The strengths and resources used by families of young women with breast cancer

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Abstract

Background The family provides the main support network when a young woman is diagnosed with breast cancer, yet few studies investigate the experience of family support. This research examined the strengths and resources used by families of young women (under 50 years of age) with breast cancer.

Method Using the Resiliency Model of Family Stress, a quantitative analysis of family strengths and resources was undertaken using a composite survey. The sample consisted of 111 participants: 64 family members and 47 women with breast cancer recruited from five oncology units in hospitals in Queensland.

Results Family members and the women displayed similar strengths and resources. Family strengths were closely associated with the family use of resources. Influencing factors were communication and family commitment and the age of family members.

Conclusion Family strengths influenced the family's use of resources. The family's use of external resources was altered by family communication styles and how the family worked together.

Keywords: breast cancer, psychosocial, family, nursing.

Introduction

The diagnosis of breast cancer is both unexpected and distressing for a young woman, and many rely on their family for support[1,2]. The support role of the family is increasingly acknowledged in the published literature, although little research has explored the depth and range of family members' responses to understand this role from their perspective. Family theorists argue that the major influence of family support is in providing a protective buffer for the woman as she copes with side effects from treatment[3,4]. However, in providing this supportive role, family members themselves can be left with unmet needs and distress[5-7]. The adjustment process for the family has numerous challenges as they experience positive and negative responses during changes in treatment and disease progression[8,9]. Some families are better able than others to work together to overcome each hurdle along the way[3,4]. This poses a question as to what enables some families to survive and do well in the supportive role, while others find the experience a major struggle. To address this gap in knowledge, the current research investigated the strengths and resources of the family in response to adversity such as a diagnosis of breast cancer that can provide insight into how the family works and the dynamics of family support. This information has the potential to provide direction for guiding families of breast cancer patients.

Background

Breast cancer is the most common cancer diagnosis worldwide, with one in eight women diagnosed under the age of 75 years[10]. About one-quarter of all breast cancer diagnoses are in young women under 50 years of age[11]. The treatment schedule tends to be aggressive and includes surgery, chemotherapy, radiotherapy and hormonal therapy[12,13]. Researchers have established that women under 50 years are particularly vulnerable to psychological and physical effects of treatment[8,14]. Families, which includes a spouse or partner, parents, siblings and/or, in the case of younger women, primary school-aged or teenage children[11,15] play an important role in helping women through the treatment trajectory and beyond. The types of family psychological and physical support for a woman with breast cancer has been identified as household assistance, pain and side effect management, and emotional support[16,17]. Because of the impact of treatment, breast cancer also influences the woman's support network, often creating physical and psychological stress, which leaves family members and supporting friends needing support and direction themselves[13,18]. Assessing the processes of family support and the strengths that families bring to this task is crucial to ensuring that both the family and patient needs are adequately addressed and supported[7].

Having a family member diagnosed with cancer creates adversity for the entire family, especially when it is a young family member. Family scholars have identified characteristics of families which enable them to move forward in the face of adversity; collectively these are called family strengths[4,19,20]. Family strengths are characteristics such as displaying a commitment to family, open and positive family communication, positive appraisal of the adversity, and cohesive family functioning[19,21]. Families who are able to work together are likely to build strength within the family and find solutions to problems through their commitment[21]. In fact, family commitment brings a sense of not being alone when facing adversity and is a significant element

of family strengths[21]. Family commitment tends to be associated with styles of communication between family members; the sharing of distress and personal concerns. Previous research has found that information sharing is one of the influencing factors in helping alleviate an individual's distress within a family[22,23].

Appraisal of the breast cancer is a fundamental influence on family communication and reaction to the breast cancer. When family members can see a positive aspect of the breast cancer, they are more likely to work together to overcome the adversity[24]. Northouse and colleagues' significant research from 2001 to 2012 has found that family appraisal influences the overall family functioning and the ability of the family to work out solutions[3,7,25,26]. Appraisal sets the stage for the type of resources families use to provide support and their capacity to access assistance and manage the situation[27]. The availability and timing of resources has also been found to influence overall family adaptation[7,28], as is the way families manage resources[29]. According to McCubbin[19] and Walsh[20], resources can be grouped into three main areas, including social support, spiritual support and health professional support. Social support has been defined as support provided by the immediate family members and those considered within the close family circle[20,30]. Spiritual support relates to the individual's use of an external medium such as religious affiliations, personal meditation or other ways of finding meaning in life, all of which help her reappraise the adversity positively[31-33]. Research suggests that health professional support includes internet information, community groups, counsellors, nurses and doctors[34]. Although there are various ways of examining how family members cope in the supportive role, the conceptual framework outlined below provides a guide to measuring support from the perspective of the family as a 'unit'.

