



The Strengths and Resources Young Women and their Family Members use during Treatment for Breast Cancer

Author

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Published

2012

Thesis Type

Thesis (PhD Doctorate)

School

School of Nursing and Midwifery

DOI

[10.25904/1912/3621](https://doi.org/10.25904/1912/3621)

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The Strengths and Resources Young Women and their Family Members use during Treatment for Breast Cancer

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Submitted in fulfilment of the requirements of the degree of
Doctor of Philosophy

October 2011

Abstract

Breast cancer is the leading cancer in women worldwide; one in eight will be diagnosed before the age of 75 years. Of those diagnosed 25% are under the age of 50 years and likely to be premenopausal and have family responsibilities (Coyne & Borbasi, 2006; Sammarco, 2001). Although all women regardless of age experience difficulties, younger women face significant difficulties after their diagnosis related to their phase of life (Bloom, Stewart, Chang, & Banks, 2004). The diagnosis and treatment of breast cancer is a time of intense physical and emotional disturbance. The women rarely go through this alone. They are supported by their family members who are distressed and lost in the situation. During this time families experience a range of responses including changes to communication, role and sense of control as they respond to the diagnosis and treatment for breast cancer. While family is the mainstay of support for young women with breast cancer there is little research that has addressed the family response to breast cancer. The aim of this research was to explore the strengths and resources young women and their family members use during treatment for breast cancer. The use of a family framework allowed the unique nature of the family response to breast cancer to be explored.

A two phase mixed method approach informed by the *Resiliency Model of Family Stress, Adjustment and Adaptation* (McCubbin & McCubbin, 1993) was used, to investigate the strengths and resources used by the family in response to breast cancer treatment. A total of 111 participants, women with breast cancer and their family members completed the composite questionnaire. A non-parametric analysis of the quantitative data included descriptive statistics, correlations between variables and changes over time. Personal interviews with 14 women with breast cancer and nine family members added richness to the research data. A family case study analysis of the 36 families provided information on the family as a group's response to breast cancer treatment.

This study provides important insights and understanding of the family experience of breast cancer. Family communication and appraisal of the breast cancer were found to be the foundation to the family ability to remain supportive of each other. Families attempt to maintain cohesion and functioning during treatment for breast cancer. However the family's

ability to do so is influenced by the resources they draw on and the ability of the family members to communicate their needs. The age of family members and socioeconomic factors such as education and occupation impacted on the family's response to breast cancer. The key findings were that the family's strengths and resources are influenced by communication within the family, the family appraisal of the breast cancer and the family functioning.

The research findings provide important insights that can inform theory and practice in future care of young women with breast cancer and their families. The need for family assessment when young women are diagnosed with breast cancer is clear. The assessment needs to include family roles, communication, resources and usual strategies when confronted by adversity. The inclusion of family members in health care and the provision of support for the family will in turn improve the support for the woman. The whole family will benefit from a family focus to nursing the young women with breast cancer. This study extends the current knowledge of the family response to adversity and contributes to theory with the development of the Coyne Family Response Framework. This study adds to the growing body of family research, providing an insight into the Australian family's experience of supporting a young woman during treatment for breast cancer.

Key words

Nursing, breast cancer, young women, family, family strengths, family resources, adjustment

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Statement of originality

The work contained in this thesis has not been previously submitted for a degree or diploma at any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signed

Date

Acknowledgments

There are a number of individuals and groups I would like to acknowledge. These include:

- I would like to thank my participants who gave freely of their time, allowing me to share their experience of breast cancer.
- Importantly undertaking this project has helped me understand the research process a little better. I would like to thank Professor Judy Wollin and Professor Don Stewart for their support and guidance.
- I would also like to thank Professor Anne McMurray for her mentorship during my PhD.
- The Centaur Fellowship, Royal College of Nursing Australia and the Cancer Nurses Association Australia for their financial support.
- My husband Michael and children Nathan, Brendan, Justin and Melissa for their understanding, patience and love, who have supported me enormously through this study.
- My parents who have been a great encouragement.
- My work colleagues at Griffith University Logan for their support and encouragement.
- My friends who helped me through this time and gave me support and encouragement when I needed it.

Publication and Conference Papers

Publications

Coyne, E., Wollin, J., & Creedy, D. (2012). Exploration of the family's role and strengths after a young woman is diagnosed with breast cancer: Views of the women and their families. *European Journal of Oncology Nursing* 16(2), 124-130. doi: 10.1016/j.ejon.2011.04.013

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Coyne, E., & Dean, J. (2010). The challenges of a multi-site ethics application: the novice researcher's perspective. *Connections*, 13(4).

Submitted

Coyne, E., & Wollin, J. (2011). Review of adult family research: an examination of theoretical frameworks and methods. *Journal of Family Nursing*.

Conference presentations

Coyne E, Wollin, J (June 2011). Family research, providing a view into family interaction from different family members. 10th International Family Nursing Conference Japan

Coyne E, Wollin, J (June 2011). Rethinking care paradigms in Australia, challenges for oncology staff in supporting the family. 10th International Family Nursing Conference Japan

Coyne E, Wollin, J Stewart D (2010). Family assessment; is it the way of future care for oncology patients and their family? 13th CNSA National Conference Perth

Coyne E, Wollin, J (2010). Exploring the concerns for young women with breast cancer; highlighting the influences on the children in the family. 12th Oncology Nurses Group Annual Conference Brisbane

Coyne E, Wollin, J Stewart D (2009). Sharing the future; how the family and the young women (<50) adjust to breast cancer. 12th CNSA National Conference

Coyne E, Wollin, J Stewart D (2009). Caring for the family: The health professional's role when a young woman has breast cancer 12th CNSA National Conference

Coyne E, Wollin, J (2009). What happens to the family when a young (<50) woman is diagnosed with breast cancer? 9th International Family Nursing Conference Iceland

Coyne E, Wollin, J (2009). Looking inside family group dynamics, when a young woman is diagnosed with breast cancer 11th Oncology Nurses Group Annual Conference Brisbane

Coyne E, Wollin, J Stewart D (2009). Mum I have breast cancer Reach to Recovery International Conference Brisbane

Coyne E, Wollin, J (2008). Researching family in the context of health: challenges for the researcher RCCCPI Research Symposium Gold Coast

Coyne E, Wollin, J (2008). Family: the strength of support 15th International Conference Cancer Nursing Singapore

Coyne E, Wollin, J (2007). The personal side of treatment for young women with breast cancer 10th Cancer Nurses Society Australia Winter Congress

Coyne E, Wollin, J (2007). Family; their role in the support of young women with breast cancer 9th Oncology Nurses Group Annual Conference Brisbane

Coyne E, Wollin, J (2006). Changing Horizons: Breast cancer, young women and their families 16th International Council on Women's Health Issues Sydney

Poems

Learning to walk: The PhD Journey

By Elisabeth Coyne

Walking and looking, investigating and deciding
 I have chosen a path, I begin the journey.
 Mazes to follow, which way to go
 Forward and backward, as the paths open and close!

The first door is visible, but can I get through
 I begin to run, and hope the pathway is right.
 I pass through the first door, only to see many more
 I begin to wonder, why am I here?
 Colleagues encourage, I begin again.

The hurdles become clear, as I move into the next level,
 I gather confidence from those who have passed this way before.
 The excitement of the next level builds in my legs
 I break into a jog as I move through this level
 Enjoying the contact with those who my story is about!

Now I must open the next set of doors
 They are heavy with knowledge, which must be reclaimed?
 The writing begins can I keep up the pace,
 At times I feel like a rabbit, running between goal posts,
 Hoping not to be caught!

But this is my choice
 And my story needs writing
 So I push towards the knowledge laden doors
 And hope one day I can pass through!

Stone

**Poem by Viv
Participant 24
2009**

There's a stone in my breast,
 A stone in my chest,
 There's a stone in my heart,
 A stone in one part,
 And it's black and it's heavy and,
 It drags at my core and,
 It drags at my soul,
 And it drags me away from my sense of self,
 And it is a stone that can dull, deaden, and paralyze.

There's a stone in my midst,
 A stone in my fist,
 There's a stone in my trunk,
 A stone in one chunk,
 And it's dark and it's gloomy and,
 It drags at my thoughts and,
 It drags at my insides,
 And it drags me away from my feeling of self,
 And it is a stone that can stun, numb, and stupefy.

There's a stone in my meat,
 A stone in my heat,
 There's a stone in my joint,
 A stone in one point,
 And it's foul and it's sooty and,
 It drags at my blood and,
 It drags at my guts,
 And it drags me away from my spirit of self,
 And it is a stone that can erode, decay, and confound.

There's a stone in my hell,
 A stone in my shell,
 There's a stone in my pit,
 A stone in one bit,

And it's wicked and it's angry and,
 It drags at my mood and,
 It drags at my reason,
 And it drags me away from my essence of self,
 And it is a stone that can astonish, daze, and overwhelm.

There's a stone in my remains,
 A stone in my pains,
 There's a stone in my head,
 A stone in one shred,
 And it must get gone and it must pass by,
 And it must go now.

There's a stone in my tissue,
 A stone in my issue,
 There's a stone in my care,
 A stone in one share,
 And I wish it would leave,
 And I wish it would go.

Oh indifferent stone,
 Oh insensitive stone,
 Oh implacable stone,
 Oh inconsiderate stone,
 Oh intractable stone,
 Callous stone,
 Stone of cessation,
 It's time for you to go,
 It's time for you to leave.
 I won't carry you any more!



The Thesis

The Strengths and Resources Young Women and their Family Members use during Treatment for Breast Cancer

Elisabeth Coyne

1 Chapter 1 Introduction

1.1 Introduction

This chapter introduces the current study, presenting the main points of what is known about young women under the age of fifty years with a diagnosis of breast cancer. The aim of the study is to extend the understanding of young women and their families' response to breast cancer treatment, and to inform future practice. In this chapter the significance, aims and research questions are presented and the thesis structure outlined.

1.2 Background

The diagnosis and treatment of breast cancer in young women is a time of intense physical and emotional disruption yet in most cases these women don't go through this alone. They are closely supported by their family who also feel equally distressed and lost in the situation. The family's role in supporting the woman during the trajectory of breast cancer is increasingly acknowledged by research. However, the complexities of the role are not well understood. The current study explored the strengths and resources used by young women and their family members during treatment for breast cancer. The study's aim was to increase our understanding of the both the women's and the family's response during the treatment for breast cancer.

Breast cancer is the most common cancer diagnosis for women under 75 years of age, with approximately 2300 women diagnosed in Queensland each year (Australian Institute of Health and Welfare AIHW, 2010). Of these diagnoses, 25% are considered 'younger', which is understood to be less than 50 years old and premenopausal at the time of diagnosis (Dunn & Steginga, 2000; Smith, 2000). These women often have family responsibilities.

The consequences of a breast cancer diagnosis for the younger woman are well documented. Research has established a range of emotional, physical, social and spiritual difficulties (Bloom, et al., 2004; Steginga, Occhipinti, Wilson, & Dunn, 1998; Wilkes, White, & Beale, 2002). By comparison, less is known about the family's response, although it is well established that the family is the main source of support for a woman with breast cancer

during her treatment (Edwards & Clarke, 2004; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002; Northouse, 2005). Cancer is recognised as a major adverse event, and it has been argued that it is the family's strengths and resources that enhance a family's ability to maintain stability during this adversity (McCubbin & McCubbin, 1993; Walsh, 2006). There is however, little known about the nature of the strengths and resources the young family use during treatment for breast cancer.

Breast cancer treatment follows a distinct pattern. During the active treatment phase, the younger woman generally experiences, alone or in combination, chemotherapy (including cytotoxic and hormonal therapies), radiotherapy, and surgical interventions with severe side effects that may result in significant disruption to her activities of daily living and her emotional wellbeing (Dunn & Steginga, 2000). This phase is characterised by intense contact with health professionals. Once active treatment is complete, breast cancer patients often continue on maintenance therapy, which is less severe in side effects but nonetheless, has problems of its own that occur in a context of relatively little sustained contact with health professionals (National Breast Cancer Centre NBCC, 2003). During both phases, the woman may draw support from the people around her; commonly her family, but the nature of the support required is likely to be different for each phase. Northouse, Templin and Mood (2001) suggest that in particular, the woman and her partner have a significant effect on each other's adjustment in the first year following breast cancer diagnosis. It is therefore important to understand the strengths and resources that each member of the family contributes to the family unit as a whole during each of the distinct treatment phases. Examining the individual family members in this way may provide important insights about the family trajectory during this life event and provide health professionals with information necessary to understand how to support the family at this time.

Important family theorists in this field include McCubbin and McCubbin (1993), who suggest that family strengths and resources are a vital component in the family's ability to remain resilient in the face of adversity. Walsh (2002) built on the strengths and resources concepts, emphasising the importance of the family's ability to effectively reorganise and adjust for the long term survival of the family unit when they encounter an adverse event such as breast cancer. The current study will use the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin & McCubbin, 1993) and Family Resiliency Framework (Walsh, 2006). The study explored the strengths and resources of

young women and their family members while the young woman with breast cancer is undertaking treatment for breast cancer.

1.3 Significance of the study

This research is significant for the following reasons. The current study extends the knowledge of young women with breast cancer and builds a foundation for understanding the family response to breast cancer. The use of a family framework and family analysis provided valuable insights into family response as a group of interacting individuals, and extend the understanding of the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin & McCubbin, 1993) contributing to family theory. Using a method which identifies the strengths and resources of the family, the current study will be able to provide a strength's based approach to the provision of future care for young women and their family. Lastly the current study will contribute to the understanding of family patterns providing a contribution to practice.

The first area of significance for the current study is the extension of knowledge around young women's responses to breast cancer treatment particularly in the Australian context. A range of international research has provided an understanding of the younger women's response to breast cancer (Bloom, et al., 2004; Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Compas, Worsham, Epping-Jordan, Grant, Mireault, Howell et al., 1994; Mellon & Northouse, 2001). Less research exploring just young women's experience of breast cancer has been completed in Australia (Connell, Patterson, & Newman, 2006; Coyne & Borbasi, 2009; Dunn & Steginga, 2000), highlighting the need to understand this cohort of women in the Australian context. This is important because of the Australian health system which is different from international health systems. The Australian health system is predominantly a medical model of care (Halcomb, Davidson, Salamonson, Ollerton, & Griffiths, 2008). The breast cancer patient is usually provided initial treatment in the hospital setting and then care is provided in the outpatient setting without involvement by the medical practitioner. The Medicare model of funding encourages short duration consultations and does not fund follow-up care, which is provided through referrals to medical specialists or other health professionals (Halcomb, et al., 2008).

The Australian setting includes rural and metropolitan areas in which the patient is provided a very different health care experience (Martin-Mcdonald, Rogers-Clark, Hegney, McCarthy, & Pearce, 2003; Rogers-Clark, 2002). Exploring the role of the family during treatment within the Australian context is important to understand the role the family plays during treatment for breast cancer across a range of settings. This study provides valuable evidence related to the Australian context which can provide direction for future improvements in the practice and care of young women with breast cancer.

Most of the research exploring the woman's experience of breast cancer has been in the first year which is the key point of treatment and disease trajectory (Boykoff, Moieni, & Subramanian, 2009; Northouse, Templin, & Mood, 2001). Similarly the current study explores the response to breast cancer in the first year although using two points of time to identify changes over time. The emphasis of the current study is on understanding the response and strengths needed to assist the family during this time. Previous research has explored the diagnosis and early treatment period for a young woman with breast cancer, identifying that it is a life-changing event that influences her ability to continue her present role (Coyne & Borbasi, 2009; Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006). This role may be as mother or as a primary support person within the family (Bracke, Christiaens, & Wauterickx, 2008). Family structure and roles are likely to be changed to enable the woman to deal with the physical and emotional reaction, especially fatigue, during this period (Bloom, et al., 2004). One of the important differences with the woman is her role within the family and the close association between her stability and the family functioning (Bracke, et al., 2008; Brown, Fuemmeler, Anderson, Jamieson, Simonian, Hall et al., 2007; Deatrick, Brennan, & Cameron, 1998). Previous international research has identified that a range of relatively predictable changes occur within the family in response to adversity, despite there being diversity in family structure and roles (Northouse, Laten, & Reddy, 2007; Walsh, Manuel, & Avis, 2005). However, little is known about the effects of diverse family forms or particular experiences of young women in a range of family structures. The current study addressed these issues concerning young women and their family's response to breast cancer treatment in the Australian context.

The second area of significance for the current study is the exploration of the family in conjunction with the young women. Research maintains that the young woman is supported by her family yet few studies include family members as participants. There are the beginnings of research exploring the family response to cancer, mostly using dyads; however no research to date explores the family response in the context of the younger woman with breast cancer. This is an oversight in the research agenda. Yet research identifies that these young women have different concerns to the older women (Bloom, et al., 2004; Coyne & Borbasi, 2006; Dunn & Steginga, 2000). Several researchers have explored the woman and her partner's response to breast cancer with a range of participant ages, and a common theme reported from these researchers is the impact on the family when the woman is diagnosed with breast cancer (Bloom, et al., 2001; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Northouse, Templin, Mood, & Oberst, 1998). The current study explored the families' response while still gaining the young woman's perspective. This has provided an understanding of the young woman's experience in the context of family. The current study will provide an understanding of the family perspective of breast cancer treatment to develop and implement interventions and models of care which support and understand the family and the young woman's strengths and available resources.

The third area of significance for the current study is the use of a family framework and multiple family members to enable the exploration of the family as a whole. The use of a family framework provided guidance for the researcher to focus on the family as a group of interacting individuals. Contributing family features and patterns can be identified during the research process thus increasing the knowledge of family interaction (Knafl, Dixon, O'Malley, Grey, Deatrick, Gallo et al., 2009; Knafl & Gilliss, 2002). Few areas of family research have been guided by a family framework and there is little extension of the current family theories (Astedt-Kurki, Paavilainen, & Lehti, 2001; Black & Lobo, 2008). Extending the work of these international researchers will advance the knowledge of family response to adversity and provide insights into how best to include family in nursing strategies.

The current study used a range of family members as participants and explored the families as a group using a case study approach. Few studies have recruited multiple family members and completed a family analysis (Friesen, Pepler, & Hunter, 2002; Schmitt, Santalahti,

Saarelainen, Savonlahti, Romer, & Piha, 2008). Traditionally family research has used one family member to portray the experience of the family to the researcher although this approach limits the generalizability of the data as it cannot be related to different family perspectives (Astedt-Kurki, et al., 2001; Ganong, 2011). To use multiple family members provides a broader perspective and the data can provide the family as a unit of analysis (Knafl & Gilliss, 2002). International researchers have also noted the need for a family framework as the conceptual base to the family research to provide guidance around the complexity of the family unit (Astedt-Kurki, et al., 2001; Ganong, 2011). One of the important findings from family studies was the recognition of family patterns that influence family adjustment. The assumption with the use of family data is that the subjective views of the individual family members provide a collective view of the family response (Astedt-Kurki, et al., 2001; Knafl, et al., 2009; Lewis, 2004). The current study will contribute to the understanding of family patterns which is an important aspect of being able to provide appropriate care for the family in response to breast cancer.

1.4 Purpose of the study

The purpose of this exploratory descriptive study is to analyse and interpret the strengths and resources that young women and their family members use during treatment for breast cancer. The study uses both quantitative and qualitative methods to gain an understanding of what strengths and resources the young women and their family use in response to breast cancer treatment.

1.5 Research question

The overarching research question was ‘What are the strengths and resources that young women and their family members use during treatment for breast cancer?’ The research question resulted in the development of subordinate research questions that were addressed in the research.

- What are the strengths the young women and their family members use during treatment for breast cancer?
- What are the resources the young women and their family members use during treatment for breast cancer?
- What are the contributing family attributes that influence strengths and resources utilised by the women and their family members during treatment for breast cancer?
- Is there a change in the strengths and resources used by the young women and their family members’ during active and maintenance treatment?

1.6 Research framework and methods

The current study was guided by the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin & McCubbin, 1993) to provide a family framework for the exploration of the family response to treatment for breast cancer. The use of a family research framework is recognised best practice for exploring family interaction and response (Black & Lobo, 2008; Knafl & Gilliss, 2002). A family framework explores the family members as individuals although recognises the influence of family members on each other in response to adversity (McCubbin & McCubbin, 1993).

To answer the research question and provide an understanding of the strengths and resources used by young women and their family a mixed method approach was used. The current study used a two phase postal questionnaire and semi-structured personal interviews. The postal questionnaire provided specific information on the strengths and resources the participants used. The analysis of the strengths and resources provided indications on the

links between the strengths and resources and the contributing family attributes. The composite questionnaire was made up of three scales. The scales were developed from the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin & McCubbin, 1993) and Walsh Family Resiliency Framework (Walsh, 2006). These scales explore the individual's response in relation to their family and indicate a level of family strengths and resources.

The semi-structured interviews provided an understanding of the family response and an exploration of strengths and resources used by the family during treatment for breast cancer. Qualitative data provides a depth to the experience and response to breast cancer treatment. The Walsh Family Resiliency Framework (Walsh, 2006) was used as a framework to guide the qualitative approach. A thematic analysis allowed the development of themes from the data using an inductive approach. Throughout the qualitative data analysis a family approach was maintained to ensure the family experience and response was revealed.

1.7 Organisation of thesis

This thesis is presented in eight chapters. The mixed method design provided both quantitative and qualitative data. Data are presented in separate chapters to ensure the unique nature of each type of data is maintained.

Chapter 1 is the first introductory chapter providing the background and significance for the current study, outlining aims, research questions and research design. The operational definitions are presented at the end of the introduction to provide clarity of the terms used throughout the thesis.

Chapter 2 provides a review of current literature regarding family research, family response to adversity and breast cancer in young women. The theoretical framework is discussed in detail providing background to the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin & McCubbin, 1993) to support the use of this framework to answer the research question. What is known about the young women's

response to breast cancer is summarised. The current literature related to the family response to adversity is critiqued and summarised. The review concludes by identifying the gaps and limitations in the current study.

Chapter 3 presents the methodological approach adopted and the specific methods selected for the current study. Study design is explained including Phase 1 and Phase 2 sample recruitment, setting, justification and data collection. The description of the questionnaires and data analysis plan provides the reader with a clear understanding of the quantitative data collected and data analysis considerations. The qualitative data collection and analysis are also outlined. The ethical considerations are presented outlining appropriate collection and storage of data throughout the research process. The chapter concludes with summarising the study's limitations.

Chapter 4 presents the quantitative data analysis. The chapter begins with the presentation of demographic information. The reliability and validity of the instruments are presented including Cronbach's alpha coefficient for each scale. The exploration of the strengths and resources are presented in sections, including the relationship between strengths and resources. The contributing family attributes are presented, exploring the range of demographic variables collected. The last section presents the family group analysis. In this section the 36 families within the study are explored as family groups.

Chapter 5 is the presentation of the qualitative analysis, beginning with the discussion of the qualitative research process, thematic analysis, presentation of the analysis and interview demographics. The qualitative analysis is presented in two main sections consistent with the research question and framework, strengths and resources. All participants were interviewed individually however the analysis of the data was focused on the family as a group. This ensured the complex interaction between family members formed the basis for the analysis.

Chapter 6 is the discussion chapter that contains the discussion and summary of the overall findings. The findings from the current study are brought together with prior research. The

discussion addresses the subordinate research questions along with the relevant outcomes and these form the body of the chapter. The chapter concludes by presenting the family group analysis and family framework.

Chapter 7 is the conclusion and presents the outcomes from the research; contribution to knowledge, theory and recommendations for practice. Final conclusions to the study are presented and limitations of the study are discussed.

Chapter 8 is the collection of appendices including questionnaires, family group analysis, Walsh factor analysis, recruitment leaflet and thankyou card.

1.8 Operational Definitions

For the purpose of the current study the following operational definitions will be used for consistency within the research process.

Active treatment

For the purpose of the current study, active treatment is defined as treatment aimed at actively treating the tumour with the intent of completely eradicating the cancer from the woman's body with the woman then seeing the oncologist frequently during this time.

Active treatment is normally a combination of surgery, chemotherapy, radiotherapy and hormonal therapy. Surgery, which tends to occur immediately after diagnosis, normally involves lumpectomy or mastectomy with or without clearance of adjacent axillary lymph nodes. Chemotherapy is generally a combination of antineoplastic agents used to reduce the number of cancer cells that remain in the breast tissue, adjacent nodes or circulating blood. It is delivered in a number of treatment cycles, which may take weeks to months. The purpose of these cycles is to enable the woman to recover from the more severe effects of treatment before undertaking the next course. The woman often receives her first course of cytotoxic therapy as an inpatient so that any severe adverse effects can be monitored; the remainder is generally administered in ambulatory care clinics.

Radiotherapy is typically administered as conventional external beam therapy to reduce the risk of a local recurrence. It is also completed in cycles over an extended period, for much the same reasons as cytotoxic therapy, and may be sandwiched between courses of chemotherapy. The woman may also be administered hormonal therapy, which alters the hormonal environment of the breast cancer cells and blocks the tumour growth promoting aspect of oestrogen. In the first six months the active treatment for breast cancer may cause major disruption to the woman's life (Frost, Suman, Rummans, Dose, Taylor, Novotny et al., 2000; Sammarco, 2001).

Adjustment

Adjustment refers to the initial response to the stress where changes are required to manage the stress (McCubbin, Thompson, Thompson, & Fromer, 1998).

Adaptation

Adaptation refers to the secondary response to stress, often after a crisis where the initial adjustment changes become inadequate. In this phase the response is often influenced by the initial response, appraisal of stress (strengths), family functioning and family resources (McCubbin, et al., 1998).

Coping

Coping is the individual's efforts to problem solve through the stressful event (Friedman, Bowden, & Jones, 2003; Lazarus, 1999)

Definition of breast cancer

Breast cancer is a malignant growth that arises from the tissues of the breast. There are two main types of breast cancer, non-invasive (*insitu*) carcinoma that accounts for approximately 80% and invasive lobular carcinoma accounting for 10-15% (Dow, 2006). Prognostic indicators are tumour size, histology, hormone receptor status, lymph node status and molecular markers such as HER2 (Dow, 2006). The survival rates and treatment are based on the stage of the tumour and the prognostic indicators.

Family

For the purpose of this research, family is defined as a group of individuals who are bound by strong emotional ties, a sense of belonging, and a commitment to being involved in one another's lives, calling themselves family (Friedman, et al., 2003; Walsh, 2006; Wright & Bell, 2009).

Family Strengths

Family strengths are what the family uses to manage stress and adversity. The components of family strengths are commitment and coherence within the family, family flexibility and appraisal of stress and communication. These family strengths can be used by the family with the aim of maintaining family function, adjustment and rebound from the adversity (McCubbin et al., 1993; Walsh, 2006).

Family Resources

Family resources are those assets the family uses to maintain family functioning and adjustment during stressful situations (McCubbin et al., 1993; Walsh, 2006). These assets may include immediate family, extended family, friends, community, spiritual support and health professional support (McCubbin et al., 1993; Walsh, 2006).

Family with breast cancer

For the purpose of the current study the definition of family with breast cancer is a family where the young woman in the family is diagnosed with breast cancer.

Health adversity

This is defined as a change in health caused by illness both mental and physical health which has adverse effects either short term or long term.

Stress

Stress is the response or consequence of the individual's appraisal of an event (Friedman, et al., 2003; Lazarus, 1999).

Stressor

Stressor is the precipitating events that activated the stress response (Lazarus, 1999; Lazarus & Folkman, 1984).

Maintenance Treatment

Maintenance treatment is defined as treatment occurring in the period after active treatment is finished with an aim to reduce the risk of recurrence. This may be in the form of hormonal therapy, often started during active treatment, but can continue for up to five years after diagnosis (Dow, 2006; NBCC, 2006). During the maintenance treatment for breast cancer the woman may experience, ongoing but different stressors to her life and continue with a veneer of normality (Bloom, et al., 2004).

Young woman

A young woman is defined for the purpose of this research as aged fifty years or less. This reflects the Australian Institute of Health and Welfare (AIHW, 2010) age bracket for breast cancer statistics and is consistent with the perceptions of women with breast cancer (Bloom,

2008; Dunn & Steginga, 2000; Sammarco, 2001). In this thesis I am discussing a number of young women but refer to a young woman when discussing a singular woman in the study or a situation of singular experience. The young women are the collective group of women with breast cancer or young women in the study.

2 Chapter 2 Literature Review

2.1 Introduction

The aim of the current study was to explore the strengths and resources the young woman with breast cancer and her family members use during treatment for breast cancer. The literature review provides a background of family research to answer the research question. This chapter introduces the literature surrounding family research exploring a health adversity, providing an understanding of the process and value of whole of family research to explore young women and their family's response to breast cancer. The family's response to illness generally, and breast cancer in particular, is reviewed in this chapter. The complex nature of the younger family's response to stress requires a conceptual framework that reflects and articulates this complexity. One conceptual framework that reflects the complex interaction of the family when faced with adversity is the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin, et al., 1998). This research was therefore guided by the Family Resiliency Model.

The first section of this chapter provides a detailed discussion of the family theories and theorists associated with a family's response to health adversity. The second section presents a critical review of the literature addressing family strengths and resources, exploring the family response to health adversity, the research methods and theories used. The third section critiques the literature addressing family response to health adversity including family members' structure and roles. Section four presents a thorough critical review of research addressing breast cancer in younger women. The fifth section of this chapter presents a critical review of the methods used in the past to explore the family response to cancer and in particular breast cancer.

2.2 Background of family theory

This section begins with a review of the theoretical frameworks associated with a family's response to a health adversity. The family theories will be critiqued historically thus providing an overview of the development of the family theories and why the current framework has been chosen.

The individual's response to health adversity has been well established by previous research, exploring both the physiological and psychological aspects of this response (Lazarus, 1999; Rice, 1999). This individual perspective provides an understanding of one part of this response however the current study aimed to explore the family response including the interaction between family members. There is limited research addressing the whole of family response. The research exploring the individual's perspective will be explored initially and then a whole of family theory and theorists will be reviewed. Current research has identified that individuals will react and adapt differently when faced with adversity (Walsh, 2006; Wright & Bell, 2009). It has also become apparent that this individual approach has limitations.

One of the main limitations of research using a single approach is that the individual's response to a health adversity is seldom an isolated event influencing only the affected person. The diagnosis and subsequent impact of the illness and treatment regimens will influence those around the individual with the diagnosis, often including the family, friends and associates over a period of time (Northouse 2005). Thus an approach which explores the family interaction and the influence of family and friends allows for an extended view of the response to the health adversity.

The family will attempt to minimise the negative influence of the illness within the family. However it is this response, which will often influence and interrupt the family functioning (McCubbin, et al., 1998; Rice, 1999; Wright & Bell, 2009). It is this expanded family reaction which has begun a new area of family research exploring the family response to health adversity and stress. To date there has been limited research addressing whole of family response to illness. This research addresses this deficit by using a family framework and inclusion of a range of family members as participants.

In order to explore the family's response to health adversity the definition of family needs to be discussed. Family is a descriptive term for a group of individuals who share a relationship of emotional closeness, commitment and dependence (Friedman, et al., 2003; Rice, 1999). Traditionally family is composed of persons joined together by bonds of marriage, blood, or adoption and residing in the same household (Friedman, et al., 2003). The traditional definition has limited use in today's society as there are a range of traditional and non-traditional family types (Silberberg, 2001; Walsh, 2006). For the purpose of this research the following definition will be used. Family is defined as a group of individuals who are bound by strong emotional ties, a sense of belonging, and a commitment to being involved in one another's lives, calling themselves family (Friedman, et al., 2003; Walsh, 2006; Wright & Bell, 2009). This definition allows the family to be defined by the individuals within the family and includes the commitment to each other by those within the family. The concept of commitment to fellow family members is integral to family as they respond to a health adversity (Walsh, 2006).

Family nursing and family theories have developed over the last twenty years as researchers have explored the individual within the context of their family. Expanding from the original nursing models, for example; Orem's Self-Care Model, and Neuman's Health Systems Model, researchers began to identify the influence and support of the family during a health adversity (Friedman, et al., 2003).

Although the nursing models gave general guidelines these theories did not reflect the complex nature of families. The Orem Self-care Model has been used to explore individual self-care behaviours in chronic disease such as chronic renal failure (Simmons, 2009), cancer (Dodd & Dibble, 1993) and disabled care (Faucette, Ellis, Underwood, Naqvi, & Wilson, 1990). The use of this theoretical framework provided researchers with an individual view of the patient's ability to understand their own self-management of their disease and the benefit of family support. There was however little understanding of the interaction and influence of family members in relation to the patient's self-care or management of their disease. Limited published research has used the Neuman's Health System Model (Anderson & Tomlinson, 1992; Robinson, 1995) and these researchers discuss the beginning of the redefining of nursing with the inclusion of family in the individual's paradigm. These nursing models

provided direction for the beginning of researching an individual's response to adversity within a more holistic view of the support around them.

The new era of family research began with the development of family nursing theories. This was a drawing together of knowledge from both nursing and sociology (Weber, 2011). Sociological research explored families during marriage conflict, major disasters and economic changes providing increased understanding to the family interactions during stress (Rice, 1999). An example of sociological research was research by Burr et al. (1994) which explored the nature of family interaction during marriage difficulties, information developing from their research was the idea of the interactive and changing nature of family during response to adversity (Burr, Klein, & Associates, 1994). Similarly research by Minuchin provided increased understanding of the family response (Minuchin, 1974). Although this research added to the knowledge of family response to adversity it fails to recognise the influence of individual and family health on the response and is thus not suited to exploring a health adversity.

The links to nursing were developed in conjunction with the major theories from family social science which have been fundamental in providing understanding into family research and nursing (Friedman, et al., 2003; Walsh, 2006). The development of combined nursing and sociology theories provided an improved way to explore the family response to health adversity. The family theories included aspects of family development as well as response to the health adversity (Friedman, et al., 2003).

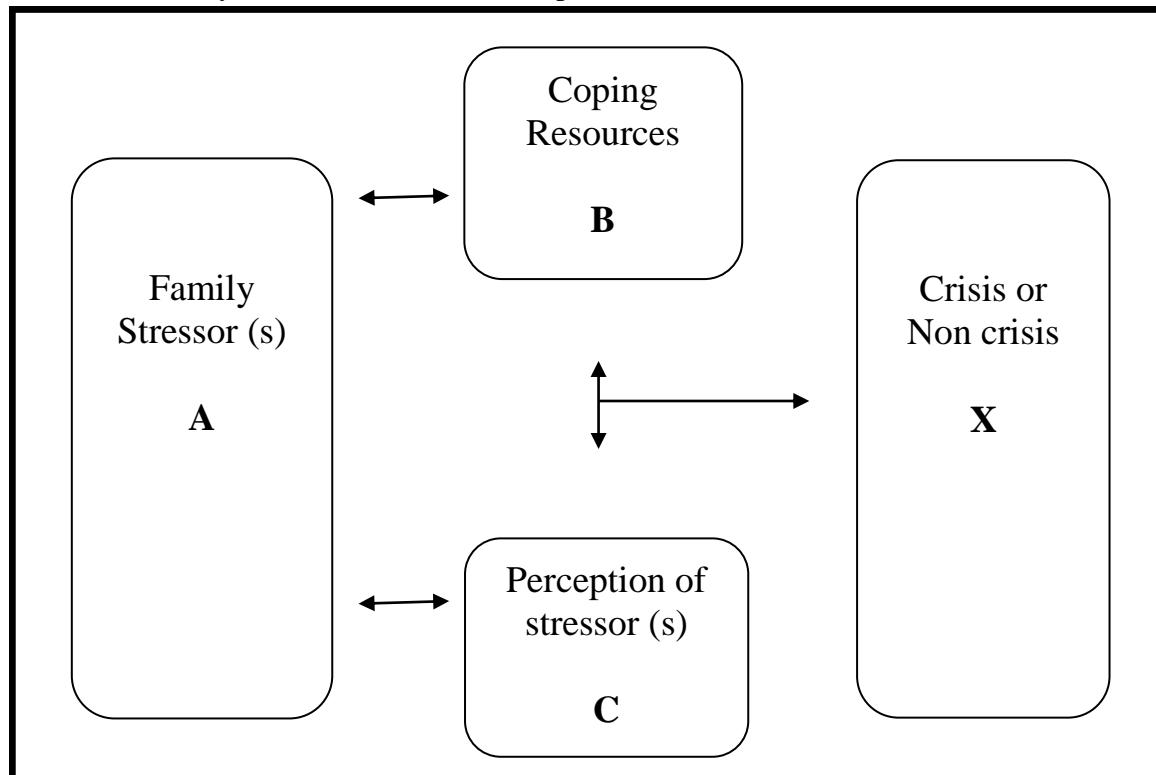
There are a range of family theories and no single approach is considered best practice. What has become evident is that each of the theories explains or explores an area of family interaction and development. Over time family theorists have developed aspects of the theories to guide family assessment and family care. Characteristics that the family theories have in common are recognition of family interaction and communication and the fluent nature of this interaction to influence family functioning (Rice, 1999). The family theory developing particularly to explore the family response to health adversity was the Family Stress Theory (Friedman, et al., 2003; Rice, 1999).

The second era of family stress theory development was from 1940 to 1970 with the exploration of family in relation to variables which influence the family response. These

variables remained the foundation for the current family research (Rice, 1999; Weber, 2011). Reuben Hill (1949) provided the basis for the development of the main family research frameworks in relation to family stress response. Hill's ABCX Model was used to initially explore the adaptive changes to families after war- induced separation. This model is still highly respected (Kahl, Carr Steelman, Mulkey, Kock, Dougan, & Catsambis, 2007; Rice, 1999). Hill's model (1949) explored the factors which influence the family, specifically the strengths and resources used to assist the family to deal with the response to the health adversity. Figure 1 displays the Hill's ABCX Model which explores the family response to a stressor with the influence of the family appraisal and family resources on concept of crisis as a point of time. This early model lacked understanding of the family's interaction when faced by a stress and the movement of the family into the next stages of adjustment and adaptation, thus expansion of the model was needed. Further models were developed and extended. These included the Double ABCX model and the FAAR (Family Adjustment and Adaptation Response) Model which had an emphasis on positive adaptation of family processes (Rice, 1999).

Figure 1 Hill's Family Stress Model

The Hill's Family Stress Model (1949) adapted from Friedman, Bowden & Jones (2003)



Further models were developed and extended in the third era of family theory development from the late 1970 to 1980. These models included the earlier variables developed by Hill (1949) extending the focus from weaknesses within the family to a more strengths based approach (Walker, 1985; Weber, 2011). Resulting in the Double ABCX model and the FAAR (Family Adjustment and Adaptation Response) Model which had an emphasis on positive adaptation of family processes (McCubbin & Patterson, 1983; Rice, 1999). Expanding on Hill's theory was work by McCubbin and Patterson (1983) which introduced the family appraisal of the stress. Including the concepts of stress and the influence of stress provided a link to the physiological and psychological aspect of the stress response thus increasing the use of the framework in relation to a response to health adversity (Lazarus & Folkman, 1984; McCubbin & Patterson, 1983).

The fourth era of family stress theory development from mid-1980 to the present sees the inclusion of increased clarity of the meaning of the variables. Understanding family functioning, shared family meanings and the cultural aspects of family as an interacting unit are also included. McCubbin and McCubbin (1993) developed the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] based on the earlier family stress models, including the ABCX model and the Double ABCX model. The Family Resiliency Model provided a framework for understanding the family response after an adverse health event. The aim of the Family Resiliency Model was to explore the family adjustment to the adverse health event. Included in the model was exploration of the response to the health event, family perception or appraisal of the event and, family resources, family coping and family functioning in relation to the event (McCubbin, et al., 1998). The model continued the earlier variables developed by Hill (1949), but with added clarity and definitions of the variables. Definitions of the variables are expanded on in the following section.

Criticisms of the Family Resiliency Model relate to questions about the usefulness of the model in terms of health promotion for healthy families as the model provides guidelines for working with a family in response to a health adversity particularly a crisis situation (Black & Lobo, 2008; Friedman, et al., 2003). However the model does include the assessment of the health of the other family members as they progress through the stages within the model (Knafl & Gilliss, 2002).

The elements of the model (family functioning, strengths and resources) guide assessment of the family's response in two phases, adjustment and adaptation. Analysing the family according to these elements may not acknowledge the unpredictable nature of a family's response as the family members interact and respond to the health adversity (Silberberg, 2001; Weber, 2011). The McCubbin model suggests that families usually cope with the adversity by drawing on strengths and resources and learned coping strategies which results in either adaptation or maladaptation (Walker, 1985; Wright & Bell, 2009). Other family models provide guidelines for assessment of the family using an approach of exploring the integration of the adversity into the family's lives [Calgary Family Assessment Model 1984 (Wright & Leahey, 1987); Family Resiliency Framework (Walsh, 2006)], including exploring the changing of family beliefs and the meaning of the adversity as part of the adjustment to the adversity (Walsh, 2006; Wright & Bell, 2009).

Explaining family appraisal of the stress or health adversity has been identified as problematic by Weber (2011). Appraisal may be defined on the basis of personal meanings or in terms of coping. Because the Family Resiliency Model fails to provide a definition of how adversity is appraised, its usefulness is somewhat compromised (Black & Lobo, 2008; Rice, 1999). The Family Resiliency Model's variability in defining the family and how the family is assessed is both a strength and a weakness in that it provides flexibility for researchers to define family on their terms but it may also be unclear in guiding assessment. A weakness of other models is that they may explore one or two family members and their responses, which may not provide a clear interpretation of the overall family response (Greenstein, 2006).

Researchers have used the Family Resiliency Model to explore the family adjustment process to various health adversities including cancer, heart disease, aged care, and paediatric conditions (Board & Ryan-Wenger, 2000; Edwards & Clarke, 2004; Leske, 2003; Leske & Jiricka, 1998; Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007; Patterson, McCubbin, & Warwick, 1990; Svaravsdottir, Rayens, & McCubbin, 2005). The Family Resiliency Model was used for the current study as this model provided guidance for the exploration of the family response after a diagnosis of breast cancer. The following section will provide an in-depth critique of the Family Resiliency Model.

2.2.1 Family Resiliency Model

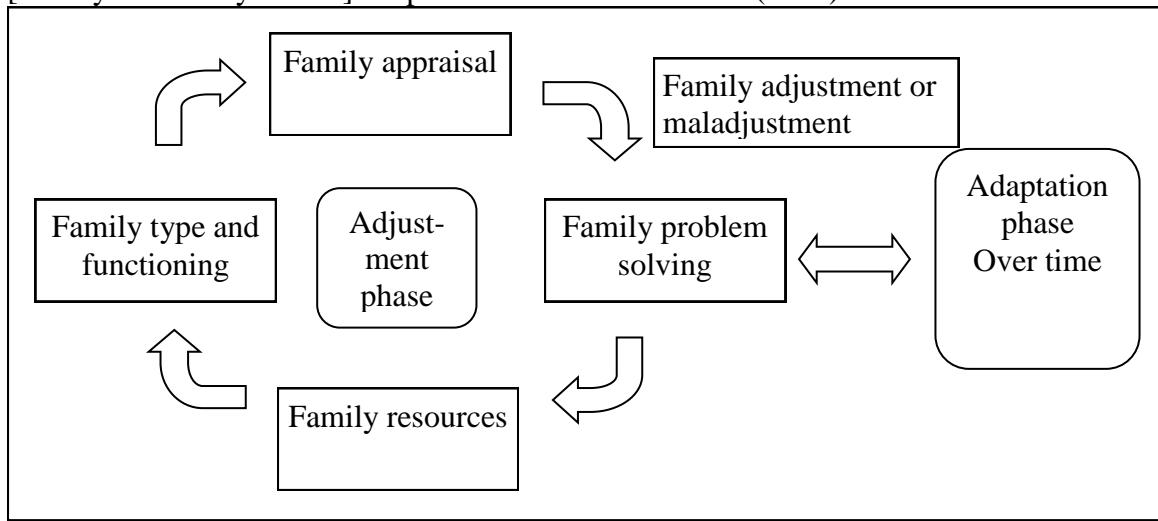
The following critical review of literature will expand on the development of the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin, et al., 1998) and justify the use of this framework for the current study. The current study aimed to explore the family supporting the young woman with breast cancer. Limited research has used this whole of family approach although a dyad approach has been used before (Black & Lobo, 2008).

The McCubbin and McCubbin scales are considered the gold standard for exploring family adaptation to stress (Black & Lobo, 2008; Friedman, et al., 2003; Rice, 1999). The Family Resiliency Model (McCubbin, et al., 1998) is based on the fundamental concept that the family tries to work together to promote family stability and functioning. The idea that a family aims to work together when faced with adversity began with early research exploring family responses to war and disaster (Burr, et al., 1994; Hill, 1949; Rice, 1999). The early family theories developed this concept and it has since been accepted as an integral part of a family response when faced with adversity (McCubbin, et al., 1998; Walsh, 2006; Wright & Bell, 2009).

The Family Resiliency Model (McCubbin & McCubbin, 1993) provides a framework for the exploration of the family as a whole during adaptation to stress, emphasising the family response to a stressful life event in two phases namely adjustment and adaptation. The framework explores the individual's appraisal of the family response in relation to several family concepts. These concepts are the family appraisal of stress or health adversity, family type and functioning, family problem solving and coping and family resources (McCubbin & McCubbin, 1993). [See Figure 2 for the representation of the Family Resiliency Model.]

Figure 2 McCubbin Resiliency Model of Family Stress

McCubbin and McCubbin *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] adapted from McCubbin et al. (1998)



The Family Resiliency Model outlined in the diagram has key concepts which influence the progression of the family through adjustment to adaptation. The first key concept within the Family Resiliency Model (McCubbin, et al., 1998), is the family type and functioning. This concept is defined as family attributes that influence how the family functions as a unit. There are three main family types that McCubbin et al. (1998) describe. These are regenerative, rhythmic and resilient. The first family type, regenerative is described as a family possessing family hardiness and coherence and ability to problem solve. The second family type, rhythmic, is described as a family who focus on routines and using the routines to reduce the response to the adversity by aiming to keep the family functioning the same way as before the adversity. The third family type is resilient. This is a combination of family skills with a sense of family flexibility and bonding within the family. McCubbin et al. (1998) suggest the resilient family is likely to adapt to stressful situations. Criticism of this concept of family type relates to the nature of grouping families into specific types when often family members may react differently in different circumstances (Wright & Bell, 2009). McCubbin's categorisation of families into regenerative, rhythmic and resilient types, stereotypes families as having predictable responses to adversity. The objective of this study was to explore the diversity that actually exists within families. The current research explored the family functioning and roles but did not use the specific family labels as described by the McCubbin model (McCubbin, et al., 1998) in order to avoid such stereotyping.

The second key aspect is family appraisal and includes how the family define the event and the shared family assessment of the event. The disruption caused by the event and how well the family manages the demands from the event are also contained within the family appraisal (Friedman, et al., 2003). This concept has been refined as the model has developed with an increased requirement to explore the adverse event and understand the influence of the adversity on both the individual and the family members (McCubbin, et al., 1998).

The third aspect of the Family Resiliency Model is problem solving and coping behaviour and refers to how the family manages the stressor, influenced by family type, resources available and communication within the family (McCubbin, et al., 1998). This concept explores the strengths of the family, how they work together. This includes the different styles of coping including emotional and problem based coping styles (Drageset, Lindstrom, & Underlid, 2010). Research identifies that different family coping styles are indicators for the family's ability to work through the problem and adjust (Feldman & Broussard, 2006; Matud, 2004). Previous research has explored the relationship between emotional and problem based coping strategies revealing links between the intrusiveness of the illness to the family functioning and the need for strategies to support the family to develop positive coping strategies for adjustment (Drageset, et al., 2010; Wonghongkul, Dechaprom, Phumivivhuvate, & Losawatkul, 2006).

Family resources are the last aspect of the Family Resiliency Model. These resources are described as attributes and supports available to the family to assist them to manage the event. McCubbin et al. (1998) emphasise three different levels of resources. Individual resources; known as knowledge, skills, personality, and emotional wellbeing. Family unit resources; known as family flexibility, organisation, and leadership. Community resources; known as extended family, friends, health care services.

Several family researchers propose that there are specific family characteristics that suggest the ability for positive coping. These are referred to as strengths within a family (McCubbin, et al., 1998; Walsh, 2006; Wright & Bell, 2009). These strengths within the family are also noted to influence how the individual and the family appraise the situation, seeing it as either a positive challenge, or as an overwhelming event (Mellon & Northouse, 2001). Exploring and understanding the strengths within a family can provide opportunities to foster family growth and adjustment during an adverse health event such as breast cancer.

Family researchers have also suggested that the resources the family use to assist them, influence the family response during the health adversity (McCubbin, et al., 1998; Walsh, 2006). Previous research identifies these resources as close family support, but also social support resources such as extended family, friends, spiritual support and community resources (McCubbin, et al., 1998; Patterson, et al., 1990; Svavarsdottir, et al., 2005; Walsh, 2006). Understanding the resources that the family may have used in response to previous adverse events and what resources the family are comfortable using provides important insights into the additional strengths and resources health professionals may engender in the family as they guide and support families during an adverse health event (Northouse, 2005).

McCubbin, et al. (1998) have developed numerous self-report measures informed by the Family Resiliency Model. These measures are aimed at examining the concepts addressed within the framework. The scales, which can be used individually, or as a set, measure specific aspects of family response to the adversity. For example the Family Hardiness Index (FHI) is designed to measure internal family strengths and durability of the family in the response to a stressful life event (McCubbin, McCubbin, & Thompson, 1986). The Family Inventory of Life Events and Changes (FILE) (McCubbin, Patterson, & Wilson, 1983) is designed to measure life changes known to influence the family's ability to respond to further adversity or stress. Other scales developed by McCubbin, and colleagues over the years are aimed at exploring different aspects of the Family Resiliency Model, for example social support, coping supports, family coherence and family resources. The limitation of these scales is that they are often quite specific in their use, for example family resources, coping inventory and life events inventory all measure specific concepts (Friedman, et al., 2003). The Family Resiliency Model however does provide a reliable quantitative framework for examining family response to stress. The current study will use two of the scales from the Family Resiliency Model namely the Family Hardiness Index (FHI) and the Family Crisis Orientated Personal Evaluation Scales (F-COPES) to explore the strengths and resources used by the family.

The Family Hardiness Index was designed to measure the three concepts of family strengths specifically sense of challenge, control on the situation and commitment to the family. These particular concepts of family strengths are noted by McCubbin, McCubbin and Thompson (1986) to influence the way the family can appraise the adversity and work together to

overcome or falter in their response to the adversity. In particular, the FHI measures the extent to which the family responds to the adversity with a high score, indicating that the family has a positive appraisal and strong commitment to work together through the adversity. Several researchers have used these scales previously in order to explore a range of adverse health conditions in a variety of ages and participant groups. The questions have been translated and used by other researchers (Chen & Rankin, 2002; Svavarsdottir, et al., 2005). One of the concerns when analysing the data from this scale is the wording of the questions, which may not resonate with Australian language. Prior to the current research the two McCubbin scales FHI and F-COPES have not been validated in the Australian context, which makes their relevance and applicability difficult to judge.

The Family Crisis Orientated Personal Evaluation Scales (F-COPES) (McCubbin, Olson, & Larsen, 1981) was the second scale used in the current study. This scale explores the use of resources by the family and how the family works through the problematic situation. Exploring the concept of family resources and coping strategies, this scale provides specific information as to the type of resources the family use and how they define their coping strategies. For example do they identify that they respond to the adversity 'head on' or take an approach of hoping it will go away? The scale measures these concepts thus providing an understanding on the type and level of resources used by the family and how the family associates with the adversity; positive and active or negative and passive. Researchers have used this scale although not as commonly as the FHI. A critique related to the Australian culture is the wording on several of the questions which are specific to activities rather than the coping strategy. Previous researchers exploring the concept of resources used by the family have often used a composite questionnaire and a mixed method design to provide a range of information to increase the understanding of this concept from the Family Resiliency Model (Board & Ryan-Wenger, 2000; Leske, 2003; Leske & Jiricka, 1998; Patterson, et al., 1990).

The Family Resiliency Model has been used by a number of researchers (Clark, 2002; Leske, 2003; Patterson, et al., 1990; Svavarsdottir, et al., 2005). These researchers have used a selection of scales to measure specific aspects of the Family Resiliency Model, often in conjunction with other stress and coping models. The use of the composite questionnaire allows for an understanding of several influencing concepts to be explored and analysed together (Polit, 2010). The aim is to use scales which complement and extend the concept and

data being generated. The following research examples used composite questionnaires including the McCubbin and colleague's scales to explore their research concepts.

In Mellon, Northouse and colleagues' American research (2001; 2006; 2007), their sample was family dyads ($n = 123$, mean age 65 years). The purpose of the research was to examine factors associated with quality of life in cancer survivors and their family members based on the family stress and coping framework adapted from McCubbin and McCubbin's Family Resiliency Model (McCubbin, et al., 1998). The study was a longitudinal quantitative study using a range of scales to obtain information related to cancer stress, physical symptoms, fear recurrence, family hardiness, social support and meaning of the illness following a cancer diagnosis (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2006; Mellon, et al., 2007; Mellon & Northouse, 2001). No specific information was provided about the subscale scores only relationships between the scales including family hardiness, family social support, family meaning of cancer, concurrent stressors, family quality of life, somatic concerns, fear of recurrence. This enables discussion relating to the nature of supporting a woman with breast cancer, although it only provides the perspective from the woman and her partner not a range of family members who would have also been influenced by the diagnosis. Their research is longitudinal allowing understanding of the changes in quality of life. However, comparisons of particular aspects are limited due to the lack of specific reporting of scales in the published research.

The Northouse and colleagues' studies (2001, 2006, 2007) recruited cancer patients through the cancer registry of data (SEER) with an initial letter and follow up phone call to establish informed consent. A broad family definition was used, with cancer survivors self-selecting an adult over 18 years whom they considered as family in a close relational bond and supporting them through their cancer experience. The definition of family allows for a clear understanding of the participants. Once consent and inclusion criteria were met by the participants a telephone interview to complete the questionnaire was conducted by the researcher. A recruitment rate of 60% was obtained with this technique of researcher follow up and telephone interviews, identifying that this method of recruitment and questionnaire completion provides a high level of participation. Analysis was completed as whole group as minimal differences were found in the initial analysis of quality of life between cancer sites (Mellon, et al., 2006, 2007; Mellon & Northouse, 2001).

Leske and Jiricka (1998) explored the family response to a critical care admission in America. The purpose of their research was to examine family demands, strengths and capabilities associated with family wellbeing and adaptation after a critical injury such as gunshot wounds and coronary artery bypass graft. Their research was guided by the Family Resiliency Model (McCubbin, et al., 1998). The Leske and Jiricka (1998), Leske (2003) research had a convenience sample of 51 family members (mean age 37 years) of adult patients after a critical care injury. The 51 family members of 21 patients were recruited after the admission of the family member to the critical care unit, but no patients were recruited. Participants received payment for participation and were recruited within two days of critical care admission and questionnaires completed in the hospital private waiting room. The completion of questionnaires at the time of recruitment ensures questionnaire completion although the participant response may not be a clear representation if questionnaires were completed quickly in the hospital setting.

Leske and colleagues (1998, 2003) used a quantitative design with several instruments to measure family demands, strengths, resources, adaptation and family well-being. Their research used the FHI and F-COPES providing overall scores although no details were provided on subscales of the scales. The FHI scores were reported with a mean of 42 / 60. F-COPES scores were reported with a mean 81/120. Leske and Jiricka (2003; 1998) reported on all 30 questions within the scale however McCubbin, McCubbin and Olsen (1981) suggest not including question 18 in the final total scores. The general findings reported strong positive correlations between family hardiness and family resources, coping, problem solving communication, family well-being and family adaptation, leading to conclusions on the need to assist families mobilise their strengths in order to promote adjustment to a critical care incident (Leske, 2003; Leske & Jiricka, 1998). The analysis was completed as a whole group as minimal differences were identified in the initial analysis between different admission criteria. A strength of this research was the use of several family members to provide an insight into the family response to critical care admission. The scales provide good information about the family member's strengths and resources, although no qualitative data gave an understanding of the aspects of the family strengths and resources.

Leske (2003) used a multivariate descriptive design based on the Family Resiliency Model with a range of scales including Family Inventory of Life Events and Changes, APACHE III (Age Physiology, Age and Chronic Health Evaluation), Family Hardiness Index, Family

Inventory of Resources for Management, Family Crisis Oriented Personal Evaluation Scale, Problem Solving Communication Index, Family Well Being Index and Family Adaptation Scale to explore the family's response to a critical care admission. Enabling the researchers to understand the family demands and assistance needed, but also the family strengths, problem solving and family communication to provide interventions tailored to the family (Leske, 2003; Leske & Jiricka, 1998).

Clark's (2002) American quantitative research guided by the Family Resiliency Model (McCubbin & McCubbin, 1993) explored the relationship of family hardiness on caregiver depression and fatigue in impaired older adults. The research design was a descriptive cross sectional study with a convenience sample of 67 care givers with a mean age of 55 years, mostly women. Clarke used a range of instruments to examine physical and emotional response including individual hardiness, family hardiness, coping and seeking help behaviours. The FHI mean scores were 46 / 60. Although the Clark (2002) research does not clearly report sample characteristics, the family hardiness scores were accomplished by care givers reporting on their personal scores and completing the family member's scores. The participant reported on the family member they were caring for, scoring on physical and emotional response to the adversity. The participant also completed a caregiver diagram to provide family relationships. This method of exploring response to adversity may not provide a clear picture of the patient's level of physical and emotional response; however the patients may not have been able to provide this information due to degree of impairment. In contrast, the current study recruited a range of family members from each family and grouped the data for the analysis of family data.

Fang, Manne and Pape (2001) American researchers explored physical and psychological impairment and the influence of marital quality on the spouse's distress in their quantitative study of 197 patients and their spouse after a diagnosis of cancer. Recruiting from an outpatient cancer centre couples were approached by the researcher after consultation with their oncologist. Questionnaires were mailed to the patients and spouse with a 39% study completion rate. A high study refusal and attrition rate was noted although this was discussed as typical for longitudinal cancer studies especially requiring patient and partner participation. The level of physical impairment directly influenced participation and continuation in the longitudinal study; the higher the physical impairment and the less likely family dyads were to continue in the study (Fang, Manne, & Pape, 2001). Exploring physical

and psychological impairment of the patient from the perspective of the patient and the spouse and the marital quality was Fang et al's. (2001) whose study noted a close relationship between physical and psychological impairment and the influence this had on marital quality.

