has collected from the Internet and other sources. Much of this research is related to diet. As well, he is often familiar with the information presented by other participants regarding both traditional and non-traditional approaches to cancer management and treatment.

In the first session Paul states that his primary desire for participating in the group is for the group interaction (“I hope to learn from other people...the gems that they’ve picked up...through their ordeal uhm to bond with people uhm share knowledge uhm share feelings in a positive way and uh::m so we can lift each other up”). This aspect of “lift each other up” is of paramount importance to Paul’s sense of well being. He informs the group in session four (“Uh I also thought about this uhm uhm caring and sharing thing - it’s very important to me – I always say ta ta ta new members [i.e., in his prostate support group]...please call me because it helps my immune system...and so does this group and that’s why I’m here”).

Paul also informs the group that he has never suffered emotionally after learning of his diagnosis (“And I’ve never been down one day where I said “Aw shit I got cancer” (inaudible) So what [my] cells decided to screw up”). This is noteworthy in that Paul states he did not react in the typical fashion described so broadly in the literature.

Gwen

Gwen is a retired radio and television writer in her early sixties who has had two bouts with cancer. She was first diagnosed with breast cancer approximately thirty years ago, which was successfully treated. In 1995 she was diagnosed with an aggressive form of lymphoma that was not thought to be curable. As well, she identified herself as someone who knew “both sides” of the cancer experience as she had cared for her thirty-five year old daughter who died from cancer one year before Gwen’s most recent cancer diagnosis.
At the time of recruitment for this research project she was actively looking to participate in a cancer group of some kind as she was “slipping” (“I think the group (1.0) situation - brings you to that sort of thinking. It removes the stress of that ... and lately I have felt that I’m slipping a little bit. So I’m thrilled that this is gonna happen - that I can have this contact”).

Like several other group members she professed a belief that stress was a major factor in the development and maintenance of her cancer (“I’m such a believer in this - in the meditating and the diet and all of these things. That it’s the stress that was removed from my life [i.e., that lead to her initial treatment success, beyond her physician’s expectations]. That I think was the stress that was the trigger [i.e., to her getting cancer]”).

Her attendance in the group sessions was episodic due to her illness and she was unable to complete the ten sessions. When she did attend she was a frequent contributor to the discussions. Given her stated commitment to attending the group, her absence made me fear that her illness has significantly progressed. Even though she committed herself to attend the three-month post group follow-up, she did not attend and despite repeated phone calls from various members, no one was able to make contact with her.

Hendrika

Hendrika joined the group in the third session. She is in her sixties and was diagnosed with kidney cancer in 1995. She was treated with surgery and at this writing is presumed cancer free. Her illness precipitated a series of negative events in her life including the loss of her employment as a sessional college instructor followed by the loss of her house due to the resulting financial hardship. As well, she subsequently suffered a heart attack, a broken ankle, and the onset of a debilitating form of arthritis. She attributes her present self-described state of a high level of physical and emotional healthiness as the results of her efforts to get to the causes of her illnesses. These causes were described as primarily rooted in unresolved emotional conflicts with other family members, as well as a style of thinking that adversely affected her life. She asserts that by addressing these unresolved emotional
conflicts and negative thinking style that she has accessed a metaphysical realm that not only keeps her healthy but as well guides her present day life. For example, in the fall of 2001 she opened a centre to provide free cancer information and support services. She asserts that her deceased sister-in-law, who was diagnosed with cancer the same time as Hendrika but has since died, has continued to assist her in this endeavour, on a metaphysical level.

Hendrika is a frequent contributor to group discussions. She, along with the majority of the participants, ascribes to notions of a 'mind-body' connection to health and illness that is manifested primarily between "stress", mental attitude, and the immune system.

Carol

Carol also first came to the group in the third session at the invitation of Hendrika. She described herself as awaiting the results of medical tests that she feared would bring "bad news". She did not actively participate in the two sessions that she attended. Hendrika later informed the group members that Carol was too emotionally fragile to continue with the group and we learned prior to the end of the group sessions that Carol had succumbed to her illness.

Susan

Susan joined the group in the fourth session. A retired businesswoman in her sixties, she was diagnosed with an advanced form of ovarian cancer in 1999, which was treated with surgery and chemotherapy. Her treatments did not completely remove her cancer but she is presumed to be in remission at the time of her group participation.

Susan describes herself as physically active, and was profiled in a local community paper for placing second in a foot race. She often makes references to the negative impact of "stress" on health, however, her focus is more on whether or not her immune system is functioning at an optimal level. She attributes the development of her cancer to a decrease in her daily exercise over the last year ("In my mind my natural killer cells or t-cells or whatever you know the immune system. They were not as strong and then that's when I got cancer"). Like Paul she too informs the group members that she did not react in a typical
fashion to her diagnosis of cancer ("I didn’t think of - that I ever thought of it [i.e., her experience with cancer] as loss or grieving or anything like that”..."I thought of it more of a learning process. I guess I don’t have a lot - I can’t think of many things about having cancer").

Susan makes regular contributions to the group discussions, but is somewhat less vocal than either Paul, Hendrika, or Gwen. She also missed the last two sessions due to a previously planned vacation, but attends the next cancer group for the missed sessions.

Mia and Lil

Mia and Lil are the co-facilitators of the group. Their profiles are included as they too have direct experience with cancer, and share their perspectives with their group. Mia, a single mother in her forties, was diagnosed with breast cancer in 1998, for which she underwent surgery, chemotherapy, and radiation. Presently she is presumed to be disease-free. She informs the group that she is co-facilitating the group, in part, to reinforce healthy behaviours.

M = Mia  L = Lil  G = Gwen

M: [to G]  uhm but like you too I mean I’d been out of groups for awhile and I did a lot of meditation an:: yoga and different things like that (inaudible) you feel like your slipping

L:  that’s right

M:  and so it was a wonderful opportunity to sort of get involved again

Lil, Mia’s co-facilitator and co-worker lost her husband to cancer in the mid-eighties. She does not articulate a specific reason for attending the group other than for her role as co-facilitator. On different occasions she shares specific experiences with the group, while Mia makes frequent contributions of her experiences.

Both Lil and Mia have extensive experience in one of the health care disciplines in
the organisation that this research project took place. They are both involved in providing
patient specific clinical expertise and staff training and education. As well as their own
personal experiences with cancer, they have direct clinical experience in a variety of settings
for patients with cancer and their families. They both state they place a high value on groups
such as this one to meet the needs of individuals with cancer.
CHAPTER IV

Research Findings

This chapter concerns itself with answering the research question of "How does an illness narrative develop in a structured cancer group?". As described in Chapter III, I answered this question by listening closely to the participants' use of language and their verbal interactions. In listening closely I noted various distinctive features of language, such as the use of metaphors and other figures of speech. I also looked for demonstrations of rhetoric in the participants' use of language. While observing the group I made initial observations of their verbal interactions and then studied the transcriptions of these sessions in greater detail. Through this process I identified certain narrative-related themes, while concurrently examining them from a discourse analysis perspective. The construction of these themes and the selection of individual quotes and longer sections of the participants' verbal interactions are by necessity subjective and arbitrary. This is a reflection of inherent research bias, the diversity among the participants, and the large volume of available selections, which can be presented in any number of ways. The participants did, however, validate that these themes and selected transcripts made sense and were meaningful to them. I leave it to the reader to assess the persuasiveness of my findings and my commentary on their meaning and significance.

The main finding is that what emerged from the analysis of the group sessions' transcriptions is an overarching illness narrative of struggle. I elected to use the terms struggle and struggling, instead of the more commonly cited term of suffering (see Charmaz, 1999; Good, 1994; Kleinman, 1988) because 2 participants specifically disavowed suffering as part of their experiences. What also emerged from the analysis is that the participants' struggles occurred primarily in a moral context, and this moral context is evidenced in the participants' verbal interactions and the accounts they give about their illness. Their accounts speak to their many struggles, not only with the challenges of their physical disease, but as
well, with their own perspectives and the perspectives of their social environment. The perspectives are often broadly concerned with the rightness or wrongness, goodness or badness, or in some fashion with various expectations or rules, of the participants' behaviour. In other words, these are moral perspectives, and these perspectives often become challenges that the participants must struggle with. The moral context of illness is described in greater detail in Chapter V.

Overview of the Research Findings

Before proceeding to the themes that evolved from the participants' verbal interactions, this next section first reports on the findings from the use of the self-confrontation technique. As noted in the previous chapter, the implementation of the self-confrontation technique was of limited success. Only 6 of the expected 8 or 9 sessions occurred, and due to technical difficulties, only 3 of the 6 sessions produced usable tapes that could be transcribed. The available transcriptions and the limited field notes, however, provide some useful information that illuminates the influence of reflexivity on the participants' interactions.

Participants were asked to recall what they were thinking and feeling during the video playback of the session in which they had earlier participated. Many of their responses concerned their reactions and/or their reflections on what various participants were saying, as well as the nature of the observer's relationship to the others. For example, there were frequent statements of how the observer recalled an affective sense of liking another, which may include a sense of identification with another's experience, and even a sense of kinship. There were also comments made of feeling emotional distance (e.g., "not clicking" with someone, of "feeling judged" by others, and one concern of wondering whether one was boring the group. As well, there were frequent comments about liking what someone said,
either agreeing conceptually with the content of what was said, and in one instance of feeling
inspired by another's statements. Many times observers identified periods of interaction
where they were simply listening to what was said, usually with a sense of agreement.

Another common theme concerned evaluating one's own and others' behaviour in
light of what was being said. One observer stated that he was simply comparing his health-
related behaviour to what was being described, while another stated she evaluated hers and
others behaviour in terms of what was being described. In one instance an observer stated she
felt a desire to practice a certain technique described by another.

When commenting on their feelings and thoughts while observing their own
verbalisations, one observer noted that she was expressing exactly what she was thinking and
feeling at the time. Another commented that she had disagreed with what the content of what
was said, but out of a sense of respect she did not verbalise her opposing opinion. As well,
another observer had an opinion about what another should do, but did not verbalise it.

From these findings, we see how the participants evaluate their own and others'
behaviour in the context of their verbal interactions. For example, one participants'
description of health-related behaviour (e.g., a visualisation technique) becomes a
consideration for others to compare or evaluate their own behaviour. Participants also
evaluate, or simply experience, a sense of emotional proximity and compatibility with each
other. These perceptions may lead one to either engage in a new behaviour or to withhold
from certain behaviours (e.g., refrain from expressing one's opinion).

This next part of this section of the paper describes the overarching illness narrative
of struggle, which is based on the 9 themes that emerged from the participants' verbal
interactions. The themes that emerged are: getting "whacked on the side of the head",
“information’s power”, “butchers” and “angels”, “the guilt train”, “how are you?”, the “wake-up call”, making a “breakthrough”, the “hard work” of cancer, and the “gift-of-cancer”. All 9 themes demonstrate how the participants struggle with a variety of concerns and dynamics related to their illness and that, with the exceptions of the first two themes, how their struggles are embedded in a moral context.

The findings also demonstrate how these moral struggles are manifested in the participants’ verbal interactions, and illuminate how participants used language to navigate their struggles. Thus, the research findings illuminates how the overarching narrative of struggle, and the moral challenges presented by the illness of cancer, are made manifest in the participants’, often rhetorical, verbal interactions in a structured cancer group.

The findings are generally consistent with the initial expectations of this research project, as described in Chapter I. In regards to the narrative-related perspectives, the role of temporality as a key aspect of illness narratives is not explicitly manifested in the participants’ accounts, however, it is inherent in the participants’ actions to surmount their illness. As noted above, the moral nature and related challenges of the participants’ illness emerged as a defining attribute of the overarching illness narrative. The main plot, therefore, becomes that of the participants’ individual struggle to surmount the challenges of their illness. The findings also demonstrate how Frank’s (1993; 1995) notions of storylines are implicit in various participants’ accounts. The findings are compatible with current emphasis on how illness narratives represent participants’ self-image, primarily as agentic characters (see Hyden, 1997; Mathieson, & Stam, 1995). Although this research study noted Kleinman’s (1997) perspective of the moral nature of suffering, it was not anticipated that moral issues would manifest so prominently.
In regards to the discourse analysis related perspectives of this research project, the findings support Potter and Wetherall’s (e.g., 1996) notions of how rhetoric, language resources, and the flexible use of language illuminate an understanding of the nature of the participants’ verbal interactions, their giving of accounts, and the development of an illness narrative. In particular, the authors notions on rhetorical struggle were key to understanding a basic dynamic of the participants’ verbal interactions, as well as highlighting the moral context of their struggles.

One unexpected finding is that there was no apparent evidence of a strong influence of the group lessons (see Appendix A) on the development of illness narrative in the group. For example, although the topics of certain group lessons (e.g., stress; mind-body connection) were evident in some of the participants accounts, the accounts had already been emplotted prior to the participants attending the group. While this situation is not necessarily suprising given the ubiquity of writings on these topics in the public arena, it does bring into question one of Potter and Wetherall’s basic challenges to certain notions of discourse and interpretative repertoires. Specifically, these authors use the term “interpretative repertoires” to denote how individuals used language flexibly, versus the notion of discourse as something that an individual “takes up” (see Burr, 1995; Gubrium & Holstein, 2000). Although the findings do demonstrate how language is used flexibly by the participants, often in rhetorical struggle as put forth by Potter and Wetherall, the findings also demonstrate how participants have “taken up” certain discourses such as stress and the mind-body connection. The implications of this aspect of the findings are discussed in Chapter V.

Themes

In this section the major themes discerned from the verbal interactions are presented,
with extensive excerpts from the transcripts. Appendix C provides the reader with the transcription notations used in the excerpts. The transcriptions reproduce the verbal interactions as actually spoken, with some modification designed to improve the ease of reading. Specifically I have rendered the transcriptions into sentences and deleted the notations indicating length of pauses, but I have maintained all other notations (see Appendix C). For the interested reader I have placed the original transcriptions in Appendix E, and I have indicated with a "T" any transcription in this chapter that has been placed in that appendix.

These themes capture what are deemed to be the important aspects of the participants' accounts. They broadly demonstrate shared perspectives among the participants, but often with some variations, which are delineated in each section. The first three themes capture the pattern of how the participants typically gave their initial accounts to each other. That is, participants introduce their "stories" to each other by recounting their initial reactions to receiving their diagnosis of cancer, the initial actions they took, and their interactions with their physicians during the treatment phase of their illness. Following are themes related to concerns with guilt, and altered relationships to family, friends, co-workers, and the wider social sphere. These concerns give rise to other themes as they typically lead to efforts to change one's life, including one's perspectives on notions of mind, emotion, and body. These efforts are seen as "hard work", but ultimately generate many benefits, or "gifts", described as highly valued by the participants, which are the last 2 themes identified in this research project.

Theme 1: Getting "Whacked On The Side Of The Head"

As described in the literature review section of this dissertation, individuals given a diagnosis of cancer typically react with fear and dread. Many of the participants in this study reacted this way, and used vibrant and richly textured language in recounting their initial reactions. For example, Debbie described how she first learned about the experience of breast cancer through affected colleagues at work, and later through the experiences of her mother-
in-law. Even though she had “learnt a lot” from others, she still reacted strongly to her diagnosis (T1: “Through her [i.e., her mother-in-law] you know [I] learnt a lot so when it came my turn - it still whacked me on the side of the head (laughs)”). A similar experience is recounted by Mia (“And it does change your whole focus cuz all of a sudden you stop in your tracks and go oh”).

A sense of disorientation is also common, as told by Gwen who relates a story told to her by another individual who gave the analogy of her cancer experience in terms of her travels in Europe when she inadvertently got on the wrong train (T2: “And she said that’s what getting the diagnosis - is uh:: - that you have cancer - you’re on the train and it’s - left the station - and you don’t know where you’re goin-“).

This sense of being carried along without knowing where you are going often leads to a search for information and “knowledge”. For example, Arnold voiced the following experience. “T3: Because - uh I - was diagnosed with cancer it was a shock...[and after his operation] I was - for myself I was stressed. I didn’t know what direction to go - running around reading books”. Once again we are given a description of a reaction of shock to a diagnosis of having cancer and a sense of great uncertainty as to what to do next. For example, Arnold’s quote above evokes a familiar expression “running around like a chicken with its’ head cut off”.

In this section the reader is introduced to the participants’ use of metaphor, the main literary device used by the participants throughout their verbal interactions with each other. One value of metaphor is that its rhetorical forcefulness allows the speaker to convey the intensity of an experience that is often difficult to describe, especially if one is in shock and bewildered. For example, the quote above “whacked me in the side of the head” uses a physical image to forcefully convey the emotional experience of feeling stunned. Similarly, the image of being lost on a train in a foreign country graphically represents the experience of feeling lost and directionless that is commonly shared by individuals with cancer.

Before moving on to what some participants did in response to their situations, it is
noteworthy to refer the reader to the profiles of Paul and Susan. They both asserted that they
did not have a strong negative reaction to their diagnoses, even though in Susan’s situation
she is thought to have an advanced form of cancer.

