A QUALITATIVE STUDY OF A PROFESSIONALLY-LED ONLINE SUPPORT GROUP FOR YOUNG WOMEN SURVIVORS WITH BREAST CANCER

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE

REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS

in

THE FACULTY OF GRADUATE STUDIES

GRADUATE COUNSELLING PSYCHOLOGY PROGRAM

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May 18, 2011

ABSTRACT

This project involved developing a coding approach for the investigation of online support groups (OSGs) in psycho-oncology. Offering support groups within the online environment is relatively new and research is beginning to make evident the processes in operation. In this work, the researchers adopted a discovery-oriented, exploratory approach. The coding strategy advanced here emphasizes group level processes in OSGs. The development of this approach occurred in two phases. In the first phase, the research team employed a Directed Content Analysis strategy. In the second phase, an Abductive inquiry was adopted to create a new approach to a human coding strategy for OSGs. The coding description is presented along with an instruction manual, which attunes the researcher to the online environment and highlights strategies for tracing the flow of group level activities. The coding system also helps identify continuity with research on Face-to-Face (F2F) psycho-oncology support groups.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

To my thesis supervisors, working on this project with you both has been a wonderfully rewarding experience. Thank you.

To Dr. MacDonald, your unwavering devotion to my development as a person in addition to professional is second to none. I am deeply grateful for the experience of knowing you.

To Dr. Stephen, your unyielding belief in me left me no choice but to pursue this project. Thank you for all you have taught me.

To my parents, Peter and Nancy, thank you for loving me. Because of your infinite support all things are possible.

To my daughter, Julianna, thank you for travelling this journey with me. You delight me and motivate me to strive for more than I ever gave thought to.

To my dear Steven, thank you for your encouragement and loving pursuit of the final product. You have created an unmistakable momentum in my life.

And to the women who know breast cancer, you are an inspiration.

CHAPTER 1: INTRODUCTION & LITERATURE REVIEW

The diagnosis of cancer carries with it tremendous impact on the life of an individual. A great number of changes in psychosocial and physical health can occur as a result of surgeries, chemotherapy, and radiation. Quality of life for individuals with cancer can be significantly affected by the experience of cancer. In addition, cancer screening and detection is more sophisticated and treatments are more powerful than ever before. In fact the number of long-term survivors is increasing and has raised to approximately two-thirds for all cancers diagnosed (Stein, Syrjala, & Andrykowski, 2008). Breast cancer is the most commonly diagnosed cancer in women (Canadian Cancer Society, 2011). Approximately, one-third of all breast cancer patients diagnosed are under the age of 45 (Mehnert & Koch, 2008). Increases in the number of young women being diagnosed with breast cancer, combined with decreases in mortality rates, mean that more young women are overcoming their disease and looking ahead to living longer lives (Bray, McCarron, & Parkin, 2004). Although this is certainly excellent news for these young women, for many, surviving breast cancer and its treatments can be a difficult process.

It is well-documented that in comparison with older women, the impact of breast cancer is much greater in younger women who tend to be leading active lives (Avis, Crawford, & Manuel, 2004; Bloom, Stewart, Johnston, & Banks, 1998; Harris, Remington, Trentham-Dietz, Allen, & Newcomb, 2002; Scheier et al., 2005; Shannon & Smith, 2003). Many experience psychological and physiological enduring and late effects after treatment has completed. Survivors are reporting that being disease-free does not mean being free of disease (Alfano & Rowland, 2006). In addition, cancer can be an

isolating experience, particularly when those around are living full lives. For many, this sense of isolation may be enhanced by geographical constraints and living in small towns which offer little in the way of services and support (Stephen, 2006).

The experience of cancer can cause a person to question many assumptions and beliefs about themselves, others, and the world around them. For some cancer survivors, these questions remain unanswered which can cause increased emotional distress for years. One way to resolve this problem is for a person to make sense of difficult experiences. Lepore (2001) suggests that evidence appears to support the idea that talking with supportive others can help a person to develop a positive self-concept, construct a coherent worldview, adopt new perspectives on their situations, learn new ways of coping and experience many other benefits. In contrast, talking about difficulties in an unsupportive or a critical environment can lead people to suppress thoughts, a process which may ultimately interfere with cognitive processing. The author identifies evidence which suggests that interventions which provide cancer survivors with information, coping skills, and the opportunity to share their experiences with supportive others may be beneficial in reducing their long-term distress. Support groups have long been favored as one approach available which can provide cancer survivors with these opportunities (Lepore, 2001).

Developments in technology provide opportunities for access to services previously unavailable. Cancer survivors are now able to access a variety of resources online, providing new opportunities for accessing the support they need. There is a potential impact through these new modalities for the provision of service to those who want it (Bettencourt, Schlegel, Talley, & Molix, 2007). However, research is beginning to

accumulate on interventions taking place in the online environment. The goal of this project was to create a coding approach to be used in the analysis of online breast cancer survivor support groups.

The following literature review will present relevant background information on quality of life issues for young women with breast cancer, research into support groups and the focus of this research project.

Quality of Life in Young Women with Breast Cancer

Impact of Breast Cancer on the Quality of Life of Young Women

Many young women, once they have left the cancer system, discover that they are left with a whirlwind of issues, impacting their lives for many years if not the rest of their lives. They report that they cannot go back to life as they knew it before breast cancer (Klemm, 2008). A number of effects have been documented. For example, several studies have reported greater risk of anxiety and depression in younger women with breast cancer than their older associates (Alfano & Rowland, 2006; Cordova, Andrykowski, Kenady, McGrath, Sloan, & Redd, 1995; Stanton, Ganz, Kwan, Meyerowitz, Bower, Krupnick, Rowland, Leedham, & Belin, 2005; Stanton, Ganz, Rowland, Meyerowitz, Krupnick, & Sears, 2005; Wong-Kim & Bloom, 2008). This may be partially attributable to a number of enduring physical changes and side effects. In a study by Ganz, Kwan, Stanton, Krupnick, Rowland, Meyerowitz, Bower, and Belin (2004), younger women with breast cancer were compared with their older counterparts on a number of dimensions including depression, negative affect, body image concerns, and sexual dysfunction and were found to have higher levels of all of these as well as lower levels of positive affect and energy. Frequently, chemotherapy treatment results in significant

altered sexual and reproductive functioning in young women and it has been reported that greater levels of distress occur as a result of interference with child-bearing plans (Braun, Hasson-Ohayon, Perry, Kaufman & Uziely, 2005; Danhauer, Rutherford, Hurt, Gentry, Lovato, McQuellon, 2008; Thewes, Meiser, Rickard, & Friedlander, 2003). Younger women with dependent children and younger partners have higher rates of family member distress than older women and they report needing resources to help them cope more effectively in this area (Shields & Rousseau, 2004; Siegel, Gluhoski, & Gorey, 1999). In addition, young women tend to experience financial changes, resulting from their inability to continue working through their breast cancer experience (Gray, James, Manthorne, & Fitch, 2004). It is, therefore, not surprising that stress syndromes including Post Traumatic Stress Disorder have also been reported at higher rates in this population (Andrykowski & Cordova, 1998; Cordova, Andrykowski, Kenady, McGrath, Sloan, & Redd, 1995; Von Ah, Kang, & Carpenter, 2008). As a result, these young women may benefit from increased access to supportive interventions. Further, given that young women with breast cancer face these numerous issues associated with their age and their diagnosis, they subsequently have a greater need for information. In study by Avis, Crawford, and Manuel (2004), researchers reported that unmet informational support needs were linked with increased levels of distress in breast cancer survivors. They suggested that these residual and frequently enduring psychological symptoms are often overlooked, greatly impacting a young woman's quality of life in the years following her breast cancer experience. The researchers further recommended that interventions aimed at this population should also consider including the opportunity for participants to share information (Stephen, 2006; van Minnen & Foa, 2006).

Psychosocial Face-to-Face Interventions for Women with Breast Cancer

For more than 20 years, investigators have been documenting benefits of Face-to-Face (F2F) oncology support groups. The outcomes of F2F support groups for breast cancer patients have been the focus of many excellent quality Randomized Control Trials (Goodwin, Leszcz, Koopmans, Vincent, & Guther, 2001; Kissane, Love, Hatton, Bloch, Smith, Clarke, Miach, Ikin, Ranieri, & Snyderet, 2004; Spiegel, Bloom, Kraemer, & Gottheil, 1989; Stephen, 2006) and meta-analyses (Lane & Viney, 2005). These studies have illustrated both statistically and clinically significant benefit of support groups on breast cancer patients' quality of life. A number of improvements have been reported including total reduction of mood disturbance, depression, anxiety, anger, confusion, and the perception of pain (Goodwin et al.). In addition, similar results have been reported for F2F support groups for women with an early stage breast cancer diagnosis (Kissane et al., 2004). Some of these improvements may be attributable to the fact that young women have needs and issues which are being addressed in these group interventions. For example, researchers studied 34 women who attended six psycho-educational support group sessions. The participants reported benefits including: acquisition of new information, improved coping skills as well as changes in self-concept, emotional expression, and family and other relationships (Avery & Nyhof-Young, 2003).

Not all studies reported positive results however. In a recent study, authors reported no changes to quality of life in 24 young women who participated in a psychosocial group intervention (Danhauer et al., 2008). In addition, there may be reason to consider the methods being used to approach this research. In an excellent 2006 review of the instrumentation used in group studies for women with breast cancer, Heiney,

McWayne, Ford, and Carter (2006) identified 19 different studies reporting equivocal results on the quality of life dimension. These authors point out that the inconsistent effect sizes reported in the literature may be due to several considerations, including: (a) the research instruments used in the evaluation of breast cancer group interventions have numerous psychometric weaknesses which have been consistently noted in the literature over the past 10 years, (b) theoretical fit for some of the most frequently used tests is questionable, and (c) no attempt has been made to address these concerns or change the instrumentation (Heiney, McWayne, Ford, & Carter). These conflicting results are suggestive of the need for exploratory research in the F2F group interventions. Moreover, as research into online support groups has not been widely reported, an exploratory approach may be beneficial.

Support Groups

Group Process in Cancer Support Groups

Clearly then, there is substantial evidence for the benefits of F2F Cancer Support Groups. Spiegel & Diamond (2001) have identified a number of therapeutic themes associated with F2F Cancer Support Groups. They report that F2F group members experience the opportunity to receive social support, express emotions, discuss and face a variety of aspects associated with death, discuss life changes as a result of their disease experience, share and learn skills associated with improved relationships with family, learn skills associated with improved communication with medical staff, share and learn new information about their situation, as well as learn and share skills for coping with symptoms and side effects. At the time of this research, it was unknown if these would be transferable to the online environment. It was expected, however, that online support

group participants would likely experience similar opportunities to their F2F counterparts.

Online Support Groups and Breast Cancer

Across many disciplines, there is continued interest in the transfer of F2F activities to the online environment. For young women with breast cancer, there is value in knowing whether participating in a group would result in the psychosocial benefits reported in the F2F literature. There are a number of reasons to pursue evidence in this area. One prevalent value within the health related professions is to meet the needs of persons who may have limited access to psychosocial resources. In the case of young women survivors with breast cancer, access issues can result from isolation and disability due to treatment side effects, time pressures associated with caring for young families and/or work responsibilities. As health care costs rise, it is incumbent upon researchers to develop interventions that are cost-effective (Lieberman & Goldstein, 2005). Individual preference is also emerging as a significant factor as the provision of psycho-technologies evolves. In fact, there are a number of identified groups who have expressed a preference for computer-mediated opportunities including online counselling and it is reasonable to expect that this interest will continue particularly as computer use expands (King, Bambling, Lloyd, Gomurra, Smith, Reid, & Wegner, 2006; Lieberman Golant, Giese-Davis, Winzelberg, Benjamin, Humphreys, Kronenwetter, Russo, Spiegel, 2003).

