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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Department of Psychology

Online Psychosocial Support for Oncology Patients: A Group Facilitation Manual

by

Kristen Mallory Richards, M.A.

Project submitted in partial satisfaction of
the requirements for the degree of
Doctor of Psychology

September 2013

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Each person whose signature appears below certifies that this doctoral project in his/her opinion is adequate, in scope and quality, as a doctoral project for the degree Doctor of Psychology.

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Jason Owen, Associate Professor of Psychology

Adam Arechiga, Associate Professor of Psychology

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ABSTRACT

Online Psychosocial Support for Oncology Patients: A Group Facilitation Manual

by

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Doctor of Psychology, Graduate Program in Clinical Psychology
Loma Linda University, September 2013
Dr. Jason Owen, Chairperson

A significant portion of the oncology population is seeking, yet not receiving, adequate psychological treatment. Therefore, the Internet has become an important resource for delivering services to those that may be limited by barriers that accompany traditional oncology support groups. While research has shown that online therapy is effective, the quality and efficacy of therapy is often unknown and/or sub-optimal and essential psychological care cancer patients deserve is compromised. The purpose of this project was to provide therapists and other mental health professionals with a structured, evidence-based guide to providing quality mental health care for cancer patients.

First, a review of the literature focused on meta-analyses that targeted psychosocial interventions for cancer patients, online therapy, and what has been done thus far with online interventions specifically for the oncology population is presented. Key ingredients identified as superior in outcome measures and clinical effectiveness include interventions that are more interactive, last 12-weeks or longer, incorporate cognitive-behavioral, educational and existential aspects, are facilitated by psychologists with more clinical experience, and target cancer patients experiencing emotional distress.

Next, a facilitation manual is outlined. Observations and clinical remarks found in this manual were written based off of this writer's one-year doctoral practicum experience as the primary facilitator for Health-Space.net., an online psychosocial support group for cancer patients and survivors that was created in accordance with the aforementioned relevant research premises. The manual was designed to outline how to create an online identity as a therapist, what to expect in an online environment, and how to manage first interactions with group members. Further, it explains twelve modules that are implemented into the group on a weekly basis; the content of the modules, as well as participant reactions and advantageous facilitator responses are discussed. Next, different components of the group are outlined, such as the discussion board, blogging tool, and the chat. Various themes, clinical responses and challenges/solutions are presented. Termination and the creation of the Alumni Group are described and personal conclusions are summarized.

CHAPTER 1

INTRODUCTION

Purpose of Project

Cancer. It is a word that has become uncomfortably familiar in the vocabulary of many when talking about loved ones, friends, co-workers, or even in reference to themselves. Cancer is now one of most prevalent and distressing conditions apparent in present society. As such, it warrants close attention and significant energy from health care professionals and researchers to continue to seek out interventions that ameliorate the destructive processes cancer can, and often does, create.

Specifically, psychologists play an important role in executing this mission. The impact of cancer effects individuals at various emotional, physical, psychological, social and functional levels; rarely is there a facet in one's life that remains untouched by a cancer diagnosis. While traditional face-to-face psychosocial interventions are being implemented for a number of cancer patients, a significant portion of the oncology population remains that are seeking, yet not receiving, adequate psychological treatment.

In an effort to seek out new vehicles for delivering services to those that may be limited by barriers that can be apparent with traditional support groups, technology, specifically, the Internet, has become an important resource. Access, convenience, flexibility, availability, and comfort are just a few of the unique advantages that are apparent when providing therapeutic services via the online environment. These distinguishing facets have made the Internet an attractive medium to explore, and as a result, research has shown that online therapy is, in fact, effective. Therefore, the large

numbers of people that are seeking and could benefit from psychological support, combined with the unparalleled advantages online interventions offer, make it clear that online therapy for cancer patients could be an important agent in providing this population with the necessary, and much needed support.

However, while there is potential for online therapy to be an exciting and effective mechanism for improving quality of life for cancer patients, there are considerable challenges that present when opening up therapy to the online world. One significant concern is that there is little to no regulation regarding the approach one could take when implementing therapeutic interventions. As a result, many of the techniques utilized in support groups may not be substantiated by research. Even when interventions are used for research purposes, many are not even outlined or described when cited in studies. Therefore, the quality and efficacy of therapy is often unknown and/or sub-optimal, which means the essential psychological care cancer patients deserve is compromised.

Clearly, there is a disconnect between providing meaningful psychological support via the promising medium of the Internet, and actual the implementation of such in a way that is responsible and effective. One way to fill this gap would be to provide therapists and other mental health professionals with a structured, evidence-based guide to providing quality mental health care for cancer patients.

The purpose of this project was to provide exactly that by creating a 12-week facilitation manual that details how to facilitate an online psychosocial support group for cancer patients and survivors. Implementing therapy based on a manualized intervention would not only ensure optimal patient care, but it would help propel research in this area

as it would provide objectivity, structure, and an appropriate level of rigor to research projects. This would improve study methodologies and thus, validity, reliability and quality of research in this area. Therefore, it is hopeful that this facilitation manual will fill an important gap in both clinical and research aspects of this field and provide professionals with the tools to successfully implement an informative, accurate, and innovative intervention with the aim of providing the highest level of online psychological care and support to cancer patients and survivors.

This project is designed to first, provide a review of the literature focused on meta-analyses that targeted psychosocial interventions for cancer patients, online therapy, and what has been done thus far with online interventions specifically for the oncology population. Following the literature review is a facilitation manual, which outlines how to create your online identity as a therapist, what to expect in an online environment, and how to manage your first interactions with group members. Further, it explains twelve modules that are implemented into the group on a weekly basis; the content of the modules, as well as participant reactions and advantageous facilitator responses are discussed. Next, different components of the group are outlined, such as the discussion board, blogging tool, and the chat. Various themes, clinical responses and challenges/solutions are presented. Finally, termination and the creation of the Alumni Group are described.

Thank you for time and interest in this project, I hope it proves to be beneficial and used as a tool in the important pursuit of providing genuine care and support for cancer patients and survivors.

CHAPTER 2

LITERATURE REVIEW

Online Psychosocial Interventions for Oncology Patients and Survivors

Prevalence

Focusing on providing compassionate and effective health care for cancer patients has never been more important; or more needed. Cancer has never been more prevalent than it is today. Stanton (2006) stated that the rate of cancer diagnoses are on the rise, increasing three fold in the last three decades. The most recent statistics reported by the National Cancer Institute indicate that as of 2012, there were an estimated 13.7 million cancer survivors in the United States (NCI, 2012). Further, approximately 1 in 4 deaths in America are attributed to cancer, making it the second most common cause of death in the United States (Siegel et al., 2012; Hong, Pena-Purcell & Ory, 2012). Clearly, a strong emphasis on cancer specific interventions is needed in order address this growing problem that continues to effect so many.

Cancer Related Distress

Not only is cancer an important issue to address due to the sheer numbers of people that will be diagnosed with the disease, but the invasiveness of cancer and its corresponding treatments in one's life is often overwhelming and substantial from an emotional perspective. Cancer hits many, and when it does, it often hits them hard. Therefore, while addressing the biological and medical aspects of cancer is absolutely

imperative, the emotional and psychological impact of a cancer diagnosis should not be overlooked. Cancer has been found to impart marked distress and life disruption (Singer, Das-Munshi & Brahler, 2010; Moyer, Sohl, Knapp-Oliver & Schneider, 2009; Hoey, Ieropoli, White, & Jefford 2008; Zimmerman, Heinrichs & Baucon, 2007; Stanton, 2006; Carlson et al, 2004; Carlson & Bultz, 2003; Rehse & Pukrop, 2003). The level of distress associated with the diagnosis and treatment of cancer has been deemed to be clinically significant in one-third of oncology patients, strongly warranting psychosocial intervention (Carlson et al., 2004; Stanton, 2006; Moyer et al., 2009). Further, it seems clear that part of the emotional distress cancer patients often experience is a direct result of the disease itself. Overall, Stanton (2006) found that significant psychological concerns and disorders in the oncology population were found to exceed those of the general population and therefore, more interventions that focus on this population and their specific needs are greatly needed. Some of the most common specific domains of distress that have been reported in the literature to impact cancer patients include: increased fatigue, pain, emotional distress, loneliness, loss of control, fears of recurrence, depression, anxiety, decreased physical and social functioning, compromised vitality, reduced self-esteem and decreased ability to perform emotional and physical roles (Moyer et al., 2010; Hoey et al., 2008; Carlson, et al., 2004; Stanton, 2006). Not only is the likelihood of psychological distress significantly increased for those diagnosed with cancer compared to the general population, cancer seems to cause marked distress even more so than a host of other serious illnesses. Polsky et al.'s study (as cited in Stanton, 2006) of 8,000 older adults found those with cancer had

significantly more symptoms of depression when compared to those who had other ailments such as chronic lung disease, heart disease, arthritis and diabetes.

Social Support

While it is evident that a substantial percentage of those who are diagnosed with cancer experience significant distress as a direct result, it is also apparent that not all cancer patients experience the same degree of emotional and psychological struggle. Evidence is increasingly indicating that there are certain factors that make it more likely for a cancer patient to experience distress. Further understanding as to who is more likely to be predisposed to distress is important, as is the ability to identify protective mechanisms that could prevent the onset of distress. Additionally, this knowledge is vital and can be utilized in the pursuit of providing interventions that are relevant and effective. Stanton (2006) identified several risk factors for distress: chemotherapy, social isolation or conflict, expectancies for low control and negative outcomes, and concerted attempts to avoid thoughts and feeling surrounding cancer predicted poor adjustment and functional limitations. Conversely, having emotionally supportive relationships and active coping skills such as problem solving, positive reappraisal and emotional expression abilities were found to be protective factors. Clearly, social support plays a substantial role in one's mental health and coping abilities. In fact, social support has been identified as an important contributor to overall well-being that buffers the impact of stressful experiences, including those related to physical illness (Hoey et al., 2008). This idea is not new. Bottomley & Jones (1997) described this phenomenon when they hypothesized mechanisms of the impacts of social support in cancer patients. They

identified social resources as having the ability to decrease the likelihood of stressful events occurring in the first place. They went on to explain that if stressful events did occur, the individual's interpretation of the event could be modified based on the extent of their social support network. In this way, they found social support to mitigate stress potential. The authors went on to present the hypothesis that because the degree to which role functionality is affected is often directly associated with stress, social resources could alleviate role strain, and thus, stressful experiences. Next, they described the idea that supportive individuals often exert a positive influence on cancer patients' coping strategies. This has the effect of bolstering and reinforcing the patient's own skills. Another way positive social contact has been hypothesized to work mechanistically is that it often supports the development of a positive self-esteem and feelings of personal mastery, which are useful for coping with health conditions such as cancer. Finally, the authors believed there to be a direct effect of social resources on adaptation level. Certainly, while there are many ways in which social support may function, it seems likely to be of significant benefit when one is facing a cancer diagnosis. From a psychological perspective, this is an important finding in that it provides researchers and mental health professionals with a critical target to work towards. Social support is a malleable facet in one's life that has the potential to be enhanced, purified and strengthened through appropriate psychosocial interventions.

Social Support Interventions: Effects and Approaches

Indeed, theory substantiates the critical component of psychosocial support and highlights the importance of focusing on ways to help augment this aspect of one's life

when dealing with cancer. An important practical question becomes: can the theoretical constructs and research hypotheses be translated to clinical outcomes? In a meta-analysis of 37 published controlled outcome studies that examined the effectiveness of psychosocial interventions on quality of life (QoL) for adult cancer patients, Rehse & Pukrop (2003) reported, “results clearly confirmed the overall hypothesis that psychosocial interventions reveal a positive impact on QoL in adult cancer patients” (p. 183). Zimmerman, et al. (2007) supported this finding in their meta-analysis of psychosocial interventions for breast cancer patients. In their analysis of over 50 RTC studies, they found an overall effect size of 0.26. They reported the success rate of intervention versus control group approximates 63% versus 37%. The authors concluded that their overall effect size was commensurate with the range of effect sizes (0.20 to 0.40) found as fairly typical in efficacious psychological interventions, as reported by Hunter & Schmidt (1990). Overall, the results of multiple meta-analyses support the conclusion that there is growing evidence that shows psychosocial interventions are likely to make an important difference in the lives of cancer patients (Rehse & Pukrop, 2003; Zimmerman et al., 2007; Till, 2003).

While psychological interventions are, in fact, known to be effective, identifying the most relevant facets of psychological functioning to target, as well as the most powerful approaches in doing so, would be advantageous in informing one about the most appropriate method of intervention. In a meta-analysis directed to explore the types of domains that have been targeted as a result of psychosocial support, Moyer et al. (2009) reviewed over 673 reports that included psychosocial interventions for cancer patients. They found that the primary goals of the majority of the studies reviewed were

to improve quality of life (QoL) and address coping skills regarding treatment side effects and physical effects of cancer. Overall, these authors found outcomes assessed were predominantly targeting psychological or emotional functioning, as well as physical symptoms.

From a more theoretical perspective, Bottomley & Jones (1997) presented the theory that social support is multifaceted and involves major constructs with the main elements being: 1) informational, 2) educational (affection), 3) instrumental (tangible such as finances and physical), 4) affirmation (sense of belonging) and, 5) appraisal. Further, they reported that health care research, including cancer care, found that the two domains that seemed to have the strongest correlation to health outcome were emotional and instrumental support. The authors reported that, therefore, it was these constructs that seemed to be the primary focus in social support interventions.

Moyer et al.'s (2009) comprehensive review identified specific intervention techniques and found nearly 33% of studies implemented cognitive, behavioral or cognitive-behavioral approaches. The authors deemed this as appropriate, as it has been indicated that a surmountable amount of cancer patients' distress arises from coping difficulties that accompany the practical and tangible aspects of a cancer diagnosis, treatment, end of life issues and survivorship. Further, the review identified that about 20% of projects were designed to be purely informational and provided patients with education regarding cancer and its secondary effects. Approximately 50% of the projects included in the literature review implemented at least some aspects of education or information. Similarly, it was found that about 50% of the interventions included ingredients to address stress and symptom management. Approximately 20% of projects

implemented “alternative medicine” approaches from a mind-body perspective. These included exercise, massage, acupuncture, meditation and yoga. Only a reported 10% of projects targeted what researchers described as “non-behavioral counseling or psychotherapy” and included interpersonal, experiential-existential, Rogerian and supportive-expressive psychotherapy (Moyer et al., 2009).

Regarding intervention format, Moyer et al.’s (2009) literature review indicated that about 50% of the projects were conducted on an individual basis, while about 33% were delivered in groups. Written materials were utilized in an estimated 33% of the projects, while a smaller, but undefined, proportion used technological components such as computers, videos or the Internet. Nurses and psychologists were identified as the most predominant intervention therapists or facilitators, although other health professionals such as social workers, physicians, or psychiatrists had been the providers in a small number of studies. Finally, a minority of projects were led by peers.

Carlson et al. (2004) reported on the most common interventions for cancer patients in a way that integrated intervention type, as well as format. They reported that the most common interventions could be broken down into four common categories; psychoeducation, cognitive-behavioral training, group supportive therapy, and individual supportive therapy. Importantly, they considered the phase of the cancer experience the patient was in when discussing efficacy of intervention type. They cited support for psychoeducation as being the most effective intervention during the initial stages of one’s cancer journey; the diagnostic/pre-intervention time period. The authors stated that patients who were in later stages of adjustment to cancer and who had more progressive disease seemed to benefit the most from support groups. Further, they found cognitive-

behavioral therapy techniques such as coping skills, relaxation, stress management, and cognitive evaluation seemed most beneficial in cases of extended treatment.

Intervention Moderators

Clearly, there are many therapeutic approaches available, however, determining more specific aspects of treatment interventions and understanding key elements that have been found to produce the best results would be important. Understanding the most evidence-based approaches provides guidance for establishing a sturdy framework when constructing and building effective clinical interventions.

The focus of many literature reviews has been just that, and they have looked to examine moderators in intervention studies that may be influencing outcomes. Rehse & Pukrop (2003) identified confounding factors that impacted the effect size of interventions. They found that psychosocial interventions proved to be most effective when they lasted 12 weeks or more. This finding was reiterated in Stanton's (2006) review of relevant research. In addition to the benefit of a 12-week treatment intervention, she reported that larger effects were found for trials in which participants were experiencing significant distress. Another important finding that was identified was that interventions seemed to have a stronger effect when the therapists that administered the intervention had more professional experience. Rehse & Pukrop (2003) went on to explain the importance of the therapeutic relationship as a moderator. They stated, "Stability and trustfulness of the relationship between patient and therapist are probably the most influential factors for psychotherapeutic treatment success" (p. 183). In fact,

they found the quality of the therapeutic relationship to be one of the strongest predictors of treatment success in general.

A research hypothesis that has been questioned has been the efficacy of having mixed-diagnosis versus similar diagnosis groups regarding cancer type. Results of Zimmerman et al.'s (2007) meta-analysis revealed that there does not seem to be evidence to support that those in mixed cancer groups find less benefit than those involved in groups restricted by cancer type. However, one finding concluded by Fawzy (1999) that is somewhat contrary to this conclusion, is that educational interventions seem to be most influential when tailored to stage and type of cancer. This claim deserves attention given the support that educational interventions seem to be not only very well represented in many different studies, but that this type of intervention seems to have the strongest effect. When summarizing the findings of numerous studies, two different meta-analyses found educational interventions to have moderate effects regarding psychosocial benefit for cancer patients (Zimmerman et al., 2007; Rehse & Pukrop, 2003). Rehse & Pukrop (2003) suggest that the superiority of education interventions may be a result of the structured nature of such approaches. They also noted educational interventions were the most available and well understood of the different intervention types. Stanton (2006) gave evidence to support the findings that educational interventions were found to be effective for cancer patients; she reported, "Effects of the educational group were significant on several quality-of-life parameters immediately after the intervention and 6 months later, largely mediated through enhanced self-esteem, body image, and reduced cancer-related intrusive thoughts" (p. 5134).

In addition to educational interventions being found to provide psychosocial benefits to cancer patients, different researchers have identified other interventions that have evidenced significant benefit. Cognitive-behavioral, relaxation, and supportive interventions were identified as having small, yet significant, effects (Zimmerman et al., 2007; Rehse & Pukrop, 2003). Stanton (2006) reported findings from her literature review that supports the efficacy of cognitive-behavioral based interventions. She stated, “Evidence suggests that interventions explicitly designed to enhance capacities to monitor and alter cancer-relevant thoughts, emotions and behaviors (eg, practice of new coping skills, relaxation training, role playing, goal setting, problem solving) produce larger effect sizes than do interventions lacking these components” (p.5135). In a previous literature review, Newell, Sanson-Fisher & Savolainen (2002) also found evidence for cognitive-behavioral interventions and added that group therapy, and counseling offered the most promising medium and long term benefits for psychosocial outcomes. Carlson & Bultz (2003) reported the results of a cognitive-behavioral intervention study with breast cancer patients. They found that women who participated in the intervention group reported less depression, overall mood disturbance, better overall quality of life, and fewer psychiatric symptoms both immediately following and 2-years post treatment when compared to the control group. The authors found evidence of an overall economic advantage to the treatment group as well. Women in the treatment group billed an average of \$221 less than the women in the control group, representing a 23.5% reduction in billing costs. Further linking health care costs with psychological health was the finding that billing over the two years following the study was positively correlated with distress levels immediately following interventions.

Therefore, the authors concluded that from a financial standpoint, addressing and treating emotional problems, including anxiety and depression, showed clear savings and resulted in fewer trips to general practitioners and specialists. The authors identified providing treatment from a group approach as one way in which treatment was made more economical. They explained that research has bolstered support for this intervention format and has found that group therapies have been repeatedly shown to be as effective, if not more so, than individual treatment for treating distress in cancer patients. Overall, these authors concluded that due to the effectiveness of interventions designed to improve quality of life in cancer patients, it would seem ill considered not to provide these services to cancer patients.

Need for Intervention Implementation

While it is clear that cancer patients often experience distress and there is a need to implement what have been proven to be effective psychosocial interventions to support cancer patients, there seems to be a disconnect between need and the amount, availability and quality of services available. This is problematic in that, not only are patient needs being unmet, but patients symptoms could even be exacerbated if not addressed. Singer, Das-Munshi & Brahler (2010) reported that evidence has been documented to indicate psychiatric conditions in cancer patients have a significant impact on disability and quality of life and will continue to worsen if left untreated. In fact, they found that 31% of cancer patients had significant psychiatric disorders, estimating that 40-90% of cases are left undertreated. Stanton (2006) bolstered this claim, reporting that in a study of 95 cancer patients, 57% of them reported that they had

needed help in dealing with cancer-related emotions, however, only 35% actually received such help. The author concluded, “Indeed, research documents important unmet needs that persist after completion of primary medical treatments” (p. 5133).

Although a number of patients seem to go untreated, findings highlighting the prevalence and underutilization of appropriate interventions are gaining recognition as a necessary part of patient care. Many have indicated that, in order for cancer treatment to be considered comprehensive, psychosocial support should be an important component of patient care (Stanton, 2006; Singer et al., 2010; Carlson et al., 2010). While this has been emphasized by many, Rehse & Pukrop (2003) summarized this idea clearly when they stated, “Therefore, some kind of psychosocial intervention should be routinely included in standard treatment programs for cancer patients completing conventional medical interventions” (p. 184). Importantly, patients seem to value and expect psychological support during their cancer experience. Newell et al. (2002) reported that 75-100% of cancer patients expected psychological therapies to assist their traditional therapies when implemented. Taken together, many agree with Carlson & Bultz’s (2003) conclusion, “Clearly, the time has arrived to promote a compassionate model for treating patients’ physical and emotional needs as a vital part of our health care system” (p. 5).

Expanding Intervention Options

Researchers and health care professionals are addressing the need for health related interventions by looking to technology, specifically, the Internet as a mode of delivering services.

Many different types of Internet interventions have been examined thus far, and the findings have been encouraging. In Barak, Hen, Boniel-Nissim & Shapira's (2008) recent meta-analysis of general Internet-based psychotherapeutic interventions, the overall weighted effect size was found to be 0.53, indicating a medium effect size. When the 92 studies reviewed were broken down, three main psychotherapeutic approaches were apparent; Cognitive-Behavioral Therapy (CBT), psychoeducational interventions and behavioral interventions. CBT interventions, indicated as such if the focus was based primarily on a combination of changing thought patterns and contents, associated with rehearsal of related relevant behaviors, were indicated to be more effective than the other approaches (ES=0.83). The least effective in an online setting was the behavioral approach (ES=0.23). Another finding was that web-based therapies that were more interactive were significantly more effective than those that were static.

Overall, research has shown that Internet psychotherapy seems to be as effective as other common types of therapy. However, it would be important to explore if these findings are also significant when exploring online therapy with the specific population of interest, cancer patients. In a recent systematic literature review, Hong, Pena-Purcell & Ory (2012) indeed indicated that the Internet is an important and effective method to work towards encouraging health-promoting behaviors among this population. With this finding, they emphasized the need to ensure interventions were culturally appropriate and evidence-based. Researchers found a growing body of evidence that, should the nature of online interventions meet these standards, "online resources could lessen the feelings of isolation, reduce stress, and provide a forum to share experiences, therefore, potentially improving survivors' ability to cope and increase their optimism and quality

of life” (p.289). The general consensus that online interventions for cancer patients seem to be effective was presented by researchers even earlier than this most recent study. Winefield (2006) confirmed a finding that had previously been described by researchers, that in examining online interventions for breast cancer survivors, messages in the online group were generally warm and supportive. He found that expressions of empathy and understanding, as well as sharing coping skills and health related information (i.e. side effects of drug) were commonplace in these types of forums. Till (2003) reported on the results of perhaps the most rigorous type of intervention, in which breast cancer patients were randomly assigned to a 12-week, web-based, semi-structured social support group. A health care professional served as a moderator and relayed information via an asynchronous newsgroup format. Findings revealed that the group was effective (moderate effect size) in reducing patients’ scores on depression, perceived stress, and cancer-related trauma measures.

Utilizing Technology

While research has recognized that online interventions for cancer patients are 1) effective, 2) needed, and 3) underutilized, it seems it would be important to focus on creative ways in which the gap between demand of services and implementation of such may be bridged. In a review of the literature on distress in cancer patients, Carlson et al. (2004) summarized the most important aspect of their study by stating, “This study serves to highlight a problem that has by now been well documented, and begs further directions and innovations in distress treatment” (p. 2303). They go on to stress the idea that more needs to be done to change the face of clinical oncology practice when it

comes to treating issues around emotional distress. Zimmerman et al. (2007) also alluded to the idea that future directions are important and should go beyond traditional approaches. They suggested that future interventions should explore formats in addition to group or individual formats. Barak et al. (2008) also emphasize the need for psychotherapy to adjust to modern times in their comprehensive review and meta-analysis of Internet-based psychotherapeutic interventions. They remarked on the idea that the use of computers and the Internet is rapidly increasing and becoming a common part of everyday life. They clearly suggested that taking advantage of this social phenomenon and utilizing this technology should be an important part of moving forward with psychological treatment. In reference to Internet use, the authors stated, “Psychotherapy and counseling should adjust to this changing world and adopt new, innovative tools accordingly to fit into the world of today and tomorrow to better meet clients’ expectations and needs...the current review shows that this is not only theoretically possible, but actually a developing professional reality” (p. 148).

Online Intervention Advantages

While Internet based interventions are still in great need of continued development, there are clear and unique advantages to providing therapy via an online modality. Researchers have recognized this and have been turning to technology as a feasible, practical and effective vehicle for providing access to beneficial psychosocial services in unique ways. Carlson et al, (2004) reported, “The data supporting the feasibility of computer-based technology is convincing, in terms of its reliability, acceptability to patients, and utility in improving clinical care around psychosocial

issues” (p. 2303). An important advantage to Internet based interventions is that the Internet is becoming a comfortable, natural, and accessible route for many. In fact, a substantial amount of the population is already using the Internet as a tool in an effort to learn more about their health condition (Klemm et al., 2003). This finding has been substantiated by Winefield (2006) who stated, “Seeking health information is now one of the most common reasons for using the Internet” (p. 193). In fact, in a recent study, Hong et al. (2012) revealed that cancer survivors report the Internet as the second most important source for cancer information after health professionals.

There are many reasons why the Internet is being so widely utilized that make online interventions advantageous. Many have reported that the shift of care outside of face-to-face interactions may have major implications for those whom access might otherwise be limited or restricted based on geographic location, service availability, transportation difficulties, economic limitations, or other restrictions (Hong et al., 2012; Winefield, 2006). For example, Carlson et al. (2004) reported results of a survey in which patients were asked why they did not utilize face-to-face interventions that were offered; 8.5% responded that it was too far to travel, while 8.1% cited problems parking as the main barriers to receiving treatment. The increasingly public and private availability of computers and the Internet are helpful in overcoming some of these barriers (Till, 2003; Taylor & Luce, 2003). Additional advantages of online forums versus face-to-face interactions include facets such as flexibility of accessibility (24-hour access) and convenience for the consumer. Specifically, online support groups have the advantage of bypassing scheduling difficulties, childcare concerns, location and space issues, flexibility in modality of therapy delivery, various facilitation options,

comparatively fewer resources required, and improved attendance rates among group members with poor health status and appointment conflicts. Further, the anonymous nature of an online interaction has been found to be another unique advantage for this forum in that it may increase the participant's likelihood of sharing and discussing more embarrassing or stigmatized topics such as sexual side effects or illegal drug use (Moyer et al., 2009; Till, 2003; Taylor & Luce, 2003; Klemm et al., 2003). Hong, et al. (2012) noted another advantage to online psychosocial support in that, because informed cancer survivors with good social support are more active and optimistic in their treatment and recovery, the use of online resources has been found to promote personal empowerment. Klemm et al. (2003) described the online setting serving an interesting advantage as an "equalizer because it avoids the visual distractions of age, gender and social status" (p. 136).

Another distinctive advantage online communications afford is the opportunity to further progress and improve research and understanding due to the written nature of online communications. Winefield (2006) introduces the idea of this unique advantage in that the written aspect of online communications allows for time for participants to "consider and polish their contributions rather than feeling pressured by the others' physical presence" (p. 196). Taylor & Luce (2003) and Winefield (2006) remarked that because the presentation of all communication in an online setting is via text, this gives researchers the advantage of examining word content in a way that may facilitate further insight into the therapeutic process.

Online Intervention Disadvantages

Of note, disadvantages of online support groups have been identified as well. Notable challenges of this modality include the requirement of computer and Internet access, the ability to be comfortable with the language in which interventions are offered, and the possibility that participants could become dependent on their online relationships, resulting in the possibility of increased social isolation (Till, 2003). Klemm et al. (2003) also identified further barriers to online support groups. They discussed the need for accessibility to a computer, modem, communication software and Internet connection, which makes online access possible. Should a cancer patient have access to all of these elements, another possible challenge the authors noted is that not all the information available on the Internet is reliable or substantiated, which may leave the individual misinformed. However, they also identify professional facilitation to help overcome this problem. They also went on to discuss one of the most controversial topics involving online patient interactions as being concern for protecting and maintaining patient confidentiality. The nature of the Internet makes this facet of online interactions less controllable, and therefore, more of an ethical risk for the researchers/facilitators. However, they noted researchers have indicated that this becomes less of a problem if the appropriate measures are taken to ensure patient information is secure and confidentiality is maintained.

Online Intervention Myths

One might imagine the main function of a support groups for many is to form close, supportive connections and relationships with others. And clearly, this is central to

many important outcomes. Cook & Doyle (2002) cited Lambert's (1992) common factors research, which stated, "relationship factors are the single largest variable over which therapists have some control, accounting for approximately 30% of therapeutic outcome"(p.95). These authors reported that one of the primary clinical questions raised regarding online support groups is the question of how effective this imperative quality of connectedness with others can be in an Internet support group. They discussed the common concern that it may be difficult, if not impossible, to form close, interpersonal relationships with others via an Internet environment. Given the central importance and substantial impact this variable has been found to have on clinical outcomes, this has been a vital area of research in the context of online interventions. Results of exploration in this area reveal, "both research and anecdotal data suggest strong and lasting relationships are being formed online" (p.96). These researchers go on further to discuss a study that compared members' offline and online relationships, in which depth and breadth were equivalent in each. Many other studies and literature reviews support these findings. In their review, Taylor & Luce (2003) found cancer patients' communication in an online setting to be similar to that found in face-to-face support groups (e.g. high levels of mutual support, acceptance, positive feelings).

More general issues than those pertaining to relationship specific concerns have been voiced. Specifically, the overall effectiveness of Internet-based interventions compared to face-to-face interventions has been questioned. In their analysis of 92 studies, Barak et al. (2008) debunk this myth with their conclusion that "Internet-based therapy, on the average, is as effective, or nearly as efficacious as face-to-face therapy"

(p.141). Similar findings have been reported elsewhere in the literature (Cook & Doyle, 2002; Taylor & Luce, 2003).

Klemm et al. (2003) addressed the concern that cancer patients with less computer experience or education may not find benefit from online support groups. Their findings revealed that age, education level, and computer experience were not shown to have any negative effect on participants' use of or satisfaction with these groups.

Future Directions

While there are many advantages, continued challenges, and unique intricacies to online interventions for the oncology population, this mode of treatment is still in developmental stages and there is a clear need for more research in this area. Even with many individuals already engaged in Internet use, there continues to be a demand for innovations in this medium. Hong et al. (2012), among many, have voiced this need stating that, "as the population continues to grow, the need to access credible, current Internet-based cancer-related resources are increasing" (p. 288). They go on to specify that cancer survivors are increasingly likely to turn to the Internet for both social and informational support, however, many support groups are often peer-lead and lack professional guidance. For those studies that are professionally-mediated, the effects of online support groups for cancer patients have been identified as preliminary. Further, while evidence for positive outcomes and promising findings have been demonstrated, it remains to be considered conclusive, and many researchers call for additional studies to go beyond the pilot stage in order to produce more broadly substantiated results.

Importantly, the need for outcomes from studies with more rigorous designs and more participants are greatly needed (Hong et al., 2012; Klemm et al., 2003; Till, 2003). In fact, Hong et al. (2012) reported that as of 2012, only four RCT studies regarding the outcomes of online cancer support have been published, three of which had a sample size under 100. Of the four RTC studies, none found significant positive outcomes for the intervention group. However, positive trends were indicated in 50% of the studies. Owen et al., (2005) clearly highlighted that their intervention group did evidence an overall trend of improved emotional wellbeing. In a second study, Hoybye et al., (2005) found that psychological wellbeing did improve, however this was found to be significant in both the intervention and control group.

A Need for Structured Interventions

Another limitation in the research literature to date is that many studies have failed to outline the mechanisms and approaches behind the interventions implemented in their studies. Many have acknowledged the importance of improving research and clinical methodologies, and researchers have expressed the need for manualized online interventions for oncology support groups. Methodologies have been described over and over as “poor” or “less than optimal” and a need for more standardized and manualized treatments has been called for (Newell et al., 2002; Klemm, 2003; Stanton, 2006; Moyer et al., 2009; Winefield, 2006; Till, 2003). Winefield (2006) made this clear when he stated:

Illness-specific websites offer patients and their associates information and mutual understanding by means of interactive discussion groups. Although many such websites exist, there are few guidelines for would-be facilitators of online support groups, or evaluations of their outcomes. After setting up

an online support group, initiators need practical and knowledgeable resources to sustain and enterprise beyond the short term (p. 194).

Moyer et al. (2009) reiterated this need when they reported that less than 33% of projects examined in their extensive review mentioned using manuals to standardize delivery of interventions. These findings implicate the important point that, clearly, more research is needed in the area of online psychosocial support groups for cancer patients and standardization of such treatments is imperative (Klemm, 2003; Stanton, 2006; Moyer et al., 2009; Winefield, 2006; Till, 2003). Standardization is necessary to ensure the most accurate and applicable findings are being reported and translated into effective interventions that result in optimal patient care. Implementing therapy based on a manualized intervention would not only ensure optimal patient care, but it would help propel research in this area as it would provide objectivity, structure, and an appropriate level of rigor to research projects. Outlining interventions via manualized treatments would improve study methodologies and thus, validity, reliability and quality of research in this area. Moyer et al. (2009) explains, “the field also could benefit from an increased focus on the mechanisms by which psychosocial interventions may have their effect and deliberate study of ways to improve diverse recruitment and retention” (p. 13). Attention is warranted at the level of transfer from research to practical, accurate applications. Many researchers have suggested this includes careful research in the area of development and implementation of effective interventions that are presented in a well-organized manner (Till, 2003; Stanton, 2006). Stanton (2006) concluded:

Many gaps remain in the knowledge base on psychosocial interventions of cancer survivors. Greater empirical consideration of the theoretically based mechanisms for effects of interventions will promote the development of maximally effective interventions [...] The promotion of evidence-based

approaches to psychosocial care is important, both through referral of patients to well-designed intervention trials and through incorporation of these approaches into practice. Pathways for effective dissemination of evidence-based interventions require much more attention. (p. 5135) Should this gap be filled, it would be an important benefit to this area of psychology in that manualized treatments would greatly contribute to making important and significant impacts on the cancer population and developing clinical guidelines and best-practice models of care (Moyer et al, 2009).

Conclusion

In summation, the literature has shown that cancer patients clearly experience significant distress that benefits from psychosocial support groups; online groups appear to evidence importance benefit as well. Extracting the components of various interventions that have been found to be most effective, and combining these facets with those that have been highlighted as needing more research attention, would be ideal in providing a vehicle for evidence-based advancement in this area. As discussed, the literature reveals that, not only do online psychosocial interventions in a group format appear to be as effective as face-to-face interventions, there are distinct advantages to the online environment which set it apart from traditional approaches. Research indicates that these advantages, coupled with the fact that cancer patients are already utilizing the Internet as an important resource, highlights the feasibility and necessity of online cancer support groups.