Theme 2: “Information’s Power”

The participants commonly referred to taking two broad types of actions following
their diagnosis of cancer. These are gathering information and diet change, two actions that
often overlap in that a major focus of information gathering is directed towards information
on diet. Information gathering is also directed to other topics, and in some cases is a singular
activity without a specific topic or objective. For example, as noted above, Arnold stated that
after his operation “I didn’t know what direction to go - running around reading books”. His
statement implies that he was looking for information in various books to help him find a
“direction” to take in his life with cancer. In a similar vein, Paul informs the group that after
receiving his diagnosis he frequently used the Internet to obtain information on how to
manage his cancer. Paul makes frequent references in his group interactions to the “research”
he has read, most often on the Internet.

P = Paul (T 1)
P: One of the things I’ve done since day one is - I got on the internet with the help of my
good buddy - an-I:: look for things to give me hope - a:nd uh: ... so - I’m on the internet
most days five days a week - looking up studies.

The preceding transcripts and quotes indicate that there is a great interest among the
participants for cancer related information. Furthermore, the participants’ discussions
highlight the public’s general interest in cancer related topics, as noted by Debbie in session
two.
D = Debbie  M = Mia (T 2)

D: There is an article probably every three months or something about breast cancer and starting ovarian cancer and colon cancer in Canadian Living or Chatelaine you know in the [popular] magazines all the time.

M: [popular]

D: [popular] magazines all the time.

The following transcript is taken from a discussion between Debbie and Paul. Paul had been describing his interaction with a couple, where the husband was managing well with the news of his recent diagnosis of cancer, but his wife was “petrified”. Debbie follows with a remark about how prostate “is a male disease” and that much of the “popular press”, referred to above, makes little reference to prostate cancer, although in a later comment she notes that recently there is more public dialogue on this subject. According to Debbie the value of public dialogue is that “through learning more about an illness we can become less afraid of it.”

D = Debbie (T 3)

D: But you know I have to say - it’s a man’s disease. Nobody in my immediate circle has it so I don’t read about it. And I don’t really know enough about it, and the science and the effects of it, so I would be like that woman [i.e., the “petrified” wife]. You know like because breast cancer it’s it’s more out there, like they just - really pushed it.

Mia invokes a variation of the Latin motto knowledge-is-power (i.e., “information’s power”), to acknowledge Debbie’s assertion about the value of cancer related information being freely available to the public. Certain information presumably has the “power” to decrease one’s anxiety by giving one the resources to face the challenges posed by one’s illness. For example, information on diet becomes a resource to directly manage one’s illness, as demonstrated by Paul’s efforts with the Internet as stated in the following
P = Paul (T 4)

P: And this tells me that we can control our sickness. And that’s one of my goals, so I’m constantly searching for foods to avoid and to ingest – and - this is so inspiring to me it gives me so much hope, and so far it worked for me six years.

In a similar fashion Hendrika states “T 5: That was the first thing I did. I started on a macrobiotic diet...pretty well I have - changed my lifestyle totally”. As well, Mia stated that “So you start off, you know, absolutely fanatical [i.e., with diet changes]”. Both Hendrika and Mia state, however, that they both relaxed their diets somewhat, but that diet continues to be a major focus of their lives. For example, following Christmas Hendrika stated she had to “detoxify” herself as she had “added a lot of Christmas goodies to her diet”.

The preceding transcripts and quotes in this section demonstrate the participants’ interest, sometimes “fanatical”, in cancer related information. Although the other group members do not make direct statements to their activities of gathering information, their contributions to various discussions indicate that this is a common activity. They indicate this by referring to specific sources of information, frequently popular books on issues related to cancer specifically and to “health” generally. As well, participants made references to relevant television shows and related audio or videocassettes that may be purchased. Many of the references are known by at least some of the participants and if not, they ask how or where these sources of information may be accessed.

The findings also demonstrate that information gathering is a source of hope for participants in meeting the challenges of their illness. Furthermore, Paul’s comment “that we can control our sickness”, in part, is an indicator of the strong sense of agency that is woven throughout much of the participants’ verbal interactions. This notion of agency is described more fully in the following themes.
Theme 3: “Butchers” and “Angels”

At different times during the group sessions references are made by various participants regarding the impersonal nature of physicians, especially surgeons (T 1: “A surgeon treats the disease”; “If you have an operation you’re just a number. You got under anaesthetic, they put you - in you go, and (inaudible) they don’t know you personal right!”). This description of the impersonal nature of surgeons is likened by several participants as that of a “butcher”, which implies that patients are simply hunks of meat to be cut-up, and that patients emotions and thoughts are routinely ignored.

“T 2: But, in a surgeon, you go in under the knife – in, out, “next one”. [A] regular butcher, one gone [and] the next one under the knife”; “But the one I had too, ya he’s totally like that, a butcher, just the organ you know [he] deals with the organ. But don’t tell us that there is something in the head too, and that you actually have feelings”

Even though physicians were often cast in a negative light, these comments were tempered by two participants who thought that surgeons perhaps need to be emotionally remote (“I think in many areas it’s better for the surgeon themselves if they don’t know that person personally you know what I mean”, or that a surgeon’s technical expertise is all that’s important (T 3: “I don’t really care about the surgeon - all I want is for him to have the hands of an angel”). As well, the physician group of general practitioners is spoken of in a positive manner, for example, general practitioners were described as “different” (i.e., better) then surgeons who are “divas”. As Hendrika asserts (T 4: “There are some enlightened doctors out there. I have one but uhm - and she has grown with me whether she wanted to or not.”). Hendrika attributes her doctor’s “enlightenment” to her persistence in expressing her opinions and the evidence of her well being, plus the well-being of other patients like Hendrika.
Illness Narrative in a Structured Cancer Group

H = Hendrika (T 5)

H: Same with my doctor. For instance, she was seven years ago totally like, you know, roll her eyes when I said something to that effect, and just didn’t believe it. And as I come along now, and I keep pushing it, like I keep pushing it. Like I keep telling her, uh she’s coming to the point too. And just recently she, she, said “You certainly have really changed... what is going on by, and I really see that that the mind and body is uhm is...”.

And when I heard that I thought, my gosh, you know [it] took seven years somehow but I’m I’m mm, I’m not the only one doing this, but her patients have shown her that by being h- well...

Thus, physicians in this account are capable of becoming aware of patients’ health practices that go beyond their narrow medical gaze, but only through the continued exhortations and the continual examples of the physical well being of their patients. Despite these individual successes many physicians are not persuaded by their patients’ examples. As put forth by Hendrika, “T 6: They do not want to hear what we’re doing...like all of this is not seen as something worthwhile. In many cases, an- I think that’s why maybe some of the cancer industry is very hostile toward what we are doing and do not see the merit of it.”

In this section we again read how metaphors are used for their rhetorical force to emphasize the participants’ experiences. As well, we see how metaphoric language can be countered or challenged by the use of other metaphors. For example, the word “butcher” connotes, in part, a grisly image of participants being hacked apart during their surgeries. This image is countered by Paul’s use of metaphor (i.e., “the hands of an angel”), that is designed to minimize the concerns about the impersonal nature of surgeons by emphasizing the importance of their technical skill.

Hendrika also uses the metaphor “cancer industry” to broaden the perspective from individual physicians or one specific physician group to the whole enterprise of cancer
treatment. The metaphor of a "cancer industry" "hostile" to the self-help efforts of individuals like Hendrika brings forth an image of physicians as part of a business that not only does not see any value to these efforts but is "hostile" because their own self-interests are threatened. These rhetorical devices emphasize the plight of individuals with cancer, struggling in isolation to be heard by dismissive physicians (e.g., "you know, roll her eyes when I said something to that effect").

Not only do most participants want to have their emotions and thoughts acknowledged, but as well, they wish to share what they have learned about helping themselves manage their illness. Thus, through Hendrika's persistent efforts (e.g., "I keep pushing it") and the efforts of like-minded individuals (e.g., "I'm not the only one doing this"), some physicians can become "enlightened." In part, what Hendrika's physician is becoming aware of is the connection between mind and body, a central tenet of Hendrika’s and some of the other participants’ attempts to surmount their illness. Notions of mind and body and their centrality to the participants’ accounts are elucidated in greater detail in some of the following sections.

We also see in this section the relevancy of Regan’s (1991) notion of moral communities. Hendrika is demarcating two moral communities, that of the community of enlightened individuals like her, and that of the hostile cancer community. The boundaries of these two communities, although not absolute, serve as a useful resource to discern a shared identity among the participants. The importance of a shared group identity is elucidated in some of the following sections.

What are also relevant are the various notions on the moral nature of illness presented above. This section demonstrates how a moral stance is inherently part of the participants’ accounts, and their use of language. In the following section are examples of the pervasiveness of moral evaluation in the participants’ lives.
Theme 4: “The Guilt Train”

Another major theme that emerged from the transcripts is the pervasive role of guilt in the participants’ lives. Gwen first raised this topic concerning her relationship with her daughter who died of cancer in her mid-thirties, approximately seven years ago.

G = Gwen   D = Debbie   L = Lil (T 1)
G: That is the most [important] thing that you touched on. Because the mother in all of us tend to have, uh, guilt over what happens with our children. And I was so bad for that and when my daughter got cancer...
D: It was your fault.
L: uhm hum
G: Yes, I kept thinking “what did I do”?
L: What did you do↑
G: What did I do? Maybe I didn’t eat properly, and maybe it was because I had a drink when I was pregnant, because we didn’t know back then okay. Ah or maybe it wasn’t that I ate properly or maybe I didn’t feed her properly. And that’s what we tend to do [blame ourselves].
L: uhm hum

From this exchange we learn that even after approximately seven years Gwen is still wondering whether she in some way caused her daughter to get cancer. She also identified that it is a common experience for all mothers to feel guilt “over what happens with our children”. In a later session Gwen cautions the group members that one can make another “feel responsible for their own illness”.

G = Gwen   M = Mia (T 2)
G: I think that one thing that’s so important though, is that we don’t… you can believe in
this, all of this, for yourself [i.e., believe in alternative health practices]...

M: uhm hum

G: ... but we have to be very careful not to impose that on someone else. What I wanna explain - what I mean by that is that what happens is you make that person responsible. You can make that person feel responsible for their own illness. An what I mean by that is when you’re doing this for someone else, which is what I did for daughter, uh buying them vitamins doing all the things an- the books an- everything okay↑ But this is not her doing it that’s me doing it.

M: u;hm hum

G: Uhm so I used to say to her uhm “Oh you did take the - you didn’t take the vitamins okay↑’. An ah really what I was doing without knowing, see I know all this now because now I realize now [doing this] weren’t right, uh so what you, what it’s really doing is making her feel, cuz that’s how I feel sometimes, “Oh god if I don’t do this then its my own fault”.

In the preceding transcript Gwen is giving an account of how she encouraged her daughter to follow alternative health practices (e.g., taking vitamins to manage her cancer). Gwen expresses guilt because in the context of her present experiences with cancer she realizes that the effect of her actions was to make her daughter feel guilt (“oh god if I don’t do this then its my own fault [i.e., that her cancer progresses in some way]”). Several participants respond by seemingly trying to help her by humorously reframing her experience as in some way unnecessarily exaggerated. Debbie responds that Gwen lives “on that guilt train” for which she got “full ticket value”. After several turns between Gwen, Debbie, and Paul, Paul paraphrases an expression in a humorous fashion.

P = Paul L = Lil D = Debbie (T 3)

P: Ever hear the expression it’s not whether you win or lose its

L: [how you]=
Illness Narrative in a Structured Cancer Group

D: ya
L: =play the game
P: how you place the blassme.
[group laughs]

The humour in Paul's "expression" is that he has turned a common saying into a pun, and the groups' laughter indicate that they 'get it' (i.e., that self-blame and guilt are common experiences among the participants and/or that they are readily recognized as part of the experiences of others).

The question of guilt in terms of the participants' own roles in the development of their cancers is put directly to them by Mia in Session 7.

"T 4: "Well does anybody feel - did you get any guilt feelings that it was your fault that you got cancer↑ I mean you know you did something wrong and that's why you got it, you didn't eat right↑, or didn't exercise, got too fat whatever. I mean we all have those feelings "well if I hadn't done this it wouldn't a happened type of thing"

By uttering "we all have those feelings" Mia is presumably speaking not only on behalf of the participants, but for the larger community of individuals with cancer. Susan acknowledges that this Mia's comments have some truth-value in that she got her cancer "because of all the things I was doing and not doing", but that this is not a situation for which she feels guilty. As well, Debbie comments "I guess I had those thoughts but they didn't last long". In part she accounts for a short-lived sense of guilt over causing her cancer due to the intervention of her boss. "He just said to me you didn't do anything don't just don't even go there". Guilt, however, plays a significant role in her life in that she had described herself earlier as "the queen of guilt" in many aspects of her life. Gwen also speaks to "this guilt thing" that has a "strangle hold" on her life, for example when she cannot meet traditional
family obligations such as taking her turn to host Christmas dinner. Guilt is so pervasive in Gwen’s life that she asks the group members to “give her a little jolt” when they “hear that coming out”. Guilt thus is a “thing” that pervades her life and with which she must constantly struggle.

The other participants also acknowledge how pervasive guilt is in their own lives. Hendrika states that “it happens to us too”, and Debbie comments “but its okay I can only say this to you because I was recognizing so much of myself”. Paul too recounts how guilt was “built into me from my religious upbringing, which I have now discarded”. Guilt forms “patterns in our lives” which have to be “shed”.

The preceding comments by Mia, Gwen, Hendrika, Debbie, and Paul speak to the ubiquity of guilt in their lives, and suggest that this is a common concern shared in many other people’s lives. The use of the word “guilt” refers not only to a felt sense related to judgements on the lightness or wrongness of one’s actions, taken or not taken, but as well can be an entity (i.e., a “thing”) that can “take hold” of one’s life, or a “pattern” “built” into one’s very being through the social sphere. Guilt, in its various presentations, is a major concern for the majority of the participants, but as put forth by Susan, is not necessarily a concern for everyone.

In this section we read how the moral dimensions of guilt pervades the participants’ accounts and their use of language. Gwen offers us the unique perspective of someone that has had cancer twice, plus cared for her daughter who eventually succumbed to the illness. The experience of Gwen’s second cancer, following the death of her daughter, allowed her to reflect on the moral nature of illness. For example, she first recounts how she wonders if her actions played a direct role in her daughter’s illness (“maybe it wasn’t that I ate properly or maybe I didn’t feed her properly”). She then asserts that one must be circumspect in how one interacts with an ill person. By cautioning against imposing our well-intentioned advice upon another, Gwen is indirectly ascribing to a moral standard of respecting individual autonomy (“but this is not her doing it that’s me doing it”). The moral consequence of not respecting
another’s autonomy in choosing their own path is to make the ill person “feel responsible for their own illness” if they don’t follow your proscriptions.

Several participants also indicate that their larger social spheres have a pervasive moral strand. For example, although no direct quotes have been provided the reader, I noted that the theme of guilt related to parenting arose in several sessions. In part, I contend that it is the moral environment of illness that lends itself to discussions about moral related topics. As well, as indicated by Paul, society generally inculcates (“built it into me”) a sense of moral behaviour. Even if one does not feel guilty one can, as did Susan, still attribute one’s illness to one’s behaviour (“because of all the things I was doing and not doing”).

Once again we read how participants use metaphors to emphasize their experiences (e.g., the “strangle hold” of “this guilt thing”). We can also read how metaphors can be used as resources for humour (e.g., getting “full ticket value” “on that guilt train”). As well, the literary device of a common saying is resourcefully changed into a pun in a humorous fashion (i.e., “it’s not whether you win or lose...it’s how you place the blame”). As noted above, the acknowledgement of this humour indicates the pervasiveness of the moral nature of their illness.

Theme 5: “How Are you”?

This section speaks to the larger social context of the participants’ relationships to their families, friends, co-workers and the wider social spheres that they inhabit. Many of their accounts speak to the many challenges, often negative, which they face in their dealings with the surrounding social world. For example, Mia, Lil, and Debbie recount their difficulties with the solicitous behaviours of others.