Research on the outcomes and processes associated with OSGs is beginning to accumulate. That which does exist has primarily been performed with asynchronous OSGs. Asynchronous groups are discussion boards where users post comments but are not required to be present all at the same time. In other words, the discussion is not

occurring in real time (Klemm, 2008; Lieberman & Goldstein, 2005; Shaw, Yeob Han, Hawkins, McTavish, & Gustafson, 2008). This is in contrast to synchronous OSGs where communication is direct and immediate. Given the momentum with which all online activities have been adopted in the current culture, good quality research continues to be required in order to provide evidenced-based recommendations for the population.

Emerging Research on OSGs

Within the present state of literature, evidence is beginning to support the beneficial effects which participants may gain from participating in online counseling. Questions have emerged about whether or not a supportive alliance between participants can be experienced in the online environment. Work supporting the link between treatment outcome and alliance-building in the online environment has been recently demonstrated in a number of studies (King, Bambling, Lloyd et al., 2006; King, Bambling, Reid, et al., 2006; Knaevelsrud & Maercker, 2007; Knaevelsrud & Maercker, 2006; Leibert, Archer, Munson, & York, 2006; Reynolds, Stiles, & Grohol, 2006). Positive benefits from online counselling have been illustrated in studies involving several different populations including eating disorders, Post Traumatic Stress Disorder, alcoholism, anxiety, infertility, HIV and others (Barak & Bloch, 2006; King, Bambling, Reid,& Thomas, 2006; Knaevelsrud & Maercker, 2007; Wagner, Knaevelsrud, & Maercker, 2006).

In recent paper by Coulson, Buchanan, and Aubeeluck (2007), researchers described their study of participants' experiences in accessing dental anxiety online support groups. Key results suggested that these help-seekers benefited from the processes of sharing their fears and receiving support from similar others. Participants

reported that the sense of emotional safety associated with the anonymous environment provided them with relief from shame they had previously experienced as a result of their condition. Furthermore, the participants reported a stronger sense of empowerment which translated into an improved capacity to participate in the treatment they were seeking (Coulson, Buchanan, & Aubeeluck, 2007). Similar processes for women with breast cancer remain largely unexplored.

In another study, researchers reported the results of testing a proposed model of how participation in internet support groups benefits oncology patients. Both asynchronous and synchronous OSGs were tested. Results showed support for their model with respect to asynchronous OSGs but not synchronous ones (Beaudoin & Tao, 2007). There are several possible reasons for this, including inherent differences between the two modalities; however, the authors suggest the possibility that the investigation of synchronous OSGs is so new that as a result of this novelty, study in this area may best be pursued using an exploratory approach.

Coding Schemes for Analysis of OSGs for Health Concerns

As noted above, some outcome studies exist on OSGs for health-related concerns. The majority of these have employed adapted methods designed for F2F research. Questions of methodology within OSGs remain largely uninvestigated. Moreover, of the OSG outcome studies, most reported on groups held in the asynchronous format. Accordingly, there is little available in the way of coding schemes derived from OSG data itself to help researchers embarking on the study of synchronous online support groups.

Two studies have employed an adapted version of Cutrona and Suhr's social support (1992) typology (Coulson, Buchanan & Aubeeluck, 2007; Coursaris & Liu, 2009) for use with F2F groups. Coulson, et al., explored the provision of social support in an online support group for sufferers of Huntington's Disease using Content Analysis. The authors adapted Cutrona and Suhr's social support behavior coding scheme (for F2F interactions) in their analysis of OSGs. This provided the means by which to explore how patients with Huntington's Disease provide and receive support in an online environment. Results of this study indicate that informational and emotional support were the most frequent types of social support provided in the asynchronous social support group. These results are useful and the authors suggest that future research should address if online asynchronous messages fit the established categories the same way that F2F data does. In other words, there is no way to know if online messages are interpreted in the same way that F2F messages are interpreted, and given that the adopted methodology was developed within the F2F environment, further developmental work is suggested. Research is needed to determine if previous F2F methods of study fit the online environment and allow for both similar and novel processes to be revealed (Coulson et al.).

In their study, Coursaris and Liu (2009) applied Cutrona and Suhr's (1992) social support typology for classification of asynchronous posts in online HIV/AIDS self-help groups. Major results illustrated that information and emotional support offered by participants were the predominant processes taking place. Although the generalizability of the adopted analytic strategy was supported, the authors recommended that context related modifications should be considered in future research. This further suggests the

need for an exploratory approach, particularly that which can describe the context of OSG environment.

Other recent studies have employed Linguistic Inquiry and Word Count Methods in the detection of emotional expression in F2F support groups and OSGs. These can be considered content analytic extrapolations from F2F methods where the researchers are investigating very particular kinds of processes (Klemm, 2008; Lieberman & Goldstein, 2005; Liess, Simon, Yutsis, Owen, Altree Piemme, Golant, Giese-Davis, 2008).

As has been reviewed here, there are few studies available on OSGs for health-related concerns. Those which exist have employed a methodology adapted from that which has been used in the previous study of F2F support groups. There is little evidence to date identifying a scheme derived from online data itself. The purpose of this work was to create a preliminary coding scheme and accompanying instruction manual for use in analyses of OSGs for young women survivors with breast cancer.

Online Support Groups and Breast Cancer: Research Focus

As described, young women with breast cancer have high needs for information and support. Many experience their breast cancer journey in isolation due to geographical location and other access limitations. Although there are inconsistent results illustrating improvements to quality of life for patients participating in F2F support groups, this intervention modality has endured and appears to be an attractive option from both a professional and patient standpoint. Some research performed on OSGs has involved asynchronous communication or message boards and little work has been reported on synchronous format or real time chat. Less is known about the processes which take place in these kinds of support groups. This study involves support groups taking place in an

online synchronous environment. An exploratory approach was adopted. Exploratory research lends itself to the processes of refining theories and hypotheses and of clarifying requirements for valid instrumentation. An exploratory strategy can make use of conceptual contributions from existing literature while simultaneously making adaptations required and improving methodological standards. The main objective of the present study is to develop a coding scheme for the analysis of the online support group sessions of young women survivors of breast cancer participating in an online support group (OSG).

Focus One. To develop a coding approach which will enable the researcher to describe and to understand the processes (e.g., educational component, emotional processing, and social support) which are taking place in professionally-led OSGs. This approach will be transferable to and adaptable for the analysis of other synchronous oncology OSGs.

Focus Two. To illustrate that the developed coding approach:

- Allows the researcher to identify processes in the OSG which have been pre-identified in F2F groups.
- Allows the researcher to identify unique processes.

CHAPTER 2: METHOD

Research Design

Abduction

This study was grounded in a qualitative research paradigm. Qualitative research is traditionally based upon the philosophy that in order to understand a phenomenon, it must be viewed within a context. This means an immersion in the phenomenon. Flexibility and openness is key in understanding the experience being researched. Furthermore, openness is essential in order to explore and to illuminate phenomena previously unarticulated and the researcher is urged to bracket assumptions and allow the data to drive inferences (Guba & Lincoln, 2005). As has been previously described, F2F oncology support groups have been the subject of much study. Despite the fact that research on OSGs is relatively recent, in this work, the researchers felt it was reasonable to expect that parallel discussions would take place. This, in addition to the fact that some unexpected processes may occur in the OSG, suggested the use of abduction as an appropriate way to approach the data. Abduction is an emergent approach which involves the process of generating hypothesis through looking at a likeness. Abduction operates in a cyclical bottom-up-top-down fashion, where the data is associated with existing theory or ideas. In other words, results from previous studies function as heuristic tools in the process of interpreting data (Richardson & Kramer, 2006). It has further been described as a method of "inference to the best explanation" (Haig, 2009, p. 219) which lends itself to the concept of pragmatism. Furthermore, the arrived-at explanation is judged in soundness by its plausibility (Haig, 2008). This project employed an abductive strategy which facilitated

the development of a preliminary coding approach emerging from immersion in session transcripts and drawing upon categories grounded in existing F2F research.

C*ontent Analysis*

Content analysis has been used in the analysis of texts for over fifty years (Berelson, 1952) and has been described as "a research technique for making replicable and valid inferences from texts to the contexts of their use" (Kippendorff, 2004, p.18). The method of content analysis can take a variety of forms. In one form, data is reduced to data units based upon coding rules. Multiple coders participate in this process to see if the data can be reliably fit into the same codes (Guba & Lincoln, 2005). The rules of coding can be done in advance of the research or it can be driven by the data itself as part of the analysis. In the application of content analysis, researchers can formulate tentative a priori categories; test the rules on a portion of the data to develop a final coding frame. There are two types of categories which can be used to analyze the data: the manifest and latent (Berg, 1997). Manifest CA is the coding of the surface content (the observable) of the text whereas latent CA is concerned with the meaning behind the text. It has been argued that considering the manifest content alone may distort the meaning of the text emphasizing the requirement to ascertain the latent meaning behind the words (Goldenberg, 1992; Stephen, 2003). Analysis of both layers of textual meaning was included in this work. The main goal of this study then was to develop a content analysis-based coding scheme which permitted the identification of similarities with the F2F experience but which also allowed for the illumination of new or different processes which occurred and were previously unidentified. Given the exploratory nature of this work and accompanying data analysis, content analysis was determined to be an excellent

fit. Moreover, one of the objectives of this research was to determine if key processes, which have been identified in F2F groups, also occur in the online support group modality. Subsequently, adopting an abductive strategy allowed for the identification of unique differences (in Phase II), if they existed, to emerge.

Abductive Analysis Procedures

This study involved an analysis of previously collected data and the following steps were employed:

1. Transcripts of twenty sessions (two separate groups attending ten online meetings) were obtained through the British Columbia Cancer Agency.
2. The transcripts were read over in their entirety in order to acquire a feeling for the flow and quality of the exchanges.
3. A coding scheme was developed in two phases:

   Phase I

   i. A preliminary category list inclusive of individual and group level content and process categories was drafted based on the F2F and Medically-related Support Group literature which was subsequently reviewed by the Committee.
   ii. New categories were added while working through the data.
   iii. Categories were described, combined and adapted to the data.
   iv. The meaning units emerged from the category list and were identified and described.
   v. Categories emerging from the ongoing conceptualization of OSG processes were grounded in the preliminary category list.

vi. Steps two through five were performed iteratively.

Phase II

A shift occurred when it became apparent that there was a lack of fit between the preliminary codes and patterns of interactions in the OSGs and this led to the following steps:

i. The research team identified the most effective level of analysis for the coding scheme, from the emerging themes and their patterns, in sessions.

ii. Core themes were formulated to illuminate the essence or main point of each meaning unit according to latent and manifest content. Latent and manifest content were accessed by abduction. In other words, latent features were illuminated by the data in a holistic manner throughout the analysis process itself, enabling the researcher to "read between the lines." On the other hand, the manifest content was accessed by describing illuminated processes which were solidly based in transcripts.

iii. The coding scheme was finalized.

Credibility Checks

Throughout the analysis, a series of credibility checks were employed. The following procedures were utilized:

1. The primary investigator created a preliminary list of categories based upon categories which have been reported in the F2F and asynchronous literature.
2. The category list was circulated amongst two judges for review.
3. The primary investigator identified the meaning units from the data and placed them into the preliminary categories.

