Grief in Women With a Family History of Breast Cancer

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Abstract

The literature suggests that women with a family history of breast cancer have high perceptions of their personal risk for breast cancer, which can often promote emotional distress such as anxiety, depression, and grief.

Objective: This paper reports on loss and grief in 31 women who participated in a study of a supportive-expressive group intervention for women with a family history of breast cancer (at least one first-degree relative with breast cancer). The literature on grief is reviewed.

Method: The women participated in a pilot study of a 12-session, 6-month supportive-expressive group intervention designed for this population. Pre- and post-group psychological measures were given, including a standardized measure of grief.

Results: The amount of loss that these women had experienced was significant: 30 out of 31 women described losing a loved one, this loss was due to breast cancer in 21 cases. In 19 cases the loss was of a mother. A baseline measure of grief prior to the group intervention demonstrated an intensity and pattern congruent with unresolved or acute grief. There was a statistically significant reduction in grief from pre- to post-intervention.

Conclusions: The findings described in this paper support the theoretical and clinical observations reported in the literature on loss and grief in women with a family history of breast cancer and have relevance for future interventions for this population of women.

Introduction

Breast cancer has an impact on the whole family. The descriptions in the literature of first-degree relatives of women with breast cancer indicate increased levels of perceived risk for breast cancer, anxiety, depression, and grief. High levels of intrusion and distress have been found to impede counseling interventions geared toward improving accurate risk perceptions for breast cancer, which may be associated with both lack of compliance with screening recommendations such as mammography or with excessive breast self-examination (BSE) or other screening activities.

During the risk counseling process a woman observes patterns in her family through the presentation of a genogram, which includes the number...
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of diagnoses, the closeness of the diagnosed relatives to herself, and the number of deaths due to cancer in her family. A woman receives an “estimate” of her personal risk of breast cancer based on family history and, in some cases where patterns indicate a possible genetic mutation of BRCA1 or BRCA2, may be offered genetic testing.

It is often the case that a woman feels very aware of her own risk for breast cancer due to her experience of close family members dealing with the disease. Many women in this circumstance have lost family members to cancer and participated in caring for the female relative with breast cancer. Such events can result in the loss of normal childhood or adolescent experiences. Furthermore, the literature suggests that the risk counseling process generates an additional sense of loss, underlining “impaired invulnerability” as women observe and contemplate their own family history. This may be experienced as a loss of confidence around their present and future health.

This paper reviews the relevant literature on grief, presents a clinical example relating the impact of loss and grief for women with a family history of breast cancer, and reports on the quantitative grief data from a study investigating the impact of a group support intervention.

Literature Review

Although there is little empirical evidence for grief amongst women with a family history of breast cancer, some studies have looked at the broader psychological impact on women who have experienced breast cancer in their families. Wellsch and colleagues studied daughters of women diagnosed with breast cancer and found that daughters who were adults at the time of their mothers’ diagnoses had the least adjustment problems, those who were children at that time had moderate adjustment problems, and those who were adolescents had the greatest overall general adjustment difficulties. In addition, the subgroup of daughters with deceased mothers had greater adjustment problems. Furthermore, Wellsch and colleagues found that the only independent variable (from a potential pool of fourteen independent predictor variables) that predicted non-resolution of feelings about the mother’s breast cancer was the alteration of long-range life plans due to the mother’s illness. These included such changes as altering school or marriage plans, or not moving because of the mother’s illness.

Wellsch and colleagues have speculated that difficulties associated with the insufficient resolution of the premature loss of a mother at an early life stage contributes to the later problems encountered by women with a family history of breast cancer. Thus the presence of grief as a significant factor seems likely in this population. The long-term consequences of maternal loss are difficult to ascertain because they are contingent on several mediating variables. However, multiple ramifications such as additional domestic responsibilities, the temporary psychological loss of the surviving parent, the permanent loss of the family unit, and the potential financial burdens, are possible. Consequences such as these are reported by women who have experienced the death of their mother from breast cancer, as shown by the case example discussed later in this article.

