

Family communication and mental health after breast cancer

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In the context of a traumatic event, such as a breast cancer diagnosis, talking with others about the event can facilitate emotional adjustment and meaning-finding. Among women with a history of breast cancer, open communication is likely to be of particular importance in the family setting, as the family is frequently a primary source of support. The goal of this cross-sectional survey study was to determine the association between open family communication about cancer and breast cancer survivors' mental health. Responses from 230 women at various stages post-treatment suggest that the majority of women are able to talk openly with their family about breast cancer. Multivariate regression analysis further indicates that open family communication is independently associated with better mental health outcomes. Given that many women live long after a breast cancer diagnosis, maintaining mental health functioning is an important long-term goal. Efforts to enhance productive communication between patients and their family members may help women cope with and overcome the challenges of breast cancer survivorship.

Keywords: breast neoplasms, family relations, mental health.

INTRODUCTION

Women who have completed treatment for breast cancer and who have entered the subsequent period of survivorship continue to experience the long-term sequelae of both the disease and its treatments. Women with a history of breast cancer face a wide spectrum of stresses, including physical disruptions, such as initiation of premature menopause and surgery-related lymphoedema, and emotional disruptions, such as those related to body image and fears about recurrence. In coping with the aftermath of breast cancer, as in coping with any stressful life experience, it is common for women to want to talk about their experiences with others (Janoff-Bulman 1992; Rime *et al.* 1992; Rime 1995).

Sharing and talking about one's experiences, thoughts, ideas and emotions is a positive adjustment behaviour, and discussion of traumatic life events has been identified as a key component of successful coping (Pennebaker 1993; Lepore *et al.* 2000). Talking about a traumatic event may help the individual to make sense of the experience (Clark 1993; Rime 1995; Lepore *et al.* 1996), find meaning (Tait & Silver 1989; Lepore & Helgeson 1998; Manne *et al.* 1999; Cordova *et al.* 2001) and achieve emotional resolution (Rime 1995; Smyth 1998). Conversely, failure to communicate about a stressful experience may hinder adjustment and contribute to psychological distress (Manne 1999). In the context of a personal health crisis, such as a cancer diagnosis, individuals are most likely to seek support from their family members (Peters-Golden 1982; Pistrang & Barker 1995; Slevin *et al.* 1996; Ben Zur *et al.* 2001).

Family communication research with cancer patients and cancer survivors has predominately examined the relationship between family emotional support (listening to, responding to and validating emotions) and patients' psy-

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chological adjustment. A number of studies have shown that patients' feelings of being emotionally supported by the family are associated with lower levels of depression and anxiety (Edwards & Clarke 2004), less mood disturbance (Spiegel *et al.* 1983; Manne *et al.* 1997; Giese-Davis *et al.* 2000; Figueiredo *et al.* 2004) and better overall adjustment (Pistrang & Barker 1995; Manne *et al.* 1999; Baider *et al.* 2003). Less is known, however, about the association between other types of communication and patients' psychological well-being. Simply talking about the cancer experience, even in the absence of direct emotional support, may facilitate adjustment. For example, in a study of cancer patients with mixed diagnoses undergoing active treatment, patients who perceived that their spouses did not want to talk about cancer-related issues experienced more psychological distress (Manne 1999). In the context of cancer survivorship, similar results have been demonstrated. In a study of breast cancer survivors and their spouses, women who reported more communication about the cancer experience reported lower emotional distress (Walker 1997). Similarly, among men with a history of prostate cancer, those who had difficulty talking about the cancer experience with friends and family experienced higher levels of distress (Lepore & Helgeson 1998).

There have been two limitations to the work that has been done in this field. First, most of the research has focused solely on the spousal relationship. This not only excludes women who do not have intimate partners, but also may not identify the most important or supportive relationship for all individuals. Second, the studies that have been conducted to date rely on very broad definitions of communication. They have attempted to measure many aspects or facets of communication, and have therefore have given us limited insight into the extent to which certain elements of communication may be more or less important in the adjustment process. It is also important to point out that only recently has much attention been paid to the period after cancer treatment has concluded. Assessment of family communication among cancer survivors is important in that these individuals may continue to be positively or negatively affected by family communication style (Ben Zur *et al.* 2001).

The study described herein expands upon previous work by investigating the relationship between avoidance, as a specific family communication style, and breast cancer survivors' adjustment. The purposes of this study were twofold: (1) to measure the frequency with which patients perceive their family to avoid discussion about the cancer experience; and (2) to explore the association between breast cancer patients' perception of family avoidance and patients' mental health status. We hypothesized that

patients who reported a less avoidant family communication style would report higher mental health functioning.