4. The primary investigator formulated tentative descriptions based upon the data.
5. Two independent judges reviewed the meaning units, edited their description and offered agreement on the placement of units into categories.
6. Expert opinions were elicited from two psycho-oncologists (trained in online support group facilitation) to offer observations and agreement. The concordance between the primary investigator, independent judges and the experts was reported descriptively and reflected in the draft coding system.

Participants

The sample used in the present study consisted of 12 young women who were located throughout British Columbia. The women had all received treatment for their breast cancer at the British Columbia Cancer Agency and were recruited for participation in a larger study (see Appendix E for more detailed description of participant criteria for that study). The 12 participants were randomized as part of the larger study into two OSGs, with 6 participants each. The selection of a dataset of 12 participants fulfilled the intention of providing a representative sample.

OSG Description

The intervention involved group meetings consisting of Internet chat which included a self-study coping skills program. Group members participated in a 1½ hour online group chat with a counselor, once a week for 10 weeks. They also received a coping skills workbook and an instructional CD to use at home. Each week they were assigned a chapter of the workbook to read which will take between 20 minutes and 1 hour. Participation time required for this group was approximately 2 ½ hours per week

for 10 weeks. The platform for this work is provided by an established non-profit oncology organization based in the United States (Stephen, 2006).

CHAPTER 3: RESULTS

As has been described above, the present study was exploratory in nature owing to the fact that little research exists on the processes particular to online support groups. The purpose of this project was to initiate the development of a coding approach and a training manual which could be used and further developed in OSG research. An exploratory, abductive approach provided a good fit with the purposes of this study and its relationship to the larger research program with which it was associated. Accordingly, two main foci were identified for the study. The first was the development of a tool which would enable the researcher to describe and to understand the processes associated with professionally-led OSGs. This work resulted in a preliminary coding approach and an accompanying training manual providing the process by which future researchers can apply the coding system. It was expected that the coding approach and training manual (the coding system) developed here would be further adapted and refined throughout its use in future analyses of other OSGs. Thus the present work has accomplished these goals as well as providing opportunities for further development. The second focus was to determine if the developed coding system facilitated the identification of processes in OSG data which have previously been described in the F2F literature. Furthermore, would that same coding system allow for the illumination of processes unique to the OSG modality? These anticipated outcomes have also been achieved. The outcomes will be described briefly in this chapter. A full description of the coding approach including training manual is presented in Appendix A.

Focus One

The Coding Approach

This project developed a tool for researchers to describe and to understand the processes taking place in professionally-led online psycho-oncology support groups. For the reader's ease, the codes are listed here. The code list itself is made up of seven distinct codes: (a) Group Cohesion, (b) Sharing Personal Cancer Stories and Experiences, (c) Offers of Informational Support, (d) Personal Disclosure, (e) Shared Processing of Emotional Impacts, (f) Sharing Integration of Significant Events, and (g) Unidentified Processes. The codes presented in Appendix A provide a detailed description of the seven codes. This description is the basis from which researchers can undertake the process of identifying, describing, and understanding the processes taking place in OSGs.

The Training Manual

Once the coding approach was developed, it was evident that a description of how to apply it would be helpful to researchers. Notably, the instructions for use of the coding approach reflect similar steps as those which the principle investigator undertook in the development of the scheme. The complete manual is available in Appendix A. Thus, the training manual articulates for researchers the steps which can be followed in the analysis of an OSG session. It outlines the detail necessary to apply the approach which corresponds to the steps taken to achieve this first stage of development. This is important as it provides the information necessary to achieve further refinement and development. In addition, instructions for how to choose codes, distinguish "best fit" codes and discriminating criteria for choices are included to provide guidance in the application of the codes.

Adaptability of the Coding Approach in Future Research

A second aspect of Focus One was to develop a coding approach which would be useful and adaptable for the analysis of other psycho-oncology OSGs (e.g., peer-led OSGs, OSGs for care-givers, and OSGs for patients with other cancers). This goal has also been achieved. The coding approach which emerged from this work pertain to the general processes which took place in the group and which researchers can reasonably expect to take place in medically-related support groups. The level of description then is specific to the processes and not to the detailed content in the data. Consequently, the codes within the approach are useful and adaptable for use in the analysis of any oncology-related support group. In addition, included in the approach is a code entitled Unidentified Processes which did not occur in the groups included in this analysis. Based upon the preliminary categories generated from the F2F and asynchronous literature, combined with the credibility checks (steps 5, 7, and 8), it is anticipated that this code is likely to be required in subsequent analyses of OSGs. Two experts were solicited for their opinions about the codes. Feedback received addressed some possible unidentified processes arising in future OSG data. For example, one expert noticed that there was no provision for the identification of destructive group processes. In this particular OSG, data destructive processes were not apparent. Thus, flexibly allowing for additional codes to emerge is a key assumption of the abductive process which is upheld throughout the development of this coding approach.

Focus Two

Utility of the Coding Approach

The second main focus of this work was to determine if the developed coding

approach allows the researcher to identify processes in the OSG that have been preidentified in F2F groups. Use of the coding approach did, in fact, result in the identification of processes which have been described in the F2F Breast Cancer Support Group literature. The preliminary list can be found in Appendix F. The list is broad and inclusive although not exhaustive. Beginning with an exhaustive preliminary list was not necessary for this study because of the nature of the abductive approach. Abduction enabled the researcher to approach the data with an inclusive and flexible framework, allowing for any differences to emerge which could then be evaluated for their novelty and distinctiveness.

Identification of Processes Unique to the Online Modality

With the second aspect of Focus Two, it was expected that the developed coding approach could allow the researcher to identify unique processes or distinct features associated with OSG. This goal has been attained. A major result of this work was the identification of meaning units and the appropriate level of analysis as they emerged from the data. As the coding approach emerged, it became apparent that a choice regarding the level of analysis was required and this led to a significant shift. This shift required the research team to decide to parcel the sessions into *blocks* of text based upon group-level interaction rather than individual posts. These blocks of text are made up of a minimum of five posts by several group members and the facilitator. In this way of coding, some individual's posts are left uncoded when the post does not evolve into a discussion by the larger group. This shift in the analysis was an exciting development. At first blush, it may appear that some important information could be left out in using this method. In fact, this method provides the researcher with a framework from which to clearly identify and

articulate when members' posts evolve into group level interaction and when they do not. In addition, adopting this block level of analysis enables the researcher to identify major shifts in group level interactions. All things considered, then, the process of group interactions in the online environment appears to occur in quite distinct blocks. Moreover, in adopting this blocking process, it is also possible to describe the flow of each session in a flow chart (Appendix A). The flow chart reflects the particular flow of blocks which occurred in one session of this dataset. The discovery of this important step has significant implications for future research (see Discussion).

The results of this project illustrate the completion of the established goals. The next chapter provides a detailed discussion of how the results: (a) can be used by researchers and clinicians, (b) link to preexisting F2F literature, and (c) are distinctive and novel. In addition, limitations and training recommendations are presented.

CHAPTER 4: DISCUSSION

This study was part of a larger program of research that endeavoured to unite young women survivors of breast cancer across Canada and provide them with ease of access to supportive interventions online. As medical treatment becomes more successful, the need for support groups is growing and funding is being provided in order to make these groups possible. Waitlists are longer than ever before as more and more patients are getting word of OSG benefits. Increasing access across many patient demographic features is a critical value within the medical field. As such, researchers, funding agencies, policy makers, and patients are in urgent need of study into this modality.

As has been extensively described throughout this project, the current state of investigation into OSGs is insufficient. Within the F2F oncology support group literature, however, evidence of benefit provides substantial reason to explore the provision of this service through online modalities. The success of F2F and OSGs combined with a growing online marketplace supply the driving impetus for the research program behind this study. Moreover, development of preferred methods of analysis is needed to advance research in this domain of study. The primary reason for this work was to generate a preliminary coding system which can continue to be developed and used to identify core facets of OSGs, whether distinctive or shared with F2F groups. Given the exploratory nature of this study, the results of the project enhance this rapidly evolving field of research.

Contributions to Knowledge and Practice

Given the current shortage of literature available regarding computer-mediated communication and, in particular, support groups online, this study contributes to a

growing knowledge base by shifting to a methodological focus. Existing literature addresses content analyses of F2F Support Groups and possible connections with OSGs. This study, in particular, presents the first research method arising from close readings of transcripts from OSGs themselves.

Three features of the coding system highlight the accomplishments of this project. The first feature is that it can be used by researchers to identify processes in support groups that are shared by F2F and online modalities. A second way the coding system can be used is that it enables researchers to capture OSG activities in a holistic way, especially in descriptive manners which are specific to the OSG research and practice environments. Thirdly, the requirement to adopt a holistic lens and the observational tools enabled by the coding approach allows researchers to illuminate the shape of group level processes taking place in OSGs. Consequently, this study presents a coding system that helps researchers observe OSG process in ways that makes it possible to trace shifts in conversations to recognize healing moments. Moreover, the results of this work provide reason to believe that additional processes, as they arise, can be identified through the use and the refinement of the coding system developed here.

Feature One of the Coding System

The first feature of the study was to discover if similar processes that have been documented in the F2F literature are also apparent in the online modality. In fact, the coding list that emerged during the analysis of the data overlaps, in substantial ways, the F2F literature. Furthermore, the list of codes presented in the scheme itself illuminated this overlap.

Code 1. For instance, the first cluster of themes which emerged from the online

data reflects the *group cohesion* category described by (Yalom & Leszcz, 2005). Those authors describe group cohesion as akin to the therapeutic relationship between client and therapist in individual therapy. In this online data, group cohesion was also evident and appeared to provide group members with the greater sense of connection and emotional safety with one another.

Code 2. The second code which emerged from the data was labelled *sharing personal cancer stories and experiences.* In their study, Overberg, Alpay, Verhoef, and Schonk (2007) reported that participants who were breast cancer survivors were primarily interested in fellow participants' illness stories. In his study investigating the benefits of writing about a stressful event, Lepore, (1997), reported that expressive writing reduced psychological distress. The F2F evidence appears to suggest that this is a key therapeutic factor as well as a participant preference in breast cancer support groups. The emergence of personal cancer stories and experiences within the current dataset provides evidence that OSGs may offer similar (to F2F groups) opportunities for group members to participate in this process.

Code 3. The third code evident in the data was given the title *offering of informational support.* A significant amount of time in these OSGs was spent in sharing resources and practical tips. Numerous F2F studies have reported the benefits of receiving information support (Stang & Mittelmark, 2009). Yalom and Leszcz (2005) suggested that the interpersonal learning present in group therapy is an essential therapeutic factor affecting outcomes for participants. The emergence of this code in this online data affirms the potential of OSGs to provide this therapeutic benefit (Yalom & Leszcz).

Code 4. Another therapeutic factor that has been described in the F2F group literature are processes connected to member *personal disclosure*. Self-disclosure in group therapy has been defined as "participant communication of personal material to other participants" (Bloch & Crouch, 1985, p. 77). In this study, the self-disclosure code was attributed to group discussions which revolved around the sharing of deeply personal information not related to the cancer experience. The fact that group members responded to a disclosure such that the discussion evolved into a block reflects the importance of the event. This phenomenon has been described in the F2F group literature. F2F evidence suggests that personal material disclosed has a significantly positive impact on the level of intimacy in the group (Kociunas & Dragan, 2008). This appeared to be the case in the OSG data as well. In other words, self-disclosure about important and very personal material which was separate from cancer appeared to have a distinct and meaningful impact on the intimacy level of the group as a whole.