Conceptual framework

Using a family stress and coping framework provides a way to explore the family as a group of interacting individuals rather than as a group of independent family members. The Resiliency Model of Family Stress, Adjustment and Adaptation[28] offers a model for exploration of the family response to adversity with scales for measuring this response as a collective family response. Key aspects of this framework include family functioning (roles), communication, coping strategies and adjustment. The Resiliency Model of Family Stress recognises that the family response is influenced by factors such as extended family, culture and community. This suggests that for family researchers focusing on the family, data should be collected from multiple family members to provide a comprehensive perspective of how women and their families use strengths and resources at this significant time in their lives.

The majority of research exploring the family response to cancer has used individuals with cancer or a dyad approach using couples[35,36]. Using a dyad approach is helpful to some extent but it does not reflect the complex nature of family[37,38]. Several studies noted the dyad approach to be a limitation due to the narrow focus of the data[25,39]. The current study addressed this lack of depth and breadth by using Resiliency Model of Family Stress as a family framework to capture the perspectives of multiple family members on family strengths and resources. Three research questions were explored:

1. What are the strengths and resources the young women and their family members use during treatment for breast cancer?
2. What are the family attributes that influence strengths and resources used by the women and their family members during treatment for breast cancer?
3. Is there a change in the strengths and resources used by the young women and their family members during active and maintenance treatment?

Method

This study used a two-phase mixed-method approach to examine the types and levels of strengths and resources used by families of young women with breast cancer. Qualitative data on family members' perspectives of strengths and support were collected using personal interviews and reported in a previous article[16]. Quantitative data was collected in two phases to measure the types and levels of strengths and resources used by the families over the course of treatment: Phase 1 during active treatment, seeing the oncologist at least every three months and Phase 2 after active treatment, seeing the oncologist at intervals greater than three months.

Sample

In Phase 1 women with breast cancer under the age of 50 years were recruited from five ambulatory oncology units in Australia: four metropolitan and one regional hospital. The study received ethical approval from all participating hospitals and the University Research Ethics Committee. All data are stored according to guidelines by the National Health and Medical Research Council[40]. Information leaflets were displayed with an invitation for interested women to contact the researcher by telephone. Those who responded were given a verbal explanation of the study and its ethical implications. An information sheet, consent form and questionnaire were then mailed to individual participants, including family members, with individual reply-paid envelopes to provide consent, which was obtained from all participants. Confidentiality and anonymity was assured, with questionnaires containing no identifiable information. Phase 2 of the research was undertaken after the participating women with breast cancer had completed Phase 1 questionnaire and were seeing an oncologist at intervals greater than three months. A single telephone call from the researcher was made to each woman with breast cancer completing Phase 1 prior to the sending of Phase 2 questionnaires to the women and their family members. This study had a dropout rate of 40% of participants between Phase 1 and Phase 2. This level of

dropout rate has been noted in previous research due to the psychological distress from revisiting the stressful event[41,42].

Inclusion criteria for the young women was a confirmed diagnosis of breast cancer within the first year, aged under 50 years, currently undergoing a regimen of active treatment for breast cancer, seeing an oncologist at least every three months and being supported by family members. Family was defined as a group of individuals bound by strong emotional ties, a sense of belonging, and a commitment to being involved in one another's lives, calling themselves 'family'[4,43]. The women with breast cancer were invited to nominate up to four family members over the age of 18 years to be involved in the study.

The final sample in Phase 1 who completed the composite questionnaire included 111 participants: 47 women with breast cancer and 64 family members. This included 36 families from within the 111 participants. A participation rate of 66% of women with breast cancer and 49% of recruited family members was achieved with one follow-up telephone call by the researcher. The Phase 2 sample consisted of 67 participants from Phase 1 who completed the questionnaire a second time; 28 women with breast cancer and 39 family members.

Measures

Demographic data were collected on all participants including age, gender, family status, education level, occupation, treatment variations, ethnicity and postcode for geographic categorisation.

Family strengths were measured by the Family Hardiness Index (FHI), which was developed to measure the internal strengths and durability of the family unit and has been validated by several researchers[25,44-47]. The FHI is a 20-item instrument consisting of three interrelated subscales addressing family functioning, namely commitment, challenge and control. The FHI prompts respondents to rate their response to particular situations using a four-point Likert scale to indicate the degree to which each statement describes the family strengths. The scores are summed to generate the FHI; a higher score identifies increased levels of family functioning. Reported internal consistency reliability of the instrument is .82[47]. For this study the Cronbach's alpha coefficient was 0.81.