M = Mia  D = Debbie  L = Lil (T 1)

M: You know how people always constantly ask me and it’s, you know↑, people ask how I’m feeling, particularly my mother, and it drives me crazy “Are you feeling - okay↑
“Yes yes I’m fine”.

```
L: You know they’re not saying “Hi how are you [they’re saying]=
M: [no]
L: =they’re saying how a:::re you.
M: Ya an- its, uh, very different scenario (inaudible).
D: Well and people who you don’t have a close relationship [with] think they can just come and ask you about it. And they would ask you “How are you”?, and and if you don’t give them a full answer they say “No I really mean it”.
L: [they’re quite - people are quite]
D: [almost like “excuse me but”] who the hell are you”? (laughs)
M: It’s true (inaudible).
L: [It’s quite true] quite bold about it
D: Ya

Following this exchange Paul states that “I chose not to tell people … my mother does not know my brother don’t know my sisters don’t know”. He took this “unusual” “different path” because “T 2: I just want to be treated normal… I don’t want people to say to me “How a:::re you Paul↑, are you okay↑”? He then recounts how his father had these experiences when he was diagnosed with cancer and “I just don’t need that, I wanna look healthy…when I beat it I’ll call them”.

Thus the participants initially describe a common experience of individuals who ask them about their well being in a manner that is seen to be unhelpful and even presumptuous. Later in this session, however, Mia and Debbie acknowledged that, in part, their difficulty with the solicitations of others was due to their illness.

M = Mia    D = Debbie    L = Lil    P = Paul (T 3)
M: So it’s hard when your sick.
L: Exactly.
P: [Ya] - [Ya ya]
L: [ya]
M: [to accept] their support. I mean [you probly found the same]
D: [it took me a year just] I guess the chemo just kicks you so:::=
M: uhm hum
D: =ha:rd that I couldn’t accept it.
....
M: And sometimes you just wanna be alone anyway.

From these exchanges we hear that not only family and co-workers viewed as offering inappropriate support, but that those with illnesses are often unable to accept the support of others. Ill people may simply desire to be left alone, especially while recovering from their reactions to their illness, and the side effects of their treatment.

We are also informed about the inherent difficulties for a family to discuss the serious illness of one of its members. For example, Gwen has been on “both sides of the fence”, having experienced cancer twice and having cared for her daughter who died of cancer. She recounts how she “wouldn’t let her talk about it because...I didn’t want her upset”. It is with Gwen’s second bout of cancer that she realises “Cuz now I’m in the same situation I can’t say things to my husband cuz I cannot bear the sadness on his face”. Furthermore, as Mia recounts, part of the challenge for her was how to discuss her illness with her elementary school aged children (“So it took a long time to tell them”).

From these accounts we are informed that a diagnosis of cancer presents many challenges for both the individual with cancer and the surrounding family, friends, and co-workers. Individuals typically need support, and those surrounding them typically desire to give it. Too often, however, all involved find it too challenging to do, or simply lack the requisite skills. Even Gwen who stated “T 4: I wish I could have had cancer first and then I would have known many things and would have handled so many things differently” with
her daughter, still could not bridge the emotional gap with her husband.

Paul offers another perspective of family, following an exchange on the nature of relationships to family members who engage in “bad behaviours”. Paul refers to a notion of “toxic people” that one should avoid, and then notes the distinction made by his brother that “there’s my real family and then there’s my birth family… and just because someone is in your birth family it doesn’t mean they’re part of your real family”. This perspective has helped Paul “to understand the feelings I have for other people. Some of my best friends are family to me and some of my family are not necessarily best friends to me”. Perhaps this perspective explains his strategy of not informing his immediate family of his illness, in contrast to his actively seeking out opportunities to share experiences with others (“I uh one of the things I dedicated myself to was… I’d say there’s my number call me”).

The participants’ accounts speak to the many difficulties and challenges in negotiating their various relationships. It should be noted, however, that in my private conversations with many of these participants, they informed me of many positive actions taken by friends, family, and co-workers. As well, the participants can have a positive effect on others, as noted in the following transcript.

H = Hendrika  P = Paul  S = Susan  (T 5)

H: …and they have seen how I changed, and so I find with my daughters especially they are really changing. And they are being much better than I was at that age, meaning you know, as persons - as spirits. They’re far developed than I was at that age.

P: In a sense your cancer has helped them.

H: Absolutely, it radiates out. It doesn’t just help you. If you want to spread it or if you want to share it with people… so I think cancer affects everybody around you.

S: Oh ya, and it can be positive.

H: Positive.

S: Or negative.
Thus, the life changes Hendrika has made affects her children at the deepest level of “spirit”. Just as Hendrika has had this seemingly profound effect on her daughters, so too can one’s family have a profound effect on the individual with cancer, as recounted by Gwen. She states that just like Paul, she too is not afraid of dying. In fact, given the “grim situation” of her diagnosis and that it was unlikely that the “horrific” treatment options would benefit her, she “almost welcomed dying”. However, “I realised that oh my god these people [i.e., her family] can’t handle another death, I’ve gotta live”. With this realisation she actively embraced alternative practices “meditating and diet and all of these things”, which she attributed to an extension of her life (“and at the cancer clinic, they - they called me their miracle”).

The preceding accounts speak primarily to various aspects of relationships with family, friends, and co-workers. Accounts are also given about the participants’ relationships to the larger social sphere. For example, both Debbie and Gwen recount their experiences wearing wigs as they had lost their hair as a treatment side effect. For Debbie, getting a wig was not a priority until her son requested her to do so. (“so I did if for him for presentation and everything”). Gwen, however, “adamantly refused” to wear a wig, which was “my one big stand...my one rebellion”, due to the suffering her daughter experienced over the loss of her hair during her treatment. The basis of her rebellion was related to the suffering of her daughter, who too lost her hair, and having to wear a wig “caused her so much pain”. Gwen describes her daughter as “magnificent looking” and “this hair thing was a big thing with her and so it was really terrible ...for her”. Thus, both Debbie and Gwen give accounts on the effect of the social sphere on their public displays. For one, it is a minor accommodation to wear one, for the other, it is an act of defiance to not wear one.

The influence of the wider social sphere is also evident in the speech of various participants. Following an exchange of perspectives regarding fighting cancer, Susan, Hendrika, and Paul speak about how they have to “let go” of cultural expectations.
S = Susan  H = Hendrika  P = Paul (T 6)

S: Living with cancer ya but still going on the path to health. Isn’t that the path that we’re all on?
H: Ya
S: ... is the path to health.
H: Ya
P: Sure we are. Your comment (helped a lot) this business of giving ourselves permission, that’s so strong in us.
S: [uhm hum]
H: [hum]
P: You know, it reminds me of a beautiful book by Melody Beatty, where she talks about the language of letting go. We all need to let go, and when we’re born we got nothing to let go of except reach out and love and be loved. But somehow the culture - the family value - something - school - I don’t know what it is.
H: Puts expectations in ourselves that are stupid.
S: uhm hum
P: They’re crazy. We can’t be super people - can’t do everything perfectly. But it’s in there. We have to let go and when we let go, boy, life changes.
S: uhm hum
P: [you’ve let go you’re ... you’ve let go]=
S: [uhm hum - uhm hum - ya right]
P: =I strived at some things I gotta let go of still. But that’s a very important catch phrase to me “give myself permission and let it go”.
S: uhm hum
P: And like you say it’s self induced, by and large - by and large, but our culture also does it to us. We listen to our [mothers and the were (inaudible)]
S: [no: you let if] They let it happen
P: well ya.
S: I-it doesn’t do, you let if [happen]
P: [and] that’s why we have to let it [go]
S: [and] I let it happen.
P: We have to let it go.
S: Right.
P: But it comes up a lot in this group doesn’t it.

From this exchange we hear them agree that “the path to health” involves ‘letting go” of unrealistic cultural expectations related to some sort of standards of perfection. These standards are “crazy”, and when one “lets go” of them life changes, presumably for the better.

Whereas the preceding standards are internalised one can be subjected to the troublesome standards of others in the surrounding social sphere. For example, others may be sceptical of one’s health practices as recounted by Hendrika. “T 7: Then when you get cancer you do all these different things and people are (inaudible) “Well all that doesn’t work”. Oh you know, that’s - you’re - just - “This is all for nothing” [and] “Well, you’re just having the most expensive urine if you take all the supplements” [group laughs]. Hendrika is recounting how “people” dismiss her taking of supplements as both costly and useless. To her, the behaviour one engages in is less relevant then whether one is “being forced by the outside world…but if you’re allowed to let go and be what you really are…I think that’s very important”.

In Session 3, Gwen recounts on the general difficulty she has with talking to “other people” due to their occasionally confusing expectations. She speaks to the complexities and contradictions of the use of language by individuals in her life, and the difficulty this gives her in her relationships with them.
G = Gwen  D = Debbie (T 8)

G: I guess part of the reason that you can’t talk to other people to is – I can’t stand the buzzwords that are used in cancer. I hate them, like if you just even say anything, that your a little bit down, then right away somebody says “Oh be positive be positive”. I don’t know what positive means, like am I positive I’ve got cancer, and like can I be positive I’m gonna live, can I be positive I’m gonna die? What does positive mean? I don’t know what that means. And then the minute I can be hopeful, I’d like that word used, and then the minute that you say anything like that, then the same person who’s told you to be positive, an-...I had this done by a doctor, actually, with reference to my daughter. I had heard this “positive” from this very same doctor, so I said the next time we were in to visit, my daughter was on the way out of the room an- I said “Oh doesn’t she look wonderful, well we’ve really got it together an- we’re gonna beat this thing”. An- he turned to me an- said “Misses [refers to Gwen], your daughter is going to die”.

D: hum

G: So what he was saying is - you - what they do is then, you’re in denial. On one hand you’re told to be positive an- then, if you do say anything positive, then you’re in denial. An- my god am I running off at the mouth?

Not only can the larger social sphere be a challenge to navigate, but, as well, Hendrika speaks of the “lost knowledge” of “natural remedies” for treating cancer that the social order of the time actively destroyed (“they burned all the witches and all the medical wise women”). This knowledge is “slowly coming back” and is to be found in such areas as the practices of “indigenous healers that cure cancer”, and Ayurvedic medicine as put forward by Deepak Chopra who “uses definitely soul-mind connection”. Paul acknowledges Hendrika’s statements with “we’re trying to grab some of their wisdom”.

These accounts put forth perspectives of a society that puts limitations and roadblocks to the “path to health”. These perspectives include a historical perspective that knowledge of
cancer cures has been actively suppressed, notions of “crazy” standards that society expects the participants to live by, direct challenges to participants’ health practices, being “forced” to live a certain way, and opposing expectations inherent in a singular use of language. Although participants can recount positive experiences from their social worlds, the predominant theme is that “we live in a very negative society” that must be actively challenged, including ridding oneself of its unhealthy expectations. Surmounting these challenges is seen to be a major avenue by which “the path to health” can be navigated. One then can learn to relax, to make one’s own desires and needs the priorities in one’s life, to feel happy, thereby enhancing one’s immune system to keep one’s cancer at bay, even to cure it, while growing emotionally and spiritually.

While the larger social sphere is often described as unhelpful, even hostile, to these pursuits, there is one social environment that is seen to be a major source of support. That source is the cancer group and other groups like it. Paul notes that “you need sort of the stimulus of this group” to support individual efforts for learning the key skill of relaxing. Both Paul and Gwen speak to the importance of interacting with each other in order to grow and even to enhance one’s health. As well, listening to others “reminds me of where I’ve gotta head”. The most consistent theme is that they learn from each other (“We’re sharing something very personal in our life and I think as we bond a little more and feel more comfortable with each other little snippets and tidbits come out that could mean a lot to any one of us at anytime”).

In this section we learn more about the complex nature of the moral challenges faced by various participants in their family and social spheres. This section began with a transcription of criticisms towards the solicitous behaviours of others (e.g., “it drives me crazy”; “who the hell are you”). The participants resent the perceived demand by others to accommodate their requests to answer the question “How are you?” One example of a participant’s criticism to this question is that it is deemed to be presumptuous (“people are...quite bold”). For Paul, the desire to not be pressured into responding to this social
demand is to take the strategic position of not informing his immediate birth family ("I just want to be treated normal"); "when I beat it I’ll tell them"). He implies this stance is taken, in part, because his family relationships are impaired ("some of my family are not necessarily best friends to me"). Thus, we read examples of how participants have struggled to resist unwelcome expectations by others. The examples demonstrate how society can place expectations on the ill person’s behaviours, and that such expectations must be socially navigated.

The moral responsibility to be sensitive to the emotional needs of others is also a concern as represented by Gwen’s comments. She recounts how she tried to protect her ill daughter from being “upset”, by not letting her talk about her illness. When Gwen was ill, she also protected her husband using the same strategy of not talking about her experiences. Gwen took her responsibility so seriously that she felt morally obligated to do everything she could to extend her life (“these people can’t handle another death I, I’ve got to live”), even though she did not want to undergo more treatment and “almost welcomed dying.”

From the preceding examples in this section, we read how participants feel pressured to accommodate social expectations, often with an implied or explicit moral quality to them. Many of these moral expectations have a complex and sometimes contradictory nature, as demonstrated in the following experiences of Gwen. She cites the “buzzword” of “be positive” used by others, and then questions what that expression actually means. Her question arises from her frustration at the ambiguousness of its’ meaning and how it is used differentially by others. She complains that even if her mood drops slightly (“your a little bit down”), others are too quick to exhort her to “be positive”. Gwen states that it is other peoples’ tendency to use expressions like this that is “part of the reason that you can’t talk to other people”. What is implicit in this example is that people are in fact engaging in moral suasion by exhorting Gwen to change her dampened mood even though she seemingly has legitimate concerns about which to be “a bit down”. Gwen elaborates on this issue by citing her doctor as one who gives her the same demand. Unfortunately, when Gwen tried to
demonstrate the behaviour of being “positive” in the presence of her ailing daughter, this same doctor admonished Gwen by stating her daughter was going to die. Thus Gwen’s frustration at the contradictory use of language by her doctor (“on one hand you’re told to be positive an- then if you do say something positive then you’re in denial”).

From Gwen’s recounting these experiences we learn how language is used rhetorically for moral suasion. The notion of positive thinking is a cornerstone of the literature on coping with serious illness, yet as Wilkinson and Kitzinger (2000) demonstrate “thinking positive” can be used as an idiom in everyday speech, and not as a clearly defined expectation about how one actually thinks. Thus, in Gwen’s situation we see how others use the idiom “be positive” to morally exhort her to change her “down” mood.

Hendrika also speaks to the moral suasion of others, by first recounting the example of how “people” dismiss her alternative health care practices, such as taking vitamins, with rhetorical statements (“you’re just having the most expensive urine if you take all the supplements”). She later identifies society at large as historically having more sinister intentions (“they burned all the witches and all the medical wise woman”) in order to suppress knowledge and practices that can help cure people with cancer. Through these assertions, Hendrika is evoking the notion of two moral communities, one the larger social community (“we live in a very negative society”), adversarial to the community of individuals with cancer.

The accounts of various participants emphasize a perspective of the larger world as morally challenging. In this environment even such a seemingly benign activity as wearing a wig took on a powerfully symbolic moral meaning for Gwen (“my one big stand...my one rebellion”). Gwen rebelled against the social expectations of appropriate appearance as a moral stand on behalf of her deceased daughter, whom Gwen states had suffered greatly over the loss of her hair during treatment.

Social expectations and related moral dilemmas can also come from within. Hendrika and Paul, with Susan’s assent, recount how “stupid” cultural expectations, for example of
illness narrative in a structured cancer group

perfectionism ("they're crazy...we can't do everything perfectly") becomes internalised in some way and interferes with one's innate ability to love ("when we're born we got nothing to let go of except reach out an love and be loved"). This quote is taken from an exchange between Paul, Hendrika, and Susan. During this exchange Paul draws upon two different resources to make a rhetorical statement about how the moral dilemma of unhealthy social expectations can be managed. Paul first calls upon the expression "giving ourselves permission", which was initially spoken by Hendrika. She makes frequent use of this expression, at one time explaining it to broadly mean not doing something simply to meet others' expectations. It is used often in a rhetorical fashion by Hendrika and other participants as a metaphor for freeing oneself from social expectations. Paul also calls upon the expression "letting go", citing as its' source the work of Melodie Beatty. He then combines these two expressions ("that's a very important catch phrase to me, give myself permission and let go") as a metaphor that again emphasizes freeing oneself of unrealistic social expectations. This metaphor has a moral quality in that the notion of giving oneself permission implies that permission had initially been denied, or at least is not forthcoming without one's own efforts. The preceding quote of Paul's also demonstrates how aspects of language can be flexibly constructed, and how the environment in which it is produced influences it.

As with the other themes we read how the participants view themselves as agentic characters, struggling to navigate within a moral social world. Seemingly innocuous activity such as a request about one's well being can be viewed as something to be resisted, or even as an act of moral defiance. The use of language by the participants and those around them therefore becomes resources and tools by which these social interactions are negotiated.