Svavarsdottir, Rayens and McCubbin (2005) used Family Life Events, Care of My Child with Asthma Questionnaire, Orientation to Life Questionnaire, Family Hardiness Index and Family Adaptation Scale in a longitudinal research to explore family adaptation to asthma in Iceland. This allowed the researchers to explore other life events influencing the family, the degree to which the child's asthma influenced the family and how the family responded and managed the health adversity.

The previous research using the McCubbin scales have demonstrated the use of these scales FHI, F-COPES, to explore the family response to a range of diseases. The scales provide numerical data of the family response related to the questions which when analysed together provide a level of family adjustment related to family strengths and resources. The previous critiqued research studies have used a composite questionnaire including the McCubbin scales and other scales to provide broader picture of the family response. A limitation of the McCubbin scales FHI and F-COPES is their limited ability to provide a full picture of the family response (Black & Lobo, 2008; Ganong, 2011).

In summary the Family Resiliency Model (McCubbin & McCubbin, 1993) has provided a guiding framework for the current study, allowing the exploration of the family as they respond to the health crisis of breast cancer. Specific quantitative scales provide a way to measure specific aspects of this response, the strengths the family draws upon and the resources the family use during this time. The current research integrated the concepts of the McCubbin model and Walsh framework to conceptualise the study. The use of two McCubbin scales and the Walsh framework helped link the quantitative and qualitative data.

2.2.2 Walsh Family Resilience Framework

The following review of literature will include the development of the framework by Walsh (2006) beginning with an overview of the family theories. Over the last two decades, family systems research has continued to provide empirical processes to explore family functioning in response to stress. Drawing together several key family research theories, Walsh's family

resilience research framework (1993, 2002, 2006) has developed with the influence of key family researchers such as Antonovsky, Roland, McCubbin, McCubbin, Patterson, Wright and Bell (Antonovsky, 1979; McCubbin, et al., 1998; Rolland, 1994, 2005; Wright, Watson, & Bell, 1996). The Walsh resilience framework is relatively new in the family research field although key family researchers have acknowledged the strengths of the Walsh framework (Wright & Bell, 2009). The Walsh resiliency framework views the family response as a holistic family response whereby the family's core beliefs and appraisal of the stress influence the family reaction and functioning (Walsh, 2006). The Walsh framework stems from both the Family Stress Theory and Family Systems Theory (Friedman, et al., 2003) and the following section will introduce and expand on the Family System Theory to provide an understanding of the processes of the Walsh resilience framework.

The Family Systems Theory provides a framework for understanding the complex processes and interaction of the family allowing for the exploration of the family unit as a group of individuals who function and interact both separately and as a group (Friedman, et al., 2003; Minuchin, 1974). Importantly the Family Systems Theory provides guidelines for exploring the family's dynamic nature whilst still assuming the holistic nature of family. The family is viewed as a whole and the theory recognises the strength of the family as a unit. The family system perspective recognises that events occurring for one family member, such as chronic illness, will influence other family members and affect the whole family functioning (Friedman, et al., 2003; Mellon & Northouse, 2001; Minuchin, 1974).

Family Systems Theory is a grand theory covering a range of phenomena and family researchers have been influenced by this holistic way of viewing the family. Family Systems Theory views the family as an interactive system within a larger system, 'the community', recognising the strength of the family as a unit (Friedman, et al., 2003; Walsh, 2003). The Family Systems Theory recognises the complexity and adaptability of the family in response to adversity. The Family Systems Theory implies that patterns of response are circular, repeated in response to new experiences and suggests that to change the pattern of response, external influences should direct the family in a positive way within their own patterns (Friedman, et al., 2003; Walsh, 1998). This is an important aspect of understanding family response when research aims to inform and improve practice in supporting families.

Family Systems Theory can be used to understand key family processes within the family such as family functioning, communication, connectedness and adaptation (Friedman, et al., 2003; Minuchin, 1974). Family functioning refers to the structure, activities and roles within the family, and the organisational structure of the family that defines relationships (Minuchin, 1974; Walsh, 2006). The communication styles and needs of the family are examined by investigating the family processes of communication such as a pattern of open or closed communications and how the family works together to maintain conversations around areas of distress (Walsh, 2006). Family connectedness is considered an essential part of family functioning within the Family Systems Theory framework. The ability of the family to rely on each other and to promote mutual support, collaboration and commitment to the family unit is an essential component of being a family (Friedman, et al., 2003; Walsh, 2006). Family adaptation is the ability of the family to restore or maintain family stability drawing on family processes such as family functioning, communication and connectedness (McCubbin & McCubbin, 1993). Family Systems Theory also includes factors that influence the family unit such as extended family, culture and community (Friedman, et al., 2003; Wright & Leahey, 1987). Family Systems Theory incorporates a range of factors to explain family response to adversity and it has also been applied to studies addressing the family response to illness (Friedman, et al., 2003; Rice, 1999). As a grand theory Family Systems Theory was considered too broad to encompass the scope of this study, whereas the Walsh framework provided a more manageable framework to complement the McCubbin Theory.

Influenced by Family Systems Theory and the Family Stress Theory, Walsh (2006) groups a broad range of intra-family processes within the framework. In this way the Walsh framework uses parts from the Family System Theory, the family connections and the aspects from the Family Stress Theory, (the response to adversity), to develop a framework that explores the family response in three dimensions. These dimensions are the illness, the individual within the family, and the family life cycle. This allows the family response to be viewed from three different angles namely how the family have responded to the illness, the influence of the illness on the family lives and the changes they have had to make because of the illness. This includes how each individual responds, personal coping strategies and their appraisal of the illness. The last aspect explored is the stage of the family life cycle, which takes into account the age of children in the family, and stage of life whether newly married or established marriage. The dimension of the family life cycle is an important consideration for the current study, which explores the younger woman and her family members. The

literature exploring these three dimensions will be discussed in the family response and breast cancer section of the literature review.

Walsh (2006) developed a second level of family exploration with the framework using three domains which explore the family response to adversity. These domains are family belief systems, organisational patterns and communication processes. The first domain, family belief systems, explores how the family appraises the adversity, how they make meaning of the adversity, their use of spirituality, and the overall family perception of the adversity. Walsh (2006) explains that it is these aspects of the family belief system that the family uses as they aim to work together to understand the challenge and adversity of the illness. Researchers suggest that these family characteristics enhance the family response when managing the situation (Walsh, 2006; Wright & Bell, 2009).

Within the domain of organisational patterns the framework examines the family structure, activities and individual roles within the family. Walsh (2006) and other researchers propose that these are strongly influenced by the extent of the family's flexibility, ability to work together and resources available to the family (Northouse, 2005; Wright & Bell, 2009). The family organisational patterns allow the family to reorganise roles and change their family structure and activities in response to the illness. When moving through illness and treatment the person with the illness will need to change roles within the family and if a family is able to respond positively to these changes research suggests that these families manage the health adversity better than a family unable to be flexible within the family structure (Greenberger & O'Neil, 1993; Northouse, Kershaw, Mood, & Schafenacker, 2005; Wright & Bell, 2009).

Communication is the last domain, comprising an exploration of the communication processes used by the family. Communication includes the type of information the family are likely to use as they respond to the illness and the influence this information has on the individual and the family as a whole. Important issues include the use of communication within the family in terms of emotional sharing and problem solving and the use of open or closed communication styles (Walsh, 2006). Researchers have highlighted the importance of communication within the family as an influencing factor on adjustment to a health adversity (Forrest, Plumb, Ziebland, & Stein, 2009; Huizinga, Visser, Van der graaf, Hoekstra, & Hoekstra-weebers, 2005; Manne, Ostroff, Norton, Goldstein, & Grana, 2005).

The Walsh family resiliency framework focuses on the family strengths as the family respond to the health adversity, rather than focusing on the stress response caused by the health adversity (Walsh, 2006). The Walsh family resiliency framework explores the family response to health adversity with an aim of understanding the processes within the family that influence this response.

While there are validated quantitative measures available to explore family strengths and family resources, there are few rigorous qualitative studies that have explored family strengths and family resources and the reasons for the use of these qualities in response to health adversity. Walsh (1998) developed a qualitative framework of family resilience drawing on previous models of resilience and appraisal of stress to explore the family response (Antonovsky, 1979; Lazarus & Folkman, 1984; McCubbin & McCubbin, 1993). Whilst it is not possible to assess the rigour of the Walsh framework by the same criteria applied in quantitative studies, several qualitative studies have used Walsh's conceptual framework (Rolland & Walsh, 2006; Silberberg, 2001). The discussion from other family researchers about the Walsh framework have indicated its usefulness and rigour in terms of qualitative work to expand the growing body of family research (Black & Lobo, 2008; Wright & Bell, 2009).

In critique of the Walsh framework, researchers have noted how the Walsh (2006) model encompasses the complex family interactions during an illness situation while still including the individual nature of each family situation (Turner, Clavarino, Yates, Hargraves, & Connors, 2007; Wright & Bell, 2009). Although this framework is relatively untested, it was useful for both the quantitative and qualitative components of the current study because it enables the family response to be explored in the similar groups both quantitatively and qualitatively.

The current study used one scale developed by Walsh (1993, 2002, 2006) as a qualitative guide to provide a set of questions which were used as a quantitative questionnaire set. Walsh's research framework (2006) provides depth of exploration to family communication and personal beliefs, extending the Family Resiliency Model which only explores the specific aspects of family response within the Family Resiliency Model (Black & Lobo, 2008). The use of the Walsh framework and the McCubbin and McCubbin Family Resiliency Model

provided a link between the quantitative and qualitative data and also allowed for the exploration of the communication between family members.

2.2.3 Summary of background of family theory

In summary, the exploration of family members within a research framework has developed from the individual context to a process of understanding the complex interactions within a family as they respond to adversity. The Family Resiliency model has proven to be a reliable research tool for the exploration of family within a quantitative framework. The Walsh framework provides a background to explore the broader aspects of communication and belief systems of the family in response to adversity. The McCubbin and the Walsh frameworks allow for exploration of the family as an interactive system and the frameworks complement each other with the slightly different interpretations of family response.

The family is a valuable resource in the context of a younger woman's diagnosis of breast cancer. There is acknowledgement that the family's strengths and resources in this situation need to be understood and recognised in research because of the influence of the strengths and resources on the outcome of the personal response to the adversity and the potential this has to inform patient care (McCubbin & McCubbin, 1993; Mellon & Northouse, 2001; Walsh, 2006). It is argued that a family who experiences a diagnosis of breast cancer may need to learn new roles within the family structure, draw on personal strengths and link with external resources to deal with the changes caused by the breast cancer (Northouse, et al., 2001; Wonghongkul, et al., 2006). Collectively, the Family Resiliency Model, McCubbin and McCubbin (1993), in conjunction with Walsh (2006), provide a useful and reliable framework to explore strengths and resources and the contributing family factors that may influence the family's response during treatment for breast cancer. The following section will discuss and critique the literature relating to the aspects of family research.

2.3 Family Strengths and Resources

The focus of this research was to investigate strengths and resources the family uses in response to breast cancer. Current research will be explored, critiquing the method and framework used to begin building a picture of the current family research exploring family response to health adversity. An overview of what is meant by strengths and resources will be

presented. Then the strengths and resources will be explored in detail in the following sections.

Research acknowledges that there are a range of family responses however there are suggestions of two main aspects of this response influencing the overall adjustment to the health adversity, the strengths of the family and the resources the family use to assist them (McCubbin, et al., 1998; Northouse, et al., 2007; Walsh, 2006). In the current study, the importance of understanding how the younger family responds to a health adversity in particular breast cancer, drawing on their strengths and using resources, provides a background to further informing health care practices.

Family strengths are defined as the qualities from within the individual family members or the family as a whole, which are used in response to the health adversity (McCubbin & McCubbin, 1993; Walsh, 2006). The family resources are defined as the factors external to the immediate family which the family can draw on to provide assistance as they respond to the health adversity (McCubbin & McCubbin, 1993; Walsh, 2006). These family strengths and resources form part of the family's characteristics, as the family identify the challenge, and the need for change. Previous research exploring family strengths and resources has not used a consistent definition for either strengths or resources. There is however, agreement on the importance of certain family attributes, that when grouped together, appear to increase the family's ability to overcome adversity (McCubbin & McCubbin, 1993; Northouse, 2005; Walsh, 2006). The following two sections will critique the literature around the strengths and resources of the family, providing a clear description of strengths and resources as explored within the current study.

2.3.1 Family Strengths

The following section will critique the literature exploring family strengths generally. An exploration of the attributes within strengths will be explored in the separate sections. Family strengths critiqued in the current study are explored within the context of the Family Resiliency Model (McCubbin, et al., 1998) in conjunction with the Walsh framework (Walsh, 2006). Family researchers have identified several attributes within the concept of strengths, including commitment to family, appraisal of the adversity, family functioning and communication and nature of these attributes.

Several researchers propose that the family unit's ability to believe in themselves and find strength to overcome adversity is a core value of the family (McCubbin & McCubbin, 1993; Sears, Stanton, & Danoff-Burg, 2003; Walsh, 2006). Families may have different levels of strengths which are viewed as positive characteristics. Inversely the negative side is their inability to believe in themselves and responding negatively to the health adversity (Low, Stanton, & Danoff-Burg, 2006). Research also suggests that it is with these strength characteristics that family organisation and functioning can be maintained (McCubbin, et al., 1998; Northouse, et al., 2005). The personal ability of family members to understand and communicate feelings provides the individual with the strength to continue and to rebound from adversity, thus increasing the strengths within the family (Sears, et al., 2003). Family hardiness is known as the ability (or not) of the individual and the family to draw upon their strengths to support each other (McCubbin, et al., 1998; Mellon & Northouse, 2001). The ability to normalise the situation, find hope and see the threat as a positive challenge is a positive strength characteristic in response to illness (McCubbin & McCubbin, 1993; Sears, et al., 2003; Walsh, 1998). There has been an association between the individual or family who struggle to find any positive aspects in their response to illness and poorer health outcomes (Mellon & Northouse, 2001; Sears, et al., 2003).

One way of assessing these strengths is suggested by McCubbin and McCubbin (1993) in their Family Resiliency Model. The Family Hardiness Index (FHI) measures three components of family strengths in the family response to stressful life events namely challenge, commitment and control. The FHI scale questions the extent to which the family use the different aspects of internal family strengths. Walsh (2006) further explores these constructs in her Family Resiliency Framework in terms of the family response to stress, according to three domains including making meaning of adversity, positive outlook and communication.

Previous research has explored family strengths by separating the concept of family strengths into the smaller measurable attributes (McCubbin, et al., 1998; Walsh, 2006). Specifically, family strengths have been separated to include commitment to the family unit, appraisal of the adversity, family functioning, roles and flexibility and family communication. The commitment to the family relates to the family's ability to pull together and work as an interactive unit. Family strengths also relate to the appraisal of the stress and refer to the way

that the individual and the family relate to the stress and how they compare this with their life. Family roles refer to the flexibility of the family to change roles within the family as needed in response to adversity. Another family strength, family communication explores the styles of communication both open and closed and how this influences the family's ability to respond to the adversity. The current study has used these attributes to measure the strength of the individual within a family and also the strengths of the family as a group. The following sections will critique the literature exploring the attributes within the concept of strengths.

2.3.1.1 Commitment to family

The purpose of this section is to explore the attribute of strength known as commitment to family, beginning with a clear definition and then a critique of current research addressing the attribute of commitment to family.

The family strength 'commitment to the family' has been defined by family researchers as the family's ability to appraise the situation as a shared challenge within the family, provide mutual support and to commit to the family during adversity (Friedman, et al., 2003).

Researchers will often use the term coherence in place of commitment so this term will also be critiqued. Coherence has been closely associated with the ability of individuals within the family unit to work together and to respect individual needs and boundaries of the family in an attempt to maintain the family unit (Antonovsky, 1979; McCubbin & McCubbin, 1993; Walsh, 2003). Walsh (2003) in the Family Resiliency Framework argues that coherence can be described as how the family maintains connectedness through family support and mentors.

McCubbin and McCubbin (1993) suggested that it was difficult to measure coherence and this was a limitation in their Family Resiliency Model and they use the term commitment to explain this concept. McCubbin and McCubbin (1993) defined family commitment as the ability of the family to problem-solve as a group and to work together to overcome the stressful event. Researchers have identified commitment as an expression of family coherence, especially in response to illness (Antonovsky, 1979; Ganong, 2011; Northouse, et al., 2001). It is therefore important that health professionals understand the importance and function of the usual commitment and connections between family members. These

connections are often affected during illness as the family responds to the changes of the person with the illness.

The strength of commitment to family has not been specifically explored by previous research. However there is often reference to the commitment of family members to maintain family functioning, but commitment has not been reported as a singular strength (Fang, et al., 2001; Leske, 2003; Mellon & Northouse, 2001). Mellon and Northouse (2001) explored quality of life and links to family strengths in their quantitative study of 123 patient and family member dyads in America. Their research provided information about family survivorship and quality of life following a cancer diagnosis. They used a range of scales to measure both individual and family indicators. The instruments measured concurrent family stressors (FPI (Astedt-Kurki, et al., 2001)), fear of recurrence, somatic concerns, family hardiness (FHI (McCubbin, et al., 1986)), social support, constructed meaning scale (Ganong, 2011) and quality of life (Quality of Life Parent form (Lewis, 2004)). Mellon and Northouse (2001) report a positive correlation between family quality of life, family strengths, reported as hardiness (measured by FHI), family social support and family meaning of the cancer. The family's internal strengths influenced their appraisal of the cancer and the use of family social support, so although the researchers did not isolate the internal family strengths it was noted in the overall influence of strengths on other family attributes (Mellon & Northouse, 2001). The family strengths, family resources and cancer related stresses were noted as the main family attributes influencing family quality of life (Mellon & Northouse, 2001).

Similar findings were presented by American researchers, Fang et al. (2001) who explored physical and psychological impairment and the influence of marital quality on the spouse's distress. This was researched in their quantitative study of 197 patients and their spouses after a diagnosis of cancer. The instruments used were Psychological Distress subscale, dyadic adjustment scale (DAS), and physical limitations (CARES). Correlations from the analysis suggested a close association between levels of patient physical impairment and psychological distress which in turn were related to lower marital quality. Fang et al. concluded that there was a link between patient and spouse adjustment and distress identifying the need to understand how the family works together in response to cancer (Fang, et al., 2001).

The family's sense of cohesion has been reported in qualitative research, providing information around the family response as family members strive to maintain normality in the face of adversity (Fergus & Gray, 2009; Kennedy & Lloyd-Williams, 2009). Canadian researchers completed focus groups and individual interviews with 30 participants, 21 women with breast cancer (mean age 54) and nine male spouses (51). In particular, Fergus and Gray discuss the strengthening of relationships as part of personal growth when faced with challenges associated with illness. Patient and partner perspectives after a diagnosis of breast cancer were explored by Fergus and Gray, who described several family strengths, one aspect being a commitment to work together as they adjusted to the diagnosis and treatment (Fergus & Gray, 2009).

Providing a different view point was research by Kennedy and Lloyd-Williams (2009) who explored the children and their parents' perspective when the mother was diagnosed with advanced breast cancer in United Kingdom. Twelve families with a total of 28 participants (adults age range 37-60) were involved in semi-structured interviews as family groups or individually depending on the family's wishes. The family members described the influence of the cancer on all family members, needing to change family routines and communication however a strong theme was the commitment by the family members to support and spend valuable family time together (Kennedy & Lloyd-Williams, 2009).

A connection was found between the commitment of the family unit and how the individuals and the family as a whole appraise the illness (Northouse, 2005). This information provided an understanding of the influence on the way the family views the illness and how they respond and work together as a family. The next section will review the literature with regard to the appraisal of the health adversity.

2.3.1.2 Family appraisal of health adversity

Exploring the concept of 'appraisal of the health adversity', this section critiques the literature providing a clear definition of appraisal of health adversity and overview of this concept.

The concept 'appraisal of health adversity' has been defined by many researchers as the personal meaning an individual places on the adversity (Lazarus, 2000; Rice, 1999). The

appraisal of the illness influences the way the individual responds to the disease (Mellon & Northouse, 2001). Numerous researchers have explored this aspect of recovery in the individual, with most concluding that if the patient can appraise the illness as a challenge with a low level of threat they are more likely to use positive coping mechanisms and demonstrate maintenance of quality of life in the long term (Compas, et al., 1994; White, 2004; Wonghongkul, et al., 2006). If there is a negative appraisal or an inability to see a way to cope with the threat the individual often uses negative coping mechanisms such as avoidance or denial of problems (Compas, Worsham, Ey, & Howell, 1996; Friedman, et al., 2003; Lazarus, 1999). Exploring the individual's appraisal of the illness provides a single view of the situation. However a health adversity is seldom experienced alone. It is a shared experience influencing the family and friends supporting the individual.

While less research relates to the family appraisal of the illness there has been a range of research with family dyads exploring the appraisal of illness from a shared perspective. Northouse et al. (2005) used an intervention study with 134 dyads (mean age 54 years) to identify whether focused family based support improved the family appraisal of the situation. Northouse et al. (2005) concluded that the patients reported a decrease in hopelessness but there was no associated change in the family caregiver's level of hopelessness. Another important finding was that there was not a sustained change in either patient or family functioning (Northouse, et al., 2005). Northouse et al. (2005) suggested that exploring and reinforcing the family strengths may improve the family management of the situation thereby increasing successful long-term management of the illness. These suggestions are consistent with frameworks of family resiliency (McCubbin & McCubbin, 1993; Walsh, 1998).

Exploring the family appraisal of parental cancer is research by Compas et al. (1994; 1996) in America. In a mixed method study 117 participants (mean age patients 41 years) Compas et al. (1994; 1996) explored the psychological distress of family members with parental cancer, examining their individual appraisal of the disease and the influence on the family. The instruments used included cognitive appraisals of cancer (Davis & Compas 1986), anxiety / depression symptom index age related (CDI, R-CMAS, YSR, BSI), and stress response to symptoms (IES). Patients with a range of cancers were recruited from the medical oncology clinics by the medical staff, and the family members were then contacted and the questionnaires for both patient and family members completed as a telephone or personal

interview (Compas, et al., 1994). The researchers concluded that personal appraisal of the disease related to the degree of structural changes needed in the family, rather than the actual characteristics of the disease (Compas, et al., 1994). The more role changes within the family that resulted from the disease, the more likely the family were to negatively appraise the situation. Furthermore, the younger the family members were, the more likely they were to appraise the situation negatively. Adolescent girls tended to negatively appraise their mother's illness, often because of greater caretaking responsibilities and their perception of a personally increased risk of the disease (Compas, et al., 1994). Compas et al. (1994) concluded that individual assessment of family members and ongoing intervention is warranted because of the complex interaction of family members in the response to stress. Although Compas et al.'s (1994, 1996) research is not recent; little current research has explored this depth of family response to cancer with the inclusion of children and adults in the study.

An important consideration with respect to younger women with breast cancer is the uncertainty of the disease in their younger phase of life and the influence this has on their personal appraisal of the disease (Wonghongkul, et al., 2006). While breast cancer has a tremendous influence on their lives and that of their family, younger women have been found to appraise breast cancer as a challenge, and show determination against the odds to survive and see their children grow (Coyne & Borbasi, 2006; Sammarco, 2001). The younger women tend to show strength and determination to not let the breast cancer take over their lives. This is a repeated theme across qualitative research and supported in quantitative research (Coyne & Borbasi, 2006; Sears, et al., 2003). Although the appraisal of the breast cancer as a positive challenge is also noted in older women with breast cancer, research presents this as a different theme for the older age group, with a focus on maintaining quality of life rather than determination for life as shown with the younger women (Dunn & Steginga, 2000; Manuel, Burwell, Crawford, Lawrence, Farmer, Hege et al., 2007).

The actual style of coping strategy the individual uses also influences their appraisal of the stress and their adaptation. For example, research has shown that individuals who appraise the situation as negative and employ negative coping strategies such as hopelessness and helplessness, report greater degrees of stress and poorer adaptation compared to those who

responded with a ‘fighting spirit’ (Lazarus, 1999; Schnoll, Harlow, Stolbach, & Brandt, 1998).

Schnoll et al. (1998), who completed a quantitative study of 100 women in America (mean age 44 years), examined the relationship between age, disease state, coping and psychological adjustment. The scales used were mental adjustment to cancer (MAC), symptom index (BSI) and functional living index (FLIC). The factors found to influence coping styles and adjustment were role and structural changes within the family in addition to physical disabilities. Consequently, Schnoll et al. (1998) argued that younger patients experience more disruptions in their lives, although they tend to use an adaptive style of coping, appraising the breast cancer journey as a positive influence.

In contrast, research by Drageset and Lindstrom (2005) in their study of 117 women in Norway who had undergone a breast biopsy reported minimal relationship between age and anxiety. However their age group of participants was older with a mean age of 54 years. The instruments used were anxiety scale (STAI), Social provision (SPS), coping (CODE) and defence mechanisms (DMI). Drageset and Lindstrom (2005) did note the use of emotion-focused coping styles by the younger participants and the connection between social support and more positive adaptation. One of the influencing factors of personal appraisal of a stress is social support provided and how this support manages to change related to the disease trajectory over time.

The appraisal of the illness influences the individual and family response to the illness, however research also highlighted the relationship between family support and a positive appraisal of the illness. The following section will critique the literature around how the family responds and functions during an illness.

2.3.1.3 Family functioning

The purpose of this section is to explore family functioning, providing a definition of the concept of family functioning and a critique of the current literature.

Family functioning is defined as the changes within the family which occur in response to illness (Friedman, et al., 2003; Walsh, 2006). When a family is disrupted by adverse events,

the flexibility or openness to change roles within the family in attempt to maintain continuity or normality is seen as a positive demonstration of the family's internal strengths (McCubbin & McCubbin, 1993; Walsh, 2006; Wright & Bell, 2009). Partners and other family members are known to be active participants within the patient's experience of breast cancer, sharing both emotional and practical concerns (Baucom, Porter, Kirby, Gremore, Wiesenthal, Aldridge et al., 2009; Bloom, et al., 2001; Mellon & Northouse, 2001). Family members will often have to become flexible in sharing of roles over the disease trajectory. It is this family flexibility that is a positive strength within a family (Wright & Bell, 2009).

Research suggests that an inability to maintain family functioning and for family members to be flexible within roles is a negative response to health adversity (Board & Ryan-Wenger, 2000; Edwards & Clarke, 2004; McCubbin, et al., 1998). The different levels of family functioning and need to change roles within the family is closely influenced by the disease trajectory and family members will continue to focus on supporting the person with the illness (Sharpe, Butow, Smith, Mcconnell, & Clarke, 2005). In some cases family often form the role of carer for the patient, however, the partner / family may actually be unsupported in this crucial role, particularly as they attempt to maintain the normality of life (Forrest, et al., 2009; Thomas, Morris, & Harman, 2002; Yates, Aranda, Edward, Nash, Skerman, & McCarthy, 2004).

Roles of the family as carer have been discussed in previous research, in terms of assisting with pain management (Yates, et al., 2004), emotional or instrumental support (Bloom, et al., 2001), support for children (Forrest, et al., 2009) and emotional support (being strong and positive) (Thomas, et al., 2002). Generally, the family carer described these roles, as significant and mostly rewarding but they also noted that at times it was distressing as they struggled with their new role and compromised family functioning (Bloom, et al., 2001).

Previous research while acknowledging the importance of the family support role, offers little in terms of how to meet the support person's needs. One of the concerns for the supporting family is the need to change roles within the family. This is especially necessary when the younger woman is diagnosed with breast cancer (Bloom, et al., 2004). Researchers exploring the family functioning and changes of roles within the family have used a range of research methods to provide information about the family roles. In most cases the research has explored the family dyad or just the patient's perspective.

An Australian quantitative study by Yates et al. (2004) of 75 patients and caregivers explored pain management by the caregivers. A variety of scales were used to measure the study variables developed from the Green's PRECEDE model of behaviour. Yates et al. (2004) reported that family caregivers (75% female, 84% over 50 years), felt confident in their new role of assisting with medication administration to their family member, although they reported experiencing early distress with this new role. A recommendation from the Yates et al. research was to develop a family focused approach to caring for patients with cancer as a commonly reported problem was inadequate communication and support from the doctor for the caregiver (Yates, et al., 2004). The roles of caregiver may often be delegated to the female in the family, as evidenced in Yates et al.'s (2004) research, which had a higher number of females recruited. However with a young woman with breast cancer the role of caregiver is often reliant on the male supporting her or the woman's mother and a situation with increased distress may result (Bloom, et al., 2001).

The support network of a woman with breast cancer provides both emotional and physical support and research has identified that the more integrated she is with this support the more she will be supported (Bloom, et al., 2001). A longitudinal quantitative study by Bloom et al. in America with 336 women (mean age 44) explored the sources of social support for young women. The scales used were physical and mental well-being (MOS SF 36), quality of life (measured by physical, social, psychological and spiritual domains), body image and coping. The Bloom et al. (2001) study reported that the women received more support if they were married, however only 34% reported they received psychosocial support in the past year since diagnosis. An interesting finding was that women reported they received more emotional support from family and friends if they were receiving chemotherapy and more physical support if their treatment was surgery (mastectomy). Expanding on the earlier findings from Bloom et al. (2001) is the presentation of their qualitative findings and longitudinal research (Bloom, et al., 2004). In these findings the researchers report the longer term influence of social support and the ability of this support to understand the emotional and instrumental support needed to assist the adjustment of the younger woman with breast cancer (Bloom, et al., 2004). The research does not describe the roles of the support provided just the women's perspective of this support to her adjustment.

In American research addressing psychosocial and support concerns, Walsh, Manuel and Avis (2005) used a sample of 220 women with breast cancer (mean age 43 years) who completed questionnaires, and provided qualitative comments. Discussing aspects such as role shifts when the younger women were not able to maintain their roles within the family, Walsh et al. (2005) describe both the positive and negative feelings as the women rely more on the family members to support them. Most women in the sample reported positive growth in their relationships although this was linked to communications within the family and the family dynamics.

Another aspect of family functioning is the leadership of the family. Current research has suggested that the family leader provides guidance and helps maintain family functioning (McCubbin, et al., 1998; Walsh, 2003). When effectively led, family members are able to link past experience to the present situation and hence are more likely to increase family stability (Forrest, et al., 2009). Many families have a central person who leads by relaying information and providing direction for family members, thus reducing the overall anxiety of the family (Northouse, et al., 2005). Although having a designated leader may be evident in some families, other families may be less organised (Giarelli, McCorkle, & Monturo, 2003). Giarelli, McCorkle and Monturo (2003) explored the wife's role in providing family leadership when their spouse had prostate cancer, finding that wives struggled with the intense nature of the caregiving role, which meant they had to learn how to balance other roles, including organising and leadership with caregiving. Lewis (2004) discussed the difficulties of changing roles and maintaining family functioning when faced with breast cancer in their review of several studies. Both Lewis (2004) and Giarelli et al (2003) recommended family focused interventions to assist the family in organisation strategies.

Using Rolland's Family Systems Model (Rolland, 1994) the qualitative study by Forrest et al. (2009) discussed the changing of leadership roles when the mother is incapacitated. Interviewing 26 fathers and 31 children Forrest et al. (2009) extends an understanding of the supportive role of communication. The flow of information and support to the children was maintained or attempted to be maintained by the father when the mother with breast cancer was unable to continue this role. However the men described this role as complex and with considerable emotional stress (Forrest, et al., 2009). The factors influencing the father's ability were the age of the children and the communication styles between family members (Forrest, et al., 2009).

The provision of nurturance, protection and guidance are also important features of leadership often provided by the woman in the family (Walsh, 2006). In particular, previous research has identified that a mother who is isolated from her family and from spousal support and guidance, tends to experience increased anxiety, particularly if normal roles and family functioning cannot be maintained (Board & Ryan-Wenger, 2000; Landmark, Strandmark, & Wahl, 2002).

In the majority of previous research exploring role changes within the family the participants have been either the person with the disease or the partners of the patient. Although this provides a view of the family roles it does not allow for the depth and back stage behaviour of the family (Greenstein, 2006). Back stage behaviour is noted as normal behaviour that the family displays at home, often not visible to an outsider. This is often described as roles of different family members and customs observed by the family. The importance of understanding this backstage behaviour is the influence of the normal at home behaviour when exploring role changes within the family in response to stress. When interviewed or asked about behaviour changes or conflicts within the family unit, participants would often reflect on these differently depending on their personal appraisal of these changes. Thus asking several different family members for a view of family role changes and flexibility provides a realistic view of the interference of the stress on the family (Aranda, Yates, Edwards, Nash, Skerman, & McCarthy, 2004; Coyne, Wollin, & Creedy, 2012; Greenstein, 2006). The current study addressed this methodological problem by the recruitment a range of family members within each family.

An important aspect of maintaining family functioning when faced with a challenge is ability to communicate effectively. The next section will explore the literature in relation to communication styles.

2.3.1.4 Family Communication

The strength ‘communication’ is presented in this section beginning with a definition of the concept and then the discussion of the importance of communication.

Family researchers have defined communication as the transmission and reception of both information and instructions (Friedman, et al., 2003; Greenstein, 2006). A good communication process allows for the understanding of not only the information, but also the context around the message (Friedman, et al., 2003; Friesen, et al., 2002). Research has highlighted the importance of understanding communication within the family including the styles of communication and the information the family members are sharing. While most of the research to date has used either the patient or dyad approach, it is important to understand the perspectives of family members (Black & Lobo, 2008; Greenstein, 2006). Although both quantitative and qualitative methods have been used, predominantly the qualitative method has provided information regarding the style of communication and what this communication means for the family's adjustment to the adversity.

A range of names for communication styles are used by researchers although the clarification of the type of information sharing and the context within which the communication occurs provides a clearer description of the communication styles (Davis, Kristjanson, & Blight, 2003; Friedman, et al., 2003). Research exploring communication styles identifies two types of communication, functional and dysfunctional and individuals may use a range of styles as they communicate with others. An important aspect of communication is not only the sending of messages, but also the receiving of the message. Functional styles of communications are defined as when a person communicates openly, clearly stating messages, clarifying feelings and inviting feedback and clarification of message. Dysfunctional communication styles are often ineffective ways of communicating messages. These styles lack clarity of the message, express feeling poorly, make judgments and assumptions of the message, often with the sender of the message unable to express their needs.

Patterns of communication are developed by individuals and families and there are often several factors which influence communication styles within families. For example the culture of the family will influence the styles of communication and the hierarchy of communication between family members (Fukui, Ogawa, Ohtsuka, & Fukui, 2009). Japanese research by Fukui et al. (2009) explored the communication styles of nurses and their ability to detect distress in oncology patients. Their intervention study identified that training in communication did enhance the nurses' ability to understand and work with patients' communication styles (Fukui, et al., 2009).

Other influencing factors are family life cycle and the context of the situation and where and who the communication is between. Research has explored these factors in relation to communication identifying the influence on styles of communication between family members (Davis, et al., 2003; Forrest, et al., 2009; Harris & Templeton, 2001).

The context of the communication is highlighted in research exploring the communication styles between the patient and their doctor or the health professional (Harris & Templeton, 2001). Canadian research by Harris and Templeton (2001) explored the concerns expressed by 15 women with breast cancer during care by the physician. The main finding was the positive influence of active listening and honesty from the physician on the women's experiences of care during their treatment.

The patient's ability to communicate distress effectively relates not only to patterns of communication within the family and their experience communicating with the nurses and health professionals. Australian research by Davis, Kristjanson and Blight (2003) explored the importance of communication patterns between 60 nurses and patients with advanced cancer. Their study revealed that communicating with the family especially in relation to explaining poor prognosis or bad news was a particular challenge for the nurses (Davis, et al., 2003). However, when nurses were able to establish positive approaches to communication with the patient and family there was a greater likelihood of them transferring those communication strategies to the home situation. Other researchers concur. The ability to communicate effectively within a family sharing both information and emotions has been identified as a significant contributor to the level of distress felt within the family (Fergus & Gray, 2009; Forrest, et al., 2009). Fergus and Gray (2009) reported that the sharing of concerns and emotional distress were influencing factors of personal growth and adjustment in family dyads when the women had breast cancer. In their qualitative study of 30 participants (mean age 54 years), including nine couples, Fergus and Gray (2009) identified different levels of communication from self-absorption, over controlling, withholding and accommodating as the couples adjusted to the breast cancer. The different styles of communication have been found to have an effect on the levels of assistance provided to the family members (Edwards & Clarke, 2004).

Similarly, Forrest et al. (2009) explored the father's role of communication with the children in the family while the mother was receiving treatment for breast cancer. In Forrest et al.'s

(2009) qualitative study of 28 fathers (mean age 46 years) whose partners had breast cancer; the fathers discussed the challenges of communicating with children while fighting their own personal distress. Different levels of communication again appeared apparent, ranging from open provision of information, reassurance, to difficulties sharing information and feelings. The different styles of communication were discussed particularly the difference between age groups within the family and the influence of this on clear communication of the message and the emotion surrounding it. In concluding, Forrest et al. (2009) argued that the family framework for exploring the interaction between family members was particularly useful. They also discussed the key aspect of open sharing both positive and negative to facilitate family adjustment.

Another aspect of communication is the sharing of humour in a situation to reduce and share the stress. For some individuals, finding the positives in a situation equates to finding humour in the situation. Young people with breast cancer are noted for their ability to find a positive side in situations, often enhancing their overall ability to cope with a stressful situation (Kershaw, et al., 2004; Northouse, et al., 2005; Sammarco, 2001). American researchers Northouse et al. (2005) completed a range of studies on women with breast cancer and their family caregiver as a dyad approach over a period of years. Exploring coping styles with several quantitative scales Kershaw et al. (2004) noted that the patients used more emotional coping styles than the family caregivers, for example humour, positive reframing and venting. In particular the female caregivers used more emotive style coping strategies than the male caregivers.

In fact, research has demonstrated that humour is particularly beneficial in stressful situations, as it provides acceptance of mistakes and sharing of common fears (Coyne & Borbasi, 2006; Johnson, 2002; Walsh, 1998). Similarly, being confident in overcoming a stressful situation is a strength displayed by individuals, the confidence of believing in themselves (Walsh, 1998). Johnson (2002) explored the use of humour in nine women one year after a diagnosis of breast cancer. Using a semi-structured interview approach questions asked specifically about their coping strategies, participants described a laugh or cry situation when coping with breast cancer helped them through. Laughter was noted as the better option to coping however (Johnson, 2002).

The confidence of family members that each member will do their best for a common goal reaffirms the family strengths and promotes positive family growth (McCubbin & McCubbin, 1993; Walsh, 2003). Communication between family members is an important part of how the family shares concerns and information, but also how the family is able to ask for assistance.

2.3.1.5 Summary of family strengths literature

To summarise, family strengths refer to characteristics of the family which influence their response to health adversity (McCubbin & McCubbin, 1993; Walsh, 2002). In this research, family strengths are characterised by the family's commitment to the family unit, their ability to view change as positive and be flexible within the family roles, and the communication used by the family members. The strengths of the family form the characteristics that shape the way a family responds to a health adversity.

Understanding how the family members appraise the illness and respond using a range of strengths in an attempt to maintain family functioning may provide guidance for health professionals (McCubbin & McCubbin, 1993; Northouse, et al., 2005; White, 2004). This is an important element of the current study, aiming to explore the strengths and resources the young woman and her family members use during treatment for breast cancer. The next section will critique the literature regarding internal and external family resources.

2.3.2 Family Resources

Family resources critiqued in the current study are explored within the context of the Family Resiliency Model (McCubbin, et al., 1998) in conjunction with the Walsh framework (Walsh, 2006). The following sections will critique the literature around resources including social support, spiritual support and health professional support.

The family is a group of individuals who bring a combination of resources into the shared relationship. It is the flexible combination of these resources that allows some families to mobilise and deal constructively with adversity while other families are immobilised by the situation (McCubbin, et al., 1998; Wright & Bell, 2009). Family resources provide the family with the capacity to access assistance to manage the situation with minimal disruption to their functioning. Previous family researchers have described family resources to include social support, spiritual support, and health professional support (McCubbin & McCubbin, 1993;

Silberberg, 2001; Walsh, 2006). Financial resources also influence the family's ability to access and make suitable use of the available resources although these were only briefly explored in the current study through the use of demographic information as opposed to financial information.

Specifically, family resources are external resources used by the family to assist their adjustment to the adversity. The resource social support is the network surrounding the family such as extended family, friends, and neighbours. Spiritual support refers to personal support from spirituality. This may be in the form of Christian or religious connection or a form of personal meditation. Health professional support is the support from community services, support groups, general practitioners, allied health and the nurses. The following section will critique the literature around the family resource of social support, providing a definition and context of social support as explored within the current study.

2.3.2.1 Social support

Family researchers have defined social support as the close family support that is provided by immediate family members, but also other members of the family who are considered within the close family circle (Silberberg, 2001; Wright & Bell, 2009). The close family support provides two aspects of care namely practical support and emotional support. The practical aspect of support explores concerns such as transport, child minding and household duties. The emotional aspect of social support relates to personal support. This is often influenced by the strengths of communication within the family as previously explored in the communication section. The majority of research identifies that social support forms part of the individual's or family's support system however researchers often do not define what is meant by social support (Black & Lobo, 2008).

The close family will often provide practical support, changing to meet the patient's needs of assistance and to assist them to maintain their role within the family (Northouse, et al., 2007). In Northouse and colleague's (2007) quantitative research exploring psychosocial adjustment to recurrence of breast cancer they reported the changing of practical support needed over the trajectory of the breast cancer. Another finding was the higher levels of emotional distress reported by the women particularly in relation to symptoms of recurrence of breast cancer (Northouse, et al., 2007).

The importance of a good support network was highlighted by American researchers, Bloom et al. (2001) in their longitudinal study of 336 women aged less than fifty years with breast cancer. This study noted that the effective integration of the woman within her social support network, and the quality of the emotional and physical support she receives, is directly related to improved mental, physical well-being and self-esteem. A woman with low self-esteem tended to have a more limited social support network and an increased reliance on ineffective coping strategies. Bloom et al. (2001) subsequently concluded that the degree and quality of the external social support network is a significant factor in the overall longer-term recovery of the woman. A limitation of the Bloom study is that it lacked a clear definition of 'social support network'.

Social support from friends and family may be either positive in assisting the patient to regain confidence, or negative, in that it may actually increase their feeling of isolation (Landmark, et al., 2002). Qualitative research by Landmark, Strandmark and Wahl (2002) identified that support from family and friends represented security and often took the form of both emotional support and practical support. Support from health professionals, however was noted to lack continuity and participants described a need for increased information and emotional support from the health professional (Landmark, et al., 2002). While Landmark and colleague's Norwegian study explored the social support of only ten women, other studies have identified similar findings, highlighting the need for an improved understanding of family support needs (Figueiredo, Fries, & Ingram, 2004; Wilkes, et al., 2002).

One of the main aspects of social support is for the family to provide support for the patient in the management of treatment concerns. In particular, previous research reports that the family may wish to be involved in the management of cancer-related symptoms, but also suffer a degree of distress during this involvement (Yates, et al., 2004). Yates and colleague's (2004) Australian research identified that family members felt rewarded by being able to assist and support their family member, and this was a role of family support. However the family members reported that at times they were challenged and poor communication and lack of support from health professionals did not improve the support situation or the patient's pain management (Yates, et al., 2004). There is limited research exploring the roles of support with the family although there seems to be links between social support and adjustment for both the individual and the family as a group (Walsh, et al., 2005).

The family resource ‘social support’ will be explored in more depth in the specific section relating to family support.

2.3.2.2 Spiritual support

The resource spiritual support covers a range of concepts relating to an individual’s use of an external medium for the provision of support in response to a health adversity (Albaugh, 2003). The next section will explore the nature of spiritual support and critique the literature exploring this concept.

Spiritual support has been explained using a range of concepts from religious to meditation through to finding meaning in life. The main point highlighted from previous research is the clear link between finding personal spiritual support and being able to positively appraise the adversity (Johnson Taylor, 2003; Sears, et al., 2003). Spiritual support can mean many things, ranging from formal religious beliefs to harmony with nature. In today’s society there is greater overlap of spiritual experiences, particularly with the growing multicultural influence. In Australia, traditional religion is reported to be associated with a belief in God, with 64% of the population identifying themselves as Christians (AIHW, 2010). In addition, Buddhism is becoming the largest non-traditional religion at 2.1%, whereas in a national census 19% reported no religion (AIHW, 2010). Hence, when exploring spiritual support it is important to understand the personal nature of spiritual experience and the broader context of spiritual support.

Several researchers have defined spirituality as looking beyond self for greater meaning in adversity explaining that this is most commonly met in spiritual faith or cultural heritage (Choumanova, Wanat, Barrett, & Koopman, 2006; Walsh, 2006). Choumanova et al. (2006) explored the meaning of spirituality for 27 Chilean women with breast cancer. The women in their study reported religion and spirituality as the primary resources for them during their breast cancer journey. Choumanova et al. (2006) identified that the women believed a belief in God and spiritual faith would help them recuperate. The authors concluded that health professionals should be aware of the role of personal spirituality as a resource for women with breast cancer in different cultures (Choumanova, et al., 2006).

Another aspect of spiritual support discussed by several researchers is the concept of finding meaning in the adversity (Sears, et al., 2003; Walsh, 2006). Finding meaning in life when faced with adversity has been noted to bring individuals to an examination of their own spirituality and faith (Johnson Taylor, 2003; Walsh, 2003). Both quantitative and qualitative research methods have been used to explore this concept. Research by Sears, Stanton and Danoff-Burg (2003) in America explored levels of benefit findings and post traumatic growth in 92 women with breast cancer over twelve months. Findings revealed that most women (83%) reported at least one benefit from their breast cancer experience. However Sears, Stanton and Danoff-Burg (2003) concluded that there was no link between benefit finding and post traumatic growth (Sears, et al., 2003). Post traumatic growth was positively influenced by a positive appraisal of the adversity (Sears, et al., 2003).

It has been established by research that religion and spirituality influence the individual's ability to positively cope with the adversity (Albaugh, 2003; Choumanova, et al., 2006; Johnson Taylor, 2000; Reynolds, 2006). In qualitative research by Johnson Taylor (2000), interviews with twenty four women indicated that personal spirituality related to the woman's ability to see her own transformation as a process of growth from the breast cancer. Further qualitative research by Johnson Taylor (2003) concluded that health professionals need to recognise non-religious acts such as caring touch, talking, listening and physical presence provided both acknowledgement and support of the patient's spirituality. Although these studies were small qualitative studies other researchers have expanded on different aspects of spirituality exploring variability in spiritual responses.

Researchers have suggested that using spirituality seems to provide the individual with a sense of empowerment associated with taking control of one part of their life and recovery when faced with adversity (Gall, Charbonneau, Clarke, Joseph, & Shouldice, 2005). Spiritual support is like a group of coping strategies that the individual uses both subconsciously [positive appraisal, positive thinking, believing in good outcomes] and actively [prayer, meditation, connection with nature] (Gall, et al., 2005; Reynolds, 2006). The ability of the person to use these strategies effectively to reduce stress assists them in the process of adjustment.

Canadian researchers, Gall et al. (2005) expanded on the Lazarus stress and coping framework (Lazarus, 2000) suggesting that personal beliefs and behaviours in response to

adversity cause an active approach to coping with the adversity. Their study of 332 women with breast cancer [mean age 61 years] and benign disease [mean age 53 years] were recruited and completed questionnaires exploring their coping strategies and religious coping. Findings suggest that when faced with breast cancer, women increased their religious coping, and this was related to their psychological adjustment. This active approach to recovery promotes a positive sense of empowerment in the individual (Gall, et al., 2005).

Finding spiritual faith is often a very personal journey, and little research to date explores how the family as a group uses spirituality to grow in strength as a family, or how it might be measured. The Walsh Family Resiliency Framework explores the family spiritual growth in a broad context when faced with the adversity. Questions ask about a belief in a supreme being and how people draw on spiritual resources such as faith, prayer, meditation, rituals and religious community (Walsh, 2006). These questions provide a quantitative measure of spiritual support as a broad view of spiritual support. The McCubbin and McCubbin F-COPES questionnaire is very specific questioning about attendance at church and belief in God, but excluded exploration of the personal nature of spiritual support or the broader context of spiritual support.

Most research exploring spirituality has been qualitative, with personal interviews providing rich description of the individual's spiritual journey (Albaugh, 2003; Johnson Taylor, 2000, 2003). However some quantitative research has provided information related to finding meaning in adversity, thus supporting the use of quantitative questions to explore this aspect of resources. The next section explores the support provided by health professionals.

2.3.2.3 *Health Professional support*

Apart from resources within and close to the family, there is also a range of external resources or health professionals that may assist the family during a health crisis. Previous research has suggested that health professional support of the family would include internet information, community groups, support groups, counsellors, nurses and the general practitioner (Friedman, et al., 2003; McCubbin, et al., 1998). The purpose of this section is to define and explore the nature of health professional support and critique the literature exploring this resource used by the family. For the purpose of the current study health

professional support was explored in general terms allowing for a beginning understanding to be developed about what health professional support is for the Australian family.

Research has not provided a consistent definition for health professional support, mainly because of the range of services available in the community (Butow, Kirsten, Ussher, Wain, Sandoval, Hobbs et al., 2007). These services are often specific to the disease and also not consistently available to all patients (Clavarino, Lowe, Carmont, & Balandia, 2002). For the purpose of the current study health professional support was defined as the support provided by non-family members in the form of support groups, internet information, counsellors, doctors, oncology nurses and breast care nurses.

The benefits of consumer support groups in the support of individuals facing a health adversity has been explored by a range of researchers (Badger, Braden, Mishel, & Longman, 2004; Fukui, Koike, Ooba, & Yosuke, 2003; Northouse, et al., 2005; Zabalegui, Sanchez, Sanchez, & Juando, 2005). One of the consistent themes arising from these studies was that while they form a good source of support and information while the person is attending the group, there is little sustained effect once they cease attendance (Fukui, et al., 2003; Northouse, et al., 2005). Developing from this argument is the point that any information, intervention or support groups should develop new skills of adaptation for both the patient and family members in an attempt to maintain the benefit of the support group (Northouse, et al., 2005; Shepherd, Tattersall, & Butow, 2008; Zabalegui, et al., 2005).

External resources such as internet information, counsellors and exercise groups all form a standard part of the oncology patient's support network for the provision of information and emotional and physical support for the person with the cancer. Previous research has also identified that people will tend to access support services that they are familiar with in an attempt to meet their needs (Greenberger & O'Neil, 1993; Isaksen, Thuen, & Hanestad, 2003; Klemm, Bunnell, Cullen, Soneji, Gibbons, & Holecek, 2003).

An intervention study by Gustafson et al. (2001) assessed the impact of a computer-based patient information support systems on the quality of life of younger women with breast cancer. The study recruited 246 women, with a high number of these women being from low-income minority groups. The intervention was to provide computers and training to this group and measured their ability to seek information pre and post-test. The support service

provided information and the ability to share experiences. While the women reported benefits from the program, Gustafson et al. (2001) reported that there was no significant increase in quality of life in the longer term. Another point made was that the women reported no increase in their health care participation during the study (Gustafson, Hawkins, Pingree, McTavish, Arora, Mendenhall et al., 2001).

A review of literature by Huang and Penson (2008) identified the range of literature available to the cancer patient. The information ranged from statistics, treatment options, dealing with side effects to psychosocial support. However, Huang and Penson (2008) questioned the reliability of the information because a considerable amount of the information was secondary source information. Their literature review revealed that up to 64% of patients were likely to access internet information to expand their knowledge or verify their treatment choices (Huang & Penson, 2008). Huang and Penson (2008) concluded that it is important for health professionals to provide guidance for the patient through the process of information gathering.

Further to this McCullan (2006) in a review of literature explained how most patients will likely gather information before the health professional consultation and take on an active role in decision making for treatment choices. In a study to explore the accuracy of internet information on cervical cancer using a predetermined criteria for accuracy, it was found that only one of the 46 sites met the full criteria for credibility and accuracy (Selman, Prakash, & Khan, 2006). However, the other sites were easy to navigate and information was deemed appropriate, although not meeting study criteria (Selman, et al., 2006). These studies highlight the need for health professionals to understand the resources their patients use and the amount of readily available internet information, whether it is reliable or not for both patients and families to access.

The National Breast Cancer Network and many other Australian cancer support services are available for the patient and family to access as reliable online and in person resources. However health care professionals tend to underestimate the level of support needed for family and caregivers and therefore fail to refer the family unit to such facilities (Sharpe, et al., 2005; Steginga, Campbell, Ferguson, Beeden, Walls, Cairns et al., 2008). Despite what appears from a critique of the literature, to be a considerable array of internal and external resources for family and caregivers, there are numerous documented unmet needs of patients

and family in relation to breast cancer support resources (Aranda, et al., 2004; Clavarino, et al., 2002; Sharpe, et al., 2005). One of the influencing factors may be that the use of support information and groups by cancer patients has been linked to their previous experience with a support group or the usefulness of the information (Selman, et al., 2006).

An important consideration in relation to health professional support is that the type of support should match the patient and family needs in an attempt to reduce their negative response to the adversity (Butow, et al., 2007; Connell, et al., 2006; Sharpe, et al., 2005; Steginga, et al., 2008). In an Australian study to explore patterns of use of psychosocial support Steginga et al. (2008) recruited 439 cancer patients (response rate 61% to telephone questionnaire). The participants (59% female; mean age 59 years) were asked to complete several surveys identifying cancer related distress, social support, social constraints and attitudes to seeking help. The results indicated that less than half of patients were aware of community based services, and only 30 -50% were provided psychosocial advice at diagnosis, which was reduced with the trajectory of the cancer (Steinga, et al., 2008).

Another finding was that women and younger participants were more likely to access help than the male participants (Steinga, et al., 2008). This Australian study clearly demonstrates that the psychosocial support services are not being used effectively. Further questions posed by research include the need to explore what resources are used and wanted by the cancer patient in their response to their diagnosis (Steinga, et al., 2008).

The type of support group is known to influence the continued participation in the support group by the cancer patient. A recent Australian study by Butow et al. (2007) explored the reasons for attending support groups. A sample of 417 cancer patients (response rate 56%) returned questionnaires provided to the patients at face to face support groups. The main reasons noted for continued attendance of the support group were having a feeling of connectedness to group, sense of community, hearing current medical information and good group leadership (Butow, et al., 2007). Another point was that the requirements of the group changed as the patients were further along their cancer trajectory. Although the Butow et al. study only explored the patient perspective, one of their recommendations was to allow for opportunities for family carers to meet separately in support groups specifically designed for the family member's needs (Butow, et al., 2007). Interestingly it was not a suggestion to have family members included in the patient support groups, although this may not have been a question asked by the researchers. Unmet needs were also identified by the Butow et al.

(2007) research, and over 30% of participants reported unmet needs in relation to financial, spiritual and physical needs, particularly wigs, side effects and equipment. These findings highlight the need for health professional support to focus increased amounts of time to provide information for both the patient and the family on these concerns.

Another type of external resource available is the exercise group, designed to assist both emotional and physical recovery (Courneya, Blanchard, & Laing, 2001; Daley, Mutrie, Crank, Coleman, & Saxton, 2004; Dorn, Vena, Brasure, Freudenheim, & Graham, 2003; Ingram, Courneya, & Kingston, 2006; Schwartz, 2004). A common finding from several studies of exercise support groups is that exercise has a positive influence on participant's adjustment. However, findings suggest that adherence to the intervention was more directly correlated to the woman's internal motivation to do so, rather than any motivation provided by the group (Courneya, et al., 2001; Schwartz, 2004).

An exercise and wellbeing project completed in United Kingdom with 120 breast cancer survivors in the first three years past diagnosis provided participants with both exercise plans and exercise counselling (Daley, Crank, Saxton, Mutrie, Coleman, & Roalfe, 2007; Daley, et al., 2004). The intervention study provided eight weeks of guided exercise for the participants in the intervention group, with this group reporting significant increases in quality of life and reduction in depression, although these were not maintained over time (Daley, et al., 2007). Exercise invention studies mainly recruit the person with cancer, so although there is benefit while completing the intervention, longer term benefits such as changes in lifestyle and family support to maintain the changes have not been acquired (Zabalegui, et al., 2005).

The breast care nurse has been noted to provide a personalized and highly appreciated level of psychosocial support and referral; however, patient access to this service is limited (Liebert & Furber, 2004; Liebert, Parle, White, & Rodger, 2001; Parle, Gallagher, Gray, Aker, & Liebert, 2001). This specialised nurse has training in counselling and physical care of the patient after breast cancer diagnosis, often providing tailored care for her allocated patients from diagnosis to final treatment (Liebert, et al., 2001). Australian researchers Liebert et al. (2001) have explored the breast care nurse service in quantitative studies with up to 217 women with breast cancer over a six month period exploring what was provided by the breast care nurse and how was this important.

In Australian studies exploring the supportive services for breast cancer patients a small percentage of these patients have reported being supported by the breast care nurse and thankful for this support (Coyne & Borbasi, 2009; Liebert & Furber, 2004; Steginga, et al., 1998). For most of the patients undergoing treatment for breast cancer their main source of health professional support will be from the oncology nurses.

The oncology nurse often becomes a key link in the organisation of resources and support for the cancer patient, although at times the nurse may feel inadequate in this role (Turner, et al., 2007). Specific training in communication and assessment of distress may improve the nurse's role in supporting the patient, and several research studies explored the nurse's role in supportive care (Davis, et al., 2003; Fukui, et al., 2009; Stone, Ream, Richardson, Thomas, Andrews, Campbell et al., 2003; Turner, et al., 2007). Patients also acknowledge that the nurse has the most contact with them and provides both emotional and physical support over their cancer journey. However, at times this support is lost in the routine care and not available to the family members (Coyne & Borbasi, 2009; Lui, Mok, & Wong, 2006; Turner, et al., 2007).

The patient's medical doctor is also noted to provide support for the patient although this tends to be directional support to specific support services rather than addressing patients' needs (Degner, 2002). Research exploring emotional distress in patients found that, in most cases, medical doctors were very poor at detecting emotional distress in their patients and patients were often reluctant to burden the doctor with their problems (Merckaert, Libert, Delvaux, Marchal, Boniver, Etienne et al., 2008; Turner, Kelly, Swanson, Allison, & Wetzig, 2005).