Family resources were measured by the Family Crisis Orientated Personal Evaluation Scales (F-COPES), which measures the problem solving and behavioural strategies families use to assist them through a stressful situation. The scale has been validated by several researchers[48]. The F-COPES scale includes 30 coping behaviour items focusing on how the family deals with internal and external problems. The items are rated on a five-point Likert scale indicating the extent to which they agreed or disagreed with the item. There are five subscales for the F-COPES: including social support, reframing, spiritual support, mobilising community support and passive appraisal. The scores are summed to provide subgroup scores and an overall coping score. Higher total F-COPES scores represent an increase in the number of coping strategies used and may lead to more successful adaptation. Reported internal consistency reliability of the instrument is .87[48]. For this study the Cronbach's alpha coefficient was 0.84.

The Walsh scale[20] is a non-validated scale with 33 questions rated on a four-point Likert scale, which provides an indication of how a family works together to maintain the family functioning. The Walsh scale has five subscales, namely challenge, spiritual support, family flexibility, resources and communication. These subscales all reflect the Walsh[20] conceptual framework. A factor analysis was performed on the Walsh scale which supported the original grouping of items. Additional investigation is warranted for future use of this scale. For this study the Cronbach's alpha coefficient was 0.95.

Data analysis

A non-parametric analysis was completed which included descriptive statistics to profile sample characteristics, strengths and resources used by the family. The Mann-Whitney U Test was used to assess differences related to family attributes. A nonparametric equivalent one-way ANOVA, the Kruskal-Wallis Test, was used to assess the relationship between family attributes and the subscales of strengths and resources. Family attributes of interest included age groups, treatment combinations, phase of life, education levels, occupation groups, and post codes. The Wilcoxon Signed Rank Test was used to assess group differences in terms of the subscales of strengths and resources in Phase 1 and Phase 2 of the study. A case summary analysis provided family group information on the 36 families in the study. Level of significance was set at $P < 0.05$.

Results

The response rate included 47 women with breast cancer having surgery, chemotherapy and radiotherapy, and 64 family members (Table 1). The family members included male and female partners, parents, children and extended family and friends of the women with breast cancer. Participating women with breast cancer identified type of treatment completed in three categories.

The preliminary analysis of the women with breast cancer and family members using Mann-Whitney U Test identified no statistical different between the scores of the women with breast cancer and the family members in the main scales (FHI $Z = -2.17$ $p < .030$) (F-COPES $Z = -.480$ $p < .63$) (Walsh $Z = -.94$ $p < .925$). Because of the similarity the family members and women with breast cancer were combined for the analysis, a technique successfully used in previous research[25,45,46]. Only one subscale showed a statistical significance, which was sense of control within the FHI scale ($Z = -3.96$ $p < .001$). This subscale investigates the way in which the participants feel they are in control of the situation, which can generally be due to treatment schedules.

Table 1: Demographics of women with breast cancer and family members

Characteristic	Phase 1 n=111 (%)	Phase 2 n=67 (%)
Age of women with breast cancer (WWBC) P1 (n=47) P2 (n=28)	29–50 mean 43	29–50 mean 44
WWBC without children	18 (38)	8 (29)
WWBC with children	29 (62)	20 (71)
Breast cancer details		
Surgery/chemotherapy/radiotherapy	26 (55)	16 (57)
Surgery/chemotherapy	9 (20)	3 (3)
Surgery/radiotherapy	5 (11)	5 (18)
Chemo/radiotherapy	2 (4)	1 (4)
Surgery only	3 (6)	2 (7)
Chemotherapy only	2 (4)	1 (4)
Total WWBC	**47**	**28**
Family members n=64		
Male family members P1 n=25 39%	18–79 mean 43 SD 14	
Female family members P1 n=39 60%	18–83 mean 49 SD 18	
Total sample		
Education level		
Secondary school	60 (54)	35 (52)
Diploma	27 (24)	16 (24)
Degree	15 (14)	10 (15)
Postgraduate	9 (8)	6 (9)
Occupation level		
Professional	42 (38)	29 (43)
Trade person	27 (24)	14 (21)
Home duties	42 (38)	24 (36)

To explore the strengths of the family the composite of subscales used were FHI Commitment, Challenge and Control (FHI); F-COPES Reframing and Walsh Challenge, Family flexibility and Communications (Walsh). From these subscales the analysis revealed that participants reported a strong commitment to the family (M = 20/24 SD = 3.2) and communication within the family (M = 24/30 SD = 5). The strengths of challenge, control, reframing and flexibility showed lower means highlighting these aspects as lesser family strengths (Challenge M = 12/18 SD = 2.9) (Control M = 13/18 SD = 7).