METHODS

Sample and procedure

Data for this analysis was collected as part of a larger study examining breast cancer survivors' satisfaction with information, the results of which have been published elsewhere (Mallinger *et al.* 2004). Study hypotheses were generated *a priori* in order to minimize chance findings. Before the initiation of data collection, approval for this study was obtained from the University of Rochester Research Subjects Review Board. Eligible women were those who had completed active treatment (surgery, radiation therapy and/or chemotherapy) for stage I, II or III breast cancer at least 3 months prior to enrolment. From November 2002 to January 2004, consecutive eligible patients were recruited from three medical oncology practices and one radiation oncology practice at the James P. Wilmot Cancer Center at the University of Rochester and from the Pluta Cancer Center, an independent cancer treatment centre in Rochester, New York. Patients' interest in the study was determined by the treating physician or nurse practitioner at a regularly scheduled follow-up visit. In order to reduce selection bias, each recruiting oncologist was encouraged to inform each consecutive eligible patient about the study.

The study coordinator, either in the office or by phone, contacted patients who were interested in learning more about the study. Informed consent was obtained from interested patients and a questionnaire was either given to the participant in person or mailed to the participant's home. Participants who did not return their questionnaire were mailed a follow-up letter and another copy of the survey. A maximum of two follow-up attempts were made for each participant, and participants who did not respond after the second attempt were considered lost to follow up.

Of the 292 eligible patients who were identified, 281 (96%) patients signed consent. Lack of interest in the study was the only reason cited by patients who declined to enrol. Completed surveys were returned by 234 (83%) subjects, while 36 (13%) patients did not return the survey and 11 (4%) participants withdrew after signing consent. The response and completion rate did not vary appreciably between the study sites.

Measures

Demographics

Clinical (types of treatment received, time since the completion of treatment) and socio-demographic characteris-

tics (age, race, marital status, number of people in the home, education, employment status, income) were assessed by self-report.

Family avoidance

The Family Avoidance of Communication about Cancer (FACC) Scale was developed by the investigators (Table 1) and was based on the investigators' clinical experience working with women who have a history of breast cancer and their families. The items refer specifically to women's perceptions that they can openly discuss the cancer situation with their family members. The FACC Scale consists of five items that measure the patient's perception of the extent to which her family avoids talking about the cancer experience. Each item was measured on a 5-point Likert scale (1 = Less avoidance, 5 = More avoidance), and the raw score was determined by calculating the mean for the five items. The raw FACC Scale scores were then transformed to range from 0 to 100, with higher scores reflecting higher levels of avoidance. Factor analysis indicated the presence of a single construct. The scale demonstrates excellent internal consistency (Cronbach's $\alpha = 0.92$).

Mental health

Mental health was assessed using the mental health subscale of the Medical Outcomes Study Short Form 36 (SF-36) health survey (McHorney *et al.* 1994). The mental health subscale is a 5-item, 6-point Likert scale that measures four mental health dimensions: anxiety, depression, loss of emotional control and psychological well-being over the past 4 weeks (Ware, Jr & Sherbourne 1992). The mental health score is transformed to a scale with a range of 0–100, with higher scores reflecting better mental health (Ware *et al.* 1993). The SF-36 has been validated in numerous patient populations and has been used successfully with breast cancer patients (Grunfeld *et al.* 1996;

Table 1. Family Avoidance of Communication about Cancer (FACC) Scale

The following questions are about your family. Please indicate how often each of the following is true.

- 1 Family members discourage me from talking about the cancer.
- 2 In my family, the motto about cancer is 'don't ask, don't tell'.
- 3 If I start talking about cancer, family members change the subject.
- 4 Almost no one in my family will talk with me about the cancer.
- 5 Family members get upset with me if I talk about cancer.

Lindley *et al.* 1998; Ashing-Giwa *et al.* 1999; Broeckel *et al.* 2000; Hanson *et al.* 2000; Helgeson *et al.* 2000; Northouse *et al.* 2002).

Statistical analysis

Univariate statistics were generated for all of the variables in the dataset. Non-parametric tests were used for bivariate analyses because data were non-normally distributed and many variables were non-continuous. Spearman's correlation coefficients were used to examine the relationship between mental health and the primary outcome measure (family avoidance), as well as continuous covariates (age, number of people in the home, time since completion of treatment). The Wilcoxon rank sum test was used to test for differences in mental health based on nominal and categorical covariates, including race, marital status, education, employment status and income.