The literature has also made it a point to emphasize that not all online support groups for oncology patients are created equal. There are key ingredients that contribute to produce the most optimal outcomes. Online interventions that are more interactive, last 12-weeks or longer, incorporate cognitive-behavioral, educational and existential aspects, are facilitated by psychologists with more clinical experience, and target cancer

patients experiencing emotional distress have been superior in outcome measures and clinical effectiveness. The following facilitation manual is based off of the findings and observations of Health-Space.net; an online psychosocial support group for cancer patients and survivors that was based off of these premises.

Health-Space.net was created, designed, and supervised and under the principle investigator, Dr. Jason Owen, Ph.D. in his Behavioral Oncology Laboratory at Loma Linda University. Dr. Erin Bantum, Ph.D of the University of Hawaii was also a primary contributor and supervisor for this project. Observations and clinical remarks found in this manual were written based off of my one-year doctoral practicum experience as the primary facilitator for Health-Space.net. Of note, I was under the close, direct supervision of Dr. Jason Owen and Dr. Erin Bantum for the duration of this project.

CHAPTER 3

ONLINE FACILITATION OF A PSYCHOSOCIAL SUPPORT GROUP FOR ONCOLOGY PATIENTS AND SURVIVORS

Online vs. Face-to-Face Interactions: What to Expect

Online and Face-to-Face Group Differences

Technical Difficulties

Technology can be a wonderful thing. Technology affords us the opportunity to connect with others that may be hundreds of miles away from the comfort of our homes. With the luxuries and benefits of technology also come the technical difficulties and accompanying frustration. It is very likely that technical challenges will arise when conducting online therapy. The online psychosocial support group that I facilitated was no exception. Challenges were experienced on both the receiving end (group members), as well as on the delivery end (facilitator and technical support). While technical glitches would be extremely difficult to avoid, the impact and frustration levels, and amount of disruption they have on group members and the group as a whole can be minimized. While an array of different technical challenges may arise and specific problems would be hard to predict, there are some strategies that have been found to be effective for the majority of problems that have come up in this type of online group setting including acknowledgement, validation and empathy, and access to technological support.

Being transparent with the group and acknowledging that while the aim is to minimize technical difficulties, small glitches here and there are likely to arise is a helpful tactic in that it seems to ameliorate frustration when/if these difficulties do happen because they are more expected. Validating group members' frustrations with technical challenges and showing empathy regarding their reactions and concerns have also been helpful clinical approaches. This demonstrates caring and understanding for group members. It has also been important to thank them for their patience and let them know how much you value them as group members and care about assisting them with these difficulties. This is important in that it would be easy for group members to "give up" the group or not be engaged if it is something that is problematic or seen as a hassle for them. On the other hand, if done skillfully, responding to technical glitches can be an opportunity to build rapport with group members.

Another important component of the response to technical issues is to have technical support for the website. Assuring group members that technical support is available and will be addressing the issue soon has served to be seemingly settling and re-assuring to group members. It has been sufficient to have someone involved in the study also serve as the technical support person(s) due to their extensive knowledge in setting up and running these types of online websites. In this study, it was the primary supervisor and another graduate student involved in the research that served as technical support for the group. They had a screen name and log-in information so that group members could contact them directly with any questions/concerns/difficulties. This served to be very beneficial and effective in solving technical challenges in a timely and effective manner. It was also advantageous that the technical support people were also

very skilled clinicians so they were able to respond to group members in a way that was very empathic and therapeutic. Additionally, designating another person/source for more logistical concerns was beneficial for me as the facilitator in that it allowed me to remain focused on clinical interventions.

Response Times

Conversation flow has been one of the most notable differences when comparing face-to-face and online interactions. While face-to-face groups encompass a constant conversation flow within a fixed amount of time, the online environment is very different in respects to the conversation flow as well as the time constraints of group member interactions. There are two major ways in which conversations flow in the online group that not only differ from face-to-face interactions, but that have a marked difference from each other within the group as well. Response times in the online group are generally delayed compared to live, real-time interactions. Instead of immediate feedback, responses/posts in the online environment may take minutes, hours, or even days. Both benefits and drawbacks were noted with a more delayed interaction style. One drawback to a delayed response system is that, depending on the nature of the comment/post, immediate feedback is often helpful in that the person making the post could likely benefit from support in the moment or at that present time, which is unlikely to happen in an online setting unless they are in the chat or another group member is online at that time. Therefore, support, empathy, comfort, or feedback to questions posed may not be immediately available. However, an observed benefit of a more delayed response style is that responses can be well thought-out, well researched or accurately

informative (if applicable), and group members and facilitators can take time and care in the wording, phrasing and the content of responses. Thus, while responses may be delayed, they may have more of an impact and/or be more powerful, informative and beneficial to the group.

The facilitator can minimize the potentially negative impact that delayed responses may have on group members by acknowledging this limitation of the online format early on in the group members' participation in the group. This has been helpful in setting realistic expectations and helping group members orient to the online environment. Validating and normalizing group members can be done by informing them that if they do not receive immediate feedback, this is normal and expected in an online setting and does not imply their response was not important, or well-received. Thanking group members for their patience and expressing empathy that adjusting to a time frame that is often very different from their usual conversations/interactions may be difficult, frustrating or unusual in the beginning has been helpful. Further, encouraging them that it often starts to feel more acceptable with time may help group members tolerate any response time difficulties. For the most part, just saying a sentence or two about this has been sufficient. It might read something like the following:

In our fast paced world we are instantly receiving feedback right away. Just think about texting or calling or having face-to-face conversations with others; for the most part, the responses we get are instantaneous. This online group will likely feel a little different for you. While we hope that this group does become a daily part of your life, we also realize that busy lives, different time zones, appointments, obligations, etc, mean that you may not be able to respond to group members posts or blogs right away. This also means that there will likely be a short delay in others responding to the activity you are contributing to as well. While it may feel a little strange at first, this slower pace is natural and what we would expect in an online group. We thank you for your patience as others respond to you, as

well as your consistent visitations to the site so conversations can flow and develop.

From a more logistical standpoint, setting up the group in a way that sends an automatic notification through group members' email if there has been group activity (a post has been made, a blog has been written, etc.) has been a great way to prompt group members to respond in a timely manner. Of note, this notification should be an optional feature if group members do not like receiving multiple emails.

Connecting with Others

One of the most common, and valid, concerns that is often heard in regards to online therapy is the idea that not having in-person contact with other group members or the facilitator makes it harder to connect with others and form meaningful relationships. In my experience, I initially perceived this as the biggest limitation of the group. The lack of feedback that one gleans from observing body language, tone inflection, facial expressions, and having a mental representation of what a person looks like are aspects to in-person interactions that help develop human connections and are missed in an online group. However, it is important to remember that this ability to connect with others, even if through a computer where individuals are isolated from each others, is one of the largest benefits of having an online group in the first place in that it permits support and access to others for people who may otherwise have a difficult time in doing so. Further, there are techniques that have been found to be very beneficial

in helping to bridge the gap between the separation of group members that is apparent in an online environment. Acknowledgement of the challenge, creative use of available forms of communication to convey non-verbal information, as well as use of language and text to describe oneself and internal emotions have all been effective solutions in facilitating deep, emotional connections with group members, even in the absence of their physical presence.

Setting the stage for group members and having a discussion with them about what they might expect as far as connecting with others has seemed to alleviate apprehensiveness in this domain. Some group members may be hesitant to participate in an online group due to previous online interactions that felt dull, or due to preconceived notions they may have. One approach that has seemed to have a positive impact has been to acknowledge that the connections with others will feel different compared to in-person interactions; there is no getting around this. However, different can be just that, different, not necessarily better or worse. Encouraging them by conveying the message that although the feeling may be different, there are tips and techniques that seem to work well in establishing connections with others that are exclusive to online interactions. Overall, establishing the interpersonal expectations of the group to be unique and deserving of specialized skills, rather than establishing them as inferior to face-to-face interactions, seems to give the group members a perspective shift that alters expectations of what they may expect regarding forming connections with others in an online environment. Additionally, highlighting and teaching different skills may have the effect of deepening the relationships formed within the group.

Facial expressions are a way in which humans often connect with others. Although this element is lacking in an online environment, emoticons have been a great way to express and convey emotions in an online setting. It has been extremely beneficial to have a variety of emoticons representing a wide range of feelings that group members can choose to select and insert into their text when conversing with others. Although cartoonish in nature, emoticons seem to serve the purpose of being a vehicle to represent and convey human emotions to others in a visual sense. Facial expressions often convey meaning such as sarcasm, surprise, joy, happiness, disgust, fear, anger, sleepiness, etc. While emoticons are only representations of these emotions and are not personalized to the individual, they can serve to have the same impact in that they can give additional meaning and guidance in interpreting context. Showing emotion in live interactions is often an indication that a person is allowing themselves to be more vulnerable, comfortable, and/or open with others. Emoticons give group members the same opportunity, which often fosters deeper connections in an online environment.

Clinically, a significant difference in using emoticons versus having face-to-face feedback is that group members are deliberately and consciously choosing what type of emotion to display. As a limitation, these self-chosen emoticons may not always be a true representation of the group members' feelings and may be misleading. However, one potential therapeutic benefit to using emoticons versus live facial expressions is that the group member needs to be in-tune and mindful of what emotion they are feeling at that moment in order to select an appropriate emoticon to display. Providing a pictorial gallery of emotional symbols to choose from can often facilitate a conscious level of

emotional awareness and aid in the skill of accurate emotion identification. This ability may evoke emotional insight on a level that may not have been previously conscious.

Giving participants the option and ability to post pictures on their page, and to personalize their avatar is a way to go a step further from emoticons in that it gives a visual representation of the person on the other end of the computer, except this time, the pictures are individualized and depict the actual person, rather than just a generic symbol of them. This has been important in deepening connections in that it gives group members a visual sense and image in their mind of whom they are talking to. It makes the interaction more personal and more meaningful.

While emoticons and pictures serve to express non-verbal reactions or states, another important skill that taps into the opposite form of expression, verbal expression. This converse, yet complimentary, technique still serves the purpose of facilitating human connection through non-human (technological) means. Making the “non-verbal verbal” has been one of the most unique, and often challenging, aspects of being a facilitator in an online forum. Using language to express and encompass one’s entire experience requires mindfulness and self-awareness. This often requires one to be aware of their internal state and ways in which one expresses outward behaviors or reactions, and being able to convey and communicate these complex emotions in text form. This has been a critical and highly effective skill. Using language to “paint the picture” of one’s current state, often has the effect of emotionally connecting with others in that it is another way to create a more individual and intimate affinity between group members. This is a skill that is unique to an environment in which the visual information is not available. In live interactions, these are things that are often observed rather than

verbalized. Often times, when one starts to experience feelings, facial expressions are an indication to others that they are having an emotional reaction and thus, are connected and responsive towards them or the situation. Giving words to these “non-verbal” reactions allows for similar emotional information. As the facilitator, I have been touched many times by blogs or chat conversations with group members. Expressing to them things that I am experiencing that they would otherwise not know has been invaluable. Here is an example:

Group Member Blog:

Dear Self,

You do not realize it yet, but cancer will teach you so many things about interpersonal relationships, personal growth, spiritual change, acceptance and appreciation of life, concern for others, and health habits, among other things.

One thing you will realize concerns acceptance and appreciation of life. You will not continue to struggle with the "why me?" attitude and actually find that by going through and surviving that you are still you - even if physically you have changed - internally, you are still the same soul - albeit, a wiser and older soul.

You say "so what?" You have been given a great gift - the gift of facing mortality and staring it in the face - only to be given another chance - a chance to really appreciate all the things you have taken for granted.

Do you not note, rather than pass over, the visual beauty of another day - another sunrise or even rain - how it feels on your face - that you are alive?

When your pets rub their soft fur against your hand or face - so much pleasure to see you when you walk in the door - you take the time now, don't you...to smile and stroke their fur - to take the time to pause and play with them.

No more the rush of getting through life - you savor each second now, slow it down, and know to value time - because time keeps going. And by slowing and taking the time - you will remember so much more as happiness - as a gift to be here - and a second chance to appreciate life.

Love to you - from you - from me - to me...

Facilitator Response: Verbalizing the Non-Verbal

WOW! I didn't even realize that I was tearing up until the end of this when I noticed a warm, wet streak fall down my cheek. This really brought me to tears (in a good way). I was very moved by your beautiful words and was wishing I could reach through the screen and give you a big hug. Reading this made me feel so close to you.

I actually took the time to put down my computer and pet my dog for a good 5 minutes and just appreciated her soft fur and warm tummy after reading this. You reminded me of how precious life is and how much the little things, (like pets!) truly matter. Thank you for sharing this and making me step back and appreciate all that I do have. (My pup thanks you too! ☺)

Online and Face-to-Face Group Similarities

While many differences between face-to-face and online groups are apparent, significant similarities have also been observed. For example group dynamics have often resembled those found in live groups. Group members have exhibited the ability to form different dynamics and interactions with each other, as well as with the facilitator. Just as there are people in face-to-face groups that choose to talk more, or less, or are more emotive or have difficulties emoting or letting their guard down, these same dynamics have been observed in an online group setting as well. Tools and techniques in handling these dynamics in face-to-face groups have also been effective in an online group format. Similar to a live group situation, addressing any problems within the group is often most effective if done while the whole, or most, of the group is present in the chat. However, if problems arise that are more deserving of individual attention, the private messaging feature allow the facilitator to address these needs and “pull people aside” in this way as well.

Most importantly, using the techniques outlined above, very real, genuine connections between those involved in the online group, both group members and facilitators, form at a very meaningful and powerful level. Further, emotions are conveyed and expressed in many different forms and at many different levels. Facilitators and group members should expect to get to know others well, feel close to them, and learn tremendously from an academic, clinical, emotional, and personal level.

Preparing for Group Members

Setting up your profile

As a facilitator, prior to interacting with group members, it is important to set up a personal profile in order to give participants access to more information about who you are. This is an important step in beginning to establish rapport and a working relationship with the group members.

One important note is that it is important that the facilitator's profile page follows the same format as group participants. A primary reason behind this logic is that it gives group members an opportunity view the facilitator's page as a model when they set up their profile page. Also, while many sections are available, each section should have a "Keep Private" option that may be clicked to order to give individuals the freedom to keep their information or responses hidden from public view. Should they choose this option, while their information may not be available to others, there is likely personal therapeutic benefit to thinking through the exercise. The different components of the profile page are as follows:

My Photo

Participants

This option serves two primary objectives: 1) It gives each member an opportunity to share pictures of themselves with the group, 2) It gives group members the opportunity to connect a visual image of other participants to their online experience of them. In a sense, it facilitates the human tendency to want to put a “face to a name”.

When sharing pictures of themselves, there are various approaches different members take. Some choose to share pictures of themselves during treatment. For example, they may be bald or sitting in a chair during chemotherapy treatment. Related to this, some group members share pictures of themselves participating in cancer related events, such as relay for life. Conversely, some members choose to share pictures of their “pre-cancer” self, before any visual effects of treatment are apparent. This may reflect their level of acceptance or comfort with the disease. For example, one participant was often very upset when she felt others were treating her differently because of her cancer diagnosis. She was a group member whose pictures were of her “pre-cancer”, pictures in which there were no obvious signs of cancer.

One potential challenge of an online format is the absence of visual representations of other group members. Thus, the option to contribute and view pictures of others is very important. Having the opportunity to visually connect with others has been important in promoting conversation, facilitating feelings of attachment, and providing a realistic sense of support. Pictures often offer a plethora of information about a person via a visual format. Thus, the more information offered, the more

opportunity to find connections with others. For example, one member posted a picture of her with her Golden Retriever, another group member shared a love for these dogs and thus, their bond was strengthened through similar interests that may not have otherwise been apparent. Also, having a visual representation of someone may make cognitive associations easier to establish, making it easier for group members to remember them or things they share with the group. In this way, when a group member posts a picture, they become more than a screen name, they have more meaning in the group.

Facilitator

Similar to participant profiles, the facilitator can use this feature to upload a picture, or pictures as well. Sharing pictures of ourselves is not something we normally do with clients either at all, or at least until we have established strong rapport with them. Therefore, as a facilitator, it may feel a little awkward to make pictures available to clients. However, the online nature of this type of group makes this a very important feature. Similar to the reaction group members may have when they are able to see each other, this provides the opportunity for group members to put a “face to the name” of the person from whom they are receiving emails, comments, requests, replies, query’s etc. Furthermore, it is important in the beginning to establish the important components of forming a human connection.

In my experience, I choose to post pictures that I was comfortable participant’s enquiring about, and pictures that I felt captured different aspects of my personality that may appeal to a wide range of people. For example, I posted a picture of my dog and me

in an attempt to connect with other animal lovers. I posted a picture of a hike I had been on to possibly appeal to those that enjoy the outdoors or fitness. Additionally, because she has been important in driving my passion for my work with cancer patients, I posted a picture of my mom and me. Finally, I chose to post a picture of when I completed the Tri For The Cure, a triathlon that benefited breast cancer, to exemplify my dedication and commitment to cancer treatment and awareness.

Cancer Type

Participants

Often times, filling out their profile is the first step group members take in their participation in the group. As such, this may be the first time they are asked specifically to open up about their cancer experience. This subject may be very overwhelming for some participants; therefore, guiding them by offering a prompt may be helpful. One example to get them started is the following: “*My understanding of cancer is:*”

Participants have tended to indicate the type of cancer, with some including more information than others, such as the stage and more information about the specific type while others are more general in their response.

Facilitator

It would not be necessary, nor would it be common, for the facilitator to have experienced a cancer diagnosis firsthand. Therefore, at first glance, it may seem that this section may not pertain to the facilitator. Importantly, even if the facilitator has had a

history of cancer, it would be important for them to have the option to disclose that at the discretion of their clinical judgment. However, it is not necessary to leave this section blank either, as having an understanding of cancer does not necessarily mean one has to have personally had cancer. Unfortunately, cancer is such a widespread medical condition that it would be rare to find anyone, facilitators included, that has not been affected by cancer in some way. In fact, it would not be uncommon for a facilitator to be interested in working in behavioral oncology because cancer has personally influenced them in one way or another. Therefore, it is likely that everyone involved in this group has some sort of understanding of cancer.

Personally, I grappled with filling in this section of my profile for a number of different reasons. I wanted to portray that, while I had an understanding of the emotional impact cancer can have, that didn't mean that I understand cancer. I wanted to be careful to make this distinction as many cancer survivors have voiced their frustration with people that have not experienced a cancer diagnosis saying they "know" what it's like for the patient. I wanted to create the impression what while I can be empathetic, I don't pretend to understand each group member's personal experience. Further, I wanted to be clear that I encourage and appreciate leaning from them about their experiences. At the same time, I wanted to offer the mindset that I can, and do, respect the profound impact cancer can have on people and support systems, as this was something that I have personally experienced. In trying to be mindful of this balance, I choose to be more conservative with my profile, as to avoid the possibility of any adverse reaction from a group member who may think I am trying to say that I "get it" by posting a personal response. As such, I choose to post a quote instead of a personal reaction. I felt that this

was a way to acknowledge a little distance between myself and those that have personally experienced a cancer diagnosis, while at the same time, express empathy for the complexity and difficulty of a cancer diagnosis.

The following what I choose to post on my profile:

Cancer comes into a life and worms its way in. It's the unspoken presence every day of the person's life- 'the cancer's back' or 'in remission' are common referenced in the life of the person with cancer. However, it continues to be the people who can fight it that make the whole disease seem beatable and worth fighting. -unknown

When Diagnosed

Participants

Most often, participants have been open to sharing when they were diagnosed. Many participants have experienced multiple diagnoses and note the type, stage, and date of diagnosis. In my observation, many of the dates participants post are very specific. This may parallel the likelihood that and these dates are very pertinent to each person and represent a distinct and specific turning point in the timeline of their life.

Facilitator

This section may or may not be applicable to the facilitator. Even if the facilitator has experienced a cancer diagnosis, they may or may not choose to share this information. This decision should be made using the facilitator's clinical judgment.

Because I have never had a cancer diagnosis, I left this section blank.

My Age

Participants

Depending on the goals, population, and recruiting sample the group is based off of, the age ranges may vary. However, it is typical to see participants in their mid 50's to early 60's.

Facilitator

In my experience, group participants have represented a wide range of ages in the group. For the most part, group members were open to sharing their age. This factor seemed to be irrelevant regarding group cohesiveness and strong bonds and connections seemed to form with group members regardless of their stated age.

I chose to leave this section blank. Being a young facilitator working with many older adults, I felt it was important for them to get to know me and for me to have the opportunity to establish rapport with them before I disclosed my age, if at all. For many of my participants, I was similar in age to their children or grandchildren. Therefore, I felt that sharing my age with participants before interacting with them might create a potential for bias. I felt that for many, there may be a reluctance in receiving "help" from someone that is much younger in age than themselves, or just that they may not be used to this idea. For many group members, they taught their children life skills, offered them advice, and shielded them from their own uncomfortable feelings in an effort to "put on a brave face" to protect them. An important aim of the group has been to discuss, acknowledge, and process negative, uncomfortable feelings such as fear, shame, guilt,

etc.; feelings older adults may try to shield from younger generations. Therefore, I felt it would be important to have the opportunity to create an environment of acceptance of all feelings, “the good, the bad and the ugly”, as I would often say. Additionally, I wanted to create confidence in them regarding my therapeutic skills and abilities before disclosing my age in an attempt to ward off any initial skepticism or apprehension that may naturally come with seeing a number that may come with a preconceived notion.

Where I’m From

Participants

This section is important because, unlike a face-to-face group where people often are from the same communities, online groups have the potential to have participants from varying locations, communities and environments. This section gives the opportunity for participants to share more about themselves based on their location. In my experience, many participants found location to be a connecting point, or way for them to relate to other group members. Many times people had visited a place another group member was currently living and they could talk about their experiences that way. At other times, people had family located close to other group members, which created a sense of connection or familiarization with the group member. Additionally, it was a unique and interesting experience for people to be experiencing different events and phenomenon, as they related to their location, and this often became a topic of conversation. For example, one participant lived in a place where there had been hurricanes and the other group members were very interested in supporting her during

that time. Another example of a way disclosing location seemed to foster a bond between participants was when two group members from different parts of the country were able to establish a connection with each other because they were both living in more rural parts of the country where a large extent of travel was necessary for their cancer treatments. Together, they were able to express their frustrations and problem-solve possible solutions to barriers they were facing related to fatigue and the difficulties this brought to the traveling process.

In most cases, group members are brief and indicate where they are currently living.

Facilitator

For my profile, I chose to disclose where I grew up as well as my current location and place of study as to give different points of reference and more opportunities to connect with others.

My Family Situation

Participants

Similar to the “Cancer Experience” section above, this is another facet of the participant profile that has potential to be overwhelming in that participants may not know how to respond. In order to help direct participants with this section, they are promoted with the following: “What you should know about my home of family life:” This is a fairly broad and open-ended prompt. While the disadvantage of this may be that

it leaves participant's not knowing what to write, a significant advantage to not asking specific questions is that it leaves it open for participants to share as much or as little about this topic as they would like. For example, for someone with a very supportive family, this leaves them room to describe the impact of their experience openly. Conversely, if a participant's family has been disappointing in their reaction or support and this is a sensitive subject, there is no probe for that information or pressure to divulge that information at this point.

There are variable responses to this section of the profile. Some group members talk more extensively than others and describe their children or significant others in detail, some leave it blank entirely and some answer in a way that reflects an answer, but is left very general may not disclose personal details.

Facilitator

Not unlike many other sections on the profile page, the facilitator's clinical judgment regarding how much they choose to disclose in this section is important. However, this is also a section where it may be beneficial to disclose more information than one normally would in a face-to-face environment in order to create more opportunity for group members to get to know you and feel connected with you as a facilitator since other opportunities to create this rapport are more limited in an online environment.

Personally, my family is central to my life and I have been incredibly fortunate with a wonderful, involved family. My reaction was to "gush" about them here and talk about how great they have been. However, I wanted to be mindful that, while I am

incredibly fortunate, and this may not be the norm with participants. Further, I wanted to avoid a situation where they might read about how much I love my family and then feel that I would not understand or be open to discussion of how family relationships may be disappointing or how they may experience other negative emotions towards or from family members. In an attempt to balance these issues, I shared my positive feelings towards my family but did not expand upon it to a large extent. Additionally, because of my mom's personal battle with breast cancer, and my father's experience with his father passing away from cancer at a very young age, cancer has had a large effect on my family. I wanted to be somewhat open with the group regarding my personal proximity to cancer and its effects in an effort to convey my understanding of cancer at a level that goes beyond an intellectual capacity. I wanted to give participants an idea that I can truly and personally connect with a lot of the emotions that cancer can evoke that may be difficult to articulate or verbalize. At the same time, I did not want the focus of the group to be on my cancer experience with my mom and my family. While difficult, I tried to find a balance between how much or little to disclose and came up with the following:

The following what I choose to post on my profile:

My family is my home. I am lucky enough to say that I have has the most amazing, supportive and living family. I have two best friends, who also happen to be my siblings. We are very close in age which made growing up so much fun! I also have two wonderful parents who mean more to me than they will ever know. My mom is the beautiful woman in some of the pictures I have posted. She was diagnosed with breast cancer about 4 years ago and after a tough battle (chemo, radiation, etc.) she is in remission and going strong!

My Interests

Participants

This section should be left available for participants to share more about themselves and to give them the opportunity to share things that may not be prompted for in other sections. Therefore, participants are given the opportunity to speak about their personality by discussing their interests. It is also an important place for group members to find commonalities between themselves and others in the group and to find ways of connecting with others in an online setting.

Facilitator

Similar to other sections, this section offers the chance for facilitators to give group members a closer look into their life and share more information than they might normally give in a face-to-face setting.

Personally, my goal for this section was to find a way of connecting with participants without divulging too much information. I chose to include interests such as my favorite sports, flowers, foods, pets and outdoor activities.

My Story

Participants

In order to cue participants, a possible prompt may start with: What you might like to know about my life and/or my cancer:

In this section, participants are offered the opportunity to give more or different information versus what was prompted for in the above sections. It is an opportunity for those who are more comfortable with personal disclosure to give details about their experience, while it does not ask specifics about one's cancer journey and pressure those that may not be initially ready to share. There are often variable responses, some group members left this section blank, others simply wrote the date diagnosed and/or cancer type, while others choose to share details and personal remarks. For example, one group member wrote the following:

I was diagnosed with Stage IIIA invasive breast cancer in March of 2010. I underwent a modified radical mastectomy, chemotherapy (Taxotete, Carboplaatin), targeted therapy (Herceptin), radiation, and am still receiving endocrine therapy (Armasin, an aromatase inhibitor.) I'm currently disabled because of pain and fatigue, many residual and ongoing side effects of the treatments. I'm currently volunteering at my cancer center in the infusion room weekly for a couple of hours, I belong to a local cancer support group for women, and recently received training from the American Cancer Society to be a Reach to Recovery volunteer. I feel that giving back, especially since I'm unable to work, helps me mentally. I love spending time with my family, and also help my husband with the bookkeeping side of his business.

Facilitator

Paralleling the opportunity for group members to disclose any other information they want to portray to the group, facilitators can use this section for the same objective. Many facilitators may be interested in psycho-oncology for different reasons and often, participants are interested in how facilitators came to be involved. As such, this section provides the platform to disclose that information to the group.

Personally, I have always had a heart for cancer research, and working with cancer patients. This changed from an interest to an extremely personal experience when

my mother was diagnosed with breast cancer right after I graduated from college. In my work with cancer patients in a face-to-face setting, I rarely disclose this information, but make it a goal for my empathy and understanding to come through via my body language, tone of voice, facial expressions etc. Because these elements are non-existent in an online setting, I choose to disclose my personal connection with cancer in this section of my profile. Because other methods of portraying this information as I would in a face-to-face environment were unavailable, I felt it was a way for me to portray more understanding, acceptance and personal relatedness with cancer.

My profile included the following:

“Kristen, what do you want to be when you grow up?” A common question my first grade teacher asked me one day. My response: “Well, first, I am going to find the cure for cancer, but after that I want to be a marine biologist.” When I was little, I was convinced the cure for cancer was something simple. Surely, the answer was just some weird combination of different foods. So, I spent hours in the kitchen (standing on a stool so I could reach the counter), mixing different concoctions trying to find the magical cure for cancer. Pickle juice and peanut butter. Mashed up grapes with flour and a dash of mustard. Coffee grounds and yogurt. Thinking back, I am not sure why my parents allowed me to waste so much food and make such a mess at the same time! Probably because when my dad asked me what I was going. I told him I was looking for the thing that could save him from ever leaving me. I thought that because his dad had cancer and passes away when my dad was a kid, my dad might do the same. I was determined that my dad, my hero, was not going anywhere! Unfortunately, my kitchen wonders didn’t do the trick. Fortunately, none of you will ever have to eat tuna cereal as a part of your treatment plan. While combining bizarre goods together may not be the answer, I believe that combining people that can understand each other, cry together, laugh together, be frustrated and angry together, be happy together, be in pain together, and be triumphant together may be a pretty good start. So, that’s why I am here! And I look forward to get to know you and your story.

Preparing for Your First Interaction

If you are starting your role as a facilitator with a group that has already been running, or you have access to viewing groups that have run previously, you have the advantage of having the opportunity to familiarize yourself with the online environment and the online format. Taking the time to become comfortable with the online forum may be important for a few reasons.

First, you will likely get many questions from group members regarding how to do certain things and where various components of the group can be found, so having a working knowledge and familiarity with the website is important to be able to show competence to your group members and be able to assist them in their online difficulties.

Another important reason is to help establish empathy and patience with group participants. To some, an online support group or therapeutic experience may be brand new. Further, many group members are elderly and may have limited experience or lower comfort levels working with the computer and/or Internet. Therefore, as a beginning facilitator, it may be helpful to note your initial challenges with the group and ways to overcome these barriers so you can share an empathetic understanding of these frustrations and offer potential problem solving strategies when group members are struggling as well.

Finally, reviewing and studying past online blogs, chat transcripts, etc. are great ways to find examples as to how people express themselves via text. Clearly, becoming familiar with different ways to express emotion and effectively communicate online will

likely help you feel more prepared before your first “live” interaction with a group member(s).

First Interactions

Send a Private Introduction/Welcome Message

For many participants, this may be the first point of contact between you and them. It is important that this contact be made as soon as possible, ideally, within 24 hours of them joining the group, in order to set the precedence that this is an active group. Responding quickly as a facilitator models the importance of this aspect of the online group.

Introduction

A nice way to start the “Welcome Message” is to mirror what you would first do in a face-to-face environment; introduce yourself. In my experience, it is not uncommon for group members to have participated in online support groups, but it is likely rare that these groups have been professionally facilitated. Therefore, outlining your training credentials and qualifications is important. Because online groups are designed to be accessible for a variety of populations, many group members may find the group through different means, not necessarily through a referral from another health provider. Therefore a more thorough explanation of your background, training and roles may be relevant for an online forum. Further, if the facilitator is a trainee, their status as an unlicensed professional should be made clear, and the contact information of the

supervisor whose license one is practicing under should be given. Additionally, the role of the facilitator should be outlined and described so expectations for the group are established.

Goals of the group

An online psychosocial support group may seem very foreign for some participants. Even for those that have participated in groups before, it is likely that there is extreme variability between groups and each one looks and operates very different from the next. Therefore, taking time to outline the goals of the group, giving the participants a good idea of what they can expect as a group member, and what is expected of them, is important.

First, the necessity of the group member to participate is critical. Letting group members know that they will get out of the group what they put into it is an important idea to get across from the beginning. Unlike a face-to-face environment, outside of the chat, immediate responses and feedback from group members and the facilitator is not realistic. Rather, there is some “lag time” between when a group member posts and when they receive a response. This is a communication experience that is unusual in face-to-face interactions, in a world where instantaneous responses are expected. Therefore, establishing this norm is important in order to help augment tolerance for delayed feedback. Simultaneously, it should be emphasized that a goal of the group is to have it be an active group. One way to work towards this goal and overcome the barrier of “lag time” is to log into the group often, daily if possible, to post and/or respond to other group members’ posts. If group members express concern over being able to

remember to do this, strategize with them over possible ways to queue them. Setting an alarm to remind them to log on, or setting a consistent time of day they plan on logging in are some examples.

Once the understanding that posting and being active in the group is important has been established, the next step in the Welcome Message would be to outline where and how to post. The facilitator should make it clear where to post and under what circumstances. For example, appropriate use of the discussion board should be clear. I have found that an “anything goes” approach to the discussion board has been advantageous, but even so, making sure group members are aware of this is important to dissipate any reluctance or uncertainty when they are thinking about posting. The facilitator should clearly state how to post to the board (e.g. ‘click the grey tab labeled “discussion board” on the upper left hand side of the first screen that appears after you log in’). Other important components would be to discuss how one goes about completing a blog and how they might put that function to use. In my experience, blogs were a great forum for completing the exercises for the weekly exercises (more on this later).

Make it Personal

While much of each Welcome Message can be the same for all new group members, it may be discouraging for many to feel like they are getting a generic “welcome”. Therefore, personalizing the Welcome Message to each individual provides a nice opportunity to make him or her feel like a valued and unique member of the group. It also lets them know that you, the facilitator, have taken the time to look over

their profile and are interested in them as a valued group member. A great way to do this is to look over their personal goals that they are asked to identify as they set up their profile and include a statement that reflects these goals. Taking it one step further, identifying ways in which the group may help them reach those goals is a way to instill hope and excitement about the group.

There are many different components to the group, including a chat room, a profile page, blogs, a discussion board, personal messaging, etc. While these facets each serve a unique and important function, it may seem overwhelming to new group members at first. A very brief explanation of each of these components in the Welcome Message may ease some anxiety and make the group feel more manageable.

The guidance modules are also an integral part of the group and provide structure and focus to the group, something that appeals to many group members. The guidance modules should be introduced in the Welcome Message and the current topic should be clearly stated.

In my experience, it has seemed that the quicker participants become engaged and active in the group, the more likely they are to remain an active member. Similarly, the sooner they start participating in the chat, the more likely they are to be consistent and active in the chat. Therefore, encouraging active participation and joining the chat as soon as you make contact with a participant is very important. In the Welcome Message, encouraging them to post and giving a suggestion about what to post about may help facilitate their participation. To evoke a sense of responsibility, ask them pointedly if they are can make the chat this week. Be sure to include the chat time and day (including different time zones) as well.

Finally, the Welcome Message should end by asking group members if they have any questions or if there is anything you, the facilitator, can do to make this a more enjoyable or meaningful experience for them. This opens the dialogue and promotes a feeling of mutual respect between facilitator and group member. It also welcomes an atmosphere of open communication and can give the facilitator important feedback on how to improve and continue to progress and nurture the group. Below is an example of an appropriate Welcome Message:

Hello _____,

Hope this finds you well! My name is Kristen, I'm one of the facilitators for this community. I'm am so excited that you have joined our health-space family :). I really hope this can be helpful for you.

I am not sure if you have tried online groups before or not. If not, I am excited that Health-Space gets to be your first! If so, you may find many differences between our group and others you may have been in. One thing that I think is a major advantage of this group is that it is professionally facilitated. What that means is that as your primary facilitator, I have been training for 4th years in a Doctorate of Clinical Psychology program at Loma Linda University with an emphasis in Health Psychology. While I am getting there, I am not licensed yet, but I am being supervised by two phenomenal Clinical Health Psychologists and am working under their license. Their names are Jason Owen, Ph.D and Erin Bantum, Ph.D. If you have any questions about them or would like more information about their interests/qualifications/etc. please see their link to the left of the sign in screen or just ask me, I am happy to answer any questions.