The family and social networks are crucial forms of support in times of trouble. However, the family must have the knowledge and financial resources to access them. It has been suggested that the socio-economically disadvantaged family often displays an increased level of anxiety due to their reduced ability to communicate successfully with health professionals (Iqbal, Qureshi, & Saeed Siddiqui, 2001; Isaksen, et al., 2003; Merckaert, et al., 2008). According to Iqbal et al. (2001) and Isaksen et al. (2003), couples with lower education levels experience increased problems with understanding medical information, which results in feelings of disempowerment and further reduction in accessing information. These families were also found to have less ability to access health professional assistance, despite their

needs being greater than their more affluent counterparts (Isaksen, et al., 2003). They concluded that there was a direct link to the ability to access health services and an overall adjustment to the disease (Isaksen, et al., 2003). A link was also noted in Steginga et al.'s (2008) Australian research of 439 cancer patients exploring help seeking behaviours where social constraints, socioeconomic status and cancer distress influenced the participants desire to seek help.

The trajectory of breast cancer is not linear, and the patient receives a range of active and maintenance treatments that may overlap. Hence the timing and availability of support needs should be considered. Yet there is little research exploring how the needs and resources of the family with breast cancer change over time. The importance of this longer term perspective is highlighted by a study based on the Family Resiliency Model (Curtiss, Klemz, & Vanderploeg, 2000) that examined the changes in family functioning and resources over the trajectory of traumatic brain injury. The Curtiss, Klemz, & Vanderploeg (2000) research identified that there were significant changes in family needs and functioning from the initial stages to rehabilitation. These changes related to the ability of the family to seek assistance, to use resources and to develop new problem-solving behaviour, and significantly influenced their adaptation to this stressful event (Curtiss, et al., 2000). These findings are similar to the Northouse, Templin and Mood (2001) study, which also noted close association between patient and family adjustment over the trajectory of disease.

2.3.2.4 Summary of family resources literature

In summary, social support, spiritual support and health professional support all form part of the family's resources as they respond to the breast cancer diagnosis (McCubbin, et al., 1998). The family's use of resources coupled with the family's strengths will influence the family response to health adversity. Research suggests the timing of these resources and the family's ability to access them are also very important. Increasing the understanding of the resources used by the family will provide further guidance for health professionals as they work with the family during treatment for breast cancer. The following section will explore what is currently known concerning the family functioning, structure and roles especially the younger family.

2.4 Family response to health adversity

This section presents a critique of the literature pertaining to families experiencing health adversity, in particular the diagnosis and treatment for breast cancer for young women. The family functioning, structure, and the roles of family members will be explored as the family contends with the diagnosis of breast cancer. The importance of maintaining the integrity of the family unit will also be discussed.

2.4.1 Overview of Family

A definition of family, an overview of family characteristics and critique the literature around the support provided by the family is presented in this section.

In the last decade, the importance of family support for a family member in response to health adversity has been recognised by numerous researchers (Bloom, 2008; Friedman, et al., 2003; McCubbin, et al., 1998; Northouse, 2005; Walsh, 2003; Wright & Bell, 2009). The nuclear family is considered the basic unit of Western society and the influence of that nuclear family is believed to closely affect the growth and wellbeing of each of the individual family members (Friedman, et al., 2003). As noted in chapter one the family must be defined to provide clarity of who is being researched. The current study used the following definition of family. Family is defined as a group of individuals who are bound by strong emotional ties, a sense of belonging, and a commitment to being involved in one another's lives, calling themselves family (Friedman, et al., 2003; Walsh, 2006; Wright & Bell, 2009). The definition includes, but is not limited by, the 'nuclear' family style of family. Thus extended family and friends can be included as family for the current study. The current study also explored the family in the context of the younger women aged less than fifty years.

Changes in our society have challenged family forms and there are now many types of family in Australian society, including sole parents, blended and step families and single sex families (Silberberg, 2001; Walsh, 2006). Families face different challenges that reflect their family form, and challenges related to economic and child rearing practices, although research has identified that these families often develop practices and strengths to maintain their family functioning (Silberberg, 2001). Extended family and friends often become an integral part of some families, providing both practical and emotional support especially in

times of difficulty (Silberberg, 2001). The sample in the current study reflected a range of family types, including sole parent families, blended families and single sex families.

2.4.1.1 Support provided by Family

It is suggested that for the individual, the family not only provides a protective buffer from society, but is also vital in creating stability and strength to cope with the pressures from people external to the family (Kim, Kashy, Spillers, & Evans, 2009; Minuchin, 1974).

Research has confirmed this concept of a family buffer by demonstrating the benefits of family support during times of illness (Bloom, et al., 2001; Wagner, Bigatti, & Storniolo, 2005). Family members are able to optimise family functioning during times of adversity, providing both practical and emotional support, (Bloom, 2008; Silberberg, 2001). Although the family are able to provide protection and support for the cancer patient, research has also identified the unmet needs and distress of the family living with the patient (Kim, et al., 2009).

In a large longitudinal study, Kim et al. (2009) collected quantitative data from 1666 adult caregivers (mean age 53 years, 79% female) over a period of five years. The study used three data collection periods of two months, two years and five years in a mailed questionnaire with a 74% response rate. From a range of quality of life and needs assessment scales several key themes are reported, including findings that family members have a range of unmet psychosocial needs. In addition, the authors indicated that age was a consistent predictor of unmet needs with the younger caregivers reporting unmet needs across the five years (Kim, et al., 2009). Socio-demographic characteristics of caregivers including education and household income were found to influence resource needs (Kim, et al., 2009). These larger research studies provide evidence of the support given by family members and the unresolved distress of family members. However, the need for further research to understand how the family provide this support is highlighted as clearly the family members are not adequately supported in their role.

Previous research has found that married women with breast cancer have been found to have an improved quality of life due to the continued support from their partner over the trajectory of the disease (Osborne, Ostir, Du, Peek, & Goodwin, 2005; Romero, Lindsay, Dalton, Nelson, & Friedman, 2008; Scott, Halford, & Ward, 2004). One of the influencing factors

identified was the type of coping strategies used by the partner. A sample of married women with breast cancer (mean age 51 years) and their partners (45 couples in total) completed several questionnaires examining relationships and coping styles after a diagnosis of breast cancer (Romero, et al., 2008). Clear communication and understanding the women's distress were related to greater satisfaction with the relationship. Recommendation arising from the research included identification of the need to encourage partners to use open communication and inquire about their spouse's emotional and social needs (Romero, et al., 2008). A limitation acknowledged by Romero et al. (2008) in their study was in the completion of questionnaires by the partners. Their estimation of the distress of the other person rather than direct collection of distress levels was problematic as the family did not accurately reflect the patient's distress levels.

Similar findings were reported by American researchers Wagner, Bigatti and Storniolo (2006) who explored quality of life of husbands (79 participants) whose wives were diagnosed with breast cancer. Using a questionnaire with quality of life, impact of illness and coping strategies scales Wagner, Bigatti and Storniolo (2006) aimed to understand the nature of coping by the husband. The research indicated that there were two different responses namely emotion-focused and a problem-focused coping strategy. The response used by the husbands influenced the quality of life of their wife with breast cancer (Wagner, Bigatti, & Storniolo, 2006). Another finding was that the disease and impact on the family also influenced the partner's response and coping strategy (Wagner, et al., 2006).

It has been suggested that the phase of life of the family may influence the family's response during a health crisis (Rolland & Walsh, 2006). What has been identified by research is the association of dependent children's ages in a family and family functioning (Forrest, et al., 2009; Sammarco, 2001). United Kingdom researchers, Forrest and colleague's 2009 qualitative study of 26 fathers and 31 children of women with breast cancer found some differences according to children's development stage. Young children were concerned about changes in family routine. Adolescents and teenagers had more understanding of their mother's illness and the severity of changes that may occur in their lives such as the fact that their mother may not survive. Each stage brought different concerns for the partners to deal with (Forrest, et al., 2009).

However earlier research did not suggest an association between dependent children's ages and family functioning (Schmitt, et al., 2008). In their quantitative study of Finnish families with cancer, Schmitt et al. (2008) found that family structure, number of children, gender and age of participants were not associated with general family functioning. The sample of children in the Schmitt et al. research had a mean age of 10.7 years (SD 3.9) with 47% over the age of 11 years. Schmitt et al.'s (2008) study had a larger sample with 146 parents and 143 children than Forrest et al. (2009). The Schmitt et al. findings suggest that the underlying influence of children's ages may not be easily quantified and the qualitative information provides an increased understanding of the nature of family response.

The first year is noted to be the most critical time for the family following a breast cancer diagnosis, as studies have indicated that during this time the breast cancer diagnosis and treatment will influence the family's adjustment trajectory over future years (Forrest, et al., 2009; Northouse, et al., 2001). The family's appraisal, role adjustment and concurrent stress have been found to have a direct relationship to the adjustment of the couple's experiencing breast cancer over the longer term (Northouse, et al., 2001). Northouse and colleague's (2001) research is part of a larger study exploring couple's adjustment to benign and malignant breast disease over time, consisting of 131 couples (mean age 51 years). A limitation of the Northouse, Templin and Mood (2001) study is the broad age range of the participants, which does not allow for the specific nature of the younger age group of interest to be highlighted. The following section will explore the importance of age in relation to the family's response to the diagnosis of breast cancer.

2.4.2 The influence of age and phase of life

The purpose of this section is to critique the literature exploring the influence of age for women with breast cancer. The age of the woman with breast cancer is an important consideration when exploring adjustment to the diagnosis because it affects both the physical, emotional and the social aspects of her life. The age of the woman tends to have a direct relationship to the type of breast cancer and the subsequent disease trajectory and treatment outcomes.

Current research clearly reflects the difference in physical outcomes between younger and older women particularly the changes to fertility and menopausal changes in the younger

women (Kroenke, Rosner, Chen, Kawachi, Colditz, & Holmes, 2004; Peppercorn & Partridge, 2008; Phillips, Osborn, Giles, Dite, Apicella, Hopper et al., 2008). However, there is still debate about which age group has the lower quality of life outcomes, with researchers recommending more research is needed to explore the younger women's trajectory in view of providing appropriate support services for each age group (Kroenke, et al., 2004; NBOCC, 2010; Phillips, et al., 2008). The support services and information currently available reflects the older woman's breast cancer trajectory (NBOCC, 2010). However, there is a definite development of information and support for the younger woman in response to an increased diagnosis of women in the under fifty year age bracket and their subsequent survival of treatment (NBCC, 2004).

The tumour type and associated treatment for the younger aged women is noted as one of the influencing factors on their quality of life outcomes (Kroenke, et al., 2004). Younger women are more likely to be diagnosed with a biologically aggressive cancer and tend to need multimodal treatment that has specific and generally severe ramifications (Dixon & Hortobagyi, 2000; Kroenke, et al., 2004). The information exploring the type of breast cancer and treatment are expanded on in section 2.5 of the literature review.

The treatment for these more aggressive tumours has subsequent physical problems in particular, infertility and early onset menopause, which has become a definite burden for the younger woman as opposed to the older woman (Partridge & Ruddy, 2007; Thewes & White, 2005; Walsh, et al., 2005). Other physical concerns relate to the multimodal treatment, with the majority of younger women needing surgical intervention as well as a combination of chemotherapy and radiotherapy (Dow, 2006; NBCC, 2004). The effects of treatment are not specific to the younger woman, however, they are often severe in nature due to levels of treatment and difficulty coping due to the expectations of their age group (Coyne & Borbasi, 2009; Fobair, et al., 2006; Thewes, Butow, Gigris, & Pendlebury, 2004). It is important to understand the influence of treatment on the younger woman and her ability to continue normal activities, which may influence the woman's response to research involvement (Northouse, Rosset, Phillips, Mood, Schafenacker, & Kershaw, 2006)

Age of the women also relates to their phase of life and their family members' ages. A woman under fifty years may be in a phase of life with an early couple relationship, or couple with primary school aged children or couple with teenage children or single (Friedman, et al.,

2003; Walsh, 1993). Each of these phase of life brackets brings different challenges for the women under fifty years, as this age group is suggested to be vulnerable to increased life stress (Rice, 1999). In contrast, the older woman tends to have a steadier phase of life with older children and established relationships (Maly, Umezawa, Leake, & Silliman, 2005; Sigl Felten & Hall, 2001).

The younger age has also been noted as the peak age for child bearing, with women aged between twenty to thirty five years being the main period of their life for having children (AIHW, 2010). As noted previously one of the concerns with a diagnosis of breast cancer for this child bearing age is the changes in fertility that the breast cancer treatment will cause. The breast cancer treatment will change the woman's capability for subsequent pregnancies, which often causes a higher level of stress in response to the diagnosis if the woman has not finished her childbearing desires (Mulcahy, 2003; Thewes & White, 2005).

In fact, younger age has been identified as a consistent predictor of psychological distress after a diagnosis of cancer (NBCC, 2004; Sammarco, 2001; Schnoll, et al., 1998; Sharpe, et al., 2005). Research suggests that younger women with breast cancer tend to be less able to come to terms with the diagnosis because of the underlying societal pressures associated with their phase of life, such as being able to see their babies grow to adulthood, or reaching their own life goals (Coyne & Borbasi, 2006; Thewes, et al., 2004). Longitudinal research by Compass et al. (2004) revealed that young women enjoyed a good quality of health after five years. However Compass et al. (2004) recommended that physical, social and psychological concerns would need to be addressed with the younger age group if they were to continue to enjoy good quality of life into older age.

Another aspect of age is the variation in the personal support network, which is known to develop over time in different age groups (Bracke, et al., 2008; Wright & Bell, 2009). The family support network will develop over a lifetime, and research identifies that there is a connection between age of the network and psychological distress and the degree of personal support provided to family members (Friedman, et al., 2003). The older person is noted to have a support network that is more capable of providing appropriate support and knowledge of referral for support (Osborne, et al., 2005; Sigl Felten & Hall, 2001). In contrast, the younger person may be still building up a support network, which is being formed in a busy and unstable phase of life (Bloom, et al., 2001; Kroenke, et al., 2004; Sammarco, 2001). This

situation often leaves the young woman vulnerable to lack of support and resources to overcome adversity.

Women with breast cancer over the age of fifty are supported by family however this family tends to be established in their own life patterns (Maly, et al., 2005; Osborne, et al., 2005). A cross sectional survey of 222 newly diagnosed women with breast cancer over the age of 55 years (mean 67 years) by Maly et al. (2005) explored health outcomes, and identified that these women were clearly supported by partners and adult children. Interestingly, one of the main influencing factors on the older women's mental health and outcomes was the adjustment of the adult children to her diagnosis. Maly et al. (2005) noted that enhancing the adult children's adjustment would have a positive influence on the mother's adjustment to her breast cancer diagnosis.

Similar findings were noted in research by Kim, Wellisch, & Spillers (2008) when they explored the distress of adult daughters when their mother was diagnosed with breast cancer. The study recruited 114 dyads and used a range of quality of life and mental health scales to identify the influence between the mother and daughter. In particular Kim, Wellisch, & Spillers suggested the quality of life of the woman with breast cancer would improve if the adult daughter was provided with a resources designed to assist them coping with their mother's psychological distress (Kim, Wellisch, & Spillers, 2008). These findings highlight the close link between mother and daughter and the supporting role that is shared between them.

There are, however, differing arguments in relation to the importance of the age of a person in relation to adjustment to a health crisis. For example, Scholl et al. (2005) concluded that the women's individual coping style rather than the support network was the indirect link between age and psychological distress. They argued that younger women tend to use more adaptive styles of coping, often reflective of their positive attitude to continue on with life to have a positive survival (Schnoll, et al., 1998; Turner, et al., 2005). This attitude of seeing positive meaning in the adversity of breast cancer and aiming to survive to see children grow up has been noted in other research examining the younger women's experience of breast cancer (Bloom, et al., 2004; Coyne & Borbasi, 2006; Mast, 1998). Lazarus and Folkman (1984) and Rowland (2006) also discuss the importance of the individual's life cycle and the

relationship to where they are in life (length of marriage, current employment, level of education) to the types of coping strategies used and psychological distress they experienced.

Additionally, Lazarus and Folkman (1984) discuss situational factors rather than age and factors that cannot be changed, such as work or family environment, which influence the individual's ability to cope with an adverse situation. Other researchers have noted that for younger women, multiple life stressors such as juggling career, marriage and children are more likely to influence the ability of younger women to adjust to the diagnosis of breast cancer (Bloom, et al., 2004; Sammarco, 2001; Walsh, et al., 2005). Regardless of what helps them cope, it is clear that these stressors may have a negative influence and some women will be able to adapt and improve their family strengths, whereas others are unable to do so. The role of the woman within the family unit becomes a fundamental consideration when attempting to understand the family's response to a breast cancer diagnosis. The following section will explore and critique the literature related to the role of the woman during illness.

2.4.3 Role of women during illness

The woman's role in the family will be discussed in this section, including a critique of current research exploring role of the woman within the family.

Many authors argue that for most families, the woman assumes the role of nurturer and is central in the role of educator, counsellor and domestic organiser within the family (Bloom, et al., 2001; Friedman, et al., 2003; McGoldrick, Anderson, & Walsh, 1989). Although this is not true in all families it is an important consideration when exploring the family unit's response to breast cancer as the woman herself is the person who can no longer maintain her role within the family. The disease trajectory and treatment will influence the woman's response and may have flow on effects to the other family members. In reality however, mothers in particular tend to assume the sick role only when absolutely necessary and with a degree of emotional turmoil (Compas, et al., 1994; Friedman, et al., 2003; Walsh, et al., 2005). Consequently, in the case of prolonged or serious illness, there may be significant repercussions within the family if the woman is unwell (Dearick, et al., 1998; Ponto & Barton, 2008).

Exploring the experience of care giving for their mother with breast cancer, American researchers, Ravies and Pretter (2004) interviewed 50 daughters (mean age 38 years) identifying the close relationship between mother and daughter and the roles these women played in their families. The daughters had to work through the challenge of maintaining their own role within their family while assuming the role of caregiver for their mother (Raveis & Pretter, 2004). An interesting finding in later research was the emotional toll of changing roles and the negative influence of having spouse and other role obligations which increased the daughter's stress and reduced her personal self-esteem (Bachner, Karus, & Raveis, 2009).

In the case of a younger-aged family with child-rearing responsibilities, the family roles and functioning may be moderately disrupted when the mother has a diagnosis of breast cancer or other chronic illness (Compas, et al., 1994; Forrest, et al., 2009). Roles of child care, transport of children, home education of children, housekeeping, including shopping and practical home jobs are likely to be performed by the woman in the home (Greenberger & O'Neil, 1993). In the event of breast cancer the family will need to share these roles to help maintain family functioning (Kroenke, et al., 2004). Women are known to be the gate keepers of informal care provided at home, defining and identifying care to be provided by other family members (Bracke, et al., 2008). Bracke et al. (2008) explored family literature identifying caregiving roles within the family and the influencing factors. Their review found that women predominately fulfilled the caregiving role when family members were sick. This finding was influenced by the age of the children. The older the children the more likely they were to help with roles within the family (Bracke, et al., 2008). The role of caregiver was often continued by other females within the family if the mother or main woman was unable to fulfil her role (Bracke, et al., 2008; Himes & Reidy, 2000). Himes and Reidy reviewed data from the National Survey of Families and Households in America to examine the role that friends play in the provision of care, finding that friends of similar ages often took on caregiving responsibilities when needed (Himes & Reidy, 2000).

The woman's role of nurturer within the family is consistently mentioned in research, although research also identifies that the woman may disengage herself from children in an attempt to protect children and encourage role changes within the family (Coyne & Borbasi, 2006; Turner, et al., 2005). The practical roles within the family are often able to be negotiated between close family members and friends or external family members, although

the woman often experiences emotional distress as she loses her normal functioning roles within the family (Northouse, et al., 2001).

The psychological adjustment for the woman after a diagnosis of breast cancer is likely to be influenced by the family interaction around her, particularly in the early stages of her breast cancer journey (Shands, Lewis, & Hooper, 2000; Turner & McGrath, 1998). If the family interaction is supportive and flexible, research has demonstrated that the woman is more likely to positively adjust to the changed roles (Mellon & Northouse, 2001; Walsh, 2003). One of the main aspects of supportive family interaction is communication. Open communication that allows for expression of emotions and honest sharing of difficulties is paramount to maintaining family functioning (Edwards, Watson, St James-Roberts, Ashley, Tilney, Brougham et al., 2008; Forrest, et al., 2009).

Although role changes also happen when the father is incapacitated, in the father's case it may be more the economic situation that is subsequently influenced (Friedman, et al., 2003). Men's roles within the family are changing in society and with these changes in family structure there is definitely not the narrow focus on women's roles and men's roles, but more a sharing of roles within a family (Bracke, et al., 2008; Friedman, et al., 2003; Silberberg, 2001). Women now have equivalent education and paid work roles, however research still identifies the woman as the main nurturer and domestic organiser (AIHW, 2010).

Women are often vulnerable in their response to illness as they attempt to maintain normal family functioning and one of the protective functions of women when faced with adversity is to isolate themselves within the safety of their family (Clark, Reid, Morrison, Capewell, Murdoch, & McMurray, 2007; Himes & Reidy, 2000). This response reduces the ability of the researcher to explore this population as the women and their families tend to refrain from engaging in research activities which highlight their concerns and response to the illness. In fact, research by Northouse et al. (2006) highlighted issues faced by the researcher when attempting to recruit and retain family members in research when they are dealing with a diagnosis of cancer. Particular concerns involved the retention of the participants throughout a study as they attempt to maintain family life while dealing with cancer. The recruitment of the family members by the person already distressed by cancer also reduces the researcher's ability to obtain a sample of participants with varying levels of adjustment (Northouse, et al., 2006).

The roles of the woman within a family are varied and when she is unable to function and maintain her usual roles within the family, the whole family is influenced. One of the resulting effects on the family when the woman is diagnosed with breast cancer can be the changes within the family as they reorientate the roles and functioning of the family. However research to date has not explored the context of changing roles within the family after a diagnosis of breast cancer, particularly exploring the family members' experience.

2.4.4 Family organisation and beliefs

The following section will critique the literature in relation to the family organisation, exploring the family role and structure when the family is faced with a health adversity. Roles within a family are based on expectations of the family members, and roles may be shared by individuals within the family (Friedman, et al., 2003). Family organisation describes the structure within the family, the roles of leadership and the beliefs which guide the way the family response.

One of the important positive features of the organisation within a family is the openness of family members to changing roles. This is conceptualised as the family's ability to regroup and meet the new challenge in the face of adversity (Walsh, 2003; Wright & Bell, 2009). The flexibility of family members to change roles as family members are unable to continue their role has been explored in many health situations, both with acute and chronic illness.

Families which struggle with role organisation and belief in the family ability are known to falter and lose direction when responding to adversity (McCubbin, et al., 1998; Wright & Bell, 2009).

Wright and Bell (2009) have critiqued the concept of family functioning in their model of Family Beliefs and Illness, noting that commitment to the family and belief in the family member's ability is a key component of the family organisation structure. The family members' belief in one another as they respond to illness has been measured in past research as the individual's commitment to the family (McCubbin, et al., 1986). Leske and Jiricka (1998; 2003) measured the family's response to a critical care admission, highlighting the overall commitment by family members to work together when faced with adversity.

Another aspect of family organisation is the role of leadership within the family especially when faced with adversity. The leadership of the family is known to vary between the woman and the man, with research identifying that female partners have a higher commitment to parenting and family role demands (such as household tasks and child care responsibilities) than their male partners (Forrest, et al., 2009; Greenberger & O'Neil, 1993). Hence during the breast cancer treatment in the first year it is acknowledged that the changing of roles within a family unit may cause additional stress on the family, although the degree of stress depends on the flexibility and cohesion of the family unit (McCubbin & McCubbin, 1993). In particular, research has identified the female role in organising the family members when their baby is admitted to neonatal intensive care (Doucette & Pinelli, 2004). McCubbin, and McCubbin (1993) discuss the leadership roles within their Family Resiliency Framework highlighting that it is a positive strength of the family to have family members who can direct the family response and provide leadership for the family members.

During breast cancer treatment, the role of the partner tends to become a complex balance of caring for the woman whilst maintaining the functioning of the family unit. Walsh, Manuel and Avis (2005) in their mixed method study of 220 young women with breast cancer discussed that some women were frustrated at being unable to continue their responsibilities, with only a small percentage thankful to transfer their role when they became too sick. Another finding was the explanation by women that family members bonded as they changed roles to accommodate for her inability to fulfil her role, and even though it was painful to watch, it was viewed as a positive step for the survival of the family unit in the event that they lost their mother (Walsh, et al., 2005). This finding is consistent with the Family Resiliency Model where one of the key processes to positive adaptation is the ability of the family to find new and positive meaning from the stress (McCubbin & McCubbin, 1993; Walsh, 2003).

Similarly, post-traumatic growth and positive changes have also been reported by families following diagnosis of a chronic disease (Sales, 2003; Weiss, 2004). The family units that are able to share the experience of the cancer, both negative and positive, tend to exhibit strong family cohesion and strength such as communication and role flexibility (Weiss, 2004). The main qualities of the strong family unit are described as depth of support and commitment to the family and families which are able to work together to overcome adversity (Weiss, 2004). The social support surrounding the family unit also influences the family's ability to be

strong in the face of adversity. For example, the extended family often combines to contribute simple care-giving support, such as child care and transport, thus providing a safeguard for the family unit (Walsh, et al., 2005; Weiss, 2004). The trend in Australia for nuclear families, sees smaller family size and geographic separation reducing the availability of the extended family to contribute anything other than emotional support by distance (AIHW, 2010; Sales, 2003). Hence the family unit may have to adjust to the breast cancer and role changes with little support from extended family.

In response to adversity the family may engage their close friends to assist and support family members. In some case these friends become extended family and included as family members (Bloom, 2008; Bracke, et al., 2008; Himes & Reidy, 2000; Northouse, 1988). Research has identified that female friends who are similar age and peer group are more likely to become involved in assisting with care than male friends (Himes & Reidy, 2000). Himes and Reidy (2000) determined the caregiving status and relationship between caregiver and recipient from data collected for the National Survey of Families and Households in United States (1992 – 1994). The results identified that approximately 35% of the women in the survey had provided care for someone in the past twelve months and 5.4% had cared for a friend. In the below 50 year age group, friends were more likely to be involved in acute care giving short term care, often related to caring for family members [children] rather than the person with the disease state (Himes & Reidy, 2000).

Another consideration relating to the changing of family roles is the cultural beliefs held by the family unit. The complexities of how the family unit views the disease process and the meaning of the illness within their cultural and spiritual beliefs may significantly influence the degree of family adjustment to the illness (Chen & Rankin, 2002; Daly, Davidson, Chang, Hancock, Rees, & Thompson, 2001; Lui, et al., 2006; Mu, Ma, Hwang, & Chao, 2002; Svavarsdottir, 2005). Research examining this aspect of family adjustment found similar patterns emerged. The main points that arose in these studies indicated that culture is a learned experience and shared beliefs influence how the family reacts to illness stressors (Chen & Rankin, 2002; Lui, et al., 2006; Mu, et al., 2002). In addition, these researchers conclude that family strengths and family resources were similar in context across cultures.

Chen and Rankin (2002) used the Family Resiliency Theory, to investigate the family adjustment in Chinese children with congenital heart disease, exploring the meaning of the

illness and the family strengths used to assist their adjustment over time. The values and beliefs of a family are not easily seen by the outsider; however Chen and Rankin (2002) noted that cultural beliefs influence the family response. Particular behaviours and beliefs such as care of sick family members, balance of personal wellbeing, religion and philosophy of life are all strongly embedded in the culture of the family (Chen & Rankin, 2002). The differences in caring have also been highlighted in European cultures where the family may have experience significant distress when caring for the woman with breast cancer feeling powerless in the situation (Lindholm, Rehnsfeldt, Arman, & Hamrin, 2002).

The ability to communicate effectively with the health professional was noted to be a significant stressor for non-English speaking families (Fukui, et al., 2003; Mu, et al., 2002). This finding is consistent with other research that highlights communication of information as a one of the most important aspects of health care across cultures (Callahan, 2003; Kristjanson, Chalmers, & Woodgate, 2003; Wollin, Dale, Spencer, & Walsh, 2000). Hence it is important, to understand the family unit's strengths and resources, as they are acknowledged to influence the family unit adjustment across time within any culture.

One of the complexities of studying families is that a family is made up of individuals, each with their own appraisal of the adversity, resulting in a complex interaction between each member, their role and their single or multiple functions within the family unit (Greenstein, 2006; Minuchin, 1974). The next section will critique breast cancer as the causative factor of the health adversity.

2.5 Breast Cancer and the younger woman

Breast cancer and the trajectory of breast cancer, including statistics and disease survival will be discussed in this section. A broad outline of treatment and a critique of the current literature exploring physiological and psychological consequences of treatment for the younger woman are presented. The active and maintenance treatment phases will be explained and literature critiqued to provide understanding of the breast cancer trajectory for the family.

Breast cancer is the most common cancer-related death for Australian women, with one in eight women being diagnosed prior to the age of 85 years, accounting for 28% of all cancer

diagnoses (AIHW, 2010). In 2006, approximately 12,614 women were diagnosed in Australia (AIHW, 2010). The majority of the women are in the age bracket of 50 – 70 years, accounting for fifty percent, with the predominance of the research and support aimed at this age group (Dunn & Steginga, 2000; NBOCC, 2010). The treatment for breast cancer in the over fifty year age group is likely to be surgery and radiotherapy with a smaller percentage of these women needing chemotherapy. Thus the disease trajectory and influence is different from the younger women (NBCC, 2001; NBOCC, 2010; Reese, 2003).

However twenty-five percent of all women diagnosed with breast cancer are aged less than 50 years (AIHW, 2010). This age group characteristically comprises women who are more likely to be premenopausal and in a phase of life involving child-rearing. Consequently they may have different specific concerns related to their disease and treatment than older women (Coyne & Borbasi, 2006; Dunn & Steginga, 2000; NBCC, 2004). The trajectory of breast cancer for these younger women is often a shared experience with their younger family and children. The age at diagnosis particularly influences the type of tumour, the tumour's growth and receptiveness to treatment. The younger the woman, the lower the risk of diagnosis, but the higher the rate of five year recurrence (AIHW, 2010).

Cancer is generally perceived as an older person's disease, hence the diagnosis is often totally unexpected during this phase of life and subsequently the women often display high levels of anxiety and negative thoughts at the time of diagnosis (Badger, et al., 2004; Epping-Jordan, Compas, Osowiecki, Oppedisano, Gerhardt, Primo et al., 1999). The initial finding of a change in breast tissue tends to be distressing even if a malignancy is not found. The subsequent process of breast screening; and then waiting for the result, is often physically painful and emotionally distressing for the younger woman (Heckman, Fisher, Monsess, Merbaum, Ristvedt, & Bishop, 2004; Northouse, et al., 1998; Smith, 2000). If a diagnosis is confirmed, the treatment phase follows quickly, often with little time for consultation or thinking about family concerns such as maintaining menopausal problems and fertility (Coyne & Borbasi, 2009; Thewes & White, 2005).

Advances in medical treatment have improved the five year relative survival rate for Australian women with breast cancer to 88 % in the period 2000 - 2006, from 85 % in the period 1994-1999 (AIHW, 2010). For younger women, especially for the age group below 40 years, the five-year survival rate is slightly lower (85%), however, their survival experience

may be different due to the aggressive nature of the disease and the need for multimodal treatment often found in this age group (AIHW, 2010; Dixon & Hortobagyi, 2000). The younger women often report persistent side effects and quality of life changes in their survival phase (Bloom, et al., 2004; Fobair, et al., 2006).

Consequently, there are a significant number of young survivors who experience different physiological and psychological distress as a result of their diagnosis than their older counterparts (Northouse, et al., 2001; Steginga, et al., 1998). The physical concerns relate to the removal of the tumour and treatment for the breast cancer, which will occur over an intensive six month period or longer. The psychological effects also relate to the treatment, for example, the stress of treatment side effects. However the associated fear of recurrence is a consistent psychological stress for younger women (Avis, Crawford, & Manuel, 2005). The details of physiological and psychological concerns will be discussed in the following sections concerning active and maintenance treatment.

Disease uncertainty and fear of recurrence for the younger aged women is a major factor in their distress (Fergus & Gray, 2009; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Following the diagnosis, the treatment phase for the younger women is based on clearing of the cancerous breast tissue and lymph node involvement and reducing the risk of recurrence (Dow, 2006). The disease for younger women tends to be aggressive with a higher disease recurrence, often necessitating similarly aggressive, multimodal treatment (AIHW, 2010; Dixon & Hortobagyi, 2000).

2.5.1 Active Treatment

This section will discuss the active treatment phase of breast cancer, providing a definition and critique of the literature exploring the characteristics of this phase.

The active treatment period is where the woman is receiving active treatment for her breast cancer and seeing the oncologist frequently during this time. There are several stages during the active treatment for breast cancer; and these stages may occur at different times for each woman depending on her type of tumour. Although this active treatment phase normally lasts between two to six months, follow up treatment which is less aggressive in nature, will then continue for up to five years.

The woman with the direction of her oncologist will decide their treatment plan. This is often particularly important for the younger woman, who has often researched her breast cancer diagnosis and is aware of choices in treatment (Bilodeau & Degner, 1996; Revenson & Pranikoff, 2005; Shepherd, et al., 2008). During this time of treatment decisions a multidisciplinary team approach is used. There will be consultation with the surgeon, medical oncologist, radiation oncologist, counselling staff and in particular the breast care nurse would also be involved (NBOCC, 2010). Participation in clinical trials will also be discussed at this time if the woman fits the inclusion criteria. The oncology nurse may not be involved with the woman in the early decision stages until she begins her treatment plan, unless she is attending one of the oncology clinics during this time.

The first phase of treatment is normally removal of cancerous tissue by lumpectomy or mastectomy, with or without axillary nodal clearance. The choice of surgery is in direct relation to the size, stage and histology of the tumour (Dow, 2006; NBOCC, 2010). Breast cancers in younger women have a higher incidence of risk factors from local recurrence, so surgery to obtain clear excision margins rather than breast conserving surgery is most likely completed (NBOCC, 2010). A breast reconstruction may be undertaken during the initial surgery, or later at the end of the active treatment phase (Dow, 2006). Surgery often will occur within a week or two after diagnosis. Initially after surgery the women will most likely have axillary drains insitu for a period after surgery to reduce the initial build-up of lymphatic fluid.

The physical effects from surgery are initially pain or discomfort, reduction of movement and swelling to the breast area (NBOCC, 2010). Once the surgical site is healed physical side effects may continue to be those of discomfort, reduction of movement and lymphoedema. Younger women tend to report more symptoms and reduction in quality of life due to the higher influence the surgery has on their ability to function at their normal level (Albert, Koller, Kopp, Lorenz, Schulz, & Wagner, 2006; Fleissig, Fallowfield, Langridge, Johnson, Newcombe, Dixon et al., 2006). The continued side effects from reduction of arm mobility and lymphoedema continue into the five year survival period for some women (Phillips, et al., 2008).

The next phase of treatment may be when the medical oncologist begins a chemotherapy (cytotoxic and/or hormonal therapy) plan according to the type, stage and hormonal receptors of the tumour. This is normally administered in an outpatient oncology setting over several weeks to months, however, the first administration of chemotherapy may require the women to be hospitalised for a short period (Dow, 2006; Hamilton & Hortobagyi, 2005; NBOCC, 2010). Often the woman will need to have a central venous access device inserted for the long term administration of medications over the course of her six month treatment period. During chemotherapy there are a range of physical side effects that may occur with varying severity. Nausea, vomiting, alopecia, and tiredness are direct effects of the chemotherapy. Anti-emetics reduce the effects of nausea and vomiting and information about diet changes assist the woman to improve her nutrition during chemotherapy. Early information about hair loss and wig requirements helps to reduce the anxiety from alopecia. Although hair usually begins to grow back within three months of completing treatment it does not have the same thickness and texture as previous hair, often causing continued distress for the younger woman (NBOCC, 2010).

The effects of tiredness are varied and there is conflicting evidence regarding the influence of age in relation to degree of tiredness, although younger women generally report higher levels of tiredness (Barsevick, Whitmer, Sweeney, & Nail, 2002; Schwartz, Mori, Goa, Nail, & King, 2001; Stone, et al., 2003). The influence of tiredness on the younger patient often relates to the phase of life where these women are often having to care for young children, and continue to work whilst continuing their chemotherapy plan (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2005; Steginga, et al., 1998). One positive consideration is the encouragement of exercise to reduce the effects of tiredness, and the younger woman in particular tends to maintain a positive exercise routine over the course of their treatment (Daley, et al., 2004).

Treatment induced amenorrhoea or menopause adds to the effectiveness of chemotherapy in the case of hormonally receptive positive tumours, but may also be an unwanted side effect for most chemotherapy treatment plans (Dixon & Hortobagyi, 2000; Dow, 2006; NBOCC, 2010). Particularly for younger women, ovarian suppression will be an aim of treatment. This however has significant side effects. Younger women with treatment induced menopause will experience a range of severity of symptoms. The symptoms range from debilitating hot flushes, libido and vaginal changes, all of which can negatively influence the young women's

quality of life (Knobf, 2001; Rogers & Kristjanson, 2002). The long term effect of treatment induced menopause includes changes in fertility which influences the young women's quality of life as well. Although pregnancy after breast cancer treatment is possible the risk factors for recurrence are evident in research (Partridge & Ruddy, 2007; Phillips, Milne, Friedlander, Jenkins, McCredie, Giles et al., 2004; Thewes & White, 2005).

Another aspect of active treatment is radiotherapy, and this phase may occur directly after surgery or chemotherapy or in combination with the chemotherapy plan (NBOCC, 2010). Radiotherapy often plays a critical role in the management of breast cancer; the therapy being tailored to the individual and administered in an outpatient setting. The woman will attend for radiotherapy on a weekly plan or with longer periods in between sessions for six to eight weeks. The localised side effects from radiotherapy are skin discolouration, tenderness, swelling, also axillary swelling and pain if axillary nodes are treated. Another side effect from radiotherapy is the build-up of fatigue especially towards the end of treatment and fatigue often compounds the previous tiredness from chemotherapy (Cancer Council Queensland, 2010; Xiaokun, 2002).

This active treatment phase often occurs over a six-month period and the woman may be challenged with the some severe side effects of the treatment during this time. The physical and psychological impact for women is fairly intense and the family is also vulnerable as they become informal caregivers who provide both emotional and physical support at this time (Sammarco, 2001; Wagner, et al., 2005). The physical effects will also be demanding including pain, fatigue, alopecia, debilitating nausea and premature menopause, all of which have the potential to adversely affect the woman's role and function within their family (Dunn & Steginga, 2000; Fobair, et al., 2006; Forrest, et al., 2009).

There is a strong association between social support, especially that provided by the close family unit, and quality of life for the woman in the first year (Northouse, 2005; Sammarco, 2001). However, for younger women, little research has actually identified what will assist the family unit during this active treatment phase, despite the acknowledged burdens it entails (Lewis, 2006; Sammarco, 2001). It is also reported that the physical symptoms from the breast cancer treatment for younger women are closely associated with the resultant psychological burden. For example, younger women often experience more severe mood

disturbances, anxiety, depression and other psychosocial symptoms than older women during the first year of treatment (Bloom, et al., 2004; Parle, et al., 2001).

In fact, the experience of breast cancer diagnosis and treatment has been described as a traumatic event capable of producing symptoms consistent with post-traumatic stress disorder (PTSD) (Golden-Kreutz, Thornton, Gregorio, Frierson, Jim, Carpenter et al., 2005; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2009). In comparing cancer with other known PTSD stressors, Zwahlen et al. (2009) used several scales to explore mental health after cancer in 224 couples in a mailed questionnaire. Findings were that the stress from cancer was not confined to one discrete event or timeframe, but often occurs after specific events such as diagnosis, active treatment and the post treatment or maintenance treatment period (Zwahlen, et al., 2009). Both Zwahlen et al. (2009) and Golden Kreutz et al. (2005) explain that the build-up of stressors and previous life experience influence the degree of stress. In addition, the age of the individual was noted to have a significant relationship with the amount of resultant stress. The younger the person, the more at risk they were of stress related symptoms. They propose that this may be from a lack of psychological preparedness for a diagnosis of a chronic disease, but also from the type of cancer treatment regimens prescribed for younger women with breast cancer (Zwahlen, et al., 2009).

The emotional or psychological effects from surgery relate to the body changes, loss of the breast and femininity (Steginga, et al., 1998). These psychological effects often relate to personal support available and coping strategies. In particular research identifies the younger woman at more risk of psychological distress than the older woman (Bloom, et al., 2001; Dunn & Steginga, 2000; Fobair, et al., 2006). The psychological component of breast cancer for younger women has been noted in several studies (Manuel, et al., 2007; Parle, et al., 2001; Sammarco, 2001). It seems this is especially so if the woman has children under the age of 21 years due to the fear of recurrence (Manuel, et al., 2007; Sammarco, 2001). Manuel et al. (2007) specifically explored 201 women aged 50 years or younger to examine coping strategies. Using a mixed method approach, with coping scales and interviews, Manuel et al. (2007) reported information about the different strategies used and the psychological effect of breast cancer for the young woman with breast cancer.

It is important to note that trauma does not necessarily provoke negative responses all of the time. For example, the potential for emotional growth was noted in Weiss's (2004) American

quantitative study of 72 husbands after breast cancer diagnosis in their wives. Other studies have also indicated that the emotional trauma of a breast cancer diagnosis can provide an impetus for personal growth for both the woman and her partner as they share the experience of the disease (Low, et al., 2006; Manne, Ostroff, Winkel, Goldstein, Fox, & Grana, 2004; Robinson, Carroll, & Watson, 2005). An intervention study by Low et al. demonstrated this ability for personal growth. With a sample of 60 cancer patients over four sessions of expressive disclosure the participants were found to report less anxiety and negative emotions (Low, et al., 2006). As a result, it is suggested that psychosocial interventions need to incorporate the couple, and to encourage the sharing of personal strengths and problems (Robinson, et al., 2005; Weiss, 2004).

During the active treatment phase for breast cancer, the woman has a range of decisions to be made with the support of the oncology team. Although the woman and her family are included in the treatment decisions this is not without psychological impact. There is a significant body of research that explores the information needs of the woman and her partner, with much of this identifying that unmet information needs continue to cause a degree of anxiety and distress (Brusilovskiy, Mitstifer, & Salzer, 2009; Nikoletti, Kristjanson, Tataryn, & Burt, 2003; Revenson & Pranikoff, 2005; Walsh, et al., 2005).

Prominent among these anxieties is the prospect of mortality, and the younger woman's need to make immediate decisions about her treatment with due consideration of the consequences of her possible death for her family members (Mellon, et al., 2007; Mohamed, Williams, Tamburrino, Wryobeck, & Carter, 2005). This urgency of decision making regarding treatment and care necessary during the trajectory of breast cancer is known to produce a degree of anxiety for both the woman and her partner (Halkett, Arbon, Scutter, & Borg, 2005; Revenson & Pranikoff, 2005). One of the related difficulties for women and their families is reported to be obtaining the right information at this time. Hence some authors stress the importance of providing an environment of informed participation in order to relieve this decisional anxiety (Bilodeau & Degner, 1996; Shepherd, et al., 2008). Another consideration is the influence of information overload or incorrect information, as young women tend to have a good ability to find information on the world wide web and yet be unable to filter this information (Huang & Penson, 2008; McCullan, 2006).

During active treatment the level of distress, fatigue and other side effects varies for women depending on age, level of fitness and level of support provided (Zabora, et al., 2001). One of the concerns of attempting to recruit patients during this time is the varying nature of this distress and the influence this has on participation in a research study. Previous research studies have used a range of recruitment strategies to increase and maintain their recruitment and retention. To obtain large samples participants have been recruited with a combined health professional and researcher contact with up to three follow up phone calls (Bloom, et al., 2004; Northouse, et al., 2006; Schmitt, et al., 2008; Sears, et al., 2003). The best method for obtaining a completed questionnaire during active treatment seems to be a researcher collected telephone questionnaire as this reduces the risk of non-completion due to side effects while still taking into consideration the patient's concerns.

Another constraint on recruitment during this time is that the woman with breast cancer who has a high degree of distress is not likely to participate in the research, skewing the sample towards those who are coping with the diagnosis (Fang, et al., 2001). Fang et al. (2001) in their study of 197 spouses of women with breast cancer noted that reasons for attrition were patient death or patient too ill to continue participation in the study. The current study recruited during active treatment and noted similar reasons for attrition from the study once participants were recruited.

There is often a crossover between active treatment and maintenance treatment, however the maintenance treatment continues for a longer period of time into what is commonly referred to as the survival period. The physical and psychological effects for the woman and her family are also not contained to a specific phase. Life does not return to normal just because active treatment is over. The next phase of maintenance treatment can have just as many challenges.

2.5.2 Maintenance treatment

The maintenance treatment phase of breast cancer will be discussed in the following section, providing a definition and critique of literature exploring the characteristics of this phase. The maintenance period is the time when a woman is not receiving active treatment and seeing the oncologist outside a three month period. The transition period from acute active treatment to longer-term maintenance treatment poses concerns unique to this period. In this period, the

woman may not have sustained contact with health professionals as only periodic health checks are needed (Dow, 2006).

This maintenance treatment phase is often difficult for the woman and her family as they come to terms with a sense of personal loss of direction and the need to reappraise their situation once the urgency of immediate treatment decision making has passed and the close contact with the health professional has been reduced (Johnson Taylor, 2000; Northouse, 2005). The nature of the treatment is also different, having different physiological and psychological consequences. Previous research has suggested that the initial response to the breast cancer diagnosis will in fact influence the longer adjustment over time with women who identified accepting and feeling positive about their recovery displaying higher levels of adjustment in the longer term (Badger, et al., 2004; Northouse, et al., 2001). The family's strengths and ability to utilise their resources are understood to assist their adjustment during this period (Mellon & Northouse, 2001; Northouse, et al., 2001). There is little research, however addressing the strengths and resources the younger family uses to assist this transition from active to maintenance treatment.

One of the long-term aims during maintenance medical treatment for breast cancer is to reduce the risk of recurrence by altering the hormonal environment of hormonally-receptive breast cancers once the primary tumour is cleared. The most common and severe side-effect of this for younger women is reported to be premature menopause (Dixon & Hortobagyi, 2000; Fobair, et al., 2006; Knobf, 2001). The treatment for altering the hormonal environment of the breast cancer depends on the type of receptors the tumour cells contain; thus treatment can vary from ovarian obliteration to anti-estrogens such as tamoxifen, but all cause some degree of ovarian failure (Brennan, French, Houssami, Kirk, & Boyages, 2005; Dow, 2006). The menopausal symptoms tend to be more intense when they are deliberately induced, causing considerably more distress and anxiety for younger women (Graf & Geller, 2003; Sammarco, 2001). Symptoms such as severe and prolonged hot flushes, vaginal dryness and sleep disturbances are the physical side effects, as well as temporary or permanent infertility (Del Mastro, Catzeddu, Boni, Bell, Sertoli, Bighin et al., 2006; Knobf, 2001). The medical concerns from premature induced menopause are the higher risk of reduction in bone density and risk of growth of other gynaecological cancers (Ryan & Goss, 2006).

Other longer-term pathways are often unpredictable, and new illness symptoms of any sort can cause a dread of progression or the possibility of recurrence. These changes in sexual and menopausal functioning may influence quality of life for both the woman and her family (Dunn & Steginga, 2000; Fobair, et al., 2006; Wagner, et al., 2005). While, some younger breast cancer survivors have been noted to report good health and improved quality of life, Bloom et al. (2004) explained that social and family support were crucial in this, especially in the first year, in order to promote the adjustment of the woman as well as her family. This finding has been reported in other studies highlighting the importance of interventions to enhance quality of life in the first year of the breast cancer trajectory (Northouse, et al., 2001; Zwahlen, et al., 2009).

An aspect of completing research questionnaires during treatment and after treatment is the psychological distress from revisiting the journey of breast cancer and the majority of longitudinal studies noted a retention problem (Northouse, et al., 2006; Northouse, et al., 1998). Studies used a range of gifts from grocery vouchers to fridge stickers increase their retention of participants in longitudinal studies (Northouse, et al., 2006; Wagner, et al., 2006). The current study noted a difficulty with maintaining the sample size for Phase 2 of the study.

In summary, the first year after a breast cancer diagnosis can be a time of profound challenge and life adjustments for the young family. An especially important time is the transition from active treatment to maintenance treatment (Mellon et al., 2001). The next section will summarise the gaps in research.

2.6 Summary of research to date

This section will briefly summarise what is known about the young women with breast cancer, highlight the unknown areas in research, and discuss the direction and reasons for future research to provide justification of the current study.

The research exploring the women's response to breast cancer has provided a depth of knowledge regarding both physical and emotional concerns (Badger, et al., 2004; Daley, et al., 2004). The younger women's experience is also well documented, including concerns such as menopause, fertility and long term emotional effects specific to the younger woman (Bloom, et al., 2004; Coyne & Borbasi, 2006; Fobair, et al., 2006; Walsh, et al., 2005). One

of the recurring themes with research exploring younger women with breast cancer is the support provided by their family. Little research has focused on the family response, particularly with the inclusion of family members. Therefore this is an area in need of exploration to understand the family experience and response as they support the younger woman with breast cancer. The importance of understanding the family experience is because research has not only discussed the significance of family for immediate support but also for the longer term adjustment of the woman with breast cancer (Northouse, et al., 2005; Schmitt, et al., 2008).

There is limited Australian research exploring the younger women's perspective of living through treatment for breast cancer and even less exploring the family perspective using multiple family members. However, there is a need to understand the family perspective and provide recommendations for future research and health professional implications particularly in the Australian cultural perspective (Bloom, 2008; Coyne & Borbasi, 2009). The Australian health system has a public and private care system and the oncology care is predominately provided in an outpatient setting by registered nurses. There is an increasing number of breast care nurses however still insufficient to provide appropriate care for women with breast cancer (Liebert & Furber, 2004; Liebert, et al., 2001; Parle, et al., 2001). There are a range of patients that may travel long distances for medical care. Australia has a culturally diverse population; the family itself tends to be a nuclear family with little extended family support. In many cases the family members are geographically scattered making it difficult to provide ongoing care.

The majority of research exploring the family response has used a dyad approach hence the multiple family approach is a novel way to explore the family perspective. Key family researchers have suggested the recruitment of multiple family members to provide a broader interpretation of the family response (Greenstein, 2006; Knafl & Gilliss, 2002). There is scant published research which has recruited a range of family members including the patient. However the critiqued research provides direction and justification for the current study. The current study addresses the family perspective by using both the women with breast cancer and their family members, to provide a complete view of the family response.

2.7 Conclusion of literature review

The family unit is a dynamic group, whose functioning is influenced by each individual member's appraisal of a stressful event such as breast cancer and by their reaction to it. An exploration of the family members within this group allows for the recognition of the strengths and resources within the family during the trajectory of breast cancer. An important consideration when researching the family unit is to acknowledge the organisation of the family and in particular, the woman's role. Where this may have been that of central nurturer prior to the diagnosis, this may undergo profound change after treatment has commenced. The studies reviewed clearly demonstrate the enormous physical and psychological effect of breast cancer on the younger woman, especially in the first year. While research has focused on the women's experiences few studies have examined the family's experience, especially the strengths and resources of the young family during this major life event. The review of the literature has also highlighted the lack of research addressing the differences over the trajectory of breast cancer, yet research in other disease states supports the changing of family functioning through the course of the disease. Much of the family research to date has used a family framework to reflect the complex interaction of the family, with some researchers using the Family Resiliency Model (McCubbin & McCubbin, 1993). The current study approach enables the exploration of conceptual links between the variables of family strengths and resources. As earlier discussed the broader aspect of resiliency will not be addressed due to the complex nature of this concept. Also the minimal amount of previous research that has addressed the underlying features of resiliency in the younger women with breast cancer has provided little understanding of the concept of resiliency in young women with breast cancer. The methodology chapter will discuss the application of this framework to explore the research question 'What are the strengths and resources that young women and their family members use during treatment for breast cancer?'

3 Chapter 3 Method

3.1 Introduction

The methodology that underpinned the current study is presented in this chapter. The steps taken to ensure methodological soundness are discussed along with relevant ethical considerations. The method used was informed by the research problem, question and the theoretical framework. Questionnaires and personal interviews were used for data collection, drawing on both quantitative and qualitative techniques thereby optimising the richness of the data. The resultant data generated provides important insights into the young women and their family members' strengths and resources used during treatment for breast cancer.

The second section presents the research question and study design. Section three describes the research process for Phase 1 of the research including recruitment and data collection. Section four describes the research process for Phase 2 of the research. Section five presents the description of the questionnaires. Section six describes the qualitative interview process including how research quality was maintained. Section seven presents the ethical considerations of the current study. Section eight presents the statistical analysis plan for the quantitative data. Section nine presents the limitations and conclusion.

3.2 Research method

For clarity the overarching research question is restated: 'What are the strengths and resources that young women and their family members use during treatment for breast cancer?' The research question resulted in the development of subordinate research questions that were addressed in the research. These subordinate questions are:

- What are the strengths the young women and their family members use during treatment for breast cancer?
- What are the resources the young women and their family members use during treatment for breast cancer?
- What are the contributing family attributes that influence strengths and resources utilised by the women and their family members during treatment for breast cancer?

- Is there a change in the strengths and resources used by the young women and their family members' during active and maintenance treatment?

3.2.1 Study Design

This exploratory, descriptive, two phase study investigated the strengths and resources used by young women (<50 years) and their families after a diagnosis of breast cancer.

Specifically the research investigated the strengths and resources families draw on during active and maintenance treatment as well as family attributes that influence the strengths and resources used. In Phase 1 the strengths and resources participants drew on during active treatment were explored as well as family attributes that influenced the strengths and resources utilised by families. In Phase 2 the strengths and resources participants drew on were identified. Changes in strengths and resources families used between active and maintenance treatment were also explored. For the purposes of this research active treatment was defined as the period two to six months after diagnosis when the participant saw the oncologist at least every three months. Maintenance treatment was defined as the period after active treatment when the participant saw an oncologist at intervals greater than 3 months.

These terms are defined in section 1.8 in the Introduction chapter.

As established in section 2.5 of the Literature review it is likely that just as treatment and related outcomes for breast cancer vary between the active and maintenance periods so may the strengths and resources families draw on (Bloom, et al., 2004). Therefore it was important to collect data relating to the strengths and resources that the young woman and her family members used during both treatment periods.

3.3 Phase 1

3.3.1 Introduction

The purpose of this section is to describe Phase 1 of the research process., which included the recruitment of potential participants into the study, administration of the Phase 1 questionnaire when the women were receiving active treatment for breast cancer and completion of personal interviews with twenty-three (n = 23) participants.

3.3.2 Sample recruitment

Recruitment was undertaken in day oncology units in three large public hospitals, one private hospital with a Young Women's Support Group and using a media release. The recruitment areas were all slightly different in physical set up and patient treatment options. Participant recruitment was completed over nine months. Leaflets were available in the hospital recruitment sites over the nine month period and newspaper advertisements were run. [See Appendix 8.8]

In addition, the researcher visited the oncology clinics at recruitment area 1 and recruitment area 2 over a period of three months. On the days the researcher attended the clinic the nursing staff identified potential participants who then sought initial consent from potential participants for the researcher to approach them. If consent was granted the researcher then made contact and explained the research and left a volunteer recruitment pamphlet with the potential participant. This method of direct approach has been used successfully in previous research to increase the rate of participant recruitment (Barriball & While, 1999). Women, who after receiving the research information were interested in participating in the research, contacted the researcher providing their address and number of possible family participants. A package of participant information letters, questionnaires and reply paid envelopes were posted to the address of women with breast cancer. [See Appendix 8.1] The bundle included sufficient questionnaires and reply paid envelopes for each of the family members the women thought might consent to participate. Women with breast cancer could nominate one to three family members. The researcher did not contact family members directly. If they wished to complete the questionnaire they did so. Consent was implied by the return of the questionnaire.

3.3.3 The Settings

Recruitment area 1

Recruitment area 1 was a large metropolitan hospital with an outpatient oncology clinic. Women with breast cancer visited the clinic for surgical review, medical treatment including chemotherapy and radiotherapy with numerous medical and nursing staff in attendance. Approximately 50 patients visited this clinic each week, of which approximately 12 women were under the age of fifty years. Forty two women with breast cancer were recruited to participate in the research from hospital 1.

Recruitment area 2

Recruitment area 2 was a large metropolitan hospital where the medical oncology clinic only treats patients receiving medical intervention (chemotherapy) with one medical oncologist seeing patients prior to treatment or for ongoing assessment. Approximately 25 patients attend this clinic each week including approximately seven women under the age of fifty years. Research leaflets were available for participants in the waiting area of this clinic and the chemotherapy area. Sixteen women with breast cancer were recruited to participate in the research from hospital 2.

Recruitment area 3

Recruitment area 3 was a regional hospital with a medical oncology clinic. Research leaflets were available for participants in the waiting area of this clinic. The breast care nurse provided these women with the research information pamphlets and the invitation to consider participating. One woman with breast cancer was recruited to participate in the research from this recruitment area.

Recruitment area 4

Recruitment area 4 was a private metropolitan hospital which holds a Young Women's support group. The breast care nurse provided women attending the Young Women's Support Group with the research information and the invitation to consider participating. This recruitment area involved women attending support groups and other information sessions, as the women did not attend this area for receiving physical treatment. Four women with breast cancer were recruited to participate in the research from this recruitment area.

Recruitment 5 media

Media recruitment was also undertaken to enhance and broaden the recruitment of women for the study. The researcher placed an advertisement explaining the research and asking for volunteers in two rural newspapers, an on-line newsletter and in a community newsletter. Four women with breast cancer who were from rural and remote locations were recruited to participate in the research from this recruitment method.

3.3.4 Sample size Phase 1

The total number of young women with breast cancer who volunteered to be involved in the research was 71. These 71 young women with breast cancer nominated 131 family members who the women with breast cancer thought may consent to be involved in the research.

3.3.4.1 Inclusion and exclusion criteria

Inclusion criteria

The criteria used to select participants for the current study included women:

- with a diagnosis of breast cancer within twelve months confirmed by oncologist.
- aged 50 years or less at time of recruitment.
- have a family member or support person who may be willing to be involved in the research.
- currently undergoing a regimen of active treatment for their breast cancer, being seen by the oncologist at least every three months.
- able to read, write and speak English in order to complete the questionnaire.