Theme 6: The "Wake-Up Call"

In session three Hendrika uses the metaphorical expression of cancer is a "wake-up call", which Mia later notes is an expression commonly used by individuals with cancer ("one of the lines you frequently hear from people"). Gwen initially challenges this
expression as she views it's usage as negative reflection of her ("if I looked at it as a wake-up call, then that would indicate that there was something wrong with me and I was responsible for it an- I needed a wake-up call"). Following this exchange there is further discussion between Gwen, Hendrika, Paul, and Mia. It is during this exchange that different perspectives on what a "wake-up call" means (e.g., "to look at you and what you're doing and what you're getting out of life"), or does not mean (e.g., not "blaming oneself for one's cancer because one lived an unhappy or unfulfilled life"). Unlike Paul and Hendrika, Gwen remains steadfast in her assertions that there is nothing in her life that she would have changed. They do, however, come to a consensus that cancer has greatly impacted their lives and that each of them must change to accommodate this impact.

M = Mia  G = Gwen  P = Paul (T 1)

M: But ahm, ya cancer changes your life an- an- how it changes your life I- I
G: Right.
M: is uh what you chose and what's important to you, in the ways that you change your life and whether, it's in relationships or your diet [or all that (inaudible)]
G: [Ya exactly exactly]

P: You know, things change as a result of having cancer, and I think it has for all of us, each of us.
G: Oh without ques[tion - absolutely]
P: [We all wanna] slow down we wanna
G: Oh I =
P: = smell the flowers
G: Absolutely, that's [what I'm saying]
P: [a lot of us] (inaudible) the hurry sickness
H: Ya uhm hum
P: in those kinds of [ways it’s]
H: [ya ya]
P: a wake up call you know like I matter and I’m gonna take time for me, an- this kind of stuff.

.............
P: It causes you to face your mortality, p-probably a lot[sooner]
G: [Oh], absolutely
P: and because of that you say “Hey you know what do I really want here”?
G: Right.

In the preceding transcript the participants elaborate upon references to how one’s cancer leads to life changes. Although Gwen challenged the notion of “wake-up call”, this metaphor is widely used by individuals with cancer, as noted above by Mia. It implies the necessity of examining one’s life in the face of one’s possibly foreshortened life expectancy and re-evaluating one’s values and priorities and to make any necessary changes. As well, some specific changes were identified in the preceding transcript such as in regards to one’s relationships, diet, and the pace of one’s life. Given the nature of cancer it is not surprising that issues of examining one’s life priorities and making changes permeate the lives of the participants. As expressed in the participants’ accounts, change is enacted within one’s relationship to society at large, including one’s family, and within the self. The self refers both to one’s behaviours (e.g., diet), and one’s inner landscape (e.g., “attitude”).

As noted above, participants gave accounts about how they made lifestyle changes after receiving their diagnosis of cancer. Accounts were also given of behaviour changes such as taking up the practices of mediation and yoga, and “taking time to smell the flowers”. These accounts of behaviour changes, however, are often actions taken in concert with a fundamental shift, or re-prioritisation, of how participants view their inner landscape. As put forward in the following section, the participants’ accounts often reference notions such as
stress, the mind-body connection, the role of the immune system in enhancing health, and accessing spiritual realms. These notions were seen to explain the positive benefits of certain behaviours, primarily diet, to maintain health and to keep cancer at bay, even to cure it. These changes in perspective about the nature of enhancing/maintaining/improving one’s “health”, as described above, often begins with acknowledging that one’s own needs and wants are of paramount importance (T 2: “You get to the point where you care enough about yourself to say...there are things I need to do right now for myself”). However, making one’s needs a priority often does not come easily and therefore one has to ‘fight’ to achieve them. Failing to ‘fight’ can lead to succumbing to one’s illness, as recounted by Hendrika in a story about a man she tried to help. “Ya there are people who die and my neighbour is one of those who lost his wife who didn’t want to at all fight-she came home from the hospital, laid down and t- died”). Susan challenges this notion of fighting one’s illness because “to me that kind of fight is a s-stressful situation”, to which Hendrika responds “uh a- in the beginning it was, it’s a blessing now, because I feel myself growing and developing and getting to the point where eventually I want to g- to be”...”so I don’t think it’s a fight now, but I think at the beginning it was before I made up my mind that I could do this...and until I realised that uh uh saw very clearly what I needed to do”

In part, what Hendrika needed to do was “give myself permission” to not feel guilty about putting her needs first, and not to engage in activities, even seemingly health enhancing behaviours, that cause her excessive “stress”. Concerns related to stress will be explored below, but the point to be made now is the importance of changing one’s “attitude” as part of the “fight”. As Paul states “you’ve heard the expression you can be better or bitter – what’s your choice”. Thus, not only is changing one’s perspective of critical importance, one is seen to have the freedom of choice, even though one may have to “fight” to obtain it.

In the previous sections we read how participants struggled with moral dilemmas and challenges within their various social spheres, and how their use of language reflected those struggles. In this section we read how the participants on occasion struggle with each other.
In the first example, Gwen challenges the notion of “wake-up call”. Even though we are told that individuals with cancer commonly use this expression, Gwen views it as implying that there was “something wrong with me” prior to her illness. In the session where this exchange occurred there was a lengthy discussion on this issue where Gwen stated “I’m feeling put upon right now do you know that”. Following that statement, several members attempt to clarify the differences between the sense of blame inherent in the activity of re-evaluating one’s life in contrast to a sense that one must simply find a way to accommodate one’s cancer. From this exchange the moral nature of illness is made explicit as the members struggle among themselves to find a common ground on this issue.

In the second example, Susan challenges the notion of fighting one’s cancer, another common metaphor used by individuals with cancer. Her argument is that the notion of fighting produces stress, which by implication is counter-productive to managing one’s cancer. As with the metaphor of “wake-up call”, even though these metaphors are seemingly widely used, they contain implicit moral messages that are challenged by Gwen and Susan. Thus, even though all participants have at different times given overwhelming support to the value of group participation, the group is not without its own moral challenges and struggles.

Theme 7: Making a “Breakthrough”

The concern with mind, emotions, and illness is one of the major themes generated by the participants. For example, in session one Paul cites “research on the internet”...”that people who are fighters...do better”, and “the people who give up and get depressed uhm don’t do as well”. He goes on to say that he speaks directly to his cancer (T 1: “I say look buddy, I die, you die”). Gwen responds by saying “I can’t believe that I- that’s what I do. Do you know what I call it↑...I call it reprogramming my brain”. She came to this perspective serendipitously during an event that she attributes to her developing a headache and then realised that “I thought look if I could think myself sick why the hell can’t I think myself well”. Gwen then recounts how she was able to control her cancer pain by sending “my new
messages” to her affected spine “and every night before I went to sleep I would send this message down to where my tumour was”. Gwen asserts that through regular practice she could rid herself of pain and that “I got to really got control of my body through my mind”.

Mia follows with her own story on “the mind body connect” related to her experiences undergoing chemotherapy with resulting nausea and vomiting. According to her account she made a decision to no longer think of her drugs as “poison”, but rather as something that would “help” her. “And halfway through [i.e., her chemotherapy treatments] I go hum I’m gonna change how I think about this I’m gonna think about this as helping me and not as a poison so I was never sick again”.

Gwen and Mia resume discussing this topic of “mind-body” in the next session. In their exchanges we learn that one’s mind can both prolong life and even cure one’s cancer. Gwen reports that she was diligent in certain practices (e.g., visualisation), the “key” to which is to “believe” (“That’s the key:: you’ve gotta believe … if it’s vitamins or it’s visualisation, you can’t just be doing it … I believe that’s why I’m still here to-day”). Mia acknowledges Gwen’s statements and then gives a story of a friend with cancer who “all over the house everywhere you look she had little affirmations written out… that say nice things or good things ya you know and she firmly believed in all that and it worked for her”.

Through the accounts given by Gwen and Mia we are informed that one’s mind can be consciously “reprogrammed” to elicit positive physical benefits to replace the former negative physical experiences, such as the pain from a spinal tumour or chemotherapy induced nausea and vomiting. As well, one can summon the power of “belief”, sometimes bolstered by affirmations to delay or even overcome one’s death by cancer. Thus, the participants inform each other that one’s mind can be utilised to actively overcome not only the negative effects of cancer and its related treatments but the actual cancer itself.

While the preceding quotations speak to a direct effect on one’s cancer by the use of one’s mind, a commonly related theme is the meditating role of one’s immune system on one’s health. As noted in the profile section, Susan asserts that the cause of her cancer was, in
part, due to her decreased level of physical activity which "lowered" her immune system and thus she got cancer. As well, Paul recounts how working with others "helps my immune system", which enhances his overall health including keeping his cancer at bay. The notion of "stress" is often associated with notions of the immune system, although more often indirectly. For example, in the preceding reference to Susan and her immune system, she gave this account within a larger context of not being relaxed ("So my mind was always it was never relaxed I was never relaxed ever"). It was in this context that she had stopped her daily routine of exercise that lead to a loss of strength in her immune system that allowed her cancer to develop.

Participants’ perspectives on certain behaviours, the immune system, stress, and illness are scattered in fragments throughout the group sessions. The following transcript from session three captures many of these perspectives.

P = Paul  H = Hendrika  G = Gwen (T 2)

P: Ya, in my case I focus on nutrition cuz I really believe it’s part of the key.

H: That was the first thing I did. I started on the macrobiotic diet and then I have now greatly relaxed since then but uhm, pretty well I have changed my lifestyle totally and I believe too that’s that’s what =

G: I have too.

H: = what uhm helped me.

G: uhm hum

H: One of the things.

G: Cuz they don’t know what the trigger is.

H: Well the immune system, if you build up your immune system= 

G: =That’s right=

H: it’s very simple really.

G: That, they have proof of.
Thus, with this exchange we get an account that one can “fight the cancer cells” by “building up” one’s immune system through lifestyle changes such as diet and decreasing the “stress” in one’s life. As well, this approach is not only simple but has been proven effective.

In session seven this accounting is elaborated upon to include notions of a negative mind-set, emotions, and spirit. Following an exchange on the topic of guilt and getting “past that and deal with the here and now”, Hendrika comments that:

“T 3: Well, I don’t think cancer really is a physical illness. I mean it has physical symptoms, but it goes much deeper that that. Or any other chronic illness really”...

“We know that the mind-body interaction - what we tell ourselves is happening - if we tell ourselves we are bad and we are doing something bad, then we feel that there is something wrong, and that will affect our immune system if we keep worrying about these things”

She goes on to say that she knew people who “have healed themselves of cancer” without making lifestyle changes but rather “they have changed their spirit they have
changed their thoughts their mind.” In part, they’ve accomplished this by addressing core life issues that encompass the “bad” things one tells oneself as noted in the transcript above. In another session, Paul refers to doing “inner work” (“you resolve some issues whether its time - guilt - uhm anything, relationships”). Hendrika then recounts her own experiences, which due to its length, has been reproduced in Appendix D. In brief, she recounts how she had three major medical events in her life that occurred in succession (i.e., kidney cancer; heart attack; and severe osteoporosis), each of which were major challenges in themselves. As well, during the time period she became financially ruined, losing both her job and her house, she broke her ankle, and experienced the death of her mother. After all of these experiences she “realised it was gonna happen over and over and over again until I actually really get what I need to do here”. “T 4: I had to first of all I had to go back to the things that I had been chewing on, like my childhood my relationship with my mother. When she died I had to do these I had to go this and work this out. On a spiritual level I had to forgive and I had to relearn again how to feel about things in my life, towards people and so on”.

Hendrika then recounts that one action she took to “work this out” was to reveal to a relative the negative effect of that person’s behaviour on her life “one of the hardest thing I had to do”. The benefit of this action is “now I am totally at peace”. She has dealt with her “resentments” and is now able to say “well it is their problem not mine I don’t have to have my life bothered by that and that’s really what I think, that is really the most important thing you have to learn.”

During Hendrika’s recounting Paul responded with “questions and conflicts was a breakthrough for you” to which Hendrika utters “Ya yah”. This notion of “breakthrough” is presented from various perspectives as Hendrika, Paul, Mia, Lil, and Debbie continue the discussion. Both Hendrika and Susan recount that the importance of forgiving oneself and others, which is a “spiritual” breakthrough where “a whole part of the spirituality is the guilt trip and then the forgiveness”). During these exchanges participants explored various aspects of dealing with what Paul called the “skeletons and festering angers” revolving around one’s
resentments towards others and one’s own transgressions. This effort is seen to ultimately lead to “breakthroughs” where one is now in a position to override the disease processes of cancer. For Hendrika it was the realisation that she had personal issues to resolve. For Susan, it was primarily a matter of “slowing down”. For Gwen, even though she preferred to die rather than endure an “aggressive” treatment, she responded to the beseechments of her family to live for them.

Mia asks the question “So does spirituality as such play a big role in our recovery” to which Hendrika and Paul respond in the affirmative. Paul adds to this by stating “T 5: I think we all have our own way to have a breakthrough, and where we make a decision and uh “I can’t live like this anymore”. I think whether its time or guilt or, you know, uh we just say “That’s it, I’m gonna move on and change”...” for the better hopefully, but (inaudible) you know those tapes and those chains, they’re heavy” [group laughs].

As this interaction progresses other aspects of “breakthrough” moments leading to a decision to change are described as moments where “the light went on” of finding “purpose” (e.g., to live for others), or simply finding “our will to live”. Hendrika asserts that “long term survivors” have “healed themselves of cancer” because they have learned to “change their spirit they have changed their thoughts their mind and so obviously it’s not only physical, but it’s not uh, the main part is - is not physical”. To this assertion Paul responds with “absolutely...somehow they’ve they’ve kicked the immune system in to take care...they did it in other ways [i.e., non-physical ways]”. When Lil asks the question “so::: that’s maybe the spiritual part of it is th beginning before you’ve taken control of it”, Hendrika answers with “But I think maybe realising too that it’s up to you”.

The key element of this self-realisation is taking responsibility to do what is important for oneself, as described above. This action enhances one’s immune system so that it is “happy”. This happiness and joy comes after one has resolved various life issues such as resentments, guilt, and forgiveness, and when one makes one’s own desires and goals of central importance in one’s life. So even though Hendrika continues to engage in behaviours
such as daily exercise and a vegan diet, she allows herself occasional indulgences such as “sweets at Christmas” without ill effect. She accounts for this lack of ill effect due to the pleasure she receives and therefore “my immune system is just jumping for joy because they love it so much”. “I am telling my immune system you are happy because I am happy”… “but I really believe that if you are happy doing something it means much more than if you do something really well and feel guilty about, or feel not quite sure that this is going to be the right thing for you anyway”. There is then the following exchange between Paul, Hendrika, and Susan.

P = Paul H = Hendrika S = Susan (T 6)

P: You’ve developed a good attitude to live.

H: Oh absolutely – absolutely.

P: Good for you. We all should be so lucky eh†.

H: It’s not luck, it’s it’s coming

P: Ya.

S: [It’s work]

H: [it’s coming] if you work on it.

P: Ya.

Thus, once again the dominance of mind over one’s cancer is asserted, with one’s immune system mediating this dominance. A key element of this dominance is one’s emotional state, unencumbered by personal issues that have been successfully resolved. Lifestyle interventions are also key, but only if they have been implemented because one values one’s physical well being, otherwise these behaviours can become another source of guilt and stress, and therefore counterproductive to an optimal functioning immune system. Notions of spirituality are included in these accounts, in part, as the process of having a “breakthrough” (e.g., “on a spiritual level I had to forgive”), but apparently more of an effect
or an outcome. For example, long-term cancer survivors are notable for working on their “inner personality” as they grow spiritually and emotionally. What is left unsaid, however, is just what forces are at play when one reaches the “breakthrough” moment, for example, the forces that stopped those unending disasters that afflicted Hendrika. So although a mind-over-immune-system-over-cancer is a dominant theme put forth by the majority of the participants, there are central elements of metaphysical or spiritual forces that are only indirectly alluded to.

In this section we read once again how the theme of agency is woven into the participants’ accounts. This rebuilding of self occurs at different levels, the most profound level being at one’s “inner personality”. This accounting of self-change can be viewed as a form of rhetoric (i.e., self as project for change), which Frank (1993) asserts is a common theme of most illness narratives. In this context, the use of the term “breakthrough” becomes a metaphor for the notion of epiphany, which Frank (1993) notes by citing May (1991) that “If the patient revives after such [life threatening] events, he must reconstruct afresh, tap new power, and appropriate patterns that help define a new existence” (May, 1993, p.22). In this section and the following 2 sections, we read how the participants are actively engaged in redefining themselves through developing new patterns of behaviour (e.g., diet changes; relaxation skills; “giving oneself permission”), and tapping new powers by modulating one’s immune system and accessing spiritual realms. All of this effort occurs in a moral context, both internally and externally, and is manifested in the use of language by the participants. We read how the participants use notions of inherently complex and scientifically controversial discourses in a simplistic and sometimes rhetorical fashion. For example, participants have cited such notions, among others, of the immune system (“well...if you build up your immune system...it’s very simple really”), of stress (“stress lowers the immune system”), and of a relationship between mind, body, and spirit (“long term cancer survivors” have “healed themselves of cancer” because they have changed their thoughts their mind”). In this way, their use of language can also be viewed as repertoires, in that they use language