Just a few tips and tricks that should hopefully help you get started. Something that can be very different about health-space versus real life is that, because we don't know each other in "real life", it can be more difficult to get to know people online without taking the risk of posting a message about yourself and/or making an effort to actually write to some of your other community members. I was taking a look at your personal goals and it really sounds like you will be a good fit for the group! I know you mentioned that you are interested in transitioning to a cancer patient to survivor (congrats!!) and learn work on not having cancer fill your mind. Coping skills is definitely something we touch on frequently and I feel that

those might really help! Also, I would really suggest the group chat for you because that is the best way to feel immediate support. We dive into some very meaningful issues but laugh a lot and have a great time in there as well!

There are many different components to the group and I know some people tend to feel a little overwhelmed by it all at first but hopefully it will become more and more comfortable the more time you spend logged in. If you take the time to write and get involved, I think you'll find that you get out of it what you put in! Posting a short introduction on the Discussion Board is a great way to get started... something about yourself, perhaps what you hope to get out of this community, and what kinds of things might be adding to your levels of distress right now? While those topics might be great ways to get started, remember that this group is designed for YOU and we want it to be as helpful as possible for you. Please feel free to post anything you would like on the discussion board: questions, comments, suggestions, stories, quotes, inspiration, frustrations, etc. This is your space. If you aren't comfortable posting something new, responding to others is also a great way to get your feet wet and also an important part of the group throughout all 12 weeks. Private messaging works a lot like an internal email system and is also available if you want to talk to someone more privately/directly. You can create blogs, which is what I will often use to use to respond to the exercise of the week (introduced in the chat and posted just above the discussion board). Also, we offer a number of "guidance exercises" (click the Guidance button at the top of the page) that you can go through completely on your own or follow the group, and, finally, most participants mention the live chat as their favorite part of the group. We have a weekly, real-time, live conversation online, once a week in our chat room- Wednesday evenings at 6pm (PST). We'd love to see you there! It's a great way to get to know everyone that's here. Do you think you can make the chat this week? It may help you get to know others and get that feedback you are looking for.

Something that you might notice that is different from an online group versus a face-to-face interaction is that there is some delay between when you post and when you get a response, just something to keep in mind as that sometimes takes some time getting used to. It is nice to get feedback as soon as possible so in order to help minimize the "lag time" I really encourage you to log onto the site as much as possible, once a day or every other day would be great!

I look forward to getting to know you!

Warmly,
Kristen

Introduce New Members To The Group

A great way to help facilitate new group members feeling welcome is to post a discussion board message that introduces them to the group. It is important not to post too much information about them, as they deserve control over how much they disclose to the group and when, but notifying the group that a new member has joined often evokes other group members to respond to the new member and engage them with the group. Here is an example of an appropriate discussion board post

Hello Health-Spacers! It is my pleasure to personally introduce _____ to the group! Hoping you will get a chance to know each other over the next few weeks. We are happy to have her join our Health-Space family!

Potential Challenges With New Group Members

They Are Inactive

In my experience, despite positive modeling and outreach to group members on an individual (personal Welcome Message) and public (introductions via the discussion board) level, some group members remain inactive. They may post very infrequently or not at all. This is one of the major challenges of an online group. While difficult to engage participants who are inactive, there are a few techniques that the facilitator can try in order to engage participants.

Send a private message to the inactive group member

This message should acknowledge the participant's inactivity in a way that is warm and empathetic, rather than accusatory. At the same time, asking for feedback on why the group member has been unable to fully participate in the group can be very informative and may facilitate a better understanding of the situation. It would be unfair to assume that the group member is simply ignoring the group or does not like the group. With cancer patients, some members may be having medical issues that are barriers from participating, such as hospital stays without Internet access. In these cases, it is important to provide support to the participant and understand that their priorities may not be to the group at this time. An example of a response to someone who said they were inactive due to being in the hospital or extremely ill may be:

I am so sorry to hear that you are not feeling well. It really sounds like you are going through a lot right now and are facing some tough situations. I completely understand that your emotional energy and time needs to be put into what is best for you and your health right now. You are the expert in how you are feeling so I encourage you to be mindful of your body and participate as much or as little as is best for you during this time. Is there anything we can do as a group to help support you right now? If so, please let us know. Thinking of you!

Another possible reason for low activity or inactivity may be that the group member was surprised by the group or it was not what they were expecting. If this is the case, a series of private messages clarifying what the group member was hoping the group would look like and how those goals can best be achieved may be beneficial. If the group members' goals were realistic among the group, problem-solving with them regarding steps they can begin to take towards those goals would likely be helpful. If

their goals are outside of the confounds of the group, a referral to resources that may better fit with their individual needs would be appropriate.

Another reason for no/low activity could be that group members may be experiencing technical difficulties or confusion with the online aspect of the group. If this is the case, sometimes a simple explanation or suggestion on how to best navigate their technical difficulty may be the only step necessary in having them become an active group member.

Unfortunately, some members may still be unresponsive even after many outreach and engagement efforts. One final option may be try to create a public opening for the group member to engage in the group. One example of doing this may be to post a public message to the discussion board, without singling group members out and making them feel uncomfortable, that acknowledges how difficult it may be to become engaged in the group, normalize this process and create an easy opportunity for the person to become involved. Here is an example:

Hi all! I hope this finds everyone having a peaceful weekend. I just wanted to thank you all again for joining the group, I know this may be kind of a new experience for many and posting publically to a discussion board full of people you hardly know or replying to someone who may feel like a “stranger” at this point may be really scary and uncomfortable. The good news is that I really believe that it becomes easier the more you give it a shot! And in my experience, in no time at all “strangers” become friends and great sources of support. So I just wanted to take the opportunity to welcome anyone who has been a little hesitant to post and I really encourage you to give it a try! Maybe start with one thing you have noticed about someone else in the group that you could relate to, or even just give us an update on your weekend. Thanks for your efforts, looking forward to getting to know more of you!

CHAPTER 4

WEBSITE COMPONENTS

The Guidance Modules

Guidance Module Aims

The guidance modules are designed to provide the group members with a new topic to focus on each week, for 12 weeks. The group facilitator should introduce and provide psychoeducation regarding the topics in the chat (see **Website Components: The Chat** for more information) and then guide any discussion regarding each week's topic. The guidance modules have been adapted from the Nucare workbook (Watts & Edgar, 2004), which aims to teach individuals how to cope with their cancer at an introductory level. The intervention focuses on two major components: (1) the enhancement of a sense of personal control; and (2) the learning of emotional and instrumental coping responses. As such, the goal is to provide didactic information, enhance training and enhance skills in problem-solving and relaxation techniques, provide cognitive coping skills, goal setting and communication skills, and augment social support and healthful lifestyle factors.

There are three different ways in which the guidance modules are used in the online group. First, group members are encouraged to read the appropriate guidance module that pertains to the current week on their own. The facilitator should clearly state what the guidance module topic is for the week and keep this updated on a daily basis to prevent confusion. The group facilitator should also make it clear as to on what day of the week the guidance module topic changes.

The second way the guidance modules are used in the group is through the chat. It has worked well to have the guidance modules rotate on the same day as the chat. In order to communicate these changes and shifts clearly to each member, a community discussion board post as well as a private message to each individual group member should be sent the morning of the chat and guidance module topic change. In the message and discussion board post, it has been beneficial to ask each group member to review the guidance module prior to coming to the chat so any questions or concerns pertaining to that week's topic may be addressed in a "live" format.

The third way the guidance modules are utilized in the group is through weekly blogging exercises. Once the module topic is introduced and discussed in the chat, this has been a good time for the facilitator to introduce the weekly "homework" assignment that is related to the module. The homework assignment is then posted on a link clearly visible on the group home page. Ensuring group members are aware of where they can find the assignment is important. Group members are encouraged to respond to the homework assignment by creating a blog. Once they have written their blog, an alert and direct link to the blog is posted to the discussion board to notify the other group members that a blog has been completed. Other group members then have the opportunity to comment on the blog. Each time there is activity, for example, a blog or comment to a blog is written, each group member receives an email notification in order to encourage them to log in and participate in the group conversation.

The module topics have appeared to be effective and thought provoking for group members. However, it seems that using the topics as general guidelines and adapting the techniques to the group members' and/or facilitator's style is suggested in order to

increase relevancy and relatability for each group. Although the particular material discussed under each topic is flexible, below are brief examples of major points discussed under each guidance module topic.

Guidance Module Topics

Week 1: Mindfulness and Coping

The mindfulness and coping module begins with a short explanation about what coping is. Below is the introductory screen:


 <p>Week 1: Introduction to Coping and Mindfulness</p>	<p>What is coping?</p> <p>Coping is the process by which we handle situations that present us with a challenge or threat. Being diagnosed with cancer clearly presents one with a physical as well as a psychological challenge; it may temporarily change your lifestyle, your relationships with family and friends, your mood, your physical well being, and your activities. Some aspects of your life may change more than others.</p> <p>Effective coping can mean lots of things</p> <p>DOIN' STUFF- being active and engaged BEING MINDFUL- awareness of how you're feeling EXPRESSING YOURSELF- to the people that care TAKING A STEP BACK- when you need to.</p> <p>Through mastering the skills presented in this seminar, you will be able to cope effectively with both the changes brought about by illness and the daily stresses in your life. Mindfulness can also help you master the other coping skills.</p>
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Figure 1. Week 1: Introduction to coping and mindfulness

The module goes on to introduce the idea that we function at three levels in relation to the world around us, including: (1) Biological (physical/medical) (2) Psychosocial (emotional) and (3) Sociological (in relation to the world around us). It highlights the idea that good coping involves all three levels. Next, the module discusses different ways in which people cope and introduces the continuum between active and avoidant coping and gives examples of these extremes, as well as an ideal of what a balanced coping style may look like. Finally, a short video (about 8 minutes) is available

that explains active and avoidant coping on behavioral, cognitive and emotions focused levels. The video highlights that it's goals are to: "Help you understand yourself better, learn new and better ways to handle cancer related stress and learn to cope better with all of the sources of stress in life in a ongoing basis".

The module then goes on to introduce the concept of mindfulness at a basic level:

What is mindfulness?

Mindfulness is...

- a. the state of being attentive to and aware of what is taking place in the present
- b. putting your mind to what you are doing, but not reacting to it
- c. a kind of meditation in daily life
- d. a way of celebrating in small ways the passage through the day

Why is it important?

It is now linked to many well-being outcomes. It is important in stopping automatic thoughts, habits, and unhealthy behaviors. You can gain new energy and a sense of joyful well-being.

How do I do it?

Like every other skill, you practice!

Figure 2. Basic introduction to mindfulness

Next, the three levels of functioning, that is, Biological (physical/medical), Psychosocial (emotional) and Sociological (in relation to the world around us) are revisited as they relate to mindfulness. Finally, the relationship between coping and mindfulness, ways in which mindfulness can help optimize coping benefits are outlined:

**Mindfulness can facilitate more effective coping.
Some things to remember about coping:**

1. Recognize that no thought or feeling is wrong in itself, but that it is what we do with it that really counts.
2. Become aware of the way that your body feels as tension begins to build up. When aware of this tension, you can choose to calm yourself down.
3. Recognize that you don't have to go through this alone. Don't hesitate to seek information or counseling if questions or concerns arise. Help is available from a wide range of sources.
4. Work to improve communication with your family, friends, and physician.
5. If you are experiencing fatigue or feeling overwhelmed, consider redistributing or reducing your responsibilities for a period of time.
6. 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 that they know how to do.
7. Your physician is your partner. Your part of the partnership is to accept responsibility for reporting honestly how you are feeling, inquiring about the concerns you have, and doing your best to deal with the adjustments that you must make.
8. Do things each day that are nurturing to you. These may include fun activities, relaxation, time alone, and exercise.
9. You can work to solve some of the problems that are causing you stress.
10. Accept that guilt and worry about things that you can't change are useless and energy draining.
11. Give yourself credit for whatever level of coping you are achieving. Remember, there is no "instant fix" for stress.

Develop a love and respect for yourself because you are a special and worthwhile person.

Figure 3. Mindfulness and coping

Weekly Exercise

The weekly exercise related to this module focuses on mindfulness, as coping is something that is more of an umbrella term that encompasses the different skills learned each week. The online forum can be used in one's favor with this week's exercise since many mindfulness resources are available on the Internet. Facilitators should search YouTube or other Internet resources to look for appropriate mindfulness exercises. A few suggestions:

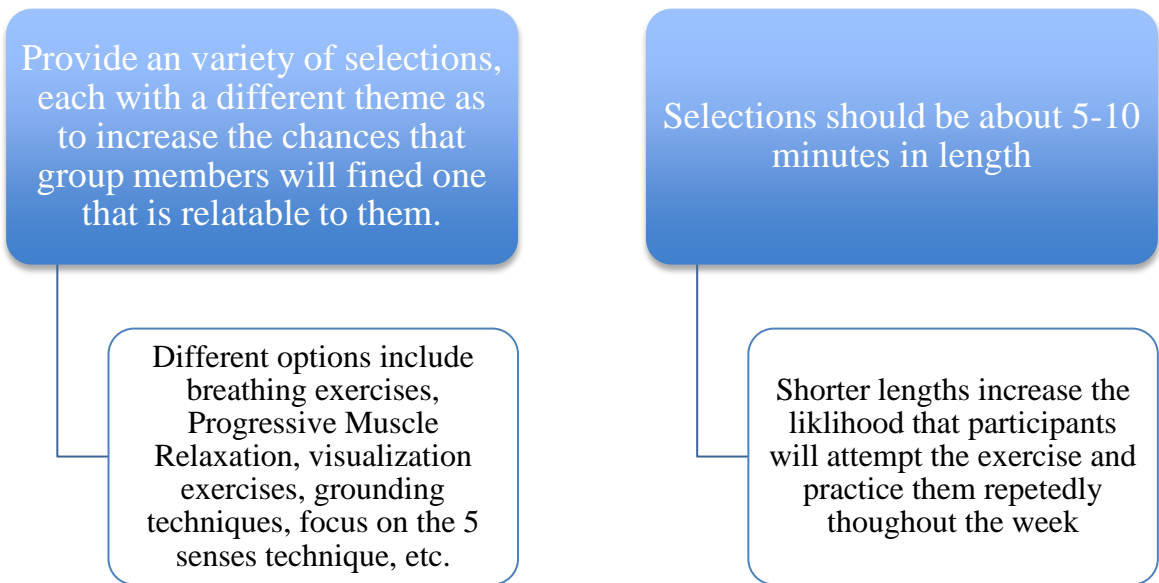


Figure 4. Mindfulness exercise suggestions

Here is an example of a weekly exercise:

Try a mindfulness exercise.

- Here are some good ones to try:
 - Floating on a cloud relaxation (guided imagery):
www.youtube.com/watch?v=b49WIEW3zqQ
 - Progressive Muscle Relaxation: www.youtube.com/watch?v=PYsuvRNZfxE
 - Guided Breathing Meditation:
www.youtube.com/watch?v=2r9OVMXwhg8&feature=related
 - Mindful Eating Exercise: www.youtube.com/watch?v=7CCr5w3ox_4

Blog about your experience:

- What did you notice as you did this?
- What feelings came up?
- Did your mind wander?
- What topics did your mind wander to?

Figure 5. Week 1 exercise

Participant Reactions

In my experience, group members have enjoyed the relaxation and mindfulness exercises, but also express some difficulties and barriers to making these exercises a part of their every day lives. Many of the group members have had exposure to some genre of relaxation techniques in the past. Overall, the level of implementation and practice is often variable. Some participants talk about how they use, or have used previously learned techniques to get them through medical procedures, chemotherapy infusions, and/or to better tolerate pain. For others, they may have never used these skills before and may try it once but have a hard time making these skills become part of their life. Barriers that are commonly expressed pertain to time availability, concentration difficulties, forgetfulness or previous bad experiences and/or ineffectiveness with mindfulness and relaxation. Normalizing these frustrations and difficulties and opening

the dialogue to these kinds of concerns is often helpful. Further, the feeling that these techniques may feel difficult, uncomfortable, even ineffective at first is important. Encouraging participants to take a non-judgmental stance regarding these issues may help lower frustration levels and increase willingness to try these skills over and over. Emphasizing the idea that these techniques require practice in order for them to feel as if they are “working” or even a workable part of their life has been key.

Another benefit to discussing barriers would be that group members may feel less like “failures” if they hear similar struggles from others. Importantly, it is often the case that at least one group member finds them helpful, effective and beneficial. Hearing success stories from other cancer survivors, rather than just a facilitator, is often very powerful for those that may be skeptical. One role the facilitator should take on is highlighting successes, including strategies for success and exploring the personal benefits that were gained. Here is an example blog from a participant:

As often, here I am attempting to be an overachiever (or, maybe just that anxious for anything that might provide some emotional relief). I especially struggle with anxiety shortly upon waking in the morning (feeling anxious and overwhelmed). I have tried all three mindfulness meditations. I think they are all helpful to the degree that they ask the person meditating to stop all the background chatter (thoughts) and focus on the exercise at hand.

Now I am going to get picky. I really liked the Floating Cloud meditation. It seemed like a soothing visualization exercise. I liked her voice and the directions were at once soothing and kind of fun! I did mentally modify it to laying on a mat/blanket on the cloud (versus directly on the "cool damp" cloud) because it was really hard to make my comfortable chair mentally seem like it was cool or moist. Like I said, I am being picky here.

The Deep Breathing (Drum) exercise definitely demanded a lot of focus/concentration, but it felt like I was being pressured to breathe at a certain speed and that was uncomfortable at times. I may go to their

website and try the longer version just to see. I feel like if I try that, I will either decide it has merit for me or know for sure that it doesn't fit my style.

The 15 Minute Body Scan was very relaxing. I tried it in a chair (and almost dozed off) the first time, and then I tried it on the floor like they suggest. I am not sure getting down on the floor would be comfortable for everyone. Maybe a bed? The exercise made me aware of where I was holding tension in my body and allowed me the opportunity to release it.

It is difficult to find the time to do these exercises when everyone has such busy lives. Doing it right away in the morning really isn't an option for me even though that seems like an obvious possibility given that is prime time for my anxiety to pop up. I wonder if doing it long-term would help with my morning anxiety/PTSD? I do see a therapist who specializes in oncology patients and that helps too. She and others keep telling me to give it more time. Patience has never been my strong suit. I am trying to develop it by focusing more in the moment. It feels like cancer looms in my brain as a new constant since my date of diagnosis (May, 2010), and sometimes I just want a break. I want that "hanging over my head" feeling to go away. During the day, it sort of comes and goes and I do get involved in thinking about other things, and, yet, it still always feels like it is there. A mindfulness exercise is helpful. It is also helpful when I do something so engrossing there isn't room for anything else--Just as an example: For the first time ever: I drove an ATV on a beautiful fall trail a couple weeks ago. It was my first time operating equipment like this, and it was so challenging and absorbing, the cancer "went away" for about a half hour. It was great.

Enough rambling. I hope these thoughts are helpful. I will be curious to hear what everyone else has to say about these exercises.

Week 2: Social Support

This module focuses on the importance of interpersonal relationships and how important these relationships are for one's well being. On the opening screen, the module introduces social support by stating:

Social support includes giving and receiving encouragement, practical help, positive feedback and rewards, understanding and caring, and role modeling.

Another aspect of social support is knowing where to go to obtain the right type of social support. People's social support network usually extends to friends, family, health care workers, and co-workers. It is not the number of people you know but the quality of care and support those people provide that matters.

Benefits Of Social Support

- Sociological studies show that as part of our involvement with others, we are more likely to engage in positive health behaviors such as exercise, medical check-ups, and health screening tests.
- In a study of older people, researchers found that having a confidant(e) significantly helped people avoid psychiatric symptoms.
- Two studies of women showed that having an intimate and confiding relationship significantly reduced the incidence of depression.
- In a study of 7000 adults, a strong correlation was shown between social involvement and length of life; it was shown to be more important to health than smoking, drinking, exercise, or diet.

From A Medical Perspective, Social Support Helps to:

- Maximize our resistance to disease.
- Give us the best fighting chance if we are ill.

From A Social Perspective, Other Benefits Emerge:

- Friends help us feel good about ourselves; they reassure us that we belong and that it's OK to be who we are.
- Friends provide emotional support- someone to talk to about our thoughts and feelings.
- Friends help us in tangible ways- help us solve problems, give us advice.
- We can assist others in attaining the same benefits.

Figure 6. Week 2: Social support module

The module goes on to emphasize the importance in knowing where to go to obtain the right type of social support. There is an exercise that helps one uncover different sources of social support:

List the people you would turn to for emotional support:

1. 2. 3.

4. 5. 6.

List the people you would turn to for practical help:


1. 2. 3.

4. 5. 6.

You may notice that your social network is not only comprised of your family and relatives. People's social support network usually extends to friends, health professionals, or whoever provides you with the particular type of support that you need. This brings us to the idea of quantity versus quality of social support. As in many instances, it is not the number of people that you know but the quality of care and support that people provide that we come to rely on the most.

Figure 7. Sources of social support

Another advantage of this module is that it acknowledges the common apprehension that asking for help or reaching out for social support involves risks.

 **Risks Associated With Asking For Social Support**

A common fear we all share is the risk associated with asking for support. "What is the risk involved if I ask person X to help me, or if I refuse to help?" Some of the risks involved in asking for support include the following:

- threat to self-esteem
- embarrassment
- fear of being seen as dependent on others
- possibility of rejection by others
- guilt
- possible loss of confidentiality
- lack of comfort in accepting support from others

Figure 8. Risks and social support

The final step in the module is to offer the idea that while risks are possible, it is likely that the benefits outweigh these risks. The module asks the group member to weight the pros and cons of seeking social support and reminds the participant that they are in control of their social support system and that refusing or asking for support is perfectly acceptable. The module ends with a reminder about the reciprocal benefit of social support and the importance of offering support to others. Lastly, the module concludes by presenting the idea that the ability to accept help and support can be a gift that a cancer patient can give to friends and family who are usually trying their best and often searching for ways they may be able to help or be useful.

Weekly Exercise

Often times, group members come from various perspectives and realities related to social support. The goal of the exercise designed to match this guidance module is to get each group member to think about the effects of social support for them on an individual level.

Blog about:

1) Your expectations of what your social support will do for you

2) Your expectations for what you will do to get what you need from your social support

Figure 9. Week 2 exercise

Participant Reactions

A portion of group members may feel very supported in their lives and are extremely comfortable both giving and receiving support from others. These types of group members often have extensive social support networks from many different outlets, including friends, family, church, work, etc. On the other end of the spectrum, there have been many group members who have felt very isolated, distant and cut off from others, or disappointed in the support, or lack there of, they have experienced. A common reaction from many group members has been that they have “always been the strong one” in their family and therefore, asking for support is somewhat foreign and some view it as a “sign of weakness”. Therefore, thinking about asking for something from others may seem very difficult. Normalizing these feelings may be a helpful first step. One suggestion in highlighting how common these feelings are is to ask the group

how many people have felt this way. Some group members might be surprised to see how many others can relate to them in this way. Once this has been established, asking the group: “How might you respond to a fellow group member who felt that asking for help meant they were a weak person?” has often evoked responses that counter this thought in a more positive way. For example, one response to the question posed might be “You aren’t weak at all, it takes a strong person to ask for help and it will probably make the person offering to help feel better knowing they can do something to help.” Helping group members realize this applies to them as well has been an efficient way in helping them gain a new perspective on what it means to ask for help. Here is an example blog from a participant:

I am blessed and grateful to have a good social support network. As I have said before, my husband has been great. My daughters, are, well, teenagers...My parents have been struggling with their own issues. My in-laws have been kind and caring. I was fortunate to have a couple close friends who were willing to hang in there with me and allowed me the freedom to cry and to vent when needed. I was also lucky to make a couple new friends that were insightful and kind during and beyond my treatment. I see a therapist who specializes in oncology patients, and I am also in a breast cancer support group that meets monthly.

What do I need from my social support network? I am not sure. I think it is my responsibility to reach out to my friends and family if/when I need them. As for wishful thinking, I wish that someone, besides my husband, would sometimes take the plunge and inquire something like "So, how is your recovery going? How are you feeling?" Am I looking for pity? I don't think so, but maybe? I am ten months out from active treatment, so it still feels very current as far as side effects (joint pain, fatigue,...) and emotionally worrisome. I think it is understandable that people don't ask. Everyone is busy. I look "normal." And, they probably think asking could be painful to me. I don't know. I used to feel that way too, but then we had a death in the family and I was appreciative of the people who asked and reached out. I learned not to be afraid to address something that is painful to someone. Just because no one talks about it, doesn't mean those who have been affected by it (whatever it is--illness or death), have forgotten it!

If people did ask, it would be nice because the ball wouldn't always be in my court. I would feel less like I was intruding on the people I love if I wasn't the only one who brought it up in conversation. It would feel like it would be more okay to talk about it if they sometimes asked me. Does that make sense?

How could I get people to ask? I guess I could ask them to inquire, but that just feels weird and like I am asking for pity. I think I just get to be an adult and to take responsibility for bringing it up when I need to bring it up.

Week 3: Self and Body Image

This module introduces a range of problems that are common to many cancer patients. It first introduces the idea of “self image” and discusses how cancer can change this mental image of oneself, citing specific examples.



Each of us has a mental picture of how we look, or our "self-image." Although we may not always like how we look, we are used to and accept our self-image.

Cancer and its treatment can change your self-image. You may have changes such as hair loss or scars from surgery. Some of these changes (hair loss) will go away when treatment is over. Other changes (scars) will always be a part of how you look. Every person changes in different ways. Some changes people will notice and other changes only you will notice. Some changes you may like and with some others, you may need time to adjust.

- You may not have as much energy as you did before the cancer.
- Your body may not be the same as it was.
- If you're single, your dating life may feel awkward. You may face new challenges in your sex life.
- If you have a partner, you may face changes in your relationship.

Figure 10. Week 3: Self and body image

After common concerns are identified, potential solutions that can help enhance one's self-image are introduced. The first suggestion is to stay actively involved in life and cites examples such as playing sports, going to exercise classes, maintaining hobbies or trying volunteer work are also mentioned as things one can do to help others, get involved and feel better about oneself.

The second idea mentioned is to get help when needed. Cosmetic solutions such as reconstructive surgery, scarves, wigs or hats are some examples given. Also, the importance of involving one's partner or spouse in facing cancer is highlighted. Finally,

the importance of talking openly about intimate issues with loved ones is presented. Problems in one's sex life on an emotional, physical and psychological level are normalized and the benefits of open communication about these issues are discussed.

The third part of the module involves a discussion on treatment side effects and self-image. A commonly encountered side effect, fatigue, is highlighted, and ways to help cope with fatigue are offered.

Finally, an exercise involving mindfulness and self-awareness of thoughts and feelings as they relate to one's body image is suggested.

EXERCISE:

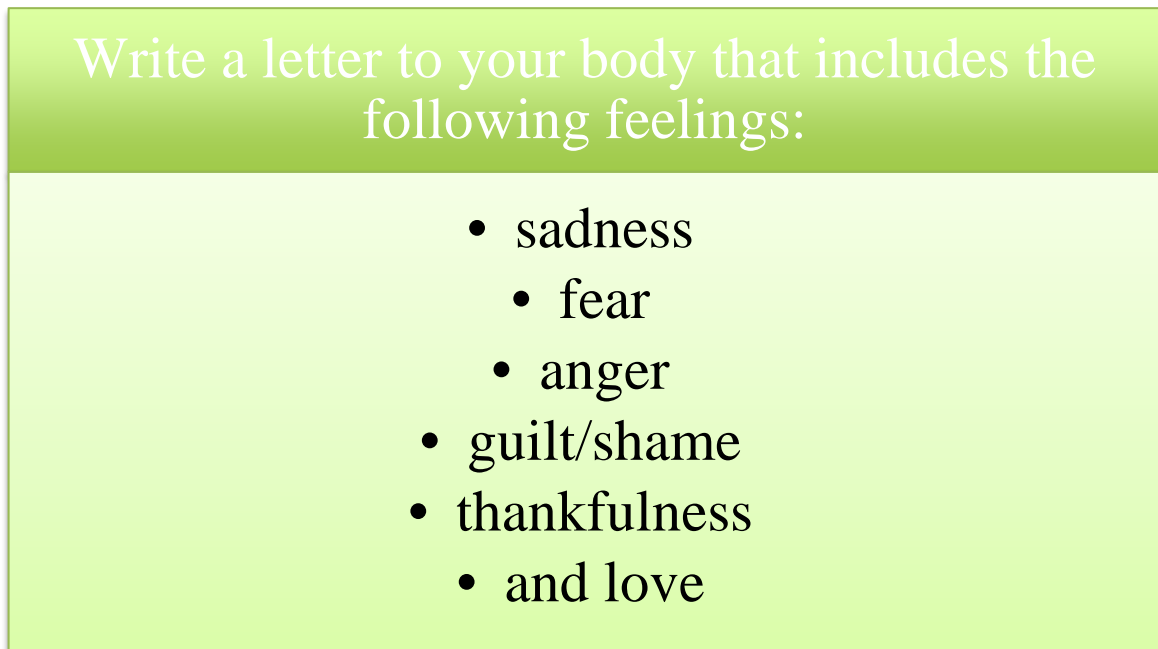
Remember back in the first week, we addressed the importance of mindfulness, which is the state of being aware of taking place in the present moment. Take a few minutes each day to bring into awareness and check in with yourself regarding your thoughts or feelings you are experiencing about your body, energy level, or ability as relating to your self-image today. If you feel comfortable, please share your thoughts with the group about how you are feeling about yourself today.



Figure 11. Self-awareness exercise

Weekly Exercise

While the guidance module itself offers participants an opportunity to try a new exercise, an additional weekly exercise that provides more specific guidelines may help direct participants and clarifying a weekly goal as it relates to self and body image. The following is an example of a blogging exercise appropriate for the Week 3 module:



Write a letter to your body that includes the following feelings:

- sadness
 - fear
 - anger
- guilt/shame
- thankfulness
- and love

Figure 12. Week 3 exercise

Participant Reactions

There are a variety of things cancer survivors report struggling with, common topics that have come up related to this module include sexual side effects, hair loss, weight related problems and other general appearance disturbances. A common theme that I have observed is that many survivors grapple with the “before” and “after” treatment self-appearances. Many have said they have a difficult time looking at their bodies, looking in the mirror, or even recognizing themselves in the mirror. Validating

their feelings, and giving them a safe place to openly express these concerns has been beneficial. Additionally, this seems to be a topic that bolsters their connections with each other. They often have similar or related concerns that are unique to this population, which promotes feelings of comradely special understanding of a sensitive and uncommon concern.

In my experience, nearly all of the cancer survivors I have had discussions with regarding self and body image have had a relatively strong response to this weekly exercise. Participants often describe this blogging exercise, written in the form of letters to themselves, as a powerful one. It has not been uncommon for participants to express strong emotional reactions to this assignment. A common theme among many is the feeling of betrayal. Many cancer patients express feelings of anger towards their body. Some discuss how they had worked hard to take care of themselves and how “unfair” it feels to have such a devastating diagnosis after their conscious efforts to avoid such ailments. The emotional progression of the exercise is often extremely moving and as a reader, I found I could almost feel the mood and emotional shift in the writers from more negative emotions such as anger and betrayal to more love and acceptance. Participants have often been open to experiencing a wide range of emotions in this exercise. In addition to some of the more uncomfortable emotions, participants have often been able to recognize the positive feelings towards themselves and their bodies as they discuss the love and gratitude they feel, often including descriptions of how thankful they feel that their bodies have been strong enough to endure difficult procedures and treatments. In my observation, the wide spectrum of emotional experience this exercise evokes parallels the overall experience of the group as a whole, in that a wide range of affective

experiences are often encountered throughout the progression of the group. Below are three examples that represent variable responses. The first is from a participant that represents more negative feelings towards her body, the second is from a participant that represents more positive feelings towards her body and the third is a response that seems to fall somewhere in between. For example:

Write a letter to my own body? What do I say to someone who I've spent so much time with and yet know so little about? If this is to be an open, and honest letter...I can sum it up in three simple words...I HATE YOU! Sound a little dramatic? I've lived inside of you for my entire life, and you've done everything you could possibly do to hurt me. When does the time come when I can just be ME? I didn't *choose* you...in fact, if I had MY way...I'd have gotten rid of you a long time ago. But, it's not up to me. God gave you to me so that I'd have someplace to live while I was here. I don't believe that God makes mistakes, so obviously, He gave you to me to learn something. (either that, or He has a great sense of humor!) Why do I hate you so much? Because you've stopped me from doing everything I ever wanted to do. I never expected you to be perfect, but this is getting to be a little bit much. I guess that I could blame it on myself for not taking the best care of you, but this nonsense has gone on since the day I moved in almost. OK, you haven't been all that bad, I guess. You could have been much worse. Still, I didn't ask much of you. It's taken a long time, but I think we're finally on the same page. We're both tired. We both keep going. We refuse to give up. Still, this could have been so much easier if you had only cooperated just a tiny bit. Even though we both live in the same "space"...you and I are two entirely different entities. I'm so different from you. You just keep doing the minimum. *I* hate that I can't do more. I know that I'm supposed to look at you as the most precious gift I've ever been given, but I just don't. Maybe you realize that, and you've just quit trying. I honestly don't know who's supposed to be taking care of whom. You've mocked me and sneered at me all our lives long. One thing I DO know...you may give up on us...you will start to wear out...but, no matter how hard you try... you won't get the best of me. I'm stronger than you are! The only thing I can hope for is that when you wear out so much that you just don't function any more, I can go some place where I can finally be free of you...where you can't stop me from *anything!* Even though I don't particularly care for you...you're all I have for now. So, I will continue to give you the best that I'm capable of giving you. I will keep taking care of you. I won't do to you what you've done to me. Maybe that's why I get to go on, and you have to stay here. You don't give me

near what I give you. It's not a balanced relationship. One of us had to step up and be the strong one, and since you didn't deem fit to do that....I guess it'll have to be me. Even though we've been together for a long time, and been through a lot together...I don't really think that I'm going to miss you when you're gone.

Here is another example::

Dear Body,

I need to apologize to you. I have taken you for granted and ignored you for way too long. I have mistreated you in so many ways. I expected you to be ready to go every morning with whatever plans I had for the day. What you needed was never something I cared to consider. I fed you whatever I wanted. You tried to talk to me, but I was too busy to listen. You were never given adequate time to rest. My philosophy was always, "I'll rest when I'm dead." Well that's not funny anymore.

Now, you are a mess. You have aches and pains in your joints, you are overweight and you are sick. You have 18 inches of scars across your chest. I've been forced to allow doctors to remove parts of you and to give you poisons to kill the cancer that was trying to kill you. I promise, there are going to be some major changes. First, I am going to switch to a vegetarian diet. This is to change your chemistry to make you a hostile environment if cancer decides to return. I will be giving you only the finest organic fruits and vegetables. Next, we are going to exercise. This is something I have hated, but you have loved. I promise to get out of the way so that you can have the activity that you need and crave. Next, I plan to listen to you and give you rest when you need it. Perhaps we'll enjoy getting a massage or a facial every once in a while. And finally, I plan to be there for you when you are sick. I will give you what you need to get healthy again.

This relationship has been one-sided, but that has now changed. You have been faithful to me and now it is my turn to be faithful to you. I love you and want to spend many years together. We're going to have some fun! Oh, and if I had realized how good you looked at 20, we would have run around naked!