Family/Friends and Support person inclusion criteria

The woman's family / support members were recruited to the study if they:

- were aged over the age of 18 when recruited.
- gave consent on their own behalf to participate.
- if they had a female family member aged 50 years or less with a diagnosis of breast cancer currently undergoing treatment.
- able to read, write and speak English in order to complete the questionnaire.

Exclusion criteria

Participants (including women with breast cancer and family / support members) were excluded from the current study if they:

- had serious illness that would affect their wellbeing and or their ability to complete the study as identified by the oncology nursing staff or participant.
- Women with breast cancer were excluded if they:
- did not have family members closely supporting them who may be willing to be involved in the study.

3.3.5 Data collection

Phase 1 first mail out of questionnaires:

A total of 202 questionnaires were posted to 71 addresses of the women with breast cancer, which included 71 women with breast cancer and 131 family members.

Response rate first mail out of questionnaires: 45 women with breast cancer (63% response rate) and 62 family members (47% response rate) a total of 107 participants (42% response rate) completed and returned Phase 1 questionnaires ($n = 107$). Twenty six women with breast cancer who volunteered did not complete the questionnaire in the first mail out.

Phase 1 repeat mail out of questionnaires

One follow up telephone call was made to the 26 women with breast cancer who did not respond to ascertain if they would consent to continue in the study. Of the 26 women with breast cancer who did not respond three withdrew stating psychological reasons and one woman had died. Several women reported having forgotten to post the questionnaire, lost it or had moved. A repeat questionnaire package was posted to 22 women who consented to continue in the study. No further follow up was undertaken after this.

A total of 63 questionnaires were posted to 22 addresses, with 22 women with breast cancer and 41 family members.

Response rate repeat mail out of questionnaires: The response rate was two women with breast cancer (9% response rate) and two family members (5% response rate) for a total of 4 participants (6% response rate from repeat mail out) who completed and returned repeat mail out Phase 1 questionnaires. The significance of researching highly vulnerable groups was addressed in the Literature review section 2.4, 2.5.

The final sample for Phase 1 was 111 participants, 47 women with breast cancer (66% of recruited women) and 64 family support persons (49% of recruited family support persons). [See Table 1 for details]

Return of questionnaire: Phase 1

- Women with breast cancer read recruitment leaflet
- Women with breast cancer then contacted researcher offering to be involved in the research.

- Researcher explained the research and verified that women with breast cancer met the participant inclusion criteria.
- Women with breast cancer nominated family members who closely supported them during breast cancer treatment.
- Researcher sent out one questionnaire package to women with breast cancer; containing a thank you letter, simple instructions for return of questionnaires, individual questionnaires and reply paid envelopes for her and nominated family members.
- Women with breast cancer gave out questionnaires and reply paid envelopes to family members.
- Women with breast cancer completed the questionnaire and returned it / family members completed their questionnaires and returned them.
- Consent was implied by the return of the questionnaires.

3.3.6 Sample justification

This self-selected sample of 47 women with breast cancer and their family members was obtained from the five recruitment sites. In Queensland each year approximately 2100 women are diagnosed with breast cancer and one in four of these women are under fifty years old (AIHW, 2010). The potential population of young women newly diagnosed with breast cancer each year in Queensland is therefore approximately 525 women. The sample of 47 young women with breast cancer therefore represents approximately 9% of the overall population in the state. This recruitment rate is similar to recruitment rates reported in several studies where participants are identified by health professionals in large hospitals and the participant contacts the researcher about possible participation in the study (Baucom, et al., 2009, 16% recruitment rate; Bilodeau & Degner, 1996, 10%; Brusilovskiy, Mitstifer, & Salzer, 2009, 16%; Bultz, Speca, Brasher, Geggie, & Page, 2000, 31%).

The sample was deemed adequate based on the following assumptions. The Phase 1 response rate of 55% reflects acceptable response rate for a postal questionnaire responses with response rates for oncology questionnaires previously noted at 60% (Asch, Jedrziewski, & Christakis, 1997; Evans, Peterson, & Demark-Wahnefried, 2004). Several studies report similar response rates to mailed questionnaires, also reporting a lower rate for family response and Phase 2 questionnaires (Fang, Manne, & Pape, 2001, 39%; Manne, Ostroff,

Norton, Goldstein, & Grana, 2005, 43%; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2009, 30%).

Although this is a small number of participants from the potential population, given the time frame and the fact that the researcher could only personally access two main research areas the sample was considered adequate for a non-parametric analysis. The number of women meeting the criteria and well enough to complete the study remained small. The difficulties associated with research including ‘hard to access’ and ‘vulnerable groups’ has been discussed section 2.4 and 2.5 in the literature review.

3.3.6.1 Data collection

Phase 1

Each woman with breast cancer volunteering to participate in the research and who met the inclusion criteria was mailed a family questionnaire package, containing questionnaires for each participant namely the woman with breast cancer and possible consenting family / support members to complete. Each questionnaire had its own reply paid envelope to ensure participants could complete their questionnaire without sharing the response with other family members unless they wished to. The family questionnaire package contained individual questionnaires and reply paid envelopes, simple instructions for return of questionnaires and a thank you letter. Consent was implied by the return of the questionnaire. The questionnaire took approximately twenty minutes to complete.

The participants were asked on the last page of the questionnaire if they were interested in participating in personal interview to explore issues arising from the questionnaire in more depth. If so, they were asked to supply a telephone number so that the researcher could contact them to arrange a mutually convenient time and place for the interview. Personal interviews were conducted with a total of 23 participants, 14 women with breast cancer and 9 family support persons. Details of the qualitative data collection are discussed in section 3.5 and the data analysis is presented in Chapter 5 Analysis of qualitative data.

3.4 Phase 2

3.4.1 Introduction

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 3 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 verify consent to continue participation in the study. Phase 2 questionnaire packages were posted and consent implied by the return of the questionnaires. The second questionnaire package was only sent to participants who had completed Phase 1 as non-completion of Phase 1 questionnaires identified that these women and their family members had decided not to be involved in the study. They were then not included in further aspect of the study or in overall number of participants. The Phase 2 questionnaire package contained individual questionnaires and reply paid envelopes for the participating woman and family members, simple instructions for return of questionnaire and a thankyou card for participation in the study. [See Appendix 8.9]

3.4.2 Sample size Phase 2

The final sample for Phase 2 was 67 participants (60%), 28 women with breast cancer (61% of Phase 1 women with breast cancer) and 39 family support persons (61% of Phase 1 family support persons). One woman with breast cancer died in the time between Phase 1 and 2 and her family were not sent the second set of questionnaires.

Phase 2 first mail out of questionnaires:

A total of 107 questionnaires were posted to 46 addresses, which included 46 women with breast cancer and 61 family members.

Response rate first mail out of questionnaires: 24 women with breast cancer (52% response rate) and 19 family members (31% response rate) a total of 43 participants (40% response rate) completed and returned Phase 2 questionnaires ($n = 43$).

Phase 2 repeat mail out of questionnaires

One follow up telephone call was made to the 22 women with breast cancer who did not respond to ascertain if they would consent to continue in the study. Several women with breast cancer reported that they found it hard to complete the Phase 2 questionnaire, as it reminded them about the breast cancer. A repeat questionnaire package was sent to the address if they consented to continue with the study. No further follow up was made after this.

A total of 64 questionnaires were posted to 22 addresses, depending on family size. This included 22 women with breast cancer and 42 family members.

Response rate repeat mail out of questionnaires: 4 women with breast cancer (18% response rate) and 20 family members (47% response rate) for a total of 24 participants (37% response rate from repeat mail out) completed and returned Phase 2 questionnaires thus the total participants for Phase 2 was 67 (n = 67). [See Table 1 for details]

Return of questionnaire: Phase 2

- Phase 2 questionnaires were sent approximately 3 months after phase 1 questionnaires were returned. This allowed time for treatment to be finished.
- Researcher telephoned the women with breast cancer who had returned Phase 1 questionnaires, and verified if Phase 2 questionnaires could be sent.
- Researcher sent out one family questionnaire package to the women with breast cancer.
- Women with breast cancer gave out questionnaires and reply paid envelopes to their family members.
- Women with breast cancer completed the questionnaire and returned it.
- Family support persons completed the questionnaires and returned them.
- Consent was implied by the return of the questionnaires.

Table 1 Participant recruitment**Table of participant recruitment over Phase 1 and Phase 2**

Phase 1	Women with breast cancer	Family support persons	Total	Total Response rate
Initial recruitment	71		71	
Questionnaires sent	71	131	202	
Questionnaire return	45/71 63%	62/131 47%	107/202	53%
Repeat questionnaires sent	22	41	63	
Questionnaire return	2/22 9%	2/41 5%	4/63	6%
Total Phase 1 questionnaires returned	47/71 66%	64/131 48%	111/202	55%
Phase 2	Women with breast cancer	Family support persons	Total	Total Response rate
Participants from Phase 1	46	61	107	
Questionnaires sent	46	61	107	
Questionnaire return	24/46 52%	19/61 31%	43/107	40%
Repeat questionnaires sent	22	42	64	
Questionnaires return	4/22 18%	20/42 48%	24/64	37%
Total Phase 2 Questionnaires returned	28/46 61%	39/61 64%	67/107	63%

3.5 Description of the questionnaires

The data set for the current study was collected from consenting participants using self-administered questionnaires and personal interviews. The composite questionnaire was made up of three scales: Family Hardiness Index (FHI) [20 items], Family Crisis Orientated Personal Evaluation Scale (F-COPES) [30 items] and the Walsh scale [33 items]. The benefits and disadvantages of composite questionnaires are addressed in the literature review section 2.2.1. Participants took approximately twenty minutes to complete the full questionnaire.

Questionnaire Section 1 Consent Information

The first section was the Plain English Information Form. This section was specific to each recruitment site ethics committee and explained the background of the study, the participant's involvement, consent to participate information, specific details of each ethics committee, the complaints mechanism and contact details for researchers and ethics committee. [See Appendix 8.1]

Questionnaire Section 2 Demographic data

In order to establish the representativeness of the sample, a range of demographic details were obtained using ten items. Participants indicated if they were either the young woman with breast cancer or a family member. The details of breast cancer treatment were collected indicating what treatment the women with breast cancer had undergone in three groups such as surgery, and or chemotherapy, and or radiotherapy. Information addressing gender, age in years, family status / relationship to patient and length of relationship in years was collected.

Ethnicity, educational and employment status were also addressed in order to confirm the representativeness of the sample. Ethnicity was divided into five groups namely Caucasian / European, Australian Aboriginal, Torres Strait Islander, Asian and other as per the Australian Bureau of Statistics (ABS). The educational status of participants was categorised according to the highest level of completed education such as postgraduate studies, bachelor degree, diploma / certificate or secondary school as per Australian Bureau of Statistics. The occupational status of participants was categorised according to the Australian Standard of Occupations (ASCO) (AusStats, 2007); management and administration, professional / associate professional, trade persons, clerical, sale and service, production and transport, and labourers. For the purposes of the current study the categories of home duties, self-employed,

unemployed, and student were also included to more accurately reflect the activities of young women and their families. Inclusion of the participant's postcode allowed for geographic categorisation. The rationale for including these demographic details was addressed in the Literature review.

Questionnaire Section 3 Family Hardiness Index (FHI)

The Family Hardiness Index (FHI) was included in the composite questionnaire used in this research (McCubbin, et al., 1986). The FHI was developed to measure the internal strengths and durability of the family unit and is validated by several researchers (McCubbin, et al., 1986). The FHI has been recently used by other researchers exploring the characteristics of strengths within the family in the face of adversity (Clark, 2002; Leske, 2003; Mellon, et al., 2007; Mellon & Northouse, 2001). The FHI is a 20 item instrument consisting of three interrelated subscales addressing family functioning; commitment, challenge and control. The FHI uses a 4-point Likert scale (false, mostly false, mostly true, true) that indicates the degree to which each statement describes the family strengths. The scores are summed to generate the Family Hardiness Index (FHI). The higher the score identifies increased levels of family functioning. The Family Hardiness Index (FHI) Cronbach alpha coefficient is 0.82. For each of the subscales commitment, challenge and control the Cronbach alpha were 0.81, 0.80 and 0.65 (McCubbin, et al., 1986). A thorough review of the Family Hardiness Index is presented in the Literature review section 2.2.

Section 4 Family Crisis Orientated Personal Evaluation Scales (F-COPES)

The Family Crisis Orientated Personal Evaluation Scales (F-COPES) was the second scale included in the composite questionnaire. The F-COPES was developed to identify the problem solving and behavioural strategies families use to assist them through a stressful situation and is validated by several researchers (McCubbin, et al., 1981). The F-COPES has been used by researchers exploring characteristics of the resources used by the family in the face of adversity (Leske, 2003). The F-COPES index 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 namely 'social support', 'reframing' the stressful event, 'spiritual support', 'mobilising' community support and 'passive appraisal'. The scores are summed to provide sub groups 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. The overall Cronbach alpha is 0.87 (McCubbin, et al., 1981). For the individual subscales acquiring social support, reframing, spiritual support, mobilising family support and passive appraisal the Cronbach alpha coefficient were 0.83, .081, 0.81, 0.70, 0.62. A thorough review of the Family Crisis Orientated Personal Evaluation Scales is presented in the literature review section 2.2

Questionnaire Section 5 Walsh Questionnaire

The Walsh scale was included in the composite questionnaire. The Walsh scale has not previously been validated however Walsh (2006) has used these questions to provide guidelines for examining the family strengths, resources and communications. The Walsh scale has 33 questions and uses a 4 point Likert scale (false, mostly false, mostly true, true). The rating provides an indication of how a family works together to maintain the family unit in the face of adversity. The Walsh scale includes the subscales of challenge, spiritual support, family flexibility, resources and communication which all reflect the Walsh (2006) conceptual framework. The results were summed to calculate a summary score.

The Walsh framework was used to guide semi-structured interviews thus allowing for cross validation of information from the questionnaires and the interviews. A thorough review of the Walsh framework is presented in the literature review section 2.2

Permission was obtained from the developers of the selected instruments for use by the researcher before commencement of the study. [See Appendix 8.1 for the questionnaire]

3.6 Qualitative semi-structured interviews

Participants wishing to be involved in a semi-structured interview completed the last section on the questionnaire. This section provided a brief description of the semi-structured interview process and asked the participants to complete their details; name, telephone number and convenient time to contact them and to fold this section separately from questionnaire when returning in the envelope to the researcher. Personal interviews ($n = 23$) were completed for each consenting participant separately in their home ($n = 15$) or conducted by telephone if participants lived more than 200 kilometres from the research centre ($n = 8$). This allowed for rural and remote interviews to be included in the study. Separate personal interviews provided an environment for open disclosure of information.

The aim of the interview was to collect information exploring the participant's experience and the strengths and resources used during treatment for breast cancer. Individual consent to participate in the interview was given by each participant, however families were free to participate as they wished. In some of the interviews ($n = 3$) other family members [husband, mother, daughter] joined the interview and left as they wished. Allowing for natural family interaction during the interviews reflects the holistic understanding of family dynamics (Greenstein, 2006).

Semi-structured interviews were conducted based on Walsh's (2006) structured interview guide. [See Appendix 8.3] This method facilitates the collection of the participant's full description of their experience and in particular strengths and resources used in response to the breast cancer diagnosis.

The interview began with participants being asked to describe how they first communicated the diagnosis of breast cancer with their family and friends. Beginning the interview this way opened the conversation and provided information about the family strength, communication. Further cue questions to expand on strengths and resources used after the diagnosis of breast cancer were used if required. These included: 1) how their family worked through problems; 2) their personal spirituality; 3) how the family worked through unexpected problems; 4) how the family worked together; 5) who the family approached for help; 6) how the family maintained open communication; 7) how the family shared emotional expression; and 8) how the family solved problems. Family dynamics were also collected at each personal interview to get a perspective of the family group.

All interviews were audio taped and the interview lasted for took between 30 and 60 minutes. Separate interviews were conducted for each participant. On three occasions family members joined the interview for short periods. The same semi-structured interview process was used for each interview to build information around the strengths, communication styles and resources family members used during the breast cancer journey. If the participants showed signs of tiring or becoming distressed, questions were stopped or refocused to allow participants time to recompose themselves and continue if they wished. The interview addressed the key themes of the research that included the strengths and resources drawn on.

After each interview, the researcher spent approximately thirty minutes having an informal debriefing discussion with the participant. A few participants disclosed that this was the first time they had openly discussed their feelings with someone, most times they had not shared their personal feelings, not wanting to burden the other family members. The researcher thanked the participant/s on the day of the interview and left contact details if they seemed concerned. The mechanism for participants who needed counselling was to provide information relating to free emergency counselling offered by the local Cancer Council of Queensland, contact included in plain language consent form.

All interviews were transcribed verbatim. The narrative data included speech breaks, crying and other personal breaks for both the interviewee and interviewer. The transcripts were checked by the interviewer with the audio to ensure the validity of audio transcription. The transcripts were also returned to the participants to check on the accuracy of transcription.

The process of thematic analysis of the qualitative data and the findings are reported in Chapter 5 Analysis of qualitative data.

3.6.1 Research quality: qualitative data

Qualitative research is based on the assumption that knowledge can be generated from narrative data and it is relative to the participant's experience. There is no single way to test for quality, thus the research process must be open and trust displayed (Grbich, 1999; Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Throughout the qualitative data collection the research process was transparent. All the participants viewed and verified that their transcripts were a true representation of their experience. Member checking is a method of ensuring validity and trustworthiness of the research (Grbich, 1999; Taylor, Kermode, & Roberts, 2007). In the interviews the researcher openly explained to the participants that she was a nurse, but was currently in the role of researcher wishing to understand their perspective. The researcher also asked several participants ($n = 5$) to view and verify the final qualitative data analysis and development of categories. Three breast care nurses were also asked to verify the development of categories. These breast care nurses were involved in the recruitment of the participants and understood the research. They were asked to read the categories and identify if they felt this to be an

accurate representation of the breast care nurses' understanding of young women and their family members' experience of breast cancer. This ensures that the data analysis was an accurate reflection of the experience and strengths and resources of the participants (Morse, et al., 2002).

Trustworthiness of data was achieved by the use of researcher field notes and reflective journaling to capture thoughts and ideas during the collection of interview data. Investigator triangulation, which involves the use of multiple researchers from different perspectives participating in the data analysis process (Denzin & Lincoln, 2000), also served to ensure trustworthiness of the findings. Two researchers (PhD supervisors) not involved in the data collection viewed the transcripts and participated in the full analysis process to ensure an accurate representation of findings from the narrative data.

Person triangulation occurred where data were gathered from multiple participants within the same group 'the family' about the same topic (Denzin & Lincoln, 2000). Data from the transcriptions allowed several different perspectives of the same journey to be explored. Different family members provided different insights on similar events within the family. Also interviews with different family members provided an opportunity for families to share each member's perspective. This is known as 'backstage behaviour' where activities of the family are not openly disclosed. However if several members are interviewed different perceptions of this behaviour become visible (Greenstein, 2006).

Space triangulation, which is collection of data from more than one site (Denzin & Lincoln, 2000), occurred with the current study as participants were recruited from multiple sites. A broad range of socioeconomic and geographic demographics are present in the participants. Details of demographics are presented in section 4.2 of the Analysis of quantitative data chapter.

Method triangulation entails combining two research methods together to contribute to the overall understanding and completeness of the investigation (Denzin & Lincoln, 2000). Participants for the current study were recruited for the larger quantitative data; however the smaller qualitative data set provided another view of the experience.

Auditability of the research has been maintained throughout the whole research process. The researcher has a decision trail identifying the research methods and data analysis process, thus justifying the consistency of the qualitative data approach (Taylor, et al., 2007).

3.7 Ethical considerations

Ethical approval was granted by the University where the researcher is based and all participating sites. The women with breast cancer and their family members who agreed to participate in the research were provided with a plain language participant consent form (PLCF) and the questionnaires to complete [See Appendix 8.1 for Questionnaire detail]. The PLCF explained the nature of the study and their right not to participate, to withdraw at any time without penalty, not to answer any question as they may wish, and details of Human Research Ethics Committee (HREC) contacts should the participants wish to make a complaint about the conduct of the study. Information for participants to contact the researcher was provided on the information sheet. Consent was implied by the return of the completed questionnaire. The participation in the quantitative questionnaires posed little risk of distress for the participants. The Cancer Council of Queensland contact details and the researcher's contact details were clearly visible on the questionnaires if participants felt distressed.

Any participants wishing to be involved in a personal interview were asked to read and sign a plain language consent form (PLCF) at the time of the interview. Opportunities were provided for participants to ask questions at any stage. [See Appendix 8.2 Information and consent for personal interviews].

The current study did not set out to influence the participants in any way. The purpose of the study was to gain an understanding of the family strengths and resources after a diagnosis of breast cancer. The researcher conducted all the interviews. The ethical code under which this research was conducted has the wellbeing of the participants as the paramount consideration. When it was judged by the researcher that the participant became distressed or indicated that emotional assistance was needed, mechanisms for support and safety were utilised and the interview was stopped. The researcher used therapeutic communication strategies such as allowing the participant to stop for a drink or chance to relax, change direction of interview and then continue with consent from the participant. The researcher allocated thirty minutes

after each interview to debrief and discuss any issues which had surfaced during the participant's interview.

All data were kept in accordance with the ethical requirements as per Human Research Ethics Manual (Australian Code for the Responsible Conduct of Research, 2007). Recruited participants had their names and addresses recorded in a single data base. Only the researcher had access to this data base. All questionnaires were sent to the participants with the single participant code recorded. Participants were not required to write their names or identifying details on the questionnaires. On return of the questionnaires they were coded as the woman with breast cancer or the family support person and entered into the SPSS datasheet. In the qualitative interviews, pseudonyms were used during the interviews and on the transcript data. The personal details were recorded on a consent form that was kept separately. Only the researcher has access to the coding key, which is kept in a locked filing cabinet in the university.

The Human Research Ethics Committees of the University and all participating sites approved the research. A copy of the recruitment leaflet and questionnaire is included in Appendix 8.8, 8.1.

3.8 Statistical analysis

The data were analysed using the Statistical Package for the Social Sciences (SPSS) version 17.0 (2009) for the personal computer. A detailed analytical plan was developed to guide the statistical analysis. [See Section 3.7.1] Data management strategies were undertaken to ensure a clean dataset. Descriptive demographic statistics of the participants were performed to examine sample characteristics. Summary statistics for the three scales (FHI, F-COPES, Walsh) and the subscales within the scales were calculated. Lastly, substantive analysis in order to address the research questions were performed as described below.

3.8.1 Data preparation

Data input, storage and retrieval was facilitated by the use of software program SPSS version 17.0 (2009). Regular backup and maintenance of files ensured accurate storage and retrieval of data throughout the study. The dataset included the responses of all participants. The participants were coded with a unique participant number, known only to the main

researcher. The coding allowed for discreet identification of women with breast cancer or family support persons and associated family group.

Data qualities were assessed to ensure accuracy and completeness. The accuracy of data coding and computer entry was checked by comparing the electronic data with the original data across the entire database (111 participants). Data cleaning included checking the accuracy of data entries, checking for missing data and outliers and examining the fit between the dataset and assumptions (Pallant, 2005). Discrepancy of demographics between the family group participants was checked and errors corrected, to ensure that the details of the woman with breast cancer treatment were consistent with that of the family members supporting her. An error rate of less than 5% was found. All errors were corrected.

Missing data were dealt with in standard ways (Polit, 2010). Data missing at random points and single missing responses were given the mean value for that item on the basis that the mean value reflected the majority of the data as recommended by Polit (2010). This was found and completed for less than 10% of the data. Participants with whole sections missing were removed from the analysis of that section on the basis that their data could not be generated with any certainty. There were three such cases in Phase 1 and one case in Phase 2.

Once data verification and cleaning procedures were completed, negatively worded questionnaire items were reverse scored as required. Scales and subscales were also constructed according to the developer's instructions. Family groups were coded and grouped. Measures were evaluated in terms of their item-scale reliability by computing Cronbach's alpha. The distribution of each variable was assessed for normality via histograms, and reviewed for skewed or kurtotic distributions. An alpha level of 0.05 was used for all statistical tests, as this is the common benchmark used by researchers (Polit, 2010). Only results with p values equal to or less than 0.001 were reported unless stated otherwise to ensure the researcher did not overstate findings due to the small sample size. Reliability and validity of instruments for the current study are presented in section 4.3.

3.8.2 Data analysis plan

Data grouping

A non-parametric analysis of data was used for each phase because of the small non-random heterogeneous sample. The FHI and F-COPES scales are Likert scales that collect ordinal data, and these scales were summed as per the author's requirements (McCubbin, et al., 1981; McCubbin, et al., 1986). The summed results were then treated as interval data providing mean and standard deviation to the overall score results as per previous research (Clark, 2002; Leske, 2003; Leske & Jiricka, 1998; McCubbin, et al., 1981; McCubbin, et al., 1986; Svavarsdottir, et al., 2005). The Walsh scale is also a Likert scale that generates ordinal data, and this scale was also summed and the summary score treated as interval data.

The presentation of summed ordinal data as interval data has been critiqued before with a range of opinions discussed (Allen & Seaman, 2007; Jakobsson, 2004; Jamieson, 2004). One of the main considerations is the importance of being aware of the underlying assumptions of the grouped data when analysis and presentation is completed (Jakobsson, 2004). The combination of scores from items in a Likert scale must have a similar characteristic demonstrated by appropriate Cronbach alpha to enhance the correctness of the analysis as interval data (Allen & Seaman, 2007). For the current study the grouped data were all similar in characteristics as identified by a confirmatory factor analysis and appropriate Cronbach alpha. The data were analysed using non-parametric analysis given the lesser requirements to psychometric properties and normalcy. [See Section 4.3 for presentation of reliability and validity of instruments for current study]

In order to explore the strengths and resources young women and their family members draw on after a diagnosis of breast cancer, the questionnaire items were clustered around subscales generated by the three scales that made up the composite questionnaire used for data collection.

The subscales generated from the FHI and F-COPES scales were grouped as recommended by McCubbin and McCubbin (1986, 1981). The FHI provided the subscales of commitment, challenge and control. The F-COPES scale provides the subscales of social support (support from family and friends), reframing the adversity, spiritual support, mobilising of outside resources (health professionals, community) and passive appraisal (acceptance of problems). The Walsh scale provides subscales; challenge (seeing the breast cancer as a challenge),

spiritual support, family flexibility, resources (including health professionals) and communication. [See Tables 2, 3, 4 for details of scales]

Confirmatory factor analyses were completed to check the subscales of questionnaire items around the FHI and F-COPES. Prior to performing the factor analyses the suitability of data for factor analysis was assessed and deemed appropriate. The factor analyses confirmed that the subscales for the FHI and F-COPES proposed by the authors were appropriate.

An exploratory factor analysis was completed with the Walsh scale to identify clustering for the subscales. The 33 items of the Walsh scale were subjected to principal components analysis (PCA) using SPSS Version 17. Prior to performing the PCA the suitability of the data for factor analysis was assessed. Inspection of the correlation matrix revealed the presence of many coefficients of .3 and above. The Kaiser-Meyer-Oklin value was .911, exceeding the recommended value of .6 and Barlett's test of sphericity reached statistical significance, supporting factorability of the correlation matrix (Pallant, 2005). Principal components analysis revealed six components with Eigenvalue values exceeding 1, accounting for 44%, 51%, 56%, 60%, 64%, and 67% of the variance respectively. Further analysis retaining 5 components identified a suggestion of 5 clusters of items which support the original grouping of items from the scale. It was decided to retain the original grouping of items as suggested from the Walsh scale. Further investigation of the Walsh scale is warranted if future use of the scale is completed quantitatively. The exploratory factor analyses of the Walsh scale is presented in Appendix 8.6.

Preliminary analysis

The analysis was completed as a whole group rather than women with breast cancer and family as two groups. This innovative approach provides a family view inclusive of both the woman and her family as denoted by the guiding family theory. Traditionally family researchers have relied on one primary family member to provide information about the family response however an approach of including multiple family members allows for a broader family understanding to be obtained (Astedt-Kurki, et al., 2001; Ganong, 2011). International researchers have completed data analysis as a whole group and the current study has used these steps to inform the method. These steps include a preliminary analysis of the separate groups, which could be different disease states or patients with cancer and support persons (Edwards, et al., 2008; Leske, 2003; Mellon & Northouse, 2001). Once minimal

difference is established between the groups then analysis can be completed as a whole group.

The current study completed a preliminary analysis using the *Mann-Whitney U Test* to compare the difference in strength and resources subscales for women with breast cancer versus family support persons. This preliminary analysis found minimal difference between women with breast cancer and family support person's response. Therefore the analysis was completed on all participants as one group. This technique has been successfully used in prior research (Leske, 2003; Leske & Jiricka, 1998; Mellon & Northouse, 2001). Leske and Jiricka (2003; 1998) analysed all participants as one group after identifying minimal difference in participants' responses between disease status groups and family characteristics. Mellon and Northouse (2001) grouped patients and family members as one group for the main analysis after preliminary analysis revealed minimal difference in participants' responses. 'The rationale for using this scoring method was driven by the family theoretical model and by viewing the family dyad as capturing the collective family perspective' (Mellon & Northouse, 2001, p. 452). The woman could nominate one to three family members as stated in the sample recruitment. [Section 3.3.2]

The current study reports the individual scores of participants as a reflection of the family response. The use of a family focused framework with a range of family members provides an understanding of the family perspective (Mellon & Northouse, 2001). The current study is based on the Resiliency Model of Family Stress (McCubbin & McCubbin, 1993) thus allowing individual scores to be used collectively to present the family perspective (Knafl, et al., 2009).

Participant characteristics analysis

Descriptive statistics (means, ranges, standard deviations, percentages) were completed to provide a profile of sample characteristics. Due to the small sample size within some of the demographic groups, variables were grouped to provide sufficient group size to allow for data analysis. The grouping of variables into new variable groups allows for meaningful analysis of the data (Polit, 2010).

The analysis was completed for the three scales as per the author's recommendations. The individual subscales within the scales were then explored in relation to the strengths and resources.

Analysis of Strengths

The first research question asked 'What are the strengths the young women and their family members use during treatment for breast cancer?' Strengths have been defined earlier as what the individual draws on in response to adversity. In order to calculate each participant's strengths descriptive statistics were used to establish means, range, standard deviation and percentages using the subscales generated from the instruments. The FHI (all three subscales), F-COPES subscale (reframing) and three Walsh subscales (Challenge, family flexibility and communication) were analysed to generate information about what strengths the individuals make use of during treatment for breast cancer.

Analysis of Resources

The second research question asked 'What are the resources the young women and their family members use during treatment for breast cancer?' Resources have been defined in the literature review as components used by the individual in response to adversity. In order to calculate each participant's use of resources descriptive statistics were used to establish means, range, standard deviation and percentages using the subscales generated from the instruments. The F-COPES subscales (social support, spiritual support, mobilising, passive appraisal) and Walsh subscales (spiritual support, family resources) were analysed to generate information about use of resources. The Spearman's Rank Order Correlation test was used to calculate the strength of relationships between the strengths and resources scales and subscales.

Analysis of contributing family attributes influencing strengths and resources

The third research question asked 'What are the contributing family attributes that influence the strengths and resources?' The *Mann-Whitney U Test* was used to assess differences related to family attributes (Independent variables: IVs) in terms of the subscales of strengths and resources (Dependent variables: DVs). Family attributes of interest included women with breast cancer / family support person, female / male, treatment variations and education groups. A nonparametric equivalent to 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 postcodes.

Analysis of change between Phase 1 and Phase 2

The fourth research question asked 'Is there a change in the strengths and resources used by the young women and their family members' during active and maintenance treatment?' The *Wilcoxon Signed Rank Test* was used to assess group differences in terms of the subscales of strengths and resources Phase 1 and Phase 2 of the study. The comparison between the two phases of the research provided information on the changes of strengths and resources over time.

Analysis of family groups

The aim of the family group analysis was to analyse the individual family members into family groups. This provided information of the family as a group of interacting individuals, clearly representing the family focus of the current study. The family members within each family were grouped as case summaries using SPSS version 17.0 (Pallant, 2005). The case summary analysis provided family group information. Variables profiling the family groups were analysed to calculate family means, range, standard deviation and trends in the subscales of strengths and resources. This analysis was supplemented by qualitative data where interviews with different family members provided an insight into the dynamics of the family as a group.

Quantitative results are presented as per Polit (2010) to ensure consistency.

Table 2 Family Hardiness Index

Subscale	Characteristics addressed	Question numbers
Subscale 1 8 items	Commitment	4,5,6,7,8*,9,11,18
Subscale 2 6 items	Challenge	12,13,14*,15,16*,17
Subscale 3 6 items	Control	1*,2*,3*,10*,19*,20*
FHI total 20 items		Sum of 3 subscales

* reversed scores

Table 3 Family Crisis Orientated Personal Evaluation Scales

Subscales	Characteristics addressed	Question numbers
Subscale 1 9 items	Social support	1,2,5,8,10,16,20,25,29
Subscale 2 8 items	Reframing	3,7,11,13,15,19,22,24
Subscale 3 4 items	Spiritual support	14,23,27,30
Subscale 4 4 items	Mobilising	4,6,9,21
Subscale 5 4 items	Passive appraisal	12*,17*,26*,28*
F-COPES Total 29 items		Sum of 5 Subscale

* reversed scores

Table 4 Walsh Scale

Subscales	Characteristics addressed	Question numbers
Subscale 1 9 items	Challenge	1,2,3,4,5,6,7,8,9
Subscale 2 4 items	Spiritual support	10,11,12,13
Subscale 3 7 items	Family flexibility	14,15,16,17,18,19,20
Subscale 4 3 items	Resources	21,22,23
Subscale 5 10 items	Communication	24,25,26,27,28,29,30,31,32,33
Walsh Total 33 items		Sum of 5 Subscale

3.9 Research considerations

3.9.1 Study limitations

The limitations of the current study relate to the self-selection of participants. The self-selected sample may not be representative of all young families with breast cancer as families at risk of poor adjustment, with limited strengths and resources are not likely to have the resources to participate in the research. This was addressed in detail in the literature review section 2.4.2, 2.4.3, 2.5. Research including participants undergoing active treatment with multiple side effects is also problematic. Again this was addressed in the literature review section 2.5.

The Phase 2 return of the questionnaires had issues related to changing of address for some of the participants. Also a few participants, both women with breast cancer and family members identified themselves as not wishing to continue in the research Phase 2. One of the reasons stated by the women with breast cancer was that completing the questionnaire for a second time after treatment finished was psychologically too challenging. This is addressed in section 2.5.2.

Even though there were limitations associated with this research, important insights have been gained and the value of the data should not be underestimated.

3.9.2 Conclusion of Method

The research methodology used to address the research questions were presented in detail in this chapter. The justification for the design, sampling and scales used was provided. The study procedure and statistical analysis were detailed along with study limitations.

Quantitative findings are presented in the next chapter.

4 Chapter 4 Analysis of quantitative data

4.1 Introduction and overview

The analysis and results of the quantitative data analysis are presented in this chapter. The analysis reflects the research question and is guided by the Family Resiliency Framework, which acknowledges that the individual within a family will be influenced by other family members as they use their personal strengths and resources to overcome adversity.

For clarity, the overarching research question is restated; ‘What are the strengths and resources that young women and their family members use during treatment for breast cancer?’ The research question resulted in the development of more concise research questions that were addressed in the research.

- What are the strengths the young women and their family members use to assist their adjustment during treatment for breast cancer?
- What are the resources the young women and their family members use to assist their adjustment during treatment for breast cancer?
- What are the contributing family attributes that influence strengths and resources utilised by the women and their family members during treatment for breast cancer?
- Is there a change in the strengths and resources used by the young women and their family members’ across time?

The second section of this chapter is the presentation of the descriptive statistics (means, ranges, standard deviations, percentages) for demographic variables from Phase 1 (active treatment) and Phase 2 (maintenance treatment). In this section the sample characteristics for both phases will be analysed. Due to the small sample size within some demographic groups, response categories were grouped to provide sufficient group sizes to allow adequate data analyses (Polit, 2010).

The third section of this chapter presents examinations of the reliability and validity of the instruments used in the current study.

The fourth section answers the research question ‘What are the strengths and resources the young women and their family members use to assist their adjustment during treatment for breast cancer?’ In order to calculate each participant’s strengths and resources descriptive statistics were used to establish means, range, standard deviation and percentages using the subscales generated from the instruments. The FHI (all three subscales), F-COPES subscale (reframing) and three Walsh subscales (Challenge, family flexibility and communication) were analysed to calculate family hardiness (FHI totals) and individual strengths. The F-COPES subscales (social support, spiritual support, mobilising, passive appraisal) and Walsh subscales (spiritual support, resources) were analysed to generate information about use of resources. The Spearman’s Rank Order Correlation test was used to calculate the strength of relationships between the strengths and resources scales and subscales.

The fifth section of this chapter answers the third research question ‘What are the contributing family attributes that influence the strengths and resources?’ The *Mann-Whitney U Test* was used examine the effect of group differences in family attributes on subscale scores for strengths and resources. Family attributes includes women with breast cancer / family member, female / male, treatment variations and education groups. The *Kruskal-Wallis Test* was used to examine the relationship between family attributes and the subscales of strengths and resources. Family attributes included age groups, treatment combinations, phase of life, education levels, occupation groups and postcodes.

The sixth section answers the fourth research question ‘Is there a change in the strengths and resources used by the young women and their family members’ during active and maintenance treatment?’ The *Wilcoxon Signed Rank Test* was used to assess differences between the subscales of strengths and resources in Phase 1 vs. Phase 2 of the study.

The last section of the analysis explores the individual scores of family members in their actual family groups, in order to reflect the family focus of the current study. In order to calculate each family’s strengths and resources descriptive statistics were used to establish means, range, standard deviation, and trends in the subscales of strengths and resources.

A non-parametric analysis of the data was completed due to the heterogeneity of the sample.

The analysis of the qualitative data from the research is presented in the following chapter. This analysis was guided by the main research question and Family Resiliency Framework.

4.2 Demographic characteristics of the sample

The characteristics of the sample were examined using descriptive statistics. Phase 1 was made up of 111 participants; including 47 women with breast cancer and 64 family members/support people who completed the Phase 1 questionnaire. In Phase 2, the sample consisted of 67 participants; including 28 women with breast cancer and 39 family members/support people who completed the questionnaire in both Phase 1 and Phase 2.

Age of participant

The mean age of all participants in Phase 1 ($N = 111$) was 45 years (SD 13 years), and in Phase 2 ($N = 67$) was 47 years (SD 13 years). The mean age of women with breast cancer ($n = 47$) was 43 years (range 29 – 50 years; SD 5 years). The mean age for the support persons ($n = 64$) was 47 years (range 18 – 83; SD 17 years).

[See Table 5 for demographics]

Table 5 Gender and age demographics
Presentation of gender and age demographics

Characteristic	Phase 1 (N = 111)	Phase 2 (N = 67)		
Gender				
Female	86	78%	53	79%
Male	25	22%	14	21%
Totals	111	100%	67	100%
	45 years	(SD 13)	47 years	(SD 13)
Women with Breast cancer	43 years (n = 47)		44 years (n = 28)	
Support persons	47 years (n = 64)		49 years (n = 39)	

Phase of life

The participants' phase of life was described using eight response categories that reflected the current categorisation of family composition (AIHW, 2010; Greenstein, 2006). Half of the

participants (54%) reported they had children which is consistent with the national demographics of this age group (AIHW, 2010).

The variations of phase of life were as follows;

Partner no children (Phase 1 n = 6, 5%)

Partner and children below ten years (Phase 1 n = 17, 15%)

Partner and children above 10 years (Phase 1 n = 37, 33%)

Single supported by family (Phase 1 n = 26, 23%)

Single with children or other dependents (Phase 1 n = 5, 5%)

Other denoted:

Mother or father of women with breast cancer (Phase 1 n = 14, 13%)

Son or daughter (Phase 1 n = 3, 3%)

Friend (Phase 1 n = 3, 3%).

[See Table 6 for Phase 1 and Phase 2 comparison data]

**Table 6 Phase of life demographics
Phase of Life demographics**

Characteristic	Phase 1		Phase 2	
	(N = 111)		(N = 67)	
Partner no children	6	5%	3	5%
Partner children <10	17	15%	10	15%
Partner children >10	37	33%	29	43%
Single supported	26	23%	11	16%
Single with children	5	5%	2	3%
Other	20	19%	12	18%
Total	111	100%	67	100%

These six categories were grouped into three groups for the final analysis to allow for comparison between groups with appropriate statistical power.

Participants with children (Phase 1 n = 60, 54%), (Phase 2 n = 41, 61%) or

Participants without children (Phase 1 n = 32, 29%), (Phase 2 n = 14, 21%).

Participants coded as mother or father, son or daughter or friend of woman with breast cancer were coded as other (Phase 1 n = 19, 17%), (Phase 2 n = 12, 18%).

Length of relationship

Length of relationship was recorded in years, however the quality of this item cannot be guaranteed. Participants reported in the qualitative comment section of the questionnaire that they were unsure which family relationship the question related to, their relationship with the person with cancer or their relationship within the family. The range varied from 0 to 50 years with a mean of 13 years (SD 12.7 years). Participants recording themselves as single often recorded zero or no score, but some noted they were supported by their parents and recorded their individual age. Given the lack of clarity with this variable, it was not included in any further analysis.

Breast cancer details

All participants were asked to identify the treatment regimen the women with breast cancer were currently completing for Phase 1. In Phase 2, the participants reported the treatment regimen which the woman with breast cancer had completed. The women with breast cancer reported surgery as the primary form of treatment ($n = 43$, 91%). Over half of the sample had a combined treatment regimen of surgery, chemotherapy and radiotherapy. The other combination accounted for the rest of the sample, with smaller numbers within each group. The following variables present the characteristics of the women with breast cancer's treatment regimen which was completed in Phase 1, active treatment seeing the oncologist at least every three months.

The Phase 2 treatment characteristics are presented to clarify that women completing both Phase 1 and Phase 2 had similar characteristics to the overall sample for Phase 1 treatment variations.

The treatment variations as follows for Phase 1;

Surgery, chemotherapy and radiotherapy. (Phase 1 $n = 26$, 55%)

Surgery and chemotherapy (Phase 1 $n = 9$, 20%)

Surgery and radiotherapy (Phase 1 $n = 5$, 11%)

Chemotherapy and radiotherapy (Phase 1 $n = 2$, 4%)

Surgery only (Phase 1 $n = 3$, 18%)

Chemotherapy (Phase 1 $n = 2$, 4%)

This range of treatment regimens reflects the typical range of the multi-modal treatments for women diagnosed with breast cancer under the age of fifty years (Dow, 2006). [See Table 7 for presentation of Phase 1 and Phase 2 for comparison. See Literature review section 2.5 for details of treatment combinations]

[See Appendix 8.4 for bar chart representation of treatment variation Phase 1, Phase 2]

Table 7 Treatment variations Phase 1 and Phase 2

	Phase 1	%	Phase 2	%
Surgery/chemotherapy/radiotherapy	26	55	16	57
Surgery/chemotherapy	9	20	3	10
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	47	100%	28	100%

Ethnicity

Ethnicity was recorded in five groups as per Australian Institute of Health and Welfare (AIHW, 2010). The majority of participants identified themselves as Caucasian / European (Phase 1 n = 103, 93%). A small percentage accounted for the rest of the sample; Asian (Phase 1 n = 2, 2%) and other (Phase 1 n = 6, 5%). No participants identified themselves as Aboriginal or Torres Strait Islanders.

[See Table 8 for details of Phase 1 and Phase 2 data]

Level of education

The level of education was recorded in four levels, similar to previous research exploring families (Northouse, 2005); completed secondary school education, diploma, degree and post graduate. Half of the sample reported completing secondary school (Phase 1 n = 60, 54%). The rest of the sample had education levels of Diploma / certificate (Phase 1 n = 27, 25%), Degree (Phase 1 n = 15, 14%), Post graduate (Phase 1 n = 9, 8%).

[See Table 8 for details of Phase 1 and Phase 2 data]

Education was grouped into two groups for final analysis to allow for comparison of groups with appropriate statistical power; ‘completed secondary schooling’ (Phase 1 n = 60, 54%) (Phase 2 n = 35, 52%) and completed diploma and above (Phase 1 n = 51, 46%), (Phase 2 n = 32, 48%).

Occupation

Occupation was recorded in ten groups as per Australian Standard of Occupations (AIHW, 2010).

The four largest groups of participants were;

Management / administration (Phase 1 n = 23, 21%), (Phase 2 n = 15, 22%)

Professional / associate professional (Phase 1 n = 19, 17%), (Phase 2 n = 14, 21%),

Clerical / sales / service (Phase 1 n = 16, 14%), (Phase 2 n = 9, 13%)

Home duties (Phase 1 n = 26, 23%), (Phase 2 n = 17, 25%).

Occupation was grouped into three main groups for the final analysis to reflect the sample;

Professional (professional / management) (Phase 1 n = 42, 38%), (Phase 2 n = 29, 43%)

Trade (trade, clerical, production, labourer) (Phase 1 n = 27, 24%), (Phase 2 n = 14, 21%)

Home (home duties, self-employed, unemployed, student) (Phase 1 n = 42, 38%), (Phase 2 n = 24, 36%)

[See Table 8 for details of occupation]

Postcodes

Postcodes were recorded as numerical data to allow for comparison of participants in different geographic areas. The post codes were then grouped into the Australian standard geographical classification remoteness areas (AIHW, 2010). Participants were classified by post code into the following groups; interstate, metropolitan, inner regional, outer regional central and outer regional north. The inner regional area were postcodes grouped into areas within a two hour drive of the metropolitan hospital, outer regional areas central were postcodes over 2 hour drive from the regional metropolitan hospital and outer regional north more than two hours drive from northern metropolitan hospital. Interstate participants had treatment in the metropolitan hospital of the researcher's state however lived in the adjoining state.

[See Table 8 for details of Phase 1 and Phase 2 data]

Table 8 Demographic characteristics
Presentation of demographic characteristics: ethnicity, education level, occupation and postcode

Characteristic	Phase 1 (N = 111)	%	Phase 2 (N = 67)	%
Ethnicity				
Caucasian	103	93%	62	92%
Asian	2	2%	2	3%
Other	6	5%	3	5%
Total	111	100%	67	100%
Education level				
Secondary school	60	54%	35	52%
Diploma	27	24%	16	24%
Degree	15	14%	10	15%
Post graduate	9	8%	6	9%
Total	111	100%	67	100%
Occupation level				
Management	23	21%	15	22%
Professional	19	17%	14	21%
Trade person	7	6%	5	8%
Clerical	16	14%	9	14%
Production	2	2%		
Labourer	2	2%		
Home duties	26	23%	17	25%
Self employed	8	7%	3	4%
Unemployed	2	2%	1	2%
Student	6	6%	3	4%
Total	111	100%	67	100%
Post codes				
Interstate	6	5%	3	5%
Metropolitan	71	64%	36	54%
Inner regional	21	19%	19	28%
Outer regional central	5	5%	2	3%
Outer regional north	8	7%	7	10%
Total	111	100%	67	100%

Summary

In summary the participant group had a mean age of 45 years, with approximately 80% being females. Approximately half of the participants identified that they had children. Women with breast cancer reported basic details of treatment with 91% reporting surgery as primary treatment and over half the women with breast cancer (55%) had a combination of surgery, chemotherapy and radiotherapy for overall treatment. Fifty percent of the participant group reported having completed secondary school and the other fifty percent reported having completed a diploma and above as the highest level of education. Responses to occupational codes indicated that 60% reported trade or home duties as their occupation and 40% as having a professional occupation. Sixty four percent of the participants reported living in a metropolitan area with the rest of the sample living in a range of regional areas.

The participants in the current study reflect population norms when compared to the characteristics found amongst women with breast cancer in the younger than fifty year age bracket (NBOCC, 2010). Overall, there was general consistency between the whole sample of participants for the current study (both women with breast cancer and support persons) and state wide characteristics of the population (AIHW, 2010). The analysis of the demographic data for Phase 1 and Phase 2 indicated that both groups were very similar with no statistically significant demographic differences between the sample that completed Phase 1 and the sample that completed both Phase 1 and Phase 2. This validates the comparison of data between the groups and supports similar information may have been obtained with a larger sample in Phase 2.

4.3 Reliability and validity of instruments

Reliability of each instrument used in the current study was assessed by using the Cronbach's alpha coefficient with the acceptable reliability set at 0.70 or higher. The internal reliability refers to the degree to which sub parts of the instrument are all measuring the same attribute. The following results are presented in relation to previous studies using the Family Hardiness Index and Family Crisis Personal Evaluation Scales (McCubbin, et al., 1981; McCubbin, et al., 1986) as indicated in the Method chapter section 3.7. Several researchers have used the FHI and F-COPES scales with similar Cronbach's alpha coefficient results to the present study (Clark, 2002; Leske, 2003; Mellon, et al., 2007; Mellon & Northouse, 2001).

Family Hardiness Index

In the current study, Cronbach's alpha coefficient was 0.81 for Phase 1 and 0.84 for Phase 2. The Cronbach alpha coefficient for the subscales in the current study were commitment 0.74 for Phase 1, 0.79 for Phase 2, challenge 0.75 for Phase 1, 0.83 for Phase 2, and control 0.48 for Phase 1, 0.49 for Phase 2. The Cronbach alpha coefficient for the subscale control indicates a weak internal reliability, however comparing the results of this research to McCubbin, McCubbin and Thompson (1986) the results are very similar with a strong Cronbach alpha coefficient for subscales commitment and challenge and weak for control (Cronbach alpha coefficient 0.65).

Family Crisis Oriented Personal Evaluation Scales

In the current study, Cronbach's alpha coefficient was 0.84 for Phase 1 and 0.81 for Phase 2. The Cronbach alpha coefficient for the subscales had the following reliability figures: social support 0.85 for Phase 1, 0.84 for Phase 2, reframing 0.72 for Phase 1, 0.67 for Phase 2, spiritual support 0.92 for Phase 1, 0.94 for Phase 2, mobilising family 0.72 for Phase 1, 0.70 for Phase 2, and passive appraisal 0.47 for Phase 1, 0.40 for Phase 2. The subscale passive appraisal has a weak Cronbach alpha coefficient at 0.47 although this is similar to McCubbin, Olsen and Larsen (1981) original research (Cronbach alpha coefficient 0.62).

Walsh scale

Cronbach's alpha for the Walsh scale has not been previously reported. The current study Cronbach alpha was 0.95 Phase 1 and 0.92 Phase 2 indicating good reliability across the 33

items in the scale. Cronbach's alpha on the sub scales for the current study were; challenge 0.89 for Phase 1, 0.77 for Phase 2, spirituality 0.93 for Phase 1, 0.93 for Phase 2, family flexibility 0.87 for Phase 1, 0.84 for Phase 2, family resources 0.75 for Phase 1, 0.69 for Phase 2, communication 0.92 for Phase 1, 0.89 for Phase 2.

4.3.1 Assessing for normality

The *Kolmogorov-Smirnov* statistic assesses normality of the distribution of scores. Three independent variables (treatment variation, age group and life phase) were explored against the FHI, F-COPES and Walsh scales. A non-significant result of 0.2 indicates normality in treatment variation, age group and life phase groups for FHI, F-COPES and Walsh scales. During the data analysis, the size of the groups was checked to ensure assumptions were not based on data groups with consistently small numbers (Polit, 2010). The two scales that explore family strengths, FHI & Walsh, are both positively skewed, consistent with participants reporting they are reasonably confident that they will work through the breast cancer as a family. This is a normal trend in the social sciences and does not reflect a problem with the scale, but rather the underlying nature of what is being explored (Polit, 2010).

The analysis of FHI scores for Phase 1 and Phase 2, which expresses the family strengths, reveals a skewed distribution to the right with a peak at 45 in Phase 1 and 50 in Phase 2. This is consistent with most participants scoring in the mostly true to true range. The normality curves are depicted in Appendix 8.5.

The analysis of the F-COPES scores for Phase 1 and Phase 2, which explore the use of resources reveals a normal distribution in both phases and is depicted in Appendix 8.5 indicating most participants reported neither agree nor disagree to moderately agree range.

The analysis of the Walsh scores for Phase 1 and Phase 2 reveals a curve skewed to the right in both phases. The graph indicated one low score in each phase; this score is actually produced by different participants in the two phases.

The results are depicted in Appendix 8.5.

4.4 What are the strengths and resources of the family during treatment for breast cancer?

Introduction

The current study investigated what strengths and resources the young women and their family members used during treatment for breast cancer. The individual data from Phase 1 (active treatment seeing the oncologist at least every three months) and Phase 2 (maintenance treatment minimal contact with oncologist) were analysed in order to answer the research question, ‘What are the strengths and resources that young women and their family members use during treatment for breast cancer?’

The following results provide the descriptive data for each of the scales exploring the strengths and resources of the participants. The three scales were analysed as per the author’s information providing general information regarding strengths and resources. This enabled the analysis of the FHI and F-COPES from the current study to be compared with previous research using the FHI and F-COPES scales. The second part of the analysis was to explore the subscales within the scales specific to the concept they represented. The comparison and grouping of the subscales is presented in the following sections.

4.4.1 Exploration of strengths

To explore the strengths that the participants reported, a composite of the subscales from the questionnaire was used. This provided a score from the Family Hardiness Index (FHI) which indicated a level of hardness. The F-COPES subscale (reframing) and three Walsh subscales (Challenge, family flexibility and communication) were analysed to provide a level of individual strengths. The overall scores from the FHI will be presented first.

Family Hardiness Index

The Family Hardiness Index (FHI) explores the strengths of the individual participants in particular their commitment to family, sense of challenge and sense of control after the breast cancer diagnosis. The FHI consists of twenty questions in three subscales scored using a four point Likert scale with zero indicating false, one indicating mostly false, two indicating mostly true and three indicating true. The total scores were generated by summing the scores of each subscale, which provided specific data relating to the individual’s response to the adversity. The three subscales address commitment, challenge and control. ‘Commitment’

relates to the individual's loyalty to the family and sense of how the family works together, 'Challenge' relates to how the individual sees the adversity and their efforts to be active and innovative as a response and 'Control' relates to how much the individual has a sense of control over the situation. This provides a reflection of the individual's appraisal of the breast cancer and how the individual works together with their family to maintain family balance. Table 2 in the Method chapter provide the details of the subscales and specific questions of the FHI scale.

Descriptive data from the FHI Phase 1 and Phase 2 are presented in Table 9. The first subscale 'Commitment' reflects a sense of commitment to the family with a mean score of 20 out of a possible 24. The participants' commitment to family across the two phases did reduce over time. However this change was not statistically significant. In the second subscale 'Challenge' the scores were lower with a mean score of 12 out of a possible 18. This reflects that the participants reported 'mostly true' to breast cancer being a positive challenge in their lives. In Phase 2 the higher score reflects a slight increase over time, but the change was not statistically significant. The third subscale 'Control' shows similar scores to the subscale 'Challenge' with participants reporting that they mostly felt they had some control on the situation and this was maintained over the two phases.

A total score for the Family Hardiness Index (FHI) was produced by summing the scores from all three subscales. The total provides an indication of family hardiness, which is an ability to overcome adversity. The potential maximum total score is 60. The higher the scores, the more the individual works with the family, seeing the adversity as something they can overcome and meet the challenges together. The score for each participant was calculated, as was an overall mean for all participants. The overall mean scores for the total FHI Phase 1 was 44 out of a possible 60 with a range from 20 - 59. This reflects the varying degree of strengths through the participants. The average score of 2 indicates that on average the participants scored 'mostly true' to 'true' across the four point scale 0 – 3. The FHI increased in Phase 2 to 46 with a range of 27 – 57 although this was not statistically significant. These scores reflect the strength or hardiness of the participants although the majority of the participants reported median internal strengths and durability of the family unit both during active treatment and in the longer term of maintenance treatment.

Table 9 FHI Scores
Presentation of Family Hardiness Index scores; Phase 1, Phase 2

	<i>Phase 1</i>		<i>Phase 2</i>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>Maximum</i>
	(<i>n</i> = 108)		(<i>n</i> = 67)		
Commitment	20	3.2	19	2.9	24
Challenge	12	2.9	13	2.9	18
Control	13	2.6	13	2.4	18
FHI Total	44	7	46	6.8	60

Walsh subscales challenge, family flexibility and communication and F-COPES subscale reframing.

The Walsh scale explores the strengths, resources and communication styles of the family as they adjust to the breast cancer. The Walsh scale consists of thirty three questions in five subscales scored on four point Likert scale with zero indicating false, one indicating mostly false, two indicating mostly true and three indicating true. The total scores represent how the individual works through problematic situations, the strengths they bring to the family, their use of resources both within and external to the family and the styles of communication used to support and assist the family through the adversity. The analysis of data from the three groups exploring strengths, ‘challenge’, ‘family flexibility’, and ‘communication’ will be discussed.

The subscale ‘challenge’ scores how the individual sees the situation and works through it. The third group ‘family flexibility’ scores how the family works together in times of adversity, leadership styles, trust and stability of the family. The fifth subscale is ‘communication’ which is the way the family shared problems through love, affection, humour and setting goals.

A representation of the scores for each subscale and total scores across the two phases is presented in Table 10. The first subscale ‘Challenge’ has a mean score of 21 out of a possible 27 in both Phase 1 and Phase 2. This indicates that participants reported that they did see the breast cancer as a challenge, but they attempted to work through it as a family trying to define things positively. The third subscale ‘Family flexibility’ has scores of Phase 1 16 and Phase 2 17 out of 21 this highlights the strong commitment and flexibility of the family during the

breast cancer. The last subscale ‘communication’ has scores of 24 increasing to 25 in Phase 2 out of 30, indicating the participants reported good sharing of information, opinions, affection and working together to reach goals.

The F-COPES subscale ‘reframing’ is included in the analysis of strengths as this subscale aligns more with the challenge of strengths rather than resources. The F-COPES subscale ‘reframing’ had scores Phase 1 24 out of a possible 32. This identifies that the participants reported trying to redefine the breast cancer as a manageable challenge. There was no change in Phase 2 scores, see Table 11 for presentation of data.