Other historical writings also address the issue of grief and loss. The phenomenon of grief was first described psychologically by Freud, who referred to the process of reviewing the internal world after bereavement as “the work of mourning,” or “grief work.” This provided an explanation for the phenomenon termed “obsessional review,” a well-documented component of grief. Others have since introduced the notion of grief work being in “stages.” There are many descriptions of abnormal grief classified by terms such as “delayed,” “chronic,” “pathological,” and “morbid.” Grief has been described as being normal, exaggerated, abbreviated, inhibited, and anticipatory, and time-limited, or as a dynamic process “changing over time.”

Individuals can experience aspects of grief and feel as if they have resolved certain issues, such as anger or guilt, only to have them resurface at a later point in time. Grief is also pervasive in that it can affect every aspect (physical, emotional, spiritual, and social) of the lives of people who experience significant loss. For example, characteristics of bereavement such as fatigue, loneliness, anxiety, somatization, guilt, anger, denial, social desirability, and depression have all been investigated in the literature. Both the “resurfacing” aspect of grief, and its pervasiveness, are pertinent to the experience of women with a family history of breast cancer, who are continually exposed to breast cancer-related activities such as the genetic risk counseling process and breast screening examinations.

Studies of life events suggest that the most difficult life-change events are those that require people to undertake a major revision of their assumptions about the world. Such events are lasting in their implications rather than transient and take place over a relatively short period of time, leaving little opportunity for preparation. These attributes are also frequently relevant to the experiences of women with a family history of breast cancer.

Lerner and Lerner suggest that the impact of loss covaries with the extent to which the psychic structures have been internalized and are autonomous from the sustaining object. Given that the lost object served a function for the person, the loss must be resisted (ie, denied) until the function has been replaced. The person may deny the loss in the hope of completing the developmental process of separation and autonomy with the now introjected object. Similarly, Horowitz and colleagues suggested that incomplete early separation from the mother figure rendered a person especially prone to pathological grief. Clearly this suggestion is pertinent to women with a family history who lose a mother to breast cancer at a young age.

One theoretical model that has been extremely influential is the attachment model of grief originally developed by Bowlby. Bowlby maintained that when close affectional bonds are threatened, powerful attachment behaviors, such as clinging, crying, and angry protest, are activated. The effective mastery of bereavement involves passing through phases of mourning, which include periods of depression. Eventually, individuals enter the final phase in which they are able to break down their attachment to the lost loved one and start to establish new ties to others and a gradual return of former interests.

Bowlby suggested that the inability to accept and express anger can lead the bereaved individual to remain preoccupied with thought and action directed at the lost object. Striving for the return of the lost object becomes repressed and
unconscious. The unconscious yearning and displacement of anger are both understood as attempts at reunion with the lost object. Such preoccupation and anger are characteristic of some women with a family history of breast cancer who have sustained distress and anger.

The bereaved woman may also identify with the lost object and her family function. Sometimes social or familial pressures determine this proxy response. For example, following the death of a mother, the oldest female child may assume the caretaking role with the younger siblings—a type of event frequently described by women with a family history of breast cancer.

Indicators of Pathologic Grief

Indicators of a pathologic grief reaction may be characterized by excessive anger, guilt, self-blame, or depression. Changes in behavior may include avoiding reminders of the loss event or avoiding/forgiving references to the death within their family or social network. Additionally, when an individual cannot speak of the deceased without experiencing intense and immediate grief, even if many years have passed since the loss, pathological grief should be considered.

Risk factors associated with loss and difficulties in adjustment or unresolved grief include the nature of the loss (i.e., parental loss versus extended family member or child loss), availability of social support, developmental level of the surviving individual, open permission to mourn, and personality style (e.g., being the “strong one” in the family).

Method

The study was designed to develop, describe, and complete pilot testing of a supportive-expressive group therapy for women with a family history of breast cancer. This article reports on pre- and post-intervention results of the grief measure. All women were recruited from two risk-counseling clinics for breast cancer and met the following inclusion criteria: age 18-65 years, having an “inaccurate” personal risk perception for breast cancer that was, on average, double that of the objective risk estimate given in the counseling session, at least one first-degree relative with breast cancer, and fluency in English.