in a variety of ways to support their construction of accounts and validating their moral behaviour. As Edwards (1999) asserts “For doing talks business, people require conceptual resources that are inconsistent, contradictory, fuzzy, and to-be-indexically-specified” (p. 288). For example, the notion of breakthrough, central to several participants’ perspectives on managing their illness, is flexibly utilized without specification as to its meaning. Similarly, Hendrika’s notion of spirituality involved going to a level that work could be done that would free her, in some unspecified manner, from the ongoing cycle of misfortune that had befallen her. Therefore we read how language is used as a repertoire to allow participants to do the work of constructing their moral accounts within the group.

**Theme 8: The “Hard Work” Of Cancer**

In a preceding section there is a notion expressed that getting to a state of healthy accommodation with one’s cancer “takes work”. As well, in other exchanges we are informed that this work can be exceedingly difficult. For example, Paul informs the group that his former occupation in the public school system was very “stressful”, and that he eventually decided “I won’t live like this anymore”…”so I made a big change in my life…but it takes courage”. This assertion was followed by a discussion about the challenge of making changes when faced with a serious illness.

**M = Mia  P = Paul (T 1)**

M: Cuz, a lot of us, you think about it. Especially when you have an illness, at some point you think gee I wanna change my life now.

P: Ya.

M: But, how do you go about doing that↑?

P: Ya, well it takes a lot of guts man.

M: (laughs) A lot of support↑.

P: Pardon?

M: A lot of support.
P: (Ya and) support. Courage.

M: It’s hard to change your life and that’s what part of this group is about.

In this exchange we hear that one’s illness often leads to a desire to change one’s life, although we are not told the specifics of what changes would be made. The expression “change your life” implies something of significant and major proportions. We are told that such change is “hard”, and requires both courage and support. According to Mia the group can offer the requisite support.

Later on in this session the notion of “hard work” is presented again, this time in a context of “stress” and “relaxation”. The group had completed a stress questionnaire as part of a structured group activity and was recounting various aspects of stress in their lives. The following transcript encompasses an exchange of the difficulties of engaging in relaxation activities.

M = Mia  P = Paul  A = Arnold  L = Lil (T 2)

M: Even though you foc- you say okay “I’m gonna breathe, I’m gonna meditate, I’m gonna - it’s really hard to [do in that stressful situation. Oh ya.]

P: [It’s like you gotta force it and I] always wonder why – naturally. We get so stressed, like why do we have to force relaxation. It’s something that has been in my head for many years.

A: Well, the timetable is not right. You to do too much at once.

M: 21st century eh.

....

P: And we can learn to relax again.

L: uhm hum

P: Back to the - when we were born and were relaxed.

L: uhm hhum
From this exchange we hear that part of the hard work of changing one’s life is to learn how to relax, presumably as one could do naturally as a child. One’s illness becomes a reminder that one loses this state of relaxation given the 21st century’s pressures to accomplish “too much at once”. Even with this realisation the practices of relaxation one engages in (e.g., breath technique; meditation) requires great effort to “break the cycle” of behaviours that lead to the harmful physiological effects of stress (e.g., “ulcers and the high blood pressure”). The hard work of changing one’s life can become a life-or-death issue, as noted by Hendrika.

“T 3: It’s very hard work...when I hear this spontaneous remission I always say “You know, that is the hardest work to have the so called spontaneous remission”. Because who has a spontaneous remission without doing anything? Very few people. Most people worked darn hard to get to that point”. Paul and Susan acknowledge her comments (“that’s true”; “agreed”).

Once one has made important changes in one’s life there is the threat of “slipping”, a sense of losing some of what one has gained in one’s struggles with cancer. In the first session, both Gwen and Mia use this term when giving an account of why they are participating in this group. Gwen states she was “slipping a little bit” and was therefore
“thrilled” to have the “contact of the group”. Mia then introduces herself and states that “this was a wonderful opportunity to get involved again” in a group, in part, because she too was “slipping” in her practices of meditation and yoga. A short time following these utterances, Gwen recounts that “my frame of mind is slipping a bit I think like anything it’s uh. You know if you don’t play it you forget how”. She therefore wants to “start getting back to the way I used to live”, where she would not overreact to the stresses of life. Gwen then asks “do you know what I mean?” to which Lil responds “I think we can probably all relate to that”, and then the whole group laughs. Presumably, the group laughter reflects a shared acknowledgement of the difficulties in maintaining health-related behaviours. As well, “slipping” refers not only to maintaining such behaviours but also resisting or avoiding “getting back into those patterns of bad behaviour” that often occurs after “time goes by”. Gwen accounts for her not engaging in helpful behaviours (e.g., drinking adequate amounts of water; exercising) as “because I’m lazy, that’s what happened to me”, to which Paul responds “aren’t we all”.

Thus, some of the participants recount that much of the changes that they have made and deemed of benefit to their well being are not only difficult to successfully implement but are also at an ongoing risk of being lost or diminished. For example, one can “slip” due to a lessening over time of the impact of one’s illness, to the inherent difficulty in maintaining new behaviours, and to the lack of the support of others. The participants agree, however, that the benefits one receives are worth the hard work it takes to achieve them. These benefits, referred to as the “gift-of-cancer”, are described in the next session.

We read in this section about the dilemma face by the participants on how to accomplish their goals. The expressions “change your life” and “hard work” both are used rhetorically, however, they are also meant to be taken literally, even if how these activities are to be accomplished is frequently not specified. Learning any new skills can be challenging, and if indeed one is trying to make oneself resilient to all challenges presented by an illness like cancer, then the task can be realistically viewed as daunting. In this context,
the moral nature of illness is emphasized when Gwen accounts for her “slipping” from maintaining helpful behaviours as due to her laziness, which is reinforced by Paul’s comment of “aren’t we all”.

Theme 9: The “Gift-Of-Cancer”

In session four Paul introduces the expression “gift-of-cancer”, which is “the other side of cancer that makes us appreciate living and face our mortality and treasure each moment and uh that’s beautiful”. Hendrika follows Paul by recounting how much fun and shared laughter she has with others at her facility for people with cancer. She states that “T 1: We’re happy because we’re here. Our life is better in many cases”. Lil adds to this exchange by commenting that she has re-examined her priorities in life, and how she has influenced friends and family to not be “negative”. One’s experience with illness is “a good wake-up call for people around you. You know when they’re complaining and whining about things (go) wait a minute”. Both Gwen and Susan comment that they are both “nicer” people due to an increased awareness of the struggles of life and therefore are able to feel greater compassion towards others.

Another benefit is a sense of more peace in one’s life, in part due to a sense of resolution with the knowledge of the reality of one’s eventual death. Cancer, as opposed to the quickness of death with a heart attack, allows time to do one’s necessary “work” and “to say good-bye”. In contrast to the notion of work in the preceding section, in this context work refers to the task at hand of learning how to relax (i.e., “cancer helps us to get off sometimes” one’s “self-imposed treadmill”).

Despite the many positive aspects of their illness, Gwen, in her challenge to the notion of cancer as a ‘wake-up call” in her life, states “I would have rather not had cancer in my life”. After a brief discussion there is the following exchange.

M = Mia  G = Gwen  D = Debbie  P = Paul (T 2)
Mia: But you’re right, I mean most of us won’t say to ourselves... We:ll you read a lot of self help stuff that’ll say “you know it’s the best thing that ever happened to me”, well I [scrap that theory (laughs). No, I’m not goi-]

G: [no that’s some – no, I’m never gonna that way]. No (laughs) that’s right

M: But it doesn’t mean it doesn’t change your life.

G: Exactly. That’s right, exactly.

P: It’s a club [that none of us wanted to join]

D: [(laughs)]

G: (laughs) That’s well said.

D: Ya.

Thus, with this exchange we hear a consensus reached that despite the many positive benefits and experiences that participants spoke about regarding their cancer, the reject the notion expressed by “a lot of self help stuff that’ll say you know it’s the best thing that ever happened to me”. Each participant has been unwillingly brought into this “club” of ill people. The expression “gift-of-cancer” is a metaphor meant to capture the positive moral outcomes of the various participants. For many, life is more enjoyable then before their illness occurred. They are “nicer” and more peaceful people, and are able to have a positive effect on those around them. In one sense they are more fortunate than those with other illnesses such as heart disease, in that they have time to do the moral work of re-evaluating their life and to make any necessary changes, as well as attending to any outstanding relationship issue. In this way, participants are able to accomplish their moral quests. Gwen’s challenge, however, to the take-it-for-granted acceptance of a notion such as “a lot of the self-help stuff that’ll say it’s the best thing that ever happened to me”, emphasizes their moral plight. Despite the many positive experiences and outcomes from their respective moral quests, they all would have preferred not to have been forced into this club of ill people.
Concluding Comments

The preceding section on the themes that emerged from the participants’ verbal interactions speaks to their many struggles. The participants’ initial struggle was to manage their reactions to their diagnoses of cancer, and to discern a course of action. Their changed life situation compelled them to seek ways to manage and hopefully to cure their illness. Their struggles took on a moral dimension as the participants evaluated their contributions to their illness and their responsibilities for its management. As well, they experienced a variety of moral challenges in their interactions with family, friends, and their wider social spheres. The participants became agentic protagonists who sought primarily to change their inner selves in order to overcome their illness. They were on what one participant called “the-path-to-health”, where reaching their goal was an uncertain process, demanding hard work that was difficult to master and to maintain. Although much of this effort was solitary in nature, it was greatly enhanced by joining the moral community of fellow strugglers. One is, however, never guaranteed a safe destination. One is always at risk for “slipping”, and thus one must maintain a constant vigil to maintain one’s location.

The overarching illness narrative of struggling is based on the 9 themes that emerged from the participants’ verbal interactions. These themes demonstrate how the participants struggle with a variety of concerns and dynamics related to their illness and that, with the exception of the first two themes, how their struggles are embedded in a moral context. The findings also demonstrate how these moral struggles are manifested in the participants’ verbal interactions, and illuminate how participants used language to navigate their struggles. Thus, the research findings illuminates how the overarching narrative of struggle, and the moral challenges presented by the illness of cancer, are made manifest in the participants’, often rhetorical, verbal interactions in a structured cancer group.

In the following chapter the reader is provided a perspective on how the findings of this research paper have contributed to answering the question of how an illness narrative developed in a structured cancer group. The moral nature of illness is described in greater
detail, and commentary is given to illuminate certain aspects of the participants’ verbal interactions. As well, commentary is given on this research project practical applications and its’ contributions to policy making.
CHAPTER V

Discussion

In this chapter the reader is provided with a perspective on how the findings of this research project have contributed to answering the question of how an illness narrative developed in a structured cancer group. This chapter first elaborates on certain moral aspects of illness as they relate to the findings, including comments on certain notions of moral quests (Charmaz, 1999; Hyden, 1995) and storylines (Frank, 1994; 1996), the flexible use of language, and how illness narratives are co-constructed. Next, commentary is given on the significance of these findings according to the parameters set by McLeod (1996) who asserts that a qualitative research study should be useful in one or more of three broad areas. That is, it should make a contribution to knowledge, be useful to practitioners, and be relevant to policy-making. This chapter ends with a discussion on the limitations of this research, recommendations for future research, and my personal reflections on engaging in this research project.

The Moral Context of Illness

As noted in Chapter IV, moral challenges broadly refer to how the participants’ behaviour can be evaluated as either good or bad, right or wrong, or in accordance or not with certain rules or expectations of behaviour, in the perspectives towards illness of the participants and within the social spheres that they inhabit. As Gwyn (2002) notes one “can not simply be ill” (p. 18) in that one has to not only come to terms with one’s changed life conditions, but also one must negotiate one’s changed social status. Gwyn (2002) and Frank (1995) cite Parsons’ (1951) notion of sick role, which posits, in part, that one is granted leave by society to be sick. The ill person is granted certain privileges (e.g., to not work), but in turn must meet certain expectations (i.e., to act in accordance of the assigned sick role). The ill person can therefore be judged or in some way evaluated as to whether those expectations are met. It is within this social climate that Charmaz (1999) and Morris (1997) assert that the
ill individual is conferred a moral status (i.e., one’s relative human worth). “Thus, a sick person can make certain moral claims and have certain moral judgements conferred on him or her, such as deserving, dependent, and in need” (Charmaz, 1999, p. 6). While the preceding quote implies the conferring of moral judgements on an individual by society at large, Morris (1997) makes an important distinction that there are different ‘moral communities’ within society, a notion also put forth by the moral philosopher Tom Regan (1991). He argues that moral communities are self-identified groups of individuals who share a common moral bond. A key characteristic of moral communities is that they confer or withhold entitlement for worthiness of moral consideration. Individuals who are considered non-members can be marginalized from that community and their plight ignored. For example, individuals who get lung cancer from smoking cigarettes may be judged by some, including the afflicted individual, as at fault for their illness and therefore of less moral worth, as opposed to a young child who gets leukaemia and is viewed as innocent and blameless, and therefore of greater moral worth. A less worthy individual can also be simply ignored, for example a skid row addict, and it is the predicament of being ignored that is the source of much suffering to ill people (e.g., Good, 1994; Kleinman, 1988).

The moral challenges to an individual of having an illness give forth to what Charmaz (1999) and Hyden (1995) refer to as a moral quest, albeit from different perspectives. For Charmaz (1999) the quest is for control of one’s status on a moral hierarchy. She views one’s moral status as always under threat of being contested. One’s moral status can be relegated to a lower level in the hierarchy, and despite one’s initial moral status, all ill individuals are at risk for challenges over time. Charmaz (1999) gives the example of how one may receive initial support and validation from one’s co-workers, but as they continue to carry the extra workload due to the ill person’s absence or decreased ability to work, they may begin to view their co-worker in a less favourable moral light. Thus, ill persons continually struggle to maintain the legitimacy of their moral status.

In a similar fashion, Hyden (1995) asserts that the ill person’s moral quest is reflected in
the stories they tell about their life. He has a specific focus on how individuals reconstruct their life narrative in response to a disruptive illness. He argues that narrative reconstruction is by its very nature a moral quest.

To transform the illness event into a biographical context is to connect the event with a specific life and with the various life circumstances of the individual. But it is also to make the illness event a part of a narrative concerning the goals and basic values of the person: who he is, where he comes from, and in which direction he is aiming....in other words, the virtues a person lives by (Williams, 1993). The illness event, like other kinds of events, is evaluated as being a part of this morally specific life. The central moral quest is to find out to what extent the illness event is a result of the kind of life the person has led. (p. 82)

This moral quest, therefore, begins with the issue of responsibility for one's illness. The ill person asks whether his actions, and/or the actions of another, contributed to the illness. These deliberations lead the individual to consider how one has generally conducted oneself throughout one's life. Whereas Hyden (1995) discusses this moral concern from the perspective of the afflicted individual, both Charmaz (1999) and Morris (1997) contend that society also makes moral judgements as to one's moral status. The individual, therefore, must contend with the moral challenges brought forth from the wider social spheres and related moral communities as well as his own evaluations and related judgements.

This concern with moral issues can be noted in the use of language and in the accounts of the research participants. Such accounts often seek "to claim a moral point" (Radley & Billig, 1996, p. 234), as ill people seek to legitimise their behaviour and moral status. Consistent with the perspectives on discourse analysis (i.e., Potter & Wetherall, 1996) used in this research project, Radley and Billig (1996) assert that the production of individuals' accounts "are always produced in situations and they gain their meaning from
the rhetorical activities of those situations” (p. 224). By examining the participants’ use of language we see how cancer is a moral illness as well as a physical disease. The struggle to contain and/or surmount one’s illness requires that one struggle with one’s own and society’s moral challenges. This moral environment shapes the participants’ use of language, as evidenced by the description of the themes in Chapter IV. Thus, this research project demonstrates that the participants’ accounts and their use of language reflects the many moral challenges they have faced, and continue to face, in their interactions and struggles with themselves and their larger social spheres, including physicians, work, family and friends, and the cancer group itself. The findings of this research project also demonstrate that the research participants draw upon various resources, including what are commonly referred to as discourses (see Burr, 1995). At times, the participants use these resources in a flexible manner, consistent with Potter and Wetherall’s (1996) perspectives on discourse analysis and what they term interpretative repertoires.