A third example exemplifies the variety of responses:

Dear Body,

Wow. You have been through a lot in the last 19 months. Sometimes I forget that and I forget to give you credit for it, or I forget to cut you some slack when you need it (i.e. run out of energy)!

I am sad for you on many fronts. I am sad about the scars (a daily reminder I see), the harsh chemicals and radiation you endured and the adrenaline I sent your way for weeks and months too. I am sad about the toll all this has taken on you.

I am afraid for you too. I am afraid of the cancer coming back. I am afraid of every ache and pain and the need for each one to be subjected to a cancer rule-out diagnosis ahead of everything else. I don't blame you, but I am not sure how much I can trust you, at least yet. I also am angry for both of us. I am angry that it happened. I am angry about the ongoing side effects when I want to move forward. Fear and anger feel like two sides of the same coin. I am learning to allow myself the anger, and also to try to move beyond the anger to more productive responses. I am not there yet.

I don't blame you for getting cancer. I feel guilty, and sometimes I do try to blame myself. I wonder if I had eaten better or exercised more or drank less or exposed you to fewer chemicals...It really bugs me that I don't know why you got cancer or what magic thing I could do to guarantee it won't come back. Sometimes having had cancer feels shameful—yes, they cut a lump out of me, yes, my hair fell out. Maybe some of it was my fault? When I start thinking about it like that, I try to quit the self-beating, but it is hard.

There is thankfulness too. I am thankful for the sisterhood of women I am connected to—you guys truly get it, the friends that have reached out, and I am thankful for a good prognosis (not perfect, but good). I am thankful that my diet and exercise habits are better. I am thankful for the weight loss and short haircut. You have hair! Different hair, but, nevertheless, hair. You have smaller clothing, even compared to high school. That should be more fun than it feels like so far.

Love. I am working on loving you again. That is a little hard without trust, but I hope I can improve over time. I hope we can move on from the hurt and move forward in health and in love. You look pretty good, so let's work on feeling good physically and emotionally and moving forward!

Week 4: Healthy Lifestyle

The fourth module focuses on living a healthy lifestyle and helping group members identify what that means to them in a unique context. The module introduces the topic with the question: “What makes a healthy lifestyle?” Examples such as

exercise, nutrition, laughter, handling fatigue, hope, spirituality, forgiveness and self-trust are cited. It goes on to discuss the benefits and effects of living a healthy lifestyle and explores some of the benefits of specific aspects of a healthy lifestyle such as:

Lifestyle means exercise! Everyone needs to get active. In fact, many of the changes that occur in our bodies as we get older may not be due to aging but to a lack of physical activity. A more active lifestyle has been proven to reduce the risk of many diseases as well as reduce the symptoms of chronic conditions.

In short, the proven benefits of exercise are many and the side-effects are few. The exercise connection can be taken one step further: people who are in good shape tend to develop other positive lifestyle habits, like a healthy diet, not smoking, and moderate use of alcohol.

There is no definitive information on just how hard or how long one has to exercise but daily physical activity is important. A good general guideline to aim for is to exercise at least 3 times a week for 20 to 45 minutes at an activity you like: walking, swimming, cycling, dancing. Graduated weight training has been proven to be beneficial to people of all ages... check it out with your doctor.

Figure 13. Exercise



Nutrition

Eating well:

A nutritious diet is always vital for your body to work at its best. Good nutrition is even more important for people with cancer. Why?

-People who eat well during their treatment are better able to cope with the side effects of treatment.

-People who eat well may even be able to handle a higher dose of certain treatments.

-A healthy diet can help keep up your strength, prevent your body tissues from breaking down, and rebuild tissues that cancer treatment may harm.

-When you eat enough food, particularly the right kind of food, your body has nutrients as a source of energy. As a result, your natural defenses are strong and your body can fight infection effectively. Your immune/defense system is especially important to you now.

The hospital dietitian is available to help you. Ask your nurse or doctor for a referral!

Excellent information from the FDA is also available on www.mypyramid.gov. This site provides personalized profiles and clear recommendations to help you make healthy dietary choices.

Figure 14. Nutrition



Laughter

Humor promotes:

- Simplicity
- Change in how we see things
- Delight
- Optimism and hope.




The benefits of humor

1. Helps circulation of blood.
2. Decreases blood pressure.
3. Lowers heart rate.
4. Increases respiration and cleans foreign matter out of the respiratory tract.
5. Increases the level of endorphins (the body's natural pain killers).
6. Stimulates the endocrine system (hormone production).
7. Stimulates the immune system (disease prevention).
8. Reduces stress.
9. Relieves muscle tension.

We have to learn not to take ourselves too seriously.

Figure 15. Humor

The module goes on to discuss more specific cancer related ways to live a healthier lifestyle, such as handling fatigue:



Handling Fatigue

In addition to exercise, setting aside time for simple restorative activities three times a week for about 30 minutes may be helpful in dealing with feelings of fatigue.

Simple restorative activities include:

1. Walking or sitting in a natural environment such as a park.
2. Tending to plants.
3. Gardening.
4. Bird Watching.
5. Reading.
6. Doing crossword puzzles.
7. Watching a movie.
8. Listening to music.
9. Taking a bath.
10. Others .


Practice:
Schedule into your weekly agenda one of the above activities. Just as we make appointments with the doctor, we need to make time for non-medical healthy activities. Learn your own rhythm and energy cycles and stop activities before deep fatigue sets in. It's easier to recover that way. Some find it energizing and helpful to keep a journal or diary where they write their thoughts, feelings, and observations about life.

Figure 16. Fatigue

Forgiveness and hope are also touched upon as topics for participants to consider.

Forgiveness has two benefits:

- Reduces stress, anger, fear, bitterness
- Increases social support

Hope is not a way out, it is a way through. Hope is much more than a desire to get well. Hope must include effort, hard work, and determination to reach that goal of wellness.

Hope looks to the future but rests in the present. It guides your present experience and reflects your love of life.

Hope has proven to be a powerful ally in the struggle to find balance in life. You are not a statistic; as some patients have said, if 20% of the people with this type of cancer are cured, I want to be part of that 20%.

Cancer patients recovering from surgery, chemotherapy, and radiation know that daily survival and well-being requires the presence of hope. Hope differs from survival. Hope is the stuff on which productive energy is built. - Elizabeth Simpson, cancer survivor, The Globe and Mail, Spring 1996

There is no cancer for which there is no treatment; and there is no cancer from which some people have not been cured. - Richard Block (H&R Block) cancer survivor

Learn to believe in miracles. Then picture yourself as part of one.

We have hardly begun to learn. We have not come to the end of knowledge by a long shot; we have only come to the edge of it. - Johnson and Klein, Staying Healthy with Cancer, 1988.

It's an uplifting thought. The decades ahead hold great promise. No one can predict what is around the corner for the individual diagnosed with cancer today. There is certainly reason for hope.

Hope is always deep within us, even though the nature of what we hope for changes, the hope itself remains.

Figure 17. Forgiveness

Weekly Exercise

Consider the following questions as they relate to your idea of living a healthy lifestyle:

- What do you consider to be your goals for your own healthy lifestyle?
- What gets in the way of you pursuing your healthy lifestyle goals?
- Are there any ways to work around these barriers?

Figure 18. Week 4 exercise

Participant Reactions

There are a wide range of reactions and conversations that are elicited by this topic. Some participants react with frustration and explain that they have made it a priority to consistently live a healthy lifestyle. As such, receiving a cancer diagnosis was quite a shock to many of them. Confusion, disappointment, anger, and distrust in the world were common emotions and themes discussed. For these conversations, I have found it helpful as a facilitator to discuss the idea that we grow up thinking the world is a orderly, safe, just and fair place. For example, the idea that good things happen to good people or people doing the right thing and bad things happen to bad people or people

that are careless can often be a world view that is shattered by cancer. Responding to posts and opening the dialogue to discussion about the reality of this idealistic, or “just” view of the world and how it has changed or been altered for group members often leads to powerful and emotional discussions. Additionally, participants often end up supporting each other in that they are able to express to other group members how getting cancer wasn’t anything the other group member did “wrong”. Facilitating this conversation and encouraging group members to consider the words and ideas of kindness they express to others and reflect these sentiments towards themselves is often effective.

The most common themes that group members refer to in this module have been diet and exercise. An expansive and diverse range of behaviors and attitudes were often expressed. On one end, some group members have described being very active and conscientious about their diet. Some have always been this way, for others, a cancer diagnosis was what they often referred to as a “wake up call” and a realization that health is important, not to be taken for granted and/or is fragile. For others, a cancer diagnosis had the opposite effect. Some that were healthy initially “gave up” on living a healthy lifestyle because they felt that it was “no use” or that this way of living had failed them in the past. As a facilitator, responding to these blog posts may involve evoking ideas pertaining to the complex, convoluted and uncertain nature of the development of cancer. Another approach that has been helpful has been to using Motivational Interviewing techniques and asking them questions such as: “Would you say that living a healthy lifestyle has had no positive effect on you?” or “Tell me what it feels like when you have engaged in more healthy behaviors in the past?”

Fatigue is barrier that is extremely common and very distressing to many group members. Discussing the balance between exerting oneself and being active and listening to one's body and providing rest, relaxation and healing is critical. This has proven to be yet another topic that cancer survivors strongly relate to and seem to bond over the implicit understanding of the difficulties that are inherent with fatigue. Highlighting some of the similar frustrations and feelings towards fatigue has been found to be an effective facilitation technique for this topic. While normalization, empathy and validation usually receive the most positive responses, facilitating this conversation may also involve asking group members to share "tips" or solutions that have worked for them in the past to help battle this common concern. For example:

No, I am not trying for gold stars here today, but I logged on because I just can't escape breast cancer today even though I have been outside doing yard work for a good portion of the time up to now. My 18-month mammogram is tomorrow...(18 months from diagnosis in May, 2010)

My goals are to continue with the healthy eating and exercise, but to figure out a balance here so I don't wear myself out! The module also talked about laughter and dealing with fatigue. It might help to have more ideas on how to find laughter (humor) as well as more ways to combat the fatigue (busy women, and we all are busy, may not have much time for self care...).

What gets in the way of pursuing healthy lifestyle goals? With diet, sometimes I just want to be part of the party (last night I had three, yep, count them, three gin and tonics in a long evening out (dinner and a sporting event) with another couple). I hadn't done that in ages, but I just wanted to laugh and feel, well, more "normal" for a change (often, I drink water or soda water with a twist). I'd love to hear what other survivors are doing or not doing...

As for exercise, it would help if I didn't have arthritic stuff from the Anastrozole/Arimidex, but I try every day to get the joints moving and work through most of the discomfort. I try to exercise 5 days per week, but I have made the workouts gentler in the last couple weeks since dealing

with "tennis elbow" sorts of symptoms lately. I miss the endorphins but I do have more energy for other tasks. I would like to find a balance between fighting cancer by making good diet and exercise choices and feeling like I am going to die if I make a bad choice. I am still trying to find balance here.

With laughter, I like the old TV sitcoms (Cheers, Everybody Loves Raymond, Monk, Dick Van Dyke...), and I would sure be up to hear more ways to add more laughter back into my life. What makes you laugh? Any book suggestions? Movies? Anything?

Fatigue is a tough one. Part of it is trying to get enough sleep, part of it is not enough hours in the day (we're all busy), and part of it is just accepting myself (rather than beating myself up) when I just plain run out of gas. I try to just take the down time when I need it without beating myself up. Other strategies?

Well, that covers it for now. I will be happy to read what others say! Thanks! (and, ah, say a little prayer for me for tomorrow too, please? I know everyone here understands what I am saying here, so thanks for listening)

Week 5: Self-Efficacy

Self-efficacy is often a term that group members are a little uncertain about. This guidance module starts with a definition and description of what self-efficacy means in the context of this group. It gives specific examples of why a cancer diagnosis may experience diminished self-efficacy and explains the importance and benefits of possessing self-efficacy. This is followed by tips for improving self-efficacy:

Here are some tips for improving self-efficacy:

Get to know yourself: Having an understanding of what we are good at and what we need to improve on is the first step to increasing self-efficacy. We first need to identify those aspects of life in which we wish to perform better. Take an inventory of what you are doing well and what you'd like to do better!

Challenge your current assumptions: Many times we have doubts about ourselves in areas in which we haven't really challenged ourselves to be better! Put yourself out of your comfort zone and see what happens. Try and be strategic when you do this plan and prepare to take on the new challenge and you just might be surprised!

Learn from others who are really good at things you'd like to do better. People are generally willing and even happy to share the skills they have used to master their goals.

Maximize your strengths: While you are attempting to learn new skills also continue doing what you do best! When we engage in activities or behaviors that we are good at, it increases our self-efficacy and might even make it easier to take on a new challenge!

Do something on your own: Many times we are used to asking for help in certain areas of our lives. For example, we might be used to asking someone to change a tire for us. Perhaps we assumed we couldn't change the tire on our own, although I want to encourage you to give it a try. You could even ask the person who generally helps with a given activity to walk you through the process. While this might initially seem like a hassle it will give you a sense of accomplishment once you complete something you didn't think you could!

Overall principle- do your best to put yourself out there and risk it!

Figure 19. Self-efficacy tips

Next, the concept of asking for help is discussed. The importance of knowing one's own limits is emphasized, and asking for help is normalized. Tips for learning to ask for help when needed are outlined:

Here are some tips to help you learn to ask for help when you need it:

1. Remind yourself that most people actually enjoy giving help, and getting help from someone can help both of you to feel closer to one another.
2. When someone tells you they'd like to help, believe them.
3. Make a list of the people you're close to or who you've given help in the past- think of these people as your support team, and don't be afraid to call on them when you need them.
4. When visiting a healthcare professional, ask about any and all resources that might be available to you.
5. Ask your group if anyone has ever needed help with something similar, and ask how they handled it.
6. Make a prioritized list of the things you could use help with. What responsibilities get in the way the most?
7. Talk often with your closest friends and loved ones about these responsibilities and what you might be able to do to make them easier to manage.
8. Getting help doesn't always require asking for help- sometimes you just need help thinking about a problem or responsibility. Find someone you trust who you can talk with, and you might be surprised by what happens next.
9. Always ask your spouse or partner for help.
10. Always share your most distressing problems with your closest friends- they'll often give you help before you realize you need it.
11. Cultivate friendships in your group.
12. If you belong to a church, temple, or religious group, talk with the leaders of those groups and let them know about your diagnosis and what you need help with.

Remember that it is important to assert yourself when you feel it is appropriate. When living with cancer, diminished self-efficacy can make it difficult to assert yourself. Therefore, if you ever need it, the following can serve as a reminder: ask for help when you need it!

Figure 20. Asking for help

Weekly Exercise

Self-efficacy is about knowing yourself, your strengths and your limits. Reflect on the following questions regarding self-efficacy to explore these ideas:

- Reintroduce yourself to...yourself! What are some things are you doing well? What are some things you would like to do better?
 - What are some current assumptions you have that you would like to re-visit? What are some doubts you may have in yourself? Are there ways to challenge these?
- It is also important to know your limits! How do you do with asking for help? What are some benefits to letting others help you or asking for help that you can think of?

Figure 21. Week 5 exercise

Participant Reactions

Regarding variability of reactions, some group members seem to have a strong sense of self, while others seem to struggle defining themselves. Regarding the latter, some have expressed getting lost in different areas such as being a mom or their work and feeling as if those things define them. Another common reaction is that group members feel that they are defined by cancer. A common theme that has been brought up is the idea that group members are frustrated or fearful that people look at them and see/think “cancer” and not truly see the person they are. Deepening conversation around these issues is important as a facilitator, as this is a common idea that may be unique to those that have experienced a cancer diagnosis. Thus, it is often a topic that promotes a

bond between group members. Further, identifying the primary concerns and/or emotions that are elicited when one believes they are seen primarily as their cancer is key. Following this path in discussion has often brought up feelings such as frustration, anger, sadness and loss. Cancer patients in this group have explained that cancer has been a defining point in their life. Many have expressed they feel they have a pre-cancer self and a post-cancer or after-cancer self and that these two selves often look, feel, behave, interact and think very differently. Many express priority changes after cancer or even different worldviews. It has been common for group members to describe caring less about “materialistic” or “superficial” things that their pre-cancer self may have emphasized.. Many have expressed feeling that their post-cancer self “knows what’s important” in life. However, many have expressed sadness and loss from their pre-cancer self to their post-cancer self and describe the latter as experiencing things such as fatigue, weakness, illness, pain, introverted tendencies, loss of importance or employment, and/or social deterioration. Talking about the differences and changes in one’s life is often a topic that promotes self-reflection in a way that group members may have not experienced before. For some that have felt they may not know who they are, this conversation has appeared to help them think about their values and begin to strengthen their sense of self.

Another commonality in reactions to this guidance module has been the difficulty in asking for help. Many group members are mothers and/or wives and have been the ones to “hold the family together”. They often describe themselves as the “caretakers” and as such, asking for help or being taken care of often feels foreign and uncomfortable. Common remarks include the idea that asking for help may show a weakness or

vulnerability that they feel they can “not allow”. Similarly, many have said that they feel if they act differently, this may make their families or loved ones frightened or concerned. This is often seen as an adverse reaction to the cancer patient that is trying to be the “strong” one and “keep it all together”. Another way some group members may perceive this is that if they “just act normal, everything will be normal”. As a facilitator, exploring what “normal” means to them and distinguishing between idealistic and realistic expectations has been helpful. Further, helping them identify the worst-case scenario if they asked for help, as well as possible benefits of asking for help are other techniques that have been effective. For example:

1. Reintroduce yourself to...yourself! What are some things are you doing well? What are some things you would like to do better?

Me... today. Who am I? Today, I am a struggling woman who seems lost. I do lots of things well, just about anything I put my mind to. I am good at gardening. My research skills are fantastic. Home improvements, been there done that, you name it, I have probably done it. Planning on going somewhere, I can arrange it and make it interesting. Baking-well yummmm, yummmm! I persevere, sometimes to a fault. Determined-yes. Logical-maybe too often. I am good with my hands as I have done painting, needlework, sewing, crafts, scrapbooking, crocheting. Did I say I can work on cars? If it interests me I try it. I'd like to think I am good at computers, but my logical skills are not what they used to be. What I would like to do better? Organize. I struggle at keeping stuff organized. Once I get it organized I am ok, but it takes me a long time to get there. I am not good at discipline. I have had that problem for a long time too... Finances, well, I could use lots of help in this department... How do I find my direction? That is a good question.....

2. What are some current assumptions you have that you would like to re-visit? What are some doubts you may have in yourself? Are there ways to challenge these?

Assumptions! That falls into the assume category and you know what they say about assuming.... So onto doubts that I have... I question my being. I question why me? I question how I can make it the best day,

however, for whom ever. If I don't get out of the house how am I to be more Christ like to others? I question why I am still alive. I question why I have to go through all the "pain". I question whether I want to be in an intimate relationship ever again. I question how I am going to keep on keeping on.....

3. It is also important to know your limits! How do you do with asking for help? What are some benefits to letting others help you or asking for help that you can think of?

Limits? I push the envelope. You only live once, you might as well have fun doing it and exploring it. If I don't like it, I don't have to do it again! I don't like to ask for help as I like to push myself. I know the benefits of asking for help, but I guess I want to "save" it until I REALLY need it. I am on a roller coaster ride. I feel some days I am crying "wolf". The counts go up, they go down, they go up, they go down, Who is really going to care when it comes down to the end? It will be just me and God....

Week 6: Relationships

While the topic of relationships seems to have come up with nearly every guidance module discussion, this week takes special focus to the dynamics between the group participant and others. The Week 5 exercise often blends nicely and easily with this module in that the introduction to this module discusses how relationships have changed since the participant's cancer experience. The module introduces things that affect relationships that are specific to issues related to cancer.

Our relationships can be affected by many things, for example:

1. Changing responsibilities. We are sometimes not able to do some of the things we once were. This can be frustrating for you, as well as for your family and friends.
2. Changing roles. If you were a take-charge kind of person before cancer, you may find that during treatment or when you're just not feeling up to snuff, someone else has to take over that role. Deciding when and how to switch back can be confusing and awkward.
3. Withdrawal. You may find that some friends and family members are avoiding you. It could be subtle or overt, such as when someone stops returning your phone calls. Either way, it hurts. People withdraw for a number of reasons. The person might not know what to say or is worried about saying the wrong thing. He or she might not know how to offer you support. Others don't know how to react.
4. Giving you too much attention. Rather than feeling lonely, you might find yourself being smothered with good intentions. Friends or family might baby you and insist on doing things for you when no assistance is needed. They love you and want to help, but in fact they're too helpful.
5. Confusing expectations. If your recovery isn't going as well as you'd hoped, you might be frustrated. You might expect everything to go back to normal right away, but that may not be happening. Try not to take your frustrations out on the people around you. If you do, you could push them away. On the other hand, you might find that others are starting to act as if things are back to normal, when they're not.

**Helping your loved ones understand your situation is a challenge to communication-
it's a skill we can all improve upon.**

Figure 22. Factors affecting relationships

The module also discusses the working components of a relationship and highlights things such as cohesiveness, how members of the relationship express what they feel and think and how well they problem solve together. The many different types of relationships are exemplified, such as relationships with friends, family, significant others, health care professionals and other cancer survivors. The importance and common denominator of interpersonal communication is emphasized.

Next, tips and techniques for enhancing relationships are outlined and described.

These include:

Start the conversation. Some people might want to ask how you're feeling, but they don't know what to say. Or maybe they think they'll upset you. Start the conversation yourself. Let people know that you welcome their questions -- or that you don't wish to talk about your cancer at that time.

Accept help. Friends and family are going to ask you if there's anything they can do to help. Plan ahead and come up with ways for people to give you some assistance, whether it's helping around the house or just being there for you when you need to talk. Friends and family feel good when they can help.

Let others know what to expect of you. Be honest about what you can do and what you can't. If you aren't ready to assume the responsibilities you had around the house before your cancer diagnosis, don't feel pressured to take up those duties too soon. But tell your family what to expect so that they aren't left wondering. When you're ready to take up your prior duties, let your family know that these tasks can help your daily routine feel more normal and help in your recovery.

Keep the friendships that matter. Some people will withdraw from you, and you'll have to let them go. Try not to expend a lot of emotional energy trying to patch up relationships that weren't strong to begin with. Invest your time and energy in the friends who are closest to you.

Plan what you'll say. You'll get questions about your cancer and your treatment. Decide how you'll answer these questions -- especially if someone asks questions you don't feel comfortable answering. In some situations you might let the person know that you don't feel comfortable answering those questions. Other times, you might avoid answering an uncomfortable question by changing the subject or redirecting the conversation.

Be patient with others. If you find yourself becoming frustrated, remember that the people around you have good intentions. They may not know the right things to say or do, so their words and actions may seem inappropriate or critical. That awkwardness may come from unfamiliarity with the situation. With time and patience, things may improve.

Stay involved when you can. Some friends or family might not invite you to do things because they assume you aren't ready for social activities. Let these people know when you want to be included -- or ask someone else to relay your message.

Figure 23. Enhancing relationships

The module continues to present ways to effectively communicate with health care professionals, since this is a population that cancer patients have significant interactions are often in constant contact with.

1. Write down a few questions or make a list of what you want to talk about. Don't leave without getting all your questions answered.
2. Let the doctor know what is most important to you. Doctors need to know what is important to you so that they can choose the best treatments for you. It's often possible to find solutions to some problems without medications or to change medications without sacrificing how well they fight cancer.
3. If you have a particularly important doctor's visit, ask a friend or family member to be with you to take notes and keep you company. Many people experience some degree of anxiety when they visit the doctor, and you may not be able to remember everything you'd like to.
4. Ask your most important questions first.
5. If you don't understand, ask your doctor to repeat in a way that is clearer to you.
6. Take a small tape recorder with you and tell your doctor you would like to record the visit to help you remember.
7. Remember that your doctor is your ally and partner. Make sure you have doctors that you trust and like.
8. Be your own advocate as you transition to life as a cancer survivor. You'll need to keep track of your medical records while you're getting important information or treatments, get second opinions, and build a team of trusted professionals to treat your cancer.

Figure 24. Communication with health care providers

Weekly Exercise

Think about how the relationships in your life and consider the following:

- Choose and discuss one relationship that you would like to strengthen. Name 1 small step that you completed this week that contributed toward strengthening this relationship. Discuss what this was like for you.
- Blog about how a cancer diagnosis has changed one important relationship in your life.
- Reconnect with someone with whom we lost touch during your cancer treatment.

Figure 25. Week 6 exercise

Participant Reactions

Relationships are often a popular and ongoing discussion. There are numerous dynamics and emotions that this topic has provoked. One common theme that has been observed with many group members is the element of surprise as it relates to their relationships. More specifically, many group members have described unexpected reactions from various people in their lives. Often times this goes one of two ways.

The first is the scenario group members have explained in which people in their life they were very close to prior to a cancer diagnosis seemed to “disappear” or “fade away” once the group member had cancer. Group members have hypothesized many different explanations for this. Some believe that this person(s) may have not known the

“right ” thing to say or way to react. Group members often voiced believes that because of this, the other person(s) felt that disconnecting from the relationship was “easier” than maintaining it. They often times have expressed that this result must mean that the friendship prior to its demise was “false” or “fake” in some way. When this is the case, participant reactions are often colored by frustration, anger, sadness, mistrust and disappointment. Validating these feelings and soliciting similar stories or feelings from other group members is often an important job of the facilitator. Additionally, helping group members to develop empathy by asking what they think might have been going on with the other person often softens some of the anger and may promote forgiveness, something that may be beneficial to the participants overall health and wellbeing.

The second scenario that often surprises many group members is one in which one or more people in their life with whom they may not have been previously close offers a great amount of help or support and a new, unexpected relationship is created. Many times this is a strong and much appreciated relationship that the cancer survivor values a great deal. Gratitude has been a strong emotion that has been common among group members when discussing these types of relationships.

Another common theme among cancer patients in this group has been how they are treated as it relates to their cancer. Again, a spectrum of reactions is observed. Some group members feel ignored, alone or not supported when people in their life don't ask about their cancer progress and experience. Others feel that the best relationships they have are with people that don't treat them any differently than they had before they were diagnosed. The reactions that are intermediate to these two are ones in which the group member has certain people they feel comfortable talking with about their cancer

experience and they have other people that they prefer to have a relationship with that does not involve cancer related discussions. In this group, the latter response has been the most common.

Family dynamics are often central to the discussion on relationships. Similar to friendships, some family relationships become more distant while others become stronger. Many times, it has seemed that families that experience more of a disconnection as a result of one member having cancer deal with a difficulty in adjusting to new roles or dynamics that are created from the cancer experience. Some in the group have described situations in which they believe their family member “can’t deal with the pain of losing me” and distance themselves as a protective mechanism. Others have discussed problematic family relationships in the context of conflicting beliefs. Some have experienced a situation in which they have discrepant values or ideas from their family member regarding attitudes or beliefs about medical decisions as they relate to the participant’s cancer treatment. Using an online adaptation of a “two-chair technique”, a question that has been powerful in helping participants clarify and express their feelings towards others: “If (insert family member name here) were here right now, what would you want to say to them?” Helping participants understand and identify their own emotions and reactions towards others, helping them to take different perspectives and embrace the idea that one only has control of their own emotions and actions and lack this control for others, and validating the wide range of reactions have all been important facilitation duties.

There is something special that many group members discuss as it relates to their relationships with other cancer survivors and group members. They often have a difficult

time describing what exactly it is that creates the strong bond they feel towards each other and often described it as an unspoken understanding between one another. It has been a common expression for group members to say “they just get it”. This is an important idea to explore and highlight as a facilitator, as this is the very premise from which this group was created. For example:

Tonight's chat really got me to thinking. Why are so many people so afraid of cancer? Does that mean that they're really afraid of ME? Are they afraid that I may die? Do they really think that any of us get out *alive*?? I had two friends (sisters) that I've only known about a year. We had so much in common and did a lot of things together. When I told them that I had breast cancer, I never heard from either of them again. I've called them several times, but there always seemed to be that uncomfortable silence on the phone. Neither of them ever called me again. When I was going through my surgery and radiation, my mom called me once. Once. She lives in Fla, and has free long distance. She calls my sister several times a week. When I finally told her how much it was hurting me, she turned it back on me and said "So, all me a bad mother, I guess!", My other sister is a big hypochondriac. After my surgery, she sent out invitations to all of her family and coworkers to a party to "Celebrate Her Healthy 'TA-TA'S'!! I haven't talked to her since! (my choice!) Tonight made me finally realize that I've had two people who actually supported me...my "good" sister, and my next door neighbor. They are the only ones that I can talk to about my diagnosis, my fears, my concerns...any of it. I've shied away from the support groups because I can't deal with negativity. Why can't people that I care about understand that I NEED them? Maybe it's my own fault. I've always been the one that everyone else turns to when they have something going on in their lives. I'm the oldest of six kids...I was always the "strong" one. Always. I could get through *anything*! And, I've gotten through cancer, so far. But, it's not the same. I need someone that I can lean on...someone I can cry to when I need to. For the first time in my life...I need people to ask to care...to understand. I'm not asking for much. But, I've never asked before. I never had to. I WAS always the strong one. Breast cancer changed all that. Now what??

Another Example:

I have a long term friendship with a girl I will call Sue. Sue and I go back to freshman year at college. Even though we now live in separate states,

both married and both with children, we have always had the kind of relationship where with a phone call or e-mail, we still understand each other/click/don't need time to reconnect. We have stayed connected.

When I was diagnosed with breast cancer last May, there was some reaching out on her part, but not quite what I had hoped. Other friends that I had felt less connected to actually stepped up more than Sue. I wrote it off to long distance, her busy career, and raising her three children.

After treatment was complete, she and her family came for a visit a few months ago that did not go well. I felt like my cancer was the elephant in the middle of the room that nobody was discussing. She and I didn't "connect." When I wrote her about this, her response was basically, "We have other people in our lives with cancer (her dad and her husband's mom), and if they don't discuss the cancer, we celebrate with them that they aren't dwelling on their cancer."

I realize that it was and is my job to initiate or not initiate conversations about cancer with my friends. Still, I feel less close to Sue and a little hurt by the whole thing. There is definitely some distance between us that wasn't there before. We have exchanged e-mails, but both of us are slow to respond to the other person and the friendship just isn't what it was before.

It was helpful to read under Week #6 Relationships here that some relationships just need to be released. I am hoping that it won't be this friendship that I need to step back from, and I am trying to weather the storm in the hopes things will get better.

What steps am I going to take? I continue to e-mail her, and I sent an e-mail this week telling her how important her long-term friendship is to me, asking what I can do to improve things, asking what is going on in her life, and telling her how I feel. We'll see.

Week 7: Ways of Thinking

The main ideas behind this week's guidance module are based off of an adaptation of the 3-factor Cognitive Behavioral Therapy model that says facts (life situations) lead to thoughts, which lead to feelings. Examples to clarify the model are given and practice exercises for the participant are offered. Further, helpful questions to

ask oneself as a way of identifying thoughts are presented. Next, ways of changing or “reframing” the thought (if unpleasant or unhelpful) are outlined with two different examples.



Note that the feeling came directly from the thought and not from the fact. We have little or no control over most of the facts in our lives, but we have total control over the thoughts. The more you feel you have control in a situation, the less stress and anxiety you feel. You always can have some impact and some degree of choice.

Practice:

Practice identifying the facts, thoughts, and feelings in your mind from time to time. Sort out one from the other. By simply being able to identify and label the facts of life we experience, we can begin to change the way we think about these facts, which may in turn change our feelings.

Questions to ask yourself are:

- 1) Is this a fact? Can it be changed? Do I have control over it? What thought results from this fact in my mind?
- 2) Is this a thought? If so, is it a helpful or unhelpful one to me? Can I change it?
- 3) Is this a feeling? If so, what thought did it come from? Is this a pleasant or unpleasant feeling? Do I want to change it?

Thus, a sense of personal control comes from our thoughts. This is a simple statement and it is extraordinarily powerful. It says that we have control over what and how we choose to think. The notion of choice is clear. For many of us from time to time, it is easier and less painful to believe that we have no control over our thoughts than to admit that we can take responsibility for them.

So the next step is to see if we can change our thoughts, even though we frequently do not believe that it is possible!

We do this by first understanding and accepting that although the brain is an intelligent organ, it also is very naive. It responds to whatever messages we give it whether they are true or not ! Here is an example to prove that point called, **THE LEMON EXERCISE.**

Changing thoughts is also called "reframing."



Close your eyes and imagine yourself in your kitchen. Find a lemon; notice the color of it. Feel its weight in your hand, feel its size, shape, and pebbly texture. Bring it to the table. Put it on a wooden cutting board, take a sharp knife and cut the lemon in half. Smell the sharpness. Now bring it up to your mouth and take a bite. What do you notice? There is no lemon but we can still feel its taste in our mouth. We can and often do trick our brain to react to things that are perceptions by the deliberate use of thoughts.

Now refer back to the fact of the person who passed you by on the street without speaking. What different thoughts might you have about that fact? What feelings would then arise?

Here is a second example to try: THE TRAFFIC JAM.

Imagine yourself caught in a major traffic jam that will probably make you late for work. You could choose to think: This is terrible. I'm going to be so late! My boss will be angry.

You could concentrate on trying to beat the traffic with frequent lane changes, and you may end up feeling increasingly distressed, anxious, and angry. Instead, you could choose to think of the situation as beyond your control and decide to use the enforced time to plan your day, organize your thoughts for work, and enjoy the music on the radio. This reframing of the situation may allow you to feel calm, relaxed and in control. You have a choice! You can change the way you feel by changing the way you think.

Figure 26. Cognitive reframing

Finally, distorted thinking is discussed. Types of distorted thoughts and how they lead to feelings are exemplified and the participant is asked to try some exercises on their own.



Here is a list of illogical and distorted ways of thinking that we commonly use to our disadvantage.

DISTORTED THINKING	FACT	THOUGHT	FEELINGS
You think in terms of "All-or-Nothing"	You fail an exam	I'm a failure	Sad
You overgeneralize	Your doctor rushes you out of his office	All doctors care about is the money	Anger
You disqualify the positive	A friend brings flowers	She felt she had to	Demeaned
You use emotional reasoning	You're asked to make treatment options/choices	I feel dumb, so I can't make any smart choices	Anxious
You use the word "should" a lot	My daughter wants me to babysit her son	I should babysit, but I made other plans	Guilt
You personalize	Your teenager failed his exams	It's my fault	Depressed

Figure 27. Common thought distortions

Weekly Exercise

This week's exercise pertains to how we think and starting to identify and evaluate those thoughts. Please try the following:

- Blog three of your own examples of: Fact/Situation ---> Negative Thought ---> Negative Feeling(s). Then, challenge yourself to come up with a REALISTIC positive thought and the resulting positive feeling(s) .
- Rate this new positive thought for how much you believe it and rate the new positive feeling 1 (worst)-10 (best). Hint: When do you know if a thought is both realistic and positive? Realistic is when you believe it at least at 75% or higher. Positive is when a new resulting positive feeling is created that exists at a 6+ on a scale of 1-10. Ex: Fact/Situation: Cancer recurrence ---> Negative thought: "I can't handle chemo a second time around"---> Feeling: Sadness. New positive thought: "Even though this is tough, I fought this before and I can fight it again, even though it's hard! ---> New positive feeling: Hope 8 out of 10, Strength 7 out of 10.

Figure 28. Week 7 exercise

Participant Reactions

This can be a difficult module for some that have never been exposed to Cognitive Behavioral Therapy or this way of thinking. For a lot of participants, this is brand new material so they often remark that it takes some time to get used to or it is “a lot to wrap my head around.” Indeed, this week’s material covers a large and potentially complex topic in a very short module. One role as a facilitator may be to clarify any questions people may have from the guidance material or expand more on how to engage in these types of thinking patterns.