Following a description of study procedures, written informed consent was obtained and the women attended a supportive-expressive group intervention. A battery of standardized psychosocial measures, which included a measure of grief, were given pregroup at 8 weeks, at 6 months (postintervention), and at 1 year.

The Supportive-Expressive Group-Therapy Intervention

The grief literature suggests that factors such as emotional support, protection through the period of helplessness, and assistance in discovering new models of the world appropriate to the emergent situation, are required for successful change around grief processes. Supportive-expressive group therapy originated from an existential therapy background and incorporates many of these features.

The intervention consisted of eight weekly sessions (intensive phase), followed by four monthly booster sessions for a total of 12 group sessions (90 minutes each) over 6 months. The group incorporated supportive-expressive principles outlined by Spiegel and colleagues and was adapted for women with a family history of breast cancer.

Supportive-expressive group therapy uses techniques to encourage individuals to directly and openly express their thoughts and feelings in a nonthreating, nonjudgmental and safe environment. The goals of supportive-expressive group therapy include the facilitation of mutual support, emotional expressiveness, improving family and social support, expanding the repertoire of coping skills, and detoxifying the threat of developing breast cancer. These components are described in detail elsewhere.

On two occasions an “expert,” such as a genetics counselor or a medical oncologist, attended the group to answer the questions of the group participants. An active component of the intervention involved having two women included in the group who had been diagnosed with breast cancer at least 1 year ago. This feature of the intervention was planned to facilitate an opportunity for women at risk to explore any fears or questions with those women who had experienced and survived breast cancer.

Study Sample

A sample of 31 women with at least one first-degree relative with breast cancer attended the group sessions. Demographics are presented in the Table.

Reports of Loss

In addition to the general demographics, information on prior losses was obtained through self-reports and as part of the Texas Revised Inventory of Grief (TRIG). Of the 31 women, 30 reported “losing someone close to them” (97%), 21 (70%) reported having lost a close relative to breast cancer, 19 reported having lost a mother, and two indicated the loss of a sister. Of the total sample, 66% reported that the loss they indicated as the focus to complete

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<th>Demographics (N=31)</th>
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<th>Ethnicity (%)</th>
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<th>Marital Status (%)</th>
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<th>Educational Level (%)</th>
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<th>Number of first-degree relatives with breast cancer</th>
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the TRIG was a “relationship closer than any or most relationships they have had with other people either before or since.” In addition, 59% of the deaths associated with the reported losses occurred more than 10 years ago. Of those women who lost mothers, the mean age of the mothers at the time of death was 51.7 years of age (standard deviation [SD]=16.2) with a range of 32–91 years of age. The mean age of the daughters at the time of death of a mother was 25.6 years (SD=14.6), ranging from 9–58 years of age. Thus, in this sample, 65% of the mothers died prior to reaching age 50 years and 71% of the daughters were under 25 years of age at the time of their mothers’ deaths.

Instrumentation

To measure grief, the TRIG, a standardized measure of grief with good psychometric properties such as α coefficients of 0.87 and 0.89 for past and present factors, respectively, was utilized. The tool is used to measure grief as a “present emotion of longing, as an adjustment to a past life event with several stages, as a medical psychology outcome, and as a personal experience.” The TRIG was developed using factor analysis and consists of a two-factor Likert-type measure of grief following bereavement. It is an easily administered self-report assessment and permits evaluation of the extent and nature of an individual’s personal reaction to bereavement. Intensity of individual or group means of grief reactions can be compared to normative means and ranges at each of four time intervals following the loss: within the first year, at 1–5 years, at 5–10 years, and after more than 10 years. In addition, the TRIG contains a set of clinical demographic questions such as: “How close were you to the person who died?”

The two grief factors are part I: Past Behavior and part II: Present Feelings. The Past Behavior subscale contains eight items which ask the subject to “think back to the time the person died,” provides content on a variety of life events that might have been disrupted by grief, and summarizes one’s initial adjustment to the death of a loved one. The Present Feelings subscale includes 13 items focusing on current feelings associated with the deceased, such as “I still want to cry when I think about the person who died.”