We also see Frank’s (1994; 1996) perspectives of storylines represented by various participants. The quest storyline is well represented in the themes above. Sadly, we see also the chaos narrative acted out by Carol who is too fragile with her “bad news” of the recurrence of her cancer to actively participate in the group. The restitution storyline is represented, in part, by Susan and Paul. Although both have strong elements of questing in their accounts, both have made emphatic statements that neither of them had been adversely affected emotionally or psychologically by their illness. They do not, however, live out this restitution storyline in that they are not passive recipients of medical care, but they are both certain that their present state of good health will continue.

With the exception of Carol, and perhaps Gwen in the end, the participants have become agentic characters in what has been termed the postmodern experience of illness (see Frank, 1995; Gwyn, 2002; Morris, 1998). Although Frank (1995) notes that the term postmodern has competing ideological claims to its usage, he broadly denotes it to mean the current social time where at least some individuals experience illness differently than in the
so-called modern times. Specifically, Frank (1995) argues it denotes a social time “when the capacity to tell one’s story is reclaimed” (p. 7). Thus, unlike Parsons’ (1951) notion of the sick role when one is presumed to defer to medical authority to tell the story of illness, individuals now give voice to their own story, previously unspoken. The findings of this research project overwhelmingly support Frank’s (1995) notion of the postmodern world of illness, as the research participants are actively giving voice to their experiences of illness. This voicing speaks to a narrative of moral struggle, with the participants as agentic characters leading the way for the medical world and society in general to follow. The findings also demonstrates how language is used flexibly, for example, Paul’s turning a common saying into a pun (i.e., “It’s not how whether you win or lose...it’s how you place the blame”), and the content of the pun reflects the moral environment in which it was produced. The participants also draw upon other resources, such as notions of stress, science, and spirituality, in their accounts. In some ways, these notions could be considered discourses in the sense that the participants could be accessing externally set and consistent ways of speaking about such notions (see Burr, 1995). However, consistent with perspectives of Potter and Wetherall (e.g., 1996), such discourses do not exist independent of the speaker, but rather as resources to be used flexibly as one constructs and co-constructs one’s accounts (Burr, 1995). Also consistent with Potter and Wetherall’s (e.g., 1996) perspectives, participants verbal interactions are often rhetorically and contextually produced. It is the context of the moral environment of illness that illuminates the rhetorical responses of the participants as they undertake their respective moral actions.

Although the participants emphasise their agentic actions, they also emphasise the necessity of interacting with others. They seek to learn from each other “to find out what other people do” and to be stimulated in unpredictable ways. From the findings of this study we see how the co-construction of the participants’ accounts is a complex and unpredictable process. For example, they may “listen for gems” and then “something clicks” that is deemed useful, but there is no certainty as which gems will click, with whom and in which manner.
This unpredictability of these interactions is demonstrated by a comment by Gwen in reference to listening to a tape by Deepok Chopra (i.e., "I dunno what I picked up from it, but, there would be something that would strike me"). Mia responded to Gwen’s comment that “ya everybody picks what works”, thereby adding another expression to be used as desired by the participants (see Kitzinger, 2000). In one sense, then, as participants introduce certain notions and expressions, these emplot their accounts but in a non-linear and unpredictable fashion. By non-linear I mean that such notions and expressions may or may not be picked up by others, and if they are picked up, they may be expressed at some unpredictable time and fashion. For example, as noted above, Paul combined a notion of “letting go” which he picked up from the writings of Melodie Beattie, with Hendrika’s expression “giving myself permission”. They draw upon what others say, as well as a variety of other resources such as books, the Internet, popular magazines, and television shows. The various notions put forth from these sources become resources by which they construct and co-construct their accounts with each other and their wider social spheres.

We see how the findings of this study overwhelmingly support the notion of the participants, with one exception, as agentic, reflexive characters, struggling to surmount the moral challenges of their illness. We also see how certain notions put forth in this study of moral quest (e.g., Charmaz, 1999; Hyden, 1995), storylines (i.e., Frank 1994; 1996), and rhetoric and the local construction of meaning (e.g., Potter & Wetherall, 1996; Radley & Billig, 1996) are manifested in the participants verbal interactions. The construction and co-construction of accounts is a fluid, non-linear phenomenon. Frank’s notions of storylines are valuable in illuminating this phenomenon. Even though the findings of this study emphasize the agentic character of all participants except one, if their disease progresses, than they are all vulnerable to being forced into a storyline of chaos. For example, Gwen personified the agentic character of the ill person struggling to overcome her disease. Yet, she did not continue with the group sessions even though she asserted that her very survival depended on her ongoing group participation. She slipped away from the group and the ending of her story
remains a mystery to us. Thus, this research project demonstrates that the strong prevalence of the notion of individual agency among the participants but that this could change as a function of one’s advancing illness and/or one’s return to seemingly unhealthy or unhelpful behaviours (i.e., “slipping”).

The various themes that emerged from the participants’ verbal interactions gave rise to a number of potential narratives. My position, however, is that in terms of their content the themes do not add anything of substantial value to the present body of illness narratives. My position is not meant to deny the unique and noteworthy experiences of any one participant, nor to elevate some experiences over others. Rather, my position is that these themes that I constructed and the experiences that underlie them have been represented in other writings. As one participant stated “well usually we find that our stories are really not our stories alone. I find the more I talk to people the more I hear the same things over and over again. We’re unique in a way but our life experiences...a lot of people have the same ones.”

In terms of the illness narrative I contend that it is an understanding of, and an appreciation for, the moral context of the participants’ struggle that is of value as an outcome of this research project. I further contend that what is also of value to the reader are my perspectives on how the participants used a variety of resources to construct their accounts from which I discerned the aforementioned overarching illness narrative of struggle. In particular, Potter and Wetherall’s (1996) notion of how individuals use rhetoric in their interactions with others (i.e., rhetorical struggle) is manifested in participants’ accounts and use of language throughout the group sessions. My findings demonstrate that the experience of having cancer is embedded in a moral world and is therefore continuously reflected in how participants take inherently moral positions in relation to their illness, themselves, and their various social spheres.

**Contribution to Knowledge**

This research study makes a unique and important contribution to the body of illness narrative research, which is “still in its infancy” (Hyden, 1997. p. 64). It not only expands
this body of research, but it is unique in that it concerns itself with the development of illness narrative in a group setting, a social context not typically researched (i.e., “rare). It also, in part, responds to Allen’s (1998) recommendation for more in-depth qualitative research of cancer groups. As well, the group environment researched is also the main psychosocial intervention for individuals with cancer (e.g., Cunningham & Edmonds, 1996), and therefore makes a contribution to understanding this important social activity. What is of particular value is that this study not only illuminates the illness narrative that evolved from the participants’ verbal interactions, but as well it illuminates how that narrative was actually constructed. Thus this research project adds to the small, yet important, body of illness narrative research, is concerned with the virtually unstudied area of a group context, and concerns itself with the most common form of psychosocial intervention for individuals with cancer, an illness that directly or indirectly affects two-thirds of the population.

This research not only illuminates an important area of social interaction, but it also validates social constructivism’s perspectives (e.g., Gergen & Gergen, 1997) and Potter and Wetherall’s (1996) perspectives on how one’s narrative is co-constructed in interaction with one’s social sphere. For example, as described in the preceding section, various resources utilised in the construction of the participants’ accounts were identified, as were certain aspects of their actual construction. Furthermore, the influence of the moral environment of illness on participants’ speech clearly demonstrated theoretical assertions of the contextual nature of talk. The research project also integrated notions of moral quest (i.e., Charmaz, 1999; Hyden, 1995) with Franks’s (1994; 1996) notions of storylines, in regards to illness narratives. That is, while Charmaz and Hyden make an important contribution to understanding the moral context of illness, Frank’s notions of storylines reflect that there is a potential range of illness experiences.

One aspect of special note is the findings of the research of a narrative of struggle and not suffering. As noted in Chapter III, 2 participants specifically disavowed any experience of suffering (e.g., “I didn’t think of it [her experience with cancer] as loss or grieving or
anything like that ... I thought of it more of a learning process”). This is noteworthy given that the illness narrative literature typically refers to suffering as the underlying experience of those with serious and/or chronic illness, and furthermore that a central value of illness narrative is that it gives voice to this suffering (e.g., Kleinman, 1988). The findings of this research project may therefore offer a more suitable term to capture the commonality of individuals experiences with illnesses such as cancer.

A related issue is in regards to the typical notions of the contextual aspects of suffering and struggle encompassed by the medical domain and the larger social sphere that challenges the legitimacy of ill persons’ experiences and their sense of worthiness (e.g., Charmaz, 1999; Hyden, 1995; Kleinman, 1988). Although these contextual aspects are evident in the participants’ accounts (e.g., see Appendix D), some of the suffering and struggle comes in the interactions with those who are well-intentioned and who value these individuals, but for a variety of reasons cannot help alleviate the suffering or struggles of the ill person (e.g., “and people who - you don’t have a close relationship - think they can just come up and ask you about it - and they would ask you how are you and if you don’t give them a full answer they say no I really mean it”). These research findings therefore demonstrate that issues of suffering and struggle are part of a broader social context than is typically described in the coping literature.

Another contribution of this research is an understanding of how one’s story and related sense of self evolves during the illness experience. As noted in the first theme identified in Chapter IV, one’s interaction with the wider social sphere often begins with a search for information and “knowledge” after the shock and sense of disorientation from one’s initial diagnosis (e.g., “I didn’t know what direction to go - running around reading books”). The search for knowledge often leads one to commonly available resources or what Frank (1993) refers to as “culturally available resources” (p. 5), such as the rhetoric of ‘self-as-project-for-change’ and storylines (e.g., Frank, 1993; 1995). These discourses are resources, which guide one’s activities including developing and telling one’s story and the
giving of accounts of one’s experiences. The rhetorical structures and vehicles by which one gives voice to one’s experiences therefore emplot the speaker’s stories and the potential identities that one can fashion to fit one’s life circumstances, such that “Stories do not simply describe the self; they are the self’s medium of being” (Frank, 1995, p. 53). By engaging in the process of developing and telling one’s story one regains a sense of coherence in one’s life, what Frank refers to as one’s “map and destination”. Thus, this research project demonstrates one avenue by which to understand the nature and process of story emplotment and of identity reformation that is commonly reflected in the illness narrative literature (e.g., Bury, 1982), as well as providing a different perspective that not all individuals with a serious illness experiences suffering.

At a broad level one could view the development of the overarching illness narrative of struggle as reflective of the basic narrative format of a story with a beginning, middle, and end (e.g., see Riessman, 1993). That is, it can be viewed as a narrative about how the participants initially faced the challenges arising from their respective illnesses, followed by how they navigated those challenges and ultimately found some sort of resolution. Therefore, in this sense the illness narrative can be viewed as broadly developing along a predictable continuum. Although this perspective has merit, the reader should be mindful that the nine themes, upon which the illness narrative is based, were constructed by the researcher connecting various comments made by different participants from different sessions over a 12-week period. I give this caution because, as described above, the development of the participants’ accounts is an unpredictable process, done piecemeal through various activities (e.g., reading self-help books) and interactions (e.g., attending a support group). Although the ‘beginning-middle-ending’ motif provides a convenient framework by which to organize accounts into a narrative, it oversimplifies the complexity of the process of development. To reiterate, my contention is that the value of this dissertation is that it illuminates the moral context of the participants’ verbal interactions, from which the nine themes and the overarching illness narrative of struggle evolved. Thus, the emphasis is not focused on the
sequential nature of narrative development, but rather upon the influences on development, such as the interactions of the individual with self and others, the resources drawn upon to construct and co-construct one’s accounts, and the pervasive influence of the moral context of illness.

This research project also makes a contribution to qualitative methodology by its novel approach to using discourse analysis to inform narrative analysis. The approach of identifying themes upon which to build an overarching illness narrative was greatly enhanced by the use of discourse analysis, which illuminated the manner by which the themes came into being. This research project therefore validates Potter and Wetherall’s perspectives (e.g., 1996) on how individuals flexibly use the resources available to them in order to construct their accounts, and it also identifies some of the resources used by the participants.

As noted in Chapter I, both narrative and discourse analysis are represented by numerous perspectives that defy simple definition. This research project demonstrates how illness narrative researchers can navigate this lack of consistency by adhering to Mishler’s (1995) notion of problem-focussed inquiry. If one allows oneself to keep the problem under investigation as the central focus, the various available perspectives become tools to support the researcher’s efforts.

**Practical Applications**

As noted in Chapter I, counselling psychology along with other professions such as nursing, aim to assist individuals to manage problematic life events, including serious illnesses such as cancer. This research project therefore has implications for the application of knowledge as described in the preceding section.

One major implication of this research is that it expands notions of coping typically described in the literature (e.g., Anderson, 1992). Coping is also an inherent aspect of the work of counselling psychologists. This research project demonstrates that individuals with cancer not only learn valuable coping skills, but also that their illness often requires that they redefine who they are through the stories they tell. Thus, in a professional’s therapeutic
interactions with ill people, equal space must be given to the stories individuals tell, not just for alliance building, but as an inherent and necessary aspect of coming to terms with one’s illness. In other words, story telling is as important as learning coping skills to someone with cancer. Furthermore, professionals can be better listeners if they can appreciate how stories are constructed and what they can accomplish in their construction. Professionals must also appreciate, as noted in Chapter I by the quote of Harre and Gillett (1994), that in order to understand the nature of mind one must appreciate the “broader canvas” of the social environment that the mind inhabits. In particular, professionals need to develop a sensitivity to the moral context of illness, which will enhance their ability to ‘enter-the-world’ of ill people, which is a cornerstone of counselling psychology (e.g., Egan, 1998).

The value of story telling raises the question of how counselling psychologists and other interested parties can in some manner positively influence clients’ stories. One key area is in regard to the “hunger” (Hawkins, 1999) that ill people have for information. Sponsors of cancer groups need to consider how useful and trustworthy information can be made available to participants. This common-sense suggestion, however, has potentially controversial and ethical challenges. For example, while there is a great deal of interest by participants in what are termed mind-body interventions, the results of this research in cancer remains controversial and inconclusive (e.g., DeAngelis, 2002a). Thus, special attention must be given to assist clients to access reliable information and resources.

Similarly, in regards to religion and spirituality, controversy reigns over their relationship to health (e.g., Koenig, Idler, Kasl, Hays, George, Musick, Larson, Collins, and Benson, 1999; Thoresen, 1998). Thus, a practitioner in cancer psychosocial care is faced with an ethical dilemma of how to support individuals’ legitimate needs, while not promoting activities of controversial or dubious value. The area of religion and spirituality is especially problematic given the inherent difficulty to comprehend in some way what Koenig et al. (1999) note “is not a single homogenous construct” (p. 128). Thus, strategies must be devised to address these needs. Examples of such strategies are found in the structure of this research
project (see Appendix A) and in the recent publication by Cunningham (2002).

In a similar fashion, even though it is axiomatic among the helping professions to in some way respect the personal perspectives of those in our care, I argue that more is required given the burgeoning demand for what are broadly referred to as alternative approaches to health care (e.g., Hawkins, 1999; Thoresen, 1998). As Thoresen (1998) notes “The notion that our physiology and even our anatomy serve at the pleasure, if not the beck and call, of our cognition has surely arrived on the health care scene with increasing momentum” (p. 409). Thus, not only is there an increasing expectation among ill people for alternative approaches for care, these expectations are based on a blend of social discourses (e.g., Hawkins, 1999) and research that does demonstrate results that at times supports this social discourse (e.g., DeAngelis, 2002b). Although a qualitative research project such as this one is traditionally not concerned with issues of truth-value, a practitioner in this area can neither avoid nor ignore this issue. Therefore, I argue that practitioners must become well informed on mind-body and religious or spiritual research, and its application in health related matters.