To explore the resources used by the family the composite subscales of F-COPES subscales (social support, spiritual support, mobilising, passive appraisal) and Walsh subscales (spiritual support, family) were analysed. The resources used were family and friends (social support M = 21/36 SD = 7) (family M = 6/9 SD = 2), health professionals (mobilising M = 10/16 SD = 3) and spiritual support (spiritual M = 5/16 SD = 5). The use of spiritual support scored low in the quantitative data although this was not reflected in the qualitative data.

The analysis highlighted the overall levels of strengths and resources. Families who reported a lower level of strengths and resources were highlighted to be at risk of maladaptation and coping problems (n = 8 FHI < 30/60) (n = 19 F-COPES < 60/116). Conversely, families with high levels of strengths and resources could be identified as having good skills in communication and positive appraisal and ability to direct resources for support. When the scores were examined across the trajectory of treatment Phase 1 to Phase 2 there was no statistically significant change in scores, although a slight increase was noted. See Table 2 for presentation of mean scores for three scales across the two phases.

Table 2: Presentation of scores for family strength and resources

Descriptive statistics for the measures of Family Hardiness Index (FHI) Family Crisis Orientated Personal Evaluation Scales (F-COPES) Walsh Scores Phase 1 and Phase 2

	Phase 1 n=108	SD	Phase 2 n=67	SD	Range
FHI	44	7.06	46	6.82	20–59
F-COPES	72	13.38	74	11.93	39–111
Walsh	74	14.12	76	11.23	24–99

The Spearman's Rank Order Correlation was used to investigate the relationship between strengths and resources. This analysis revealed significant positive correlations. Positive correlations were found between the FHI commitment and FHI challenge ($r = .44$, $n = 108$, $p < .001$); FHI commitment and F-COPES reframing ($r = .51$, $n = 107$, $p < .001$); FHI challenge and F-COPES social support ($r = .46$, $n = 108$, $p < .001$). These positive correlations indicated that the higher commitment within the family the more the participants reported seeing the breast cancer as a positive challenge, sought support from external family and were able to reframe the adversity into something positive.

The subscales within the F-COPES scale were also found to be positively correlated with the Walsh scale; particularly F-COPES social support and Walsh family flexibility ($r = .51$, $n = 108$, $p < .001$), Walsh resources ($r = .62$, $n = 108$, $p < .001$) and Walsh communications ($r = .55$, $n = 108$, $p < .001$). The results indicated that families who were able to communicate concerns were, in turn, more likely to use social support and external health professional support. These are significant findings, indicating a connection between the family appraisal of the breast cancer, communication between the family and the ability of the family to be flexible and seek support (Table 3).

Family attributes were analysed using the Kruskal-Wallis Test to explore the relationship between variables with one or more groups and the continuous variables from the three scales FHI, F-COPES and Walsh. The age of the family members was the main influencing factor for the family's use of strengths and resources as seen by the correlations with age across the three

scales FHI (x^2 (4) 21.0, p < .001), F-COPES (x^2 (4) 15.5, p < .004), Walsh (x^2 (4) 12.7, p < .01). Treatment schedules, stage of life (with children, no children), education and occupation were found to have an influence on use of strengths and resources, although these associations were not strongly significant.

Discussion

This study investigated the strengths and resources family members and the young women use to cope with breast cancer. The combined family sample proved to be a unique way to explore the family experience, reinforcing the usefulness of combining McCubbin's and Walsh's frameworks. Overall, the study found that the women with breast cancer and their family members used similar strengths and resources as they responded to the breast cancer diagnosis. This result highlighted the cohesive nature of families when faced with adversity. Overall, these families do endeavour to work together and maintain family functioning, although some families struggled and displayed high levels of stress and maladjustment.

This research found that the level of strengths and resources used by the family did not increase significantly in the first year between Phase 1 and Phase 2, highlighting the difficulty of coping with breast cancer over a longer period of time. This finding concurs with other longitudinal research exploring women with breast cancer, which found that the first year's response and support influenced the woman's long-term adjustment[35]. The fact that the first year is influential in the long-term adjustment for the patient highlights the need for appropriate assessment and guidance for the woman and her family within the first year of her breast cancer diagnosis[49,50].