Our research question was addressed using a generalized linear model predicting mental health based on family avoidance and adjusting for age, marital status (married vs. not), number of people in the home, education (bachelor's degree vs. not), employment status (working outside home vs. not) and length of time since the end of treatment. Patient race and income variables were excluded from the multivariate models because of the skewed distribution (race) or frequency of missing data (income). Missing values were estimated for use in multivariate modelling, using the mean value for continuous data or the mode value for categorical data. Analyses were conducted using SAS version 8.02 (SAS Institute, Cary, NC, USA).

RESULTS

Subject characteristics

Table 2 describes the characteristics of the 230 eligible participants. The average age of the women in the sample was 57 years (mean age = 57.6 years, standard deviation = 11.0). The majority of women in the sample were Caucasian, married, lived with one other person and had at least some college education. Approximately half of the participants were employed outside the home. Twelve per cent of the participants did not report their income level. The available responses suggest that most of the income clusters at the lowest and highest income levels; at least one-fifth of the sample had an annual household income of less than \$30 000, and another fifth had an annual household income of greater than \$100 000. The range in time since completion of treatment was wide, but most had completed treatment within 3 years prior to enrolment. Eighty

Table 2. Characteristics of the sample

Variable	<i>n</i> (%)
Age (year)	
<50	55 (24)
50–59	76 (33)
60–69	68 (30)
≥70	31 (13)
Race	
Asian	3 (1)
African American	15 (7)
White	209 (91)
Not reported	3 (1)
Marital status	
Married/living with partner	168 (73)
Single/divorced/widowed	62 (27)
Number of people in home	
Lives alone	48 (21)
One other person in home	109 (47)
More than other person in home	73 (32)
Employment status	
Working outside home	123 (53)
Not working outside home	105 (46)
Not reported	2 (1)
Education	
Less than high school	7 (3)
High school degree	57 (25)
Some college	57 (25)
College degree	47 (20)
Graduate degree	60 (26)
Not reported	2 (1)
Income	
<\$30 000	46 (20)
\$30 000–\$59 999	52 (23)
\$60 000–\$89 999	47 (20)
>\$90 000	57 (25)
Not reported	28 (12)
Time since completion of treatment	
1 year or less	39 (17)
2 years or less	59 (26)
3 years or less	38 (17)
4 years or less	30 (13)
5 years or less	20 (9)
More than 5 years	28 (12)
Unknown	16 (7)
Treatment received	
Surgery	228 (99)
Radiation therapy	183 (80)
Chemotherapy	153 (67)
Tamoxifen	170 (74)
Total sample size	230 (100)

per cent of the participants received radiation therapy, 67% had received chemotherapy, 53% had both chemotherapy and radiation and 74% had been prescribed tamoxifen.

Most respondents reported that their families actively communicated about the cancer situation, although the data were widely dispersed (mean = 13.2, SD = 23.4). Respondents in our sample reported high mental health (mean = 72.8, SD = 19.1). Univariate results are reported in Table 3.

Table 3. Univariate analysis of primary variables of interest

Variable	Minimum	Maximum	Mean	Standard deviation
Family avoidance	0.00	100.00	13.17	23.41
Mental health	8.00	100.00	72.75	19.16

Table 4. Regression modelling mental health

Variable	Beta	Standard error	<i>P</i> -value
Family avoidance	–0.28	0.05	<0.0001
Age	0.36	0.15	0.02
Married	–1.59	3.27	0.63
Number of people in home	0.46	1.41	0.74
College-educated	2.93	2.51	0.25
Working outside home	3.24	2.93	0.27
Months since end of treatment	0.05	0.04	0.25

Bivariate analysis

Family avoidance and mental health were moderately negatively correlated ($r = -0.29$, $P < 0.0001$). There was also a weak association between mental health and both age ($r = 0.17$, $P = 0.01$) and number of people in the home ($r = -0.13$, $P = 0.05$). No association was demonstrated between mental health and time since the end of treatment. Wilcoxon rank sum tests similarly failed to show any difference in mental health scores based on marital status, education or employment status (data not shown).

Multivariate analysis

The multivariate linear regression model was statistically significant (F -value = 5.70, $P < 0.0001$). As shown in Table 4, the model demonstrates a strong negative association between family avoidance and mental health ($P < 0.0001$). The parameter estimate for the family avoidance variable indicates that each 10-point increase on the 100-point FACC scale is associated with an approximately 3-point decrease in mental health score, independent of socio-demographic covariates. The only other statistically significant variable was age (beta = 0.36, $P = 0.02$).