**Policy-making**

As noted in Chapter I, health care organisations (e.g., Canadian Nurses Association, 1997; Canadian Council of Health Services, 1997) have made a call for consideration of caring for the needs of the public from a holistic or comprehensive perspective, a core tenet of counselling psychology (e.g., Egan, 1998). During the fall of 2002 there was much media attention given to the future of health care in Canada, unfortunately little official acknowledgement has been given to the psycho-social health concerns of the Canadian population (Canadian Psychological Association, 2002). Thus, while the need for psychological support is well documented, and effective measures are available (see Anderson, 1992; Cunningham & Edmonds, 1996), the primary focus on physical health de-emphasizes this need. This is unfortunate as the results of this research study, as described above, expands the traditional perspective on what actually occurs in a cancer group (i.e., as described above, coping is more then the simple acquisition of certain skills) thereby
increasing the complexity of how best to sponsor such groups.

Given that individuals with cancer continue to struggle with challenges that go far beyond the disease itself (i.e., moral struggle), one major implication of this study is that the health care system must address these needs in order to fulfil its public mandate of comprehensive care. In part, this requires various health care disciplines and regulatory bodies to expand notions of psychosocial care beyond traditional perspectives of coping. For example, the moral aspect of cancer illness could be incorporated into health care professional education programs. As well, public health community education programs could incorporate this perspective to better address the needs of persons with cancer.

To this end, more qualitative research on this aspect of group interaction is warranted. However, in a recent special edition of Canadian Psychology (2002), several authors (e.g., Stoppard, 2002) argue that the Canadian psychology arena is not generally hospitable to qualitative enquiry. Thus, while I echo the Canadian Psychological Association’s (2002) assertion for the necessity of continually advocating and lobbying for services to meet psycho-social health needs of the population, one must be mindful that the task is daunting and long-term.

**Limitations of this Research Project**

The biggest challenge to a qualitative study that involves multiple voices is how best to make a representation that can make a legitimate claim to fairness and honesty to all the participants. This task becomes even more challenging with the realisation that it is not only the researcher’s biases that are at issue, but also that within the group itself some participants spoke more often, and sometimes more forcibly then others. Therefore, the question arises as to what might have been expressed with different individuals or under different circumstances? A related issue is that individuals in their verbal interactions often make halting, incomplete, and overlapping utterances that are often somewhat incoherent in comparison to written grammar. Analysis is therefore inherently subjective and open to a variety of interpretations.
Another major area of limitation is the exclusion of other contextual considerations beyond the moral dimension described above. Although the moral dimension of illness significantly illuminates the participants’ verbal interactions, other important dimensions or aspects are likely to be of importance. One example is the multiple losses individuals with serious illness can experience, as recounted in Appendix D. Hendrika endured 4 years knowing something was seriously wrong with her health before she was properly diagnosed.

“So I had four invasive procedures [over a 4 year period] ... knowing that there was something wrong ... so that the diagnosis [of kidney cancer, versus a malfunctioning bladder] was, uh, like an anticlimax really”. During her hospitalization her house was broken into and family heirlooms were stolen. She eventually lost both her employment and her house, and suffered more physical adversity, that is, a heart attack and severe osteoporosis. Her story demonstrates how illness can precipitate a cascade of losses and/or limit one’s ability to manage and surmount other unexpected life challenges. Any or all of these challenges could influence the account one gives of one’s illness.

A related influence to the preceding issue of loss(es), is one’s position on one’s illness trajectory. Hendrika’s present account reflects her successful surmounting great adversity and how her life has greater meaning because of her success. In contrast, one can infer from her present accounts that her accounts during the worst moments of her illness were quite different. As well, I have speculated elsewhere about a concern for the well being of Gwen, who may have experienced a worsening of her physical health and therefore quite possibly a change in her accounts. Thus, one’s account can evolve and change in concert with one’s changing illness trajectory.

Other factors and considerations likely influenced the participants’ accounts, some
which were indirectly alluded to in their verbal interactions. For example, in Theme 2, Debbie’s comment on how prostate cancer “is a male disease”, points to issues of the influence of gender on how one might give accounts of one’s illness. Paul recounts how in his prostate cancer support group he challenges other members’ struggles to resist treatment because of concerns about sexual functioning, with his rhetorical question of “Do you want to live or do you want to die with a hard-on [i.e., an erection]”? Similarly, Kitzinger and Willmont (2002) give a report of how the physical manifestations of polycystic ovarian syndrome on gender image influences the accounts of the participants in their study. Thus, gender concerns related to illness can be highly influential in participants’ accounts.

One can also speculate about other potential influences on participants’ accounts that are simply unknown or undetected. Factors such as age, cultural and religious backgrounds, previous experiences with illness, the relative seriousness of one’s illness, other health concerns, and the stability of personal, social and financial resources, are but a few of the many influences that may or may not impact one’s account. As well, one can question the influence on the giving of accounts by those who are prompted to attend an activity that exposes them to scrutiny of a researcher, in contrast to those who chose not to attend.

All of these aforementioned influences are worthy of investigation, and potentially offer greater illumination into the participants’ verbal interactions than is provided by this dissertation. This research project therefore shares the common issue among other qualitative research projects in that no solid claim can be made as to its relevance beyond the particular context of the groups at those times of study and as represented by the researcher. One can only make a claim to have made the best attempt possible under the circumstances and within the self-proclaimed mandate of the researcher. Consistent with the perspectives of Potter and
Wetherall (1996), I contend that it is ultimately up to the reader to decide for himself the relevance of the findings.

**Recommendations for Future Research**

As noted above, the research findings are an inherently subjective outcome of a project that potentially could be represented differently by another researcher. Although this might raise concerns over the worthiness of the project, Mishler (1995) reminds us with his perspective on narrative as a problem-focussed area of enquiry that different perspectives are welcome depending on the nature of the study. For example, one might take the same transcripts and perform a ‘fine-grained’ analysis, such as conversation analysis (e.g., Drew, 1996), in order to perform a discursive approach (e.g., Kitzinger, 2000; Wilkinson & Kitzinger, 2000) to illuminate other aspects of the verbal interactions of ill people. One potential area of investigation is to examine the use of the many metaphors and figures of speech employed by ill people. For example, Wilkinson and Kitzinger (2000) demonstrated that the use of the term “thinking positive” was actually employed as an idiom in the participants’ verbal interactions, rather than a reflection of a coping strategy. Furthermore, Kitzinger (2000) demonstrated how participants used various strategies to resist the rhetorical use by others of the idiom “thinking positive”. Participants’ verbal interactions are rich with such expressions and are fertile ground for more research.

Another area that might prove fruitful is an exploration of the experiences of those who experience a serious illness yet claim not to have suffered in any way. Such a claim, as described above, contradicts typical assertions of those who write about illness narratives (e.g., Kleinman, 1988) and therefore warrants further study. In a similar vein, more research on how individuals successfully navigate the various moral challenges of their moral
environments could assist caregivers in their work with ill people.

My next comments concern themselves with the “doing” of research rather than pointing to other avenues of research. My working with videotapes heightened my awareness of the communicative value of that medium. Even though I attempted to faithfully represent the development of the group participants’ overarching illness narrative of struggle through the medium of writing, the use of videotape would convey much more of their actual interactions. For example, tone of voice along with other non-verbal behaviours are typically thought to communicate more information than the actual content of the spoken words (e.g., Egan, 1998). This issue is especially salient for the study of the interactions within groups given the number and complexity of those interactions. My recommendation is not to replace written analysis but rather to include video portions to better communicate the totality of the interactions in a more direct and efficient manner.

My final comments concern the complexity of doing illness narrative research by using narrative analysis and discourse analysis. It has been a very difficult endeavour to find my way through the various theoretical perspectives and avenues of research, as well as the extensive pages of transcripts. Thankfully, I had Mishler’s perspective of problem-focussed area of enquiry to guide me. Eventually I was better able to appreciate the wisdom of this perspective in that there is no definitive map to doing narrative research. The researcher must determine one’s own, arbitrary, boundaries for the research project. I also discovered late in my endeavours the writings of Burr (1997), who advised not to do research in this area alone. Although I did have the support of my research committee, much of my work was solitary and I would have benefited by the presence of an active co-researcher.
Personal Reflections

Chapter I began with the history of my personal experiences with cancer groups and a description of how I marvelled at the way individuals with cancer could face a grim future through their participation in groups. I previously sought to understand this phenomenon by studying group intervention strategies based on certain notions of coping (e.g., Anderson, 1992), and then later investigated approaches that also incorporated existential and/or spiritual perspectives (e.g., Cunningham & Edmonds, 1996). From these efforts I learned a great deal about how to assist individuals with their struggles with cancer. However, it was not until I analysed the transcripts of the participants’ verbal interactions that I began to comprehend how embedded ill people are in a moral world. Through the process of becoming aware of the moral world I have come to believe that in fact each and every one of us lives in this moral world, and that it is experiences such as having a serious illness that brings this reality into focus. The moral world is the background of our individual gestalts. This is the most important learning that I will take from this research project.

I also have a greater appreciation for the importance of including existentialism and/or spirituality in my work. Although I have always valued these perspectives, I realise that my previous training and education did not adequately prepare me for how one actually goes about including them, beyond simple acknowledgement that they are important theoretical considerations. By doing this research project, I have learned much about the “doing” of existentialism and spirituality and I intend to apply my learning to my professional career and my personal life.
References


Illness Narrative in a Structured Cancer Group


Gerhardt, U. (1990). Qualitative research on chronic illness: The issue and the story. Social Science and Medicine, 30 (11), 1149-1159.


Illness Narrative in a Structured Cancer Group

Science and Medicine, 38(6), 789-800.


Appendix A- Format of Structured Cancer Group

Note: there are ten weekly sessions, two hours in length. Participants are provided a manual, and given weekly assignments. Each session begins with an opportunity to review previous sessions and the assignments, and ends with a group discussion.

Session 1 - Introduction

Participants are introduced to each other. An overview is provided on defining cancer; the connection of mind and body; and the impact of stress. There are assignments for: breathing exercises; starting a journal; and keeping a log of exercises and journal writing.

Session 2 - Progressive Muscle Relaxation

The nature of stress is reviewed, followed by a session on progressive muscle relaxation.

Session 3 - Deep Inner Relaxation

Session on the “language” of the unconscious mind and its relation to imagination, as a preparation for relaxation imagery. This is followed by breathing and guided relaxation exercises.

Session 4 - Goal Setting

Session on role of hope, faith and motivation to live. This is followed by session on goal setting. This is then incorporated into a visualisation exercise.

Session 5 - Imaging T & NK Cells

Session first provides information on the immune system, followed by visualisation exercises.
Session 6 - Imaging: Cancer and Defense Images - Feelings

Session continues with exercises to integrate breathing and imaging skills, and to identify emotions that may inhibit successful practice.

Session 7 - Spirituality

Session presents concepts related to spirituality and religion, and participants are invited to articulate their own thoughts and feelings on these topics. Next the topics of loss, guilt, and existential concerns are discussed, and participants are given a series of questions designed to answer basic existential questions in their lives.

Session 8 - Inner Healer

Concepts related to the unconscious mind and inner wisdom are presented, followed by a guided imagery exercise.

Session 9 - Meditation

Concepts related to the meditation practice are presented, followed by a practice session.

Session 10 - Taking Control

Concepts related to goal setting are first presented. Participants are then asked to brainstorm major areas of lifestyle that they wish to set goals for, followed by an opportunity to set personal goals.
Appendix C

Transcription Symbols

(.5) minimum pause.
(.) pause too brief to count
(1.0/2.5) pause for over 1 second
hh, hh in and out breath
hehh, hahh laughter
((sniff)) ((cough)) non speech sounds
((noise)) (h) denotes non-speech sounds
cu- dash denotes a sharp cut-off of a prior word
lo:::ng colons show word was elongated
latch=ing equal signs link to differing utterances not separated by a pause.
also used in the case of overlap to link speaker back to previous turn
underlinemphas underline indicates emphasis given
CAPITALS indicates speech noticeably louder than that surrounding it
>fast< talk speeds up
<slow> talk slows down
over[lap] denotes overlapping talk
Appendix D

Hendrika’s Story

H: was sick for four years (1.0) and i wasn’t diagnosed because people (1.0) I had five urologists at the end or four of them and and the last one twice uhm (2.0) so i wasn’t i f- i was sick (1.0) an- knew it was my kidney and of course i was a menopausal woman and they always would (1.5) they never urologists never look you in the eye have you noticed that never

(group laughs)

L: cuz they’re not used to lookin- there

H: no (laughs) exactly

(group laughs)

L: i’m sorry

H: no no this i (1.5) what i was referring to ya really (1.0) they just (1.5) look at you sort of

L: sorry

H: to the other end and say you’re a menopausal woman so it’s your bladder (1.0) and for (1.0) for four years i kept saying it’s my kidney i know which kidney too (1.0) i had the typical (system) uh::: (1.0) symptoms (1.0) my blood was such that my doctor would say to me i have never seen blood like yours (1.0) it’s just horrible it’s uh like a garbage heap (1.0) or it’s like garbage and i would say well what is it (1.0) what’s wrong (1.5) well antibiotics so i would go to the urologist more antibiotics i had two dee and sees (1.0) which i (1.0) said i do not need and i do not want i have nothing wrong with my uterus (hhh) it’s my kidney (1.5) we know we know (1.0) we’ll do what we think is right (1.5) uh i had they went twice in the urethra (1.0) and stretched it (1.0) and this is really something painful and invasive (1.0) so i had four four invasive procedures that i didn’t need (1.0) and so for four years i was i was fighting (1.5) i was feeling sick i was of course (1.5) knowing that there was something wrong (1.0) one bout of antibiotics after the next (1.5) so the the the diagnosis at the end (1.0) was uh like an anticlimax really (1.5) well finally i have a diagnosis and the
way it was given to me again was too (1.5) well it's cancer after all go and make an appointment with my secretary to for surgery (2.5) so somehow i went through a lot of of trauma (1.0) to even be diagnosed (1.0) and then again being treated like this (1.0) uh:mm then i:: i was devastated financially (1.0) i was a single mum (1.5) and uhm they wouldn’t give me disability (1.0) when i came h- when i was in the hospital they were already telling me that uh you know that the cutbacks (1.0) there’s no disability (1.0) so i had already been sick for four years i had been unemployed pa:rt of the time (1.0) uhm so i lost my house (1.5) i was told by one of the poli- politicians assistant that i went for help (1.0) that i could always take my daughter out of high school and let her work until (1.0) and then she could go back to school again (1.5) so things like that it was (1.0) i wasn’t only fighting cancer (1.0) as i was in the hospital (1.5) when i came home on the way home my: my younger daughter (1.5) second daughter said to me mum (1.0) you have uh: insurance on the on the house don’t you (1.0) and i said yes i do (1.5) she said well i have to tell you something (.5) you were robbed and vandalized because i had told my youngest daughter to stay with my older daughter (1.0) while i was in the hospital i didn’t want her alone in the house (2.0) it was probly kids that went in (1.0) because not only did they steal (1.0) what was valuable they destroyed everything else (1.0) so i came out of the hospital to a house that was vandalized (1.0) that uh all my teaching stuff all the stuff was either vandalized or (1.5) they had put it together in a in a pile in my bedroom (1.5) and so this was one thing after the next it was really difficult for me to sort of find my way (2.0) and they had stolen things that were (1.0) irreplaceable (1.0) like the engagement pendant of my mother that my father had given her things like that that you cannot i should have (1.0) but them in a box i know (1.5) didn’t do it (2.0) uhm (1.0) so there were a lot of things that meant nothing to anybody but me (1.0) and so even coming to that house i didn’t feel safe (1.0) as i was trying to heal (1.0) i was constantly and of course they had broken the windows (1.0) downstairs so i was constantly thinking i was alone there (1.0) and (1.0) i didn’t feel safe in the house anymore (1.5) i didn’t feel safe at all anywhere that i had no money coming in (1.0) i had still a child at home so
these were things that really made this very difficult and i did have to deal with a lot of things at once so things have come together and then of course i kept going back to austria to look after my mother because she kept falling apart she had severe osteoporosis uhm so i kept going back back and forth and i didn’t really have the time i did all the things that i was supposed to be doing like the diet and all things but at the same time spiritually or emotionally i didn’t really have a lot of peace it was very difficult for me to find the peace because the i was being torn in all directions and at the same time i was thinking in the back of my mind there is there are my children who really don’t want me to die who are very very concerned about that my daughters saying i needed to live because she was pregnant after nine years and we had looked forward to this baby for nine years and here i was going to die my younger daughter of course that we youngest who was still at home she didn’t have a dad she doesn’t have a dad so therefore i am it so it was very difficult i didn’t just have to go through the the pain of surgery and and worrying about whether it’s gonna come back there were all these other things to take care of and so i guess i it was a wake up if cancer’s a wake up call i needed another one because i did not do that well looking after what i really needed to do so then i had a heart attack i bounced back very quickly after that too but then i thought well why am i getting something else here there has to be a reason for that and then uh couple years later then my mother died died in february and in june as i was supposed to go back again to look after the condo clear out the condo i fell and broke my my foot or i have i have three uh plates and thirteen screws in that foot and at the time too well you’re gonna be as the doctor said i said i have booked at the end of june i have booked a flight and he said next year at this time you’ll be walking with a cane well three months later i was there end of august i was there cleaning out her house but uh again that after the third time i walked into hope house to the psychologist who has been at the groups and i said to him okay this is three three times now