There has often been a very strong positive reaction to this module. Group members have expressed feeling significantly better after taking the time to work

through the necessary steps. Once they understand the premise behind this way of thinking and are able to identify their thoughts, they are often very successful at finding alternative, more beneficial ways of thinking and thus, feeling.

One barrier group members have identified pertaining to this topic has been difficulty in identifying and being able to articulate what they are thinking. Often times they give the feedback that they “just feel” one way or another; understanding where that feeling is coming from may be unfamiliar and challenging. Normalizing this experience and validating that this way of thinking is not something we tend to naturally do may be helpful. Encouraging them to practice a little every day and notice improvements have been proven to be encouraging and provide a stronger sense of self-efficacy. Also, asking other group members what they have done in the past to begin to be successful with this skill may help other group members who are struggling.

A second common barrier that group members have expressed has been around the cognitive energy and time that going through these progressions of stages (identifying thoughts, evaluating thoughts, adjusting thoughts, rating emotional intensity, etc.) requires. Concerns that cognitive time and energy that this exercise entails may not be available when they are “in the moment” have been expressed. Again, the idea of practice should be emphasized. Group members should be encouraged that, just as not noticing one’s thoughts has become automatic through time and repetition, being able to recognize and balance them should come more quickly and naturally with practice as well. Here is an example blog from a participant:

Practice, practice, practice - It is an ongoing thing.

Fact/Situation #1: I had twinges of pain deep in one of my reconstructed breasts. It is like ghost pain - I cannot see it and know that there is nothing there except for the implant - the breast tissue has been taken out.---

Negative thought: "It is the cancer trying to grow back."--

Feeling: Fear/Anxiety.

New Positive thought: "It cannot be cancer - there is no place it can grow. It is the healing twinges - as my breast tries to heal nerves."

New Positive feeling: Excitement 8 out of 10, Strength 7 out of 10.

Fact/Situation #2: The scars across each of my breasts are long - about 5-6 inches and uneven.--

Negative thought: "They are not healing well - may be some infection that hasn't surfaced."--

Feeling: Frustration/Stress.

New Positive thought: "No - it is not a sign of infection - they are long because the surgeon made sure that she got every inch of breast tissue that could possibly grow cancer cells. They will get lighter and fade.

New Positive feeling: Calm 7 out of 10, Relief 8 out of 10.

Fact/Situation #3: My husband complains about the house not being picked up - doesn't want to hear "it", when I explain that I am still on a roller coaster - even almost a year and a half out from diagnosis and at times, so exhausted and questioning whether a clean house is ever a possibility or if it is even important.

Negative thought: "I look for excuses to not straighten up and use the cancer as a reason to not try - I can't really be this tired most of the time - what's wrong with me?!"

Feeling: Hopelessness/Depressed.

New Positive thought: "The healing is a slow continual process - both in mind and body. If my husband complains, I do not have to feel defensive and less of a woman because he says my house does not "sparkle." Heck, I don't even have to give him reasons - he does not know how I feel at times and I will get the house straightened when **I am** up to it - not when **he wants** me to; and when I do - I do it for **me** and not to make everyone **else** happy at the cost of my **very real** physical and emotional feelings!

New Positive feeling: Defiant 8 out of 10, Relief 8 out of 10.

Week 8: Self Talk

The self talk guidance module is an extension of the previous week's 'ways of thinking' topic. It introduces self talk as another way to modify thoughts. It starts with some practice exercises that allow the participant to come up with positive self-talk statements for different scenarios.



A. Preparation for Stress

I've succeeded with this before. What exactly do I have to do?
I know I can do each one of these tasks. It's easier once I get started.
I'll jump in and be alright. Tomorrow I'll be through it.
I won't let negative thoughts creep in.
or .

B. Facing a Challenge

I will take it step by step, I won't rush. I can do this, I'm doing it now.
I can only do my best.
Any tension I feel is a signal to use my coping exercises. I can get help if I need it.
If I get tense, I'll take a deep breath and relax. It's OK to make mistakes.
or .

What IS a positive attitude?

It's not necessarily positive, but necessarily not negative!
It is a sense of connectedness to something bigger than the self. It is a sense of control over how we handle the events in our lives. It is an ability to visualize a life with hope.

C. Coping with Fear

Relax now!
Just breathe deeply. There's an end to it.
Keep my mind on right now, on the task at hand. I can keep this within limits I can handle.
I can always call . I am only afraid because I decided to be. I can decide not to be.
I've survived this and worse before. Being active will lessen my fear.
or

Figure 29. Self-talk practice exercises

The module ends with a quiz asking the participant to remember how facts, thoughts and feelings fit together. It also reiterates the ideas that feelings come from thoughts, and while we may not have control over the facts, we can have control over the thoughts.

Weekly Exercise

How do you talk to yourself? Consider this and please try the following:

- Come up with a positive self-talk statement. This can be in the category of preparation for stress, facing a challenge, coping with fear, self congratulations, or affirmation. Practice saying this statement to yourself during the week at least 3x per day. Try it before you eat a meal. Write about what you noticed when including this new positive phrase into your week.

Figure 30. Week 8 exercise

Participant Reactions

Many group members have expressed confusion about ways in which this week's module is different from the previous week's module. The question "Isn't this what we did last week?" has come up quite a bit. Once the facilitator explains that this week is another technique to help build more beneficial and helpful thinking patterns, and emphasizes that these are important and effective techniques that improve with practice, group members have seemed more accepting of the module.

Reactions from group members regarding self talk seems to be more dichotomous versus other reactions and topic discussions. It appears that either individual participants engage in negative, condescending and even cruel self talk, or they are generally more

positive, forgiving and patient with themselves. Some group members are aware of the way they engage in self talk while others remark that they haven't truly considered their internal dialogue before. Those that are often more likely to be harder on themselves are often unaware of the potential outcomes and damages of this kind of self treatment and considering it's consequences is often a novel task. The facilitator should promote an open dialogue that explores the potential benefits and harms of self talk. Consideration of the feelings and behaviors that can result often from internal dialogue towards the self often leads to insight in individuals and a new emphasis on the importance of positive self talk has emerged with many.

Barriers group members have often brought up reflect the same concerns that are often mentioned in the previous week's exercises and include trouble remembering to notice, examine and implement self talk, as well as time barriers in that going through the steps of recognizing and altering self talk can be difficult to do in the moment. Practice is again emphasized, and normalization and validation of these difficulties should be provided. One skill that has been well received and is unique to self talk has been to encourage participants can come up with pre-determined positive self talk statements that they can use to replace more negative or neutral thoughts. Participants are often open to the idea of thinking about "pep talks" they can give themselves in common situations they find themselves in. They have largely responded positively to this idea in that it is more proactive than reactive and thus, may be easier to employ in the moment versus coming up with changing the "hot thought" on the spot. As a facilitator, encouraging those that naturally do this in their blogs is important, as is

suggesting the idea via a blog comment to those that may have not been able to come up with a positive, pre-conceived self talk statement(s). For example:

I guess I already practice this to a certain extent. When things get me down - literally, I will say to myself "Stop! What can be good in this situation?" "Look for the good." It does help because if I can focus successfully on something good or someone's good - I can change my mood at times from half-empty and sad -- to half-full and glad (liked the rhyme ;))

It does get difficult when my family reinforces the "negative" - I have to rationalize why the person (husband, son..) says the hurtful or critical things that they do at times - I do think it is a way of showing their insecurities by venting their hostility or finding fault. Unfortunately, they don't realize that they would probably be a lot happier if they could find something nice to say or do for someone.

I believe it takes two parents to back each other up - to promote a united and consistent front - when children try to question rules and my difficulty has been time and time again - the playing of good cop (my husband) and bad cop (me) around my sons while they were growing up. So...when they question me, criticize, or act disrespectful, I do tell them that it is not acceptable but sadly, I have to acknowledge that part of that upbringing came from our "parenting" and the fact that we don't do it in a supportive way to each other and then show that to the kids.

Then, I have to realize, after going through a number of physical changes - that I cannot "fix" them - but I sure as heck voice my opinion and how I want to be treated. They hear it "a lot" now - I am not the easy scape-goat for their frustrations and negativity - nope, not anymore, life is too short! There is a new affirmation - "Life is too short - let's not waste it!"

Week 9: Relaxation and Imagery

The relaxation and imagery module begins by describing the benefits of relaxation, including more feelings of control, inoculation against future stress, beneficial effects on chronic pain and having a general calming response. Importantly,

the module points out that these effects are often not immediate and practice is emphasized as necessary. Specific practice recommendations are outlined, including suggested frequency and duration (daily for 2-4 weeks), techniques (allowing thoughts to roll on, breathing and cue words) and expected outcomes. It also briefly mentions the relationship between stress, anxiety and physical tension and how relaxation can break the cycle that may positively reinforce these things.

The module continues by mentioning some research findings as well as the positive effects relaxation can have on tension.

The research supporting the use of relaxation techniques is extensive. As a treatment for pain, stress and medical conditions, relaxation has been clearly shown to be effective. It helps to achieve a sense of peace by letting go of tensions, clearing the mind and allowing release from problems. It is almost impossible to think or feel negatively when one is relaxed. Relaxation is the starting point in the process of calming emotions and changing thoughts. Thus, relaxation acts both as a distraction and an energizer. It allows the body to function in a healthier way, for example by lowering high blood pressure, and strengthening the immune system.

Practice at home so that relaxation becomes another coping tool to be used to help you accomplish what you value. Reading, watching TV, talking to a friend, being on holiday, jogging or walking, enjoying nature, etc. are all examples of light relaxation. Just as there are different stressors for different people, different types of relaxation will appeal to different people. Progressive Muscle Relaxation (PMR), however, brings about a deeper, more profound sense of well-being, and can be used with other forms of relaxation.

With practice, relaxation clears the mind and rids the body of unwanted tension in minutes.



Figure 31. Research on relaxation

As a practical tool, brief relaxation techniques are described and include the clenched fist, the deep breath, the breathing countdown and the warm hands.



1. **The clenched fist:** Clench your fist tightly for a count of ten. Release and let your whole body go completely limp.
2. **The deep breath:** Take a full deep breath and hold it for a count of ten. When you exhale let it all out at once, letting your body go completely loose and limp. This is related to the first technique in that it too involves an initial tightening (holding the breath for a count of ten followed by a sudden and complete release as you let your breath out all at once.) In addition, it takes advantage of another basic principle — the fact that the body is most relaxed when exhaling.
3. **The breathing countdown:** Breathing normally, let go more and more as you release each breath, while counting slowly from 10 to 0, one number per breath. By focussing on the “letting go” feeling as you let out each breath let go even more to produce a cumulative effect. Counting backwards (one number per breath) helps create the effect of descending (as if you were in an elevator going down another floor with each breath) becoming more relaxed with each breath.
4. **The warm hands:** Imagine yourself basking in the warm sun on a beach or soaking in a hot tub until you can actually feel warmth come into your hands. This technique uses the principle that the power of thought directly affects the body. An example of this principle in action is what happens when you’re hungry and begin anticipating your favorite meal. Your mouth automatically starts watering—a physiological response (salivation) caused by a thought. In the same way, the thought of warmth can have a direct effect on circulation. And since we know that the blood flowing out to the extremities is directly linked with relaxation, thoughts of warmth—especially warm hands will cause an automatic relaxation response.

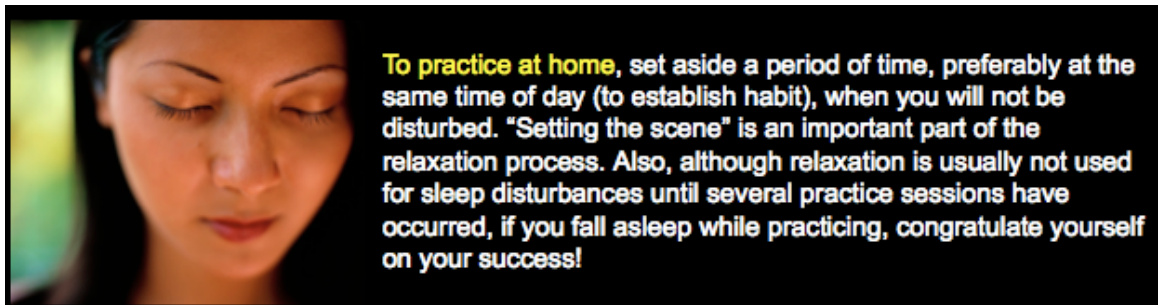
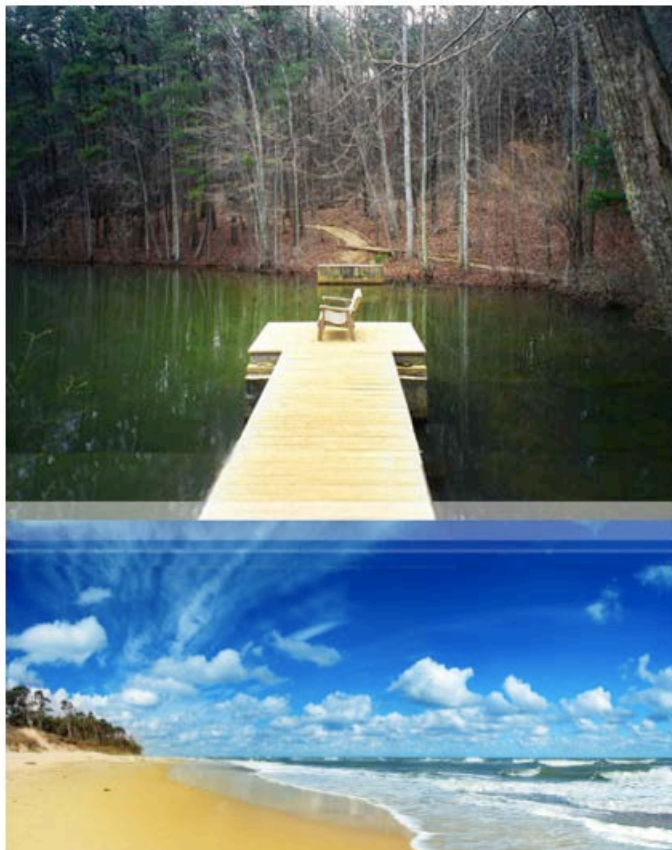



Figure 32. Relaxation techniques


Finally, more practical and useful information is provided, including different links to various types of relaxation streams and guided meditation exercises.

Relaxation Streams

Try these quick, skill-building exercises to help you learn to integrate relaxation into your daily life!



 [Introduction to Using Positive Imagery](#)

 [Learn to Progressively Relax Your Muscles to Reduce Tension](#)

 [Develop Slow-Breathing Skills](#)

You might also want to try some [excellent guided meditations](#) offered by Elana Rosenbaum, MSW. Elana is an oncology social worker and a cancer survivor. Her website is well worth checking out.

Figure 33. Relaxation resources

Weekly Exercise

This week is about relaxing.
Please try the following:

- Complete 2 relaxation exercises from the module and blog about your experience.

Figure 34. Week 9 exercise

Participant Reactions

Overall, group members have tended to welcome and enjoy this week's topic and related weekly exercises. It is not uncommon to hear group members say that they don't often take time for themselves and that the idea of doing so is sometimes not even considered. Some even remark that they feel guilty taking time out of their day to focus on themselves. As mentioned previously, many group members have assumed and settled into the caretaker role in their living environment and as a result, it may feel uncomfortable and strange at first to be doing something for themselves. Should this come up in a blog, it may be beneficial for the facilitator to ask them what kinds of benefits may come in their daily life if they were more relaxed. Many times, participants

are able to recognize the personal advantages but also the benefits a more relaxed self could have on their interactions with others. This may alleviate some of the “guilt” and may help them be cognizant of the importance of self care and how this may translate to their care for others as well. For some that may mention in their blog that they are finding it challenging to remember to do the exercises or may feel overwhelmed by finding time to practice the techniques, commenting on the blog and helping them specify the days, times and duration which they intend to practice has been shown to increase compliance and make it a more concrete, manageable task. For others, the “me time” is quickly embraced and is very much welcomed.

When group members are able to try the relaxation and imagery exercises, common comments are that when they do tend to “slow down” and take a few minutes to try to relax, it is often difficult to concentrate on the relaxation technique or exercise itself due to racing thoughts. Many have said that slowing down the thought process or “clearing one’s mind” is a significant challenge. This is often more the case in people who do not have much experience with relaxation and try the more passive relaxation exercises such as breathing or repeating a single word or mantra in their mind. For many group members, especially those who have not had extensive prior practice or experience in this area, some of the imagery based exercises seem to be more “successful” or less frustrating to them because they involve a more active cognitive process, in that they have more of a pointed instructive process which minimizes the mind’s opportunities to wander. Therefore, one observation has been to start participants with the more imagery based and guided exercises before moving on to the more open relaxation exercises.

Another observation from group member's reactions is that they tend to be very hard on themselves when they do get "off track" or have a hard time focusing on the exercise due to a wondering mind. Asking other group members if this has ever happened to them may be a useful technique as a facilitator in that it normalizes their difficulties. The importance of having a non-judgmental frame of mind while engaging in these exercises is imperative and should be emphasized, especially to those that respond to their less than ideal attempts with negative self talk.

Regarding reactions that relate these (or similar) exercises directly to their cancer experiences, there have been variable results in terms of these techniques being beneficial for participants during treatment. Some group members have shared that they use relaxation or imagery during procedures or treatments and that this has been very helpful in managing anxiety and fear. These group members are often the ones that have had practice or experience with relaxation and imagery before and actively practice these things on a somewhat regular basis. Commonly, those that have tried to implement these techniques and feel they "didn't work" have not had a significant amount of practice or experience with these interventions. This could be an opportunity for the facilitator to highlight the substantial impact of practice, as well as the importance of practicing in situations that are calm and relaxing in order to gain the confidence and skills needed to effectively implement these techniques in more stressful situations. For example:

I am enjoying the "me" time. Thank you for this homework! I have listened to the meditations on this website and the 18-minute Elana Rosenbaum MP-3 download from Amazon for 99 cents. I like the idea that I can't do this wrong, that it is about the process or the journey rather than evaluating or grading myself (something I do too much of the time). It has been soothing to create a safe internal place to go do these exercises. I am

enjoying "going to the beach" and the simplicity of the breathing exercises. I found a really comfy reclining chair at home where it is very comfortable to do the "homework."

I had done some guided imagery meditations when going through chemo and radiation, but I stopped after treatment ended. I feel like the slow child in school. I don't know why it didn't occur to me that some of these techniques would be helpful in "creating a new normal" and adjusting to life and moving forward after active treatment was completed. It is empowering to have more tools in my toolbox. I plan to download or purchase some additional mindfulness meditations. Any suggestions?

Week 10: Disclosing Thoughts and Feelings

The emphasis of this week's module is successful communication. It begins by outlining the different types of communication, verbal and non-verbal and talks about how communication affects coping, feelings and health. It highlights the importance of affective communication skills in cancer patients in that it can affect treatment and quality of life. The module specifies tools for successful communication including being committed and wanting to develop a clear and healthy relationship, allowing growth, and feeling equal in the relationship. The module emphasizes the important process of being assertive in communication and distinguishes assertive and aggressive communication styles. The module then discusses anger and introduces five steps that may help facilitate effective communication when one feels angry.

Step 1. Listen and find some truth in what the other person is saying.

Step 2. Listen and put yourself in the other person's shoes and try to see the world through his or her eyes.

Step 3. Listen and ask gentle, probing questions to learn more about what the other person is thinking and feeling.


Step 4. Find something positive to say to the other person.

Step 5. Express your feelings with "I" statements.

Figure 35. Steps to effective communication

It then talks about the importance of realizing the feeling behind anger and putting this into an “I” message what assumes ownership of one’s feelings. It outlines the three parts of an I message as: I think, I feel, I want. Next, the module gives the participant different scenarios and the opportunity to practice distinguishing the difference between “You messages” and “I messages”.

A. Disclosing thoughts, feelings and wants



Situation	"You message" Blame	"I message" Ownership
Your mother calls every day to ask you how you are doing	You are driving me crazy, —stop asking me how I feel.	Mom, I feel frustrated having to report about my health everyday. I'm really trying to live a normal life.
Fill in an example of your own here:		
Situation	"You message"	"I message"

Figure 36. Disclosing thoughts and feelings

Finally, the important process of asserting oneself is discussed in more detail and steps for practicing this effectively are described.



B. Asserting self: Yes/No

How many people say "yes" when they really want to say "no"? What if our "yes" worth is we never say "no"?

Making and Refusing Requests

When making requests be clear, specific, and factual. In order to appear confident, expect your requests to be accepted. Avoid long apologetic statements.... "Do you suppose.... Kind of..... Maybe.... Perhaps...."

Saying No:

Brevity is crucial. Be as brief as possible, i.e. give a legitimate reason for your refusal, "I don't have the time." Avoid elaborate explanations and justifications.

Acutally say the word "no" when declining. The word "no" has more power and is less ambiguous than "well, I just don't think so..." or "i really can't just now..." etc.

Broken record technique. Repetition and persistence may be necessary. You may have to decline several times before the person "hears" you. It's not necessary to come up with a new explanation each time; you can use your original reason over and over again.

Shake your head when saying "no." Often people unknowingly nod their heads and smile when they are attempting to decline or refuse.... this is a double message. Make sure your non-verbal gestures mirror your verbal messages.

Shake your head when saying "no." Often people unknowingly nod their heads and smile when they are attempting to decline or refuse.... this is a double message. Make sure your non-verbal gestures mirror your verbal messages.

Limit the words "i'm sorry" when saying "no." Try to be conscious about using this phrase to excuse your refusal or to otherwise weaken your credibility (habitual use of this phrase can be distracting to your real intent).

Buy time for yourself. Say, "let me get back to you on that," or "I'll think about it."

C. Prevent Disappointment

If we are angry and accusatory using "you" statements, we often hurt and alienate others around us which may in turn make us feel more isolated. Others can't get angry at us for the way that we feel, and we help others to connect with how they effect us by using "I" statements. Thus, we can improve interactions and lessen the chance of becoming angry or disappointed by others in the future through the use of "I" statements.

Figure 37. Asserting yourself

Weekly Exercise

Communication and how we communicate is key! Consider this and please try the following:

- What do you need from the relationships in your life and why?
- Who is the best person to ask this from?
- Give it a try! Ask for something you need and talk about what it was like

Figure 38. Week 10 exercise

Participant Reactions

More often than not, responses to the first question asking what participants need from their relationships has resulted in expression of needs that were primarily emotional. Things such as empathy, understanding, and patience were very common needs that group members expressed. There was often a theme of being frustrated regarding how they were being treated during or after their cancer treatment. Two different scenarios were likely. They felt that they were either being treated too similar or too different as a result of their cancer diagnosis and treatment.

In the first scenario, participants often described situations in which they were pushed too quickly to get back into a “normal” routine, often times this happened when they started to have a physical appearance that was more “normal”. For example, group members would describe situations in which their families expected the same level of productivity, activity, emotions, and behaviors from the cancer survivor once their hair grew back and they no longer had the obvious physical indications of a cancer diagnosis. Group members would often describe this as difficult and very taxing. It was also a situation that would often make them feel badly about themselves or guilty if they were unable to meet the same standards that they were held to prior to having cancer. Many participants would describe great struggles with fatigue and frustration when they were unable to do the things they used to be able to do prior to their cancer experience. Aside from physical demands, there were similar struggles with psychological processes as well. Many participants would say that people assumed they were doing well emotionally and psychologically when they started to “look good” externally. Many participants explained that the way they appeared on the outside (“much better”) did not always or even often accurately reflect internal processes. For example, group members have said that they were still “haunted” or bothered by cancer related concerns, such as a constant fear that the cancer could re-appear, or the constant struggle with the residual physical pain or frustration of memory and/or concentration difficulties. Many times, these concerns were intensified as the group member started to appear more “normal” to others. At this point, it was often the case that others are no longer asking them about their feelings or thoughts regarding cancer related concerns, or considering how these longer-term issues may be affecting them. Those who had external pressures from others

in their life, compounded with their own internal pressures, often engaged in negative self-talk (“I should be able to be the same person as I was before”, “I look better, I should be feeling better”) and were often the most distraught group members.

The module and homework exercise was designed to help guide participants to take the time to identify their needs and understand them at a deeper level by verbalizing them. From here, they are encouraged to identify a person that they could ask for this need from and then give it a try. It is very common for this process to seem frightening to group members and many are apprehensive of asking for an emotional need. Group participants have often mentioned that they believe this would expose vulnerability or show a “weakness” in their character. Many times, these group members expressed the believe that they are the caretakers and “strong one” in the family; they are the one holding everything and everyone else together. They believe if family or friends see them expressing fear or sadness or pain, this would be perceived as weakness and may render these same emotions to others or frighten loved ones or family members. In many cases, group members has explained that if she pretends the cancer or side effects aren’t there, they will have less of an impact on her and her family. This mentality often makes this homework exercise, which queries what they may need from others, an uncomfortable one because it encourages them to recognize that their emotional life may not be as “clean” as they may like to think; they likely do have needs, some of which may be unmet. However, it was often observed that group members did eventually express these needs.

There seems to be two main reasons why group members who initially presented as reluctant to acknowledge and verbalize their needs were more likely to do everything

in the group. First, many have said that this group feels like a “safe place” to express their fears, worries and other emotions they often try to hold back, hide from others or deny. Group members have often remarked that the safety they feel comes from being a part of a group where others have been through a similar experience and can empathize with what they may be going through. Group members begin to normalize the process of experiencing uncomfortable emotions and fears for each other as they begin to discuss this issue amongst themselves. This often leads to a positive feedback cycle in which, as group members feel their emotions and needs are more “normal” and acceptable, they continue to express themselves further. The second reason group members have said they are more comfortable expressing their more vulnerable side in this group has been related to the anonymity that comes with an online group. Having just a screen name as a personal identifier, living in a different town or state than the receiving parties, and not having to show one’s face, are some of the reasons group members have mentioned that make them more likely to open up, as they are less likely to fear judgment on a personal level.

The person the group members often identify as the person they feel they could ask for something from is a family member. For many, it is a spouse. Many group members express frustration that these close family members do not know what it is they are feeling, or that they do not ask the right questions or treat them in the way they feel they need to be treated. As a facilitator, it has been helpful to help group members explore the reasons why they feeling frustrated with their family member, what is reasonable to expect from them, and in what ways they might go about getting closer to their realistic expectations and goals. Most often, communication difficulties are at the

center of the frustration and confusion. Group members have often discussed how a close family member “should just know” how they are feeling. As a facilitator, it has been effective to normalize this concern by recognizing that we often feel like others that we spend a lot of time with should know us well, but at the same time, expose the fallacy of mindreading and explore how this may pertain to their situation. Talking with the participants about the benefits and consequences of practicing assertive communication with their family members often leads to a more detailed discussion of how they could begin to approach the situation and family member. Outlining a concrete, and detailed plan of action has been found to be a positive predictor of the likelihood that a participant follows through with the communication exercise. Some group members may be ready to try this within the week, while others are more hesitant. Meeting each participant where they are at in their readiness to implement these communication changes is important and each should feel supported. Even if a participant is not yet ready to ask for help, it is often the case that thinking about these ideas and being able to recognize their needs and how they might verbalize them to others is an important and beneficial process.

Regarding participants that did ask for help, the most prevalent reactions were, overall, a positive experience. Many group members expressed they initially feel their family member “knows” what they are thinking and what their needs are, but find they are often surprised to find out the family member is not always aware of these thoughts and needs. Once these discrepancies are brought to the attention of the participant and the family member, many constructive conversations are initiated and result in more empathy, understanding and patience in both parties. Few have described a substantial

change in their relationships, while most express a more subtle change. Facilitators should highlight the positive aspects that come from effective communication in order to help encourage group members to continue to practice these communication skills.

Example blog from a participant:

Example 1:

I felt that the last chat was great and certainly covered this topic pretty much. Let's see:

1. What do I need out of the relationships in my life? On the top of my needs - I would think patience and a bit of empathy at times.
 2. Why? Because sometimes life seems to go faster than my thoughts and after going through one challenge and yet another, I guess having the patience to allow me to work things out in life at my pace (which is slower than before cancer) would alleviate a lot of stress and depression off my shoulders. Empathy - why? Because just as I have learned to be compassionate and that there is always someone worse off - I still need someone to care enough to value my existence in this world - to want me to be happy and whole.
 3. Who is the best to ask this from? Well, I have been asking more of my husband - even though he is right now not the best at all -
 4. But I have also been clarifying my feelings more this week - as opposed to wondering why he can't "read my mind or see what's right in front of him." I realize that he is a bit "thick" and sometimes needs feedback for him to "act" in a way that can be more responsive to my feelings.
- Of course, there are always the ladies that I know that have either been through trials of their own; or are just natural caring human beings. I do think women come by this pretty much by being maternal and nurturing towards their families.
- So, I have noticed slightly, when I do clarify what I am feeling and why - my husband does take a step back and doesn't jump at the jugular quite as quickly. He is still very impatient and my sons follow suit but I have noticed that they take notice if I speak with a calm voice rather than getting a bit defensive or talking "over" them. Small, miniscule, but still...progress.

Example 2:

At this point in my life (17 months out from dx and 9 months out from active treatment), what I would really like from the relationships in my life is understanding. Understanding. Understanding. Understanding. My hair

has grown back (though it is short and I think it is thinner than it used to be) and people say I "look good." I think the assumption is that because I "look good," well, then, everything must be good. What is going on inside me at those moments, might be pretty far from good or normal, or even new normal. I might be stressing about physical pain (side effects from Arimidex, most likely) or worried about the cancer returning, or feeling overwhelmed because it is hard to keep up with everything in my life right now when my mind is foggy, concentration is poor, and physical pain is there.

The homework asks why I need this (understanding) from my relationships? The answer is really that I don't. I don't in the sense that I understand the difference between a want and a need, and my desire for understanding is a want. I don't need meals or assistance or even hours of "girl talk" about the cancer. What I do want (not need) is just people checking in now and then with a "How are you? How is recovery going?" At this point in treatment, I feel sort of medically abandoned because I'm not seeing doctors nearly so often and a little socially abandoned too because we all have busy lives and people think things are back to normal. Maybe my want is selfish? Or, being too needy?

At this point the best person for me to ask for understanding has been my husband. He has been very understanding. I have told him that things aren't normal in vivid detail, and he "gets" it. He has been very loving and patient, and tears come to my eyes as I type just thinking how hard it would be if I didn't have his love and continued support right now. I think he gets it because he is closest to me and I have consistently and honestly told him what is going on day by day, even now after active treatment. To keep my friends and the rest of my family that informed at this point would feel too needy to me at this point and, frankly, take extra energy that I just don't have right now. My friends who are survivors are my friend support in this area right now. I really look forward to hearing what the rest of you have to say about this topic. Thanks for listening.

Week 11: Goal Setting

While many people set goals, setting them in the right way may often be the difference between success and failure. This week's module helps group members set goals that set them up for success. The beginning of the module outlines reasons why goal setting is important including helping one re-establish a normal, daily routine,

helping them set priorities and accomplish tasks that are important to them. It talks about the difference between short term and long-term goals and gives guidelines for goal setting. These emphasize how realistic the goals are, how important they are and how it fits with values and beliefs. There is a space provided for participants to write down a goal they intend to work towards for that day. The next part of the module talks about successful goals and the advantages of goal setting.



The Advantages of Goal Setting

- Helps to establish a normal daily schedule.*
- Helps to prioritize at a time when there may be many demands.
- Is a realistic means of accomplishing tasks that are important to you.**
- Clears thinking on a day to day basis.
- Increases self-esteem and self-confidence through a sense of accomplishment.
- Reaffirms the future.*
- Gives meaning and purpose to life.**
- Encourages better use of the imagination.*

Figure 39. Goal setting

Next, questions one may ask themselves to help define their goals based on their values are presented and include prompts such as, “Given that I don’t always get what I want, what could I be willing to settle for?” and “If you had just 48 hours to live, what would you want to do with that time?”

Weekly Exercise

Goals are important and setting the right goal may be the difference between success and failing to meet your goal. Please try the following:

- Identify a key value that you have (i.e. family, health, career, patriotism, friendship, self-growth) and then pick one small goal this week that you can accomplish that will help bring you closer to this value. Blog about this experience.
- Remember goals should be SMART!
 - Specific: Significant, Stretching, Simple
 - Measurable: Meaningful, Motivational, Manageable
 - Attainable: Appropriate, Achievable, Agreed, Assignable, Actionable, Ambitious, Aligned, Aspirational, Acceptable, Action-focused
 - Relevant: Results-oriented, Realistic, Resourced, Resonant
 - Timely: Time-oriented, Time framed, Timed, Time-based, Timeboxed, Time-bound, Time-Specific, Timetabled, Time limited, Trackable, Tangible

Figure 40. Week 11 exercise

Participant Reactions

The reactions to goal setting are often either enthusiastic or apathetic. The nature of a participant’s response most often is due to their prior experience with goal setting. Those that have been unsuccessful in the past are generally reluctant to set goals. These types of participants often associate goals with failure and disappointment and have even

reported feeling that goals are detrimental and aversive. It is likely that these past goals have been unrealistic or difficult to attain. Conversely, participants that are interested in goal setting have likely had a positive experience(s) in their past and have felt the sense of accomplishment and excitement that accompanies goal completion.

Given the drastically different attitudes that can ensue as a result of goal completion or goal failure, the facilitator has the important job of guiding group members set goals that generate success. Many group members have lofty and vague goals such as “I will lose weight”, “I will eat healthy” or “I will get in shape.” It is important to help group members make goals that are specific, measurable, attainable, realistic, relevant and timely. For example, for a group member that says she will eat healthy, it is important to help her specify what that means on a daily basis. For example, what will her breakfast, lunch and dinner consist of and how much of each item? Are the changes drastic or realistic? Is there room for the group member to grow and improve? For this participant, a goal of “I will substitute my usual doughnuts for oatmeal for 4 out of 7 breakfasts this week” is a good goal because it is specific, measurable and realistic. Some group members find this difficult and may feel that the “little goals” or “baby steps” the group is encouraged to focus on will not make a substantial difference in their life and thus, they may challenge the facilitator when small steps are suggested. Therefore, it is important for the facilitator to explain that goals can always be increased or re-defined once they are met, but the sense of accomplishment of meeting the goals is an important process that provides forward momentum and positive self-efficacy.

Example blog from a participant:

Example 1:

I have always taken my health for granted and figured that I had time to lose those extra pounds, build muscle, and clean up my diet. Since my diagnosis, I realize that I ran out of time. I am overweight, I stopped working out and my diet needs to change. So, now I begin the crawl back to health.

I have been reading about the benefits of a vegan diet. The diet is thought to promote a healthy body as well as make it inhospitable for cancer cells to grow. Sounds good - except that I'm a carnivore. So, my goal is to work my way toward a modified vegan diet. I reserve the right to eat a steak every now and then (and I refuse to give up cheese). To get this going, I am going to remove all meat from breakfast and lunch. Dinner will still include meat, but not every day.

I just don't get the whole idea of setting goals or making resolutions for a new year. I've learned the hard way that tomorrow is going to bring what it's going to bring, and it's really out of my hands. I can control some things...most I can't. I've found that when I DID set goals or resolutions, something always popped up to get in the way of them. I really just take each day as it comes and get through it as best as I can. I had goals when I was younger. Life happened, and those goals went right out the window. How do you keep setting goals when you know that life is going to jump in there and block them? It's easier for me to just get through every day and be happy rather than to try to set a goal that sets me up for disappointment. It's easier for me to be happy rather than disappointed.