Code 5. The fifth code, *shared processing of emotional impacts* has also been described as important in the F2F literature. Processing emotional impacts has been defined by Spiegel (1993) as "…the best way to cope with illness is to do the hard emotional work of recognizing and feeling what [accompanying] losses might mean" (p. 1199). Research on F2F emotional processing provides evidence for improved quality of life. A number of important results have been reported. One relevant outcome was that women who engaged in coping strategies involving active processing and expressing of emotions showed fewer medical appointments for cancer associated concerns, improved physical health, lower distress, and a better quality of life (Stanton et al., 2000). Consequently, this kind of group work appears to hold great value to survivors with

breast cancer. The data used in this study suggests that the online environment can also provide opportunities for emotional processing.

Code 6. The sixth code entitled *sharing integration of significant events* has also been described in the literature in the domains of post traumatic growth and existential therapy. Post traumatic growth has been referred to as positive emotional change as a result of the struggle with a highly challenging life event (Vishnevsky, Cann, Calhoun, Tedeschi, & Demakis, 2010). Moreover, F2F evidence appears to suggest that active assimilation of experiences into one's life narrative is an essential step in successfully overcoming difficult experiences. In addition, researchers report that benefit finding and acceptance correlate to improved psychological outcomes for women with breast cancer (Carver & Antoni, 2004; Manne, Ostroff, Winkel, Goldstein, Fox, & Grana, 2004; Sears, Stanton, & Danoff-Burg, 2003). Our data appears to suggest that this was occurring in the moment as group members shared in the integration of their experiences.

Code 7. The final code was entitled *unidentified processes*. This code was established to provide the opportunity for discussion blocks arising in future analyses that do not fit the coding list developed thus far to be placed in a separate category. A number of potential additional codes have been described anecdotally. Clinicians have noted that in some groups an event may occur which seems to alter the way the group takes shape. An example of this kind of event is a member's disclosure of a cancer reoccurrence (K. Flood, personal communication, March, 2011). Although our data did not contain material which fit this code, it is reasonable, based upon anecdotal reports, to expect that this will appear in future analyses.

In sum, the coding scheme which emerged from our OSGs are clearly linked to

previously reported processes in the F2F literature. As a result, this project lends further support for the provision of OSGs for women survivors.

Feature Two of the Coding System

The second feature of this coding approach is the way in which it facilitates holistic description of the data. In adopting the assumptions of abduction, not only were expected processes identified, but distinctives also became apparent. For example, a key distinctive was the identification of a block which captures an emerging focus of discussion in the group (see Appendix A for the procedure for identifying blocks). Indeed, the novel unit of analysis determined in this project was the block of text that helps to identify salient ways the group chose to pursue clinical themes together. This unit of analysis has important implications for group facilitators as well as future clinical research. Firstly, these blocks capture group level activities. Secondly, the blocks are relatively easily identified by a trained coder. Once identified, the blocks in each session can illustrate the pattern of chosen activities by the group. Subsequently, this coding system can readily be combined with clinical and research questions; for example, group activities might be examined to determine how they contribute to individual quality of life outcomes. Consequently, the discovery that there is a level of analysis which lends itself to effective clinical practice and efficient research is the pivotal contribution of this study.

Feature Three of the Coding System

The very simplicity of the coding system confers incremental benefits arising from clinically informed research strategies and immersion in OSG transcript data. The identification of blocks in OSG groups highlights and raises theoretical questions about

group process in the online environment. For example, the diagramming capabilities of this coding system (Appendix A) can provide valuable tools that can be used to help clinicians as well as researchers attune to salient OSG activities. Tracing the flow of discussion provides a representation of the shape of each session which facilitates the identification of functional processes. Moreover, speed of coding is possible with trained coders, facilitating rapid comparisons between groups of various constellations and enabling ease of communication about the group activities. As a consequence, it appears that adopting this method of analysis could provide opportunities to identify helpful or disruptive patterns of session flow. Finally, the development of this coding scheme has implications for future research that combines group level with individual level outcomes for the advancing knowledge about OSGs. As this coding system is further developed with additional OSG data, additional nuances and distinctives may well emerge, helping guide integrative literature reviews and theory development.

The coding system can offer benefits directly to clinical services in addition to its utility in research. This system may be used to facilitate the planning of groups. For example, tracing the process a particular group is undergoing may be performed between sessions. This would allow the professional facilitator to make adjustments such as fixing or changing the flow of the group to achieve best outcomes. In addition, there are training implications for facilitators. For example, Owen, Bantum, and Golant (2009) studied the benefits and the challenges experienced by professional facilitators of online support groups for cancer survivors. Facilitators reported experiencing uncertainty about their roles in this novel modality. In particular, they expressed the need for specific techniques to deepen the discussions. Tracing sessions could provide needed feedback

about how a group is proceeding, enabling adjustments which could increase one's sense of efficacy as the facilitator. In a recent study, researchers' investigation into the online facilitation experiences of psycho-oncologists yielded results suggesting that when facilitators could perceive therapeutic value of online sessions, they became more motivated to increase their own learning about the role and to develop their own skill acquisition (Stephen et al., 2010). Clearly then, tracing the flow of sessions could increase a facilitator's understanding of group members' beneficial experiences and could also create further opportunities to hone facilitation skills.

Continuing Development of a Coding System

The Coding System

As presented in Appendix A, the coding system represents a first version. It is the intention of the research team that the system will undergo development with continued application and interpretation. This was substantiated by expert reviewers' comments. For example, the feedback regarding destructive comments has been extensively described in the group literature but is not evident in this first draft coding list. It is reasonable to expect that upon the analysis of more data, a category for this may be generated; however, it was not present in the dataset employed to create this coding system. Moreover, it may be useful to note that destructive comments are often comments by themselves. The unit of analysis in the current version of the coding system is the block and as such, may best fit particular kinds of research questions not related to individual comments. More specifically, unless a destructive comment burgeoned into a destructive process (e.g., was picked up by the larger group), it would not be identified as a block and no coding label applied. This does not mean, however, that destructive

comments are unidentifiable. Once a session has been coded, individual comments such as these stand out as separate from the overall flow of the group. This observation connects to a number of implications previously stated; one such implication is that, from a clinical perspective, identifying these kinds of processes across sessions provides the opportunity for a professional facilitator to shape the flow of a group including an outlier's contributions.

Training in the Coding System

Another important aspect worthy of discussion was the development of the coding manual (Appendix A). This was generated in order to facilitate training of coders as well as the ongoing use of the codes throughout the coding process. It is similarly expected that this is the first draft of a working document. With multiple applications, additions and clarifications are anticipated.

Due to the ongoing exploratory nature of this research, there are two expectations with respect to the training of coders. Firstly, performing this kind of research requires the reflectiveness and the self-awareness that comes with advanced psychology or counselling training; therefore, it is recommended that coders, at a minimum, have completed first year graduate studies courses and a practicum in a psychology or counselling psychology program. Secondly, given the preliminary nature of the codes and manual, it is recommended that initial trainings be done by the primary investigator until a degree of comfort has been attained by coders.

Limitations and Future Research

Limitations

There are several limitations associated with this project. The developed coding

system was informed by clinical perspectives on psycho-oncology support groups, and that requirement is reflected in the coding manual and the analyses supported by these observations. Coders trained with this manual will need a minimum level of clinical background for effective use of the system. Moreover, establishing adequate intercoder agreement will require further development of the training protocol to accompany this coding approach.

Additional Directions for Future Research

The two expert reviewers provided feedback that converged on an important aspect of the coding approach. They both questioned the articulation of identified blocks as discrete from each other rather than overlapping. At this time, this method articulates the blocks as discrete units; however, this is not a precise reflection of how they occur. As these reviewers point out, in this data, new blocks began within previous blocks and subsequently advanced into the new blocks. The research team chose not to attempt to describe the transitions precisely. The main reason for this was to simplify the coding approach in order to provide broader utility. This does not negate the importance of the transitions; in fact, they become even more visible once a session has been coded or blocked. It is conceivable, then, that further development addressing transitions can be attempted and included in the model.

Conclusion

Throughout this project, the researchers endeavoured to accomplish two main goals. The first goal was to create a coding system that would enable researchers to identify, describe, and subsequently understand the processes taking place in online support groups for young women with breast cancer. This goal has been accomplished

and a coding system has been created and is now available for use and further development. The second accomplishment of the study was to employ abductive inquiry and ascertain overlap and novelty of OSG processes with those previously identified with F2F groups. This goal has also been achieved and presented throughout the document. The coding system is the first of its kind arising directly from the online data itself and enables the tracing of session flow potentially providing meaningful impacts for both clinical and research applications.

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APPENDIX A:

THE CODING APPROACH

INSTRUCTIONS FOR CODING AN ONCOLOGY ONLINE SUPPORT GROUP SESSION

Step 1: Read through entire session to get a sense of the flow and content.

Step 2: Parcel each session into blocks.

i. ***Notice how the session flows in blocks.*** Blocks are sub-sections characterized by several lines of text (e.g. from five posts to several pages of posts) within the session. Blocks are never one or two posts only. In general, blocks occur when one post contains an offering for discussion which then gets picked up and responded to by other posts. Subsequent posts then focus primarily around one theme. Usually, one subsection of posts does not end before the next one begins, rather there is overlap (possibly between two or more subsections). As a result, it is necessary to read forward and then backtrack to notice that the group has transitioned into a sub-section now identifiable as a block.

ii. ***Identify theme(s) within the blocks.*** Each block of text contains notable themes. Identify and list possible themes. These themes can be "felt" by the coder (e.g., the members are resonating with each other's emotional experience). Moreover, in blocks associated with some codes (e.g., "Shared Emotional Processing of Significant Events"), the coder can notice a deeper emotional response in him or herself. This response within the coder's own experience is an important signal that is the appropriate code for these blocks.

This is an important part of the coding process. As coders notice and reflect on their own emotional experience, they experience a smoother process in determining which codes to apply to which blocks.

Step 3: Apply one of the eight codes to each session, using the following 4 steps:

i. ***Choose a code.*** Label the block with one of the eight codes (see Description of Codes). Choose the code which reflects the main theme within the block. This can be thought of as:

- the theme which the entire block revolves around or is organized around; and
- the main theme which is driving the other themes.

ii. ***When more than one code fits***. Several codes may appear within a block. Choose the best code. This is the code which stands out as the *main reason* the discussion is occurring. This code can be distinguished from other codes by the "feel" of the block. In other words, what appears to be the main point of discussion in the block. Which code description best matches the coder's "feel." What this means is that the best code begins with the felt sense of what is going on in the block which then gets matched to the codes presented.

Example: In the example here, two codes are possible: Personal Disclosure or Group Cohesion. Although, the participants are offering "personal details which exist independently of the participant's cancer experience", the discussion is occurring as a result of "check-in". Therefore, the best code is Group Cohesion. It is possible that best code may be disputed by other coders since the decision reflects an interaction between coder and material.

Differences between coders such as personal experience, academic training, and area of interest of study will create variability across coders, determining a method for resolving these will emerge as this coding approach is employed.

iii. ***When no code seems to fit.*** Review the section for themes. Carefully review the code descriptions, in particular for Offers of Informational Support. If no code appears to be appropriate, list the themes with examples. Articulate what the coder's "felt sense" is of what is going on in the block. Consider the possibility of developing an additional code.

iv. ***How to identify transitions.*** Rarely are there clear endings and beginnings to new blocks or codes. Rather, blocks overlap. The coder only understands that the flow of the session has transitioned into a new block by reading along with the understanding that the data will flow into another block or code and he or she will know that the data has shifted once he or she is there. At that point he/she may return to determine where and when the shift began.