To address the *post hoc* finding that the family avoidance variable was highly skewed towards non-avoidance, we dichotomized family avoidance to reflect 'no avoidance' ($n = 137$) and 'any avoidance' ($n = 91$). The findings from this *post hoc* analysis were consistent with the previously reported findings, and indicate that women who report any family avoidance have mental health scores that are approximately seven points lower than women who report no family avoidance.

DISCUSSION

Our findings suggest that in the family relationship, as has been previously demonstrated in the spousal relationship, communication is related to cancer survivors' psychological well-being. Further, our findings specifically suggest that avoiding discussion of the cancer experience is a family communication pattern that has negative consequences. Although the cross-sectional design of this study precludes us from inferring a causal relationship between family avoidance and mental health, it is likely that such a complex relationship is bidirectional. That is, regardless of whether family avoidance is a causal factor in poorer psychological adjustment, decreases in avoidant behaviours are likely to have some effect on survivors' mental health.

Although this study is unique in that we surveyed long-term breast cancer survivors about a very specific element of family communication (avoidance), our results are not surprising in light of work that has been conducted previously. In studies with cancer patients and cancer survivors, increased emotional support and more open communication have been associated with better psychological outcomes. Interestingly, the results of our multivariate analysis suggest that after controlling for family avoidance, time since the end of treatment is not associated with mental health. While one might expect psychological adjustment to be associated with length of time from the breast cancer diagnosis, family communication appears to be a stronger explanatory factor in the variations in current mental health status.

One could argue that we have made the assumption that family avoidance is at the negative end of a family communication spectrum, implying that open communication is a positive alternative to avoidance. Confounding this issue, the literature suggests that open family communication may be detrimental, particularly if the family responds negatively to the patient's disclosures (Lepore *et al.* 1996; Cordova *et al.* 2001). It appears that open communication works best in the context of positive communication skills such as validation of and empathy for the cancer patient's experience (Burleson 1994; Burleson & Goldsmith 1998; Burleson 2003). Thus, in future studies, it will be helpful to capture both the amount and the quality of family communication, in order to further clarify these issues.

Several methodological limitations of this work must be noted. First, our instruments measured perceived family avoidance, which may or may not correlate with actual family avoidance. Thus, we must be careful to interpret our results as indicating the associations with

perceived, and not actual, family avoidance. It may be of interest to investigators in the future to measure both patient and family perceptions of avoidance, in order to determine the optimal focus for interventions. For example, if both the patient and family members perceive high avoidance, interventions to facilitate open communication may be useful. On the other hand, if only the patient perceives high avoidance, then interventions to help the patient evaluate his or her expectations may be more appropriate. Along the same lines, we asked about only a very limited spectrum of avoidant behaviours, specifically, verbal communication about the cancer experience. Additional work is needed to clarify the effects of other types of avoidant behaviours, including avoidance of emotional expression. Consideration should also be given to patient perceptions of the *reasons* behind family members' avoidant behaviours, as these assumptions may affect or be related to the quality of family relationships.

The second methodological limitation of this study is that we did not define the term 'family' in our questionnaire. As such, patients may have interpreted this term differently, and may have responded based on different interpretations of what constitutes 'family'. On one hand, this may provide us with a unique perspective, as patients responded based on their interactions with persons they considered to be family. As some important relationships are likely to exist outside of the framework of the immediate – or nuclear – family, allowing patients to define 'family' allows us to comment on the more general effects of avoidant communication. On the other hand, it is difficult to compare patients' experiences with their families when a consistent definition is lacking. It is also difficult to compare across studies in the absence of a specific definition. Therefore, it would be useful for future studies to provide a clear definition of the term 'family' so as to allow determination of the unique effects of different types of relationships on patient well-being. Another important question to answer in future work will be whether avoidant communication has a more or less significant impact on patient well-being depending on which family member is involved. This may require that investigators query about each relationship separately.

A third limitation of this study is that we did not collect information about stage of disease, which may be related both to the family communication behaviours and to mental health. Finally, our sample, while representative of the population from which it was drawn, is fairly homogeneous, and generalizations to other populations may not be valid.

Implications

Findings from our study have several implications for clinical practice. We have identified a subgroup of women with a history of breast cancer who perceive greater family avoidance and who are also more likely to experience mental health disturbance. By becoming aware that such a problem exists, healthcare professionals may become more vigilant in screening for negative family communication styles. Healthcare providers may be able to counter these family behaviours through informal family counselling, or may find it useful to refer families who are having difficulties to a specialist who is more experienced in family therapy techniques. In addition, by asking breast cancer patients and survivors about their perceived level of family support, healthcare providers may also be able to identify women who want to talk about their cancer experience and who will benefit from other resources, such as support groups or community support organizations, that are external to the family.

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