Example 2:

Key Value: Self-Growth

To bring me closer to this - small goal accomplished the past week:

I noted little blocks of time - just "me" time - on my mental calendar. I started with 15 minutes per day - usually trying to find a quiet place to read or meditate.

By the middle of the week - I expanded my time "allotment" to 30 minutes - it ended up being hard to set aside and find the 30 minutes - I settled for 20 minutes - which was doable - without having someone in my family have a "need" or "want" - to include my pets - and having to cut my "me" time.

At the end, I felt that 20 minutes was a great thing to give just to "me".

But, I still want to get to 30 minutes on weekdays - so if I am at 20 - I will try to go over the time and telling my family in no uncertain times that this

is my "mental health or break time." I got some strange looks when I started the week with this - but they did leave me alone for a bit! Eventually, I would like to get to where I have "me" time to accomplish something physically rewarding - such as my cross stitch. I enjoy the rare feeling when I have completed something - it is just so difficult to practice beginning something - just for "me."

Week 12: Benefit Finding

The modules conclude with the topic of benefit finding. The module introduces the topic by defining what is meant by benefit finding and states that it is the experience of significant positive change (personal, interpersonal, or global) that may arise from the struggle with a major life crisis. It also mentions that finding meaning or considering positive implications or benefits of the event minimizes or mitigates the negative implications. Further, it cites research that 90% of breast cancer survivors report finding benefit from adversity and that this benefit is often found in a variety of other cancer diagnosis as well. The module suggests that survivors find benefit from emphasizing benevolence over malevolence and meaningfulness over randomness. Often people learn their strengths when faced with adversity or gain insight into the meaning of their life. Examples of how some cancer patients have found benefits from their experience are offered.

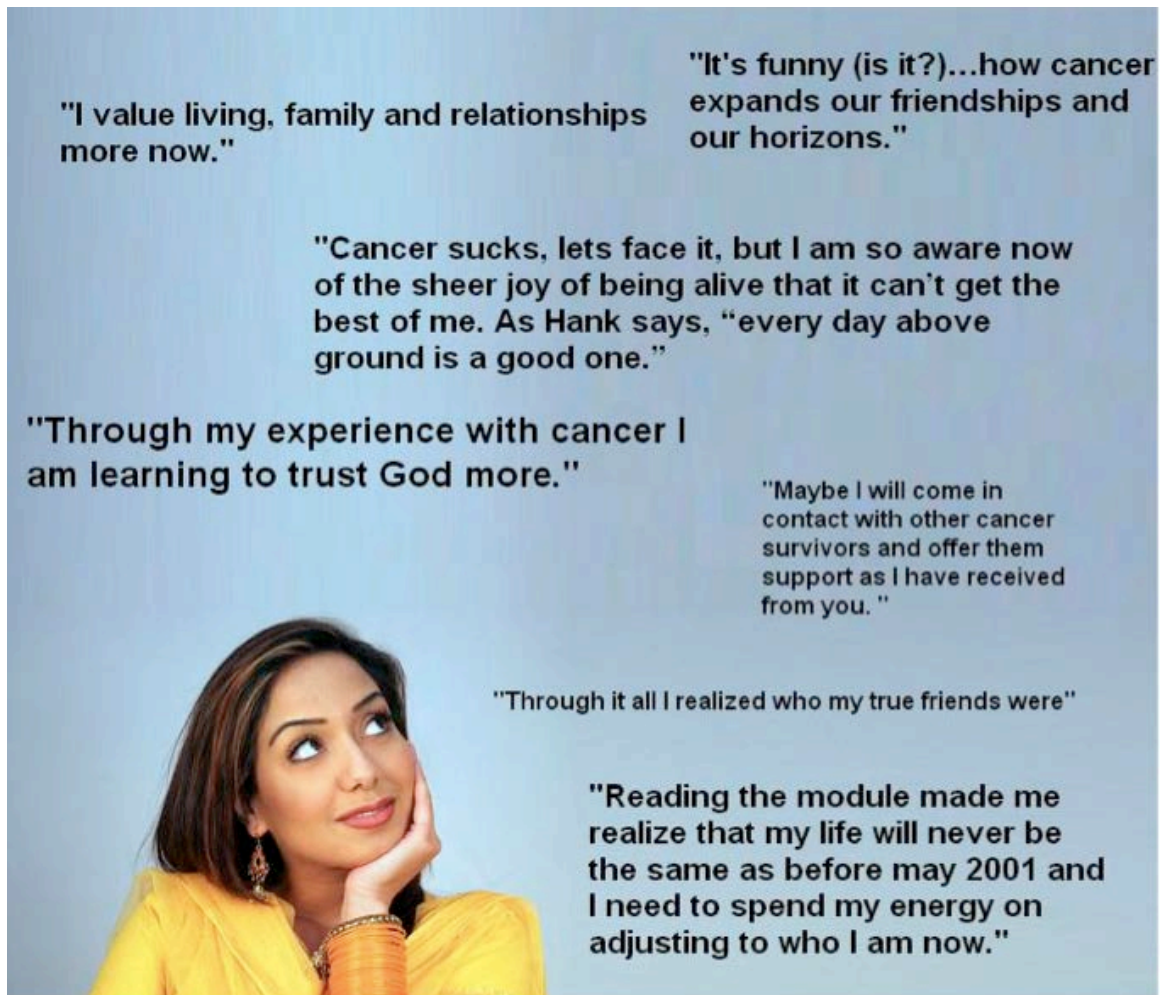


Figure 41. Benefit finding

Finally, common categories of benefit finding are outlined and include benefits in interpersonal relationships, personal growth, spiritual change, acceptance and appreciation for life, concern for others/altruism/global concern and improved health habits.

Weekly Exercise

Write a letter from you pre-cancer self to your current self that begins with the following prompt:

- Dear Self,
- You do not realize it yet, but cancer will teach you so many things about interpersonal relationships, personal growth, spiritual change, acceptance and appreciation of life, concern for others, and health habits, among other things.
- Choose one or several areas to focus and expand upon in your blog.

Figure 42. Week 12 exercise

Participant Reactions

This has been a powerful and emotional blog topic. This blogging exercise has evoked significant self-reflection and insight from group members into their cancer journey. The majority of participants have been honest, forthcoming and open about their experiences with cancer. While each participant has a unique relationship with cancer and their emotional journeys are exclusive to themselves, common themes were noted in this exercise. Priorities, appreciation for life and time, change, spiritual beliefs, relationships, health, strength, and personal growth are topics that were described as meaningful for many group members.

Nearly all group members who have participated in this exercise have mentioned a priority shift that they experienced as a result of facing a cancer diagnosis. For many, cancer clarified their values and the things they invest time, emotion, and resources into. Group members often remarked that these new priorities are a shift from things that were important prior to having cancer. For most, family and spending time with loved ones becomes the primary priority after cancer whereas work, for example, may have been the thing they invested most of their time into previously, but now takes a back seat.

Many have also discussed a new appreciation for life. Cancer has been an experience that, for many, abruptly showed them that they are vulnerable and life is fragile. For some, cancer has been their first experience with the reality that time is limited. Many participants have said that they have a new appreciation for enjoying the moment and taking time to focus on the present.

Issues related to religion or spirituality have been very common as well, although the nature of responses are variable. Some express a sense of anger with their higher power, usually God. Many of these participants have said that they feel betrayed by God and don't understand how their God could "allow" this to happen to them. Thus, for some, their experience with cancer has weakened or even broken their relationship with God. There have been a few participants who have reported that although they used to have a close relationship with God, they no longer believe in a higher power after they received a cancer diagnosis. For others, their religiosity and/or spirituality were strengthened as a result of their cancer experience. Many have expressed how they have found meaning and purpose in their cancer journey and have a strong belief that their experience is all a part of God's plan for them. There have also been participants who do

not believe in a God or a higher power. Overall, it seems as though group members who reported feeling betrayed or abandoned by God tended to have feelings of anger and resentment, while those who experienced positive growth in their relationship with God generally expressed feelings of peace and were able to find more positive results from their cancer experience. As a facilitator, it is important to address issues of spirituality and religion and welcome and deepen these conversations. However, it is critical that the facilitator does not push his or her own religious or spiritual beliefs onto the group members or make judgments about participants' beliefs. Because religion can be a somewhat controversial and heated topic, the facilitator also needs to ensure other group members are conversing appropriately with each other. Unlike the facilitator, other group members may interject their own opinions and/or challenge one another's beliefs. While this may conjure depth and emotion into a discussion, the facilitator should be cautious to ensure people are not becoming personally offended to the point of being uncomfortable in the group. If this begins to be the case, the facilitator should take action and defuse the situation. This may be done in different forums including commenting on the community blog or discussion board, sending the involved participants a private message, and/or bringing up the topic in the live chat and discussing it there. The facilitator should examine each individual situation and use his or her clinical skills to determine the most appropriate course of action.

Relationships other than those tied to spiritual or religious beliefs are also mentioned very frequently. Similar to religious relationships, responses fall on a spectrum and are often variable. Some participants discuss their relationships with a particular person or a few particular people. Family members, including significant

others and children are often discussed. For many, the group member's relationship with the family member grew stronger and some even discuss the relationship transforming into a new, closer, deeper relationship as a result of the cancer experience. In parallel with personal processes, many group members discuss how the cancer experience exposes family members to the fragility of life and is a reminder that time with loved ones is limited. Some group members express the pride, gratitude and love they feel towards people who have supported them. Some express pleasant surprise regarding the level of care, concern and support they have received. In other situations, group members are disappointed in their relationships but often are able to discuss these circumstances in a way that promotes growth. For example, some group members discuss how they were able to move on from relationships they were previously holding onto that may have been more destructive than positive. Repeatedly, group members have said the cancer experience clarified the relationships in their life that were meaningful and important to them. Group members also discuss their relationships with other group members. Often times, they report feeling very bonded to one another and express appreciation for the space to be honest, open and vulnerable with each other.

While some participants mention health concerns, the responses regarding health are overwhelmingly positive and appreciative. Group members are often health conscious and cancer has made them appreciate the importance and potential effects of living a healthy lifestyle. For many, health become more of a priority than it was prior to their cancer experience and they are much more committed to taking care of themselves, whether it be through diet, exercise, relaxation, minimizing stress levels, self-care, or other vehicles of health.

Personal growth is a topic that has been apparent with every group member who has completed the exercise. Many discuss how much they have learned about themselves, their relationships, their values and their priorities. Group members have described surprising themselves regarding their level of personal strength. They often report a new-found level of strength they may not have believed they possessed prior to going through their battle with cancer. Many are appreciative of the person they have become and many believe they are a better person because of their experience. There is often a strong sentiment of love and gratitude towards the self, which is a powerful and beautiful way group members conclude their module exercises and group participation. Example blog from a participant:

Example 1:

Dear Self,

You do not realize it yet, but cancer will teach you so many things about interpersonal relationships, personal growth, spiritual change, acceptance and appreciation of life, concern for others, and health habits, among other things.

One thing you will realize concerns acceptance and appreciation of life. You will not continue to struggle with the "why me?" attitude and actually find that by going through and surviving that you are still you - even if physically you have changed - internally, you are still the same soul - albeit, a wiser and older soul.

You say "so what?" You have been given a great gift - the gift of facing mortality and staring it in the face - only to be given another chance - a chance to really appreciate all the things you have taken for granted. Do you not note, rather than pass over, the visual beauty of another day - another sunrise or even rain - how it feels on your face - that you are alive?

When your pets rub their soft fur against your hand or face - so much pleasure to see you when you walk in the door - you take the time now, don't you...to smile and stroke their fur - to take the time to pause and play with them.

No more the rush of getting through life - you savor each second now, slow it down, and know to value time - because time keeps going. And by slowing and taking the time - you will remember so much more as happiness - as a gift to be here - and a second chance to appreciate life. Love to you - from you - from me - to me...

Example 2:

Dear Self,

You do not realize it yet, but cancer will teach you so many things about interpersonal relationships, personal growth, spiritual change, acceptance and appreciation of life, concern for others, and health habits, among other things. You have lived life as if it will never end. While this can be good, it also has allowed you the opportunity to procrastinate. Priorities have been upended and you have not been as compassionate as you should be. Well, change has come!

Now, cancer will show you many areas for growth - but only if you pay attention. Priorities will be realigned so that life can be lived with fullness. No longer will you look at other peoples sufferings without realizing that it could happen to you. Life is so much better when you realize that all humans deserve love, respect and compassion.

Your relationship with God will grow. Life here is finite and knowing your eternal destiny will bring you peace. God wants to bring comfort and love, but you need to be quiet long enough to listen.

You have neglected your health for too long. You have spent years making sure that the family has had everything they needed. Except you forgot that they need you too. It's time to stop neglecting yourself. Diet and exercise are crucial to your recovery. And, while your family will not be happy with the time you are spending to get yourself healthy, they will love the results.

Now, the next time you want to procrastinate, remember my words. Life is too short to put off doing the right things.

Example 3:

Dear Self,

You do not realize it yet, but cancer will teach you so many things about interpersonal relationships, personal growth, spiritual change, acceptance

and appreciation of life, concern for others, and health habits, among other things.

You will learn that you are truly blessed by your marriage. You will learn how much you love your husband and how much he loves you. He can't "fix" your breast cancer, but he can be by your side and comfort you tremendously. You will learn how kind people can be, including people who you didn't know very well before the diagnosis. You will be touched by the love and support that reaches out to you.

Oh, Self, you will learn that the days do add up, chemo has an end-date (at least for now), and that you can get through this! You will get better at living in the moment, appreciating the small things, and, dare I say it-- learning patience!

You will also learn ways to deepen your faith and renew your spirit. You will read your bible more. It will mean more to you than it has meant before, and even make a little more sense.

You will learn to take better care of your physical and emotional self, and you will learn that you truly have a spiritual self that is above, beyond, and behind your mental, physical, and even very emotional self! You will learn to exercise and eat better! You will be rewarded by a body that is actually healthier in many ways than you were before your devastating diagnosis. You will also grow in compassion and your ability to reach out and love others who are struggling with things in their own lives. In short, this will be a time for you to grow.

By the time you are 19 months out from diagnosis (now), you will not be done growing. You will better accept that the experience is a process and more willing to give yourself the time you deserve to work through the process. You aren't alone, Self, the self-beating is done, and I've got your back!

Other Blogging Topics

It is the role of the facilitator to clearly communicate the group members that the blogging component of the group can and should be used to communicate and share any and all thoughts, emotions, information or other topics that may not be addressed by the coping skills modules. It is important to respond to miscellaneous blogs that are written

in a way that is encouraging, supportive and expresses interest in the group member's topic of choice in order to reinforce group member activity.

One example of blog topic that is commonly seen is a termination blog, or a blog a group member will write right before they graduate from the group. Often times, these blogs are emotionally rich and commonly express feelings of gratitude, care, support, loss, hope, and encouragement. For example:

After we got together and chatted last night, I truly realized how much each one of this group has come to mean to me. You've each brought something into my life...each in your own special way. I would not trade a single one of you for anything! I've come to depend on the different personalities of each of you. I've come to think of you as real friends...not just some research group. How does that happen?? Lol. However it happened, I'm grateful that it did, and I want each of you to know that you have brought some special meaning into my life. You've made my life happier. You've made my life better. Thank you to each of you...I don't think you realize what you have given me, and I only hope I can give even a small part of that back to you!

Chat and Blog Interactions

A fairly consistent finding throughout the study has been that the most likely participants to write blogs are those that have attended and been engaged in the weekly live chats. It has been very rare to have a participant who does not regularly come to the chats engage in the weekly blogging exercises or that they even blog at all. The guidance exercises for the upcoming week are presented and discussed in the chat and it has been observed that the chat seems to spark blog topic ideas. As such, blog topics are often similar or somehow related to a topic or conversation that was brought up in the chat.

Therefore, encouraging group members to participate in the weekly chat is very important and is likely a moderator that predicts blogging activity.

Potential Challenges with Guidance Modules

Confusion

Challenge

A commonly occurring challenge with the guidance module component has been participant confusion around the timing of the modules. While a rolling admissions procedure has many benefits, it includes limitations as well. The biggest limitation we found was related to the guidance modules and participants being confused regarding what week in the guidance modules the group was currently focused on. For example, as a consequence of a rolling admissions process, a new participant might enter the group when the guidance module is on Week 3 and feel very confused as they are in their first week of participation in the group.

Potential Solutions

A helpful solution has been for the facilitator to take time and care into providing a clear explanation regarding the discrepancy between the week numbers as labels versus the number of weeks the person has been a participant in the group. While confusion has appeared to be a source of participant frustration, the facilitator can use this barrier as an opportunity to build rapport with the participant. Addressing

participant's reaction to this situation should be done in a way that expresses empathy and normalizes participant confusion. Building rapport with new group members is of the utmost importance, as initial interactions of the website and impressions regarding the interpersonal dynamics seem to predict the likelihood of participant's future activity. The following is an example of a participant-facilitator exchange regarding this issue:

Example:

Participants post about her confusion:

Hi Kristen!! I just wanted to touch base and ask a few questions if you don't mind...here's my question for the week (again!) ...what's our topic for this week? Which week are we on? lol...I just never did get this whole topic thing figured out!

My response:

Hi K, no worries about the questions...ask away! Hope I can help clear a few things up for you, I know some aspects of this group can be VERY confusing and frustrating so I am so glad you have been able to look past those things and stay with us, we love having you here and really hope some of the benefits can outweigh the confusion!

I know, it can be very confusing!! Let me see if I can help...so as far as the guidance modules go, we are currently on Week 5: Self-Efficacy BUT we move forward in the guidance modules every Wed (to coincide with the chats) so, starting tomorrow we will be on Week 6: Relationships. However, the week you joined the group doesn't necessarily coordinate with the guidance module week numbers. And in your case it doesn't (sorry, adds to the confusion for sure!). The best thing I can tell you is not to bother with the week numbers since they are off, but just focus on moving through a different topic each week in the order they are listed, does that make sense? I will be sure to clearly state which topic we are moving to when I send out the chat reminders Tuesday evening. Hope this helps and please let me know if you still have questions or if I can clear anything else up for you. Have a wonderful rest of your day and I will look forward to seeing you in the chat tomorrow!

Lack of Participation

Challenge

Active participation in the blogging exercises that are based on the guidance module topics seems to elicit rich emotional expression from group members; however, participation rates often tended to be low. While the number of blogs written varies depending on the level of overall engagement within each cohort, an average number of blogging exercises completed seems to have been between 2-4 per week. This number has been greater with the more active cohorts and less with groups that are less active overall. Additionally, group members seem to be motivated, encouraged and/or responsive to one another. As such, if one group member writes a blog for the week, it is often more likely other group members will complete the exercise for the week as well. Conversely, if no one initiates or completes a blog, there is often a lack of overall activity for the week. Therefore, there is often a bimodal distribution pattern of activity, with some weeks where multiple blogs are written and other weeks where no blogs are written.

Group members have offered many different reasons that likely account for lack of participation in the guidance exercise homework. Forgetfulness, lack of time, difficulty gaining computer access, lack of personal significance or relatedness to the blogging exercise, lack of energy/increased fatigue, and/or feeling ill have been common examples.

Potential Solutions

Based on the consistent observation that group members are often more likely to write blogs when other group members have done so, facilitators should focus on providing encouragement to the group as a whole to participate in the blogging assignments. This can be done via many avenues. One option is to post a public message on the discussion board that is visible to all group members reminding them about the exercise for the week. This option targets the barrier of forgetfulness as well as encouragement for participation. In order to sustain the group member's attention, the message should be kept short. The content should relay the facilitator's excitement and value in reading group members' blogs, hearing their thoughts, and supporting them in their emotional expression regarding the topic for the week. Another mode of communication that encompasses the same dual purpose of serving as a reminder and source of encouragement to complete the blogging exercise is to privately email each group member. Based on the principle of diffusion of responsibility that can occur in groups, this method has seemed to be more effective with the probability that it is more likely to induce a sense of personal responsibility given that the email was sent to the individual. It also reflects that there is very much a "personal" quality to the group, that their individual input and blogs are important and valued components of the group. Additionally, focusing on the objective of encouraging group member participation has the additional benefit of addressing the barriers that reflect a lack of motivation (i.e. too tired, not enough time, feeling too ill). Based on the observation that the greatest predictor of group member participation seems to be other member activity, it is likely

participants are more likely to overcome these barriers if others are modeling blogging, as this establishes this activity as the norm for the group.

A less common barrier that has been identified is when group members find that the module exercise is not relevant to them. However, if this is the case, a potential therapeutic response would be to encourage them to write about the reasons why the topic may not resonate with them. This may elicit clinically relevant information, and encourage positive reflections or feelings of appreciation for the group member. For example, a group member may state that “Disclosing Thoughts and Feelings” isn’t a problem for them and they therefore have a hard time completing the exercise for that week. As a facilitator, a therapeutic response would be to highlight and reinforce this quality about the individual. Further, the facilitator should encourage them to discuss the outcomes of this skill, ways in which they have been able to do this, and how it has had an effect on them. If relevance and potential benefit of the skill being emphasized is being expressed from a member of the “in group” versus coming from a facilitator, who may be looked at as being apart of the “out group”, it is likely to further legitimize and validate the importance of the coping skill.

The Discussion Board

Discussion Board Aims

The discussion board is the home page for the online group. It is the page that appears for participants each time they log onto the site and, therefore, is the most visible and public component of the online group. The discussion board is designed to provide

an open forum where group members can connect and communicate with other group members at any time by creating posts that are visible to all group members and facilitators. It is meant to be a place where participants not only generate posts, but are able to respond to posts made by fellow group members as well in order to facilitate ongoing conversations.

Many other aspects of the group are aimed at providing guided discussions that focus on specific material, skills or topics. The discussion board is a unique component to the group that provides an opportunity for group members to make posts about things they generate on their own, content that may be completely unrelated to any topics or material provided by group facilitators. This has been found to be a very beneficial aspect to the group in that it allows group members to freely express issues that are most relevant and important to them at that given time. Additionally, this is an informative process in that without facilitators imposing topics that have been shown to be relevant to the oncology population as a whole, it creates an opportunity for facilitators to observe and learn more about what issues are most central for the individual cancer patients and survivors that make up their particular group.

The discussion board functions in a way that is designed to mimic “natural” or face-to-face communication. Once a post is made, all group members and facilitators have the opportunity to comment and/or respond. That response is directly linked with the original post. This keeps the conversation simplified and streamlined in that back-and-forth exchanges are uninterrupted by other posts. Further, group members involved in conversations that originated on the discussion board are alerted via private email

when others respond to the conversation thread. The alert email also gently encourages participants to respond back in order to promote ongoing dialogue within the group.

Facilitator Use of Discussion Board

The discussion board is an excellent tool for facilitators in that it provides a place for important messages to be posted that are centrally visible to all participants. This is an effective way to communicate with all participants simultaneously and can help the facilitator save time versus contacting each participant individually.

One way the facilitator can use the discussion board is to welcome participants to the group. When just starting the new group, the facilitator should make an initial post on the discussion board in order to help model it's use and guide/invite participant interaction right away. Additionally, the facilitator should talk a little about him/herself in an effort to help the group feel more familiar and comfortable with them. The message should be warm, inviting and informative. Here is an example of what the first post to the discussion board might look like:

Hi there!

I am so excited to get started getting to know you. My name is Kristen, I am one of the health-space facilitators and I wanted to extend a very warm welcome to the group! I hope you find this group to be helpful and supportive, I also want to welcome open lines of communication right from the start so if you ever have any questions or concerns, please let me know. I hope you have had some time to set up your profiles and get familiar with the site. I am eager to get our journey started and start learning more about you! So, if you would be up for it, posting a "Welcome Message" or a little something just to kick things off to the discussion board, would be great. Just some ideas...you can post a little about your experience with cancer, where you currently are in treatment and/or a fun fact about yourself and your interests. For example...as I said, my name is Kristen, I am a 4th year doctoral student at Loma Linda

University and I have a very special and personal interest in working with people who have had the experience of a cancer diagnosis. I have worked in labs doing the very "scientific" side of cancer research but find it much more rewarding working with people like you. I am constantly inspired by the bravery, courage and grace that the people I have had the honor of working with display but, I also appreciate how necessary it can be to talk about the extremely difficult, exhausting and "ugly" side of cancer and it is my goal to provide a safe environment to talk about the ups and downs of everyday life. Fun fact: a few weeks ago I completed my first triathlon, Tri for the Cure, which benefited breast cancer. It was incredibly special to me because I completed it with my 58 year old mother (don't tell her I told you her age!) who was diagnosed with breast cancer in 2007. She went through multiple surgeries, as well as chemo and radiation and I am so happy to report that she has been cancer free for a few years now and is stronger than ever. However, it was a tough road for her to get to where she is now. My mom has always been my best friend and seeing her go through everything she did makes me really appreciate how cancer can really change everything. Having said that, I have never experienced it myself and look forward to learning more about your individual experiences. Welcome to health-space, I am so glad you are here :)

Once the group has been established and active, a briefer message may be more appropriate for new group members as they enter the group on a more individual basis. Introducing new group members to an active cohort serves a few very important purposes. First, it helps new group members to feel included in the group. This can be difficult on a rolling admissions basis because some members may feel "intrusive" when they enter a group that has already formed. The public welcome provides them with an opportunity to become visible to the group and, often times, elicits a response from the new group member, thus initiating group participation. Second, it alerts existing group members that a new participant has joined, which often prompts them to introduce themselves and welcome the new member. This first contact with other group members has been a very important interaction and has often predicted new group member

participation and activity level in the group. Below is an example of a way to welcome a new group member(s).

Hi there! I would like to take a minute to extend a warm welcome to a few new members of the group. WELCOME Coriam, Dino and Donnabee to our Health-Space Family! I can say with complete confidence that the ladies in this group are phenomenal and can provide great support. We are excited that you have decided to join! For our ‘veterans’, do you have any advice for the new group members on how to get started in here? What was most helpful for you? For experienced and new members alike, please use the discussion board to get to know each other ☺. I hope this can be a positive experience for you all! Enjoy and looking forward to seeing you in chat tomorrow evening!

Another way facilitators can productively use the discussion board is to remind participants about weekly chats. It has been effective for facilitators to make a post to the discussion board clearly stating the time and day of the upcoming chat. Because one advantage of an online environment is that there are no barriers regarding participant location, the chat time should be listed in all time zones within the United States in order to reduce confusion. Facilitators should also indicate the upcoming guidance module topic that will be discussed in the chat and encourage participants to read this module prior to coming to the chat. It has been found that if group members have background knowledge of the guidance module topic, this gives them the opportunity to ask for clarifications, or questions and provides time to think about ways in which the particular topic may apply to them. The chat information/reminder post should be made the day before the chat. This way, the post serves the additional function of being a reminder regarding the chat, which often helps increase the number of chat participants. A facilitator’s post may look something like the following:

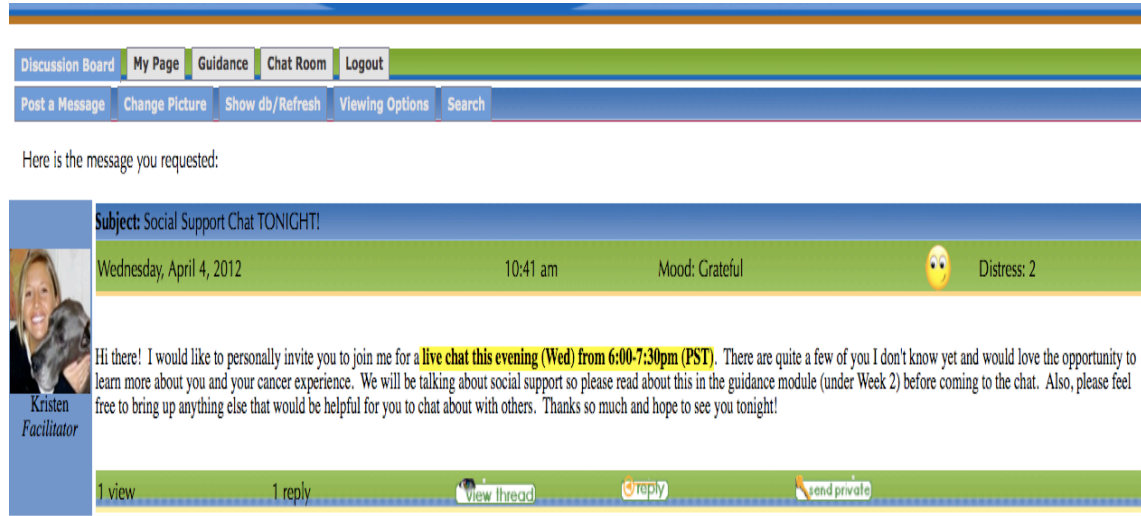



Figure 43. Chat reminder discussion board post

In an effort to positively reinforce chat participation, publically highlighting and showing gratitude for group members that were active chat participants has been found to be an effective use of the discussion board. This intervention is likely to serve two useful purposes. First, it likely reinforces chat participation for those who were present in the chat. Second, it is meant to further emphasize the importance of the chat to all group members, including those that did not participate in the chat, in an effort in increase future chat participation.

Further, this post can serve as a means of announcing the progression of guidance module topics. This effort brings awareness to the guidance module topic and exercise, which helps remind participants to engage in these aspects of the chat and clarifies the module topic for the week. An example can be found below:

Subject: Thanks Mary Ruth and Kathy!

Wednesday, May 2, 2012 7:33 pm Mood: honored Distress: 2


Kristen
Facilitator

It was pleasure to be joined by Mary Ruth and Kathy in the chat tonight. I always find myself smiling after chatting with you both. Thank you for your time and effort in the group, as well as your honesty and willingness to be open. For everyone, please check out this week's new guidance module topic, Week 6: Relationships, as well as the blogging exercise that is now posted! Thanks so much, have a wonderful week!


0 views 1 reply [view thread](#) [reply](#) [send private](#)

Figure 44. Recognizing chat participants

In face-to-face groups, one facilitation skill is to engage group members with each other and to use reflection in a way that helps participants find commonalities and relate to each other. The same skill set can and should be used in an online group, however, it has been found to be more difficult to keep this skill in mind, as there has been a tendency to respond to individual posts independently of one another. Possible hypothesis for this inclination is that there is clear visual separation between comments. This visual disconnect may make cognitive disconnect between comments more likely. Further, the response options to make comments on individual posts guides the online user to respond to each post separately. However, in an effort to built group cohesion and support, the facilitator should be mindful of these issues and make an extra effort to find a bridge between group members' posts. The following facilitator post exemplifies this skill:

Subject: Concentric Circles

Tuesday, August 30, 2011 3:21 pm Mood: Distress:



Kristen Facilitator

Hello all, I have to tell you ladies that I am BLOWN AWAY with the level of thoughtfulness, support, honesty and wisdom and I have read so far on this site. Your blogs and your discussion board posts have been incredible. You have all been through so much, each in your own, unique way, and you all bring something very special to the group...how is everyone feeling about everything so far? There is so much to respond to (which is great!) and I feel like I really want to respond to everyone but this is YOUR group and I am loving the flow of back-and-forth between you all so I really want that to continue! There were so many moments/sentences/phrases that were very touching for me but I just wanted to highlight a few things that stuck out for me because they related to the "Relationships" theme this week...our math teacher jerees talked about thinking her her social support system as concentric circles (which I really liked!) She described it beautifully but as I understand it, she has an inner circle with people that she feels closest to and the most open with and then having people in outer circles that are maybe not so close, or that she feels maybe a little more censored with, and the circles continue to grow outside one other, with the larger circles supporting the inner circles. There have already been some great responses to this depiction but I was wondering how each of you felt about this idea...do you feel like there are any missing links in your circles? Any circles missing entirely? Circles that you would like to strengthen or create? How about that innermost circle...the one where you can express your emotions openly and freely, do you feel you have that in place? Another comment...Barb so eloquently reminded us that each of our experiences is important and valid in it's own way, I loved it when she said "Maybe we are each just allowed to feel what we feel regardless of differences in treatments and prognoses?". I hope you all do feel like that, that no matter what you have been through, big or small, easy or hard, painful or painless, your feelings are very real and important and worth sharing :) Thanks again for all your hard work and effort and take care of yourselves today!

5 views 0 replies [reply](#) [send private](#)

Figure 45. Bridging posts


While the above are examples of useful ways facilitators may utilize the discussion board, facilitators should remember that the discussion board may be used for a variety of purposes as well. A few examples of other ways in which the discussion board has been utilized have been to announce any changes or updates to the website, post about recent events, or post relevant articles or news stories, to name a few.


Common Discussion Board Topics

While the discussion board provides an open forum for group members to discuss whatever topics are relevant to them, common themes group members discuss or inquire about have been observed.

In the introductory email facilitators send out to group members once they are enrolled (see “First Interactions” section), participants are encouraged to make an initial post to the discussion board to share a little about themselves, including their cancer type and a few words about their experience. Not only does this serve introductory purposes, it helps group members become comfortable and familiar with the discussion board, which seems to make it more likely they will continue to post throughout their time in the group. The amount of information shared is variable with each participant, some share detailed messages that are more personal in nature, while others post brief introductions. One common theme that surfaced was questions/concerns/comments about the group in general. This may include questions that are more technical in nature such as computer difficulties, inquiries about navigating the different pages and components to the group, and/or requests to clarify certain aspects of the group (i.e. guidance module topics or weekly exercises). Facilitators should respond to these questions in an empathetic, friendly and clear way, remembering that many participants are older and may not be as technologically advanced as others. Ideally, responses should be made within 24 hours of the post. Here is an example of a response to some logistical confusion about the guidance topics:

Subject: Clarification on Tracking Weeks on Guidance Modules

Monday, August 29, 2011 9:09 am Mood: Thankful  Distress: 2

 Kristen Facilitator

Hello all! In reading through some of the discussion board posts (which have been great...keep it up!) I noticed there was some confusion about where to start on the guidance modules and feelings of being "behind" since we are on Week 6..I apologize for the confusion and definitely see why you would be a little puzzled! Let me try to clear that up...so everyone in this group so far has started over this last week, you ladies are all part of a new cohort. However, the computer doesn't know that and automatically stuck to it's own schedule (computer's can be so inconsiderate sometimes, can't they?) and started you all on Week 6 because that's where the computer system was when we started this new cohort. SO what that means for you is that you **do not** have to read weeks 1-6 to be caught up, as long as you just read Week 6 this week, you will be right where you should be (just think of Week 6 as Week 1...sorry, kinda confusing). This does not mean you will miss out on weeks 1-5...we will get there. You are in this group for 12 weeks so for you, the order for the readings will be Week 6, 7, 8, 9, 10, 11, 12, 1, 2, 3, 4, and then you will end on Week 5. Again, I know it doesn't make much sense but they are all independent topics so just focus more on the topics rather than the week number and you should be good! Does that help? Any other questions about that? If something does come up just let me know, I am happy to try to help. Thank you :)




6 views 0 replies  

Figure 46. Addressing logistical confusion

At times, group members may have initial reactions to the group or to certain components of the group. In general, it has been observed that participants who are willing to voice concerns and/or opinions are often participants that have become active group members, as they are demonstrating they are comfortable sharing their thoughts, feelings and opinions. Therefore, participants should be positively reinforced for sharing their thoughts and/or concerns and efforts should be made to address such reactions in a way that encourages further participation. As is highlighted in effective types of therapy, participant reactions to items presented can often elicit important information about that person, therefore, responding in an understanding, empathetic way is important. It has been found in this type of group setting that reactions are often based on previous experiences with support groups, online environments, or other experiences. Additionally, a warm response from the facilitator, especially in reference to a comment

from a participant who may be frustrated or unhappy, often models the open, non-judgmental, empathetic and supportive nature of the group environment. Additionally, it can help participants feel comfortable being honest without fear of negative reactions from the facilitator in future interactions. Below is one example of this type of interaction:

Subject: Mood Faces




Friday, March 2, 2012 7:51 am Mood: what do you think?  Distress: 0

Hello Again,
 I am new and just posted for the first time, last night. I must confess I am a bit put off by the "mood faces". They are waaaaay too much like the faces in pre op that the kiddies use to express their pain levels. We adults were asked to use a number scale, more appropriate when one is having a breast cut off, don't ya think? I will be "celebrating?" the anniversary, this month. Any one else feel the same way? I found Mary BC treatment to be quite brutal. Ya know the old saying, "You can put a man on the moon but....." Given that I could not get on this board without completing a survey about my feelings, assume it is alright Ruth to "express" here.