Example: The block (page 48) is labelled with the best code: Group Cohesion**.** The excerpt is taken from the beginning of the 4th session. The group is entering the virtual room and catching up with each other since their previous session 1 week ago (e.g., check-in).

F (08:52:22 PM)
No worries - we are just greeting everyone.

F (08:52:34 PM)
I think we may just be missing 5?

1 (08:52:54 PM)
Hi all, I am here and all the dogs are accounted for. They are monkey's, too .... on four legs. I had a chance to go through the transcripts today - boy, did I ever miss a great session when [name] went AWOL! It was good to read so many important things again and I just wished I could ask so many questions of you all!

2 (08:53:11 PM)
Awesome news, My grandmother has had a miraculous turn around and has had her prognosos moved from 1-2 weeks, to 3-6 months

3 (08:53:22 PM)
Awesome 1!

4 (08:53:29 PM)
That's wonderful 2!

F (08:53:34 PM)
Hi 1 - I am so glad that your dog is safe and sound and so glad that the transcripts are up now so you can catch up on missed sessions!! Great news!

1 (08:53:38 PM)
Ye, 4

4 (08:53:47 PM)
Wow -1 what good news

2 (08:54:15 PM)
I has really made my day

1 (08:54:16 PM)
Oh, how wonderful, 1! Every minute counts so much

2 (08:54:26 PM)
Nana is sooo happy too

2 (08:55:10 PM)
she's being moved from the hospital to hospice home, whic is also sooo great for her

4 (08:55:17 PM)
my friend's dad who has leukemia was given about 5 years and now he is in his 12th and doing wonderfully - makes you wonder what the predictions are really based on...

1 (08:55:46 PM)
I volunteered for hospice in [place] - they are amazing places to be!

Step 4: Diagram each session flow

- to highlight and identify the group's priorities for that session
- provide opportunities for comparison between sessions/groups

LIST OF RECOMMENDED CODES

1. Group Cohesion
2. Sharing Personal Cancer Stories and Experiences
3. Offers of Informational Support
4. Personal Disclosure
5. Shared Processing of Emotional Impacts
6. Sharing Integration of Significant Events
7. Unique Processes

DETAILED DESCRIPTION OF THE 8 CODES

Code 1: Group Cohesion

This code fits blocks in which group members are participating in activities which create and/or maintain every attendee's membership in the group. In other words, this code fits when the furthering and/or deepening of the group experience is the main reason the block is occurring. These blocks always occur at the beginning and the end of sessions and are frequently woven throughout the session. In addition, the code should be chosen when group members' posts carry the purpose of creating and maintaining safety and stabilization. This is particularly evident when they occur immediately after Shared Processing of Emotional Impacts. In these instances, the coder may notice that the blocks

fitting this code contain a felt sense of relief amongst members. This could be further described as the sense that group members have found a home for their experience.

Notable themes include:

- Introductions, check-ins, closings
- Posts about how members are feeling in the group now
- Love bombings: intense offering of support
- Expressions of wanting to connect with each other outside of group time

Discriminating criteria for the code:

The feel of the block carries with it the main purpose of creating and/or maintaining the group connection; keeping a particular member connected to the group; establishing, expressing and/or keeping one's own connection to the group. These blocks may contain posts which could fit the code Personal Disclosure or Sharing Personal Cancer Story and Experiences but can be differentiated by noticing that the themes (associated with those codes) are brief and do not gain momentum in and of themselves. In other words, responses by the rest of the group do not reference the content of the disclosure or cancer story. Rather, subsequent posts revolve around the important role the group is having for its members.

Example:

G.M. 1 (10:16:03 PM)
and we can use eachother for a compass G.M. 2

G.M.2 (10:16:40 PM)
LOL G.M.1

G.M. 3 (10:16:44 PM)
I'm much more settled than I was before this conversation. I feel so comforted just by being the company of all of you

G.M. 4 (10:16:56 PM)
Fine.

G.M. 3 (10:17:04 PM)
"in the company" (sorry)

G.M. 5 (10:17:17 PM)
I'm just soaking up everyone's feelings, and am glad we all have issues in common. I'm feeling alright.

F (10:17:21 PM)
you are also the company of us!

G.M. 2 (10:17:37 PM)
OH, I love the kindness that is going around this group. Kindness and compassion, Really builds on the safety. Oh no, lots to read again

Code 2: Sharing Personal Cancer Stories and Experiences

This code is used when posts revolve around members' experience since first noticing physiological changes associated with cancer. Posts about others' (including close, distant others and pets) cancer story may also be included in this block. These blocks contain the "felt sense" that the details of each member's cancer journey are very important. There may be the sense that members are not emotionally tied to the details they are presenting despite their intensity. This is evident in the tone of the posts which are matter of fact and exhibit detailed knowledge about their cancer related experience. In fact, these blocks can contain numerous facts about cancer itself, the diagnosing process (e.g., staging), ongoing treatment decisions (e.g., cosmetic rebuilding) and many other cancer related experiences.

Notable themes include:

- Diagnoses
- Symptoms
- Treatment Side Effects Experience
- Treatment Decisions
- Interactions with Oncologists and other medical staff.

Discriminating criteria for the code:

This code tends to be easily identifiable and occurs in the posts that pertain to treatment decisions, side effects, and interactions with medical system. The main purpose of these blocks is to share the details of what happened to each individual member as it relates to their cancer story. In addition, members share ongoing treatment side effects and/or treatment and rebuilding decisions they are wrestling with now. Frequently, this code is followed by blocks of Shared Processing of Emotional Impacts or Offers of Informational Support. On occasion, a group member will offer a post or two about their cancer story but the group does not respond with each member sharing more of their own cancer story, rather, they will move to Shared Processing of Emotional Impacts.

Example:

G.M 1 (10:08:08 PM)
i will have tomorrow an appoinment with the surgeon...about double mastectomy and implant ...what do you think?i am very weak sometimes..it will be difficult i know

G.M 2 (10:08:14 PM)
G.M 3, you can sleep on it and with cooler head approach your partner tomorrow. I always like to say what i feel, even if it the next day. Otherwise it just bugs me.

G.M 4 (10:08:19 PM)
becuase wasn't control one of the issues in the first week - the lack of control?

F (10:08:49 PM)
Hey, any help for G.M 1?

G.M 3 (10:09:10 PM)
G.M 1 ...have you already had a double mastecomy

G.M 4 (10:09:16 PM)
G.M.1 - you have a big day ahead of you....how are you feeling about your options?

G.M 1 (10:09:35 PM)
the genetic test ...it will be between 5--7 months=i can't wait that long....

F (10:09:37 PM)
yes, and your current thoughts

G.M 4 (10:09:38 PM)

I had the meeting with the surgeon and can't have any surgery until at least 1 1/2 years after the ilitial surgery. It was a very quick matter of fact meeting and I am not sure if I will, but am keeping all options open

G.M 3 (10:09:59 PM)
I have have had the one and when I finally get to see the surgeon...I hear its one hell of a wait list I want the other off too and a tramfax or what ever its called

F (10:10:14 PM)
tram flap?

G.M 4 (10:10:32 PM)
whats a tram flap?

G.M 3 (10:10:33 PM)
yup

G.M 3 (10:10:34 PM)
lol

G.M 4 (10:10:42 PM)
I am lookng at the tramflap too and the surgeon looks like he is 12 years old

G.M 1 (10:10:53 PM)
i think it will be over one day

G.M 3 (10:10:58 PM)
I never had any option like they do in

F (10:10:59 PM)
so, G.M 1, the genetic test (if you waited) would that lead you to want a double mastectomy?

G.M 3 (10:11:14 PM)
Van ...it just got taken off

F (10:11:52 PM)
G.M 4, instead of an implant, they use muscle in stomach, or back, to create another breast

G.M 4 (10:11:54 PM)
i am thinking of having the double even with out any genetic testing, I just want to hedge my bets about keeping my life

G.M 1 (10:11:57 PM)
my plastic surrgeon told me that i have to have reduction on my left br and ...i decided to have mastectomy

G.M 3 (10:12:23 PM)
G.M 4 its like having a tummy tuck at the same time they take your abominal musle from and tuck it under your breast bone to make a breast or two

G.M 1 (10:12:23 PM)
because my cousin had 6 years ago and is back 3 rd time

F (10:12:50 PM)
so you chose a mastecomy as opposed to a lumpectomy?

G.M 4 (10:13:00 PM)
it is a long surgeroy, about 8 hours with 5 day recovery in the hospital, was what I was told. Then about 4-6 weeks recovery

G.M 3 (10:13:05 PM)
I"m a 38 D well one anyway ....I don't care what size I end up with a

G.M 1 (10:13:05 PM)
yes

G.M 1 (10:13:15 PM)
i had mastectomy last april

G.M 3 (10:13:18 PM)
B or C as long as I have two

F (10:13:38 PM)
G.M 1, I just want to understan, and now you are considering a double mastectomy is that right?

G.M 1 (10:13:55 PM)
yes

F (10:14:08 PM)
and how are you feeling about this decision?

G.M 4 (10:14:23 PM)
I figure no one is using mine set of girls, but I would like something smaller, enough to fillout a sweater, but smaller so I can safely go running

G.M 1 (10:14:46 PM)
because my oncolog .told me because i am under 35=33== and i have very quiqly aggresive cancer i have double risk for c .recc

G.M 3 (10:15:07 PM)
I hear ya G.M 4...I want my other breast taken off and then a trans flap to reconstuct both...

G.M 1 (10:15:58 PM)
i decided myself at that appoinm at the plastic surrg office when he told me that i need a reduction

F (10:16:06 PM)
G.M 1, will you feel less fear if you have the other breast off? will if help you "move foward"?

G.M 4 (10:16:07 PM)
I know a woman who lost both her mother and her sisiter to cancer, very aggressive and very fast. She had no cancer but did the double many years ago and is doing great. She had the opperation after her second was born who is now about 17 years old

G.M 2 (10:16:16 PM)
Sorry, ladies, please don't think i am ignoring you all. Its just that i am reading through all this and can't imagine going through a mastectomy and say anything cause i was fortunate enought to have lump.

G.M 3 (10:16:17 PM)
G.M 1....only you can make the descion but you have had one surgery ....and to see your babies grow up...I would encourage you to have a second mastecomy

G.M 1 (10:16:27 PM)
and i asked him...his answer was 1 in a million for c recc

F (10:16:41 PM)
thanks for letting us know G.M 2!

G.M 4 (10:17:08 PM)
For your PEACE of mind, I would have a double

G.M 4 (10:17:37 PM)
I am with G.M 3 on this one G.M 1

G.M 4 (10:17:51 PM)
sorry i was lumpectomy as well - but limb over life for me...if i had to chose

F (10:18:03 PM)
G.M 1, you need to make your own decsion, one that you will feel comfortable with, one with the least regrets.

G.M 4 (10:18:07 PM)
G.M 4, you said it exactly

G.M 3 (10:18:23 PM)
Think of it this way...if your going to have reconstuction...let the doctor have a clean canvas to give you a new set of girls

G.M 3 (10:18:30 PM)
I know that sounds flippant

F (10:18:55 PM)
G.M 1, do you want an original breast?