McCubbin *et al.*[28] hypothesised that in response to adversity the family will draw on their strengths to assist them maintain family functioning. The current study supports this hypothesis with the suggestion that the family aims to reach a new normal. Key strengths the family reported were a commitment to working together when faced with a breast cancer diagnosis. The family commitment was closely influenced by the family appraisal of the breast cancer. If family members were able to see some positive aspects from the breast cancer, they were more likely to use resources such as health professionals and cope as a family. The influence of appraisal of a health adversity was explored by Sears *et al.*[33], whose findings indicated that if the individual is able to identify the adversity as a positive challenge they are more likely to be able to work out how to deal with the challenges. Implications for health professionals are that they are in a position to provide guidance to the family members, as the family works through their feelings about the breast cancer. Health professionals need to assist the family to understand their appraisal of the experience to improve long-term adjustment for the women and their families.

Communication levels between family members were found to significantly influence the family strengths and use of resources in both Phase 1 and Phase 2. Types of communication ranged from open sharing to a closed response. Sharing feelings between family members was identified as a problem at times by lower scores on the communication subgroup items. This was probably an attempt to reduce the stress for the woman with breast cancer. Evidence suggests that an open style of communication where feelings are disclosed and discussed as a family will benefit the overall functioning of the family[23,51]. In times of stress, communication between family members was reported as difficult; this is similar to Forrest *et al.*[23]. The communication between family members was one of the main factors influencing a family's ability to identify concerns and work through them. Support from the health professional in providing safe avenues for the family members to express concerns is an important step to being able to guide the family through challenges of breast cancer treatment.

This study found that the age of the participants and the age of the family members influenced the strengths and use of resources. Families who had younger aged members reported lower levels of strengths. This finding was related to the other stresses that these families were dealing with. These results are consistent with previous research, which has explored only the women's response[1,35]. Bloom *et al.*[35] contend that the younger the woman with breast cancer, the higher levels of distress she displays due to conflicting life stresses.

Another finding was that if the family was able to see the breast cancer as something they could deal with they were more likely to access external support. External support obtained was health professional support, including counsellors, oncology nurses

Table 3: Presentation of significant correlations between the subscales of strengths and resources

	F-COPES reframing	Walsh communications	Walsh challenge	Walsh flexibility	Walsh family resources
FHI commitment	.514P	.562P	.690P	.587P	.356P
F-COPES reframing		.548P	.647P	.514P	.269P
Walsh communication			**.772P**	**.733P**	.443P
Walsh challenge				**.822P**	.423P
Walsh family flexibility					.479P

P < .001 n=108

and internet information. Conversely, families who had trouble identifying positives from the breast cancer reported less use of external health professional support. This association highlights the need for health professionals to identify families with low family strengths and poor appraisal of the breast cancer so they can be provided with guidance to access appropriate information and support.

The family framework and data from a range of family participants ensured this study makes a significant contribution to the current knowledge of the family trajectory through breast cancer. The data provided an understanding of the complex interaction within a family in response to adversity. A young woman with breast cancer travels her journey supported and sharing with her family and nurses need to continue to gain information about how her family is functioning in order to assist her longer term adjustment. The use of a family assessment tool provides the health professional with information about the family members' strengths and resources and would benefit the longer term adjustment of the women with breast cancer.

Conclusion

This study has highlighted several important aspects of family strengths and resources as families cope with the treatment for breast cancer. Commitment to work together as a family is one of the strengths of the young women's supporting family and it is important to engage the family in discussion around support needs. The family's appraisal of the breast cancer and styles of communication influenced the family's overall responses. Communication specifically influenced the sharing of concerns and acquiring appropriate external support to maintain family functioning. Provision of family guidance regarding communication with family members and their children could therefore help to improve family functioning.

Limitations

Despite the evidence provided by this study, several limitations need to be acknowledged. The collection of basic treatment information from the patients was noted as a problem as it reduced the ability of the study to identify the influences of treatment. The study had a range of family members; however, the collection of data from more family groups would improve the depth of family data. The conceptual and theoretical focus of this study was on the family unit; limitations of the analysis of family data must be noted. The analysis of the data as groups rather than individuals provided a perspective of the family; however, due to the small family numbers it was difficult to demonstrate individual differences between family groups. The sample was mainly collected from participants living in metropolitan areas; a range of rural and remote families would provide information from this more diverse setting. These aspects would strengthen the information around the family experience of breast cancer.

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