Analysis

Descriptive statistics were calculated on the demographic variables and for the TRIG. In addition, paired t-tests were completed on the TRIG between pre- and post-intervention time points.

Results

The intervention had a significant impact on a battery of measures which included instruments of risk comprehension, psychosocial functioning, breast cancer risk factors knowledge level, and promoted screening adherence. These results are provided in detail in a previous report. The results of the TRIG are presented in the Figure. The “Past Behavior” mean of 22.9 (SD=7.2) at baseline is significantly higher than published norms, indicating considerable grief and significant disruption at the time of the prior loss. As one would expect, this subscale did not change over the course of the intervention because the subscale aims to capture the amount of disruption “at the time of the loss.” The “Present Feelings” pre-group mean of 36.3 (SD=11.9) represents a significant amount of grief and is in the upper quarter percentile for norms, taking into consideration the amount of time since the losses occurred. In addition, the pattern of the two subscales measured before the intervention is congruent with a pattern of unresolved or acute grief.

At 6 months following the complete intervention (intensive and booster phase) there was a statistically significant decrease in the “Present Feelings” mean score (P=.034). In examining the change in grief scores, for those who lost a close relative to breast cancer, the majority, (11 out of 19, SD=57.9%) of the study participants scored an average reduction of 5.7 points (or half an SD) on the Present Feelings subscale, indicating a moderate effect size in reducing the intensity of grief. The following case example will illuminate the clinically significant grief processing that occurred for many women in the program.

Case Example

“Ms. B” is in her mid-forties and came to the group expressing marked tear and anger, particularly towards the medical system. She had participated in caring for her mother until she died when Ms. B was 19 years of age. She became fearful particularly when describing her mother’s surgery, suggesting that her mother had been “butchered” and left with “horrible scarring.” She was immensely afraid of breast cancer and felt she would not accept chemotherapy or radiation treatment if she were herself diagnosed with breast cancer. She had chosen not to marry and had not had children. She was driven to obtain any information on diet and exercise or genetics that could assist in reducing her sense of risk. She was fearful to even identify a risk level for herself, stating that “it is just a number... and anything can come along and boost the risk up.” She also believed that if she stated what she felt her true risk was, “It may cause breast cancer to happen.” She was interested in genetic testing, but frequently inquired about whether or not continued on page 63

Figure

Change in Grief for Women With Loss of a Relative to Breast Cancer (N=21)

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<th>Pre-group</th>
<th>Post-group</th>
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<tr>
<td>Past Behavior</td>
<td>df=18: 22.9 (7.2)</td>
<td>df=17: 36.6 (11.9)</td>
</tr>
<tr>
<td>Present Feeling</td>
<td>df=18: 22.4 (5.4)</td>
<td>df=17: 33.8 (11.3)</td>
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DF=degrees of freedom.

there was some psychological test that could indicate whether or not she could handle the news.

Ms. B was amazed at the level of grief that she expressed in the group, believing that she had finished grieving more than 20 years ago. In the group she heard stories with themes of anger at the medical profession that echoed her own experience of her mother’s death. In particular, she had fearful images involving surgical procedures and treatments associated with breast cancer; she also suffered intense memories of concerning caring for her very ill mother. The women in the group shared their own losses with Ms. B and she was able over time to express her emotional reactions as well as gain a more accurate and balanced view concerning her own life, medical options, and health behaviors. Through the support, vicarious learning, and modeling in the group, she became able to relate to the loss of her mother in a less intense manner. In particular, she expressed feeling grateful for the closeness and caregiving experience she had experienced through the time of her mother’s illness. She was able to integrate the loss in a fashion that permitted her to separate her mother’s experience from her own.

By the end of the group, Ms. B was also able to identify differences in the medical system, such as treatment options and health preventive measures that could allow her to live her life currently with less hypervigilance. She developed the view that even if diagnosed with breast cancer, she could survive. In addition, she also discussed the loss of her mother more openly with her sister—her main link to her family—and developed a greater understanding of their unique and different reactions to their loss, which had been a factor in her experiencing a sense of isolation.