G.M 1 (10:18:57 PM)
i felt my lump in aug 2006 nobody checked...out just 7 months later...even the specialist told us is a plugged duct because i was breastfeeding

G.M 4 (10:19:08 PM)
so GM2 how are you feeling? what are your thoughts? fears?

G.M 3 (10:19:11 PM)
but I'm just trying to suggest that get rid of the chance of re occuance and have a new set

G.M 1 (10:19:28 PM)
implant

G.M 4 (10:19:29 PM)
then they can be perky for when you get older.

G.M 1 (10:20:02 PM)
i am a little stressed

G.M 3 (10:20:07 PM)
sweety thats what underwire bras are for

G.M 3 (10:20:15 PM)

GM2 are we stressing you

G.M 3 (10:20:16 PM)
sorry

G.M 4 (10:20:33 PM)
implant is also an option. My surgeon would prefer to do a tram flap for me, but everyone is differnet, all with good results

G.M 4 (10:20:46 PM)
it is your decision....do whats best for you

G.M 1 (10:20:52 PM)
but 100% decided that i will have mastectomy,but i am worried about i will be very weak..after ..i am weak now somethimes

G.M 3 (10:21:02 PM)
G.M 1 what does your husband suggest

F (10:21:13 PM)
G.M 1,if I'm reading you corectly, it looks like you have decided to have the healthy breast removed and replaced with an implant - but ah! worried about fatigue, I see now!

G.M 2 (10:21:14 PM)
G.M 1, just remember in the end its your decession and how you and your husband feel about this. I am not saying it is his decission, but let's be honest it matters.

G.M 1 (10:21:17 PM)
and an other surgery...is not easy with 2 litlle ones i know

G.M 4 (10:21:33 PM)
YOu have two kids, is it tired (and rightfully so) or weak? or both?

F (10:21:44 PM)
can you dealy the 2nd surgery until you have more strength?

F (10:21:51 PM)
delay, sorry

G.M 1 (10:22:07 PM)
what do you think?

G.M 4 (10:22:23 PM)
that where the friends and family come in....when you need them

G.M 3 (10:22:35 PM)
Do you have family to help grandmas or aunts

G.M 1 (10:22:50 PM)
my mother is here now and i would like to be over.....because my cousin had 3 times in 6 years..that's why

G.M 1 (10:23:30 PM)
nooo...we don't have family here just my mom visiting us

G.M 4 (10:23:31 PM)

I thought the concern line was aunts, grandmothers and mothers?

F (10:23:43 PM)
hmm, it sounds like you have made up your mind

G.M 4 (10:23:55 PM)
all within the last generation.

F (10:24:02 PM)
but worried about fatigue - yet your mom is there for you now to help...

G.M 3 (10:24:29 PM)
How soon can you get your sergury....will your mother still be here

G.M 4 (10:24:38 PM)
Perhaps after the meeting with surgeoin, more of your concerns will be answered. Do you have a list of questoins prepared?

G.M 1 (10:24:56 PM)
yes i do

F (10:25:14 PM)
G.M 4 - that is right, but I imagine G.M 1 is carrying her cousin's story in her head - is that right G.M 1? fearing it could happen to her, it could happen to you?

G.M 1 (10:25:16 PM)
thank you for encouraging and understanding me

G.M 4 (10:25:29 PM)
Having questions gives you some control, so you are doing the right thing, being proactive and until you hve answers, you can't make the decisions

G.M 1 (10:25:32 PM)
YES “Facilitator”

G.M 3 (10:26:05 PM)
G.M 1...your doctor can be very helful too to make your decision

G.M 4 (10:26:08 PM)
it is often the waiting between events or appointments that is have

G.M 4 (10:26:13 PM)
hard - not have

F (10:26:18 PM)
G.M 1, listen to your gut, what will bring you the most peace and happiness?

G.M 4 (10:26:24 PM)
G.M 1 - good luck tomorrow.....we will all be there with you in spirit. be strong

Comment on example: The main theme taking place throughout this block was the sharing of a treatment decision of one of the group members (G.M.1). Although, some posts within the block could fit other codes (e.g., Offers of Informational Support), the

main reason for the overall discussion is about G.M. 1's decision. In addition, note that the first part of this block overlaps briefly with the previous block of the code, Sharing Self or Personal Disclosure. The last part of the block overlaps with the next block of the code, Group Cohesion.

Code 3: Offers of Informational Support

Blocks that fit this code are those in which members within the group offer informational support. Informational support includes advice, suggestions, or directives. These carry with them the sense that group members are trying to assist another member in responding to a personal or a situational demand. These blocks can contain many facts and details. The felt sense, however, is the facts are connected to members trying to help each other by sharing information which they themselves found helpful. In addition, these blocks have a very practical feel. They may contain how to's for members on a variety of topics. Blocks which contain a significant amount of problem solving also fit this code.

Notable themes include:

- General resources (e.g., book titles and/or book content, websites)
- Community and BC Cancer Agency programs
- Expert resources (e.g., counselling and oncology professionals)
- Communicating with non-oncology others about the cancer journey
- Problem-solving

Discriminating criteria for the code:

These blocks are quite easy to identify. They may contain a post or two which fit other codes (e.g., Personal Disclosure) however, this code should be chosen when the group launches into many posts which have practical content. The coder may notice a

personal response of interest in what the group members are posting (e.g., thoughts of "I didn't know that"). As an example, the block becomes primarily about the sharing of resources rather than the member's personal disclosure. In another example, this code may occur before or after Shared Processing of Emotional Impacts. In this scenario, the group moves fluidly from the first block to the next and the Offers of Informational Support provides a felt sense of energy and support.

Example:

G.M. 1 (08:59:53 PM)
G.M. 3...I keep forgetting I want to give you a name of a local gal [city name] called "Ann" she has a web site and a blog ...she is your age or close too and has two little girls

G.M. 1 (09:00:00 PM)
www.[name].com

G.M. 1 (09:00:13 PM)
I think you would get alot of inspiration from her

F (09:00:16 PM)
what is the website about?

G.M. 1 (09:00:41 PM)
its just her personal history...she first had breast cancer at 23

G.M. 3 (09:01:07 PM)
thank you

G.M. 1 (09:01:11 PM)
then now in her early thirties just while breast feeding has a second breast cancer

G.M. 1 (09:01:20 PM)
she is stillon herceptin

G.M. 1 (09:01:27 PM)
but is a real trooper

G.M. 3 (09:01:57 PM)
thank you very much i will look later

F (09:02:08 PM)
how does it help you G.M. 1? to see stories like this?

G.M. 1 (09:02:33 PM)
She is a great inspriation and as she is local...I have chatted to her ....what a fighter

F (09:03:10 PM)
that is good to hear - and intersting as tonight the "focus" is social support.....

G.M. 1 (09:03:18 PM)
she is also part of a young womans group...18-40....you could ask her what its called but they have much in common young babies husbands ect

G.M. 3 (09:06:20 PM)
YACC is the name of that group 18--40 cancer survivors?

G.M. 1 (09:06:34 PM)
yes that sounds familiar...

G.M. 3 (09:07:30 PM)
they have meetings On first Monday every month at [town name]

Code 4: Personal Disclosure

This code is applied to blocks where a member is disclosing information about personal situations that are independent of their cancer story or experience. These are situations that exist in their lives anyway and may have existed prior to the cancer experience. The felt sense associated with these blocks is that the disclosures are about life situations that have been or would be difficult to cope with regardless of the additional burden of the cancer journey. In addition, there may be the sense that the disclosure carries some interpersonal and immediate risk for the sharing member with respect to how she or he would be viewed in the group.

Notable themes include:

- Family Contexts (e.g., married, single, children, divorced)
- Close others situations (e.g., family member's illness)
- Work Relationships (e.g., conflictual interpersonal interactions)
- Sexual Orientation

Discriminating criteria for the code:

Choose this code when blocks involve personal contexts which would elicit discussion in the group regardless of the kind of group and not necessarily oncology. In

these blocks, members rally around the disclosure which is evident in the number of posts related to the revelations made. On occasion, the group might discuss how the cancer experience has increased the participant's difficulty achieving personal mastery over these situations; however, the main aspect of the block revolves around the member's initial disclosure. In addition, the sharing member may disclose some vulnerability about their disclosure within the group. These blocks may contain posts which fit Offers of Informational Support or Shared Processing of Emotional Impacts but the block can be distinguished by the main purpose of the discussion being around a member's disclosure.

Example:

G.M. 1 (09:12:19 PM)
I'm feeling stressed and frustrated 'cause I'm always using these communication techniques at work and my staff don't seem to get it...they're a very difficult group of people to get along with.

G.M. 3 (09:12:30 PM)
I like that! Is that the "pieces"book?

G.M. 4 (09:12:42 PM)
yes, "Picking up the Pieces"

F (09:13:05 PM)
So do we want to talk a little about communication or go in a different direction?

G.M. 1 (09:13:09 PM)
I feel so much better now that I'm with you guys.

G.M. 2 (09:13:11 PM)
that's prusteratin G.M. 1

G.M. 2 (09:13:23 PM)
wha? frusterating

G.M. 3 (09:13:26 PM)
Yes, I remember you saying that before, G.M. 1. That the public were so much more supportive than your co-workers. That must hurt.

F (09:13:28 PM)
G.M. 1. So good to hear!

G.M. 1 (09:13:29 PM)
Huh...what's that?

G.M. 4 (09:13:45 PM)
G.M. 1, what happens with the people at work when you try to communicate?

F (09:14:07 PM)
Good question G.M. 4!!

G.M. 1 (09:16:10 PM)
I'm used to the people I work with but to be frank, they are very young, narcisistic (spelling?), arrogant and think anyone over 40 yrs is a loser, and anyone who isn't "cut" in shape shouldn't be doing our job. Unfortunately, our mgmt group are the same way. There's been a lot of turmoil in our dept. lately. I don't really want to talk about it 'cause I don't want to waste the energy getting frustrated...sorry.

F (09:16:45 PM)
Do you have any allies G.M. 1?

G.M. 1 (09:17:26 PM)
Everyone my age and older have fortunately retired early...they couldn't put up with the crappola. Most others have quit their jobs or moved over to a police agency.

G.M. 4 (09:18:00 PM)
It is hard sometimes to find allies to communicate with, not everyone can handle what I want to talk about sometimes

G.M. 3 (09:18:06 PM)
that's just so wrong. that so much bad attitude can have such power

F (09:18:12 PM)
So you are not alone in your experience of the work environment if everyone who doesn't fit the dysfunction leaves. That's tough...

G.M. 1 (09:18:22 PM)
To answer your ? G.M. 4, whenever I've used the "I feel ...", they always respond by saying "it's always about you when you say

G.M. 1 (09:19:10 PM)
...I feel..." None of these people have attended communications courses so I'm hoping they'll gain that experience as time goes by in their work.

G.M. 4 (09:19:47 PM)
it doesn't sound like somewhere that holds any positivity for you. Difficult when we tend to spend so much of our lives working

F (09:20:06 PM)
I guess the question is how can you take care of yourself in such a negative work environment G.M. 1? It just sounds so tough.

F (09:21:06 PM)
I also know that I have talked to cancer patients who really question their work or their workplace after cancer treatment- kind of wonder if this is what they want to be doing? Wonder if that is true for you or anyone else?

G.M. 1 (09:21:13 PM)
My experience is similar to that firefighters scandal re: discrimination vs. women firefighters. Even the seasoned inspectors are afraid to speak the truth. It's very sad. I've been looking for a new job since my return to work but it's quite difficult these days. Everyone wants a degree.