what is it i'm not getting obviously there is something to this how often am i going to go on every two years now i'm gonna have something big happening (1.5) and that's when it stopped (2.0) cuz that's when i settled down and realized that (1.0) obviously there is something to this (1.0) why is it happening to me (1.0) why is abo- all these things happening that are really devastating and what do i need to learn from that (1.0) and that's when things really fell into place (2.0) that's the third wake up call did it (1.5) so i say i'm a slow learner (1.5) took three times but (1.0) i did learn it then i did find out what i needed to do so

H: well this is absolutely it (1.0) because it's obviously that i didn't need to do the diets (1.0) i didn't need to do all of these things as much as i did need to find out why i needed to stopped (1.0) and what i needed to learn from that (2.0) and that's where it comes in (1.0) (inaudible)

P: in your case things changed whe::n

H: the third time around when i started to look at what it was that i needed to learn here

D: a what did you [learn]

P: [and] and what did you learn

H: i had to first of all i had to go back to the things that i had been chewing on (1.0) like my childhood my my relationship with my mother (1.5) when she died i had to do these i had to go through this and work this out (1.5) on a spiritual level (1.5) i had to forgive (1.5) and i had to to re-learn again how to feel about things in my life (1.5) towards people and so on

P: great

H: that is the major part of it ya it's not it wasn't the physical thing so much (2.5) it and this is what i i i had to go through and i'm not (1.0) i'm not saying i am perfect now: i can't do this i never will but i certainly have learned the last few years i have learned more than i ever did in my life before
Appendix E

Theme 1

1. “through her [i.e., her mother-in-law] you know learnt a lot so when it came my turn (1.0) it still whacked me on the side of the head (laughs)”

2. “and she said that’s what getting the diagnosis (.5) is uh:: (1.0) that you have cancer (1.0) you’re on the train and it’s (1.0) l- (.5) left the station (.5) and you don’t know where you’re goin-”

3. because (2.5) uh I (1.0) was diagnosed with cancer it was a shock…[and after his operation] I was (1.0) for myself I was stressed (1.0) I didn’t know what direction to go (1.0) running around reading books

Theme 2

1. one of the things I’ve done since day one is (1.0) I got on the internet with the help of my good buddy (1.0) an-I:: look for things to give me hope (1.5) a:nd uh: … so (.5) I’m on the internet most days five days a week (1.5) looking up studies

2. D = Debbie M = Mia

D: but there is an article probably every three months or something about breast cancer and starting ovarian cancer and colon (1.5) colon cancer in Canadian Living or Chatelaine you know in the

M: [popular]

D: [popular] magazines all the time

3. D = Debbie

D: but you know I have to say (1.0) it’s a man’s disease nobody in my immediate circle has it so I don’t read about it (1.0) and I don’t really know enough about it and the science and the effects of it so I would be like that woman [i.e., the “petrified” wife] (1.0) you know like because breast cancer it’s it’s more out there like they just (1.5) really pushed it

4. P = Paul

P: and this tells me: that we can control our sickness (1.5) and that’s one of my goals (1.0) so I’m constantly searching for (1.0) foods to avoid (1.5) and to and to ingest (1.5) and (1.0) this is so inspiring to me it gives me so much hope (1.0) and so far it worked for me six years
4. that was the first thing I did (2.5) I started on a macrobiotic diet...pretty well I have I have changed my lifestyle totally

Theme 3

1. a surgeon treats the the uhm the disease; if you have an operation you’re just a number (1.5) you got under anesthetic they put you in you go and (inaudible) they don’t know you personal right

2. but in a surgeon you go in (1.0) under the knife (1.0) in out next one regular butcher one gone the next one under the knife”; “but the one I had too ya he’s (1.0) totally like that (1.0) a butcher (1.0) just the organ you know deals with the organ...but don’t tell us that there is something in the head too (1.0) and that you actually have feelings

3. I don’t really care about the surgeon (1.0) ther- all I want is for him to have the hands of an angel

4. there are some enlightened doctors out there I have one but uhm (.5) and (1.0) she has grown with me:: whether she wanted to or not she has

5. H = Hendrika
H: same with my doctor for instance (1.5) she was seven years ago totally like you know roll her eyes when I said something to that effect and just didn’t believe it and as I come along now and I keep pushing it (1.5) like I keep pushing it (1.5) like I keep telling her uh she’s coming to the point to and just recently she she said you certainly have really changed (1.0) what is going on by and I really see that that the mind and body is (1.0) uhm is w- and when I heard that I thought (1.0) my gosh you know (1.0) took seven years somehow but I’m I’m mm I’m not the only one doing this but (1.0) her patients have shown her that (1.0) by being h-well

6. they do not want to hear what we’re doing...like all of this is not seen as something worthwhile (1.5) in many cases (1.0) an- I think that’s why maybe:: some of the (1.0) cancer industry is very hostile toward what we are doing and do not see the merit of it

Theme 4

1. G = Gwen  D = Debbie  L = Lil

G: that is the most thing that you (.5) touched on (1.0) because the mother (1.0) in all of us (2.0) tend to have uh guilt over what happens with our children (1.0) and (1.0) I was so bad for that (1.0) and when my daughter got cancer

D: it was your fault

L: uhm hum
G: yes I kept thinking (2.0) what did I do
L: what did you do↑
G: what did I do (.5) maybe I didn’t eat properly and and (1.5) maybe it was because I had a drink when I was pregnant because (1.0) we didn’t know back then okay (1.5) ah or maybe it wasn’t that I ate properly or maybe I didn’t feed her properly (1.5) and that’s what we tend to do
L: uhm hum

2. G = Gwen M = Mia

G: I think that one thing (1.5) that’s so important though (2.0) is that (1.5) we don’t (3.5) you can believe in this (1.0) all of this (1.0) for yourself [i.e., believe in alternative health practices]
M: uhm hum
G: but we have to be very careful (3.0) not to impose that (2.0) on someone else (3.5) what I wanna explain (1.0) what I what I mean by that is is that (1.0) what happens is > you you you you< make that per::son (3.5) responsible (1.0) you can make that person feel responsible for their own illness (1.5) a-an what I mean by that is (.5) when you’re doing this for someone else which is what I did for daughter (2.5) uh buying them vitamins doing all the things an- the books an- everything okay! (1.5) but this is not her doing it that’s me:: doing it
M: uhm hum
G: uhm (1.5) so I used to say to her (2.0) uhm (1.0) oh you didn’t take the (1.0) you didn’t take the vitamins okay! An ah (1.5) w-really what I was doing without knowing see I know all this now because now I realize now weren’t right (1.5) uh so what you (1.5) what it’s really doing is (1.0) making her feel cuz that’s how I feel sometimes (1.0) oh god if I don’t do this then its (2.0) it’s my own fault

3. P = Paul L = Lil D = Debbie

P: ever hear the expression it’s not whether you win or lose its
L: [how you]=
D: ya
L: =play the game
P: how you place the bla::me

4. well well does anybody feel (.1) did you get any guilt feelings that it was your fault↑ that you go(hhh)t cancer↑ (1.0) I mean you know you did something wrong and that’s why you got it you didn’t eat right↑ Or (1.0) didn’t exercise got too fat whatever I mean we all have those feelings (1.0) well if I hadn’t done this it wouldn’t a happened type of thing

Theme 5

1. M = Mia D = Debbie L = Lil
M: you know how people always constantly ask me and it’s you know↑ (1.5)
people ask how I’m feeling particularly my mother and it drives me crazy (1.5) are you feeling - okay::! (1.0) yes yes I’m fine
L: you know they’re not saying hi how are you (1.0) [they’re saying]=
M: [no]
L: =they’re saying how a:::re you
M: ya no an- its uh very different scenario (inaudible)
D: well and people who (1.5) you don’t have a close relationship (1.0) think they can just come and ask you about it (1.5) and they would ask you how are you and if you don’t give them a full answer they say no I really mean it
L: [they’re quite (.5) people are quite]
D: [almost like excuse me but] who the hell are you↑ (laughs)
M: it’s true (inaudible)
L: [it’s quite true] quite bold about it
D: ya

2. I just want to be treated normal... I don’t want people to say to me how a:::re you paul! (1.5) are you okay!”

3. M = Mia  D = Debbie  L = Lil  P = Paul

M: so it’s hard when your sick
L: exactly
P: [ya] (1.0) [ya ya]
L: [ya]
M: [to accept] their support (1.0) I mean (1.0) [you probly found the same]
D: [it took me a year just] (2.5) I i guess the chemo (1.0) just kicks you so:::=
M: uhm hum
D: =ha:rd that I couldn’t accept it
.....
M: and sometimes you just wanna be alone anyway

4. > I I I < wish (1.0) I could have had cancer first (2.0) and then I would have known (2.0) many things and would have handled so many things differently”

5. H = Hendrika  P = Paul  S = Susan

H: …and they have seen how I changed (1.0) and so I find with my daughters especially they are (1.0) really (1.0) changing (1.0) and they are being much better than I was at that age (1.5) meaning (.5) you know as (1.0) as as persons as spirits (1.5) they’re far developed than I was at that age
P: in a sense your cancer has helped them
H: absolutely this it radiates out it doesn’t just help you if you want to spread it or if you want to share it with people...so I think cancer affects everybody around you
S: oh ya and it can be positive
H: positive
S: or negative

6. S = Susan    H = Hendrika    P = Paul

S: living with cancer ya but still going on (1.0) the path (1.0) to health (1.0)
   isn’t that the path that we’re all on
H: ya
S: is the path to health
H: ya
P: sure we are (1.0) y-n your comment (helped a lot) this business of giving
   ourselves permission (1.5) that’s so strong in us
S: [uhm hum]
H: [hum]
P: you know (1.0) it reminds me of a beautiful book by melody beatty (1.5)
   where she talks about the language of letting go (1.5) we all need to let go
   (2.0) and when we’re born we got nothing to let go of except reach out and
   love and be loved but somehow the culture (1.5) the family value
   something school I don’t know what it is
H: puts expectations in ourselves that are stupid
S: uhm hum
P: they’re crazy (1.0) we can’t be super people (1.5) can’t do everything
   perfectly (1.0) but (1.5) it’s in there we have to let go and when we let go
   (1.5) boy (1.0) life changes
S: uhm hum
P: [you’ve let go you’re (.5) you’ve let go]=
S: [uhm hum (1.0) uhm hum ya right
P: =I strived at some things I gotta let go of still but (1.5) that’s a very
   important catch phrase to me give myself permission and let it go
S: uhm hum
P: and like you say it’s self induce d (1.0) by and large (1.0) by and large but
   our culture also does it to us (1.0) we listen to our [mothers and the were
   (inaudible)]
S: [no: you let if] (1.0) they let it happen
P: well ya
S: I-it doesn’t do you let if [happen]
P: [and] that’s why we have to let it [go]
S: [and] I let it happen
P: we have to let it go
S: right
P: but it comes up a lot in this group doesn’t it

7. then when you get cancer you do all these different things (1.0) and people are
   (inaudible) well all that doesn’t work (1.0) oh you know that’s you’re just this is
   all for nothing (1.0) well you’re just having the most expensive urine (2.5) if you::
take all the supplements” [group laughs]. Hendrika is recounting how “people” dismiss her taking of supplements as both costly and useless. To her, the behaviour one engages in is less relevant then whether one is “being forced by the outside world…but if you’re allowed to let go (1.5) and be what you really are…I think that’s very important

8. G = Gwen     D = Debbie

G:  i guess part of the reason that (1.0) you can’t talk to other people to is (1.5) i can’t stand the buzzwords that are used in cancer (1.5) i hate them (1.0) like (2.0) if you j- just even say: anything (1.0) that your a little bit dow:n (1.5) then right away somebody says oh be positive be positive (1.0) i don’t know what positive means like am i positive i’ve got cancer (1.0)
and like can i be positive i’m gonna live can i be positive i’m gonna die: (1.5) what does positive mean (1.0) i don’t know what that means (1.5) and then the minute (1.0) i can be hopeful (1.0) i’d like that word used (1.0) and then the minute that you say:: anything (1.5) like that (1.5) then the same person who’s told you (1.5) to be positive (1.0) an- i had this done by a doctor actually with reference to my daughter (1.0) i had heard this positive from this very same doctor so i said (1.0) the next time we were in to visit (1.0) my daughter was on the way out of the room an- i said (1.5) oh doesn’t she look wonderful well (1.5) we’ve really got it together an- we’re gonna beat this thing (1.5) an- he turned to me an- said (2.5) misses [refers to Gwen] your daughter is going to die

D:     hum
G:     so so what he was say:ing is you what they do is then you’re in denial (2.0) on one hand you’re told to be positive an- then if you do say anything positive then you’re in denial (1.5) an- my god am i running off at the mouth

Theme 6

1. M = Mia     G = Gwen     P = Paul

M:  but ahm (1.0) ya cancer changes your life an- an- how it changes your life
I- I
G:  right↑
M:  is uh what you chose and what’ important to you (1.0) in the ways that you change your life and whether it’s in relationship::ips or your die::t [or all that (inaudible)]
G:  [ya exactly exactly]

...........................
P:     you know (.5) things change as a result of having cancer and I think it has for all of us each of us
G:     oh without ques[tion (1.0) absolutely]
P:     [we all wanna ] slow down we wanna
G: oh I =
P: = smell the flowers
G: absolutely that's [what I'm saying]
P: [a lot of us] (inaudible) the hurry sickness
H: ya uhm hum
P: in those kinds of [ways it's]
H: [ya ya]
P: a wake up call you know like I matter and I'm gonna take time for me:: n- this kind of stuff

P: it causes you to face your mortality (1.0) p-probably a lot[sooner]
G: [oh] (1.0) absolutely
P: and because of that (1.0) you say hey you know what do I really want here
G: right

2. you get to the point where you (1.0) care enough about yourself to say...there are things I need to do right now (1.0) for myself

3. Susan challenges this notion of fighting one's illness because “to me that kind of fight (1.5) that a fight is a s-stressful (1.0) situation”, to which Hendrika responds “uh a- in the beginning it was, it's a blessing now (1.0) because I feel myself growing and developing (1.0) and getting to the point where eventually I want to g- (1.0) to be”...”so I don’t think it’s a fight now (1.0) but I think at the beginning it was before I made up my mind that I could do this...and until I realised that (2.5) uh uh saw very clearly what I needed to do”

Theme 7

1. “I say look buddy (1.0) I die (1.0) you die”). Gwen responds by saying “I can’t believe that I- (1.0) that’s what I do (.5) do you know what I call ca:ll itt ... I call it reprogramming my brain”.

2. P = Paul H = Hendrika G = Gwen
   P: ya (1.0) in my case (1.5) I focus on nutrition cuz I really believe it’s part of the key (2.5) part
   H: that was the first thing I did (2.5) I started on the macrobiotic diet and then I have now greatly relaxed since then but uhm (1.5) pretty well I have changed my lifestyle totally and I believe too that’s that’s what =
   G: I have too
   H: = what uh:: helped me
   G: uhm hum
   H: one of the things
   G: cuz they don’t know what the trigger is
   H: well the immune system if you build up your immune system=
   G: =that’s right=
   H: it’s very simple really
G: that they have proof of
H: ya and they have proof (1.0) if you can [build up your]=
G: [that’s right]
H: the:n (1.5) you can fight (1.0) fight the cancer cells
G: and prove that=
H: =it’s that simple=
G: =prove that stress lowers the immune system
H: ya stress [a:::nd]=
G: [that’s right]
H: =diet and like the [whole lifestyle]=
G: [that’s right] (1.5) exactly

3. well I don’t think cancer really is a physical illness (1.0) I mean it has physical symptoms (2.0) but it goes much deeper that that (1.0) or any other chronic illness really...we know that the mind-body interaction (1.0) what we tell ourselves is happening (1.0) if we tell ourselves we are bad and we are doing something bad (1.0) then we feel that there is something wrong (1.5) and that will affect our immune system if we keep worrying about these things

4. I had to first of all I had to go back to the things that I had been chewing on (1.0) like my childhood my my relationship with my mother (1.5) when she died I had to do these I had to go this and work this out (1.5) on a spiritual level (1.5) I had to forgive (1.5) and I had to to relearn again how to feel about things in my life (1.5) towards people and so on

5. I think we all have our own way to have a breakthrough (2.0) and where we make a decision and uh (2.0) I I can’t live like this anymore I think whether its time or (1.0) guilt or (1.5) you know uh we just say (1.0) that’s it I’m gonna move on and change”...”for the better hopefully (1.5) but (inaudible) you know those tapes and those chains they’re heavy” [group laughs]

6. P = Paul H = Hendrika S = Susan

P: you’ve developed a good attitude to live
H: oh absolutely (1.) absolutely
P: good for you (1.0) we all should be so lucky eh↑
H: it’s not luck it’s it’s coming
P: ya
S: [it’s work]
H: [it’s coming] if you work on it
P: ya
Theme 8

1. M = Mia  P = Paul

M: cuz (> a lot of us <) you think about it (1.0) especially when you have an illness (1.0) at some point you think gee I wanna change my life now
P: ya
M: but (1.5) how do you go about doing that↑
P: ya well it takes a lot of guts man(hhh)
M: (laughs) (3.0) a lot of support↑
P: pardon
M: a lot of support
P: (ya and) support (1.0) courage
M: it's hard to change your life and that's what part of this (1.5) this group is about

2. M = Mia  P = Paul  A = Arnold  L = Lil

M: even though you foc- (1.0) you say okay I (1.0) I'm gonna breath I'm gonna meditate I'm gonna (1.0) it's really hard to [do (1.0) in that stressful situation (1.0) oh ya]
P: [it's like you gotta force it (1.5) and I] always wonder why (1.0) naturally (1.0) we get so stressed (1.0) like why do we have to force (1.0) relaxation it's something that (1.0) has been in my head for many years
A: well the time table is not right (2.0) you to do too much at once
M: 21st century eh↑
....
P: and we can learn to relax (.5) again
L: uhm hum
P: back to the (1.0) when we were born and were relaxed
L: uhm hhum

M: ya! (1.0) well that's a good point (1.0) that's what we're trying to do
P: ya
M: get back there
P: ya (2.0) (great)
L: isn't it unfortunate that (1.5) we had to get sick (2.0) to remind ourselves (1.5) that we need to relax
A: ya

3. It's very hard work...when I hear this spontaneous remission I always say you know (1.5) that is the hardest work to have the so called spontaneous remission (1.5) because who has a spontaneous remission! (1.5) without doing anything↑ (2.0) very few people (1.5) most people worked darn hard to get to that point". Paul and Susan acknowledge her comments (that's true; agreed)
Theme 9

1. we’re happy because we’re here (1.0) our life is better in many cases. Lil adds to this exchange by commenting that she has re-examined her priorities in life, and how she has influenced friends and family to not be “negative”. One’s experience with illness is “a good wake-up call for people around you (1.0) you know when they’re (1.0) complaining and whining about things (go) wait a minute

2. M = Mia  G = Gwen  D = Debbie  P = Paul

Mia: but but you’re right I mean most of us won’t say to ourselves we::Il you read (1.0) a lot of self help stuff that’ll say you know it’s the best thing that ever happened to me well (1.0) I [scrap that theory (laughs) no I’m not goi-

Gwen: [no that’s some (1.5) no I’m never gonna that way] (1.0) no (laughs) that’s right

Mia: but it doesn’t mean it doesn’t change your life

Gwen: exactly (1.5) that’s right exactly

Paul: it’s a club [that none of us wanted to join]

Debbie: [(laughs)]

Gwen: (laughs) that’s well said

Debbie: ya