Discussion

These interesting pilot data add to the theoretical and clinical literature describing women with a family history of breast cancer who have experienced the loss of a significant other. The baseline demographic items suggest that the women who participated in the group intervention had undergone significant loss, particularly in relation to cancer, and in many cases at a young age. The baseline TRIG scores suggest that the losses occurred frequently during childhood or adolescence and indicates that there was considerable disruption and emotional impact during the acute bereavement period. These women experienced the loss of their mothers at a time when they were highly active in family roles. The fact that the mothers were young, on average, at the time of their deaths may have contributed to the sense of injustice and the notion, held by many group participants, that the death was highly premature. The women in this study may be similar to the sample described in Wellisch’s earlier study on daughters of mothers with breast cancer.11

The “Present Feelings” level further supports the hypothesis that women in this population have to contend with significant bereavement as the mean indicates a high level of grief. The elevated “Present Feelings” scores are remarkable, given that the average time since the occurrence of the loss was more than 10 years prior to measurement. The other baseline psychosocial measures (10) indicate that there was also a significant amount of other kinds of distress among these women, which is consistent with previous reports.5 For example, 37% of the women in the study exhibited depression in a clinical range for the CES-D and there were elevated levels of Intrusion and Avoidance as measured by the Impact of Event Scale.9,10

The “Present Feelings” mean and average change scores demonstrated a statistically and clinically significant reduction in current grief intensity following completion of the intervention, for the majority of participants. This finding is clinically significant given the magnitude of change and the fact that the grief processing and resolution occurred more than 10 years after the actual loss. It is also in contrast with an earlier report of a 6-week structured group intervention that failed to significantly alter a measure of grief in a similar sample of women.44 The grief experience, specifically when combined with high levels of intrusion or depression, may play a role in the inability of short-term or information-oriented interventions to modify inaccurate risk perceptions as has been noted in the literature.11,10

These findings suggest that women who have undergone significant prior losses may require intervention beyond individual risk counseling or a short-term psychoeducational intervention. Optimal interventions should aim to address the expression of grief and the emotions associated with earlier (and in some cases ongoing) sense of loss.13,15,16 The supportive-expressive group is an ideal intervention in this regard, given its focus on emotional expression over a period of time with therapists skilled in eliciting and managing affect and through the facilitation of mutual support and the examination of existential themes.5,10 The vicarious learning and modeling that occurs throughout the group experience addresses these themes optimally. In fact, the group did “feel,” in many ways, like a bereavement or grief group to the therapists, particularly during the early sessions.

In considering the case, Ms. B was seeking risk counseling and the exploration, expression, and resulting discharge of affect that occurred in the group therapy may have permitted her to resolve her loss issues and allow for a more direct examination of information. By the end of the group intervention she was able to more readily integrate and process the complex risk information. She also exhibited more optimal coping in dealing with her breast cancer risk and even demonstrated a sense that she may not develop breast cancer or at least could survive it.

Limitations

This pilot study utilized a small sample and self-report measures, and therefore, these findings must be interpreted with caution. In addition, all the women were recruited through risk counseling clinics and this may limit the generalizability of the study. Despite these limitations, the data contribute to the empirical literature of women who have suffered losses to breast cancer and who present at risk clinics. These women may require additional intervention beyond that of standard care in order to address their concerns, modify risk comprehension, and facilitate coping. More definitive conclusions could be drawn from a prospective randomized controlled trial that is currently being conducted by our group.

Conclusion

This article reports on grief data from a pilot study of women with a family history of breast cancer participating in
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a supportive-expressive group intervention. The sample suffered a significant amount of loss and exhibited high levels of grief, supporting theoretical and clinical observations in the literature. The supportive-expressive intervention appeared to alter the experience of grief, in a direction congruent with the resolution of acute grief. Supportive-expressive group therapy may be particularly relevant for women who have suffered severe loss due to breast cancer. These findings have implications for future descriptive research and intervention studies for women with a family history of breast cancer.

References