G.M. 2 (09:21:47 PM)

can you get your degree?

F (09:21:48 PM)
So it sounds like survival for you right now G.M. 1 until you can find something else. Yuck!

G.M. 1 (09:23:00 PM)
I don't have the time to attend school 'cause I sometimes work nightshift/graveyards. I always hope for good change and try to put myself in their shoes. There's always a reason why people behave what I think to be badly. Like that movie, "Something's Gotta Give" sooner or later.

F (09:23:48 PM)
So putting yourself in their shoes helps a little?

G.M. 4 (09:24:04 PM)
good on you for trying to stay so positive and empathetic, must be hard in the face of it often

F (09:24:41 PM)
I remember the communication stuff that I know - assertiveness is taking in the needs of self and the needs of other. A balance of both.

G.M. 1 (09:25:01 PM)
I distract myself by saying "I'm lucky I'm alive!" and I am respected by the public. I actually got flowers the other day, so nice. And yes F, I figure some of these staff have probably been bullied at one time or they've had privileged upbringing so they don't understand what humility is or how others feel.

F (09:25:35 PM)
Good to have the flowers every now and again G.M. 1!!

Code 5: Shared Processing of Emotional Impacts

This code is applied when blocks involve posts about significant events which have had and/or continue to have elicited negative emotional impacts for members. In these blocks, the coder may notice the felt sense that group members are intensely resonating with each other's emotional experience. These blocks carry with them the sense that individual group members and/or the group as a whole are trying to make sense of the emotional impacts. Another felt sense may be that one or more of the members is articulating, usually implicitly through the attempt of making sense of, the idea of being stuck. Expressions of emotional and cognitive contradictions or incongruence are also an indication that the block can be coded with Shared Processing of Emotional Impacts.

Notable themes include:

- Fear (e.g., of unknown, re-experiencing)
- Shock/Confusion
- Sadness
- Hopelessness/Helplessness/Stuckness
- Loss (e.g., of dreams, time)
- Death (e.g., terror of)

Discriminating criteria for the code:

In these blocks the coder will notice a deep emotional response or resonance in him or herself. The coder may feel as though he or she has experienced an emotional change as a result of reading the block. In other words, the coder may notice needing some time to consider and/or emotionally process what she or he has read and assess meaning about the block as it relates to the coder's own lived experience. As the coder reads on through the transcript, she/he may notice another internal shift which is akin to relief from emotional intensity. This response within the coder's own experience is an important signal that the group is transitioning into new block.

Example:

G.M. 3 (09:57:15 PM)
Soooooo.....social support.....does anyone know how to gain back relationships that were lost from cancer?

G.M. 2 (09:57:28 PM)
I find that too actually G.M. 5, I'd rather talk about sex than..well, just about anything actually

F (09:57:31 PM)
good Q G.M. 3!

G.M. 2 (09:57:34 PM)
written or in person;0

G.M. 2 (09:57:37 PM)
;)

G.M. 2 (09:57:39 PM)

G.M. 4 (09:58:01 PM)
good one, G.M. 3! One would have to be a very forgiving person, I reckon

G.M. 1 (09:58:12 PM)
I think about that question everyday.

F (09:58:42 PM)
hang on - it may depend on how or what relationship was lost, I see some assumptions might be being made here....

G.M. 2 (09:58:47 PM)
I, personally, am not interested in gaining back the relationships I lost...but that is based on the subjexts lost and their constant nagativity about everything in life..then blaming me for being sick and hurting their feelings when they had to think about ewhat I was going through

F (09:58:54 PM)
can we have more context G.M. 3?

G.M. 2 (09:59:34 PM)
so yes, expansion is probably neccessary,,,there are so many posisibilities

F (09:59:37 PM)
ah, G.M.2's context is clear!

G.M. 1 (09:59:49 PM)
My upbring/values tell me to forgive but like you say G.M. 2, some friendships aren't worth the stress.

G.M. 5 (09:59:59 PM)
Oh my god G.M. 2. Ye, those kind of people are no big loss to 'lose'. I can't believe that they were blaming u for getting cancer. How did your cancer become about them? That's aweful.

G.M. 4 (10:00:25 PM)
I remember I used to get so collossically angry when people didn't visit dying friends and relatives anymore because they "wanted to remember them like they were when they were well" - well, I wouldn't want somebody like THAT in my life. Fears or not, that's just too shabby and sometimes there is nothing wrong with swallowing one's fears

G.M. 3 (10:00:29 PM)
The particular person I'm thinking of is a good friend of mine. We use to speak on the phone weekly and then I got sick and she barely ever phoned. The usual 'I didn't want to disturb you' response. BUT its never improved. We go a couple months without talking and its just not the same. I'm wondering will it ever and/or is it possible?

G.M. 2 (10:01:10 PM)
everything seems to be about them...EVERYTHING...I was getting tired of it even before I was diagnosed, but when they lost their anger on me because "how could I be honest about what I was going through, didn't I know what that made them feel like..."etc...it was all to easy to say "fine, I won't tell you about it anymore" and just walk away

F (10:01:15 PM)
do you want it to change G.M. 3?

G.M. 3 (10:01:34 PM)
Yes, I want it the way it was.

G.M. 2 (10:02:02 PM)
could it be though? Had she lost someone else?...I'm just throwing ideas out here, sorry

F (10:02:08 PM)
Have you spoken to this friend about how you feel G.M. 3?

G.M. 5 (10:02:39 PM)
I find that this is when u know who your true friends are. G.M. 2, these people sound more like children, rather then peers/friends

G.M. 2 (10:02:55 PM)
family unfortunatley

G.M. 2 (10:03:03 PM)
it'll make for some interesting wedding and such

G.M. 2 (10:03:05 PM)
but oh well

F (10:03:13 PM)
I'm sorry G.M. 2

G.M. 3 (10:03:45 PM)
Kind of.....not really. There is just some things we don't talk about and thats one of them. Don't get me wrong she asks how I'm doing extra. Maybe we just got out of the habit of talking to each others weekly and our lives are going two different directions now that are so different we're not reconnecting.

F (10:04:04 PM)
It's interesting in the chapter they highlight people who give u various forms of support, but not what to do when those you thought would support you, don't. All too common unfortunatley

G.M. 3 (10:04:08 PM)
Don't get me starting on family.....I know exactly what you mean G.M. 2.

F (10:05:01 PM)
G.M. 1, you were saying too the hospital was your support, as others were not for you..I'm imagining you can relate in some way?

G.M. 2 (10:05:10 PM)
One of my friends , close friends, had started doing that with me G.M. 3...I talked to her about it and she revealed that after watching her sister go through brain cacner and almost loosing her (amongst some other losses, that I promised not to carry on outside our conversation) she just didn't have anything for me...I tried to tell her otherwise but we had to agree in the end that she couldn't do it yet...and that we would touch base again once everything is over

G.M. 3 (10:05:38 PM)
And have you?

G.M. 4 (10:05:40 PM)
You know, G.M. 3 when we talk about people "getting it" - perhaps she understands that and is afraid that you might see that she isn't getting it? Or something along that line. I know that my friends all had hard times of not being able to be me or understand whatever cancer is

G.M. 2 (10:05:42 PM)
not yet

G.M. 2 (10:06:13 PM)
she's on my facebook, so she knows that I'm finished treatments and such...I keep wanting to call her but I haven't been able to yet

G.M. 2 (10:06:21 PM)
I think I'm secretly waiting for her to reach out

G.M. 3 (10:06:36 PM)
Unfortunately you might be waiting awhile G.M. 2.

G.M. 2 (10:06:45 PM)
it was pretty painful to be dropped, although I can understand why, so I think I need her to reach out to me in order for me to be able to pick it back up[again

G.M. 2 (10:06:48 PM)
does that make sense?

G.M. 5 (10:06:49 PM)
Sounds like your hoping that she will make the first move G.M. 2

G.M. 2 (10:07:27 PM)
definitely...I know that if I do though, that I will always feel like the whole ante of the relationship is on me...like it's one sided right?>

G.M. 2 (10:07:42 PM)
what about yourself G.M. 3>?

F (10:07:49 PM)
reconnections take two, does it really matter in the end who makes the first move? (I"m just asking, I don't have the answer)

G.M. 5 (10:07:53 PM)
Ye, it certainly makes sense. I think that I would react the same way. I guess it just feels vulrneable and it's up to the other to deal with their issues and reach out first - as it is them who had to go away in the first place.

G.M. 2 (10:08:02 PM)
exactly

G.M. 1 (10:08:07 PM)
Yes F. This topic painful for me as it is with this group. All my friends 15-30yrs I've had turned their backs on me at the same time. One of the RN's wanted to "throttle" one of my friends for making me wait 2 days for Xmas dinner, which I never got. Angry as I still am, somewhat, I can't accept they were all weaker than me. The hospital and my (former) doc were my only support. The 2 co-workers came along afterwards (we don't actually work in the same building), so I'm thankful for them, and for support groups like this to help my survival.

G.M. 2 (10:08:12 PM)
I also don't want to push her, when it all is quite painful for her

G.M. 5 (10:09:17 PM)

G.M. 1, how did you cope emotionally during such a difficult time?

G.M. 2 (10:09:19 PM)
G.M. 1 that must have been sooo hard. Most of my family tried so hard to be with us, but they all live quite far away so it was tough...but I had so many strangers become friends through ought this whole process

G.M. 2 (10:09:34 PM)
I can't imagine that not happening...how did you do it?

G.M. 3 (10:09:57 PM)
Out of all the reading I've done from the material given to us the one line that stands out the most, was a huge eye opener and just hit home was 'recognize that family and friends have to deal with their feelings too. They may be helpful or unhelpful to you. They are, however, probably doing the best they know how.' That was HUGE for me to accept and understand.

G.M. 4 (10:10:02 PM)
Ohmigod, G.M. 1, that is so hard. And you have been with this group for a while now and it is really obvious what a lovely, cool woman you are.

G.M. 2 (10:10:39 PM)
G.M?, what about your friends...I feel like I may have side tracked you...and that's not my intentions...I was only trying to relate

G.M. 2 (10:10:44 PM)
friend...sorry

G.M. 2 (10:10:46 PM)
not friends

G.M. 5 (10:10:49 PM)
G.M. 1, u must have developed so much strength after such experience. u went through it on your own. It's one of those "if u can make it there, u can make it anywhere". I really admire what u survived.

G.M. 3 (10:11:47 PM)
I agree G.M. 5.

G.M. 2 (10:11:50 PM)
how do you feel about contating her and talking to her about it?

F (10:12:19 PM)
Earlier on, one of you said how different this group might be were you all in geographically in the same room. And witnessing your understanding of each other and support for each other right now, frankly, to me, it feels we are all in the same room.

G.M. 2 (10:12:31 PM)
yes G.M. 1, you are one able person

G.M. 3 (10:12:35 PM)
Sorry G.M. 2...not ignoring you just reading all this big enteries! As for my friend.....we do talk its just not the same.

G.M. 2 (10:12:45 PM)
oic...

G.M. 1 (10:13:04 PM)
Ah thanks guys. I coped by trying lots of anti-depressants, and just "vegging" a lot of days. I thought about suicide during those days 'cause I couldn't believe they didn't care enough and just left but I now think how foolish that was. I have to live on...that's why we're all here...we're survivors. Life's a B----, that's for sure.