So far, my salvation, if it can be called that, in all this, is having read "Pink Ribbon Blues" by Gayle Sulik, an interesting expose on the "pink culture" that has taken over breast cancer in this country and around the world. Much of the book delves into the false expectations expected of those who have had BC and the sexualization of the disease.


Well, I did try to get around the "mood faces" before posting, apparently without success. so suppose, I will have to pick one and see if this post shows up.

MR




11 views 1 reply   

Subject: re: Mood Faces

Friday, March 2, 2012 10:36 am Mood: Calm  Distress: 2



Hi there Mary Ruth and a big WELCOME to the group! My name is Kristen and it is my honor to be the facilitator for this group. I am so happy to see you have joined and am hoping this group will be of benefit for you. I am sorry the "mood faces" seem a little juvenile to you, I can understand that, it is definitely something to get used to, kind of a "blast from the past!" Some of the thinking behind it though is that one of the challenges of an online group is that you can really miss out on some of the very important nonverbal cues and information that you would get in a "live" group setting so it is a way to try to connect with that a bit more and make it a little more "human" even though the faces are just cartoons, does that make sense at all? As some of the group members who have been in the group a bit longer can tell you, there is kind of a learning curve to figuring the group out but I think it is worth it to stick with it and give it a try! And YES!! The discussion board and anywhere in this group is the perfect place to express your feelings...the good, the bad, the frightening, the inspiring, the disappointing...all of it. It is my goal to facilitate an environment where you feel safe to talk about everything and anything so I really hope that becomes the case with you. It definitely sounds like you have been through A LOT and BC treatment has been very difficult. You mentioned the old saying "You can put a man on the moon but..." and I was really interested in that, I was wondering if you could say a little more about how you feel that relates to your experience? I am so glad you found a book that you can really connect with and relate to. It sounds like you have really had a different experience from what the media portrays when it comes to BC. I can imagine that it can be frustrating to have such a painful and difficult experience be misrepresented to the public at times, is that accurate on how you are feeling? I am really curious to hear more about your experience with it and how it differs from that "pink culture" you mentioned. Phew! I just gave you a ton to talk about and it is only your first few days in the group! Take your time in responding, we have lots of time to get to know each other and for you to get to know the other group members and for them to get to know you so hopefully I didn't overwhelm you with the first response back, you just brought up a lot of really interesting points but like I said, we will have lots of time to get there. More than anything I am just glad you are in the group and want to thank you again for taking the time to join us! Have a great weekend and I will look forward to hearing from you soon!

9 views 1 reply   

Subject: re: Mood Faces

Friday, March 2, 2012 1:10 pm Mood: relieved  Distress: 0

Thank you for the welcome, Kristen. I appreciate being encouraged to tell how I really feel about the BC experience. I belong to another BC board where that has not been encouraged, to any real extent, and have been chastised, in the past, for scaring "nubies". I think I represent more of my ilk than society, or even ourselves, are willing to acknowledge. The prevailing sentiment is to "put on a happy face". So, yes your explanation of the "faces" does make sense, in that respect. I reacted badly as the faces brought back, so vividly, my time in pre op, before the darkest moment of my life, when I noticed them for children to express their discomfort. Re: "You can put a man on the moon but....." It would seem to me that we have not made a whole lot of progress, regarding the treatment of BC. As Dr. Susan Love has so eloquently put it, "slash, burn and poison" are still the standard treatments and have been for decades. My personal experience has been with the "slash and burn". My first cancer was early stage but because of being Her2+ considered aggressive, so basically the medical community wanted to throw the book at me with the "slash and poison". To this day I regret the mastectomy, but did refuse ALL adjuvant therapy \$100,000 dollars worth, because of quality of life issues. All, AC chemo, Herceptin and aromatase inhibitors, can be heart toxic and there is a strong history of congestive heart failure, in my family, though that was not addressed by the oncologists. That was information I had to dig out myself! I went into this a real "babe in the woods" and came out a real cynic. I assumed, my concerns would be addressed and my needs met. I found that was not the case, at least for me, and believe there are many others who have not found their voice, regarding treatment and its pitfalls. Have to admit I probably did more research than most, after the surgery. I should have done more before. While I asked many questions, I was not aware of all I should have asked until I experienced the after effects, which I was totally unprepared for. Re: "Pink Culture" I found myself surrounded by Pink ribbons and smiling faces when I had just been mutilated! I didn't understand how "survivors, thrivers etc." could feel so happy and blessed by such a horrific experience. Was there something wrong with me that I could not "embrace" cancer, that it did not seem to improve my life, that I had not learned some important life changing lesson from it? Who I am now has definitely not been enhanced by cancer. Then Gayle Sulik came out with her book "Pink Ribbon Blues" (gaylesulik.com) and I felt like I had come home. I was no longer alone, there are others like me who will not be "pink washed". I also found Barbara Ehrenreich who wrote "Bright Sided", the first chapter devoted to her perception of pink culture as she was going through BC. OK, I have written a book here! I could go on and on and have done several pieces on the subject, one almost published as "A Breast Cancer Primer" but pulled at the last minute as it was considered scary and controversial. Thank you, Kristen. I hope I have addressed the points you mentioned in a manner that is comprehensible to you and the other members of this board. MK

11 views 0 replies   

Mary Ruth

Figure 47. Responding to frustration

Another common discussion topic is related to cancer treatments. Group members often discuss and describe the different cancer treatment types they have experienced, and/or have knowledge or questions about. Survivors will often discuss the various modalities, timelines, and intensities of relevant treatments. Further, participants often confide in each other regarding side effects of cancer related treatments. Group members will often share coping techniques they have acquired that help them better manage side effects. These conversations are very common and often promote discussion with many different participants. This particular topic is one that facilitates significant feelings of connection and cohesion between group members, as many participants can relate to experiencing difficult side effects. It is often that, not only the physical aspects of side effects are described, but the emotional effects are very apparent

and powerful for participants as well. In my observation, it is almost always the case that the emotional and/or psychological effects of treatment are very concerning and relevant for participants. Further, many group members feel the side effects they discuss are unique to this population and therefore, group members have expressed significant benefit and support being able to identify and relate with others who share a similar understanding. Many group members have expressed substantial benefit in talking with others who “get it.” Below are examples of posts group members have made regarding side effects and outcomes of treatments, both physical and emotional, as well as responses from group members and the facilitator that are representative of common exchanges seen throughout the group.

The discussion board is also a great place for group members and facilitators to keep in touch with and learn more about other participants throughout the week. Often times, important topics and/or upcoming events will come up in the chat. Unlike many face-to-face groups that meet weekly or monthly, the discussion board provides the opportunity to remain updated and provide support for other group members between chat or “group meeting” sessions. This unique forum provides a place for group to communicate with supportive others at all times, 24 hours a day, seven days a week. This may provide many benefits. One potential benefit is that it provides a place for participants to go that offers safety and instant feelings of support. Further, group members can express themselves immediately rather than having to wait for their next group meeting. This is beneficial in that thoughts and emotions that are expressed in the moment are often more accurate than they would be in situations in which there is a time delay and participants are trying to recall thoughts and feelings that happened in the past.

Additionally, providing the resources for group members to be able to express themselves through verbal communication is likely to help them explore, identify and further understand their own emotional reactions. This may promote insight and personal awareness, which creates more of a likelihood that participants will become more cognizant of their emotions, thoughts and/or behavior and may therefore choose an adaptive response in response to this insight.

Potential Challenges With the Discussion Board

Lack of Participation

Challenge

As with other components of the online group, low activity has been the primary challenge with the discussion board. Posts tend to be made in phases or waves, with a few days of higher activity and days or weeks with low or no activity.

Potential Solutions

Identifying themes or aspects of the group that seem to be co-occurring with different levels of activity are paramount in finding a potential solution to the challenge of low activity. It has been observed that times in which participants tend to be more active is when they are engaged in a conversation(s) with each other and are making comments/responses back and forth. Another finding has been that activity seems to increase when questions are posed which are interesting and relevant for group

members. Therefore, in an effort to promote more discussion board activity, facilitators may identify ways in which group members may relate to one another with hopes they will then engage in conversation amongst themselves. Posting an interesting question that is likely to intrigue group members may stimulate activity as well.

Another method is to be transparent with group members and post a process comment about the issue of concern. One note of caution is that this is likely to be most effective and received in a non-defensive and productive way when strong rapport has been established between the facilitator and group participants. The language should be empathic and reflect genuine interest and care in group members' well-being. In previous experiences with this method, group members have had responded positively to the post and it has been an effective intervention. The example below models this type of post:

Hello Health Spacers! I have been thinking about you guys quite a bit and wanted to check in and say hello. How has everyone's week been? I am not sure why but it has been pretty quiet lately and I just wanted to see if anyone had any feedback for me about how you are feeling about group and how things have been going, if there is anything you would like to see change to help you engage more in the site, and/or if you had any ideas/comments. I know this is the last week (sad!) for many of you and I would LOVE to be able to say good-bye and check in one more time. If you are able to make that the chat this week, that would be great! If not, I would love to hear your thoughts about how you are feeling and check in via the discussion board. Personally, I have been missing many of you! I feel very close to this group and it has been such an honor and a pleasure to get to know you. For those of you that have been coming to the chats and some of the new people that have been active, I have loved talking with you and I am excited about where the group goes from here! For those of you ending this week, remember there is an Alumni Group that you can stay apart of. Basically, you have the same access to the group and everything looks the same, except you facilitate your own chats and make them your own. Hope to hear from you all soon!

The Chat

Chat Room Aims

The chat component of the online group is the element of the online forum that is most similar to a face-to-face group. The purpose of the chat is to provide a “live” environment where participants can interact with each other in real time. An important benefit of the chat room is that group members get immediate feedback and support from both the facilitator and each other. In this way, this forum seems to be the most efficient and quickest way to communicate with group members.

Setting Up the Chat

It is important to advertise the chat component of the online group, as this aspect of the online group has been repeatedly highlighted as a favorite among participants. One of the facilitator’s roles is to ensure group members are aware of the chat, know when it takes place, and know how to access the chat room. The function and time of the chat should be emphasized in the initial contact email each group member receives when they join the group. Additionally, the chat should be advertised on the discussion board, since that is the most visible part of the online group. Through experience and experimentation of different ways to try to encourage chat participation, it has been found that posting a discussion board message the day before the chat reminding group members about the chat, clearly stating when the chat is, and identifying what the main guidance module topic will be has been beneficial. If group participation remains low,

sending individual emails to group members the night before or morning of the chat and asking them if they are able to make it has been helpful. This personalized message, along with a direct question, may increase group member's sense of responsibility to join the chat. It is important to remember that because of the online forum, group members may be in different time-zones and can easily get confused about what time the chat may start. Therefore, posting the start time of the chat in all possible time zones has been an effective way to evade possible confusion and missed opportunities for group members to join the chat.

Determining the time of the chat can get tricky in that coordinating multiple schedules in multiple time zones is not an easy feat. One way to determine the chat time is to ask for group member preferences and input. A benefit to this approach is that it may maximize the probability of group members being free to join the chat. However, it may be challenging to reach a consensus around a time that works for all participants. Additionally, if input is solicited and a time is chosen that does not match what a particular group member suggested or requested, that group members may feel insulted or devalued. Therefore, it has been found that assigning a specific time in the early evening (encompassing as many time zones as possible) has worked well and minimized any sense of group member favoritism or preference. If the facilitator receives multiple requests to change the chat time or is getting feedback from group members that they are unable to make the specified time, it may be helpful to solicit group member input/requests and adjust accordingly.

Chat Expectations

An online chat experience may be novel for some group members and they may feel uncomfortable or unsure of what or when or how to respond/participate in this setting. Unfamiliarity often leads to discomfort, which often leads to decreased likelihood of participation. In order to alleviate this barrier, it is important to give group members an idea of what they might expect when coming to the chat prior to the chat experience itself. In an email message to new group members, the facilitator should outline the purpose and design of the chat. Included in the email should be the expectation that group members come on time in order to achieve maximum benefit and group participation. Additionally, an anticipated time the chat will end should be designated so group members know how much time investment is involved. What sorts of topics the group will cover (discussion of guidance module topics), and the nature of the group regarding emotional context are also important items to address.

Highlighting the emotional permissions the chat affords has proven to be of particular importance to the group. Some group members have shared that they have participated in other cancer support groups and have had the experience of the group having a “cheerleader” feel to it in that the only emotions encouraged were those that had a positive connotation. While support and encouragement is an important aspect of this group, the facilitator should emphasize that this group is one in which the entire spectrum of emotional expression can, and should, be encouraged in the chat, as well as in other aspects of the group. Many participants have reported therapeutic benefits from having this particular group be one in which they felt comfortable expressing a range of emotions, including more difficult experiences such as fear, discomfort, disappointment,

sadness, loss, anger, and frustration, to name a few. On multiple occasions, group members have identified the “permission” this group provides to express emotions that are more “forbidden” in other groups and in the context of their lives in general, as being key in normalizing their emotional experience and alleviating stress and anxiety secondary to feeling “pressure to be okay all the time.” Group members have described this aspect of the group as allowing them to “let my guard down”, while others have made comments such as, “I finally have a place where I can be honest.” Here is an example of a discussion board message that clearly outlines the chat:

Hello everyone! I just wanted to post a friendly reminder about the **LIVE CHAT that will be taking place tomorrow (Wed) evening**. I know this is a first chat opportunity for many of you new members so how it works is that everyone that is interested gets online around the same time-**6 PM (PST)** and then you click the "chat room" tab at the top of the screen and that will send you to the chat room, sounds easy enough, right?! We will chat for an hour and a half so it will run from 6-7:30 PM. How it works is I usually like to check in with everyone and see if anyone has anything on their mind they would like to bring up, all topics are welcome...the good, the bad and the scary. Then I like to spend some of the time talking about the guidance module topic that will be the topic for the week. I know it is kind of confusing because you guys just started (so ignore the week number) but starting tomorrow, the topic will change to **Week 9: Relaxation and Imagery** so we will discuss some skills as they relate to that in the chat and then I will post a related exercise for you to try during the week. So, in preparation for the chat, please read **Week 9: Relaxation and Imagery** under the "guidance" tab so you have some background knowledge before the chat and can come with any comments/questions/etc. Sound okay? Really looking forward to the chat tomorrow night and hoping you can join me! Thanks so much!!!

In The Chat

Welcoming New Great Members

Due to the rolling admissions design of the group, group members are joining the chats continuously and at different times. With such a kinetic group, one potential difficulty is ensuring a sense of group cohesion and comfort. Therefore, a vital role of the facilitator is to foster a warm and welcoming environment. One way to do this is to model the social norms of a face-to-face situation when a new member is present; the facilitator should provide a formal “welcome” and introduction with the newest addition to the group. At the beginning of a chat with a new group member, the facilitator should highlight the new member’s presence. Positively reinforcing their decision to join the chat and showing interest in the new member in an effort to integrate them into the group has been beneficial in fostering more seamless transitions. This likely makes the new member feel valued and more included into the group. Stating how excited the group is to have a new member, asking the group member what name they would prefer to go by in the group (many “screen names” are not the person’s first name) and asking them to introduce themselves to the group by sharing “a little about you” has worked well in incorporating new group members in the past. When the facilitator asks the new group member to share about themselves in this open-ended way rather than asking direct and pointed questions, it leaves room for the new participant to disclose as much or as little as they would like in a way that feels comfortable to them. There are often a variety of responses that vary in the depth of self-disclosure. Some group members share intimate details of their cancer experience, while others provide very minimal or

“surface” information. In every instance that new group members have been introduced to the chat and group members in this way, they have been warmly welcomed and encouraged by pre-existing group members.

Mood Check

Once group members are acquainted with each other, a nice way to begin the group chat has been to start with a “mood check.” The facilitator can introduce the mood check as something like this:

I'd like to check in and see how everyone's mood is tonight. Please rate your mood from 1(lowest)-10(highest) and say, in a sentence or two, why you rated your mood in that way. Additionally, please give your “usual” mood rating as well. I will use myself as an example: Today my mood is a 8, my usual is a 7. Today my mood is better than usual because I just came home from a relaxing dinner with a friend I haven't seen in quite some time, it was great to catch up with her.

The purpose of the mood check is to give group members a focused way to immediately get involved in a topic that is clinically significant. Asking participants to attend to their mood increases self-awareness and introspection, which is important in a psycho-social group setting. Additionally, it provides the space for each group member to share their experience for the week and invites them to be an active participant from the very beginning. Requesting that group members rate both their current mood and their usual mood is a nice way to give the group context and it often helps the facilitator conceptualize how the rest of the chat may go. For example, if one or many group members are experiencing moods that are discrepant from their typical mood rating, this

is an important area of discussion. Should this be noticed, the facilitator should check in with that particular group member and ask permission to talk with them about why their mood is atypical. If the group member grants permission, the facilitator should add this topic to the “agenda” for the chat. Both significantly higher and significantly lower scores are important to attend to in an effort to draw out conversations about topics that should be celebrated and also to highlight areas where a group member may be struggling so the group can attend to that need and provide support.

Agenda Setting

With different group members joining the chat at different times and with different topics and conversations going on at once, structure for the group is important. The facilitator should be comfortable setting an agenda at the beginning of the group. Not only does this provide structure and increase expectations and understanding of what the chat will entail, but it ensures everyone has an opportunity to bring up topics/issues/emotions that are pertinent and important to them. Importantly, agenda setting gives the facilitator an opportunity to address anything important for all group members to know, such as any updates or important announcements. Additionally, the facilitator should use this time to remind group members of the guidance module topic for the week. Further, this approach provides space for the facilitator to ensure this topic is inserted into the chat with ample time. There are often many responses to agenda setting, some group members often have items they wish to discuss while others are more comfortable supporting others with their concerns, and of course, there are group

members who play a part in the agenda setting that is somewhere in the middle. Here is an example of a chat transcript that includes the agenda-setting component:

kristen K,L and I talked briefly and we are going to take some time tonight to talk with her so let's put that on the agenda first thing, I know it's really important. But really quickly, I would like to add two things to the agenda... I would like to check in and see how chemo is going for B and then also talk about this weeks Guidance Module topic, Ways of Thinking for about 30 minutes or so as well. How about the rest of you, does anyone else have anything they would like to add to our agenda for this evening?

kd not here

jdm1957 Nope, I don't, just want to hear about L and how chemo is going for B

kd I don't have anything for tonight. B...how are you doing tonight?

b Chemo has been good. I feel great. A couple of crash days then back to normal.

b Now to L

kristen Okay so first and foremost...L, we are worried about you. For those that may have missed your post, are you comfortable telling us how you are doing and what might be going on?

Figure 48. Chat transcript

Chat Themes

While an important component of the chat is discussing the guidance module topic for the week, it also provides a great opportunity for group members to open up the topics and conversations and discuss anything that is relevant to them at that time. While many different topics transpire, there do seem to be certain themes that often arise. Common themes include issues such as adjusting to a “new normal”, interpersonal interactions, dealing with fears of recurrence, and treatment or medically related questions and/or concerns.

Common Theme: The “New Normal”

Many group members have expressed how much of a role change the cancer experience has demanded. Many have discussed a sharp contrast they see from their “pre-cancer” self to their current or “post-cancer” self. Group members often discuss how their experiences and schemas, as they relate to their energy level, activity involvement, occupations, physical attributes, and personal identities, are altered after or during cancer. Regarding energy levels and perception of self, many group members have expressed frustration and discuss how “unproductive” or “worthless” they feel, as they do not have the stamina or physical or emotional energy during/after their cancer experience as they once did. For many, the comparison from their “new self” to their “old self” is disappointing in that they do not feel they are meeting the same behavioral goals or seeing the same results or feeling the same amount of energy as they did “pre-cancer.” Many have expressed they feel like they are inadequate. Group members have often felt this way when they impose the same expectations of themselves, before going through treatment or symptoms of cancer, on to their current self. A likely reason this often leads to feelings of inadequacy is because they may not be fully taking into account the effects that cancer and cancer treatment has had on their bodies and adjusting accordingly. For many participants, they often have witnessed how their personal experiences of life have been completely changed by cancer, yet at the same time, the world around them did not stop. Group members have expressed how, because much of their environments did not change, they feel they need to get right back to where they “left off” before their cancer experience. When they struggle or are unable to

do so, they often are left feeling poorly about themselves and their concept of their “new self.” It has not been uncommon for group members to discuss the longing or desire for things to “be back to the way they used to” or to “be my old self.”

Common Theme: Interpersonal Interactions

Cancer and the impact of its corresponding treatments and side effects does not occur in a vacuum and often has a substantial effect on not only the cancer patient themselves, but on their whole system as well. While group members often hold expectations of themselves that are not commensurate within the context of their current condition as a result of cancer and/or treatment side effects, loved ones and/or others in their life may have similar unrealistic expectations. For many group members, they have become accustomed to playing a certain “role” in their environments. For example, many group members are mothers, and have come to be familiar with “duties” in their families that are associated with this schema of what they “should” do as a mother. Many group members described how they were often the one to keep up the household duties and attend their kids’ events. Other family members became used to them in this role as well. Group members talked about their occupational roles and the affiliated expectations their boss and/or co-workers had of them in those professional roles. Further, the issue of what it was like to be a friend or fill some other type of social role would be discussed. In each of these cases, interpersonal interactions with others were important components of the group members identify in that role. As such, the other components of the corresponding system (the other people involved) often expected certain things that matched the schema of the role that group member had been in to be

accomplished or fulfilled. Participants expressed frustration and interpersonal difficulties when others did not alter their expectations and did not express flexibility in a way that was adaptive to the group member's current state after or during cancer and associated treatments. Similar to situations where this lack of adaptability created internal struggle when applied to the self, group members would often describe how this inflexibility from others would often create interpersonal struggle. Group members would often describe feeling as if others "don't understand." For example, one participant was experiencing difficulties with her boss when she returned to work as a teacher because she would often become extremely fatigued by the end of the day and was having a hard time meeting deadlines in the same way she was able to before her cancer experience. She described how her workload upon returning to work was the same as it was before she started her cancer treatment and that this was very difficult to maintain which created tension between herself and her boss. In this instance, many group members were able to relate to the extent to which fatigue had played such a large and debilitating role in their ability to reach the same achievements they were able to make prior to cancer. To exemplify how much flexibility from others can be beneficial, another group member was able to share her story. She discussed how her boss was very accommodating and adjusted her workload to a smaller amount, which was gradually increased as she continued to gain her strength back. In this second situation, the group member described actually strengthening the interpersonal connectedness between herself and her boss because she was so appreciative of the understanding and support she received.

Similarly, many group members have discussed how their “new self” would have a difficult time functioning in their role as a family member in the same way post-cancer. An example of this was apparent in a group member’s discussion of her romantic relationship with her husband. She described how he expected her to cook and clean and how, due to her heavy fatigue and intermittent nausea, she often had a very hard time accomplishing all that she had been able to do around the house prior to her cancer experience. She talked about how her husband would get angry and frustrated with her and often called her “lazy” when she was unable to meet his rigid expectations. His inability to adapt his expectations of her created substantial marital difficulties as it not only impacted their relationships, but it strongly impacted how she felt about herself after his consistent hurtful comments.

Another thematic interpersonal interaction that was often discussed by group members was one in which family members, friends, or co-workers would respond in a way that the group members felt was “too much.” Many times family members and/or friends would end up taking over many of the group members responsibilities or do things for them that they were capable of doing on their own. Often times in these situations, the group member would experience feelings of helplessness, worthlessness, inadequacy or describe feeling overly dependent when others would change their interpersonal interactions to a degree that was greater than what was necessary or desirable from the patient’s point of view. Group members described feelings of loss as they related to their sense of independence, which was very important to many. Participants expressed feeling uncomfortable and powerless in this “sick” role. On several occasions, group members described a desire to “just treat me like normal.”

Another interpersonal dynamic that was less apparent overall, but did surface on multiple occasions, was when an important person in a group member's life tended to exhibit a state of denial. Some group members expressed how husbands or other family members would refuse to discuss cancer, one group member even described how her family coined cancer "the 'C' word" and it became somewhat of a forbidden topic. This lack of acknowledgement was often times hard on the group member because they did not feel as if they were validated in their experience and it created pressure for them to "put on my happy face for everyone" when, often, this was disproportionate to their internal, physical and/or emotional experience. Group members in these situations often described feeling "trapped" and described many instances in which they would "break down" because they did not have an adequate emotional outlet or ability to be honest which created pressure and tension that often "blew up." The discrepancy between their overt actions and internal struggles was often very difficult for the person to manage emotionally.

While there were many conversations of problematic and difficult interpersonal interactions that materialized from issues related to one's cancer experience, there were just as many, if not more, expressions of positive and strengthening interpersonal relationships that group members discussed. For many, their cancer experience exposed the fragility of life. As a result, group participants described how they had a new appreciation for the people in their lives that most would describe as emanating from the realization that their time with others and the opportunity to spend time and enhance relationships has limits.

A common theme woven throughout such conversations was the idea that the cancer experience, even with those who were in remission or had good prognosis, seemed to give participants a perspective change from living in the future and worrying about things to come, to living in the here and now and prioritizing what mattered most to them. By and large, the most common values expressed, that is, the thing that was most often first and foremost on group members' list of priorities, were described as spending more time with loved ones, often family members. Many discussed how, pre-cancer, they felt they had taken their relationships with important people in their lives for granted and behaved as if there would always be time in the future to spend with that person. Engaging in time with loved ones as an alternative to other activities of daily living (i.e. working long hours, etc.) was a common value for many.

Not only was the amount of time important for group members, but there was often an expression of desire to enhance the quality of time and the depth of important relationships. When discussing this aspect of interpersonal connectedness, group members would often describe a desire to be more "present" with the people in their lives and to value and cherish the time they spent together. For some, this meant letting go of thoughts, concerns, or worries that were distracting them from the present moment; for others, this meant being more open in their communication styles and expression of love and/or caring for the people they were connecting with. In many cases, both quality and quantity of relationships had a new sense of importance for the cancer patient. They would often report similar and reciprocal reactions from loved ones, which enhanced the relationships even more.

While strengthening previously established relationships was the case for many, some group members discussed how the realization that time will not always be available propelled them to make advances in reconnecting with people. Often these were people they had lost touch with and had, at one point, been important to them. Reasons distances were created with others included scenarios in which there were ruptures and “fall-outs”, while other causes of disconnection were more a matter of time or distance. Results of such outreaches were variable among participants. Some attempts materialized into important relationships while others did not.

Common Theme: Fears of Recurrence

One of the interesting dynamics of the group was that participants were at various stages of cancer progression and prognosis. Some were currently being treated for cancer; within this sub-group, some had cancers that were remitting and responding well to treatment, while for others the opposite was true. Other group members were not currently being treated and were in remission for various amounts of time. For some it was months, for others, years. It was interesting to find that overall, most group members expressed a fear of cancer recurrence no matter what stage of treatment and/or remission they were in. The intensity and frequency at which participants experienced this fear was variable, as was the impact this fear had on their quality of life. On one end, there were group members who would discuss thoughts of recurrence as debilitating at times; racing thoughts they had a hard time getting out of their minds that may have interfered with things such as concentration and sleep and often evokes a strong sense of anxiety. Some group members would describe having “panic attacks” at times when this

fear became overwhelming. This happened at different times, for some there were identifiable triggers such as going to doctors' appointments, for others, their symptoms seemed to come on more suddenly.

While not all group members would experience frequent feelings of anxiety related to fear of recurrence, most group members would describe a strong reaction when they found or felt things that they would have ignored or thought nothing of in their "pre-cancer days." For example, any sort of lump or bump or ache or pain would cause some to immediately assume their cancer was "back" and would instantly evoke racing thoughts and strong symptoms of anxiety.

Less commonly, there were a few group members who had taken more of an avoidant approach when it came to fear of cancer recurrence. There were a few group members who would describe not "allowing" themselves to think about fears of recurrence and "ignore" physical signs or indications, no matter how big or small, of cancer recurrence. For example, one group member insisted that she never let cancer "control my life" or come into her thoughts. She reported that while many expressed their concern that she was "in denial" and encouraged her to follow up with doctor's appointments, she felt she was "completely okay" regarding any issues of fears of recurrence. Clearly, responses to cancer and how it shapes one's life are incredible individualized and should be respected as such.

Common Theme: Treatment or Medically Related Issues

There seemed to be a strong curiosity between group members in that most of them were interested in what types of treatments others received, and what types of

responses or “side effects” others experienced. The invasiveness, intricacy, severity, and methods of treatment interventions varied greatly between group members. Often times, group members would discuss their experiences with treatments and query the group for anyone who had a similar experience. Not only were interventions discussed, side effects of treatments were often topics group members seemed very interested in. Group members would share their reactions to certain treatments and the effects those side effects had on them. This was often a theme that united group members, possibly because they found someone who had a strong understanding of their physical experience and thus, could easily empathize. It was very common for group members to offer “tricks” and “tips” to others who had similar experiences and coping skills were often explored.

Participants’ relationship with their medical providers was an additional theme that would arise often in the chat. As with many other topics, group member experiences were incredibly varied. Some described a relatively sterile, formal relationship with their health care providers that did not seem to have a strong effect on them. For others, they experienced many difficulties with their personalities. Some such sources of friction were personality conflicts, lack of trust in their doctors, lack of trust in “the system”, distress due to lack of information, disruptions/difficulties with communication, distress due to unsatisfactory medical results, etc. Yet another sub-population that would often become apparent in this type of discussion were the group members that had very positive experiences and relationships with their medical providers. They often discussed how important these relationships had been to them and how helpful it was to have this

type of relationship during the cancer journey. Overall, these participants often had encouraging prognosis and successful treatments.

Structured Themes

The common themes and unstructured topics discussed have often seemed very relevant and important to group members and thus, often take up a good amount of time in the chat. However, there are some more structured components of the chat that are important to address on a consistent basis. This includes checking in regarding the previous week's homework, introducing the current week's guidance module topic, eliciting any notable or significant upcoming events and asking for feedback in order to continue to improve the group.

Asking group members what their experience was like with the previous week's homework has been an important component to the chat in that it emphasizes the importance of actually participating in the weekly assignments. Further, it provides the opportunity to answer any questions or make any necessary clarifications. Asking about the assignment specifically seems to make it more likely that group members will embody a sense of personal responsibility and/or dedication to the exercise. Instead of chastising group members who did not do the homework, it has been more important to encourage and highlight those who did complete and/or attempt the assignment. This should serve the purpose of maintaining positive rapport, and using positive reinforcement and modeling for those who did the homework. In previous chat sessions when the previous week's homework was not addressed, it seemed to signify that the

assignment didn't hold much importance; therefore, lower participation rates were often observed.

If care is taken to emphasize assignments and participation rates continue to be low, a technique that has been helpful has been to ask the group about any barriers that are getting in the way of doing their homework. This may shed light on problems or difficulties that may be worked out through problem-solving with the participant any possible solutions or ways to overcome the barriers. These types of conversations can provide important feedback information that can help improve group participation in weekly assignments.

After discussing the topic from the previous week, the chat is the ideal place to introduce and discuss the guidance module topic for the upcoming week. While group members are encouraged to read the module topic prior to coming to the chat, the chat is a great forum to expand the module topic to increase further understanding and to answer any questions or make clarifications right away. Another advantage of discussing the appropriate guidance module topic in the chat is that it offers the opportunity to tailor and individualize the topic to make it more relevant and bring it to life. Introducing and discussing the guidance module in the middle or roughly two thirds of the way into the chat has had benefits in that the facilitator can use examples from the chat that night and tie them into the topic. Using specific examples for each group member not only makes the guidance topic more clear, it also has been useful in making the group members feel important and relevant to the group and the topic. If they can easily see how the guidance module information applies to them, it is probable that it makes it more likely they would practice/think about the topic in the future.

The latter parts of the chat has been a great time to ask the group if anyone has any specific events/situations/treatments in the upcoming week that would be important for the group to know about. An advantage of the online group is that group members have the ability to maintain close communications throughout the week, not only when the group meets. Therefore, asking about important events has been beneficial in that it promotes the opportunity to provide additional support for the person who has the upcoming event. For example, it has not been uncommon for group members to discuss important doctors' appointments, treatments or procedures they are concerned about. This gives them space to explore their feelings about the situation, and also has been helpful in that the facilitator and other group members then have the chance to encourage the person along the way.

Finally, as the chat starts to come to a close, it has been informative to ask the group for any feedback they may have had regarding the chat. While the majority of the time, the feedback is positive and highlights how important and useful the chat sessions are, there are times when participants may voice difficulties or concerns they experienced with the chat. This provides important information as well as a valuable opportunity to continue to nurture and improve the group. If the concern is relatively small and easily fixable, discussing possible solutions in that moment has been sufficient. If the concern is larger, it may be better for the facilitator to make a point to validate the group member providing feedback and thank them for their opinion but ask their permission to follow up with them via email messaging in order to close the group on time. It is important for the facilitator to follow up with them as soon as possible; the same night or the next day. This timeliness is necessary in order to reflect to the group

member how important it is to address their concerns. If it is something they would like to address more publically or if they express a preference for talking about things in a chat format, encourage them to bring it up at the next chat when setting the agenda is an acceptable response.

Thanking the group for their hard work and participation, and reflecting on some of the important “highlights” or “lessons learned” from the group has been a nice way to summarize the chat experience for the week. Wishing everyone well and encouraging active group participation via the discussion board, messaging and blogging, as well as their return to the chat next week, are all fitting ways to end the chat for the evening. Of note, it has been important to end on time in order to make sure the chat has appropriate boundaries and to give group members confidence that the chat times are predictable, reliable and stable.

Therapeutic Interventions

While the individual styles and strengths of each facilitator should be employed during the chat, there have been a number of therapeutic responses that have been found to be effective when addressing the common themes discussed. These include patient-centered skills, cognitive behavioral skills, emotion-focused skills, and existential therapy techniques.

Patient-Centered

This group is no different from any other client-therapist interaction in that establishing a strong, positive rapport is absolutely essential in order for other

interventions to make an impact. For this group experience, the strength of the therapeutic relationship seemed to be a strong predictor of group member activity and participation, and also seemed to be correlated with the amount of depth and openness a group member was willing to share. As one would expect in other therapeutic settings, a Rogerian person-centered approach should not be overlooked, as the importance of this method and corresponding micro-skills have been evident in the group chat setting. Empathic, supportive and active listening, reflecting and re-framing, normalizing, and validating participants have been skills that have been of the utmost importance when facilitating the chat. As discussed above, interpersonal and adjustment issues are common with participants. As a result, many group members have discussed how difficult it can be at times to feel as if they are being understood in their cancer experience. Implementation of these micro-skills has been a powerful intervention in that it gives cancer patients the experience of having someone take the time to not only listen, but to help them continue to explore and express their thoughts and feelings. Many have described a feeling of “relief” when they feel they are being heard from an empathic perspective. Normalization has been an important tool in that many participants have discussed feeling “all alone” or isolated in their experiences. Unlike responses to the cold or flu where almost everyone experiences these things and has similar symptoms, responses to cancer are varied. Based on the individual, the type of cancer, the progression of cancer, the types of treatments, etc., there are infinite possibilities and probabilities regarding ways in which people are “supposed” to respond to the cancer; a response template simply does not exist. For many, they are not sure how they are expected to respond to the emotional and physical issues they are facing.