**Table 10 Walsh scores strengths
Presentation of Walsh scores; Phase 1, Phase 2**

	<i>Phase 1</i>		<i>Phase 2</i>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>Maximum</i>
	(<i>n</i> = 108)		(<i>n</i> = 66)		
Challenge	21	4	21	3	27
Family flexibility	16	3	17	3	21
Communication	24	5	25	4	30

**Table 11 F-COPES scores strengths
Presentation of F-COPES subscale reframing; Phase 1, Phase 2**

	<i>Phase 1</i>		<i>Phase 2</i>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>Maximum</i>
	(<i>n</i> = 108)		(<i>n</i> = 66)		
Reframing	24	4	24	4	32

4.4.2 Exploration of family resources

To explore the resources that the participants reported, a composite of the subscales from the questionnaires was used. The F-COPES subscales (social support, spiritual support, mobilising, passive appraisal) and Walsh subscales (spiritual support, resources) were analysed to provide information about use of resources.

Family Crisis Oriented Personal Evaluation scales

The Family Crisis Oriented Personal Evaluation scales (F-COPES) explores the strengths and resources used by the family to assist them overcome the adversity of breast cancer. The F-COPES consists of thirty questions in five subscales scored on a five point Likert scale with zero indicating strongly disagree, one indicating moderately disagree, two indicating neither disagree nor agree, three indicating moderately agree and four indicating strongly agree. Question 18 is not included in analysis due to low factor loading as per original scoring procedures (McCubbin, et al., 1981). The total scores represent how the individual works through problematic situations, the use of coping strategies and seeking assistance. This provides a reflection of the family resources and functioning as a family as they adjust to the diagnosis of breast cancer. The subscale ‘reframing’ is included in the subscales associated with strengths for the analysis of subscales as it aligns with these subscales.

The total scores were generated by summing the scores of each subscale. This provided an overall score and specific data relating to different aspects of the family’s use of resources. The total score provides a reflection of coping strategies. The five subscales address the following aspects of resources; ‘social support’, ‘reframing’, ‘spiritual support’, ‘mobilising’ and ‘passive appraisal’. The first subscale acquiring ‘social support’ measures the individual’s response to actively seeking support from extended family and friends. The second subscale ‘reframing’ relates to the capacity to redefine the stressful event into a more manageable response. This subscale is included in the analysis of strengths. The third subscale ‘spiritual support’ focuses on the individual’s response to acquiring spiritual support specifically related to church activities and having faith in God. The fourth subscale is ‘mobilising’ and actively seeking health professional and community support. The fifth subscale is ‘passive appraisal’ relating to the acceptance of problems and active family involvement. These scores are all reversed when calculating scores. Table 3 in the Method chapter provides the details of the subscales and specific questions of the F-COPES scale.

Descriptive data from the F-COPES Phase 1 and Phase 2 are presented in Table 12. In the first subscale ‘social support’ the mean score for Phase 1 was 21 out of a possible 36 indicating that the individual actively seeks social support some of the time. A slight increase was found in Phase 2 with a score mean of 22. In the third subscale ‘spiritual support’ the Phase 1 scores of five out of 16 suggest the participants had a low connection with the use of church or God as spiritual support. A small increase in scores was noted in Phase 2, but this

was not statistically significant. In the fourth subscale ‘mobilising’ the scores in Phase 1 and Phase 2 have minimal difference with a mean of 10 out of 16. This identifies that the participants sought health professionals and community support equally in both phases to a moderate degree. The final subscale ‘passive appraisal’ also had minimal difference between mean scores Phase 1 and Phase 2 with scores of 11 out of a possible 16, the scores are reversed so the higher the score the more actively the participant is involved reducing their stress. Participants reported a moderate level of active involvement in adjusting to the breast cancer.

A total score for the Family Crisis Oriented Personal Evaluation Scales (F-COPES) is produced by summing across the five subscales (including reframing). The total sum of the scores presents how the individual works through problematic situations, the use of coping strategies and seeking assistance. The higher the scores the more the individual identified the problem as something they could work through and were able to use coping strategies and seek assistance for. The potential maximum score is 116. The total scores for the F-COPES Phase 1 ranged from 39-111 with a mean score of 72. In Phase 2 scores ranged from 49 – 106 with a mean of 74. This reflects the varying range of coping strategies and use of resources to assist the family. There is a slight increase in the mean in Phase 2 and less range of scores; however this is not statistically significant. The score for each participant was calculated as was an overall mean for all participants. The mean score of Phase 1 was 2 and Phase 2 was three. This indicates that on average the participants scored neither agree nor disagree in Phase 1, and moderately agree Phase 2 across the four point scale 0 – 4. Overall this represents participants reporting a reasonable sense of identifying the problem as positive and being able to reframe the breast cancer and work through it as a family using a range of coping strategies and seeking outside assistance.

Walsh subscales spiritual support and family resources

The Walsh scale explores the resources of the family as they adjust to the breast cancer. It consists of seven questions in two subscales scored on four point Likert scale with zero indicating false, one indicating mostly false, two indicating mostly true and three indicating true. The second subscale, ‘spiritual support’, scores the participants rating regarding use of spiritual resources such as prayer, medication and rituals. This subscale has a broader focus than the F-Copes ‘spiritual support’. The fourth subscale ‘family resources’ is the openness to

accepting help and asking for help from family, friends, health professionals and community. Table 13 presents the Walsh subscales spiritual support and family resources.

**Table 12 Complete F-COPES scores
Presentation of Family Crisis Personal Evaluation Scale; Phase 1, Phase 2**

	<i>Phase 1</i>		<i>Phase 2</i>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>Maximum</i>
	(<i>n</i> = 108)		(<i>n</i> = 67)		
Social support	21	7	23	6	36
Reframing	24	4	24	4	32
Spiritual support	5	5	6	5	16
Mobilising	10	3	11	3	16
Passive appraisal	11	3	11	3	16
Total F-COPES	72	13	74	12	116

**Table 13 Walsh scores resources
Presentation of Walsh subscales; Phase 1, Phase 2**

	<i>Phase 1</i>		<i>Phase 2</i>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>Maximum</i>
	(<i>n</i> = 108)		(<i>n</i> = 66)		
Spiritual support	7	3	7	3	12
Family resources	6	2	6	2	9

Walsh total of combined subscales

A total score for the Walsh Scale is produced by summing the five subscales. The total scores represents how the individual sees the breast cancer, personal strengths, family strengths, how the family works together, outside assistance and communication styles. The higher the scores, the more the individual identified the problem as a positive challenge, and worked with the family using flexibility and good communication. The total Walsh scores for Phase 1 had a range of 24–99, with a mean of 74; of a possible full score of 99. A slight increase of scores was reported in Phase 2 with a range of 32 – 96 and a mean of 76. The range of responses reflects the varying degrees of strengths and resources reported within each individual. An average was also calculated to provide the mean of the actual individual responses. This was 2 identifying that most participants scored in the ‘mostly true’ to ‘true’

range when answering the questions relating to their strengths, resources and communication styles they used when facing the breast cancer. Table 14 presents the scores for the Walsh scale. Table 4 in the Method chapter provides the details of the subscales and specific questions of the Walsh scale.

**Table 14 Complete Walsh scores
Presentation of Walsh scores; Phase 1, Phase 2**

	<i>Phase 1</i>		<i>Phase 2</i>		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>Maximum</i>
	(n = 108)		(n = 66)		
Challenge	21	4	21	3	27
Spiritual support	7	3	7	3	12
Family flexibility	16	3	17	3	21
Family resources	6	2	6	2	9
Communication	24	5	25	4	30
Walsh Total	74	14	76	11	99

The following table presents the scores from the three scales for Phase 1 and Phase 2 providing information on the range of scores, totals and possible total of scale.

**Table 15 Scores Phase 1 & Phase 2
Presentation of scores Phase 1, Phase 2**

	n	Min	Max	Mean	Possible	Std Deviation
					Total	
FHI P1	108	20	59	44.4	60	7.061
FHI P2	67	27	57	45.6	60	6.825
F-COPES P1	108	39	111	71.9	116	13.383
F-COPES P2	67	49	106	74.1	116	11.938
Walsh P1	108	24	99	74.1	99	14.126
Walsh P2	66	31	96	75.5	99	11.232

Summary

These findings indicate that the participants' overall strengths were relatively low in comparison to the maximum scores. The participants reported a reasonably strong

commitment to the family and communication within the family. They responded in terms of a slightly lower sense of seeing the breast cancer as a positive challenge and being in control of the situation. These strengths were maintained over time. The findings indicate a relatively low use of resources used by the family. The resources used were family and friends, with health professionals used slightly less. The use of spiritual support scored low in the quantitative data although this was not reflected in the qualitative data. The overall scores indicated a slight increase in family strengths, family resources and communication from Phase 1 to Phase 2 suggesting that over time there may be an increase in the family's ability to adjust and cope with the adversity of breast cancer. In summary, the findings reflect families working together to remain positive and strong in the adversity of breast cancer, although with less external assistance. Together with the qualitative findings these family strengths and resources will be discussed in the discussion chapter. The following will explore the influencing factors of the family strengths and resources.

4.4.3 What is the relationship between the strengths and resources?

The relationship between Family Hardiness (as measured by FHI) and Family Crisis Oriented Personal Evaluation (as measured by F-Copes) and Walsh family resilience (as measured by Walsh scale) was investigated using Spearman's Rank Order Correlation. This enabled an exploration of the relationship between the strength and resources and the subscales.

Preliminary analyses were performed to ensure that there was no violation of the assumptions of normality, linearity and homoscedasticity. Associations between the three scales were measured in both phases. There was a strong positive correlation between all three scales FHI, F-COPES and Walsh in Phase 1 ($r = .54 - .69$, $n = 108$, $p < .001$). [See Table 16 for details] In phase 2, there was only a strong positive correlation between the Phase 2 Walsh scales and Phase 1 FHI, F-COPES and Walsh ($r = .55$, $n = 66$, $p < .001$). The following explored the relationships between the subscales within the scales.

**Table 16 Correlation FHI, F-COPES, Walsh
Phase 1 Correlation between FHI, F-COPES, Walsh scales**

	FHI	F-COPES
FHI		
F-COPES	.535**	
Walsh	.693**	.619**

* $p < .01$

** $p < .001$

$n = 108$

4.4.3.1 What are the significant correlations between all three scales

The analysis of all the subscales identified key correlations in Phase 1 between six subscales. These are significant findings, suggesting a connection between the appraisal of the breast cancer, communication between the family and the ability of the family to be flexible. These correlations support the ability of these three scales to measure significant strengths and resources of the family and identify connections between them. These key correlations form the basis for the Family Response framework suggested in the discussion chapter section 6.4. [See Table 17 for correlation details]

Table 17 Correlation between 3 scales
Phase 1 Significant correlations

	F-COPES Reframing	Walsh communications	Walsh challenge	Walsh flexibility	Walsh family Resources
FHI	.514**	.562**	.690**	.587**	.356**
Commitment					
F-COPES Reframing		.548**	.647**	.514**	.269**
Walsh Communication			.772**	.733**	.443**
Walsh Challenge				.822**	.423**
Walsh Family flexibility					.479**

**p < .001

N = 108

4.4.3.2 Relationship between FHI and F-COPES

The relationship between the individual subscales within the Phase 1 FHI (commitment, challenge and control) and the subscales within the F-Copes (social support, reframing, spiritual support, mobilising and passive appraisal) were investigated using the *Spearman Rank Order Correlation*. In Phase 1 the results suggest strong positive correlations between FHI commitment and FHI challenge ($r = .44$, $n = 108$, $p < .001$); FHI commitment and FHI control ($r = .39$, $n = 108$, $p < .001$); FHI commitment and F-COPES social support ($r = .27$, $n = 107$, $p < .001$); FHI commitment and F-COPES reframing ($r = .51$, $n = 107$, $p < .001$).

These positive correlations indicated the higher commitment to the family the more the participants reported seeing breast cancer as a positive challenge, having control over the situation, seeking social support and ability to reframe the adversity into something positive.
[See Table 18 for correlation details]

The subscale FHI challenge was strongly correlated with FHI control ($r = .40$, $n = 108$, $p < .001$), F-COPES social support ($r = .46$, $n = 108$, $p < .001$), F-COPES reframing ($r = .30$, $n = 107$, $p < .001$), F-COPES mobilising ($r = .37$, $n = 107$, $p < .001$) and F-COPES passive appraisal ($r = .29$, $n = 107$, $p < .001$). These results suggest that the more the participant reported the breast cancer as a positive challenge, they also reported higher levels of control over the situation, seeking support, reframing the situation and mobilising the family, but also

the less they reported being passive in the situation (passive appraisal is negatively scored so the higher the score the less you participated passively). There was a weak negative correlation between FHI challenge and F-COPES spiritual support suggesting that the more they identified the breast cancer as a positive challenge the less they looked to a belief in God.

The subscale FHI control was strongly correlated with F-COPES passive appraisal ($r = .36$, $n = 107$, $p < .001$). One might conclude that the more sense of control the participants reported the less passive they were in the situation.

**Table 18 Correlation FHI & F-COPES Phase 1
Phase 1 Correlation between FHI and F-COPES scale**

FHI	F-COPES	F-COPES	F-COPES	F-COPES	F-COPES
	Social support	Reframing	Spiritual support	Mobilising	Passive appraisal
Commitment	.276**	.514**	.091	.232*	.143
Challenge	.467**	.303**	-.011	.370**	.297**
Control	.124	.166	.119	.227*	.368**

* $p < .01$

** $p < .001$

$n = 108$

In Phase 2 the subscales were not as strongly correlated. The Subscales in the FHI, challenge ($r = .32$, $n = 66$, $p < .001$), and commitment ($r = .45$, $n = 66$, $p < .001$), were strongly related to F-COPES reframing similar to Phase 1. The subscales challenge ($r = .36$, $n = 66$, $p < .001$), and control ($r = .49$, $n = 66$, $p < .001$), were strongly related to passive appraisal. This result is different from Phase 1 where commitment had minimal relation to passive appraisal. The subscale social support has minimal correlation to the FHI in Phase 2 identifying that in Phase 2 there is less correlation between the hardiness or strengths of the participants and the use of social support to assist one during this time. [See Table 19 for Phase 2 correlation details]

Table 19 Correlation FHI & F-COPES Phase 2
Phase 2 Correlation between FHI and F-COPES scale

FHI	F-COPES	F-COPES	F-COPES	F-COPES	F-COPES
	Social	Reframing	Spiritual	Mobilising	Passive
	support		support		appraisal
Commitment	.231	.453**	.158	.227	.298*
Challenge	.060	.318**	.135	.153	.358**
Control	.059	.137	.005	.206	.496**

*p <.01

**p <.001

n = 66

4.4.3.3 Relationship between F-COPES and Walsh

The relationship between the individual subscales within the F-Copes (social support, reframing, spiritual support, mobilising and passive appraisal) and subscales within Walsh (challenge, spiritual support, family flexibility, resources and communication) was investigated using the *Spearman Rank Order Correlation*. The results for Phase 1 suggest a strong correlation with F-COPES social support, reframing and mobilising with all the subscales from the Walsh scale. Correlation between F-COPES social support and Walsh challenge ($r = .27$, $n = 108$, $p < .001$), Walsh Family flexibility ($r = .30$, $n = 108$, $p < .001$), Walsh resources ($r = .62$, $n = 108$, $p < .001$) and Walsh communications ($r = .30$, $n = 108$, $p < .001$). Correlations between F-COPES reframing and Walsh challenge ($r = .65$, $n = 108$, $p < .001$), Walsh spirit support ($r = .37$, $n = 108$, $p < .001$), Walsh Family flexibility ($r = .51$, $n = 108$, $p < .001$), Walsh resources ($r = .27$, $n = 108$, $p < .001$) and Walsh communications ($r = .55$, $n = 108$, $p < .001$). Correlations between F-COPES mobilising and Walsh challenge ($r = .33$, $n = 108$, $p < .001$), Walsh spirit support ($r = .37$, $n = 108$, $p < .001$), Walsh Family flexibility ($r = .33$, $n = 108$, $p < .001$), Walsh resources ($r = .48$, $n = 108$, $p < .001$) and Walsh communications ($r = .23$, $n = 108$, $p < .01$). These results suggest social support, positive appraisal and seeking external support are all strongly associated.

The Walsh subscale spiritual support is positively correlated with the F-COPES subscale spiritual support ($r = .61$, $n = 108$, $p < .001$). The spiritual support questions in the Walsh scale were broader in nature than the F-COPES scale, asking about the individual's personal

spiritual support, meditation and faith rather than just about belief in God and going to church as in the F-COPES scale. The strong correlation between F-COPES spiritual support and Walsh spiritual support subscales is indicative of the consistency of these two measures. The qualitative data strongly supports this notion of personal spirituality and personal faith which is not necessarily a Christian faith. Section 5.4.2 addresses spiritual support. [See Table 19 for details of correlations between subscales]

**Table 20 Correlation F-COPES & Walsh Phase 1
Phase 1 Correlation between F-COPES and Walsh scale**

F-COPES	Walsh	Walsh	Walsh	Walsh	Walsh
	Challenge	Spiritual support	Family flexibility	Resources	Communications
Social support	.273**	.243*	.304**	.618**	.303**
Reframing	.647**	.365**	.514**	.269**	.548**
Spiritual support	.121	.609**	.218*	.179	.029
Mobilising	.334**	.368**	.333**	.475**	.230*
Passive appraisal	.189	.037	.045	.158	.173

*p <.01

**p <.001

n = 108

In Phase 2, the correlation between subscales in F-COPES and the subscales in the Walsh scale was weaker. The F-COPES subscale social support was positively correlated with Walsh resources ($r = .53$, $n = 66$, $p < .001$). In Phase 2 the results suggest strong positive correlations between F-COPES subscale ‘reframing’ and Walsh subscales ‘challenge’, ‘family flexibility’ and ‘communications’. This is similar to Phase 1 demonstrating the continued ability of the participant who is able to reframe the adversity to be more likely to report higher sense of ‘challenge’, ‘flexibility’ and ‘communications’ with the family. There is a reduced correlation with F-COPES subscale ‘mobilising’ in Phase 2, however there is an increase in the positive correlation between the Walsh subscale ‘spiritual support’ in Phase 2. This indicates that the participants reporting a strong sense of spiritual support were also reporting the ability to mobilise family and resources to assist with adjusting to the breast cancer. The subscale F-COPES ‘passive appraisal’ indicates a strong positive correlation with

Walsh ‘challenge’ ($r = .33$, $n = 66$, $p < .001$), different from Phase 1 where this was a weak correlation. This result suggests that active participation and seeing the breast cancer as a positive challenge that increases overtime. [See Table 20 for details of Phase 2 correlations between subscales]

**Table 21 Correlation F-COPES & Walsh Phase 2
Phase 2 Correlation between F-COPES and Walsh scale**

F-COPES	Walsh	Walsh	Walsh	Walsh	Walsh
	Challenge	Spiritual support	Family flexibility	Resources	Communications
Social support	.228	.213	.219	.528**	.169
Reframing	.701**	.373**	.586**	.203	.610**
Spiritual support	.082	.828**	.258*	.113	.147
Mobilising	.186	.442**	.355**	.367**	.256
Passive appraisal	.332**	.085	.281*	.259*	.261*

* $p < .01$

** $p < .001$

$n = 66$

4.4.3.4 Relationship between FHI and Walsh

In Phase 1, the relationship between the subscales in the FHI subscales and Walsh subscales suggests a strong positive correlation with all subscales except Walsh, ‘spiritual support’. There is, however a strong correlation between FHI ‘control’ and Walsh ‘spiritual support’ ($r = .31$, $n = 108$, $p < .001$). This result suggests that if participants have a higher sense of control over the situation they also report using spiritual support to assist their adjustment.

The following were correlations between FHI ‘commitment’ and Walsh ‘challenge’ ($r = .69$, $n = 108$, $p < .001$); Walsh ‘family flexibility’ ($r = .59$, $n = 108$, $p < .001$), Walsh ‘resources’ ($r = .36$, $n = 108$, $p < .001$) and Walsh ‘communications’ ($r = .56$, $n = 108$, $p < .001$). The correlations between FHI ‘challenge’ and Walsh ‘challenge’ were ($r = .58$, $n = 108$, $p < .001$); Walsh ‘family flexibility’ ($r = .50$, $n = 108$, $p < .001$), Walsh ‘resources’ ($r = .44$, $n = 108$, $p < .001$) and Walsh ‘communications’ ($r = .58$, $n = 108$, $p < .001$). The correlations between FHI ‘control’ and Walsh ‘challenge’ were ($r = .44$, $n = 108$, $p < .001$); Walsh ‘spiritual support’ (r

= .31, n = 108, p < .001); Walsh ‘family flexibility’ (r = .38, n = 108, p < .001), Walsh resources (r = .28, n = 108, p < .001) and Walsh communications (r = .26, n = 108, p < .001). [See Table 22 for Phase 1 correlations]

Table 22 Correlation FHI & Walsh Phase 1
Phase 1 Correlation between FHI and Walsh scale

FHI	Walsh Challenge	Walsh Spiritual support	Walsh Family flexibility	Walsh Resources	Walsh Communications
Commitment	.690**	.282**	.587**	.356**	.562**
Challenge	.581**	.222*	.497**	.444**	.577**
Control	.443**	.314**	.376**	.276**	.260**

*p <.01

**p <.001

n = 108

In Phase 2 the results are similar to Phase 1 with less correlation between Walsh ‘resources’ and the FHI scale. There is a continued strong correlation between Walsh ‘challenge’ and the three subscales from the FHI, suggesting that participants who continue to see the breast cancer as a positive challenge after treatment maintain a strong commitment to family and positive strengths within the family. [See Table 23 for Phase 2 correlations]

Table 23 Correlation FHI & Walsh Phase 2
Phase 2 Correlation between FHI and Walsh scale

FHI	Walsh challenge	Walsh spiritual support	Walsh family flexibility	Walsh resources	Walsh communications
Commitment	.514**	.256*	.439**	.048	.618**
Challenge	.578**	.313**	.585**	.209*	.611**
Control	.324**	.019	.309*	.129	.186

*p <.01

**p <.001

n = 66

4.4.3.5 Summary

The results indicate there is a strong correlation between strengths and resources in Phase 1. However, there is less correlation between the subscales in Phase 2 suggesting there is less association between the strengths and resources of the participant after the initial treatment phase has passed. In summary, these results indicate that the higher the family strengths are associated with a more active use of resources such as extended family, health professionals in Phase 1. These results will be discussed further in the discussion chapter.

4.5 Family attributes that influence strengths and resources

The relationship between two independent categorical variables against the continuous variables from the three scales FHI, F-Copes and Walsh was compared using the *Mann-Whitney U Test*. The research questions to be explored were; was there a difference between the scores of women with breast cancer and support persons; gender males and females participants in the study; treatment groups and education level groups?

4.5.1.1 Women with breast cancer and family support persons

The first question to be explored was; Is there a difference in scores between the women with breast cancer and their family support persons? The continuous variable FHI showed a statistically significant effect in Phase 1 ($Z = -2.17$ $p < .03$). Further analysis of the FHI scale identified that there was a statistically significant difference in the scores for the subscale ‘control’ between the women and the family support persons in Phase 1 ($Z = -3.96$ $p < .001$). These results indicate that the women with breast cancer ranked lower than the family support persons, therefore reporting less control of their lives during the active treatment phase. However this was not sustained in Phase 2. There was not a statistically significant difference between the women and the family support persons in the other scales.

4.5.1.2 Gender

The second question to be explored was; Is there a difference between male and female participants in the study? In both phases the statistical difference was minimal between male and female scores. In the FHI variable, the subscale ‘control’ was the only statistically significant subscale. This result was in Phase 1 ($Z = -2.26$ $p < .02$) with the women ranked lower than the males (female 51; males 67). This result reflects the previous result that the women with breast cancer reported less control during active treatment Phase 1. Analysis of the family members revealed no statistical difference between males and females.

4.5.1.3 Treatment variations

Differences across treatment variations were explored by using two treatment groups such as Group 1 consecutive treatment of surgery, chemotherapy, and radiotherapy or Group 2 combination of one or two treatments (surgery, chemotherapy, and radiotherapy). No statistically significant difference was found between treatment Group 1 receiving surgery,

chemotherapy and radiotherapy and Group 2 combination of treatment during both Phase 1 and Phase 2. The mean ranking of the two treatment groups identify that Group 1 reporting surgery, chemotherapy and radiotherapy consistently ranked higher in Phase 1 in the three scales. The influence of different treatment on the FHI, F-COPES and Walsh scores was further explored by using *Kruskal-Wallis Test* to explore the difference between specific treatment variations. [See Appendix 8.4 for details of mean ranking for treatment groups Phase 1 and Phase 2]

4.5.1.4 Education groups

The last question explored the difference between education groups (diploma and above compared to just secondary school) and the continuous variables FHI, F-Copes and Walsh. Here education groups, refer to one group of participants with diploma and above compared to another group with secondary school education only. This group difference was associated with a statistically significant result in the FHI score in both phases Phase 1 ($Z = -2.63 p < .01$) and Phase 2 ($Z = -2.17 p < .03$). When further explored, the subscales in Phase 1 ‘commitment’ ($Z = -1.98 p < .05$), ‘challenge’ ($Z = -2.3 p < .02$) and ‘control’ ($Z = -2.05 p < .04$) were statistically significant. In the F-COPES scores the subscale ‘mobilising’ Phase 1 ($Z = -1.96 p < .05$) had a statistically significant result. Group differences were found for the Walsh scores, more specifically the subscale, Walsh ‘challenge’ Phase 1 ($Z = -2.098 p < .04$) and Walsh ‘flexibility’ Phase 1 ($Z = -2.027 p < .04$). However in Phase 2, education was significantly associated only with FHI ‘commitment’ ($Z = -1.98 p < .05$). In terms of mean ranks, the group diploma and above group consistently scored higher than the secondary school group.

The relationship between education groups and continuous variables was further explored by the *Kruskal-Wallis Test* to examine the relationship between education levels and occupation. An association between education level when grouped, diploma and above versus secondary school was found in relation to the reported strengths and resources of participants. The outcomes are consistent with participants being more likely to report personal strengths if they have higher education levels and an association between education levels and use of resources both within the family and external to the family to assist their adjustment to the breast cancer. However this was not statistically sustained over time.

[See Table 24 for Phase 1 Phase 2 details]

**Table 24 Relationship Education FHI, F-COPES, Walsh
Relationship between education level and continuous variables**

FHI, F-COPES, Walsh

	Phase 1	Phase 2
	n = 108	n = 66
FHI		
Commitment	.05*	.05*
Challenge	.02*	
Control	.04*	
F-COPES		
Mobilising	.05*	
Walsh		
Challenge	.04*	
Flexibility	.04*	

*p<.05

4.5.1.5 Summary

In summary, the results indicate minimal difference between women with breast cancer and support persons, and also between males and females. So, in subsequent analyses, these were included as a combined sample of 111 participants Phase 1 and 67 participants Phase 2. Although, the differences between treatment groups were also minimal, there were, however, significant differences for levels of education. The influence of treatment and education was further explored in the next section.

4.5.2 What are the contributing family attributes that influence the strengths and resources?

The research questions explored were; was there a difference in the strengths and resources reported by the participants influenced by age group, treatment combinations, phase of life, education level, occupation and post code? The *Kruskal-Wallis Test* was used to explore the relationship between variables with one or more groups and the continuous variables from the three scales FHI, F-Copes and Walsh.

4.5.2.1 Age groups

The first question to be explored was the relationship between age and the continuous variables FHI, F-COPES and Walsh. In Phase 1, the analysis revealed statistically significant differences in several of the subscales. These subscales were FHI scale, ‘challenge’ (χ^2 (4) 21.8, $p < .001$), ‘control’ (χ^2 (4) 22.6, $p < .001$), and FHI total (χ^2 (4) 21.0, $p < .001$). In the F-COPES scale the subscales ‘social support’ (χ^2 (4) 13.7, $p < .01$) and ‘mobilising’ (χ^2 (4) 16.6, $p < .002$), F-COPES total (χ^2 (4) 15.5, $p < .004$) were statistically significant. In the Walsh scale the subscales; Walsh ‘challenge’ (χ^2 (4) 13.0, $p < .011$), Walsh ‘family flexibility’ (χ^2 (4) 13.5, $p < .009$) and Walsh total (χ^2 (4) 12.7, $p < .01$) were statistically significant. [See Table 25 for presentation of age groups across variables]

An inspection of the mean ranks for the Phase 1 results identified the age group of 41-50 years as having the lowest scores, with the age group of 0-30 as having the next lowest scores, and then increasing with age. The age group of 41-50 included the largest number of women with breast cancer. When comparisons were made between support persons and women with breast cancer, the subscale ‘control’ and FHI variables showed significant decreases in scores for women with breast cancer. An interesting result is related to the subscale F-COPES ‘reframing’, that reports on the participants’ ability to redefine stressful situations. The age group 0-30 years scored highest in the subscale F-COPES although their scores were not significantly different to those in other age groups (χ^2 (4) 3.00, $p < .55$). [See Figure 3 for scores of FHI across age groups]

In Phase 2 there was no significant difference between age groups. However, when the mean ranks are examined the age group 31-40 years was often the highest ranked, except in terms of spiritual support, where it was the lowest. This result is different from the Phase 1 rankings where the age group 31-40 was the third lowest, in most of the group comparisons. This result is consistent with the age group of 31-40 having a greater increase of scores over time than other age groups.

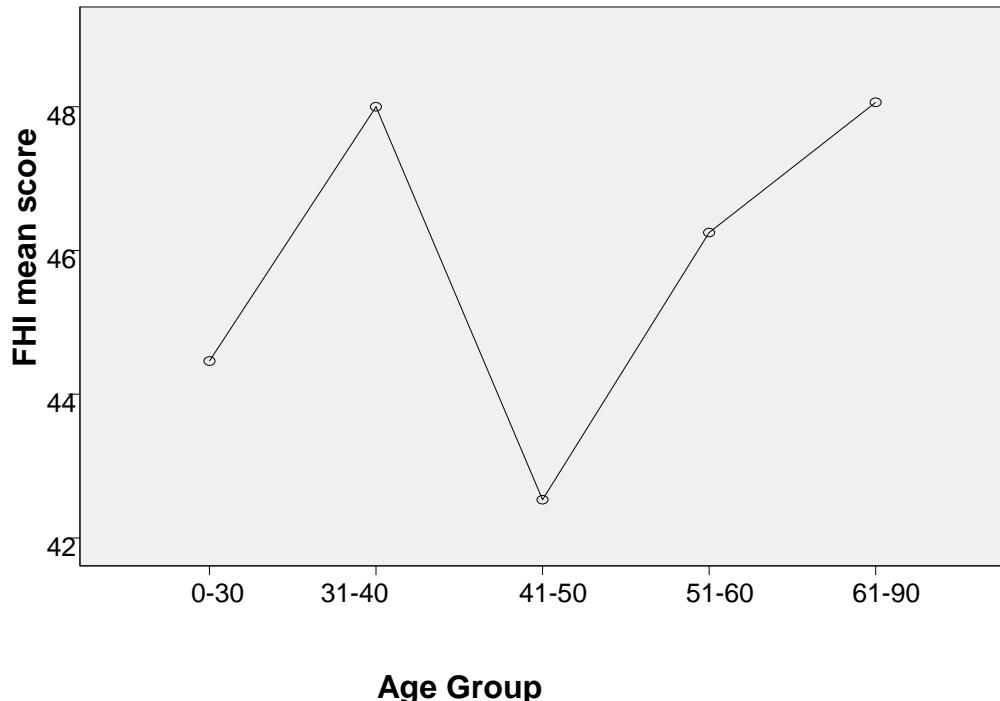
**Table 25 Relationship age groups FHI, F-COPES, Walsh
Relationship between age groups and continuous variables Phase 1
(no significance for Phase 2)**

Phase 1	Chi-square	P values
n = 108		
FHI	21.0	.00**
Challenge	21.8	.00**
Control	22.6	.00**
F-COPES	15.5	.00**
Social support	13.7	.01*
Mobilising	16.6	.00**
Walsh Total	12.7	.01*
Walsh challenge	13.0	.01*
Family flexibility	13.5	.01*

*p < .05

**p < .001

**Figure 3 Relationship of age groups
Presentation of FHI scores Phase 1**



4.5.2.2 Treatment combinations

The second question explored the influence of different combinations of treatment on strengths and resources used by the participants. In the output generated comparing the individual treatment groups to the continuous variables FHI, F-COPES and Walsh in Phase 1 and Phase 2 revealed no significant differences. The lesser treatment groups (surgery or chemotherapy only) tended to have lower scores across the subscales except in passive appraisal Phase 1 (ranking 85: 51). This correlates with the previous analysis of the treatment based on two main groups: Combined treatment (surgery, chemotherapy, radiotherapy), and; Minimal treatment, with the combined treatment group obtaining higher scores.

In Phase 2 there was no clear pattern in the ranking of scores across subscales. These results were most probably influenced by the time of treatment (women with breast cancer receiving treatment) as some participants were in the middle of a treatment schedule, while other participants might have been at the end of treatment. The general tendency of these results suggests that during active treatment the more combinations of treatment you have, the greater the physical and emotional change for both the woman with breast cancer and her supporting family, with higher strengths for the participants and also a higher use of resources. Because this group of participants had a complex level of treatment, the women with breast cancer and perhaps their family members saw the health professional more often and might have then been able to obtain more guidance. Although these findings are not statistically significant due to small numbers the overall trend is worth discussing in the discussion chapter, in terms of the extent to which other research studies support these findings. [See Section 6.3]

4.5.2.3 Phase of life

The next question explored the influence of phase of life (Children vs. no children) on the strengths and resources the participants used to assist their adjustment. In the output generated comparing the phase of life to the continuous variables, FHI, F-COPES and Walsh in Phase 1 five subscales there was a significant difference for the participants with children compared to participants with no children. These were the subscale FHI ‘control’ (χ^2 (2) 6.01, $p < .05$), and in the F-COPES scale the F-COPES total (χ^2 (2) 6.91, $p < .03$), and subscale ‘social support’ (χ^2 (2) 10.0, $p < .01$), ‘mobilising’ (χ^2 (2) 27.86, $p < .02$). In the Walsh scale,

the subscale ‘resources’ (χ^2 (2) 6.18, $p < .04$) had a significant difference in scores. The mean ranking identified that it was the group with children that ranked lower except in the subscale FHI control where the group with no children ranked lower.

In Phase 2, no significant group differences were identified. The generated results differed from those in Phase 1, consistent with changes over time. In the FHI subscale control there was no difference in the scores for women with children vs. those without children in Phase 2, a difference that was statistically significant in Phase 1.

In the F-COPES subscales in Phase 1 the group with children ranked lower in Phase 2. This group often ranked higher or the same, except in reframing where those with no children ranked higher Phase 1 (χ^2 (4) 3.01, $p < .22$), (ranking 63:51), and Phase 2 (χ^2 (2) 1.27, $p < .53$), (ranking 39 : 33). These results suggest some negative influence for families with children in being able to maintain control on the situation, and obtain social support however this was only an influencing factor during active treatment.

4.5.2.4 Education level

In the output generated comparing the education level to the continuous variables FHI, F-COPES and Walsh there was a significant difference in the education level in two subscales, the Phase 1 FHI subscale ‘commitment’ (χ^2 (3) 7.88, $p < .05$) and the Walsh ‘challenge’ (χ^2 (2) 8.04, $p < .04$). In all groups except F-COPES ‘social support’ and ‘spiritual support’ (F-COPES and Walsh) the more education the participants had the higher their scores ranked.

In Phase 2 no significant group differences were generated and the ranking identified the higher education, the higher the rankings, except in the subscale ‘spiritual support’. These results expand on the earlier results exploring the education groups and reinforce the tendency for the participants with higher education to report a higher level of strengths and use of resources within the family.

4.5.2.5 Occupation groups

The analysis of occupation groups for Phase 1, the F-COPES and subscale F-COPES mobilising revealed only the F-COPES generated significant differences between occupation groups. The scale F-COPES (χ^2 (6.39, $p < .04$) and the subscale ‘mobilising’ (χ^2 (2) 7.07, $p <$

.03) had significant differences between groups. The mean rankings identified that trade groups scored lower and the participants at home scored highest in most subscales.

The output generated for Phase 2 had only one significant difference between occupation groups for the F-COPES subscale ‘passive appraisal’ ($\chi^2 (2) 5.9, p < .05$) in this subscale the professional group scored higher (ranking 50: 40), whereas in Phase 1 these scores were very similar (ranking 35: 34). When education level and occupation groups are explored using Spearman’s correlation a strong positive correlation between education and occupation groups is present. This highlights the links between education and occupation, and ability to gather family strengths and resources to overcome the adversity of breast cancer.

4.5.2.6 Post codes

The last question to be explored in relation to influencing factors was the post code or area where the participant lived. The post code grouping provided an indication of distance from metropolitan areas and easier health care access and support. The analysis comparing the post code groups to the continuous variable FHI, F-COPES and Walsh revealed no significant group differences identified in either Phase 1 or Phase 2.

4.5.2.7 Summary

In summary, the age of the participant influenced how they identified with the breast cancer and adjusted to this adversity during active treatment. Over time the influence of age was not significant. The different types of treatment schedules had a small influence on the participant’s adjustment to the breast cancer with participants who identified that they or their family member had less active treatment, for example surgery and chemotherapy reporting lower scores in general. In relation to the phase of life; with or without children the family members with children generally reported lower strength scores and lower use of external resources. The level of education and occupation had a comparable influence on the participant’s adjustment during active treatment, with the lower groups being secondary school education only and trade occupation groups. The influence of distance from the metropolitan area had no significant influence.

4.6 Changes in strengths and resources across time?

In order to determine if there is a difference in the participant's use of strength and resources across the two phases a time phase analysis was completed. The comparison of scores was explored using a *Wilcoxon Signed Ranks Test* to evaluate the changes of scores from Phase 1 to Phase 2. There was no significant change in scores across the two time phases although there is a slight increase in the actual scores. Presentation of results from *Wilcoxon Signed Ranks Test* in the FHI scale ($Z = -.727$, $n = 66$, $p = 0.467$); F-COPES scale ($Z = -.726$, $n = 66$, $p = 0.468$) and Walsh scale ($Z = -.469$, $n = 66$, $p = 0.639$). A further examination of the subscales within the scales revealed no significant change in scores between Phase 1 and Phase 2 in any of the subscales. These results indicate that the participants reported minimal difference in their use of strengths or resources between the two phases.

4.7 Family group analysis

The final part of the analysis was to group the individual family members into their family groups. There were 36 family groups with an average of three family members participating in the research for each family group, a total of 100 participants organised into 36 family groups. This provided an indication of family strengths and resources when the three subscales were analysed together for each family group. [See Appendix 8.7 for details of family groups]

The family groups were analysed as case summaries using SPSS 17.0. The demographic information including gender, age, life phase, education groups, occupation groups and post code groups were included in the presentation of the family group information. The FHI, F-COPES and Walsh family scores for Phase 1 and Phase 2 were examined for similarities. The mean scores of the family groups for the FHI, F-COPES and Walsh scales allowed a comparison of family group means against contributing family attributes. The family scores revealed several families with low overall means in all three scales. The qualitative family data expands on this quantitative data providing details of strengths and resources used by the family in response to the diagnosis of breast cancer. [See Chapter 5]

When analysing the family group variables the small family group data meant the analysis did not have statistical power. However patterns from the results can be interpreted. Manual exploration of family group data shows that if one family member's scores are low there is a

tendency for the other family members to also have lower than average scores. Also if the family group has higher scores in Phase 1 the overall average is higher and the Phase 2 scores also tended to be higher. The contributing family attributes of the individual family members influenced the family group scores. For example, families having either younger family members participating in the research or families with children tended to have overall lower scores. [See Table 27 for family 16 and 49 scores]. Family 16 participated in both quantitative and qualitative aspects of the research. Their family was made up of parents under the age of 50 years, two teenagers and one child under five. The table of scores identifies a family with low scores who would be assessed as vulnerable. This family did not complete Phase 2. Family 49 participated in Phase 1 and Phase 2 and the scores can be seen to change and reduce in Phase 2 in some of the scores. Both families had young children and multiple treatments. Although both families were supported by the parents of the woman with breast cancer, the older support parents' scores can be seen to be higher overall.

Table 26 Family group 16; 49

Presentation of family 16 and family 49 mean scores.

Family group	Participant Number	Phase 1			Phase 2			Treatment	Age group
		FHI	F-COPES	Walsh	FHI	F-COPES	Walsh		
16	161 ⁺	27	55	38	41-50
	1621 ⁺⁺	35	39	66	0-30
	1622 ⁺⁺	39	57	65	41-50
Mean		33.67	50.33	56.33				2	
49	491 ⁺	39	85	71	37	78	69	41-50	
	4921 ⁺⁺	41	72	64	46	78	77	41-50	
	4922 ⁺⁺	40	67	60	36	65	62	0-30	
	4923 ⁺⁺	46	77	74	39	84	86	61-90	
Mean		41.50	75.25	67.25	39.50	76.25	73.50	2	

*Treatment code 1 = combination of surgery, chemotherapy and radiotherapy

*Treatment code 2 = completed surgery, chemotherapy and radiotherapy

⁺Women with breast cancer

⁺⁺Family members

The qualitative family data consisting of interviews with several members provides depth to the quantitative analysis of the family groups. See Chapter 5 for presentation of qualitative data. The qualitative data from family members also supports the general findings from the quantitative data in relation to the influence of individual scores on the overall family scores. [See Table 27 for scores of family group analysis]

Table 27 Family group analysis
Presentation of scores family group analysis Phase 1, Phase 2

	n	Min	Max	Mean	Possible	Std Deviation
	Total					
FHI P1	98	27	56	45	60	6.3
FHI P2	62	27	57	46	60	6.8
F-COPES P1	98	39	111	72	116	13.3
F-COPES P2	62	49	106	74	116	12.2
Walsh P1	98	32	99	75	99	13.2
Walsh P2	62	38	96	76	99	11.4

4.8 Conclusion of Quantitative Analysis

In conclusion the analysis of the data generated in this research suggested a number of important findings. The sample consisted of women with breast cancer and one to four family members with an average of three participants for each family group. The participants had an average age of forty five years. The majority (91%) of the women with breast cancer reported surgery as primary treatment for their breast cancer with then other treatment combinations. The treatment for over fifty percent (55%) of the group of women with breast cancer was a combination of surgery, chemotherapy and radiotherapy. Half (54%) of the participants reported they had children, with fifteen percent (15%) with children below ten years old. The education level for fifty percent of the group was to secondary school and the other half was diploma and above.

The data analysis revealed minimal difference in scores between the women with breast cancer and her support persons highlighting that the strengths and resources are similar for all the family as they adjust to a diagnosis of breast cancer. There was also minimal difference in scores between females and males across the participant group.

The three scales generated data related to the strengths and resources the participants used in the two phases namely Phase 1 actively receiving treatment seeing the oncologist at least

every three months and Phase 2 after active treatment. In answer to the research question, ‘what are the strengths and resources of the women with breast cancer and their family members?’ several factors are apparent. These factors are the strength of the commitment to family and the use of communication within the family. Also the use of resources by the family to assist them through the adversity of breast cancer seems to be related to the family’s ability to see the breast cancer as positive, something they can deal with as a family.

The data analysis revealed a close association between the study variables of family hardiness (FHI) and family resources (F-COPES and Walsh). This result suggests that participants reporting strength within the family are also likely to access more resources and display higher levels of communication within the family. Within the subscales of the main scales there was strong association between seeing the breast cancer as a challenge, being in control and actively seeking assistance and reframing the adversity into something more positive. There was also a strong association between actively seeking support and family flexibility and communications within the family.

The data analysis confirmed that the families in the current study report similar levels of family strengths (FHI) and family resources (F-COPES) to previous studies with families suffering adversity (Clark, 2002; Leske, 2003; Mellon & Northouse, 2001). This will be further expanded in the discussion chapter. The Walsh scale supported the data from the FHI and F-COPES scales with strong correlations between the three scales. The data analysis revealed a slight increase in the scores over time, however not statistically significant.

The main influencing factor related to family strengths and resources was age, although this result was not sustained across the two phases. The treatment, life phase, education level and occupation had a slight influence in Phase 1 on some of the variables. There was a strong positive connection between the subscales suggesting the more positive strengths the participant has the more likely they are to use external resources and strong communication styles to assist them to move forward from the adversity of the breast cancer.

In closing, the analysis of the quantitative data provides the basis for the discussion on the strengths and resources that young women and their family members used during treatment for breast cancer. The analysis identified a number of contributing family attributes influencing the strength and resources that the women and their family members use during

treatment for breast cancer. The qualitative analysis presented in Chapter 5 provides both depth to the discussion on the strength and resources used by the young women and their family members during treatment for breast cancer but also allows the family to be explored as an interactive unit.

Interviews

By Elisabeth Coyne

Being invited, wondering what their story will be,

Entering their world

Sharing and sitting, listening and hearing

Stories of sadness

Stories of joy!

Stories

They share they remember

Tears of sadness, tears of joy!

Why is it so hard to remember what has past?

The shock and the fears are recalled

It was hard, so hard to survive!

The tiredness, the nausea, trying to forget!

To remember, to survive

A new level, a reward

To be young, to be strong!

5 Chapter 5 Analysis of qualitative data

5.1 Introduction

The analysis and findings from the qualitative data are presented in this chapter. A qualitative component was incorporated into the research to provide depth to the overarching research question ‘What are the strengths and resources young women and their family members use during treatment for breast cancer?’ The analysis reflects the research question and is informed by the Family Resiliency Framework.

The first section of this chapter will present an overview of the qualitative research process, including recruitment of participants, interview process, analysis and presentation of data and demographics of interview participants.

The second section of this chapter will explore the research question ‘What are the strengths the young women and their family members use during treatment for breast cancer?’ This section will present the analysis of these strengths, exploring the personal response to breast cancer.

The third section of this chapter will expand on a specific strength that emerges in the analysis that is ‘communication’. The analysis will explore the different types of communication styles used by the participants.

The fourth section of this chapter will explore the research question ‘What are the resources the young women and their family members use during treatment for breast cancer?’ This section will present the analysis of the resources used by the participants and discuss how these resources assisted their adjustment to breast cancer.

5.2 Qualitative research process

This section presents an overview of the qualitative research process. The overview will discuss the recruitment of participants for the qualitative interviews, interview process, analysis and presentation of data and the demographics of the interview participants.

5.2.1 Qualitative recruitment method

The method for recruiting participants for the qualitative aspect of this exploratory descriptive research was by an invitation on the last section (p. 5) of the Phase 1 questionnaire. Participants were asked if they would like to participate in a personal interview to discuss what assisted them to work through a stressful situation. Participants were asked to write their name and contact number and a convenient time to call on the removable page of the questionnaire. This section was isolated from the main questionnaire on return and the researcher telephoned the participant and arranged a time and place convenient for the participant to conduct for the personal interview. [See Section 3.2.2, 3.5 for specific details]

5.2.2 Interview process

Personal interviews were completed for each participant separately in their home ($n = 17$) or conducted by telephone if participants lived more than 200 kilometres from the research centre ($n = 8$) due to the size of the study area. Thus rural and remote interviews could be included in the current study. Separately conducted interviews provided the participants with an environment for safe, open and honest disclosure of information. The setting and interview process are recognised as being important in building good rapport with the participants, thus enabling a free flow of information (Grbich, 1999). Participants gave individual consent, however families were free to participate as a group if they wished. In three of the interviews other family members [husband, mother, and daughter] joined the interview and left as they wished. All participants were telephoned prior to the interview to ensure the participant understood the interview process.

Rapport with the participant was established with social talk prior to the actual interview. During this time the interview process was explained. This ensured a full understanding of the research prior to the interview. At this time the written informed consent form was signed or verbal consent was gained for telephone interviews and the participant chose a pseudonym

to be used in the interview and reporting of the research. The participants were also informed of their rights to discontinue participation in the research at any time without penalty and that they could decline to answer any particular questions in the interview. Developing trust and believing the interviewee is recognised to be a valuable part of the interview process helping to ensure an open disclosure of information (Grbich, 1999).

The semi-structured interview questions were based on the Walsh Resiliency Framework. The researcher obtained the question key prior to the current study from author Froma Walsh who has used the qualitative question key in previous research (Walsh, 2003, 2006). The interview questions began with 'How did your family share the initial diagnosis of breast cancer?' The participants were then guided through the following questions: 1) how their family worked through problems; 2) their personal spirituality; 3) how the family worked through unexpected problems; 4) how the family worked together; 5) who the family approached for help; 6) how the family maintained open communication; 7) how the family shared emotional expression; and 8) how the family solved problems. The qualitative analysis revealed rich, in-depth information, with new themes emerging strongly during the thematic analysis. The interviews were all taped and transcripts written verbatim.

The written questionnaires (analysed in the previous chapter) also had a section for personal comments. Participants wrote comments in this section ($n = 47$) and these comments were included in the qualitative data analysis.

5.2.3 Analysis

The qualitative data have been thematically analysed using a grounded theory approach (Miles & Huberman, 1994; Strauss & Corbin, 1990). This approach was used due to the nature of the personal data where individual participants spoke of their journey in different terms. The researcher chose the personal engagement in the data as a process of analysis rather than the use of the program NVIVO. Thematic analysis is a method for identifying recurring patterns and themes within the narrative data. The analysis explored different patterns across the entire data set and grouped these beginning patterns into themes. The researcher used an inductive approach working with the data identifying themes strongly linked to the data without trying to fit the data into pre-existing codes (Braun & Clarke, 2006). The analysis aimed to unravel the narrative data to reflect the deeper meaning of this

personal journey with breast cancer. The narrative data were analysed across the data set as a whole. The family group data were analysed by exploring each family member's transcripts together as a group to understand the complex nature of the family group response.

The first step in the qualitative data analysis was the reading and rereading of the narrative data, and this stage was completed to familiarise the researcher with the data (Braun & Clarke, 2006). This active content reading of the transcripts and underlining of phrases is the first step to identify themes. Reoccurring topics within one transcript and the data set as a whole can then be grouped. The whole data set was worked through during this phase. The researcher used a cut and sort method (Miles & Huberman, 1994) once key phrases were identified. The different participant types were printed on different coloured paper to allow easy identification by the researcher as to the type of participant, for example women with breast cancer, mothers, partners, children and other support persons. The groups of phrases were then grouped into themes, to allow a beginning stage of defining and naming of the themes. A thematic map was also built at this stage as initial themes linked and overlapped in the analysis. In this stage of the analysis differences between participants' roles and responses started to become evident.

The refinement of the themes was the next step undertaken. Themes were defined as important details of the data which represented a patterned response (recurring across transcripts); or data relating to the research question, for example, spiritual support or resources used. The transcripts were revisited during this step to identify any missing phrases from the whole data set as new themes emerged from the analysis. The phrases within these developing themes were also checked to identify from which participants the phrases had come. Then the other participants' transcripts were reread to identify if specific phrases had been missed. An example of this was phrases relating to the 'shock of diagnosis,' which all participants discussed in varying detail. Family group themes were identified in this phase as themes from one family member were identified and then checked in the transcripts of other family members.

Underlying assumptions and conceptualisation began to emerge with the successive analysis of the data. This level of data analysis has been called a latent thematic analysis where the researcher explores the data beyond the semantic content level to underlying ideas shaping the data (Braun & Clarke, 2006). The researcher explored the data for broader assumptions or

meanings within the data that are not clearly articulated in the data. For example, the exploration of the theme related to spiritual support was investigated and found to reveal an extended theme of what participants used personally to assist their adjustment. The ongoing defining of themes and grouping of themes into categories continued in this step of the analysis. This stage was about defining the essence of the theme and what the narrative data were representing. Although field notes were written during each stage of the analysis, a detailed story of each theme and category was completed at the end of this stage, to provide the researcher details of the meaning of each category and the aspects it was exploring.

The final step of the data analysis explored the data and subsequent themes to determine links between the Walsh Family Resiliency Framework (2006) and the McCubbin and McCubbin (1993) Resiliency Model of Family Stress, Adjustment and Adaptation. The discussion chapter presents the links connecting to data to the framework.

Member checks

Member checking is the involvement of the participants to check that research findings are a valid representation of their true experience. This is completed in order to increase reliability was completed (Holloway & Wheeler, 2002). All interview participants were sent their full narrative transcript. The researcher asked five of the participants who she felt would be able to review the themes without risk of personal distress to review resultant themes from the data. The participants agreed with the resultant themes and commented that it was similar to having a name given to their feelings about their breast cancer journey. The researcher also used three breast care nurses to review the themes as these were health professionals who deal with women with breast cancer on a day-to-day basis and they would be able to understand and comment if the resultant themes were appropriate. The breast care nurses agreed that resultant themes were appropriate and reflected a typical woman's adjustment to breast cancer.

Journaling

The researcher kept a journal during the research process. The research journal documented the process of ethics, recruitment, interviews, and data analysis. The researcher's experiences were recorded as they occurred. The keeping of a research journal allowed reflection after the interviews, which were often distressing and tiring. The researcher also sought the assistance of an experienced counsellor during the recruitment and interview stages due to the intense

nature of interviewing women close to the researcher's age with a life threatening disease. Two of the participants died within a month of the researcher talking with them. In the journal the researcher wrote about her personal journey from research proposal, ethics, recruitment, interviews to final writing up of the research. Two articles have been published from this reflection process (Coyne, 2010; Coyne & Dean, 2010). The researcher also wrote poems to describe the experience of the research for her. [See Poems xiii] The writing of a research journal is an accepted method of reflection, which has been regarded as a form of honest reflection of the researcher's own transformation through the research process (Grbich, 1999).

5.2.4 Presentation of analysis

The aim of this qualitative inquiry was to gain an insight into the way the family moves through a diagnosis of breast cancer. The analysis focuses on the strengths of the family, such as family commitment, communication styles and structures within the family that may assist them to plan and cope with breast cancer diagnosis and treatment. The resources of the family were also explored, specifically the types of resources they used during this time and the role of these resources. Through the use of narrative data, an in-depth exploration of the family response has been obtained.

The key findings from the twenty three interviews conducted are presented in this chapter. The interviews were conducted with women with breast cancer and their partners, mothers, sisters, children, friends, who all closely supported them during their breast cancer journey. The findings are presented using thick description and discussion to support each theme (Denzin & Lincoln, 2000). The researcher explored a broad range of themes thus allowing the reader to become acquainted with the study and the experience of the participants. Illustrative quotes from the interview transcripts attempt to portray the participants' perspectives by capturing the complexity of their experience.

The themes are presented as two main categories, 'strengths' and 'resources', to align with the research framework and overall research question. The first category is the 'strengths' of the participants and their personal adjustment to breast cancer. A subcategory 'communication' is included in the strengths category, exploring how the participants shared

their story. The second category ‘resources’; explores the types of support that the participants described as assisting their adjustment to the breast cancer diagnosis.

5.2.5 Interview demographics

A total of 23 interviews were conducted. This included 14 women with breast cancer and nine support persons. The 14 women with breast cancer were aged between 35 - 46 years, with a mean age of 45 years. The nine support persons were aged between 18 - 65 years and consisted of three male partners, and eight females who consisted of adult children (n = 1), sister (n = 1), mothers (n = 3) and an aunt (n = 1). Family members who joined the personal interviews were Kaz’s Mother, KM and Mia’s daughter, L. [See Table 29 for details of interview participants and their names]

Participating women with breast cancer reported undergoing a variety of treatments, including combined surgery, chemotherapy and radiotherapy (n = 5, 36%) and a combination of surgery, chemotherapy or radiotherapy (n = 9, 64%). The phase of life demographics for the women with breast cancer indicated that there were those with children less than 17 years (n = 6, 43%), those with adult children (n = 6, 43%) and those with no children (n = 2, 14%).

The demographics for both women with breast cancer and support persons is as follows: Ethnic origin Caucasian (n = 21, 91%), other (n = 2, 9%). Education level diploma and above (n = 12, 52%), secondary school only (n = 11, 48%). Occupation groups professional (n = 10, 43.5%), trade (n = 3, 13%), home (n = 10, 43.5%). Postcode interstate (n = 3, 13%), metropolitan (n = 12, 52%), inner regional (n = 5, 22%), outer regional central (n = 2, 9%), outer regional north (n = 1, 4%).

An exploratory analysis of quantitative data of the interview participants compared to the complete sample was completed to check for variation. Demographic data of the interview participants had minimal variation from the main participant group. The scores from the FHI, F-COPES and Walsh scales for the interview participants showed minimal variation from the main participant group. This demonstrates that the interview participants had similar demographics and scores to full sample set.

[See Table 28 for details of interview participants]

Table 28 Demographic interview information

Name	Participant number	Age	Children Number then age	Relationship to patient	Treatment
Lyn	41	43	2 < 20 years	Patient	Mast / chemo / radio *
Kate	421	62		Lyn's mother	
Jane	121	44	2 < 20 years	Patient	Mastectomy x 2 chemo / radiotherapy disease recurrence
Sam	1222	43		Jane 's sister	
Sophie	1221	18		Jane's daughter	
Anna	71	38	1 < 5 years	Patient	Mastectomy / radiotherapy
Charlie	721	39		Anna's husband	
Barbara	722	62		Anna's mother	
Karen	111	39	2 < 15 years	Patient	Mast / chemo / radio Disease recurrence
Mabel	1121	65		Karen's mother	
Sally	431	39	No children	Patient	Advanced cancer on diagnosis lumpectomy / radiotherapy
Ivan	4321	50		Sally's husband	
Viv	241	41	No children	Patient	Mastectomy / chemotherapy
Jai	2421	39		Viv's partner	
Kaz	161	44	3 < 17 years	Patient	Mast / chemo / radio / reconstruction
KM				Kaz's Mother	Spoke for short period during interview with Kaz
Mia	81	45	2 < 25 years	Patient	Mastectomy/radiotherapy
L	821	20		Mia's daughter	Spoke for short period during interview with Mia
Donna	191	43	2 < 15years	Patient	Mast / chemo / radio
Rachel	441	46	2< 15 years	Patient	Mastectomy / chemotherapy
Robyn	11	32	2 < 5 years	Patient	Mast/chemo / radio
Gail	51	46	3 < 30 years	Patient	Mastectomy
Anne	211	46	3 < 30 years	Patient	Mastectomy / chemotherapy
Cath	681	44	3 < 30 years	Patient	Mastectomy / chemotherapy
Annie	551	62		Patient's aunt	Patient 29 yrs Mast / chemo / radio

*Mast = Mastectomy Chemo = Chemotherapy Radio = Radiotherapy

5.3 Strengths

This category explores the personal aspect of how the participants drew on individual qualities in response to the adversity of a diagnosis of breast cancer. The strengths of the participants related to how they saw the breast cancer initially, their response to the breast cancer and then how they worked through their personal adjustment. The themes presented are challenge, personal strengths, balancing life, changing focus and adjustment.