G.M. 2 (10:13:12 PM)
have you talked about her "ignoring" you...do you think it might help you both open up and grow from it

G.M. 2 (10:13:25 PM)
sometimes those talks can make friendships even better than they were before

G.M. 2 (10:13:28 PM)
sometimes

G.M. 2 (10:13:54 PM)
G.M. 1, I'm so sorry you had to go through that

G.M. 2 (10:14:01 PM)

F (10:14:06 PM)
G.M. 1, thank heavens for those anti-depressants to get you through those scary thoughts. You do have so much to live fore. So much!

G.M. 1 (10:14:28 PM)
Ah, thank you all for being here, truly...that's what this is all about.

G.M. 3 (10:14:32 PM)
I haven't but then I don't get a lot of talking time when we do talk It's always tended to be focused on her rollercoaster.

G.M. 2 (10:14:43 PM)
hmmmm, I see

G.M. 2 (10:15:05 PM)
I hate to admit it, but I have been that friend before

G.M. 5 (10:15:21 PM)
These type of hardships are simply chapters in our lives and if it was really tough, and if u survived it, it only made u stronger and more empathic towards others who go threw pain. There is a lot we learn from pain, especially emotional pain

Comment on Example:

Note: at (10:14:28 PM), G.M. 1 posts “Ah, thank you all for being here, truly...that's what this is all about.” This is the first post signalling that the group might be about to move out of this block and into a new one. Subsequently, the group moves into a block which fits the code Group Cohesion.

Code 6: Sharing Integration of Significant Events

This code can be used for blocks in which group members post about positive changes experienced as a result of the significant events they have experienced. Often group members will express gratitude for cancer and its struggles as well as the accompanying improvement and personal growth they are experiencing. These positive impacts are not simply a return of pre-cancer states, but rather are also expressions of being richer as a result of their overall life journey of which cancer has been a part. In addition, these blocks contain discussions about intensely positive experiences related to giving back, a deepening spirituality, and greater meaning to life in the present.

Notable themes include:

- Gratitude
- Altruism
- Spirituality
- Existential
- Meaning
- Cancer as a vehicle for change/ Cancer as a gift
- Death (as extension of life)

Discriminating criteria for the code:

In these blocks there can be a felt sense of deep resonance between group members. Members are sharing in the process of actively integrating their cancer experiences into the larger story of their individual lives. In other words, together they are storying the impacts of cancer into their individual lives. As such, group members may express that the associated struggles become less significant in comparison with the

personal growth experienced as result of their cancer. These blocks often occur following blocks of Shared Processing of Emotional Impacts and Sharing Personal Cancer Stories and Experiences and are often followed by blocks of Group Cohesion.

Example: G.M. 1: i see the cancer experience as a "blessing"
it allowed me to re-assess my life

Faciliatator (F): how so?

GM: from the time i was diagnoses last april to now

F: ah, it sounds like it from your DB message

GM: i have moved, reno'd my house
quit my job to start soemthign new
i'v had the time and opportunity to resolve many issues that lay dormant in my mind/heart
regarding: marriage failure and betrayal by my ex
my financial situations, etc etc
not many people get that opportunity. i truly feel it was something i needed ..

F: wow, that is a lot of change. it is nice you could think about issues, many other patients can only be patients and get through all the treatments!

GM: and if it was cancer i had to go thru to get where i am now, then i am grateful. there were many lessons to learn during the year ..
i'm glad you shared that because i feel that as well about other patients..

F: and no doubt a lot of learning about you.

GM: i'm finding that many of the women in our group are feeling that.

F: yes, some are still very much just getting through.

GM: the "victim" mentality...i guess it's natural...? but u know, i never once thot of myself as a victim..i looked at it as a learning expeirnce - a healing

F: it is nice for them to hear your expereince too I suspect, that some see opportunity for change if they want it. Others don't want change, they just wnat their life back as it was (becuase they liked it)

a healing, that sounds useful for you

GM: yes, i sense that as well. they want things to be "normal" or their life back. i'm fortuneate i was able to see it as a time to move forward - not back.
because of that i was able to heal emotionally and psychologically in a lot of ways.

Code 7: Unique Processes

Examples of blocks which fit this code did not occur in the online groups that were included in this study. Based upon reports from F2F groups there is reason to believe that

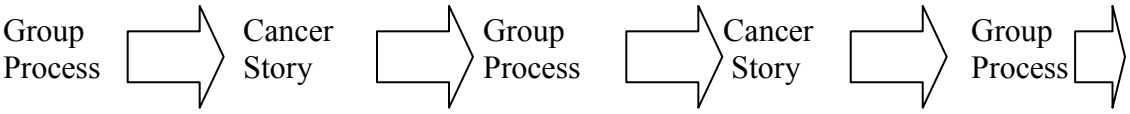
a pivotal event can occur which profoundly affects the way in which the group proceeds. An example of a pivotal event is when a member discloses to the group that they have received a diagnosis of recurrence of their primary cancer. Use this code when events of this type occur and blocks of sessions revolve around these pivotal events.

Step 3: Diagram Session Flow

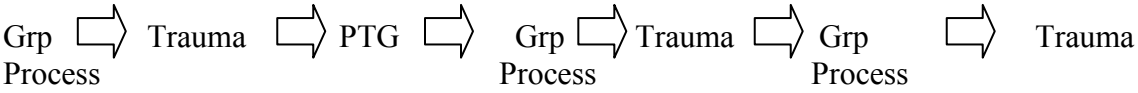
4 Different Session Diagrams

Following is an example of the process of tracing 4 session flows by diagramming the identified blocks of text from each session. Diagramming the sessions provides a quick overview of what has happened in the session as a whole. It is very interesting to see a number of session flows diagrammed on the same page. In addition, with training, a coder can become adept at the coding approach, reading through entire sessions, and rapidly sketching the flow of blocks.

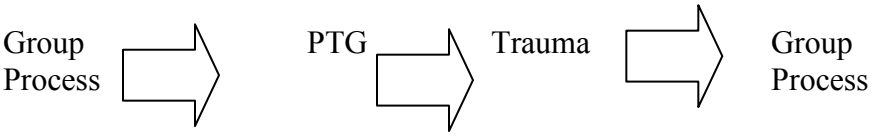
Group 3 /Session 3



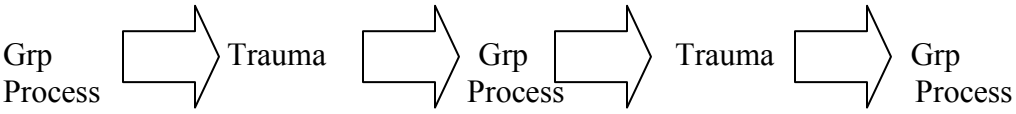
Group 3/ Session 4



Group 2 /Session 7



Group 2 /Session 8



APPENDIX B:

OSG DESCRIPTION

This is a group intervention consisting of internet group chat and a coping skills program. Group members participated in a 1½ hour online group chat with a counsellor, once a week for 10 weeks. They also received a coping skills workbook and instructional CD to use at home. Each week they were assigned a chapter of the workbook to read which took between 20 minutes and 1 hour. Participation time required for this group was approximately 2 ½ hours per week for 10 weeks. The platform for this work is provided by an established non-profit oncology organization based in the United States. In Canada, Nucare is an example of this intervention and was developed by researchers at McGill University. It was designed for use with cancer patients and was adapted for specific groups. Nucare has been found to effectively improve Quality Of Life and reduce depressive symptoms in Canadian breast cancer patients. Nucare is a brief psycho-educational coping strategies intervention with a primary aim of teaching individuals how to cope with cancer. It is comprised of instruction and a didactic workbook that has eight components: good coping, ways of thinking, communication, and effective use of social support, problem solving, techniques, goal setting, healthy lifestyle, and relaxation training. n a sample of patients with head and neck cancers, outcomes were similar though slightly weaker to those found in Face-to-Face delivery.

(Source: Stephen, 2006)

APPENDIX C:

THEORETICAL FRAMEWORK OF THE GROUPS

The intervention builds upon stress and coping theory, cognitive and behavioural approaches to emotion-regulation, and solution-focused approaches which teach practical methods for managing complex problems such as those involved in cancer. All methods incorporated under the rubric of psycho-education enhance the use of active coping strategies and the sense of personal control.

The OSG component, will provide members the opportunity to discuss and share with peers their most difficult thoughts and feelings. Discussion leads to increased awareness, and, in the presence of supportive others, emotional acceptance, and opportunity for learning through modelling of other's coping efforts. Sharing in a supportive social environment facilitates cognitive processing through contemplation and integration of traumatic experiences, which leads to the management of the trauma symptoms of intrusion and avoidance coping commonly seen in cancer patients.

(Source: Stephen, 2006)

APPENDIX D:

DESCRIPTION OF FACILITATOR

The facilitator holds a PhD, is a Registered Clinical Counsellor with the BC Cancer Agency. With 20 years of clinical experience, 10 in cancer, she currently offers psychosocial services to patients living with cancer and their families, specializing in working with those with breast cancer. At the BCCA, the facilitator has facilitated groups including the Relaxation Group, the Young Women's Support and Networking Group from 2005-2009, Cognitive Behavioural Therapy, and online groups through CancerChatCanada.

APPENDIX E:

CHARACTERISTICS OF PARTICIPANTS

Attendance. Attendance has been high in the young women's OSGs; among the 11 participants who completed the two groups under evaluation, the attendance rate has been 84% over the two groups.

Attendance in OSGs				
	Number of Participants	Number of Sessions	Total Number of Possible Visits	Actual Number of Visits
Breast	11	20	110	92

Age: The average age of young women participants was 43, with a range of 32-49 years.

Education: Education levels tended to be high though varied somewhat within the groups. Two young women with breast cancer had completed grade 12, whereas four participants had undergraduate university education, with one having completed a graduate degree.

Region: Young women with breast cancer enrolled from across the province and the Yukon Territory. Most participants lived in the more densely populated Lower Mainland (n = 8), but they also lived in smaller and rural communities in the Interior of BC (n = 2), Vancouver Island (n = 6), Northern BC (n = 1), and Yukon Territory (n = 1).

Description of Participants

Participant	**Age**	**Education**	**Online Comfort**	**Online Info Seeking**	**Region**
Group1					
1	40	Masters	1	Y	A
2	49	University	1	Y	B
3	44	HS	2	Y	C
4	41	College (2yrs)	1	Y	D
5	43	College (2yrs)	1	Y	E
6	37	College	1	Y	F
Group 2					
1	48	College	2.5	Y	G
2	45	University	1	Y	H
3	47	HS	1	Y	I
4	40	University	1	Y	J
5	32	HS	1	Y	K
6	42	University	2.5	Y	L

(Source: Stephen, 2006)

APPENDIX F:

PREIDENTIFIED THEMES FROM THE FACE-TO-FACE SUPPORT GROUP LITERATURE

Psychoeducational Resources
Clarifying Communication/Group Purpose/Safety
Offer Encouragement/ Support/Agreement
Member to Member Influence of Attitude/Modelling
Seeking help/ Agreement (from the group)
Acquiesces to the Group without Resolution
Disagrees with Group
Being Present/Feels Supported Now/Resolves an Issue /Expresses Attachment to group
Takes Action
Connects
Seeks Information/opinions
Offers Information/Brainstorms/opinion
Coping
Humour
Expresses Needs
Personal Info
Effect on/with close others
Medical Experiences
Current Symptom Experience
Negative Emotion/Pain/Confusion/Loss
Anger
Depression
Fear
Resistance
Trauma
Self-Criticism
Crisis
Positive Emotion
Hope
Altruism
Traumatic Growth/spirituality
Tech issues
Seeks Professional Opinion (from Facilitator)