Many group members have discussed how cancer is often misrepresented in the popular media and they feel they are “wrong” if they do not have the same reactions as those presented in Hollywood. Many may feel invalidated and concerned about their personal responses, both physically and psychologically. Therefore, normalization and validation that their response is bona fide in it’s own right because it is their experience and because there are no “correct answers” can be a very powerful intervention. In a more general sense, many group members have commented on how helpful the chat has been in providing a safe environment for them to feel supported and cared for.

Cognitive-Behavioral

Once a strong therapeutic relationship has been established, there have been many times when cognitive behavioral therapeutic interventions have proved to be valuable. Similar to any other population or individual, group members in the online chat express what Cognitive-Behavioral Therapy (CBT) describes as cognitive distortions. As with all CBT interventions, the first step to identifying these cognitive distortions is to get participants to engage in “thought stopping.” While a challenge to many CBT patients in face-to-face therapy is that they often have difficulty complying to the process of actually writing down their thoughts, the online aspect of this group provides an important advantage in that every thought that is expressed in the group is already in a “written” or concrete form. Because written expression is the only form of communication in the online chat room, it was apparent that the idea of keeping a written thought record was normal and expected in this setting.

In the chat, it was noted that cognitive distortions were apparent in a variety of contexts. For example, one participant exhibited all or nothing thinking when she said, “If my cancer can’t be cured, I might as well give up and die.” Another example of a common cognitive distortion that was observed was overgeneralization. One group member stated, “I can’t do anything the same as I used to.” Magnification/Minimization was noted frequently as well. One participant seemed to display magnification when she made the comment, “My bald head is the only thing anybody ever notices”, while another group member tended towards minimization and stated, “I am fine, I don’t let my cancer bother me.” Fortune telling was a very widespread cognitive distortion as it related to their cancer prognosis or cancer recurrence. Many group members would endorse thoughts such as, “I just know my cancer is going to come back.” Overall, the types of categories that are common in traditional CBT were also observed in the online group. Helping group members recognize when they were engaging in distorted thinking and having them label the thought as such seemed to be beneficial to them in that they were then able to consider it further and not just accept it as a fact. As the facilitator, posing questions that seemed to help the group member engage in reality testing or thought balancing was helpful. For example, when a group member expressed an all or nothing cognition, asking a question such as, “I wonder if there are any exceptions to that rule?” may help them balance their thoughts and hone their thinking to be more flexible.

Using the CBT of finding core beliefs was found to be helpful in getting group members to consider the origins of their cognitions. While more difficult to address individual core beliefs in a group setting, there were a few times when the “downward

arrow” technique, common to CBT practice, was implemented. While core beliefs were not often a focus of the chat, when group members were able to identify or consider their core beliefs, the understanding of where they may have come from seemed to be beneficial in helping them look at their beliefs from a different perspective rather than automatically take them to be true. One interesting aspect of core beliefs that was observed in this population that may not be as prevalent in the general population was that there were a number of group members that were able to identify specific situations when their core beliefs changed. In the general population, core beliefs are often developed over time, but what was observed with some members of the oncology population was that their cancer diagnosis or treatment was a defining point that had an effect on their core beliefs. For example, one group member described how she was very career-oriented and it was a core belief that her value came from her professional accomplishments. However, after she was diagnosed with cancer, her core belief shifted to reflect a sense of self-worth that came more from spending time with loved ones and family and the amount of importance she put on her professional career and what it meant to her was no longer a core belief. The theme of “pre-cancer self” and “post-cancer self” was very apparent when CBT-type interventions were implemented.

While there are two guidance modules dedicated to cognitive interventions, the chat is a good place to implement CBT skills in that it provides in the moment feedback which can help assure group members are understanding the ideas presented. Additionally, distinguishing thoughts from feelings was found to be difficult for many group members, therefore, being able to instantly respond and further explain or clarify issues instantly, instead of having the time lag that is often apparent in blogs and

discussion board posts, was another advantage when CBT was implemented in the chat setting.

Emotions-Focused and Existential Therapy Skills

Emotions-Focused Therapy (EFT) and Existential Therapy techniques have proven to be very valuable when implemented in the chat. For example, when existential issues were discussed, strong emotions were most often apparent due to the nature of the existential topics. Many group members described how issues and conversations around death and dying were so often “taboo” or “forbidden” in their everyday world. For some group members, the restriction on discussing death and dying came from an internal place and it was difficult for them to consider or talk about these topics. Others expressed feeling that these were important conversations and were more willing to explore these difficult realities. From the beginning with the Welcome Message, the facilitator should be mindful of making it clear that any and all topics are “fair game” when in the chat. Overall, participants have discussed how important this aspect of the group had been for them in that they had a forum where they feel safe enough to fully express themselves without hesitation. Some group members described a feeling of freedom when they knew they could talk about all aspects of their cancer, the good times and the bad, and do so with others who would be able to understand and “get it.” Further, many group members explained that often times, they feel pressure to act a certain way or to make others feel a certain way. For example, group members often expressed a desire to “protect” loved ones by filtering their discussion topics in a way that may not fully represent their true feelings but instead, present them as doing better

than what may actually be true. Thus, the overall expression of their well-being was being restricted and was not fully representative of their experience. Many participants described how important existential questions and reactions were often running through their minds, yet they were rarely asked about them so pointedly. Many described how this “bottling up” approach lead to anxiety, frustration, sadness, anger and other emotional struggle. Encouraging participants to share the range of the emotions they are feeling, even the “forbidden” ones such as fear or anger has been very important. EFT techniques were efficacious in that they allowed group members to explore and further understand their emotions. Asking participants to describe what the emotions feel like in their body was a great way to give them “permission” to fully attend to and experience their emotions.

Group members seemed to relate to each other on very personal levels when existential issues and deep descriptions of emotions were discussed. One observation was that when such topics were discussed, the group members were very attentive and responsive to each other, seemingly more so than when other topics were discussed. While other topics often led to group members sharing their own personal experiences, group members tended to very much support the person who was emoting or discussing existential issues. Unlike many times during the chat where there are often 2-3 chat themes in play at once, this was often a time when there was uniform focus on these types of issues. In the chat experiences for this group, participants have been very adept with balancing serious topics with more lighthearted ones. The facilitator should model the flexibility to discuss all aspects of the cancer experience, from topics that bring tears to those that bring laughter.

Potential Challenges with the Chat

Low Participation

Challenge

While the chat is often the component of the group that exhibits the most amount of participant activity, there have been weeks in which only a few, or even no group members present to the chat. Parallel to the activity levels of the group in general, chat activity seems to come in phases or waves where there are multiple weeks with lots of activity, followed by a few weeks where the chat room will be quiet.

Potential Solutions

Most often when there are stretches of chat room activity, it is a consistent cohort of participants that show up regularly. While there has never been a time in which the whole cohort shows up, the most amount of chat activity for the most consistent amount of time has been when there are anywhere from 3-8 of the same group members that come to the chat on a regular basis. Because of their regular activity, and because they are receiving feedback and responses from other group members at a rate that far exceeds that from other forums in the group, such as discussion board posts and messaging, they seem to get to know each other at a deeper, more intimate level much quicker in the chat setting. It has been apparent that the personal connections they form with one another have often to lead to more emotional investment and involvement in the group, which seems to predict the likelihood of them continuing to come to chats and

be engaged and active in the group, thus, creating a positive feedback loop. Therefore, it is an important job of the facilitator to promote and emphasize emotional connections between group members as much as possible. While this serves many clinical advantages, it also has worked well in increasing chat activity. One way to do this during the chat sessions is to not only respond personally to group members that are sharing, but to, and perhaps more importantly, highlight and look for opportunities to connect group members with each other by tying group members together as much as possible. Emphasizing shared or common experiences often fosters this process. When you, as the facilitator, notice commonalities, expressing these with phrases such as, “Participant X, I think what I am hearing is very similar to what Participant Y had mentioned last week, is that right Participant Y?” Another facilitator technique that has been helpful and serves the same purpose of uniting group members is to listen for overall themes, even if some of the specifics are unique, and highlight how they seem to be having similar experiences. For example:

I am noticing that many of you have described having these racing thoughts about “what if” scenarios. For some of you, they are about your cancer coming back, for others, they seem to be about how your relationships will look, while others have discussed fear in how side effects will interfere with your life. While there seem to be many potential scenarios and thoughts that come after the ‘what if...’ it does seem like, I general, it has been very difficult for many of you to ‘turn off’ these racing thoughts at times, is that accurate?

Shared experiences promote a level of understanding that many group members have described as emotionally powerful, even if they may have a hard time verbalizing what/how this process may work. On multiple occasions, when describing their

relationship with others in the group, group members have stated, “they just get it.” Overall, it seems to be the warm, caring, safe, and understanding environment that predicts group member participation.

Should chat activity remain low or non-existent for multiple weeks in a row, it has been helpful to engage in outreach attempts, either by the facilitator or by encouraging other, more active group members to encourage less involved participants to join the chats.

It has often been the case that there are consistently a handful of group members that express benefit from the chats and are active members of the chat. Further, the chat has been yet another place where many group members have commented that it has been useful to connect to others who “get it” and have shared experiences. Therefore, encouraging active group members to reach out to other, under-engaged group members has been effective. It is likely that when group members hear of benefits from the chat from other group members, rather than just the facilitator, they may feel more strongly about the possibility of the chat holding benefit for them. It is probable that this outcome stems from the idea that others tend to have more trust or relate-ability to those in their “in-group”, in this case, other group members who are cancer-survivors as well. If they can hear “from the horses mouth”, as the saying goes, that the chat is a positive, effective experience, they may be more likely to attend.

As the facilitator, sending messages or posting to the discussion board is a way to reach group members and open the dialogue to discuss any barriers/problems/issues they may be having that are interfering with their ability/interest in engaging in the chat. As always, empathic statements that convey special interest in the group have been found to

be effective and clinically beneficial interventions. Asking the group if there are ways in which the chat can be altered or improved in order to increase the likelihood of chat participation demonstrates flexibility and a true desire to give participants the best group experience possible. Exchanging these types of dialogues has been most effective when it is done in a more public forum, such as the discussion board, so that all group members have an opportunity to contribute. If potential problems/barriers are identified, working with the group to come up with possible solutions (i.e. changing the chat time) should be the next step. It may be that if a group member suggests a change and that change is implemented, they may feel a stronger sense of connection to the chat and thus, may be more likely to attend. Soliciting group member feedback regarding any changes also makes it more likely that they feel a sense of community and collaboration, an important aspect of any group.

While the strong emotional connection and feelings of importance in a group have been the likely factors that promote group activity, logistical issues should not be overlooked. An important job of the facilitator has been to ensure group members have accurate information regarding the correct time and ways to access the chat. Sending messages and making discussion board posts conveying this information, as previously discussed, should be a weekly task the facilitator engages in.

Lack of Commonalities Between Group Members

Challenge

While the group is designed for a special population, cancer patients and survivors, there is an incredible amount of diversity and varying factors within this population. Factors such as cancer type, stage, progression, prognosis, interventions, treatments, side effects, support systems, age, abilities, functionality, available treatments based on income/location, etc. have all come into play. When considering the unlimited factors, it is clear that, while the diagnosis of cancer may be shared, the personal impacts of cancer are extremely variable. Therefore, some group members have shared that they have had a hard time relating to others. More than once, group members who have had more positive prognosis and/or less severe cancer experiences have expressed feeling guilty being in the group because they feel like they “got off easy” compared to others and “feel bad complaining when my situation isn’t nearly as bad.” At the other end of the spectrum, group members who may have a poorer prognosis and have had a more drastic cancer experience have reported “feeling bad talking about all my problems and brining the group down.” In other situations, the vast differences in cancer type have resulted in a large degree of many different functional outcomes, some being very sensitive in nature. For example, the first few Health-Space cohorts were comprised of a variety of cancer diagnosis, including both men and women. Some participants described feeling uncomfortable talking about some of the problematic effects they were experiencing, especially when they were intimate in nature. For example, many men expressed having trouble feeling comfortable talking about issues

such as sexual dysfunction, in a group that was so diverse and made up of many women and other participants who did not share these concerns. Conversely, multiple women, for example, would express having a difficult time talking about the specifics of their breast cancer with men in the chat. As such, within group differences seemed to present a challenge to the group and seemed to limit the degree to which group members were comfortable and/or willing to share the full extent of their concerns.

Potential Solutions

Ultimately, the goal of the group has been for all group members, regardless of cancer specifics, to feel comfortable, valued and relevant in the online group. Ways to work towards this goal that have helped in the past include use of the micro skills, as discussed earlier, to validate each participant's perspective and experience. Additionally, being transparent to the fact that there are many differences between group members may help group members feel more permissive and/or comfortable in expressing their individual differences rather than feeling as if they need to "fit in" or "hide" any aspects that may be unique compared to other participants.

Further, because one of the criteria for being eligible for the group was that the individual interested needed to have been experiencing a certain level of emotional distress in order to be admitted to the group, emotional distress was an underlying commonality that all group members shared, despite any other differences. Therefore, validating that the cancer experience can be difficult, no matter the specifics, was an important theme for the facilitator to be aware of. Keeping the chat conversations focused on the emotional aspects and the psychological impacts of the cancer journey

seemed to make it more likely to result in shared experiences and commonalities among group members. Therefore, emphasizing the ways in which experiences are similar, versus highlighting details that make group members different, proved to be an effective way to decrease diversion among group members.

While identifying commonalities has been beneficial, and is an important part of unifying group members, it is true that different types of cancer result in different types of outcomes that may be more difficult to discuss in the presence of participants who may not share certain experiences. After all, the idea of feeling close and connected with other group members because they “just get it” is an important one that was continually emphasized by group members. Therefore, a potential solution was to create a cohort that shared a specific type of cancer diagnosis. Due to a large amount of available participants who had experienced breast-cancer, it was decided to keep this sub-population of participants together rather than interspersed with other cancer diagnoses. As a result, it was observed that there was generally a greater degree of activity involvement and overall, the cohorts that were breast-cancer specific seemed to form somewhat closer and more intimate bonds with each other. Further, within these cohorts, there were many times where intimate details, such as sexual dysfunction or side effects were discussed. While it is uncertain if it was the seclusion of cancer-type specifically that fostered these types of intimate relationships and discussions, it may be a contributing factor and is an important consideration when designing the parameters of the cohorts in future groups. Of note, even within this sub-population, many individual differences were still apparent and many group members still expressed feelings of “guilt” because of these differences. Therefore, validation and emphasis on common

perceptions and experiences remain to be important facilitator skills. Additionally, being more selective based on cancer type may limit the number of eligible participants, which could reduce group activity. Further, it may exclude people from the oncology population that may otherwise benefit from being apart of the group. These limitations should be considered and weighed against the potential benefits when making inclusion criteria decisions.

“Herding Cats”

Problem

One thing that differentiates an online group chat, from a face-to-face group is that with an online environment, everyone can be “talking” or typing all at once. An abundance of activity and incoming text in the chat is often a great indication that group members are engaged and interested in the chat, a primary goal of the group at large. However, having too much activity at once in a setting where timing and “taking turns” is not evident due to the lack of non-verbal cues that are often available in direct encounters, the potential to create feelings of disconnection or fragmentation is greatly increased. Further, because the dialogue is visual rather than auditory, it may be easy to overlook certain comments or questions. Additionally, with different typing speeds and computer abilities, the flow of the conversation tended to be variable. One person may be responding to something, but because of the fast-paced environment of text coming in all at once, their response may become disconnected with the original statement they are responding to and text can easily get out of order. Basically, the chat can feel chaotic and

overwhelming at times. Maintaining all group members on the same topic, at a similar pace can be quite difficult and may feel like the metaphorical non-stop chase one would imagine in a task of “herding cats.” From the perspective of the facilitator, knowing what pace to model responses, how quickly the facilitator is actually able to type/respond, knowing what to respond to and when, who to respond to and when, and the overall responsibility of prioritizing responses can be difficult aspects of the online chat.

Potential Solutions

An important job of the facilitator is to keep the conversation of the chat feeling cohesive. While this can be difficult, there have been techniques that have been found to be helpful.

First, the facilitator should make an effort to stick to the chat topics that were identified in the “agenda setting” phase of the chat at the beginning. If a topic comes up that seems relevant, but was not identified as being apart of the agenda, the facilitator should make a comment that models the importance of sticking to the agenda, while at the same time, demonstrating flexibility within the chat. A comment that may suffice may sound something like, “I noticed we are talking about a topic that we didn’t put on the agenda at the beginning but it seems to be important. Is this something you all would like to add to the agenda?” If the group decides it is not important to add to the chat at that time, or if there are a number of other important or time-sensitive topics that were already identified to be discussed, the facilitator can validate the importance of the topic, and suggest that it be put on the agenda for the chat next week. Alternatively, the

facilitator may suggest that the group discuss the topic on the discussion board throughout the week. This way of giving importance to sticking to certain topics has been helpful in alleviating a sense of chaos in that it gives the chat organization, structure and limits that are reasonable and established collaboratively.

Another way the facilitator has been effective in providing focus and structure to the chat has been to be strategic regarding which comments he/she chooses to respond. One important lesson learned was that it is not necessary to respond to every single comment that every single participant stated, every single time. As discussed before, because of issues such as typing speeds, distracting from the environments, etc., some group members may be responding to things that have already been addressed or things that are no longer relevant. The facilitator should balance the concepts of validating each group member and making them feel heard and incorporated into the chat, with keeping the responses on topic and not creating “side conversations” or responding in a way that would encourage getting off topic. The best way to do this has been for the facilitator to choose the most pertinent topic (ideally, the one that has been identified by the agenda) and make their responses relevant to that topic. When other comments are made, depending on the nature of the comment and using clinical judgment, the comment can either be ignored (if it can be done so in a way that maintains positive rapport), redirected in a way that relates to the target topic, or acknowledged but then the person is encouraged to return to the current topic/discussion.

Clearly stating what the topic is and asking how people relate to it can be another useful way the facilitator can keep the chat on target. At times, it may be more difficult to identify the overarching theme when group members are giving specific details and/or

personal accounts. Being able to “step back” as the facilitator and identify commonalities between the different comments group members are making is an important way to develop a theme. Stating the theme more globally can unite the conversation in that it is difficult for group members to stay on topic if the nature of the topic is unclear. Labeling the common themes and links has been advantageous in that it can often tie parts of the conversation together to make the topic a more identifiable construct. For example, the facilitator may say something like the following:

It sounds like Participant Y is describing how difficult it has been to talk to her family about what her true thoughts and feelings are while Participant X has been keeping a journal. Participant Z has been discussing how great it was for her to have lunch with her friend this week. While there seem to be many different things going on with each of you, it seems to me that overall, the importance of communicating your thoughts and feelings, whether that be through family (or difficulty with such), written expression, or friends, is something that is important to you all, is that accurate?

As one can see, responding to each participant’s individual scenario in the case may have led to three different, simultaneous conversations; tying them all together by finding the underlying theme keeps the conversation cohesive.

It is often the case that, if you as the facilitator are starting to feel overwhelmed and fragmented, the other group members are as well, if not more so. Using self-disclosure to address this has been a powerfully effective technique. When this kind of response has been made, more often than not, group members have responded favorably and have agreed that it felt a little “all over the place” and are thankful for the structure. The following is an example:

Wow, I am seeing so many themes and topics come up all at once. The all seem interesting and important and I want to be sure we are addressing each one to the extent that it deserves and that we are all feeling apart of the same conversation. Would it be okay if we picked one of the topics to talk about now and then addressed the others in order? Which one feels most important to you at this moment?

The important, yet sometimes difficult technique of redirection is an important tool that the facilitator should be comfortable exercising in the group, especially when a topic feels as if it is “unfinished” or if it was not resolved to the degree that would feel meaningful for the group and/or facilitator. Making transparent statements about getting back on focus has been effective. For example, one type of statement may be something such as the following:

I noticed we were talking about helpful coping strategies to help with feelings of fatigue but then I noticed we changed pretty quickly over to talking about ways in which talking to your doctors has been difficult. I realize communication with your doctors is important and I want to be sure we get to that either today or add it to the agenda for next week but before we move onto that just yet, I was hoping you all might be able to share a little more about how you have handles extreme feelings of fatigue, has there been anything you have done that has been helpful for you?

At times, it seems to be more the pacing of the responses, versus the topics themselves that can make the conversation feel very quick. Group members and facilitators alike have commented that the group can feel “exhausting” at times when one is trying to furiously type to stay caught up with the group. This is another situation in which if the facilitator is feeling rushed and hurried, it is likely a parallel process to what the group members are feeling as well. Making this feeling explicit can normalize the situation for group members. For example, making a statement such as,

Phew! I don't know about you guys but my fingers are starting to sweat I feel like I have to type so fast to keep up with everyone! I am finding myself wanting to respond to everyone right away and I can see how that may be the case with some of you as well, let's just do this...let's slow things down a bit. We have plenty of time and I want to be sure we are catching everything and giving everyone the time they need to respond, how does that sound?

Once the facilitator has suggested easing the pace a bit, it is important to be able to model this as well. Taking time to breathe, and be thoughtful in one's answers is important. However, modeling that you, as the facilitator, are taking deep breaths and being thoughtful can be difficult because of the lack of non-verbal observation opportunities. Making these more behavioral cues apparent through text has been one way to address this issue. For example, the facilitator may say something like,

I am thinking about what Participant X just said and I know that it had a profound impact on me. I am just wanting to take the time to get my thoughts together so I can express my reaction appropriately. Also, this is a pretty significant topic we are talking about so I want to be sure I am not rushing through things...so if it's okay with you all, I am going to take a minute here to take three deep breathes and then to put some thought into my response...so if I am quiet here for a few minutes you will know why. Be back with you in a few!

While there are many different ways to respond to a feeling of "herding cats" it seems that some of the most effective responses come from being transparent and utilizing the skill of self-disclosure describing how you, as the facilitator, are feeling. This seems to work in that it makes what is most likely implicit with other group members, explicit to the group, which can have a powerful effect. Additionally, it models open, honest communication and empathy which are important factors in

forming relationships online as well. Further, it bring to the surface any issues the group may be having and states them clearly in a way that allows for problem solving and re-focusing which can repair many feelings of discomfort or anxiety. Making the group feel as comfortable as possible is one of the most important goals of the chat and open communication has been very important in making forward progress towards this goal.

CHAPTER 5

TERMINATION AND BEYOND

The Alumni Group

The Alumni Group did not exist in the initial creation of the online group. Rather, its inception was based off of feedback that was being communicated by group members whose time in the group was coming to an end. Many of the engaged group members expressed how beneficial and valuable the group had become to them over their 12 weeks of participation. A significant amount of participants expressed a desire to stay in the group and continue to have access to the materials, chats and connections with each other. However, due to the research-focused nature of the group, it was important to stick to the protocol of restricting group members to 12 weeks of intervention/facilitation in order to substantiate the reliability and validity of the study. In an effort to give group members the continued support they were looking for, and keep the research quality of the study intact, the Alumni Group was created.

Alumni Group Aims

The primary aim of the Alumni Group was to provide optional ongoing support for group members after they graduated from their 12-week intervention participation. The Alumni Group was an on online group that looked identical to the intervention group. Group members had immediate access automatically and even used the same log-in information. Thus, a space was provided where group members could continue to keep in touch with each other, have access to the psychoeducational components of the

group (the guidance modules), and have a safe place to continue to express themselves without compromising research rigor or quality.

Alumni Group Design

The Alumni Group was specifically structured to be as similar to the original intervention group as possible in order to promote a sense of familiarity and comfort for graduated group members and to minimize confusion or technical difficulties. In fact, the Alumni Group was designed as an exact replica of the active intervention group except for one component; the facilitator. As a member of the Alumni Group, group members continued to have 24/7 access to chat rooms, discussion boards, blogs, messaging, and guidance modules, however, the facilitator was not involved. This lack of facilitation was due to limited resources/time, as the facilitator's focus was prioritized to the active intervention cohort.

Termination

As group members begin to move through their 12-weeks in the group, issues of termination should be discussed in a timely manner, just as they would be in a face-to-face group. One advantage to the online forum was that group members had access to a personalized information page that tracked their time and progress in the group. Further, they would get automatic reminders when they were in their last week of the group. Between these online tools, and because the set amount of time in the group was established from the very beginning, group members were familiar with their timeline and termination was expected.

The facilitator should be mindful of group members' timelines as well. Beginning to discuss termination issues 3-4 weeks before their time in the group came to an end was found to be useful. Termination issues were processed and included discussions regarding the group members experience in the group. Specifically, it was helpful and informative for the facilitator to elicit any suggestions regarding how to improve the group, as well as feedback pertaining to the aspects of the group that were especially important/impactful/beneficial for them. Asking the group members to discuss any growth and/or changes they may have noticed while in the group was an important termination discussion as well. Further the facilitator should take the time to disclose any progress they noted, as well as highlight the person's strengths. Suggestions for further support, including a detailed discussion about the Alumni Group, should be made clear to participants. It has been helpful for the facilitator to explain components of the Alumni Group such as log-on procedures, what to expect from the Alumni Group, and leave adequate time for any questions or comments regarding this process. Further, clarifying with participants ways in which the Alumni Group may differ from the active intervention group is an important facilitator task and should include issues such as the lack of facilitation, the reasoning behind this limitation (to minimize feelings of personal abandonment), and how this may alter their experience.

For some, minimal termination issues were apparent. These were often group members that had adequate social support aside from the group. Below is an example of this type of termination response.

Example 1: Blog from participant with good adjustment to termination

After we got together and chatted last night, I truly realized how much each one of this group has come to mean to me. You've each brought something into my life...each in your own special way. I would not trade a single one of you for anything! I've come to depend on the different personalities of each of you. I've come to think of you as real friends...not just some research group. How does that happen?? lol However it happened, I'm grateful that it did, and I want each of you to know that you have brought some special meaning into my life. You've made my life happier. You've made my life better. Thank you to each one of you...I don't think you realize what you've given me, and I only hope that I can give even a small part of that back to you!!

Example 2: Discussion Board post from participant with good adjustment to termination

Hi group, I am so sorry I missed my last chat with you before I move on to the alumni group. I work shift work, and have been working very erratic hours this week. I have been very fortunate to have been your 'virtual' friend, and have enjoyed your guidance and advice immensely. Best wishes to you, and thanks for everything.

For others, termination was more difficult and they expressed a hesitancy to no longer have the connections to the other group members and/or facilitator. With these members, creating space in the chats 2-3 weeks before their time in the group ends seemed to be helpful in allowing them to process their experiences with the facilitator and others in a format where they received instantaneous feedback. Giving them time to say good-bye to other group members and the facilitator was a nice way to slowly, rather than abruptly, allow them to have a sense of closure with the group. As the facilitator, it was often necessary and beneficial to take extra time with these group members to discuss such issues. This could be done utilizing multiple facets of the online group. For example, a private message was one form of communication that was often chosen if the termination issues were more personal and/or if the facilitator believed a discussion

beyond that which might be appropriate for the entire group would be beneficial. If the termination issues were more indicative of interpersonal relationships between group members, facilitating a conversation in the chat between group members was an effective means of processing termination issues. Finally, if the person was unable to make the chat or requested more time and/or space to present issues regarding their time in the group, a discussion board post or blog was found to be the preferred forum in that it seemed to eliminate the pressure of time, which was often more apparent in a chat. If a particular group member seemed to be having an especially difficult time, discussing ways in which they could continue to feel supported outside the group was advantageous. In these cases, discussions encouraging participants to engage in further mental health treatment have been necessary. Below is an example of a participant that experienced more challenges with the termination process:

Example 3: Private message exchange with participant struggling with termination:

Participant:

Hi Kristen!

Just wanted to send you one more email since I'm not sure exactly when I'll be kicked off. Today's notice says that I have five days left, so I may be at the chat on Weds, and I may not if I don't get entrance! ;-) I'm hoping for one more facilitated chat, since I have yet to do the whole relaxation thing. I learned self hypnosis many years ago to help me deal with back pain, and it can really make a huge difference. I'm hoping that I'll have the opportunity to share with the group how I managed to keep doing it until it finally worked!

In case I don't get in to the chat, I just wanted to thank you again for being the wonderful young woman that you are. You are so caring and I honestly don't know how you manage to keep up your great outlook day after day. I can imagine that it would get aggravating trying to keep a positive attitude when all you deal with are sick people....[some content deleted due to

space] A bit of advice...take extra good care of yourself, ok? You know that I only mean that because I want the best for you. As I said...I don't know how you keep on doing this! You've asked us, week after week...how are we coping...how are we feeling. I know that's your job, but you need to take care of yourself, too!

Well, just wanted to send one more email before you disappear...take care and enjoy your life. Learn the lesson from this group...that life is so very precious and you deserve as much happiness as you can grab on to. Don't let things get to you, and don't take yourself too seriously. Look down the road and picture yourself being 90yrs old and sitting in your rocking chair....see yourself sitting there and rocking, and smiling because you lived your life to the fullest. That's what I do...my "bucket list", if you will! lol Don't live life with any regrets, ever. And always remember..."What comes around, goes around"...it will come back to you and you've brightened so many people's lives in your young life, that you will surely have happiness and contentment all your days forward! Good luck in all you do, but make sure you do what you WANT...not what you think you should. Take risks, but try to foresee the outcome before you do. Love others, and that love will come back to you thousand-fold. The things you do DO make a difference and you have touched others' lives and made them better.

Love and blessings!
K

Facilitator Response:

Hi K,

Well, wow. I just read both your final blog post and your message to me and I am sitting here teary eyed and a little speechless (in a good way, of course). I wish I could reach through my computer and give you a hug. Kathy, I am truly touched by both your kindness and wisdom. In a lot of ways, the way you live your life, the way you love others, and the way you face the challenges that you are faced with is remarkable and not something I will never forget.

A few thoughts I wanted to share with you. I know you have expressed how hard it will be to have the group end and that you are feeling a little abandoned, I can definitely understand where you are coming from. I know it is incredibly difficult opening up to complete strangers about some of the very personal reactions and intimate physical and emotional complexities that come with a cancer diagnosis. When you do that, you develop a natural bond with people and to place time limits on that bond seems frustrating. I am really going to miss you guys and our chats as

well. But thank you so much for understanding the nature of the group and why it is structured the way it is. And the alumni group should be great!!

In sticking to the true "K Way" there are so many positive outcomes that I have had the honor of witnessing that I wanted to share with you as we wrap up our time together. I have to say, I have seen SO much personal growth from where you started on Day 1 to where you are now, not to say that you started out in a "bad" place whatsoever, but I think you have allowed yourself to explore the many layers of emotions that come with your experience, you have allowed yourself to be vulnerable and share very real and honest feelings with the group. You have really been open to this experience. I know doing that is MUCH harder than the alternative of taking a back seat. I said in the very first email I sent you that "you will get out of the group what you put in" and you really put your heart and soul into this group and I can't tell you how much I appreciate that. I think you have been open to talking about some things that are really scary and uncomfortable (thinking about making the doctors appt, for example) and yet you have done those scary things, you have once again fought and overcome! Another thing that stands out about you is not only your willingness to open up to the group but your willingness to support others. You are genuine and heartfelt in your interest and concern for others and you are incredibly positive, motivating and encouraging as well. You really were an important part of this group and I know you will continue to be in the alumni group as well!

You are SO right that this is more than a study, more than a research project...this is your life! And the lives of other extraordinary women. And I have to tell you that this is so much more to me than a study or a dissertation project as well. This group, you and the other women, really brought this "study" to life for me and I really found myself loving and looking forward to our Wed evening chats. Ya know, I will be honest, there have been times in my doctorate program where I feel exhausted and sometimes even questioning my decision to be in school for so long, but this group was quite the opposite. It was people like you and the other group members that made me feel energized and excited about what I have chosen to do with my life, so thank you for that. While I will miss you guys in the alumni group, I will think of you often and I am so excited for you to be able to continue to connect with each other. I know your winning attitude, your gratitude for life and your love for others will bring bright, happy days in your life. It has been my honor and privilege to be able to share some of those days with you these last few months. Thank you K!

Take care of yourself and thanks again for all of your hard work!
Kristen

Emotional Impact of Termination

Overall, termination in an online setting proved to be very similar to face-to-face groups regarding the emotional impact. Most group members expressed their feelings of gratitude, support, and care. As with all groups, the level and written expression of these feelings were variable. As the facilitator, similar emotions were felt towards group members. Thus, these experiential findings support the idea that close connections can, and were, established even in an online setting.

CHAPTER 6

PERSONAL CONCLUSION

This manual was written with the primary purpose of responding to the need for manualized treatments for online psychosocial support groups for the oncology population. The intent of this project was to contribute to the health psychology field by communicating effective research-driven clinical interventions for cancer patient and survivors. A research goal was to structure and detail the process of an online psychosocial intervention in an attempt to demonstrate rigorous methodological properties that should be included in valid, reliable research in this area. Clinically, the primary aim was to provide an effective, evidence-based clinical tool for other mental health professionals to utilize in an attempt to provide quality care to a greater number of cancer patients, especially those that may not otherwise have access to therapy.

The clinical skills I learned from top-notch supervisors and through this unique clinical opportunity have been extremely valuable and significant in promoting my growth as a young psychologist. This experience challenged me on an intellectual level and has substantially contributed to my developing clinical skill set. At the same time, my involvement with this project had a profound impact in a different sense; I grew in a way that extended outside my professional world as well.

I often logged onto the group website feeling frazzled over an upcoming exam, or feeling concerned that I did not adequately explain the cognitive triad to my morning patient. I often logged off from the group feeling immensely different; lighter, grounded. As the facilitator, I was often in a position where I was teaching group members various

coping skills, explaining psychological principles, or providing relevant psychoeducation. To most, I appeared to be the primary “teacher” in the group, the one imparting knowledge to group participants. However, as I often expressed to group members, I feel as though I learned more from them than I could have ever “taught” them in years. While I hoped to have communicated some lessons on assertive communication, the basics of cognitive restructuring, or principles of mindfulness, I received lessons as well. These lessons, however, were ones that I would have never found within the thousands of pages of textbooks and training manuals I read throughout my graduate school training. They were life lessons; wisdom imparted by those faced with the ultimate challenges. Exploring a vast range of emotions at a deep, visceral level with group members who had often been through so much more than even they thought possible, frequently offered a perspective shift among group members, as well as within myself. My interactions with these compassionate, angry, kind, challenging, gentle, resilient, complex, brave, scared, strong, frail, understanding, confused, wise and caring individuals not only fulfilled my training expectations; they nurtured my soul.

Though I suspect they didn’t even realize they were doing so, group members impacted me and evoked a personal appreciation for life and clarified my priorities. While I was mindful to implement self-disclosure to the degree to which it was clinically effective and beneficial for the group members, there was not often a time where this did not seem appropriate, as the power of the human connection, even through a computer monitor, nearly always felt important, necessary, and powerful. Overall, I was amazed by the depth of relationships that were formed, the degree of openness group members displayed, and the amount of honesty and emotional investment group members braved.

While the primary focus of my work in psycho-oncology and the place where I feel the most personal fulfillment comes from helping others, there was an added value to this project in that it was an experience that was rich and fulfilling both personally and professionally. It is my hope that others, both facilitators and cancer patients, are able to benefit from use of this manual and are able to experience the powerful effects of exploring the impact cancer often has on an individual's life, as well as the reward that comes with working with these individuals to help them to live in a way that reflects their values and improves their quality of life. As I communicated to many group members, it has been an incredible experience and a huge honor to work with this population and I will be forever grateful for this invaluable opportunity.

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