Communication will then be presented as a separate subcategory of strengths. The links to the quantitative data are presented at the beginning of each theme when applicable, allowing for associations between the quantitative and qualitative data to be identified. See Chapter 4 section 4.4 for additional details of quantitative data.

5.3.1 Appraisal of breast cancer

5.3.1.1 Challenge of breast cancer

The theme ‘challenge’ explores the response to the breast cancer. In the qualitative data the participants spoke about different time periods and how they responded over time. The subscale ‘challenge’ of the quantitative data measured how participants defined the adversity: positively or negatively. The questions asked how they worked through the problems, with the family, actively supporting each other. The analysis of the quantitative data indicated that when asked, most participants agreed that they saw breast cancer as a challenge and acknowledged the need for family assistance to manage.

Diagnosis and treatment

Diagnosis is the point where the participant’s life was changed. All participants described the diagnosis period as a time of intense emotions. For some participants they had only just begun their breast cancer journey. Their interviews were thick with emotions as they describe this intense period, but they all wanted to share their story. The participants were in their first year since diagnosis with two women with secondary cancers who were completing further treatment.

One of the first aspects of diagnosis was the different circumstances in which the women and their families were told the news. Some participants felt supported and comforted by the medical staff while others describe being left to cope by themselves. Rachel explained that

for her family, they wanted to know what they were dealing with and she described a good connection with the medical team.

Because we need to sort it as quickly as possible. So I rang them [doctor's surgery] and they were awesome. ... But she did basically imply by the time we left that it was bad [crying]. Rachel (9 weeks since diagnosis)

The women in this age group often went to the doctor by themselves not expecting to be told of a diagnosis of breast cancer. Their partners were often at work or minding children.

However they described that getting the news on your own was very difficult. Viv, a professional woman, explained that she did not expect the news to be bad and Jai, her partner, was at work. Viv wrote a poem called 'Stone' to describe her experience of diagnosis. [See Poems xiii]

I was actually at the doctor's surgery and I had driven myself there and I realised that I couldn't drive, so I had to ring Jai and just basically tell him on the phone and it was devastating and I just had to sit in the car park until he came and got me. Viv

Others spoke of needing to know their diagnosis and recalled the distress caused by waiting. Sally talks of the distressing period of not knowing, but she thought that the number of tests she was having suggested it was not good news '*So hubby and I kind of guessed and we confronted the Doctors and said, "Is it cancer?" and they still wouldn't commit*'. Some women and their families spoke of a gut feeling that the news would be bad.

Sally's partner Ivan, actually spoke with the doctors after no clear information was given explaining that he wanted to be at the hospital when Sally was told the final diagnosis as they expected it to be bad. Sally was eventually diagnosed with secondary breast cancer in her hip.

Because I had an inkling in the back of my mind that it might have been the case, and I didn't want Sally to be on her own when they gave her the information, and they had to wait until I actually physically arrived before they could share that information with her. Ivan

This gave Ivan a sense of control on the situation so he could be there to support Sally, who was born with Spina bifida and this diagnosis was going to be an additional challenge for both of them. Sally's response to the diagnosis was shock, 'gob smacked' however she describes the great support that Ivan provided in this early stage of her breast cancer journey.

Another participant who spoke of positive family support was Gail who had several adult daughters who supported her from the first shock of diagnosis through treatment. Gail described how they rang family who gathered to support and then the planning started.

My daughter was with me, I was just so glad that I had her with me because I just, it was shock, couldn't believe it was happening to me, it just couldn't be and from there we just, I rang on my phone and my daughter rang with hers and we just rang all my other daughters and my husband so they were all ready and waiting for us when we got back home and it was just, yeah it was because I was in shock. I just cried and cried for about an hour and I said "Well that's it now I've had my cry now I'm going to get up and fight it". Gail

Mia describes a similar situation where her family go through the shock stage then progress into planning. Passing through the grief stage seems to allow the participants the space to move on and gather their strength.

At first everyone was really upset and um, yeah then we just, after probably two days of crying, not by me, from the others, ... and then we were going to do one thing [treatment was organised] Mia

An important aspect identified from this research is the intensity of the emotions for the whole family in this early diagnosis period. Charlie recalls the day of diagnosis with his wife and the intensity of his emotions.

Yeah you've got to cry and you know I meant the diagnosis I can't remember what day it was but I mean one day I'd actually threw up um because I felt so bloody awful about it all yeah. Charlie

Followed closely by the shock of the diagnosis was the 'why me'. The women and family members spoke of this in different terms. The women described going through the '*I am too young*', to '*what have I done to deserve this*'. Although they also explained they did not allow themselves to spend much time with these thoughts as they were harmful to keeping positive.

"Why me?" I said, "No, no I wouldn't," you know you can't, we can't answer that question so you don't spend time on it but in a way I actually was spending time on it...Karen

All the family members described the 'Why me' however the mothers' reaction was the strongest as they struggled with the anguish of why has my daughter been diagnosed with this disease.

You know, Pop's 91, and you think, "Oh God," and he thinks as well, the little bit that he knew about it, he thinks, "Why her? Why her?" And we all went through that, why her? And then you do think what could it possibly have been caused from. Annie [Aunt of 28 year old woman with breast cancer]

Shortly after diagnosis the treatment phase begins, participants described this period of time as either waiting or moving quickly, and either was difficult. Waiting was stressful. They waited for results, waited for surgery, and waited to see the medical team. Cath tells her story of having to wait for surgery in the public hospital system. Unfortunately, because she was not in the oncology system until after surgery she also missed out in supportive care. Once she had her surgery she had the support of the Breast Care Nurse which was valuable.

But then I had to wait, like six to eight weeks for the actual operation and it was getting bigger the lump. Just in that short period of time and that's when you really freak out. Cath

The younger patients who had an immediate start to treatment quickly described a lack of adjustment time and also worried about breast cancer treatment.

'It all happened so quickly ... the speed was like instantaneous...and that worries you' Annie [Aunt of 28 year old woman with breast cancer].

'It happened all so quickly. It was like one week I was alright and next week I was having the lump out, you know. That was, I don't think we got a chance to think, you know.' Mia

The diagnosis signified the beginning of their journey with breast cancer and they used personal strength to move them through this stressful period to try to cope with the demands

of treatment. The next section explores the different types of personal strength the participants used and how each helped them move through treatment.

5.3.2 Commitment to family

5.3.2.1 Personal side of breast cancer; personal strengths

This theme explored the personal qualities of the participants and how characteristics such as leadership, flexibility, positive thinking emerges from the data as they recall their response to the breast cancer and treatment. The quantitative data indicated the importance of this sense of strength with scores of mostly-true. [See Section 4.4] The personal side of this sense of strength was not seen in the quantitative data. The subscale ‘control’ was statistically lower for the women with breast cancer than it was for the support persons and this is also evident in the qualitative data, where the women describe their personal journeys.

The personal side

The transcripts gave a sense of different personal approaches although some of the participants’ personal style did not positively assist them in adjusting to the breast cancer diagnosis. The participants’ personal appraisal of the breast cancer and what the breast cancer meant for them ranged from something which helped them grow to something that controlled their lives. This theme mainly related to how the women coped. In the interviews with their family support people, the family members related that their personal approaches vary closely related to how the women with breast cancer were responding. If the women with breast cancer were not able to direct family roles then all the family were adversely affected.

Although, the women with breast cancer often pushed themselves to maintain their role in the family. Cath puts this plainly when she explained she had trouble but she needed to keep going or the family would be in trouble.

You'd have your days when you got extremely depressed and upset and all that but at the end of the day you've got to be the one to get yourself out of it or you can end up in all sorts of strife can't you? ... Got kids, have to move on. Get up and don't be so stupid. You know and really push yourself Cath

The role of being the mother, leader of the family came across consistently. Women who had strong leadership characteristics described themselves as being able to direct and plan the

family resources. These characteristics were being able to see a direction forward in the changes and ability to communicate with the family. This was good when all went well however with the uncertainty and effects of breast cancer treatment and having to relinquish the leadership role sometimes caused stress.

By the end of the night though you were pretty, really tired and you know... Mia's daughter Dragonish [laughter] Yeah, I tried, yeah, because I've always been the one that's the leader. Mia

Some of the women were able to keep their roles as leader for a lot of the time, although this seemed to cause stress within the family. It was difficult for them to get a balance between keeping going and allowing the body to recuperate.

Yeah, well she basically, she's in charge of a lot of things [chuckle] and she didn't relinquish that role while she was sick. Sam [Jane's sister]

Some of the women, overwhelmed with the breast cancer and treatment, had no strength left to maintain their role within the family. Kaz talks of just trusting her family to look after themselves while she focused on trying to cope with the treatment. Her parents helped out with her three children, two teenagers and one pre-schooler. Later in the interview she recalls how the children and her husband did not cope and how the family just hung in there.

I guess I kind of just let them all get on with it and hoped that someone was looking after them [laughs] and just trusted that everyone else would just take care of it while I, you know. Kaz

The women talked of how they went into 'survival mode' to cope with the side effects of the treatment and the uncertainty of the breast cancer. This was a strategy used by several of the women in an attempt to maintain some control over their lives.

Like I said, it's like survival mode you know, you really minimise the things that you don't think are important like social outings and certain people. Robyn

It was personally hard for them not to have any control over the situation. The women spoke of times when breast cancer did control their lives, but they also spoke strongly of trying not to let the breast cancer take over.

Very stressful because I'm, I'm a, I'm a self-confessed control freak and I need to know what's happening and when you're in a situation where you can't know what's

happening or you don't know what's happening, that in itself is extremely stressful.

Sally

Their capacity to appraise the breast cancer as positive and find a way to work this out emerged as a personal strength in some of the women's interviews. The women described this strength in many ways. Annie describes her personal resolve with breast cancer '*we are just gonna cope as best we can, tackle each day as it comes, treat each day as your last, just deal with it*'. Some of the women also explained it was important for them not to let breast cancer take over their life. '*It shouldn't define you*' is the way Viv explained how she was dealing with her breast cancer diagnosis.

The women used aspects of this personal strength to keep themselves positive, seeking out personal friends who helped them stay positive. Robyn explains her personality helped her cope '*Sort of just my own personality I'm quite social and if I'm feeling down I'll go and seek out some friends*'. Robyn had two children under five years and very little family support. However for some of the women, family was there to encourage and support the women every step of the way, guiding and assisting them in their '*down times*'. Gail tells the story of her children's supportive attitude; '*No Mum we are going to beat this, that's it we're just going to beat it*'. One of the points the women described, is they get tired of being told to stay positive. Anna explained this very plainly as she described her well-meaning friends attitude '*"Oh, but you've got to stay positive, you know, got to." And I'm like, "What the...?" What do these people know about staying bloody positive?*'

Negative emotional aspect of breast cancer

In this theme, the negative aspect of breast cancer is captured and the personal lows experienced by the women and their families living with breast cancer explored. The participants talked of the strong emotions they felt. They talked of crying in the shower to not let family see how upset they were or their tears of frustration. They described the negatives of their journey with strong and emotional language such as '*pretty much a mess, horrible injections, terrible year, hard awful journey, absolutely gutted, horrendous thing to go through, bloody evil fairy godmother, no choice*'. Although these emotions were described strongly they did not always take over the lives of the participants. Most of the participants did not continue to dwell on the negative aspect except for Kaz and Anna who described their journey in a fairly negative light. They were also able to see some positives in their lives.

5.3.3 Family functioning

5.3.3.1 Balancing life

This group of themes related flexibility of the individual and the family members to the difficulties of life faced by those with breast cancer, and their families' attempt to find balance in their lives. The quantitative data showed a strong commitment to family and family flexibility suggesting that families are committed to trying to work out a plan for adjustment to the diagnosis. The qualitative data supported and expanded on this theme.

Planning flexibility - trying to regain control

The participants discussed trying to plan and regain some control within their lives, planning to gain control on the '*travelator*' of breast cancer. Charlie talks of his experience and their family's travelator ride with breast cancer and needing time to work things out.

It's not really a roller coaster, it's more of, for want of a better word, a travelator.

It's something that's pulling you in a direction so the, you know the doctors tell you one thing and they just want to almost push you through the machine and our view is that we want them to get off that machine and we want the time to think Charlie

Getting a plan together was often very hard, some talked of no time to plan and also their treatment changing so needing to replan. Robyn and Karen spoke of the '*goal posts*' changing constantly as they struggled with their aggressive type of breast cancer. Robyn, a mother of two preschool children, explains about her treatment plans changing.

Things like your oncologist may say "Okay we'll start this and you'll have four treatments of this" and then you're two treatments into it and then he says "Oh no we're having six to eight". So you've mentally prepared where that finishing line is and getting yourself through small, thinking "Okay I've got so many weeks until I finish the chemo, I've got so many weeks until I finish this" and having those goalposts change all the time you've got to really, that's quite hard to deal with because you've got to refocus and plan. Robyn

One aspect of balancing life was the way different participants were able to accept change whereas others found this stressful. The women's stories highlighted that the more flexible

they were with their roles in the family, the less stress the family as a whole felt. Sally, Cath and Lyn talked of playing it day-by-day so they did not get too stressed, but they also tried to plan for long term goals. Cath explains how she had to organise her life so then she could focus and recover from the breast cancer.

Cause I was working full-time. I had to organise work, to get time off and sort all your bills, you know, cause coming out of work when you get that it's a big stress, and I just worked it out with the family and that was good. Cath

Sally talks of how they '*just cruised most of the time*' although she also described that at times this was stressful for her as she liked to be in control. Sally goes on to describe how for her next lot of treatment she planned as much as she could to reduce her stress.

I guess in a way, the planning we're doing is making sure we've got plenty of things to occupy our time..... so we've already got accommodation booked for when we're, where we're staying so we'll just give the address to people so they can write to us...Sally

Planning was often done as a family team approach, it was all about 'What can we do to move forward and try to keep a balance on life?' The women mainly talked of planning, organising jobs, how to organise the children, planning time away, planning for losing their hair. Their partners often spoke of organising work to have time to help and being prepared for the unexpected. Jai spoke of setting goals. This helped them focus, which Jai describes as an important part of their adjustment to the diagnosis. '*I think that's an important aspect of her recovery program and the fact that we're both focused on doing things and getting things achieved and having targets and goals.*'

Normality - keeping life normal

Similar to planning, a theme around normality emerged which was about trying to keep life as normal as possible, not letting breast cancer take over. The participants often described this reaffirmation process of being normal and taking control during the breast cancer treatment. This was often described in negative terms as the women did not always achieve the level of normality they wanted. Viv describes it well when she discussed her attempt at normality '*I've just tried to be absolutely as normal um as possible and then when I can't be normal, at least be humorous [laughs]*' Viv and Jai did not have children and this seemed to be a big influencing factor on their response to breast cancer. Women with children always described

trying to keep the children's routine normal, through school and after school activities. 'So, 'cause the kids then were fourteen and sixteen so they're still at high school and had to just keep going like normal.' Jane.

Another mother spoke of how it didn't really work but life went on.

They didn't cope well at all really yeah ... But there wasn't much disruption. Their life went on ... Well we tried to just keep their life as normal as possible, yeah so I tried to keep what was happening to me, just to me and you know not let it impact them too much Kaz

Some of the women described the cancer as taking over their lives yet also how they tried to keep it separate. Sally spoke of this 'You know just, just to feel semi normal, Like to have some kind of a grip that it's not just all about the cancer but there is another life'. Sticking to a routine helped the women feel that their cancer had not taken over their lives.

Distancing, self-preservation

This theme describes strategies around how some of the women tried to have some parts of their lives free of the cancer. The analysis revealed this theme of separating parts of their lives from the cancer, a sort of self-preservation. The participants described how they did not tell colleagues and friends they had breast cancer in an attempt to have part of their life where they did not have breast cancer and treatment worries.

"No more, no more, I just want to go to work and be normal." And you know that's why I wear the wig to work because I can walk in here and except from the people that I've told. ... So you do find your escapes where you can. I don't let things command my life unless I choose them to. You know this is a part of my life and I have to recognise that but it's not what my life is all about and that's one of the things that I've really struggled with because it does become so consuming. Lyn

Mia, Karen, Donna and Cath all discuss continuing work and trying to keep this as an area which was an escape from the breast cancer. Although this was hard at times, Mia explains how she organises her treatment to go to work afterwards but she also got very tired at times.

Cause I had to be there [treatment] at 8 o'clock in the morning that was a bit daunting, getting up every day and then I could work and yeah. But, I didn't have to, I probably coped with it better than I thought I'd cope Mia [Mia lived rurally about 1 hour from the radiotherapy unit]

One participant described how they moved to a new house. It gave them a chance to be normal again without the questions of how her breast cancer was going.

So, moving was brilliant, because we felt like we're going to a new place, anonymous for a while. No one knew my story, which was great. Anna

Other participants described keeping the breast cancer out of parts of their lives, especially the families with younger children. Anna particularly kept her diagnosis from her young child, [2 years], in an attempt to have this part of her life as special with no breast cancer.

I just think there's some things young children don't need to know about. It's a good question. I just want him to be innocent for as long as possible. ... yeah, it's an instant, playful, fun part of life and that's why I wanted to keep it as long as possible.

Anna

Robyn and Kaz also talk of trying not to let the breast cancer take over their lives as they attempted to maintain the balance in their lives with their young children. Robyn explains, '*You don't want their memories to be bogged down by you know mum being so sick that you couldn't enjoy things. So I still used to do a lot of things with them.*

The transcripts of the family support persons did not mention this separation from the breast cancer as strongly as the women. Charlie, Anna's partner discusses how it was important for Anna to keep the breast cancer from the child, but not from his perspective. The mothers of the women also spoke about their daughters separating themselves from their breast cancer in some areas of their lives.

Crisis

Crisis was described as a period of time in the participant's life where the breast cancer became overwhelming. A crisis point may be brought on by a small thing such as change in treatment, which disturbed the fine balance the participants were maintaining. This crisis point was also described as points of realisation of having breast cancer and the effect the disease had on them. This was seen as positive as they then moved forward making order of their journey and started to find new direction in life. Most participants had gone through a period of crisis. Although, the participants very early in treatment schedule, only described the diagnosis period as a time of crisis.

Jane described how she also lost her mother during her treatment and this caused overwhelming stress for everyone '*cause we lost Mum around the same time [cries], so yeah it was a lot of time with her [sister] just talking.*'

Kaz and her mother described a turning point and how this was a positive part of recovery and adjustment to the breast cancer.

What Kaz did was one day after we came down and did her breakfast or her lunch or whatever and left her a fruit and tidied up, we'd put her to bed for an afternoon rest and she got up and said, "I'm not doing this anymore." She put makeup on, got dressed beautifully and went to the shops. She said, "I'm not going to lie down here and take this anymore." Kaz's mother

Kaz goes on to explain '*And that was like a turning point you know. I just felt that was enough, Yeah enough of letting it take over me, yeah, yeah. ... Yeah I'm going to control it, yeah it's not going to take over, Yes it did feel better, yeah a lot better yeah.*'

The women spoke of different ways they dealt with crisis points in their lives. Lyn described how she allowed herself to hit crisis then used her personal spirituality to feel positive again and move forward.

I'm the sort of person that once the crisis is over I'll probably crash and burn for a little while and then I'll probably look at my spirituality a bit deeper but while the crisis is happening I prefer to just deal with getting that solved. Lyn

As the participants travelled through their journey they all, both women with breast cancer and family support persons, experienced some degree of crisis. This was often also a turning point for them, a change of focus.

5.3.3.2 *Changing focus*

As the participants dealt with breast cancer, they were able to refocus and see the breast cancer as a challenge which has changed their lives. This concept of changing focus based on the challenge of the experience was also measured quantitatively with significant variations identified. The participants rated how they saw the breast cancer and their efforts to be active and move through the adversity as a family in the FHI subscale 'challenge'. The F-COPES

subscales ‘reframing’ and ‘passive appraisal’ measured the participant’s response to the stressful event of the breast cancer diagnosis. The three subscales (challenge, reframing, passive appraisal) had similar mean scores where participants reported mostly true to the questions [See Section 4.4]. There was also a strong correlation between the three subscales however, a difference was identified with influencing factors being the age and phase of life of the participant.

The contributing family attributes of age and phase of life also came across in the qualitative data as the participants talked of changing focus and the effect the breast cancer had on the family with children or on them as a couple. An important aspect of this theme was the support from the family, which was definitely an influencing factor on how the individual was able to move forward. Donna talks of the challenge of her breast cancer as a way of growing, *‘Yeah, well life tends to throw different experiences at you, and you only grow by, by getting challenged.’*

Jai sums this up as moving forward with the challenge of breast cancer for himself and Viv

And now I’m more concerned about her getting better, her getting through the chemo, her getting through the radiotherapy, just physically and mentally recovering so that next year, say late next year is going to be like a, okay it’s going to be a clean slate.’
Jai

He goes on to describe how they went through different stages of accepting and moving forward from the breast cancer diagnosis together as a couple.

Yeah and in a very positive way, so in a strange kind of way you know the immediate sort of, “Shit I’ve got breast cancer and this is what I’m going to have to do” has turned into one door’s closed and the other doors opened. So she’s taken another path now and it’s very, very interesting to sort of see this. Jai

Participants described how accepting the challenge was often a difficult process. Robyn explains how she had to cope with the children and their normal stress yet she was becoming a different person.

Definitely challenging. I mean you think you’ve got enough on your plate with young children without having to, and we run our own business sort of thing, ... But yeah

it's challenging in itself but I always believe that people aren't given more than they can actually handle ... "Okay well it is a survival mode". Robyn

Several participants described how they had changed the way they plan their lives, appreciating life, but also not planning ahead and then being disappointed. Anna's partner Charlie talked of this expressing his attitude to other people around him.

I think I'm worse than I used to be because I really can't be bothered with um, with time wasting because that's literally what you are doing, you're wasting time ... you've got to really focus on the things that are important because you know, you really don't know how long things are around for Charlie

Barbara, Anna's mother also described this attitude reinforcing this nature of family changing focus together in the face of adversity.

I think one does learn to love each day. I know that sounds very [laughs] sentimental, but, you know, you just, I've got friends who worry about worry you know, worrying what's going to happen? I think, what's the point? Barbara

The changing focus in their lives occurred over time. Annie described this, '*I don't think it's come to that yet. And it took a fair while, like a couple of months now, and we're all sort of smelling the roses so to speak, at every instance, you know, which I'm that sort of person anyhow.*'

Some of the participants described this as not so much as a changing focus, but more of an acceptance. In the family group analysis these were often participants not well supported by family. Cath explained how her husband left her shortly after recovering from breast cancer, and she describes an acceptance rather than a change.

It's good now, yeah. To feel normal again ... Sometimes you sit down and think and you think how lucky you are too to have got through all that too ... Only the good die young they reckon ... You just got to be strong I suppose Cath

Recurrence

Recurrence was another aspect of living with a breast cancer diagnosis. The women with breast cancer spoke of this as being part of everyday life for a long time. Jane commented on the healing influence of time. '*I mean it's really good to get to a point where it's not the last*

thing you think of before you go to bed or the first you think of when you get up.' Other participants describe the difficulty of '*letting go*' of the thought of cancer. Anna explained that her meditation helped her.

[When Anna felt healthy she describes being able to forget the cancer] *If I can go through days, weeks when I feel perfectly fine, I don't even think about the blasted cancer. But, it's... you know, if things are good... I, I think that is the meditation.*

Anna

Anna discussed how she felt her family was not thinking about it. This was interesting as although family members admitted to fearing recurrence, it did not consume their thoughts. '*For them [her family] it's hard to, to start thinking about it again. Whereas for me, let's face it, it's never far from my mind. You know, it's everyday*'. Hearing about recurrence in other people was always difficult. Mia describes her response after the death of Jane McGrath from breast cancer. '*Yeah, if I see something on TV then I seem to dream or I'm awake at night, not sleeping, you know, thinking, thinking.*'

Farewelling

Two participants had been diagnosed with particularly aggressive inflammatory breast cancer and during their interviews they described a need for protective planning for goodbye as they fought with treatment and recurrences. During the course of the research two participants died and two were diagnosed with secondary cancer highlighting the aggressive nature of breast cancer in the younger age group.

Jane spoke of discussing her funeral with her sister Sam. It was done with a bit of humour.

God love her, she said oh, she said, "How about you?" because I haven't got any life insurance so she said, "How about I pay?" and she had a, got a few more plans set up and that sort of stuff, just really good practical... we just talk a bit about um, [laughs], what I want my funeral to be like and if they don't get it right I will come back and haunt them all [laughs]. Jane

Sam [Jane's sister] talks of getting organised although she also explains it was a burden.

Now we need to be sensible as well. We're all going to die. You know, hopefully not before we want to though [chuckle]. Um, and let's be realistic and let's get things organised. ... Cause that's a very big burden, not only on the person that's got the cancer, but for the family members too. I think that's just tragic. Sam

Sally was only recently diagnosed with breast cancer however she already had secondary cancer; she describes the conversation with her husband and how hard it was.

Yeah, we've, we've discussed you know dying, we've discussed funerals, we've discussed a whole bunch of stuff that, at our age and, and at our time of life only being married four years, you really should never have to discuss but by avoiding it wasn't going to make it any better ... "Did I want to be buried or cremated," and that kind of just came out of the blue so that showed me that he was really thinking it was serious as well ... Sally goes on to share her thoughts "Well this is it, I'm never gonna get back to my home." Sally

The interview with Karen was a month before she died and although at the time she had not been told of secondary cancer she shared a sense of knowing she was not going to survive. Karen was a single mother with two young boys. Karen's mother Mabel was also interviewed for the research. Karen took her boys on a holiday to see the family and make sure they knew the family who would care for them after she died.

The aim of the trip was to make sure that I took the boys to see family, so it was, the boys and I we went and saw lots of family along the way. ... Probably for my own piece of mind, its meant that I know my boys are well cared for Karen

Mabel talks of this farewelling as positive and helpful for friends and family.

They all sort of shared the weekend and it was really very helpful for Karen and a happy time for her friends and in a way was a farewelling by Karen because she's been doing that. She's been going around ah, her old school, ah her old work acquaintances and friends and actually doing that, she's actually been doing the travelling to see them. Mabel

The family shared a weekend as well and it was hard for Mabel to talk about but she said it was a nice memory, '*Yes it was lovely actually, mmm it was a real memory*'.

In the interviews it was hard for the participants to talk of not surviving. Often interview breaks were taken, although the women all wanted to tell this part of their journey.

5.3.3.3 Adjustment, what helps?

This theme brings together what the participants described as strengths of the family. The sharing of roles, the provision of both emotional and physical support was described by all participants as what helped along their journey. One of the main aspects of this theme is the support person's role as told by both the family and the woman with breast cancer.

Just being there

The participants described this as what they did to help especially during treatment, often in the form of distraction. This role was often conducted by the supporting women around the woman with breast cancer, for example, their mothers, sisters and friends.

Kate, Lyn's mother, describes the drive into treatment as special time to help prepare Lyn for treatment. Lyn also talks of the drive into treatment and her mother's help.

Um, but driving to [clears throat] treatments [clears throat], no it was sort of, we may as, I mean there were times when you thought we were probably going on a picnic. Kate

Yeah she [Lyn's mother] comes in every Friday with me ... So I think the bond that it's formed; it's certainly shown our strengths as a family and bought us all so much closer together Lyn

The role of being there was very much an emotional support role, someone to let your guard down with and show true emotions. Sam [Jane's sister] describes how she was there for Jane.

But in those dark moments, where like the middle of the night, she'd [Jane] be up in the middle of the night. ... So it wasn't as if I was there on hand to [chuckle] you know, for a shoulder to cry on at that point. It was just down the track as we talk, you know, she'd just have days that, that she would just break down Sam

The support person was often helpful during doctors' visits and several participants explained they used specific family members, as they were good at asking questions. Anne took her mother as her support, as her children were older male children.

Mum generally just comes to the doctors with me anyhow, you know, just as a third person there to, for any questions and queries that I might have forgotten, she'll ask Anne

Mia took her daughter and sister-in-law for support and to help remember what the doctor said. '*L's come with me, and my sister-in-law. We took her because she was; she's pretty good at remembering stuff*'. Gail's daughter was useful as she was a nurse and this helped

Gail feel confident in the situation. ‘*My youngest daughter’s a nurse so she made sure she came with me to the, sort of to see the surgeon so that she knew exactly what was happening’.*

Mabel [Karen’s mother] sums it up ‘*I think being around is important. Just you know, not being too, even if you’re away, try to be around somehow*’. She explained how she visited just to sit with Karen, maybe do some washing or help but mainly just be there for them.

Another aspect of ‘being there’ was phone calls, care packages, meals and child minding. These all helped along the journey especially during treatment. Kate [Lyn’s mother] explains how family all helped ‘*[Laughs] it was always, “Are you going down to see Lyn today?” “Yeah.” “Call in ‘because I’ve got a care package for her.”*’. Care packages contained cards, nice soap or something special. Sally who was away from home explained the importance of letters, cards and phone calls from home.

Keeping in contact with people at home, here where I live, it’s gonna have to be just basically by phone and also a lot of letters and cards in the mail. Sally

Being supported or supporting

The journey of breast cancer is long and difficult with many emotional ups and downs. This theme explores the changing roles of being supported, but also supporting those around you. Mia describes their first weekend after her diagnosis when she was supporting her family. After this they worked together, strongly supporting each other.

I think he holds it up for me, too. Yeah. His initial, he spent like the whole time, the whole weekend crying and that really shocked me, but once he sort of did that, he then moved on and yeah, he was strong. Mia

Sometimes the family support went wrong. Mia explains how she did not have much support from her mother when she needed it.

But we had a bit of an argument and she [Mia’s mother] got all shirty and then we communicate by email ‘cause that’s the only way I can talk without crying, you know, about all these things and I said to her, “Well all I really wanted was a hug.” Mia

The interchange of support between family members was described by the women with breast cancer and their partners. The roles sometimes changed from supporting the woman with breast cancer or to the woman with breast cancer supporting her family. Ivan and Sally

had only been married for four years when Sally was diagnosed with breast cancer and had to have treatment in a metropolitan hospital a long way from home.

She [Sally] was more concerned for me and there have been a couple of times when I was withdrawn and had to go off and sort things out myself but on the whole we look after one another pretty well. She will pick me up if I'm feeling down and I'll pick her up if she's feeling down and at the moment I'm doing more of the picking up than she is. Ivan

Sally tells how hard it was for her family as she struggles to keep brave in the face of her diagnosis. '*With the extended family, it's been hard because I've been trying to keep a brave face [cries]*'. Annie, who is the Aunt of participant 55, a 28 year old woman closely supported by her family, also describes the difficulty of needing to support those around you even if you are the person with the breast cancer.

I think that just makes it doubly hard on the person going through it, if you've got to be brave for yourself plus everybody else. You know, be the cushioning agent for everybody Annie

Family members described times when they needed help and support often not being sure where to go. An underlying aspect which emerged with this theme was the concealing of personal distress while providing support for the person needing help. Sam [Jane's sister] describes concealing her true feelings when Jane needed support, but then she describes her own personal cry for help.

I'd never let her see how upset I was [chuckle], and even now I guess I try not to show my feelings in front of her. Because when she's having a down moment she's obviously coming to me for support, she doesn't need me to bawl my eyes out [chuckle]. I know one day I was so desperate I rang the help line. Sam

Sometimes the women with breast cancer became consumed with concern for their family especially if there was poor communication. This particular family had low communication scores in the questionnaires and in the qualitative data displayed poor adaptation to the breast cancer.

I was worried about mum and dad because there was so many other things my dad was very ill in the middle of it and I just, I just thought the whole family was going to, I was worried about my girls because they're young and you know, it's not a good

age to have all that going on but in my mind I felt like that it didn't affect them very much at all but it obviously did. They just didn't speak to me about it yeah. Kaz

Family Flexibility: Changing roles

This theme describes the changing roles within the family and extended family. Often it was difficult for the woman with breast cancer to let someone else assume her role in the household when she became unable to fulfil this role due to treatment or side effects. At times, the changing of roles caused some distress amongst family members. Having a plan was noted as helpful and provided the woman with breast cancer more control over her situation as she relinquished her role as household organiser.

My mother in law was the main one. The other thing is that the mums at school rallied and did up a roster about meals, they used to cook meals, which was a huge help and every week I used to get meals cooked. You know they offered to come and scrub the toilet and things like that but I really felt uncomfortable about people coming in and, it's quite hard to accept help sometimes, especially people coming in and doing things that you feel you should be able to do yourself. Hard not being able to do your role

Robyn

Accepting that the breast cancer was going to change your life and you were going to need help was the first step in moving forward.

It was good to prepare you because, oh for me that, okay it was very dead serious, you know we're not playing around here, it's, yes you've had a diagnosis, it's cancer and it helped me understand that I really would have to accept help

Karen

Other participants explained that they were fine and didn't need outside help. Although this was often a strain on family members, even if it was not openly acknowledged. Charlie explains '*We weren't, you know we weren't infirm. I mean Anna sort of treated herself as if she wasn't ill.*' Barbara [Anna's mother] shares another side of this family '*we just thought she needed professional help by then because she couldn't cope with her little boy, and just crying and, just so tired or shocked, the whole thing.*' This aspect of being able to accept role changes and have individual and family strengths is demonstrated in the quantitative data, in that participants who scored higher on F-COPES subscale 'mobilising' also scored higher in the total Family Hardiness Index (FHI).

5.3.4 Summary of strengths

In summary, the strengths of the person were very individual, but also influenced by the family. The participants described how these strengths had an effect on their response to the breast cancer and that this often flowed down to the whole family including the children. The following section will explore the communication within the family and the influence this has on the family response.

5.3.5 Communication: Living with the story

This subcategory of strengths explored the communication styles of the participants. The qualitative data showed a sense of strong sharing and communicating family decisions. The participants described different levels of communication and this was a very important aspect of their overall response. The participants often talked of openly sharing, but they were often only just talking about the simple things in life not the deep emotional concerns influencing their response. The quantitative data measured by the Walsh subscale ‘communication’ was reported as mostly true, to true, by the participants, suggesting a good level of communication and sharing of information. [See Section 4.4] However, qualitative data provides an insight into the depth of this communication, and clearly highlights issues with the levels of communication used. The presentation of the analysis of ‘communication’ reinforces the key aspects of communication within the family and the conceptual link between strengths of the family and resources.

5.3.5.1 Sharing or just talking

The participants described openly talking to family about how they were going. They spoke of sharing news with extended family, however during the analysis it became apparent that this was often a superficial level of communication. Some of the women described how sharing their real thoughts and fears was too difficult. Communication styles within the family influenced the support the individual received from the family. If participants were able to relate feelings and distress, then other family members were able to assist them. Mia explains how this worked in her family, *‘if something’s wrong with me, we’re all pretty open and yeah, we communicate if we’re grumpy, or if we’re sad, yeah. We just sort of stick together and do things in our own little quiet way.’*

Sally and Ivan also spoke of being able to share with each other easily and how that made Sally’s process of adjustment to breast cancer easier. Both Sally and Ivan spoke of discussing the hard subjects, but also of understanding when the other person needs a break.

We’ve had open communication, because we’ve already established that when we first got married, we’ve been married four years, because that had already been a well-established pattern, in some respects it made it easy just to process all of this ... It’s only when it keeps, it’s only when you keep hiding things and when you don’t discuss things that they become too scary and, too overwhelming Sally

The participants described how keeping feelings hidden often influenced their relationship with the family. Lyn explains this style of communication with her children and mother. '*I think we're comfortable in each other's knowledge and what we are struggling with we ask each other Get it out on the table, be open with it and just get on with stuff.*'

Some families had different styles of communication with different family members. Jane, for example, explains that they never really had a family style of communication. Sophie, Jane's daughter [See Table 28], explains how she did not share her distress with her mother so her mother did not get upset. '*Probably not share, because I would just keep more to myself*'. Jane thinks her daughter coped well and shared her emotions with her. '*Um, and she would talk about it with us if she had a problem, you know*'. Her husband was happy to go along with whatever she wanted. '*I don't think we sort of sat down as a, as a family unit and looked at things. Um, my husband's pretty easy going so it was you know, whatever you think [laughs].*' Jane and Sam [Jane's sister] both comment that if there was talking to do, or decisions to make, they used each other. Although Sam also describes how she felt Jane's husband was probably a bit lost with not being able to talk with anyone.

Well he's a very quiet and reserved person anyway, um I personally believe that he, he spent many hours worrying over if she was, you know, how long is he going to have his wife, and that's probably still a reality to him anyway. ... I'm not aware that he's even shared his feelings with my husband. Sam

Sharing the diagnosis with family and friends was difficult as it brought lots of questions to the fore, which was often difficult when the women were only just coping themselves. Mabel, [Karen's mother] recalls the early stages when Karen was struggling with her diagnosis and did not want to talk about it. Karen moved on from this stage and became open with her feelings to her family, especially in the last stages of her life.

I think initially when Karen didn't discuss very much, she just didn't, didn't want to be talking about it all the time, I think that was one of the things you know, just every time you met anybody, how are you doing and you know this is where we're up to you know like as, as in grieving. Mabel

Other families described a guarded type of communication where open disclosure was difficult. Barbara [Anna's mother] describes the difficulty of not being able to talk about her daughter's breast cancer with her '*you don't actually say "breast cancer" you don't talk...*

you know – that's how it was. ' In Anna's interview she describes not talking about her breast cancer and her fears with her partner.

I do feel also, sometimes I don't want to burden him [partner] with it. ... I'll just keep it to myself some days because it is a lot for him to take on. I don't know, but who else do I tell, really? I mean you can't, you know, friends don't want to know. Anna

Anna goes on to explain how they did share together, but not with other family or friends, '*Yeah, so we're, very, very close, closed unit I guess.*' Charlie speaks of their close relationship and staying away from the outside world in an attempt to cope with the diagnosis. He talks of walking the dogs, watching movies to help them stop thinking about the breast cancer. '*The last thing we want to do is just sit in the house and talk or think about specifically the problem.*'

For some participants, openly sharing the diagnosis becomes part of the healing process. Ivan and Sally talked of sharing their story with the disability services and how this helped them. Kate [Lyn's mother] also talks of actually saying Lyn had breast cancer when talking with friends became easier once she started. '*But I found once I started using the word a lot more and saying, you know, "cancer" instead of "Lyn's not well", it was far better*'

Communication was an area where all the participants explained different levels of sharing and how this was often closely related to how they were adjusting to the diagnosis. From the analysis it can be seen that the families which had open two way communication of feelings and concerns were able to work together in an attempt to reduce distress and adjust to the adversity of the breast cancer.

5.3.5.2 Humour

The participants described the use of humour as a way to stay positive, and they spoke of sharing happy times, laughing at odd aspects of their breast cancer journey. Treatment changes, such as the women losing their hair were often turned into a humorous situation to reduce the stress from this time during treatment. Cath explained her family joked about her having a bald head '*Yeah, "bald headed old bugger."*' For some of the participants where their hair loss was a big issue seeing a humorous side definitely helped reduce stress. Jai and Viv talk of their wig choosing day and how they made it into a game to reduce Viv's personal

stress. Viv describes herself as having beautiful hair. This also let friends be involved and part of the process.

We took photographs of ourselves trying on multiple wigs in a similar pose and then we made up a game, an online game where we emailed people all these photos and they had to choose. They had to choose the one that they liked the best and then the one they thought I actually ended up with. And it became fun and it became um, a really easy way for my friends to realise that it was wig time. Viv

Participants also joked about the severity of the cancer and the situation in an attempt to lighten the pressure. Karen describes her family discussing how to cope with their younger sister getting breast cancer. '*You know we'll sit around and have a drink and swear and yeah, "yeah, bloody thing," um "Of all the cancer's to get, you get the, the really good one"*'

Humour was also a positive strength for some of the participants. It helped them to see the diagnosis and life changes in a positive light. They described laughing together at '*boobless*' photos and nurses being silly during treatment and laughing as they looked over journal entries. Participants talked of humour being a positive strength and an aspect of character building.

The qualitative data from the questionnaire comments section also had several comments ($n = 8$) relating to keeping humour in their lives being part of their adjustment to the breast cancer. For example, comments included: 'sense of humour, positive attitude, lots of laughs, sharing jokes, happy conversations with relatives and encouragement'.

5.3.5.3 Missing data 'the unspeakable'

This theme related to what was not described or verbalised during the interviews. After the initial building of themes from all of the transcripts a second analysis of the data revealed missing parts in some of the transcripts. This concept is known as 'missing data' where participants intentionally or unintentionally avoid certain topics (Ryan & Bernard, 2003). The following describes this concept in relation to the families' journey with breast cancer.

Silence, missing parts

One of the important issues with researching family is to understand the backstage behaviour, which is normally not visible to the outsider (Greenstein, 2006). The interviewing of multiple family members within a family group at separate times allowed the researcher to gain an insight into this hidden family behaviour. For example, the sister and daughter of one participant both described how Jane (woman with breast cancer) often could not sleep due to anxiety, explaining it was a fairly big issue as Jane struggled with her diagnosis with secondary cancer.

But in those dark moments, where like the middle of the night, she'd be up in the middle of the night. So it wasn't as if I was there on hand to [chuckle] you know, for a shoulder to cry on at that point. It was just down the track as we talk, you know, she'd just have days that, that she would just break down. Sam [Jane's sister]

Yet in the interview with Jane she did not mention sleeping issues except to briefly explain '*how the life becomes a blur and you don't even notice a lot of stuff anymore*'. In Jane's interview she focuses on the positive aspect of her life only briefly mentioning the negative side to her diagnosis.

This theme of 'missing parts' was repeated in most of the family group interviews. Another example of a family's backstage behaviour was not discussing the breast cancer at home in front of their young child. Anna, a mother of a two year old child decided that she was not going to tell her child about the breast cancer or appear sick in front of him. Anna explains in her interview that she feels she has no choice. '*And it's not something you think about, you just do it. Have no choice. Well, we know, we knew we couldn't... you can't look sick to a two year old, or, I guess.*' This was very difficult for Anna's support persons, Charlie and Barbara [Anna's mother]. Although in Anna's interview she felt it was only her problem to keep the diagnosis from the child and did not realise the distress this was causing for her support persons. In particular, Barbara [Anna's mother] struggled with trying to support her daughter yet not being able to talk about the breast cancer.

'And she doesn't... maybe she does now... but then it was – you don't actually say "breast cancer" you don't talk... you know – that's how it was. And if there was anything on the T.V or anything about it, you don't talk about it. ... it was difficult – the strain was on... it was difficult.' Barbara

For another family group Sally and her partner Ivan, this concept of avoiding a difficult area was again highlighted after both interviews were completed. The first interview was with Sally who described her journey as '*a whole gamut of emotions all day, every day*' as she struggled with her diagnosis of breast cancer with secondary cancer in her hip. Sally spoke of a disability from birth, which provided her experience of dealing with hospital procedures. However she never alluded to the severity of this disability in her interview and how it had affected her physically. Sally discusses telling the family.

We shared that with the family and of course everyone was very much in shock because of my age and the fact that I've already been through so much physically because I was born with a disability. Sally

Ivan in his interview clearly discusses the influence of the diagnosis of breast cancer and secondary cancer in her hip on Sally's disability. Sally was born with spina bifida and after the diagnosis and treatment for breast cancer now needs full time care, which is distressing for Sally and an added pressure for Ivan, as he struggles to keep the family going.

Then there's just the normal things like picking stuff up that you've dropped on the floor, she can get up out of the normal armchair back into her wheelchair by herself now without any assistance, putting clothes on is another thing she can't do because she can't just stand there and balance and pull a pair of shorts up... Ivan

'Missing parts' is a significant and important finding. Often when patients travel through the medical aspect of their diagnosis and treatment for breast cancer they may leave out parts of their story in an attempt to shield themselves from the emotional distress it causes when they openly disclose it to others. This finding highlights the aspect of communication which may not be visible as the family responds to the diagnosis of breast cancer.

Silence the unspeakable

The actual saying of the words 'breast cancer' was also noted to be missing in several of the transcripts. A deeper analysis of the transcripts revealed that participants who were struggling to accept and cope with their breast cancer diagnosis, often did not actually say the words 'breast cancer' at all in their interview, rather leaving a gap or pause in their speech. The interviewer then rephrased what they were saying in an attempt to draw more information from the participant, as demonstrated in the interview with Kaz. In this interview section, Kaz talks about her initial searching for information about breast cancer. Kaz '*Yeah but not*

support. I was just looking up [pause]' Interviewer '*What was happening?*' Kaz '*Yeah what was happening and the disease and [pause]'*

Another point here is the significance of what is repeated and reinforced through the interview. Often participants reinforced that they were 'coping well' numerous times during the interview, but as the researcher and the participant reflected on what they had said during the interview, they may actually be indicating that they could have done with some help. Mia discusses this with the tape off and even suggests she might call the breast care nurse again. Other participants describe their response to the breast cancer, but then reflect on still having days when you need to let go and just cry. Anna describes using 'time out' to help her cope.

'We just, days out there with the dog and I think days when C's [2 year old child] in day care, we'd have days out on our own and the dogs and just walk, talk, cry, whatever.' Anna

In some of the interviews the participants told stories of not openly expressing their distress, but as they progress through their story they share personal concerns. Kaz expresses her concern that she was not really doing all that well at the end of her interview.

Yeah because I mean I feel like I'm going mental and I'm just you know absolutely tied up in a knot so I don't know exactly what's going on Kaz

The communication styles influenced the resources the participants were likely to use and also the help they obtained during this stressful time.

5.3.5.4 Help for future families

During the interview the participants were asked if there was anything they would like to discuss such as anything in relation to what helped them adjust and anything that they thought would be important for future women in similar circumstances. Jai and Viv commented that the writing of a letter explaining what had happened and providing information leaflets for their friends and family was definitely helpful in reducing their stress.

We made this little package with the pamphlet, typed letter, handmade card, little souvenir photograph ... instead of me having to phone people all the time we came up with this letter and that certainly made it a lot easier because we requested that you

know that people just sort of ease up on all their questions and that's why the letter spelled out exactly. Jai

Another aspect participants described as being important was sharing the diagnosis and encouraging their friends and family to be aware of their breasts. Karen describes a small positive from her journey: '*Spoken to all my friends and they've all gone and had mammograms too' [laughs], I said, "Well you know, if that's what comes out of it, good"*' [laughs].' Viv describes a similar situation although she was worried about her friends, '*Can you please go and get yourselves checked out so I can stop thinking about you guys, cause I know what's wrong with me.*'

5.3.6 Summary of communication

In summary, communication is an important strength of the participants. The communication styles used by the participants ranged from openly communicating fears and distress to keeping feelings hidden. Another style was the guarded communication where participants described a level of sharing concerns often evading certain painful issues in an attempt to reduce distress. The use of humour was described as a positive communication style which allowed a lighter view of the breast cancer to be shared. Another aspect of communication which emerged from the analysis was the missing data and words as family members described their response to the breast cancer diagnosis. The analysis of the qualitative data clearly links communication between family members as a key aspect of the ability to ask for assistance and share joys and distress. See Figure 1 for the demonstration of links between strengths and resources. The next section will explore the resources used by the participants and why they used them.

5.4 Resources

This category explored the resources used by the individual and the family in response to breast cancer. The themes forming the resources were the family, extended family, friends, ‘women’s business’, spiritual support and health professional support. The quantitative data indicated that most participants reported using assistance, when asked to rate their use of assistance in response to breast cancer as measured by the two subscales ‘social support’ and ‘mobilising’ (health professional support). [See Section 4.4] However the qualitative results provide a deeper understanding of the resources and support used. [See Chapter 4 section 4.4 for specific details of quantitative data related to use of resource support]

5.4.1 Social support

5.4.1.1 Partners’ themes

This theme related specifically to the partners’ responses to the breast cancer diagnosis and how they supported the female partner during this stage. Also this theme explores how the partners coped and where they went to gain strength and support. Most partners were a great source of both emotional and physical support for the women.

He’s always got the right thing to say which will reassure me. He’s incredibly reassuring. Yeah, I do feel also, sometimes I don’t want to burden him with it. ... I didn’t have to worry about the kids being fed and you know, all those sort of things

Jane

The partners were proud of their support and protection of the woman with breast cancer. Charlie explains his part of supporting Anna *‘I’m going on every single appointment’ I just said, “No we’ll do this together”*. Ivan [Sally’s partner] also talks of this support, but also of how it was at times.

So I’m in here for the long haul and when we married that was also the go, so I’m fairly loyal and because you love that person you’re more inclined to go beyond what you would normally do. Ivan

Some of the women did not have such specific support, but this was also reflected in their overall adaptation outcomes. Again communication style was one of the main influencing factors of how well the family members were able to be supported.

He'd make dinner and all that stuff and looked after me and that but didn't really talk a lot about it. I bought a pamphlet home one day, that one of the nurses had given me, on men, the partners and I got him to read that but he sort of put it aside like there was nothing wrong with me, you know. I think he found it hard, that's probably why he left in the end. Cath [Cath's husband left after she finished treatment]

The partner's response did not always match the woman with breast cancer's response and this caused strain in an already difficult situation.

I know with my husband, he just wants it all to go back to the way it was before and it's never going to happen and I don't want it to. You know I've changed myself personally and I don't want to go back to the way it was and as much as it's a negative thing that's happened to me I see it as a positive thing in my life Robyn

The partner's emotional difficulties were often not met during the course of the women's breast cancer treatment. The partners or the women with breast cancer described them struggling, being emotionally unsure of where to go for help or not wanting help, just hoping it would go back to normal. The following responses reflect this need for assistance from their partners as the partner responds to the diagnosis of breast cancer.

My husband is not one to seek out counselling so he never used it and I think, I really think he needed to and he didn't use it while he was going through it and I think even now he's still dealing with things. Robyn

Kaz describes her husband's trouble adjusting to the breast cancer and the changes although he does eventually accept help.

He just sort of you know kept it all to himself and retreated into a little shell and you know acted like he was coping with it but I don't think he was coping with it very well I think he did eventually. It took him a while but I think he did realise that yes, there was help that was needed, yes, yeah Kaz

Although it was difficult for the partners, some were able to use family as support to assist them during this difficult time. Gail had a big family and although her husband would have benefited from external counselling, she explains he did talk to other family members.

I know my husband, he hid a lot from me because he didn't want me to see how distressed he was, it was only from now, later that he's come clean [chuckle] and

admitted it just absolutely terrified him, absolutely and he didn't know. He was a little bit lost and I think he probably could have done with a bit of counselling but he spoke to his mum and a couple of my really good friends. Gail

In comparison, Ivan who was happy to seek assistance found this helpful when he needed additional help. '*I'm fairly fortunate in the fact that I also have counselling that I can just jump on the phone and ring up the men's helpline if I really, really get stuck*'. Ivan also explains his basic coping mechanism was time out with computer games. '*I find that the pressure is too much and you've got to just sit down and regroup, that means I just take off into my cave here and play computer games for a few hours a night*'.

Jai explains how the counsellor really helped him during a time of need so he did not need to burden Viv with his emotional distress. '*They happened to have a counsellor who was free and she spoke to me and I offloaded on her, no I opened up and just dumped it all and she was fantastic*' Jai goes on to say he knew this service was available if he needed assistance again and that was a big relief.

This theme demonstrates the partner coping by both recognising the need for assistance and seeking help. It also shows the partner not accepting that the breast cancer diagnosis is influencing their lives and that they may benefit from seeking external help.

5.4.1.2 Children themes

The diagnosis of breast cancer also influenced the children within the family. The participants' interviews displayed different ways of assisting the children to cope with the changes resulting from the diagnosis of breast cancer. Interviews with children over 18 years, allows an insight into their world of coping with their mother's breast cancer. The women with breast cancer explain the initial distress of telling their children they had breast cancer.

We told the older daughter [17 years] straight away and um she was very upset. Um the younger daughter [15 years], she was very upset and you know cried and quite you know, what's going to happen? Am I going to lose my mum? Kaz

Some of the women deferred telling the children until they had all the information, although this was also distressing and difficult to hide from the children.

Um we didn't tell the kids [15 & 12 years] the first week. What we told them was that I had found a lump in my breast and that it was being investigated. And then once they came home I tried to be normal. So you know, getting dinner ready and sorting out homework and driving them to soccer practice and it was all whatever. So every day we would fill them in on a little bit more and a little bit more so we weren't lying, but we were withholding some information until we were sure what everything was and what we were going to be doing. Rachel

This ‘stepping out’ of information was a common theme from the mothers with breast cancer. The use of resources to assist their communication with the children if they were offered and available was also described. Rachel explains she was offered a great book for her teenage children. This really helped provide information in their language.

Excellent resource that has just been put out for teenagers, it's got chapters in it with really cool headings like “Head Stuff”, “Heart Stuff”, “Friend Stuff” and all this.

Rachel

One family explains they did not tell their two year old child at the time of diagnosis at all. Anna explains that she did not want to spoil her relationship with her child. *‘I just think there's some things young children don't need to know about. I just want him to be innocent for as long as possible.’* Anna goes on to say she had no choice *‘Have no choice. Well, we know, we knew we couldn't... you can't look sick to a two year old, I guess’.* Barbara [Anna’s Mother] explained how it was hard to keep the diagnosis from the child *‘But she never went to bed, she just... he doesn't even know that she had an operation, she just wanted to carry on. I think the important thing was for her not to, in any way, show a sick mother in front of her child, it was very difficult’.* The interviews with the three family members show this elaborate planning of treatment around the child’s day care and ability of Anna’s parents to mind the child.

On the other side, Robyn, also with young children, describes how her children were involved from the beginning and were affected by her diagnosis. Robyn did not have much support from her partner and extended family.

I had to go cold turkey and wean him [breast feeding] and that was hard emotionally and it was hard on him too. And even it has affected him because he is very, if he gets distressed he's always got to be touching a female's chest unfortunately. You know I

had a mastectomy and he's quite fascinated by that. You know they know about it, unfortunately, my daughter actually came in, I didn't really want to show her that suddenly but she came in one time when I was getting changed and sort of said "Oh Mum what happened to your boob?" you know "Where's your boob gone?" Robyn

The diagnosis of breast cancer affected all the children regardless of their age. The interview with Sophie who was aged 17 years at her mother's first diagnosis clearly demonstrates the way children hide their true feelings in an attempt to reduce the distress for both themselves and their mother.

I didn't really show. I just kept it all to myself so she [mum] didn't know anything. I didn't really talk to my friends because they didn't understand and they didn't have anyone with cancer in the family so they didn't know what I was going through.

Sophie

The interview with Jane, Sophie's mother, gives another perspective and highlights the different styles of communication within a family, as Jane thought her daughter had friends at school to talk with and that she was going okay.

'Sophie was lucky 'cause there was a boy in her class at school at the time whose mother had been through breast cancer, so I think she spent quite a bit of time chatting with him.' Jane continues on to explain her son's response 'my son just closed down completely I think. You know if we had to go up to school for anything it was, "Can you wear a beanie so you just look like you're cold" and yeah he just had a really rough time' Jane

The teenage children came across as the age group which struggled with their mother's diagnosis the most.

You know my daughter showed me a letter she did at school about how devastated she was you know the night we told her and that she cried all night and I mean I didn't know any of that, didn't know any of that because you're so wrapped up in yourself Kaz

Other families with children in this same age range struggled with trying to keep normal activities running or having the children at home more to reduce the stress on the family. Mia comments about her 19 year old daughter '*Yeah, that made us all sad and Lauren, she was doing a dance course in Brisbane and she just stopped. She said "I can't dance anymore*

'cause I'm too sad.'" Sophie describes a similar story '*I used to do dancing back then but it got too expensive because of the treatments we had to pay for so I left that.*' The families with teenagers also described stress relieving activities their children would use. A comment from Karen shows this, '*my teenager uses skateboards and physical activity and that included thumping people at times [laughs]*' Sophie comments '*I used to always go for walks and bike rides and stuff [laughs]*'

The families interviewed displayed different styles of communication, although one common theme was the underlying distress the children displayed at any age. Lyn discusses how they had very open communication with her children. Lyn was well supported by her mother Kate, however Lyn comments on her son's reaction from her diagnosis as a sort of crisis in his life; '*this diagnosis was like another crisis for him, so he sort of probably regressed a bit and got a bit anxious for a while there*'. Lyn's son is 12 years and having trouble at school. Lyn explains how she discussed her diagnosis with her son and how it affected them.

There is a fine line between humour and brushing it aside and accepting it and dealing with it and I said to him "You know there are things you can't use it as an excuse but you have to recognise when things are really affecting you." So it's okay to sit here and laugh about things but it has really affected us and that's just our way of dealing with it. Lyn [Lyn's son had trouble at school]

Even the women with older children in their family commented on their children's reaction. Most of the older children went into a '*What are we going to do?*', however not seeing a negative side to it, or not showing this to their mother. Anne describes when she told her daughter (30 years old)

"Oh by the way, blah blah." I said, "I've got breast cancer." "Oh yeah?" And I was dumbfounded, she never cried whatsoever, and she said, "Okay," she said, "What's gonna happen?" Yeah. Anne

The families with children all used different ways to assist their children, but there was always a sense of a need to protect the children in their stories.

5.4.1.3 Strength of extended family

This theme captured the general feeling that the family worked together and often formed a closer bond, although there was occasionally an underlying feeling of protecting each other

by not being totally honest about their feelings and response to the breast cancer. The women described a rallying of family with the first news of diagnosis and then planning how everyone could help.

Gail explains how her family would come together at night and talk. They lived in the small town where family was close by. During this time they also decided leadership roles and planned how they were going to organise treatment, remembering they were in a rural area.

Come night time we've got all the kids to bed and we'd sit out the back and talk about how we we're going to handle it all and yep there was never, they would never let me think negatively but I didn't, I became very positive because I had all their love and support so it made me very positive. Gail

Kaz's Mother shares a story of the family coming together after her treatment was finished '*Yeah remember the night we all stood out there and we did a garden makeover for her. She's got a beautiful family*'.

Family played a vital part in transport, child minding, and financial costs. Mabel, Karen's mother explains how Karen's son and family raised money to pay for her treatment, '*They raised a lot of money and her son raised some money, just, just to get, you know to be able to buy the drugs.*'

Family also disseminated information about the diagnosis to each other and the extended family, reducing the pressure on the immediate family members. The family was also useful when it came to finding information about treatment choices and side effects. Karen explains the roles her family adopted. '*My brother got on the internet and looked at the actual disease and found out as much as he could and my sister went on and she found out about the disease and also the doctor that I was seeing*'. Viv and Jai explain how Viv wrote a letter about how she was going, the treatment she received, and included information booklets. They sent this to family and friends as Viv and Jai were becoming distressed with the constant phone calls. Viv also included a note indicating that if they wanted to help, donations of money for her wig and prosthesis would be useful. '*So we made this little package with the pamphlet, typed letter, handmade card, little souvenir photograph so to speak, put it all together ... it gives people suggestions on how to do things*'.

5.4.1.4 Friends

The participants described the friend's role as slightly different from family. Friends were often used to forget about the breast cancer and participants explained that they would tell different stories to friends depending on how the friend could cope with it. Lyn explains how some friends couldn't cope. '*It's almost like they'll cross the road because they're scared they're going to catch it themselves and that's just their inability to deal with the word "cancer" because it's a big word, it's a really big word.*' Sometimes telling friends was difficult and the participants explained they often had too many questions, unlike family members who would discuss things amongst themselves. Karen, a single mother, describes her close group of friends and how they became part of her supportive family network.

I've got a tight group of friends, and they came down, I think it probably took me a few days to be able to get up the courage to make the call to one of them and then um, she spread the word. Karen

Lyn explains that with little family support, her friends became a lifeline when she needed support. '*Sort of just my own personality I'm quite social and if I'm feeling down I'll go and seek out some friends.*' Most of the other women described similar stories of friends who were there to just chat with. Ivan and Jai also explained they used friends as a social outlet away from the breast cancer.

Not all the participants were supported by friends and Anna and Kaz explain that they mainly used family for support. Kaz describes her support '*D was one friend I did talk to a little bit, but not really in a close way. I spoke to my younger sister who probably was a better friend.*' Friends were there as support for the women, providing often physical support, transport and child minding. However, from the interviews it was clearly their family that formed the main supportive network for the long journey of breast cancer.

5.4.1.5 Women's business

The theme 'women's business' explored the concept that supporting the woman with breast cancer was done mainly by the women in the family group. The feeling of women supporting women came across in all the transcripts, even those with a male partner for support. The participants explored issues such as personal disclosure of distress, physical issues and specific feminine issues during their interviews. Even interviews with the male partners

disclosed that at times they were excluded from the women's club, as the support needed was female support. Jai explains his partner's hair was a very personal aspect of her femininity and this was women's business.

It's like when my partner started to lose her hair and it got down to that real sort of thinned out look, she kept it hidden from me, but we'd spoken about the need to just shave it off. And so we had a friend a girlfriend who was the only person who could do that. My partner felt comfortable getting her to do that. She wouldn't let her sister do it. But this woman, this friend of ours, she could trust her to do that because of her personality. So you have those little things to draw on. Jai

The woman's mother, daughter, sister or girlfriend tended to form a close support around the woman with breast cancer. Annie talks of the support she gave her sister when her sister's daughter was diagnosed with breast cancer. '*My sisters and I are exceedingly close, so there were no secrets and no hint of not sharing everything*'. Jane and Sam [Jane's sister] also discussed this closeness they shared. Most women ($n = 11$) described how their mother, daughter or sister went with them for treatment and provided emotional support often '*just being there*' for them. Anna and Viv were supported by their partners and Robyn explained how she went by herself while her mother in-law helped with the children.

Mother's themes

Within the theme 'women's business' was a minor theme related specifically to being the mother of the woman with breast cancer. Feelings of anguish and wanting to take away the pain from their child were clearly evident. The mothers just wanted to be there for their daughters. Barbara [Anna's mother] sums it up clearly '*Being a mother, I felt like, "My God, this can't be. It should be me," because how can you protect your child from something like that and you can't do anything about? And that's the first thing, but I just got to be very strong, and hold her and just be there.*' Annie an aunt to 28 year old with breast cancer has her own daughters and she discusses how hard it has been for her sister supporting her 28 year old daughter with breast cancer. '*I think the hardest job is being the mother, to be quite honest.*'

Most of the women discuss the importance of having their mother there, with them, as emotional support. Cath describes just needing her mother '*When you hear "cancer" you think you're dead don't you? That's what you used to think. "Oh, no," and yeah I just went to*

*my mother's and just balled my eyes out and I was right'. Jane discusses the distress when her mother died during her treatment but goes on to say how important older ladies in her support group were '*I guess the first couple of ladies were older ladies, they were sort of both older than Mum and I guess with Mum dying at that time they became like new mothers.*' Viv explains how Jai's mother was closely supportive '*it was quite hard because, I don't have a Mum, she's not alive, Jai's Mum's like my Mum*'.*

Treatment times seemed to be the hardest times, and several of the women explain how their mother came to treatment with them to support them. Karen describes her mother's role, '*like my Mother has taken a role of coming and being with me when I'm actually having chemo, so just sitting with me.*'

Not all the women had the close support of their mother even when they really wanted to be mothered. Mia expresses her need to be mothered '*I said to her, "Well all I really wanted was a hug."*'

The family formed a very protective umbrella around the woman with breast cancer, especially the women within the family as they worked together supporting her emotionally and physically.

5.4.2 Spiritual support

Spiritual support was a theme within the qualitative data. Yet, spiritual support was not accurately reflected within the quantitative data as the questionnaire did not provide the participants with an avenue to describe their personal spirituality. The quantitative data measured participants' use of spiritual support however the questions were specifically about belief in God and attending church. [See Section 4.4] The qualitative data provided the depth and range for what participants described as their personal spirituality.

All the participants were asked to describe what they used for spiritual support in their lives and how this helped in their lives. The final analysis revealed four types of spiritual support and all very diverse. The four types had differing benefits for the individual and each will be described separately.

Christian beliefs were described as a big strength in their lives by six participants. One of the aspects of Christian belief was that it gave them an extended family to provide emotional and physical support, for example for meals and transport. They spoke of their strength from God and having faith in a plan for their lives. Sally describes her faith in God.

It's been very useful because through my Christian faith I have just hung onto God and the promises in the Bible um, that you know God was gonna take care of me and that you know, he has a plan for my life, Sally

The next aspect of spiritual support was **meditation**. Eight participants spoke of meditation tapes, tea lights, nature and spiritual healers, which they considered gave them time to regenerate their personal self. Lyn, Robyn, Annie, Viv and Anna talked of using meditation tapes to help them with the chemotherapy, especially in relation to the pain and nausea.

That's been a God-send I think, it probably sort of, I don't know, saved my sanity at some stages. I still listen to the CD most days that I can, a meditation CD, so that's time out. Anna

Craft, journaling and distraction were described by nine participants when asked about their personal spiritual support. Viv, Mia and Sally spoke of using this time as a time when they did not think of the breast cancer. Some of the participants commented that it was cathartic, getting their thoughts of breast cancer out. Viv explained she wrote, letters, poems and drew. '*I wrote two letters, they were the most cathartic aspect of the whole process*'. Sophie, the 18 year old daughter of Jane, spoke of her drawing as something that helped her cope with her mother's diagnosis. '*I took it out on drawing and colouring in and doing my art stuff*'. While Mia described completing a scrap book, for her 18 year old daughter. She also wrote verses for her children just in case she didn't survive the breast cancer.

'I wrote all these verses and you know, things like that, which I've now done for my son as well, so, yeah. You sort of, you think are you going to be here? Mia

The last area in spiritual support was **distraction** by television or music. Jai, Viv's partner, discussed what they all [Jai, Viv and flatmate] used together to forget about the breast cancer and regroup ready for the next challenge.

All three of us have immersed ourselves in music and film and books and conversation and good food and things like that. Jai

Jai also spoke of his love of nature as a time to regenerate his personal spirituality. Unfortunately, Viv's breast cancer had put their camping on hold for a while. Two of the participants when asked about their personal spiritual support said '*no nothing*'. Kaz went on to say she just spent a lot of time with her mother and father as time out from her young children. Cath, another woman with breast cancer said she used the TV to just take her mind off the breast cancer.

Time out

Another theme closely associated with spiritual support was time out. Time out was slightly different in that all participants spoke of this as just time away from breast cancer. They didn't discuss this with any growth aspect, but as a time to regroup. The three partners [Charlie, Jai, Ivan] all describe music, television and gaming as time out from the breast cancer. They spoke of television, movies, shopping, cooking, to shut off thoughts of the breast cancer. Sally sums it up when she describes her time out as time to escape.

I guess part of me wanted to escape everything that was happening so I would dive into reading or you know doing, doing crossword puzzles and stuff sort of as an escape. Sally

The partners and mothers of the women spoke of time out, as their time away from the breast cancer and the women they were supporting. Ivan, Sally's partner spoke of his time out as time in his cave.

For me personally, sometimes I find that the pressure is too much and you've got to just sit down and regroup, that means I just take off into my cave here and play computer games for a few hours a night Ivan

Sophie tells her story about what she used to do for time out and how yet again life was not easy for her as she supported her mother.

I used to always go for walks and bike rides and stuff but my bike got stolen so [laughs] I don't do that anymore, but I don't know, I just used to always chat with mates and just relax with them Sophie

The participants also spoke about needing time out, but they were unable to get away from the breast cancer. This was especially difficult for Sally and Ivan who were also coping with Sally's spina bifida and hip replacement from secondary cancer. Ivan explains how they have

been housebound which does not help Sally '*she's been so sore we haven't even been able to get out, go for a drive, and do some of those things that she likes.*'

At times some of the participants explained the need to refocus using their personal strength. Cath who used time out commented how at times you just need to stop and move on.

'You see you think you are strong and you can deal with it and you can sort it. ... Well, you just say, "stop feeling sorry for yourself, there's people worse than you. Get over it." That's what I used to tell myself all the time'. Cath

Anna, in another point of view explains her anger with her mother, Barbara who went for a holiday during her treatment to give Barbara a chance to refocus. This was an issue that caused some friction between mother and daughter and is highlighted in all three family members' interviews. Anna sums it as a chance to run away. '*Great but I didn't get the chance to run away myself*'. Barbara discusses the holiday as something she needed to do to recharge although adding that she did not feel Anna forgave her.

I decided that I need to go and recharge and see her [other daughter in England]; and I did that. My daughter [Anna] was going to start radiotherapy... and I'm telling you this because I don't quite know how I did that; or why; ... and I said, "Well why have I done that?" I spoke to my husband the other day about this and I said, "How did I do that?" and he said, "Because you needed to" but I just don't know if she ever forgave me for doing that. Barbara

The participants used spiritual support to assist them to move forward and adjust to this adversity in their lives. The participants also described the use of external support to assist their adjustment.

5.4.3 Health professional resources

The theme health professional support explored the different types of health professional resources the participants used. The quantitative data measured in the subscales F-COPES 'mobilising' and Walsh 'resources', revealed that participants reported they neither agreed nor disagreed or moderately agreed that they seek health professional assistance. [See Section 4.4] The analysis of health professional support will be presented in three minor themes to reflect the range of health professional resources used.

Information

Information about breast cancer, treatment, and accessing help increased the woman's and her family's sense of trust and power with the health professionals and the situation. They felt they had some control of the situation if they understood what was happening. Information helped inform their decisions regarding diagnosis and treatment. Information also gave them confidence in their medical team, as they used the information they gathered to reinforce what the doctors were saying. Viv's comment '*Everything I read backed up what the doctors were saying*'. Viv described herself as the '*Queen of the internet, I have got folders of information*'. The participants explained that they used all available resources for information. This included the internet, medical profession and other persons who had been in a similar situation. Often family members did the searching for them both for the benefit of the woman with breast cancer and themselves.

*Then my dad and my brothers all got on the internet about cancer and everything. ...
It helped them I think? Cath*

One concern that was highlighted by several of the participants was the danger of too much information, and negative information from the internet, and listening to stories from others. Lyn explains that sometimes you just need to stop and move on with your life.

There is a plethora of information out there and you just get to the stage where you think "No more, no more, I just want to go to work and be normal." Lyn

Each participant described different needs in relation to information, and the mothers of the women said they thought '*too much information was a bad thing*'. Several of the women explained after searching the internet that they became more distressed. Mia describes not being able to sleep with worry after looking on cancer sites.

Information in the form of booklets was good and this was often used to give to other family members, especially their children, and friends. This information could be read at any stage of the treatment. Women with teenage children described how they left the information for their children to read and then answered questions from them. Mia talks of her teenage daughter and how the information was available, but she did not push it on her. '*She would have just probably maybe looked at some of the pamphlets when I wasn't home.*' One of the women explains that she actually looked at the treatment specific information after it had happened as she found that the nurses were better at explaining what was going to happen,

for example the placement of her peripherally inserted central catheter (PICC). Anne liked the nurses to explain for her; '*This is what's gonna happen, blah, blah and this is how it's gonna hopefully end, that's what it means*'.

The participants described different relationships with the medical staff. The doctors provided information but the participants did not always have a connection with the doctor, however the nurse often provided the needed information and support.

'But you know what professional men are like you know? Like although he seemed very nice and all the rest of it, that's not his deal, dealing with that the nurse, She was brilliant. She was really, really good. She took us into a room on our own and we had a chat.' Rachel

The partners described a lack of information as guidance for them as younger aged support persons. Jai explains, '*I felt, you know, great the women are important, your partner is important but where's the information for me to help me create a strategy to cope.*'

Getting help

This theme related to getting external help. The quantitative data identified different levels of support used from a range of areas as measured by F-COPES subscales 'social support' 'mobilising' and 'family resources'. The higher the scores of seeing the breast cancer as a positive challenge, the higher the scores of use of external resources. [See Section 4.4] In the qualitative data, the women seemed to guide the help the family obtained and often this was talking with the breast care nurse if available. Nurses helped with getting information, and they understood the women, although sometimes they were perceived as too busy to smile. Kate discusses the clinic and chemotherapy. '*They [oncology unit] are always packed now, always full of patients ... Why don't they [nurses] smile.*' Anne has a similar comment about the pace of the clinic areas and the lack of understanding of the nurses sometimes. '*I think they understand, I just think it's because they see so many [patients]*'. Lyn [Kate's Mother] also commented about the nurses but in a positive way. '*Oh I wonder if so and so is going to be there today?" and you know and we got sort of delving into the nurses [laughs] lives*'.

The access to the breast care nurse was invaluable for the women and their families, supplying both information and direction. Not all the women had access and sometimes it was only telephone consultations. However, some of the rural areas did have breast care

nurses [McGrath Foundation Nurses], which were described as very positive especially when most of their treatment is away from home.

Breast Care Nurse here in town, has been a wonderful support, she's given me a, a whole bunch of DVD's and literature and stuff, to look at and also a diary, a my journey type diary where I can catalogue not only medical notes but my own personal thoughts of what I'm going through Sally

The oncologist was the next person the participants went to for information, but not emotional support, as the participants felt they needed to be confident in their doctor. Jai explains his planning for all aspects, whereas other participants used small aspects of this combination.

I had confidence with the surgeon. I had the personal sort of touch from the breast care nurse. The orange book provided me the sort of broad picture and the research or when I went online and just the emotional back up that I had was from the student counsellor so the combination of all. Jai

Some of the participants discussed needing emotional counselling, but were unaware what was available or felt no help was offered. Kaz describes being lost in the hospital system.

Well when I think about it now, it probably would have been really good to have had some sort of counsellor support you know through it but it just, I didn't know of anywhere to access it. Kaz

Kaz goes on to discuss her misunderstanding with the helpline. '*I suppose I thought you know the cancer helpline and all that really was for older people you know it wasn't really aimed at younger people with families and you know*'.

Sally describes being able to see that she needed help and could start to ask for counselling. This is a major influencing factor, with the participants describing their acknowledgement that they need help and then being able to ask for direction. Sally, '*also too the fact that knowing I need, I need help, like counselling and I'm in the process of seeking that out so that you know, that's gonna help me be stable as well*.' Some of the participants explained they used family if they needed to talk with someone, not realising the benefit of the external counsellor in assisting their adjustment. Viv explains. '*I didn't need to go to a stranger*

because I had lots of people who I wanted to actually talk to.' Interestingly, Jai her partner openly acknowledges the benefit of the counsellor for his adjustment.

The support group was seen in different ways as well, and some women found they provided both emotional guidance and information, where others found them very negative. Barbara, Anna's mother, comments about the support group being a club. '*I know that my daughter didn't want to be a part of the club. So I suppose I can understand that she didn't want to be a part of this club. She wanted to be normal*'.

Once again the mother and daughter theme comes across strongly as the participants talk of going to support groups. Sophie and her mother Jane both went to the support group and Sophie comments that it was good to be with the other women. '*I've met a whole lot of them now so and they all know me so it's pretty good. Yeah they've always said if you need me, I'm here and I like it*'. Annie talks of the support group that T a 28 year old with breast cancer, and her mother go to at the hospital. '*There are always people that you can talk to and there are groups that you can talk to. ... I think she finds that a great benefit*'.

Some of the women went to a support group, but then found it was not for them. Cath tells a story about her experience of the support group.

I only went once, but they were all nice. A lot of them were all talking their stories, their treatments and everything else. I just thought, "oh, well." "Mine's different to yours." Trust me to get the worst one. Cath

The community support was helpful, but sometimes it was hard to access and organise. Ivan talks of trying to organise home help for Sally and how the church helped out.

'To get people from the community actually coming in to visit her but that's taken a fair bit of planning through our local church to actually access a lot of that sort of stuff.' Ivan

Other participants also described using support from the church as accessing community services was very difficult. Some talked of needing home help, but not being able to access anything.

Treatment concerns

The participants all spoke of the concerns arising from treatment. The women talked of tiredness, nausea and inability to continue their usual roles, or feeling different emotionally from the treatment. Robyn explains it was the whole nausea, memory loss, nerve damage all of which she had to cope with while caring for her two small children.

Yeah I'm on tamoxifen as well so that I mean, the memory, really poor memory and I've got some side effects from the Taxol in my feet you know the nerve damage so yeah. Robyn

The women with breast cancer described struggling with the treatment and side effects, this was a really difficult time for them when the family needed to pull together to help the woman through this.

I was so sick with the first lot but then the next two, you know well I, they were crappy but not as physically ill as that first time so I get cranky with the side effects that it's left me. Jane

Mia explains the difficulty of just keeping going with the pain from treatment. '*I don't know whether people understand that sort of pain. I think, yeah.*' Lauren, Mia daughter, comments, '*By the end of the night though you were pretty, really tired and you know, Dragonish*'.

Other discussions related to decisions of treatment and concerns about trying to reduce their risk of recurrence. Once again, confidence in the medical doctor was important. Viv '*The fact is, I did have confidence. if you find a good surgeon you have confidence – that does help.*' Kate and Lyn had an attitude of just do everything you can to beat the cancer, '*let's just get on with, whatever they tell us, we're gonna do it and just get on with it*'.

The resources each participant and family used varied, influenced by the strengths they had within the close family unit, but also by the communication within the family.

5.4.4 Summary of resources

In summary, the resources used by the participants, related to their family structure and functioning. Close family members were influenced by the woman with breast cancer and her response to the breast cancer treatment. Themes from the partner's, children, mother's and

extended family provided information on how different family members reacted and how they were involved in the family functioning. Women's business was a theme related to the support provided by women for the woman with breast cancer. Spiritual support explored the personal use of spirituality and alternative therapy to assist the individual to relax and refocus during treatment for breast cancer. Support by the health professional, including doctors, nurses, counselling staff and information was explored, providing an understanding of the different services by family members in response to breast cancer treatment.

5.5 Conclusion of Qualitative analysis

The completion of twenty three personal interviews provided rich qualitative data allowing a view into the experience and interaction between family members after a diagnosis of breast cancer. The analysis revealed the distress the family experienced at the point of diagnosis and how they then interacted as a family to support the woman with breast cancer and attempt to maintain family functioning.

Particular themes emerged related to the strengths of the family and the communication within the family. These related to the commitment to share and support each other within the family, although the level of support and sharing of distress varied for different family members. The participants spoke of the personal side of breast cancer, the hidden distress, but also the change of attitude and looking for positive outcomes from the diagnosis. Maintaining normality and balancing life was discussed, in particular 'keeping things normal' for children. Participants also shared how they tried to distance themselves from the breast cancer, seemingly in an attempt to survive the stress of the breast cancer and its overwhelming nature.

The communication styles within families were also discussed and this theme emerged strongly in the analysis, particularly relating to different types of communication. The communication style seemed to link with other aspects of the strengths and resources used by the family. The interviews with a range of family members within a family clearly identified hidden or 'backstage' behaviour or rules. The different styles of communication related to open sharing of distress and emotions, guarded communication or the use of humour within communication. Also important was the aspect of communication where missing data and

words were left out as family members described their response to the breast cancer diagnosis. Communication emerged as one of the links between strengths and resources.

The analysis explored the use of resources by the participants. This revealed the varying level of support provided by different family members and how this influenced overall family functioning. The qualitative data also provided a view into the response of the children within the family, identifying the distress they felt and also a lack of support and direction for the children as the parents struggled with the diagnosis themselves. Extended family members played a role in the support of the woman with breast cancer, often providing specific help such as internet resources, child minding, or assistance with doctor's visits. Interviews with extended family members, particularly the mothers of the women with breast cancer, revealed their distress and feelings of anguish about the situation, also how they felt helpless to take the pain away from their daughters. Another resource identified was the use of spiritual support. This ranged from Christian beliefs, meditation, craft, nature or just 'time out' with the television or music. In all cases the participants spoke of the benefit of being able to forget about the breast cancer for a while and regenerate their strength.

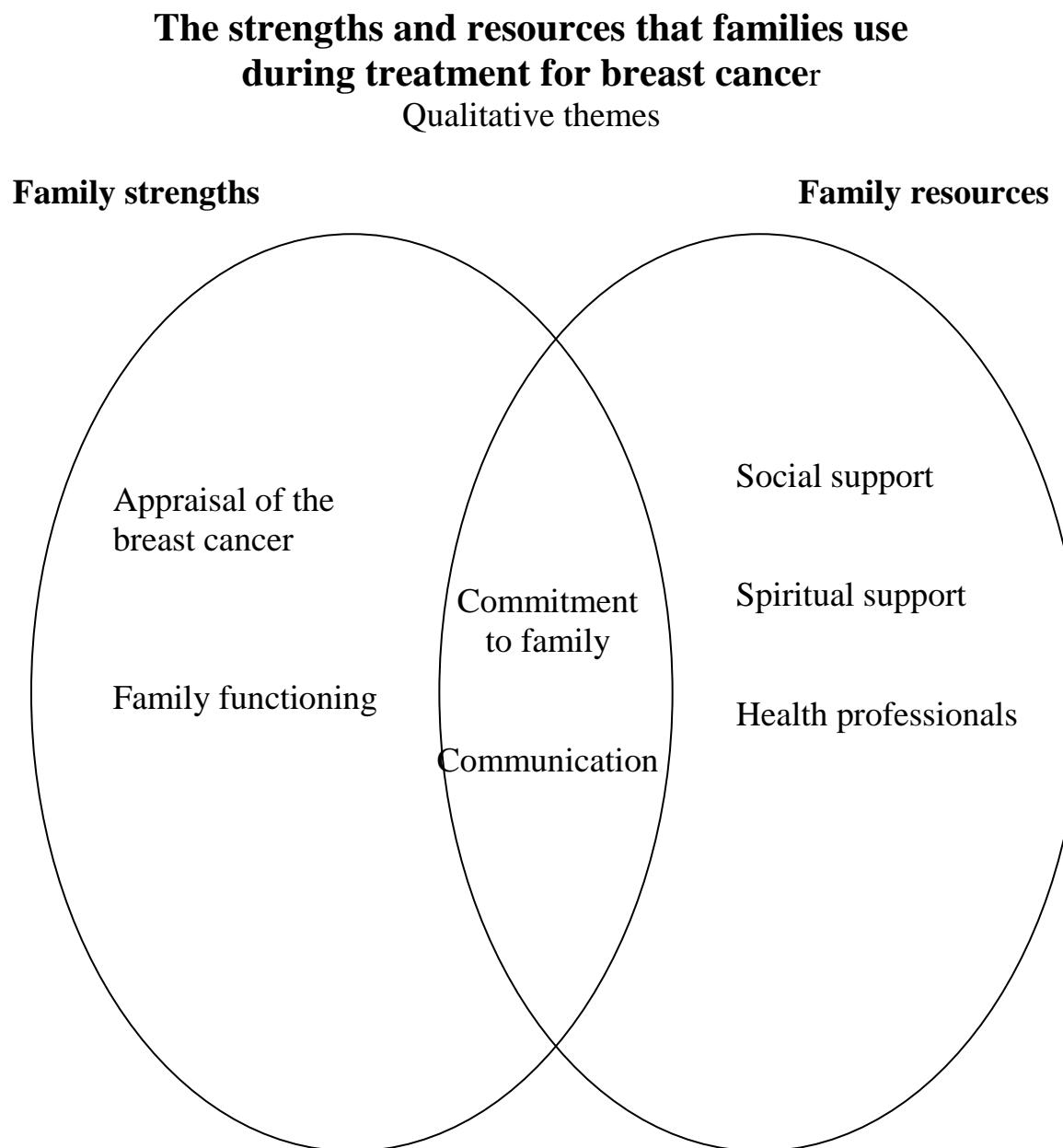
The use of health professional support was also explored with a range of responses from participants. Most participants spoke of gathering extra information from the internet to supplement their knowledge and assist their decision-making relating to treatment. The use of health professional support was influenced by the resources available, and the breast care nurse was noted to be excellent however not always available. The oncology nurse was identified as especially important for breaking down the information so it could be understood. However this support was often not available for the family as a whole, who described themselves as being 'lost' and unable to get support. Support groups were spoken about both positively and negatively and the use of the counsellor was also a very personal choice and not used by all participants even though they spoke of personal unresolved distress.

Overall, the analysis revealed the strengths and resources used by the family, also providing an insight into the interaction between family members. The two linking aspects between strengths and resources was the communication between family members and the commitment of family members to work together as a family to maintain family functioning

in the face of the adversity of breast cancer. Figure 1 provides a concept map of the linking between strengths and resources developed by the qualitative data.

In conclusion, this chapter presented the participants' experiences as they described their response to the breast cancer. The qualitative analysis adds depth and description to the quantitative analysis. The qualitative analysis describes the personal strengths of the participants, the communication styles within the family and the resources they used and why they were important. The next chapter discusses the quantitative and qualitative data analysis bringing together the foundation of what strengths and resources the women with breast cancer and their family members use during treatment for breast cancer.

Figure 4 Concept map of qualitative themes



6 Chapter 6 Discussion

6.1 Introduction and overview

The purpose of the current study was to explore the strengths and resources that young women and their families use during treatment for breast cancer. In this chapter the findings from prior research addressed in the literature review and the findings from the current study will be brought together. The discussion addressing each specific research question along with the relevant outcomes form the body of the chapter. Factors influencing the research methodology will also be considered.

To optimise clarity for the reader, the research questions, theoretical framework and definitions are briefly restated. This exploratory descriptive two phase research was guided by the *Resiliency Model of Family Stress, Adjustment and Adaptation* [Family Resiliency Model] (McCubbin & McCubbin, 1993) and Family Resiliency Framework (Walsh, 2006), which facilitates the exploration of the family response to illness. The overarching research question was: ‘What are the strengths and resources that young women and their family members use during treatment for breast cancer?’ The main focus of the discussion will include an exploration of the strengths and resources used by women with breast cancer and their family members drawing on previous research to discuss the results of the current study. The factors influencing the strengths and resources used by the family members and the changes to the family unit over time are addressed. The influences that family dynamics has on the family’s adjustment are also discussed.

The definitions for the current study are presented in the introduction section 1.8. The participant sample was both young women with breast cancer [< 50 Years] and their family members. The *Resiliency Model of Family Stress, Adjustment and Adaptation* provides a framework for exploring the family as a group of interacting individuals as they respond to adversity (McCubbin, et al., 1998; Walsh, 2006). The framework explores the family’s response using a number of key family attributes including strengths and resources (McCubbin & McCubbin, 1993; Walsh, 2006).

This material is addressed in detail in the literature review in sections 2.2 through to 2.4. The current study extends the body of knowledge relating to the family response to a health adversity by the use of a range of family members as participants.

6.2 Representativeness of the sample

Three important innovative strategies were adopted in this research which added to the rigour of the research. The research rigour ensures that the findings add to our knowledge and understanding of the strengths and resources the families used during treatment for breast cancer. The first innovative approach was to use a range of family members and family groups as the research participants. This innovative approach to data collection is suggested by Northouse et al. (1998, 2001, 2005) and Bultz et al. (2000) to provide a perspective of the differences between family members. Northouse et al. (1998, 2001, 2005) explored family dyads namely male and female family partners after a diagnosis of non-specific cancer and one of their recommendations from their research was to use of a range of family members to provide a broader understanding of the family as an interacting unit rather than a family dyad. A similar recommendation was made by Bultz et al. (2000) whose research sample was made up of 34 dyads and involved providing an intervention for partners of women with breast cancer with a mean age of fifty years. The current study addressed the important question of family unit functioning by having a range of family members as participants.

The second innovative strategy was a two stage analysis of the data. The main analysis was completed with all 111 participants to provide an understanding of the women and their family member's response as individuals with a family context. This meant that the questionnaires asked the participants to report on the family response and support thus providing a family perspective. The range and number of family members provided information to expand on the current literature to date. The second analysis was completed with the family members as family groups. An indication of the family response as a group can be seen from this analysis. The analysis was able to link family characteristics and family scores to enable an interpretation of how the family functioned during treatment for breast cancer. [See Appendix 8.7 for the table of family group analysis]

The third innovative strategy to ensure research rigour was the adoption of a contemporary definition of family. The definition of family for the current study was that a family is a

group of individuals who are bound by strong emotional ties, a sense of belonging, and a commitment to being involved in one another's lives and who call themselves 'family'. The sample for the current study was made up of young women with breast cancer and their family which included spouses/partners, children, parents and friends as defined by the women.

Different configurations of 'family' participated in the current study. Each family member, the young woman and her family members completed the questionnaires. The analysis of the data involved exploring their individual response and also the response of the family as a unit. The findings reflect the individual response and the clustering scores of all family members' responses were presented as a family response. This method of analysis provided an understanding of the family's response to breast cancer. This method of data analysis has previously been used successfully to obtain collective family perspective (Mellon & Northouse, 2001).

The participants in the current study are similar to previous research samples where researchers addressed young women with breast cancer (Bloom, et al., 2004; Dunn & Steginga, 2000). The family members' age, phase of life, treatment, education and occupation will be discussed in relation to previous research exploring either young women with breast cancer or family research.

Age and family characteristics

The young women with breast cancer who participated in the current study had a mean age of 43 years ($n = 47$). Over half (62%) of the women with breast cancer in the current study had children, with 15% percent having children below the age of ten years. The demographics of the research participants indicate that these families are commonly in the 'child rearing' phase of life. This is an important consideration when making recommendations from this research. The research participants' demographics are similar to the previous work of Bloom et al.'s (2001), justifying the comparison with previous research exploring just the women's experience. The recommendations arising from this research are addressed in Chapter 7.

Treatment schedule for breast cancer

The treatment for the women in the current study reflected best practice guidelines (NBOCC, 2004), with primary surgery (91%) followed by a combination of radiotherapy and

chemotherapy (55%). Treatment schedules are presented in Chapter 2.5. The standard treatment regimens are aggressive and multimodal and influence the women's ability to maintain normal roles including caring for their family and children. Similar to the current research Bloom et al.'s (2001), sample of women reported that 97% had primary surgery with 51% having a combination of surgery, chemotherapy and radiation therapy therefore providing justification for comparing the current study with previous research exploring just the women's experience.

Educational status

In the current study sample 54% of all participants and 49% of the women with breast cancer had only secondary school education, with the remaining 46% of all participants having completed a diploma or above education. In contrast, Bloom et al.'s (2001) sample of 336 women with breast cancer was made up of 20% with only secondary school and 80% with college level education. Similar to the current study, Northouse et al. (2005, 2007) researched a sample of 123 dyads with general cancer with a mean age of 65 years, reporting a mean level of education as 12.3 years (completed secondary school). The current study is similar to the education level of the dyad research of Northouse et al. (2007), but with a lower level of education than Bloom et al.'s (2001) sample.

Employment

The employment status of the current study is similar to prior research. In the current study sample 28% of all the participants were not employed and while the remaining participants (72%) were in a range of occupation levels, with 38% working in a professional or management position. In the research by Bloom et al. (2001) their sample reported 23% not working and 77% in full or part time work. Specific occupational types were not identified in the article. Northouse et al. (2005, 2007) reported family income but not occupational type.

These sample characteristics indicate that the current sample is representative of the target population of young women with breast cancer in Australia and internationally. These similarities establish the external validity of the current study and mean that the findings can be generalized to similar demographic groups internationally.

6.3 Strengths and resources used by the family during treatment for breast cancer

In order to answer the research question ‘What are the strengths and resources used by the young women and their family members during treatment for breast cancer’ a composite questionnaire was used. Justification of the composite questionnaire is found in the literature review in section 2.2. The current study used qualitative data in the form of semi-structured interviews to provide in-depth understanding of the strengths and resources used by the women and their family members during treatment for breast cancer.

In order to answer the overarching research question, ‘What are the strengths and resources used by young women with breast cancer and their family members during treatment for breast cancer?’ four subordinate questions were devised.

- What are the strengths the young women and their family members use to assist their adjustment during treatment for breast cancer?
- What are the resources the young women and their family members use to assist their adjustment during treatment for breast cancer?
- What are the contributing family attributes that influence strengths and resources utilised by the women and their family members during treatment for breast cancer?
- Is there a change in the strengths and resources used by the young women and their family members’ across time?

In order to answer the research questions each participant, that is the young women and their family members, completed the questionnaire. The analysis was completed as individual responses and then as family group response. One of the important findings from the current research is that there was no significant difference identified between the response of the women with breast cancer and the response of the family members except that the women with breast cancer had a lower response to the subscale sense of control. This is an important finding as it indicates that both the woman with the diagnosis and their family members use very similar strengths and resources in response to living with the treatment for breast cancer. Previous research exploring young women with breast cancer has not explored the responses

of the family unit that is the women and family together. This finding is an important first in this area of research. This finding extends previous knowledge as most research has only explored individual family members (Bloom, et al., 2001; Northouse, et al., 2007). This research has demonstrated that families draw on the same strengths and resources as does the woman affected during treatment for breast cancer.

The findings of the current study are consistent with previous research using the McCubbin scales to explore strengths and resources. Similar scores were reported in the Leske and Jiricka (2001, 2003), Clark (2002) and Northouse and colleagues (2001, 2006, 2007) research using the Family Hardiness Index (FHI) (McCubbin, et al., 1986). The Leske and Jiricka mean scores for FHI were 42/60; Clark (2002) mean scores for FHI were 46/60, the current study FHI mean scores were Phase 1 44/60 and Phase 2 46/60 suggesting similar reporting of family strengths during adversity. Northouse and colleagues (2001, 2006, 2007) did not report specific information about the FHI scores only relationships between variables, which are similar to the current study. The F-COPES scores from the current study were similar to previous research, the mean scores for the current research were 72 / 116 and for the Leske research 81 / 120 (Leske, 2003; Leske & Jiricka, 1998). [Leske used all 30 questions in the questionnaire for the final analysis however the instructions from McCubbin, McCubbin and Olsen (1981) suggest not including question 18.] These previous researchers provide credence for the current study overall scores, highlighting similar levels of family strengths and resources. The current study discusses the separate aspects of strengths and resources in more depth to provide an insight into the family response to adversity and their strengths and resources. The following sections of the discussion chapter address the four subordinate research questions.

6.3.1 Strengths of the women and family members

The first subordinate research question to be addressed was ‘What are the strengths the young women and their family members use during treatment for breast cancer?’ The strengths were measured by the Family Hardiness Index (FHI) (McCubbin, et al., 1986), one subscale of the Family Crisis Personal Evaluation Scale (F-COPES) (reframing) (McCubbin, et al., 1981) and three subscales of the Walsh Questionnaire (challenge, family flexibility and communication) (Walsh, 2006). Qualitative data provided information regarding the strengths

used and the understanding of how these strengths helped the women and their family members adjust to a diagnosis of breast cancer. [See Section 4.4.1, 4.4.3 and 5.2 for details].

Four separate elements of strengths were explored in this research. [See Section 2.3.2 for details]

- Commitment to family, defined as the ability of the family to appraise the situation as a shared challenge and provide mutual support and commit to working with the family during the adversity.
- Appraisal of the adversity defined as the meaning the individual places on the adversity, which in turn influences the way they respond to it.
- Family functioning defined as the changes within the family occurring in response to the illness.
- Communication defined as the transmission and reception of both information and instructions within the family and externally with community and health professionals.

The process of data collection and questionnaire details are presented in Chapter 3.

The four different elements of strengths will be discussed in separate sections.

6.3.1.1 Commitment to family

The first element of ‘strengths’ to be discussed is the commitment to work together as a family. Commitment to the family was measured in the subscale ‘commitment’ in the Family Hardiness Index (FHI). [See Section 4.4.1, 4.4.3 and 5.2 for details]. The participants were asked to rate how they worked together as a family. The results indicated that families with good communication between family members aim to work together as a family to support the woman and maintain family functioning. The way families worked together was linked to the way the family viewed the breast cancer and the family’s ability to change family member’s roles and functioning. This is an important finding as it clearly demonstrates the individual family member’s commitment to the family in response to the breast cancer, but also the close relationship of this commitment to other strengths and the use of resources. Although the strength commitment to family has been discussed in previous research the current study quantifies this particular response (Mellon & Northouse, 2001; Sittner, Hudson, & Defrain, 2007).

The qualitative data corroborated the quantitative data. Qualitative data indicated that family members put their lives on hold, to be there for the woman with breast cancer who may have been their partner, mother, sister, daughter or close friend. Mia's daughter highlights this commitment. She went with her mother to all the appointments, giving up her dance course to be her mother's support person. [See Table 28 for interview information] This strong commitment to working together as a family is consistent with previous research which has explored this from the perspective of communication and partner support (Brusilovskiy, et al., 2009; Romero, et al., 2008).

Previous researchers has established that better communication and support between family members was linked to better adjustment and health outcomes for the women with breast cancer (Brusilovskiy, et al., 2009; Romero, et al., 2008). Brusilovski et al. (2009) in their study of 66 women with breast cancer, went on to suggest that focusing on assisting the family to provide a supportive relationship would assist in addressing the women's psychosocial needs. While the woman is given the diagnosis of breast cancer, the impact and response influences the whole family and they need to work together and support each other to gain optimum adaptation (Walsh, 2006). Previous research has not explored in such depth the response of family members' in the support of the younger woman with breast cancer. The family commitment is closely linked to how the family and individuals within the family appraise the breast cancer.

6.3.1.2 Appraisal of breast cancer

The second element of strengths to be discussed is appraisal of breast cancer. Appraisal was measured by several subscales within the quantitative data 'challenge' FHI and Walsh scales, 'control' FHI scale, and 'reframing' F-COPES. [See Section 4.4.1, 4.4.3, 5.2 for details of data analysis] The participants rated their appraisal of the breast cancer, but also the description of how they saw the breast cancer in their lives. The three aspects of appraisal of breast cancer are the challenge of breast cancer, sense of control on the situation and ability to reframe the adversity, as previously discussed in literature review section 2.3.1.2. The appraisal of the breast cancer can be both positive and negative depending on the individual's consideration or sense of control of the stressor, although it is noted as a strength a negative appraisal becomes a poor or low strength (McCubbin, et al., 1998).

Challenge

The first aspect of appraisal to be discussed is challenge, the way the family saw the breast cancer's influence on their lives. The results indicated that individuals who were able to see the breast cancer as a positive challenge in their lives were more likely to be able to organise support both within the family and external resources. Individuals who were overwhelmed by the breast cancer and unable to see any positive from the breast cancer struggled to organise support from within the family and also did not accentuate asking for external help from health professionals during treatment for breast cancer. These findings are consistent with previous research exploring older women with breast cancer, where research findings indicated that women who were able to find benefit and positively appraise the breast cancer were active in the process and intentionally pursued positive outcomes (Sears, et al., 2003).

The qualitative data provided additional rich insights into the responses. The participants, both the women and their families, clearly described the challenges of breast cancer and how at diagnosis this was an overwhelming feeling and often quite negative. Mia talks of her family's reaction; the way they were shocked and crying but then became strong and supportive for her. However as the family rallied together they were able to work together and the challenge of breast cancer was seen more in a positive light and a sense of positive change came into their lives. Kaz identifies in her interview a lack of ability to see some way forward from the breast cancer. Some family members struggled with finding any positive in their lives after the breast cancer diagnosis and this was reflected in the low quantitative scores of these particular families.

Previous research suggests that when challenged through adversity some individuals emerge stronger having experienced personal growth while others are unable to pull together strengths to overcome the adversity (Low, et al., 2006; Sears, et al., 2003). Both the women with breast cancer and family members spoke of crisis points, and often these were related to external family stressors or a combination of stressful events. For example Lyn talks of her crisis point when she had to have a central venous access device inserted and was not prepared for the pain and change in her life. Lyn also talks of this as a turning point once she had recovered with the support of family. Finding a turning point after a crisis is a recurrent theme in the qualitative data. This theme is similar to the hypothesis of the Family Resiliency Framework which suggests that the family reaches a crisis point and then refocuses to move forward into the adaptation point (McCubbin & McCubbin, 1993). The individual's and the

family's appraisal of the situation is also influenced by their ability to see how a way to change on the situation and how much control they have on the situation.

Sense of control

The second aspect of appraisal is the individual's sense of control over the situation. This was the only aspect of the family's response to treatment to breast cancer that the women with breast cancer and the family had significantly different scores. [See Section 4.5.1.1] The women with breast cancer reported a lower sense of control on the situation than the supporting family members. This finding is understandable as it was the women with breast cancer that had to undergo the treatment. The majority of the women had all three treatment types, surgery, chemotherapy and radiation therapy and would have had little control of the timing or side effects from these treatment schedules.

The participants reported that in Phase 1 active treatment they felt less control over their situation than in Phase 2. During active treatment the family reported that their sense of control was influenced by how they considered the impact of breast cancer on their lives. The support from the family and if they were able to ask for health professional support also altered the sense of control the individuals had over the situation. However in Phase 2, the results indicated that over time the individuals took more of an active role on their situation, rather than a response influenced by their family support. Previous research has reported that if the individual can see they have some control on the situation they tend to respond to the adversity in a more positive manner (Sears, et al., 2003).

Although sense of control has not specifically been explored in young women before, the women's experience of having minimal control in their breast cancer journey has been established in prior research (Bloom, Stewart, Johnston, & Banks, 1998; Coyne & Borbasi, 2006; Dunn & Steginga, 2000; Sears, et al., 2003; Steginga, et al., 1998). The predictors of finding positive growth from the breast cancer two years after treatment has been explored and the findings suggest that women feel more in control of the breast cancer and yet still perceived their cancer as moderately to very stressful in their lives (Sears, et al., 2003). The current study showed a trend of a higher sense of control during Phase 2 than Phase 1 suggesting that over time the participants experienced more control over their lives.

Research also suggests that disease and treatment factors influence the women's sense of control of their life with the breast cancer (Bloom, et al., 2004). The current study explored the influence of treatment. However no specific findings were identified. This was probably related to the timing of data collection. Participants in the current study completed the questionnaires at different times within their treatment schedule depending when they were recruited. The data suggests that women receiving consecutive treatment, surgery, chemotherapy and radiotherapy responded to this physical and emotional change with a higher level of engagement to the breast cancer and seeking to get some control back in their lives than women who had a lesser combination of treatment schedules.

Bloom et al. (1998) explored the intrusiveness of breast cancer on the young women's lives and noted that the severity of the disease and treatment factors such as body image and physical symptoms were the influencing factors to change. The influence of family support has been put forward as a motivation for change in the women's adaptation to the breast cancer, particularly the ability of the family to change roles and support the woman (Bloom, et al., 2001; Northouse, et al., 2001; Sears, et al., 2003). Similar findings were noted in the current study, particularly the qualitative data, which identified the connection between intrusiveness of breast cancer in the women's lives, her family support and her feeling of being in control of the situation.

The qualitative data indicated that the sense of control was often about keeping normal, maintaining part of your life without the feeling of always having breast cancer. [See Section 5.2] The women with breast cancer in the current study spoke of this, mentioning wearing wigs to work so colleagues did not constantly ask how them how they were going with breast cancer treatment. Several of the women continued to work as they tried to cope with the breast cancer treatment. Maintaining normal activities in life has been noted to increase the women's sense of control on their life in previous research. However, this is not always reported as a positive coping strategy (Boykoff, et al., 2009; Northouse, et al., 2005).

The family members described trying to keep routines in the home as close to normal as possible in an attempt to reduce the strain for the family, but also to maintain a sense of control on their lives. The women with breast cancer spoke of doing positive things with their children so the children did not remember their mother as being always sick from the treatment. The extended family often helped with maintaining routines for the children by

picking up children and helping with meals. Although not all the families in the research allowed this type of help, but instead chose to continue on like there was no breast cancer to deal with.

One family in particular did not actually mention the breast cancer within the family. The activities of the family were arranged so the child did not know that his mother was having treatment for breast cancer. Research identifies this as a negative coping mechanism because children will sense something is wrong and think it is their fault (Compas, et al., 1996; Turner & McGrath, 1998). This theme of maintaining normality for the children has been previously identified in research, although it has been associated with a closed communication style which may not be conducive to positive adjustment over time (Kennedy & Lloyd-Williams, 2009). Exploring the children's and parent's perspective of advanced cancer in one parent, Kennedy and Lloyd- Williams (2009) found that the children are greatly affected by the diagnosis and open communication of information and support increases their chance of a positive experience. Similar to the current study Kennedy and Lloyd- Williams found that parents tried to maintain normality for the children, although this was often at the expense of open communication, and was therefore a negative coping mechanism. This supports the earlier discussion on the woman's attempt to be in control even with acute treatment symptoms. The feeling of control was linked to the family functioning as the families tried to maintain family life.

Reframing

The third aspect of appraisal was reframing, which is the ability of both the individual and the family to redefine the adversity into a more manageable burden and being able to have flexibility around how to handle the adverse event. The results relate to the personal appraisal of the adversity and how the individual can see the family working through the situation. The individuals identified a sense of vulnerability in the situation as they attempted to work out how the family would cope with the breast cancer. The ability to see a solution was influenced by the support of the family and seeing the breast cancer as a positive challenge implying the more support you have from the family the more the individual is able to appraise the stress as positive.

The way the family was able to understand the situation and change roles within the family to meet the woman's and family needs was indicative of how supported the woman felt during

treatment. This was consistent with previous research, where links between family appraisal and role adjustment have a direct relationship to long term adjustment (Northouse, et al., 2001). One of the aspects of the reframing was the family's ability to work with the woman with breast cancer to organise roles to complement her ability as she progressed through treatment. The qualitative comments from the women revealed two sides to being cared for by the family. Some of the women were happy to be cared for, while others did not want to assume the 'sick role' at all. Prior research provides little understanding of the changing roles within the family, however Bloom et al. (2001) found that the more integrated the woman was within her support network the more she accepted help. This is consistent with the findings from the current study.

Research has reported that partners often felt poorly prepared to assist the women both emotionally and physically, often leading to an inability to change roles appropriately to support the woman (Manne, et al., 2005; Northouse, et al., 2001; Ponto & Barton, 2008; Romero, et al., 2008). Similarly, the partners in the current study also reported feeling lost and overwhelmed as they tried to support the woman with breast cancer. They had difficulties adjusting and working out how they were going to maintain the family functioning when the woman with breast cancer could not continue her role as mother. McCubbin et al. (1998) in their explanation of the Family Resiliency Model discusses the close association between the appraisal of the stress and the functioning within the family. This highlights the need to understand the interactions within the family. In fact several researchers have completed specific intervention studies to increase the partner's ability to assist the women's adjustment (Bultz, Specia, Brasher, Geggie, & Page, 2000; Lewis, Cochrane, Fletcher, Zahlis, Shands, Gralow et al., 2008; Northouse, et al., 2005). Although they had small participant numbers, researchers noted evidence of benefit for both the women and partners (Bultz, et al., 2000; Lewis, et al., 2008). In particular, communication between the couple was improved, thus increasing the understanding of the changing of roles within family.

6.3.1.3 Family functioning

The next element of strengths to be discussed is 'family functioning'. The participants were asked to rate how they felt their family was flexible to change in response to adversity. The family functioning in the current study was measured by 'family flexibility' in the Walsh scale. [See Section 4.4.1, 4.4.3, 5.2 for details] The ability of the family to understand and

change roles within the family was one of the influencing factors of the family's ability to move forward positively whether it was the woman with breast cancer or one of the family members. The results indicated the participants reported they felt their family was able to change roles when dealing with the unexpected adversity of treatment for breast cancer. This was evident in Phase 1 with the family response being correlated to other strengths such as commitment to the family and the appraisal of the breast cancer. However, in Phase 2 there was less influence from the other strengths and families reported a higher level of family flexibility. A small number of the families did not report a high level of family flexibility and these families tended to have lower scores generally and younger aged children with less family support when a closer analysis of the family group was completed. [See Section 4.7 for details]

The qualitative analysis revealed that family members worked together to assume different roles in most of the families, although some family participants commented about the mother's role being stable. This seemed to imply that keeping the house as close to normality was less stressful. The changing of roles within the family was related to the women's sense of control on the situation. Consistent with previous research, some women in the current study reported a difficulty in allowing others to complete some household tasks often feeling distressed by having to assume the 'sick role' (Bloom, et al., 1998; Compas, et al., 1994; Walsh, et al., 2005).

No clear leadership roles were identified in the current study, although participants spoke of specific roles to suit the situation. McCubbin et al. (1998) suggested that families with clear leadership roles are able to use past experience and coping strategies to maintain and increase family stability. Leadership by the father was identified by Forrest et al. (2009) where the father maintained the flow of information and support to the children. The families in the current study were a diverse range of families from single parents to extended families and this may be the reason why the leadership role was not clearly identified.

The participants in the current study did, however speak of changing their roles within the family to meet the needs of both the woman with breast cancer and the family. The women in particular spoke of choosing family members specifically for different support roles during treatment. These choices were based on the perceived individual's skill such as going to the doctors as they were good at remembering, and asking the right questions, doing specific

tasks around the house, or having someone who was just good at '*being there*' for them. Flexibility of family supportive roles has been highlighted previously. However the current study has explored this concept from the actual family members' experience (Coyne & Borbasi, 2009; Mellon & Northouse, 2001; Northouse, et al., 2005). The influence of the cancer on partner relationships and the changing of roles has been discussed in previous research, particularly themes related to the relationship changes after breast cancer (Walsh, et al., 2005). Although having similar findings, the current study did not identify such depth of relationship issues, probably because the questions and analysis related to the strengths and resources of the family.

A finding in the current study was how some of the mothers completing the interviews discussed their continued role of mothering their young children even when they were physically very tired and stressed from the treatment. Similar to the current study, Walsh, Manuel and Avis (2005) reported how the women discussed role changes within the family and challenges associated with the changing family dynamics, particularly feelings of personal grief and distress for their children. In contrast, some women in the current study spoke positively of their children's adjustment. The teenage children interviewed in the current study also identified a sense of positive role changes, 'growing up' with the family during the treatment for breast cancer. Concerns were identified, but the family members often discussed how they were dealing with the problems within the family and with the children in a positive manner. Other families did reveal concern and distress regarding their children, particularly families with little extended family support. The single mothers and the families without parents who were not close enough to assist in their recovery to breast cancer discussed difficulties regarding their children and role changes.

The importance of open communication to enhance family relationships in response to adversity was reported by Walsh, Manuel and Avis (2005). This was a consistent finding in the current study. Families who openly shared information and discussed concerns displayed positive adjustment both qualitatively and quantitatively. The changing of roles was closely associated with the ability to understand the family position and communicate effectively with other members.

6.3.1.4 Communication

The last aspect of strengths was ‘communication’ which relates to use of closed and open communication styles. The subscale ‘communication’ in the Walsh scale measured the use of communication such as; sharing love, humour and goal setting within the family. [See Section 4.4.1, 4.4.3 5.3 for details] The participants were asked to rate how they used different styles of communication within the family in response to the adversity of breast cancer treatment. Overall the families reported that family communication was a strong aspect of their family during treatment for breast cancer. There were also links between the other family strengths particularly being supportive of other family members. These findings are consistent with previous research exploring communication after a cancer diagnosis (Bloom, et al., 2001; Northouse, et al., 2007; Walsh, et al., 2005). These findings suggest that the families in the current study had good communication skills. When explored qualitatively the range of family communication styles was identified during the analysis.

The qualitative analysis indicated that the family members used a range of communication styles. The participants talked of sharing concerns with the family, often this was within their own terms for some families. Sharing openly seemed closely related to the way the family members were able to change roles and accept difficulties. The male members of the family were described by the women to have difficulty in openly sharing emotions noting comments such as ‘*he doesn’t talk about it*’ or comments from the male partners similar to this comment; ‘*the last thing we want to do is just sit in the house and talk and think about specifically the problem*’. Interestingly, these participants during the interview said they had open communication within the family, but did not seem to understand that sharing their feelings about the breast cancer may actually assist them to be supported both by the family members and health professionals.

During the interviews some of the participants did not actually use the words ‘breast cancer’, but spoke of ‘it’, ‘the problem’, or just paused in their speech. This avoidance of the stressor or avoidance coping is a process to protect from further distress. However it is recognised as a negative coping mechanism (Fergus & Gray, 2009; Rice, 1999). This can often lead to increasing communication problems, lower self-esteem and increasing anxiety, all of which influence the individual’s ability to adjust to the breast cancer (Lazarus, 1999). The quantitative and qualitative data of these participants demonstrates the links between lower scores quantitatively and signs of distress and lower levels of adjustment qualitatively. This

was a key finding which identifies the link between communicating distress and personal needs and working together as a family to overcome the adversity.

The current study provides an understanding of the styles of communication between the family members, particularly with the inclusion of different family members. The interviews with several members from the same family highlighted the backstage communication. [See section 5.3.5.1] Greenstein (2006) suggests that backstage communication is very important to understand how family members communicate and behave in their own environment. Issues such as the sharing of emotional distress could be seen within families. Family members would chose to share emotional distress or hide it from their family depending on how the woman with breast cancer was coping. Decisions about the breast cancer treatment were also shared or not shared depending on the family members involved. In other family interviews the positive things in their journey were shared by several family members, especially humorous parts. The results from the current study expand on previous singular or dyad research by the inclusion of several family members and the benefits this provided regarding exploration of the communication within the family (Fergus & Gray, 2009; Huizinga, et al., 2005; Pistrang & Barker, 1995; Turner, et al., 2005).

Another communication style used by the family members as their response to breast cancer was humour. In the current study humour was seen as a positive coping strategy to reduce stress and normalise the situation, which is similar to previous qualitative research (Johnson, 2002; Walsh, 2006). The use of humour as a positive communication style was diverse ranging from the use of family jokes about boobs to watching favourite movies to reduce the strain. Both Anna and Charlie explained this gave them something else to talk about and just helped ease the strain. Walsh (2006) asserts that humour is an invaluable coping mechanism giving the individual power of a positive attitude instead of feelings of helplessness. Although used in excess or as a cover up the use of humour becomes a negative avoidance coping measure (Walsh, 2006).

Overall communication styles described by the participants were positive coping styles and this supports the quantitative analysis of communication. These findings are similar to previous research exploring communication styles in participants with cancer (Lewis, et al., 2008; Mellon & Northouse, 2001; Northouse, et al., 2005). Several studies have used communication interventions for family dyads to improve the use of open communication

styles with an aim to improve overall adjustment to a cancer diagnosis for both women and their partners (Lewis, et al., 2008; Northouse, et al., 2005). The current study highlights the need for communication within the family to be assessed and appropriate guidance provided to improve overall family functioning.

6.3.1.5 Summary of strengths

This section presented the discussion of the family strengths, expanding on the four elements of strengths of the family. The discussion of the four elements of strengths, commitment to family, appraisal of breast cancer, family functioning and communication has provided an understanding of strengths of the family during treatment for breast cancer. The findings from the current study indicate that the strengths of the family have an influence on the family response. The recognition of family strengths provides a clear approach for working with the family and directing them on appropriate resources they may need. The results identify that the family strengths are a strong commitment to the family unit which is sustained during active treatment and into maintenance treatment. The families displayed an ability to be able to recognize how to deal with the changes related to the treatment for breast cancer although this was difficult at time for some families. This identifies the intrusiveness of breast cancer on both the women and their family members as they try to maintain normal life. The families reported communication within the family as strength however communication styles differed across family members. The next section will discuss the resources used by the family during treatment for breast cancer.

6.3.2 Resources used by the women and family members

The second subordinate research question to be addressed was ‘What are the resources used by young women and their family members during treatment for breast cancer?’ The resources were measured by three subscales from the Family Crisis Personal Evaluation Scale (F-COPES) (social support, spiritual support, mobilising, passive appraisal) and two subscales from Walsh (Spiritual support, resources). The qualitative data provided explanation of the types of resources used and why these were important for their family.

[See Section 4.4.2, 4.4.3, 5.4 for details]

Three separate elements of resources were explored in the current study. [See Section 2.3.2 for details]

- Social support is defined as the support provided by the immediate family members as defined by the woman with breast cancer.
- Spiritual support covers the individuals’ use of an external medium from religious through to mediation for the provision of support.
- Health professional support explores the use of external resources such as health professional support, internet, and community support.

6.3.2.1 Social support

The first element of resources to be discussed is social support. Social support has two aspects included in this element namely social support and passive appraisal. The first aspect to be discussed is social support. Social support explores the support from extended family and friends and participants are asked to rate the amount and type of social support used during treatment for breast cancer. This was measured by the subscales F-COPES ‘social support’ and Walsh ‘resources’, and qualitative data. [See Section 4.4.2, 4.4.3 and 5.4 for details] The results indicated that during treatment for breast cancer participants, both women with breast cancer and their family used mainly close family members as support. There was an association between having family as support and being able to see a positive aspect from the breast cancer, meaning that if they could see some positive in their life with the breast cancer, the individuals reported a stronger connection with family support. This was stronger in Phase 1 than Phase 2. This supports the previous discussion on the need for active engagement of the family during active treatment when participants reported higher levels of distress and a lower sense of control.

The qualitative data indicated that families used a range of close family members for different aspects of support during treatment for breast cancer. The participants spoke of delegating roles to different family members, for example psychological support such as someone to talk with or physical jobs such as child minding or meals. Both the women with breast cancer and the family members discussed this during their interviews. The aim of using social support seemed to be for reducing personal distress (psychosocial) or assisting organisation for the family (physical). This level of social support has not been previously disclosed by research in an overall family view.

The psychosocial side of social support had two aspects, being able to discuss the cancer with someone or not talking about it at all. In particular, the mothers and female support persons of the women with breast cancer talked of sharing their concerns with family and friends. The women in the family group demonstrated a definite tendency to share concerns with other female members although often not directly with the woman with breast cancer.

A theme in the qualitative data was called ‘Women’s Business’. This theme identified the female side of breast cancer as the women in the study shared their experience and the support for each other during treatment. [See Section 5.4.4] Women’s Business was particularly important for the feminine problems of breast cancer treatment or supporting someone with breast cancer. The participants discussed the loss of hair and choosing of wigs as something that your female support persons did with you. Going to support groups was another aspect of women’s business. During actual treatment sessions the women with breast cancer were supported by their female support person more often, which may have been their mother, sister, daughter or female friend. This concept of women closely supporting women during feminine stress has been noted in previous research, particularly maternity care (Kim, et al., 2008; Price, Noseworthy, & Thornton, 2007). This highlights the range of support persons the woman with breast cancer may have and the need for health professionals to understand and include them in information and support sessions.

The male support persons, however, explained a different aspect to psychosocial support. Quantitatively the males reported lower scores in their use of social support. The qualitative data provided details of their use of social support. [See Section 5.4.1] Their discussion was divided between seeking professional help or ‘*going into their cave*’ as one partner put it, while few spoke of discussing their concerns with family or friends. The male support

persons discussed the lack of connection with the written support material. They commented that it was not aimed at them as males supporting a younger woman and this made it hard for them to access help and understand the process and changes related to breast cancer treatment. The male communication issues have been highlighted in previous research exploring the father's role in dealing with children in the family after a diagnosis of breast cancer (Forrest, et al., 2009). The male support person within a family needed to support the woman, but also to maintain and support the children in the family. The current study only had three male interviews, although the women described their partner's support providing an understanding of the male's role during treatment for breast cancer.

The psychological aspect of social support has been well researched from the point of view of the patient identifying that good social support is directly related to improved physical wellbeing (Bloom, et al., 2001; Northouse, et al., 2007). The current study identified that social support was strongly associated with seeking professional help, thus the more the individual felt they were supported by the close family members the more likely they were to also seek professional help outside of the family. Or the reverse, if the individual did not have good family support or felt lost, they had trouble finding how to seek professional help. Both the quantitative and qualitative data supported this inference.

The other aspect of social support, reflected in the qualitative data, was physical support for helping with the changing of roles within the family. During treatment, there were fluctuations in physical functioning for the woman with breast cancer and times when she could not maintain her role as mother, wife, and organiser within the household. She had to be prepared to let go of her role while recovering from the treatment and this was not always easy. Some women talked of accepting their diagnosis and how this helped them understand how to accept help. Although not all the women were able to comfortably accept help, often making it difficult for the other family members. The woman's role within the family was often pivotal and letting go of this role was often seen as a personal failure by the woman with breast cancer and yet another loss of control in her life. This concept is supported by previous research which has explored the women's role in a family (Greenberger & O'Neil, 1993; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000). The next aspect of social support is that active process of support namely passive appraisal.

Passive appraisal

The second aspect of social support is passive appraisal. This aspect explores the active involvement of the family in the process of seeking assistance. This subscale was measured by F-COPES passive appraisal and the scores are reversed, giving an indication of active involvement of the family in providing assistance. The information fits within social support in the discussion as it is the participants' engagement in getting support. The family reported an active engagement in getting support although this was not rated as high as the social support group. The findings suggest that to see the breast cancer as manageable, helps the individual to be active within the family during the process of change. [See Section 4.4.3] Being active in the adjustment process has not been clearly defined in previous research, although some researchers have noted the process of being engaged in finding meaning within the family through changing of family patterns (Endo, Nitta, Inayoshi, Saito, Takemure, Mingeishi et al., 2000; Sears, et al., 2003).

The qualitative data indicated that the families moved through different phases as they actively engaged or did not engage in the process of adjustment. Qualitative findings from the current study highlighted the process of role adjustment and the difficulties experienced by the family during this time. Similar to the current study, Endo et al. (2000) highlighted the importance of communication as the families attempt to change patterns. An important part of Endo et al.'s (2000) research was the nurse's involvement with the family to guide them through the process of recognising change. Little research has explored the active changing of roles within the family in the response to adversity.

The roles of close and extended family members were discussed in the current study. A range of family members became active in the process of assisting the woman with breast cancer to cope with treatment. Comments related to family using the internet, asking friends, reading information to assist with decisions or the emotional support aspects of providing care packages or organised visits. [See section 5.4.1.3] The family members explained how being active in their response to breast cancer made them feel that they were helping and in turn made them feel more positive about the breast cancer. These comments related to finding meaning in their experience of breast cancer linking back to previous research which explores that concept of finding something positive in the cancer experience (Sears, et al., 2003).

6.3.2.2 Spiritual support

The second element of resources to be discussed is spiritual support. Spiritual support is the use of the spiritual resources in response to adversity. The level of spiritual support was measured by the subscale F-COPES ‘spiritual support’ and Walsh ‘spiritual support, and qualitative data. [See Section 4.4.2, 4.4.3 and 5.4.2 for details] The participants were asked to rate their use of spiritual support, in particular the questions were specific to religious support. The results suggested that the majority of participants did not see spiritual support as part of their resources, although the questions were very specific to belief in God and attending church, which does not reflect the Australian culture. The participants who reported that they used belief in God and spiritual support were more likely to also see the breast cancer as a situation that did have some positive aspects and that they did have some control over. The quantitative data used may not have given a clear indication of actual use of spiritual support. To capture the Australian culture of spiritual support a better question would be one which explored the participant’s personal spirituality in response to adversity. The question could ask what the individual used to restore or reconnect with their spiritual self. This would allow for complementary therapies to be rated by the individual, such as, meditation, nature, or time out.

The qualitative data provides a much broader picture and illustrates the diversity of support participants used for their own personal spirituality. [See Section 5.4.5] When the participants were asked what they used as personal spiritual support some spoke of a strong Christian faith and support from their church. Their faith in God helped them find meaning in the adversity of breast cancer and reassurance from their belief. Comments related to their strong Christian faith and trust in God. Other participants spoke of praying in times of need, but not of attending church for guidance. In contrast to the Christian belief other participants spoke of meditation, yoga and nature to refocus personal energy in an attempt to adjust to the adversity of breast cancer. Previous literature has focused primarily on the stress reduction and positive growth from the cancer not the broader aspect of what different members of the family have actually used to assist them (Ledesma & Kumano, 2009).

The current study found that participants reported the use of alternate complementary medicine [meditation and yoga] for stress relief, anxiety, fatigue and sleep disturbances in response to the breast cancer diagnosis. Similar findings were identified in Ledesma and Kumano’s (2009) literature review although no family members were included in these

studies. The qualitative data in the current study supports the concept of positive adjustment, with participants explaining they used their spiritual time to refocus and strengthen themselves. Not all the participants talked of positive meaning from the cancer, but they did talk of an increasing awareness of '*appreciating the day*'.

The current study identified that the use of personal prayer and meditation was a way for some of the participants to improve their sense of control on the situation. Exploring spiritual support as a complementary medicine has been noted as a means of taking control in part of your treatment, as well as providing a way to derive meaning from the cancer experience (Johnson Taylor, 2003; Reynolds, 2006). An important aspect is the health professional's attitude towards the patient's use of complementary medicine and the provision of support and direction to the patient for these strategies rather than an attitude that would alienate the patient (Johnson Taylor, 2003). In the current study, the participants did not talk about the health professional's role in their spiritual support, only their family's role as they worked together using spiritual support to reduce their distress and anxiety from the breast cancer.

The participants at the end of treatment spoke of positive growth from the cancer and of stronger relationships within the family. The current study focused on participants and family members within the first year of diagnosis and this was probably too early to reach a full understanding of any positive change in attitude or personality from the breast cancer experience. A larger study exploring growth in cancer patients and their partners 18 months after diagnosis found that there is a close relationship between the woman and her partner for positive growth over time (Zwahlen, et al., 2009). Zwahlen et al. (2009) found the higher the emotional influence of the cancer and the more change needed, the higher the posttraumatic growth experienced. The current study identified a connection between participants who had multiple treatments and greater change in their lives with an indication of higher overall scores during Phase 1. This is an important trend to understand and more research is needed to explore the trajectory of families after a diagnosis of cancer.

Walsh (2006) in her Family Resiliency Framework discusses that spiritual support can be the use of rituals and meditation to provide an opportunity to reflect on the individual's personal journey. With personal reflection, new possibilities and strength may be found. This in turn can lead to personal growth and potential for change. In the current study, participants spoke of using time out and rituals either using specific mediative type activities (yoga, meditation

tapes) or just distraction (movies, television) as a time to refocus. Some of the women talked of time out, listening to music, meditation or nature. However others reflected on their journey and how they refocused to pull through difficult times. They used time out, to give themselves space and then come back stronger ready to go on again. The diverse range of spiritual support reflects the Australian culture which does not continue to have strong Christian beliefs (Frydenberg, Lewis, Kennedy, Ardila, Frindte, & Hannoun, 2003; Zittel-Palamara, Cercone, & Rockmaker, 2009). The Australian culture has more reliant on physical and diversion activities for spiritual support Interestingly, the participants in the current study spoke of very little assistance from health professionals to provide guidance for their personal growth. The next section will discuss the use of the health professional by the participants to provide assistance with adjustment.

6.3.2.3 Health Professional support

The last element of resources explored was the use of assistance from outside the family. The participants were asked to rate their use of support groups (other people with similar problems), community programs, doctor or counsellor. Health professional support was measured by subscales F-COPES Mobilising and Walsh resources and qualitative data. [See Section 4.4.2 and 5.4.3]. The families reported that they did use health professional support although mostly during Phase 1 active treatment. There was a connection between the support provided by the family and the use of health professional support. Consistent with the current study is the concept that persons with close family support are more likely to use outside assistance as a coping strategy during the adversity of breast cancer (Bloom, et al., 2001). Bloom et al. (2001) explored the sources of social support for young women with breast cancer. Their findings indicated that the size and inclusiveness of the women's social support network directly affected her emotional well-being and in turn her ability to utilise external support to assist her adjustment. The Bloom et al. (2001) study did not specifically report the types of social support used.

The qualitative data from the current study provides the specific nature of the types of external support the family used and the reasons why. The use of health professionals during active treatment was primarily the oncologist and the oncology nurses. However several participants described that, although the oncologist provided the information it was the nurse who gave them the understanding of the information. The participants described the use of

written information to support their discussion with other family members. Several participants actually built their own information packs for family members to read. This was noted to help in reducing the amount of repeat information provided to extended family. Of note was the partners wish for information related to supporting the younger women with breast cancer. They explained that although information was available for partners, it was aimed at the older woman not including information related to their phase of life. Parents of the young women also felt they lacked information on how to support their daughter during this difficult time. These findings are consistent with previous research where both patients and partners researched have explained a need for information that addresses their level of understanding and needs (Kilpatrick, Kristjanson, Tataryn, & Fraser, 1998; Nikoletti, et al., 2003).

Previous researchers have explored the issues with patient and health professional communication stating that the attitude of the health professional sets the scene for patient discussion (Fukui, et al., 2009; Gilbar & Zusman, 2007; Harris & Templeton, 2001). The health professional needs to establish a trusting relationship and detect the distress of the patient and the level of their understanding so that they can encourage the patient to discuss their concerns (Merckaert, et al., 2008; Shepherd, et al., 2008).

Although the qualitative data did not specifically explore the health professional's approach, several participants described having a trusting relationship with their oncologist, which enabled them to be well supported during their treatments. Other participants described a feeling of not having the personal connection with their doctor and this influenced the trust and sharing of emotional distress with the doctor. Luckily for most of the patients there was also a nurse to assist them. This concept may also relate to the theme of needing a female to discuss the personal issues with when dealing with breast cancer treatment. This information clearly highlights the need for health professionals to understand and respect the patient's need for information and work with the family's needs.

Another aspect of health professional support was the oncology nurse and the breast care nurse, both of whom were held in high regard by the patients and family alike. Although not all the women had access to the breast care nurse, comments were made also about the lack of quality time with the oncology nurse during treatment. This has been a recurring theme within oncology research in Australia (Liebert & Furber, 2004). Several participants noted

the importance of the follow up phone call from the breast care nurse during their recovery from treatment. Research has shown that the use of telephone support for cancer patients is beneficial and concluded that the personal phone call provided reinforcement of information and direction for the family (Bloom, Stewart, Chang, & You, 2006; Donnelly, Kornblith, Fleishman, Zuckerman, Raptis, Hudis et al., 2000). Higher levels of support from the specialist cancer nurse are still clearly required within the Australian health care system.

Interestingly research exploring the nurse' attitudes to providing supportive care for families of children with cancer identified that they often lacked the knowledge and skills to provide this care (Turner, et al., 2007). However the nurses felt this was a core part of their role as oncology nurses (Johnson Taylor, 2003; Turner, et al., 2007). Comments from the participants in the current study support this notion of nurse as emotional carer. In particular, the chemotherapy treatment areas were noted as a time where you developed a relationship with the chemotherapy nurses. This relationship also helped the patient relax during treatment. Although research has identified this as one of the aspects, which the nurses found difficult, the provision of support yet keeping an emotional distance from patients for their own self-preservation (Turner, et al., 2007). Further research and support for the registered nurse is needed to ensure a continued understanding of this close supportive role for patients and their families.

Another finding from the current study was the minimal use of a professional counsellor to assist the women and her family during often very difficult adjustment to breast cancer. One participant commented she did not need to talk with a '*stranger*', while others commented they just used their family and friends. It was, in fact, some of the partners of the women who discussed using a counsellor, the reason being that they did not want to burden their loved one, but they needed emotional guidance. Research exploring help seeking behaviours for patients with cancer identified that patients who were females and of a higher education and higher socioeconomic status were more likely to access health professionals for assistance (Steginga, et al., 2008). A similar pattern emerged in the current study's data except the females were more likely to access the nurse rather than a professional counsellor for emotional support. For some of the women with breast cancer in the current study it was availability of time around caring for young children and treatment that they identified prevented them from accessing more health professional support.

The use of support groups was also not discussed in detail by the participants in the qualitative data, although some of the participants accessing support groups for young women found them invaluable. Some of the participants had attended support groups but found them distressing or not appropriate for them due to their age. This is a difficult area as the services provided by support groups are questionable (Butow, et al., 2007). Research exploring this concept noted there were several main reasons for continued attendance at a support group. The reasons noted were that the support group needed to be well facilitated by a person with cancer (was most appreciated) and leadership training, held in health centre or community room, monthly meeting preferred with continual meeting and no regulation of membership (new members accepted, different diagnosis stages) (Butow, et al., 2007). Regarding meeting style there was a preference for a moderately structured meeting provision of emotional support and also meetings designed for family involvement (Butow, et al., 2007). Some of these aspects were mentioned in the current study by both the women and the family members.

Also of note from the qualitative data, was the use of the help line for the family members as they felt they should not use valuable time of the nurse for their own personal problems. No current research has explored the predictors of seeking help for family members, although research exploring the patients attitudes to the help line identified minimal use of this type of service even though they understood it's availability (Steginga, et al., 2008).

6.3.2.4 Summary of resources

The current study found the resources used by the participants were mainly close family and friends. Family members were relied on for both physical and emotional support, often with specific role delegation to assist the family adjustment. In line with the Family Resiliency Framework the flexibility of the family members to change roles seemed to influence the family response to treatment for breast cancer. This finding is consistent with previous research exploring a wider range of cancer and chronic diseases (Northouse, et al., 2007).

The use of spiritual support by the participants provided both personal direction and time to refocus although it was not specifically the use of religious support. Spiritual support included a diverse range of support from religious support to meditation and nature which

provided the participant with a time of personal reflection and refocusing to assist them during treatment for breast cancer.

The current study identified a pattern of health professional support that has not been emphasized before. This included poor communication between family and the health professional and a sense of being lost in the system. This was related to their younger age at diagnosis and young family members. An important finding was the connection between commitment to family and use of resources highlighting that family members who were supported by their family were more likely to seek extra support to assist their adjustment to the breast cancer. The importance of this aspect is that often the families with minimal support are the very families who are least likely to ask for extra assistance and guidance.

Understanding the resources that families are likely to use assists the health professional in guiding the family to additional resources which may in turn improve their experience and response to breast cancer treatment.

6.3.3 Contributing family attributes

The third subordinate question addressed was ‘What are the contributing family attributes that influence strengths and resources used by the family during treatment for breast cancer?’ In the current study, the *Kruskal-Wallis Test* explored the contributing family attributes for the strengths and resources used by the participants. The demographic attributes explored were participant age, phase of life, treatment combinations, education level, occupation and geographic area. [See Section 4.5 for specific details]

Participant age

The main contributing attribute on the participant’s strengths and resources was participant’s age although there were several aspects that related to the age of the participant. The results indicated that there were two significant age groups, which influenced two of the subscales namely the sense of control and seeing the breast cancer as a challenge in the participants’ response to breast cancer treatment. [See Section 4.5.2.1 for specific details]

The age group of 41-50 scored lower than the other age groups. Further investigation revealed that the women with breast cancer reported lower scores than the support persons in

this age group. These results suggest that the women with breast cancer in this age group struggle with finding control in their lives. This is evident in the qualitative data where the women with breast cancer report 'being lost in a system' having little control and just following the doctor's direction. They also reported a sense of trying to maintain control and normality although not always achieving this balance in their lives. Interestingly, this influencing factor was strongest in Phase 1 active treatment with the complexities of the treatment schedules for these women and the loss of control they feel during this time. These findings support previous research which has identified that the younger the age of the women when diagnosed with breast cancer the more psychosocial difficulties and distress experienced (Bloom, et al., 2004; Coyne & Borbasi, 2006; Sammarco, 2001).

The participants aged between 0-30 years also reported lower scores generally than the older participants. These participants were mainly the adult children of the women with breast cancer, reflecting this age group's difficulty with appropriate social support and understanding of coping mechanisms. Previous research has also identified similar results of the younger the age the more risk of personal distress and suggest that past experience has an influence on coping ability and the use of resources to assist adjustment to cancer (Bloom, et al., 2001; Compas, et al., 1994). Research suggests that young adult children are significantly influenced by their mother's response to the breast cancer and tend to use emotion focused coping (Compas, et al., 1994; Kennedy & Lloyd-Williams, 2009). This was evident in the current study's qualitative analysis of the family dyads, responses from the parents reflected that the family was coping and maintaining family functioning and the children's responses reinforced this. The qualitative comments from some of the women with children reflected that if the mother was not confident in her adjustment and coping with the breast cancer then the whole of the family tended to struggle with the breast cancer experience. This finding also reflects the lack of life experience of this age group where they do not have the ability to work through emotional distress and seek external professional support.

The age of the participant was also an indicator of the use of resources. The lower the age the less likely they were to use external health professional support. The results suggest that the age of the participant influences how they ask for assistance and where they acquire assistance from. This finding is consistent with previous research which has identified that the younger the person with cancer, the less likely they are to access and continue to use

external social support (Dunn & Steginga, 2000; Steginga, et al., 2008). Scant research has explored the family unit's use of resources after a diagnosis of cancer.

Phase of life

Closely associated to the age of the participant was their phase of life and age of children. The results identified that families with children had lower scores than the families without children particularly in Phase 1. This suggests that having children in the family during treatment for breast cancer influences the family's ability to manage the breast cancer and maintain family functioning. There is a close relationship between the age of the participant and their phase of life as the younger the woman with breast cancer the more likely her family and support persons were also likely to be younger. Demographics from the current study identify that over half of the participants had children, and of those, fifteen percent were aged younger than ten years. These findings reflect the difficulties of dealing with children, family functioning and a diagnosis of breast cancer consistent with previous research exploring families with breast cancer diagnosis (Forrest, et al., 2009; Kennedy & Lloyd-Williams, 2009).

Generally, families are noted to struggle with the role of managing the children and coping with the distress of the cancer diagnosis and the influence of communication is a key factor on the overall family coping and adjustment (Forrest, et al., 2009; Kennedy & Lloyd-Williams, 2009). The current study's qualitative data identified the range of communication styles used by the parents when talking with the children, varying from positive sharing and clear communication to not sharing at all with the children. The age of the children and parents and cultural aspects influenced this interaction. It was closely related to how the parents themselves were coping with the diagnosis of breast cancer. Concerns such as appraisal of the breast cancer and family support influenced the ability of the parents to provide information and support the children in the family. In fact, previous research clearly identifies the importance of family communication in not only preparing the child, but also in maintaining the family cohesion over time (Davis Kirsch, Brandt, & Lewis, 2003; Edwards, et al., 2008). Inclusion of the child with family discussions such as information and treatment changes were noted to positively affect the child's reaction to the parental cancer. This is an important finding with the current study, the influence of having children in the family and the need for taking this into account when providing patient and family information and support.

Treatment

In the current study the influence of different treatment combinations on the participants' strengths and resources was difficult to clearly identify. There was however a suggestion that participants (women with breast cancer and their support persons) who had multiple treatment combinations reported higher strengths and resources. One inference from this may be the more treatment the woman has to go through the more contact she has with health professionals and thus an increase in support and direction provided. Another assumption, supported by previous research is that the event becomes a catalyst for change and positive growth with the family (Sears, et al., 2003; Walsh, 2003; Weiss, 2004; Zwahlen, et al., 2009). Thus a woman with minimal treatment required for her breast cancer needs to make few changes in her life in relation to the treatment, and the breast cancer prognosis tends to be more positive thereby being less of a catalyst for change.

Although no previous research has specifically explored different treatment combinations, links between the perception of the disease and how respondents engage with the stressor have been explored, finding the more intensive the initial engagement the more likely they are to have positive growth from the stressor (Sears, et al., 2003; Zwahlen, et al., 2009). The influence of treatment needs to be further explored to understand the influence of the treatment and types of supportive care needed.

Education and occupation

The level of education and occupation were closely linked when explored as contributing factors of the family's strengths and resources. The results indicated that participants with the higher education reported higher strengths and resources than participants with lower education in Phase 1. This was evident also in the occupation with the participants working as professionals scoring higher than lower occupation groups especially in the use of resources. These results suggest that education and occupation level of the family members influence the level of family strengths and use of resources to assist the family to cope with the adversity of breast cancer. Previous research supports this link to education and occupation in the exploration of a cancer in general (Clark, 2002; Isaksen, et al., 2003; Kim, et al., 2009; Mellon & Northouse, 2001). These results identify that participants who are able to engage with a higher level of intellect are more likely to be able to understand the disease process and direct health professional support to assist them.

The qualitative data provided further information regarding family strengths and use of resources in relation to education and occupation levels. The main aspect of having a lower education was an inability to understand the information presented and thus being able to access further help if needed. Participants with lower education explained that they did not read the information pamphlets, but would rather have the nurses explain them. They spoke of strong family commitment, but it was at times not clearly directed to positive adjustment. For example, families from a lower education level discussed watching television together to help forget about the cancer and this may not be a positive coping mechanism.

Socioeconomic status is often closely linked to financial resources, and families spoke of raising funds for their mothers' treatment and the stress of not knowing if they would be able to afford treatment and time off work. This increases the stress for the family and a tendency for avoidance of issues (Iqbal, et al., 2001). Research exploring unmet physical needs of cancer patients highlights a close link between physical needs and psychosocial adjustment over time (Kim, et al., 2009; McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2009). These results highlight the need for assessing and understanding the family's level of education and socioeconomic status so appropriate levels of information and support can be provided in a timely manner for families.

Time

The fourth subordinate question explored changes across time in the strengths and resources used by the young women and their family members' The *Wilcoxon Signed Ranks Tests* was used to determine if there were changes across Phase 1 and Phase 2, however no significant changes were found. The results indicate a slight increase in the family's strengths and family resources over time.

The current study investigated the treatment phase of breast cancer, thus the trend of increasing strengths and resources would need to be further explored with a longer time frame. The participants in the current study were probably still in the early adjustment phase and the results indicate the need for continued support for the woman and her family in the first year not just in the immediate treatment period. Research has identified that the first year after diagnosis is often the most stressful with improvement over time although often with psychological effects still noted five years later (Northouse, et al., 1998; Steginga, et al.,

1998). The current study did not seek to explore specifically the psychological aspect of their breast cancer only the strengths and resources they used over this period.

The qualitative data identified that the participants did describe changes over time. One finding was that goal setting was an important aspect of maintaining the strengths and resources of the family over time. Goals were small and specific, often about ‘getting through the treatment’. Longer term goals were difficult as there was always the ‘what if’ the breast cancer returns. The family members also talked of staggering personal visits from extended family over time to provide the best use of the family resources as treatment schedules were for a long period of time.

Consistent with previous research exploring cancer in general (Northouse, et al., 2001) the participants in the current study reported they adjusted with minimal problems when there was a range of good family strengths and resources to use. This may be related to the strong family commitment reflected in the quantitative and qualitative data over time.

6.3.3.1 Summary of contributing family attributes

Overall, the findings from the present study suggest the age of the woman and her supporting family is one of the main influencing factors in the use of strengths and resources during treatment for breast cancer. The age of the supporting family related to the age of children or phase of life for the family. The education and occupation status had some influence on the strengths and resources used, although the education and occupations were only significant during Phase 1 active treatment.

Although treatment had minimal statistical significance in the current study further research exploring the effect of different treatment would be useful in providing tailored health professional support to increase family strengths and resources. The current study found no significant difference in the strengths and use of resources from active treatment to maintenance treatment. Further longitudinal research is needed to determine if family strengths and resources change over a longer period of recovery.

These findings lead to the recognition that the family member’s age, education and occupation have an influence on the overall adaptation of the family as a group. The strengths

of the family, their sense of control and seeing the breast cancer as a positive challenge were the main aspects to be influenced during active treatment. The resources the family used external to the family unit were closely influenced by the age, education and occupation. This means health professionals need to assess the family in relation to age of family members, education and occupation. The health professional can then work with the family to increase their strengths as a family as this has a close association with the use of resources and overall adaptation. The education and occupation are likely to be closely linked to socioeconomic status so this factor should be identified and education and health professional support aimed at the appropriate level.

6.4 Family group analysis

This section discusses the family group analysis which specifically grouped family members as a case in both the quantitative and qualitative data. This section expands on the overall presentation of strengths and resources with the specific links between family members within a family. The family quantitative analysis explored the mean scores for each participant within the family group across time including demographic information of the family. Several aspects of family adjustment were revealed during the analysis although due to the small numbers of case studies (36 family groups, 100 participants) only trends are identified from this data. [See Section 4.7 and Appendix 8.7 for details]

The results suggest that if one family member had significantly low scores in either strengths or resources the other members of the family often had lower than average scores. Across the two phases if one family member had low scores in Phase 1 this was then reflected by lower scores in the family members' Phase 2. These results identify the vulnerability of families to recover and increase low strengths and resources across time. Conversely, if family members had high scores in Phase 1 then in Phase 2 the overall scores tended to be higher for all family members. This is reflected in previous research where psychosocial problems left unmet early in diagnosis are often still a problem years later (Bloom, et al., 2004; Northouse, et al., 1998). This trend identifies the need for inclusive family assessment to ascertain how the family as a group are travelling and supporting each other after a diagnosis of breast cancer. Research exploring the woman's trajectory supports this concept of the need for family support however prior research has not explored the family as a group in the context

of adjustment after a breast cancer diagnosis before (Bloom, 2008; Bloom, et al., 2004; Vivar, Whyte, & Mcqueen, 2009).

The family members reported similar scores of social support [support from family and extended family] within family groups although there was a slight reduction in these scores in Phase 2. This may reflect the difficulty of continued family support for the woman with breast cancer over a longer period of time. The family may move on from the breast cancer treatment period and not understand the need for continued support. One of the aspects of the Family Resiliency Framework is the influencing factors of individuals on the overall family adjustment. The current study reflected the dynamics of this type of continued support for the woman as she coped with treatment and changes in her body. There is a beginning body of research which has explored the partner's role in this dynamic family adjustment, and also noting the influencing factors of the individual as they attempt to maintain support over time (Forrest, et al., 2009; Northouse, et al., 2007). Additionally research identifies that continued care-giving role can often lead to stress related diseases and poor self-esteem (Sharpe, et al., 2005). The qualitative data in the current study reflected the changes within the family members as they continued to support the woman, including stress, avoidance and changes in goal setting.

The qualitative data indicated that fluctuating levels of family support were needed as the women travelled through different treatment schedules. The support from extended family reduced over time as the acute nature of the breast cancer changed to a longer term supportive role. These role changes were often seen as difficult and stressful for the whole family. Friends were noted to reduce contact and they often were unable to provide this continued supportive role. Research notes the importance of family support, but also the stressful nature of supporting someone with cancer (Maly, et al., 2005; Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008). Previous research used psychosocial interventions to decrease psychological distress for the person with cancer and improve coping mechanisms for the family dyad (Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Northouse, et al., 2005). These researchers involved partners and were not family inclusive, however their results did identify an increase in communication between spouses, although this was not always maintained over time.

One of the important innovations with the current study was the inclusion of a range of family members as denoted by the family themselves. Thus participants included partners, parents, children, extended family and friends who were closely supporting them. This allowed for a realistic view of the family from several different angles and provided not just a linear view of the family, but a dimensional view of the family. An example of this was in the interviews of several different family members within a family which gave a range of views on the same topic. One of these themes which became visible from the family group analysis was the cultural aspect of breast cancer.

The qualitative analysis revealed a cultural aspect of breast cancer. Caring for a woman with breast cancer was 'women's business'. This came across strongly in both the male and female participants' interviews. The women in the family were definitely the key supporters for the woman with breast cancer even if she had a male partner. This was in the form of both emotional and physical support. Interestingly similar themes have been identified in research exploring the older woman with breast cancer where she is closely supported by her daughter (Kim, et al., 2008). Research exploring the supportive roles during child birth identified the unique nature of women supporting women and the cultural aspect of this type of support (Price, et al., 2007). This theme reinforces the nature of women to more openly communicate their needs with other women although at times the women in the current study discussed how they kept their personal feelings private to reduce the stress of the other person. This is an important finding as it highlights the need for the health professional to be aware of the cultural aspect of breast cancer. Health professionals should include female support persons in information sessions, particularly sisters and mothers of the women with breast cancer. They should be aware of the cultural differences that may be perceived by the woman with breast cancer when dealing with male and female health professionals. The women may not share intimate concerns with a male health professional, as was highlighted by one of the women with breast cancer when she spoke about being upset by her male nurse assisting her to shower.

Another qualitative theme identified with the family group analysis was the unspoken words of breast cancer. Whether this was the actual word 'breast cancer' or just the discussion around having cancer and the connections this suggested such as recurrence and dying. The current study found some of the participants during the interviews did not use the word breast cancer. This theme was reflected by different family members. In some cases the lack of

engagement with the breast cancer was mentioned by other family members often causing distress for different family members. When the quantitative scores were checked for these participants and families, a correlation between low scores and low qualitative perception was evident. This is an interesting finding as it identifies these families as at risk. However they are also very unlikely to seek external help as they are not acknowledging the breast cancer influencing their lives. Missing data has been discussed before by qualitative researchers, who have highlighted topics that have been intentionally or unintentionally avoided by the participant (Ryan & Bernard, 2003).

This concept has not been identified before in breast cancer research. However there has been discussion regarding the benefits of engaging with the stressor [breast cancer] to find personal growth in previous research (Sears, et al., 2003). Sears et al. (2003) found that the more intrusive the engagement with the stress the more likely the participants were likely to have posttraumatic growth. This identifies that families able to engage in the breast cancer response actively are more likely to be able to see positive benefits from the breast cancer in the longer term. The families in the current study who did not openly engage in the breast cancer were noted to score lower quantitatively and show lower adjustment qualitatively, which demonstrated this concept in reverse. In a similar pattern this was reflected in the quantitative scores related to contributing factor of treatment where participants with high levels of treatment had a trend of higher over scores for strengths and resources.

In summary, the family dynamics influence the family as they move through the treatment for breast cancer. The individual strengths and resources of family members influenced the overall family response supporting the concepts of the *Resiliency Model of Family Stress, Adjustment and Adaptation* by McCubbin et al. (1998). The cultural aspect of ‘women’s business’ came across strongly in the analysis of the family groups clearly identifying the need for understanding of the women in the family group and the special support they may need. The concept of unspoken words or not sharing the diagnosis was also identified in the family analysis. This supports the importance of communication as a key aspect of adjustment for the family. The family may only function at the level of the least functioning individual. Therefore it is important to assess and support the family to provide an environment for family and individual growth.

6.4.1 Family framework for adjustment

The present study is unique by the inclusion of multiple family members to provide information about the strengths and resources of the women and family members during treatment for breast cancer. The findings indicate that specific strengths and resources are used by the family in response to the diagnosis and treatment for breast cancer. The current study extends the *Resiliency Model of Family Stress, Adjustment and Adaptation* by McCubbin et al. (1998) with the identification of three key variables which influence the trajectory of the family. The appraisal of the breast cancer, family functioning and the family communication styles were identified to influence the family adjustment.

Both the quantitative and qualitative analysis emphasized that the family strengths; appraisal of the breast cancer, family functioning and communication within the family influenced the overall family response. The participants in the current study spoke of their response to breast cancer treatment as a '*learning to live with the breast cancer*' which could be either, positive or negative. The quantitative analysis revealed that the variables of communication, challenge and family flexibility strongly correlated with overall the strengths and resources. [See quantitative analysis Section 4.4.3 for details of correlations] Previous research supports these concepts as being key influencing factors of the adjustment to adversity. However, no research has presented the variables of communication, appraisal and family functioning as collective concepts to understand family adjustment to adversity (Bloom, et al., 2004; Forrest, et al., 2009; Northouse, et al., 2007).

Communication between family members influenced how individuals within the family understood the needs of family members. Families which were able to share both positive and negative feelings were more likely to identify family needs and be able to respond appropriately in support of the women with breast cancer. The communication within the family was influenced by how the individual responded to the breast cancer. Individuals who were able to see the breast cancer as a manageable situation with some positive outcomes were more likely to share these feelings with the family. Conversely family members who did not share feelings were unable to get help during their time of need and at times the rest of the family felt guilty for not being able to help.

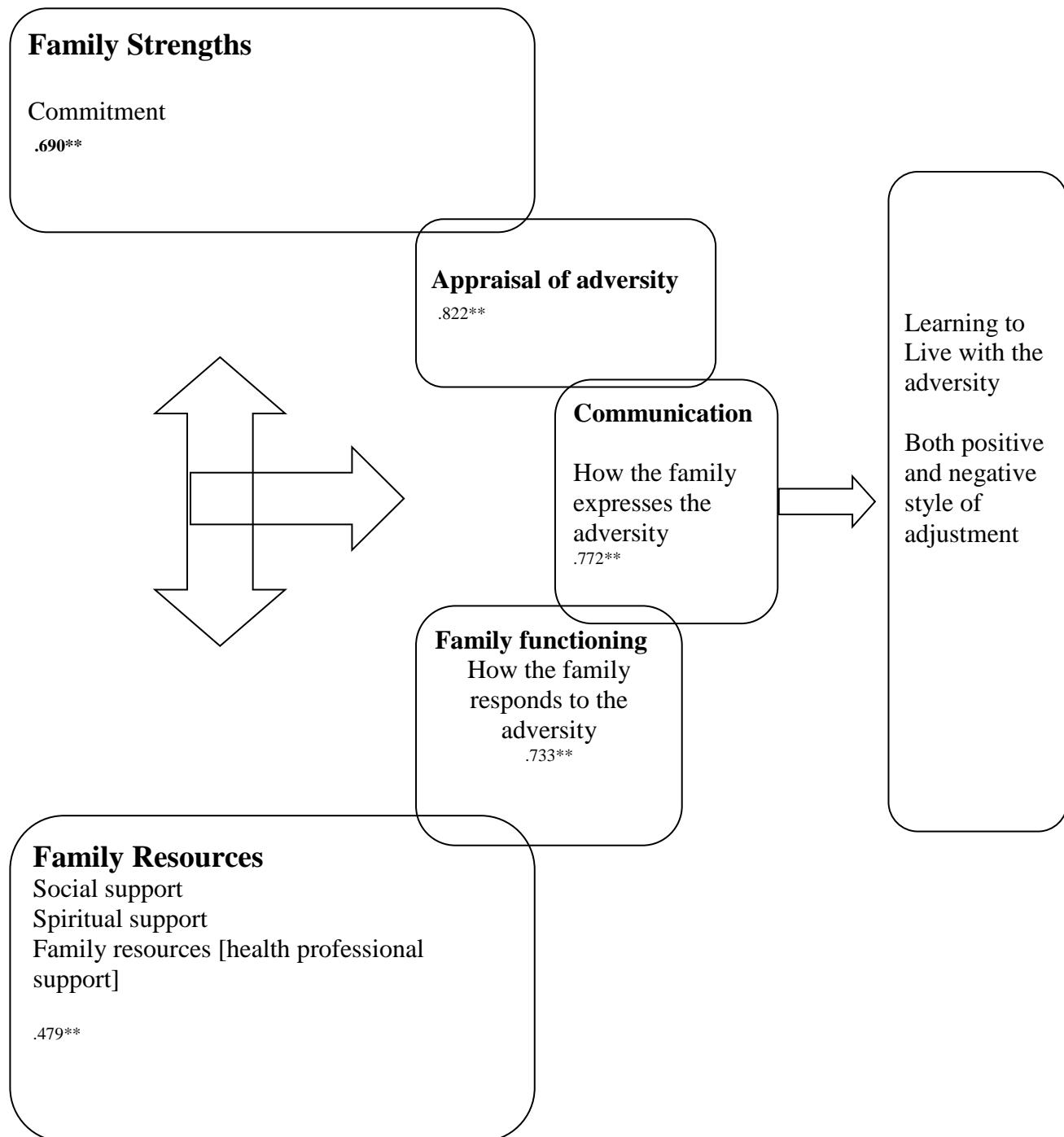
It is this feeling of being overwhelmed which reduces the family members' ability to share and seek help. Importantly, families who were able to see the breast cancer as a manageable

situation were more likely to be flexible and able to change roles within the family to the benefit of the overall family functioning. The communication within the family enabled family members to understand the needs of the different family members and also engage outside assistance if needed.

The *Resiliency Model of Family Stress, Adjustment and Adaptation* by McCubbin et al. (1998) identifies that the family uses a range of resources to assist their adjustment. The current analysis revealed that social support was the main type of support young families used, with strong connections between social support and overall strengths of the family as opposed to spiritual support and health professional support. The main association between getting support for the family was the communication within the family. The communication within the family influenced how the family appraised the situation, shared distress, and how the family functioned and changed roles in response to the adversity. This response influenced the resources the family used, a combination of social support, spiritual support and health professional support.

These three variables, appraisal, family functioning and communication, provide a point for family assessment to begin. Including these aspects in family assessment provide an understanding of how the family response to adversity. These key points of the family response also provide the health professional with areas to focus on when assisting the family when faced with a health adversity. The Coyne Family Response Framework is a significant contribution to information and understanding of the family response and adjustment to breast cancer. [See Figure 5 for Coyne Family Response Framework] The following chapter will present the contributions of framework to knowledge, theory and clinical implications.

Figure 5 Coyne Family Response Framework
Coyne Family Response Framework for adversity



6.5 Methodological issues

While the current study has contributed to the understanding of family response to breast cancer treatment, there were some limitations.

Similar to previous research exploring vulnerable populations the current study had problems with both recruitment of women with breast cancer and their family members and retention of the participants over time (Northouse et al., 2006). Problems of recruiting the women with breast cancer related to the complexity of the treatment schedules and the physical effects of the treatment. The oncology nurses were the gate keepers of the women with breast cancer, only allowing women well enough physically to be approached for the study. This could have potential for biases as women with severe physical and emotional problems were excluded from the study as set by ethical standards. This is similar to other research exploring women with breast cancer (Nikoletti, et al., 2003; Schmitt, et al., 2008). However biases were minimised by a multi-site recruitment and a range of participants were recruited with differing levels of physical and emotional health.

There was a 40% response rate for Phase 2 from Phase 1 participants, which identifies concerns of retention of participants between Phase 1 and Phase 2. The main reason for non-participation in the Phase 2 of the study was deterioration in physical and psychological condition of the women with breast cancer. In fact one woman with breast cancer died between Phase 1 and Phase 2. This is similar to previous research as noted in Literature review section 2.4.3. To maintain retention in longitudinal studies other researchers have used various techniques such as follow up phone calls, payment, cups, fridge magnets and other household items to remind the participants of the continuation of the study (Edwards, et al., 2008; Northouse, et al., 2006; Sears, et al., 2003). However the number of participants in Phase 2 was still adequate to perform a non-parametric analysis and obtain reliable data. A comparison analysis was completed on Phase 1 and Phase 2 participants to ensure characteristics were similar between the participants completing Phase 1 only and those completing Phase 1 and Phase 2. This is presented in Analysis of quantitative data section 4.2. The limitation in relation to recruitment and retention of vulnerable groups was acknowledged in Method section 3.9.

The second limitation was the lack of specific data on the treatment schedules and timing of treatment for the women with breast cancer. The absence of this data reduced the ability of the current study to have specific information and connection between treatment schedules. The data collected has allowed for general trends related to treatment schedules to be presented. This has provided an understanding of the influence of different treatment schedules on the response from the women and their family members during treatment for breast cancer.

A third limitation is the possibility that the use of an American questionnaire may not have captured the participants' response to spiritual resources. The questions asked participants to rate the use of spiritual support used specifically as church activities and faith in God. In the Australian society this was not culturally appropriate as Australian's view of Christianity is a broader context of spiritual time and prayer not attendance to church (AIHW, 2010; Grafton, Gillespie, & Henderson, 2010). This was discussed in section 4.4. Future research is needed to examine the Australian culture of use of spiritual resources in response to adversity.

The generation of data from several family members is an unique way of generating a combined family opinion (Mellon, et al., 2007). This technique has been used previously by several international researchers, Northouse, Mellon, Edwards and Clarke. However most have only used a dyad approach although the responses have still been summed to provide a family response. Future research would be to explore more of the family interaction with the use of other methods of data collection and analysis (Knafl, et al., 2009).

6.6 Conclusion of Discussion

Overall the current study has a significant number of new findings related to younger women with breast cancer and their family members' strengths and resources. This exploratory descriptive study found that there was no statistical difference in the strengths and resources reported by the women with breast cancer and their family members. This is a significant finding as no previous research has explored the family as a group and their response to a diagnosis of breast cancer in younger women. Research exploring the partner's response identified a similar result with partner's acknowledging that the women's breast cancer diagnosis influenced their lives (Bultz, et al., 2000; Northouse, et al., 2001). The current study found that the women with breast cancer and their family members reported a

reasonable level of family strengths and use of resources during the active treatment phase whilst actively seeing the oncologist every three months. This level of strengths and resources did not increase significantly over time, during maintenance treatment. This finding is consistent with previous research exploring just women with breast cancer where they report levels of distress remain consistent for at least the first year after a diagnosis (Bloom, et al., 2004).

McCubbin et al. (1998) hypothesized 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. Further interventional research would be useful in identifying if the family can be guided to improve their strengths as a family unit and thus assist adaptation in the longer term.

The main strength of the family in the current study was commitment to the family unit, communication styles and positive appraisal of the breast cancer. These strengths were influenced by the participants' age, education and occupation. The main resources were close family members and friends. There was a strong connection between asking for more assistance and strong family support. The more flexible the family roles, the more the family reported they felt in control of the situation and able to see the breast cancer as a positive. This is similar to previous research exploring cancer in general (Northouse, 2005; Northouse, et al., 2001).

The current study extended our understanding of the family experience of breast cancer. The family described their journey with breast cancer as one which was not linear but with numerous ups and downs and at times backward. A '*travelator pulling them in different directions*' was part of the challenge of breast cancer treatment. The quantitative data provides a snap shot of the two different phases. The qualitative data offers insight into the whole journey as the families travelled from diagnosis through treatment. These findings extend our understanding of the younger women and their family's response to breast cancer in the first year after diagnosis. The current study provides specific information on the family strengths and resources used during active treatment and then maintenance treatment. The concluding chapter will discuss recommendations from the current study.

7 Chapter 7 Conclusion and implications

7.1 Introduction

The outcomes of the current study are presented in this chapter. The outcomes include contribution to knowledge, theory and practice. The outcomes are presented with links to previous research. The supporting evidence from the current study is referenced from the body of the thesis to allow the reader easy access to the detailed discussion of the literature, method, analysis and discussion.

7.2 Research problem and questions

The purpose of the current study was to determine the strengths and resources young women and their family members use during treatment for breast cancer.

For clarity the overarching research question is restated; ‘What are the strengths and resources that young women and their family members use during treatment for breast cancer?’ The research question resulted in the development of four subordinate research questions;

- What are the strengths the young women and their family members use during treatment for breast cancer?
- What are the resources the young women and their family members use during treatment for breast cancer?
- What are the contributing family attributes that influence strengths and resources utilised by the women and their family members during treatment for breast cancer?
- Is there a change in the strengths and resources used by the young women and their family members’ during active and maintenance treatment?

7.3 Outcomes of the study and contribution to knowledge, theory and practice

There are several outcomes from the current study that form the basis for informing knowledge and implications for extension of theory and clinical practice.

7.3.1 Contributions to knowledge

The current study has several contributions to the understanding of the family response to breast cancer, particularly young women and their family. The first contribution to knowledge relates to the demographic information collected. The women with breast cancer under the age of fifty years were predominantly in a phase of life with children. The mean and mode age of the current participants was 45 years. Over half of the women had children, with 15% of those families having children below the age of ten years. [See Section 4.2] This is a significant finding as the information from the current study relates to a particular group of women and their families, where little research has previously focused.

An innovation of the current study was the range of family members included as participants which provided an extension of the current knowledge. The analysis revealed minimal difference in participants' response, between the women with breast cancer and their families' members. This indicates that family members go through a similar response to the diagnosis and treatment to breast cancer as the women themselves, supporting the need for family inclusion in all aspects of the care of the women to ensure she is fully supported by her family if possible.

The second contribution to knowledge from this research is identification of key family strengths. The first family strength was that the family members demonstrated a strong desire to support each other during treatment for breast cancer. In most cases family members worked together with an aim to reduce distress for the woman with breast cancer and maintain family functioning. Conversely, families who were struggling found it hard to support the woman with breast cancer. The family support was closely linked to how the family appraised the breast cancer or changes from the breast cancer. Families who appraised the breast cancer in a positive way, recognizing that they could work together to overcome the adversity established strong links between family members. These families also identified the use of external support for example health professionals. Conversely if families were not

able to see any positive from the breast cancer and felt overwhelmed, they demonstrated poor communication and links between family members. Often not disclosing personal feelings and minimal family direction for support was discussed between family members. These families were also less likely to use external health professional support. [See Section 4.4, 4.5, 5.2, 6.3]

Communication between family members was a key family strength and influencing factor in the family response to breast cancer. Communication styles between family members varied, and this was related to the individual's appraisal of the breast cancer and how they were responding to the adversity. Communication styles ranged from open and flexible to a closed style of communication where family members did not share their feelings about the breast cancer. The recognition of communication styles in the assessment of the family provides health professionals with a way to guide and support families during this response. [See Sections 2.3.1.4, 4.4, 5.3, 6.3]

The third contribution to knowledge was the understanding of the families' use of resources. The support from close family members was the most important part of the family support network. The use of health professionals was only used by some families in their response to breast cancer treatment. Families described a range of spiritual support, including meditation and alternative therapies. This is a significant contribution of original knowledge extending previous research exploring the woman's use of resources.

The fourth contribution to knowledge addressed factors influencing the strengths and resources utilised by the women and their family members during treatment for breast cancer. Age, education and occupation influenced the family response. [See Section 4.5] The younger the age of the family members the fewer available strengths and resources they had to draw on. The younger the family members the more the family appraised the breast cancer in a negative way with a higher degree of loss of control. This confirms previous research exploring the younger women's experience of breast cancer (Bloom, et al., 2004; Sammarco, 2001).

Education and occupation influenced the families' use of resources. Families with a higher education level reported a higher use of external resources particularly health professionals.

They were also more likely to demonstrate a higher level of family functioning, including seeing the breast cancer as manageable and feeling more in control of the situation. This related to their ability to understand information and navigate through the health system. These findings extend prior research exploring only the women's response providing details on the families' responses (Iqbal, et al., 2001; Isaksen, et al., 2003).

7.3.2 Contributions to theory

The contribution of the current study to theory is the development of the Coyne Family Response Framework. This framework extends the *Resiliency Model of Family Stress, Adjustment and Adaptation* (McCubbin & McCubbin, 1993) with the addition of specific family aspects, which influence the family response to adversity. The Coyne Family Response Framework proposes that the strength, family communication influences two other family strengths. These are appraisal of the adversity and family functioning. These three strengths influence the overall adjustment of the family as the family responds to adversity. In particular these three strengths influence how the family asks for assistance and how they work together as a family in response to adversity.

The first contribution to theory was the finding that in response to treatment for breast cancer one of the main family strengths was the commitment to working together as a family to assist the woman with breast cancer. Similar information has emerged in previous dyad research. However, the current study identified this strong commitment to working together as a family from multiple family members, including children through to parents of the woman with breast cancer. The significance of this finding is the option to include 'family' broadly defined by the woman with breast cancer in assessment, as reciprocally-defined family member(s) are clearly the main support for young women with breast cancer.

The second contribution to theory is that overall family strengths and resources were influenced by the communication within the family, family appraisal of the breast cancer and family functioning, and this finding led to the development of the Coyne Family Response Framework. The influencing factor of communication and appraisal has been suggested in previous research (Edwards, et al., 2008; Mellon & Northouse, 2001). The current study extends this knowledge with the inclusion of the family members' experience and communication styles. The increased understanding of the family functioning and role

changes during treatment for breast cancer has contributed to the understanding of this concept within the *Resiliency Model of Family Stress, Adjustment and Adaptation* (McCubbin & McCubbin, 1993).

The current study supports the McCubbin et al. (1998) hypothesis that in response to adversity the family will draw on their strengths to assist them maintain family functioning. These findings expand on previous research by the use of a range of family members to provide complex information about the family unit's strengths and resources when faced with the adversity of breast cancer. Further interventional research would be useful in identifying if the family can be guided to improve their strengths as a family unit and thus assist adaptation in the longer term.

The fourth contribution to theory from the current study is that the family aims to reach a new normal, but that this trajectory is not linear but erratic or circular as the family journey through the treatment for breast cancer. Differing from the trajectory suggested from the *Resiliency Model of Family Stress, Adjustment and Adaptation* (McCubbin & McCubbin, 1993) the current study identified that family does not travel easily from adjustment to adaptation. The family may move between these two levels depending on treatment schedules and influencing family factors such as age of family members and education levels of the family. The influence of the breast cancer trajectory on the family suggests that at times families or individual enter crisis points. Some families adjust and grow in response to the crisis, where other families find the crisis point adds to the already unmanageable situation and the family becomes insular as a response, just to survive.

7.3.3 Recommendations and implications for practice

The main recommendation for future practice is the use of a family assessment framework to inform holistic family practice. Family assessment provides the health professional with important insights related to individual family members within a family environment. Increasing the health professionals' ability to support the woman with breast cancer and reduce the family members' distress is paramount to improved family adjustment. The current study identified three key aspects of understanding of family strengths particularly (1) communication styles, (2) family appraisal of the breast cancer and (3) family functioning. All provide the health professional with guidance for providing family assistance.

The Coyne Family Response Framework recognises these three specific areas which influence the family response to adversity; communication, appraisal of adversity and family functioning. The communication of the family is a key area that has been identified to impact on the adjustment of the family. Communication within the family ensures family members can share feelings and distress, as well as ask for and provide support and direction of family members. Previous research has identified the importance of communication, although not with the inclusion of a range of family members providing an understanding of family behaviour from within the family (Huizinga, et al., 2005).

The family appraisal of the adversity was linked to communication within the family. This means that a family who is able to see the breast cancer as manageable is more likely to share their feelings about the breast cancer. In turn, they are able to get appropriate support from both within the family and external health professional support.

Family functioning or the ability to respond to the adversity and change roles is the third aspect of the family response framework. Family functioning is influenced by the communication within the family and in turn the family functioning will influence the family use of resources. These resources may be family members, external family members, spiritual support or health professional support. When completing family assessment it is important to understand the influence of these three key aspects of the family response.

The current study was guided by the *Resiliency Model of Family Stress, Adjustment and Adaptation* however this framework does not provide a clear clinical assessment tool for family assessment. The Calgary Model of Family Assessment provides an easy to use family

assessment tool (Wright & Leahey, 2005). The Calgary Model informed by the *Resiliency Model of Family Stress, Adjustment and Adaptation*, recognises the importance of family change, communication and family functioning. This model has been used successfully in clinical practice in Canada, Japan and Iceland (Duhamel, Dupuis, Reidy, & Nadon, 2007; Endo, et al., 2000; Svavarsdottir, et al., 2005). The assessment tool takes fifteen minutes to assess a family and provides guidance for health professionals. The assessment tool examines the family roles, development stage and family functioning.

The inclusion of family members in the health care discussions, providing care and direction for the family will improve the support for the woman and the overall family trajectory. The family needs clear information that they can understand. So when the family are caring for and supporting the woman at home they understand the treatment and expected changes. The importance of listening to the family members as they supported the women and recognising their personal distress and need for guidance by the health professional were also highlighted from the current study. The family members will also need psychosocial follow up similar to the woman with breast cancer to ensure their continued adjustment to breast cancer after the woman has finished active treatment.

Another contribution to clinical practice is the finding that women supported women and there was a strong association with sharing of distress and provision of mutual support between the women. This has been documented in maternity care although this is the first time it has been clearly identified in oncology research. The health professional needs to understand the cultural aspect of breast cancer with regard to women's business. The choice of female nurses and support by female oncology staff were noted as important in the current study.

7.3.4 Further research

The implications for practice and theory point to areas in need of further research. One area is the need for research to develop and measure a family assessment intervention for young women and their family after a diagnosis of breast cancer. This would provide information in relation to the young woman with breast cancer and their family in response to specific support aimed at their phase of life.

Further research is needed to extend the spiritual support used by Australian families as the current study questionnaire did not adequately address this area. The qualitative analysis identified that the Australian families used a range of spiritual support. The development of an Australian questionnaire exploring spirituality would provide information regarding the families' use of this resource.

Further research recruiting families from rural areas is recommended to understand the response of these rural families in Australia. The current study recruited a small number of rural families. However this did not provide a clear understanding of this sample of families.

7.4 Final conclusions

The current study aimed to explore what strengths and resources are used by young women and their families in response to breast cancer treatment. In answer to this question several strengths were identified. The families in the current study displayed a strong sense of supporting each other during treatment for breast cancer. The communication between family members was one of the main influencing factors as to how the family members supported each other. The family appraisal of the breast cancer and how the family was able to work together influenced how the family sought help if required.

To answer the second part of the research question the resources used by the family, the current study found that the participants were supported by their close family. The use of specific family members for different roles assisted the women with breast cancer. Health professionals formed part of the family resources, particularly in the active treatment phase however health professionals were not used by all family members. Spiritual support was used to have time away from breast cancer and refocus. Religious beliefs, meditation and distraction by craft or music provided a time where the participants had control and could prepare for the next challenge of breast cancer treatment.

The age of the family members influenced their response to treatment for breast cancer. Particularly the younger women with their families had the most trouble adjusting and seeing the breast cancer as a manageable situation. The education level and occupation of participants influenced their ability to understand and feel some control of the situation. The

use of the oncology nurse to provide assistance and direction was important for some of the families to overcome the lack of understanding of the health system.

The current study has emphasised the need for family assessment to understand the family strengths and resources. By understanding the strengths and resources of the family, health professionals are better able to guide families through the treatment for breast cancer.

In conclusion, this study has highlighted the family response to breast cancer for the younger woman and allowed an insight into the difficulties and joys of supporting a young woman with breast cancer. It has provided the families involved in the study with a way to improve the future for other young women who are diagnosed with breast cancer.

8 Appendix

8.1 Appendix 1 Main questionnaire



**Information Sheet / Consent form for questionnaires
What are the strengths and resources the young woman and her family
members use during therapy for breast cancer?**

Researcher: Elisabeth Coyne RN, RM, BN, MN (Hons with Dist) PhD (Candidate)

School of Nursing and Midwifery, Logan

Telephone: 07 33821503

Email: e.coyne@griffith.edu.au

Background

The family is acknowledged to form the main source of support for woman after a diagnosis of breast cancer, yet little is known about the family's experience of this support. This study aims to explore the strengths and resources the young woman and her family use during therapy for breast cancer. Your family's experience of breast cancer is extremely important and to explore the strengths and resources you and your family used during your breast cancer trajectory will provide information on how as a family you adjusted for future families. If you are in the age group of 25 to 50 years old with a diagnosis of breast cancer and undergoing curative treatment for your breast cancer (chemotherapy, surgery, radiotherapy). I would like to invite you to participate in this study, to discuss your experience of breast cancer and how your family adjusted during your breast cancer journey.

What participation in this study involves

Participation in this aspect of the study will involve completion of questionnaires (approximately 20 minutes) on two separate occasions. The first occasion will occur when you are receiving curative treatment for your breast cancer. The treatment may be any treatment from surgery, chemotherapy or radiotherapy. The second occasion will occur when you have finished the curative treatment and may be receiving maintenance treatment.

Consent to participate

Your participation is voluntary and you are not under any obligation to consent to participate in this research. You are, of course, entirely free to discontinue your participation at any time without penalty, or to decline to answer particular questions. Should you feel distressed please contact the free emergency counselling offered by the Cancer Council of Queensland.

Risk

Participation in this research poses no risks as the research asks only to identify the strengths and resources you and your family used during your therapy for breast cancer.

Confidentiality

All information discussed will be treated in the strictest confidence, and the questionnaires will be de-identified. All questionnaires will be stored in a locked filing cabinet in Elisabeth Coyne's office at Griffith University for five years. They will then be destroyed as confidential waste. Only members of the research team will have access to the questionnaires. A report of the general findings from the study will be made available to participants.

Complaints mechanism

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Research Involving Human. If you have any concerns or complaints about the ethical conduct of the research project you should contact the Manager, research Ethics on 38755585 or research-ethics@griffith.edu.au

If there are any concerns that you may wish to discuss with me prior to agreeing to enter the study, I would be pleased to talk with you. It is entirely your choice to participate and you are free to withdraw at any time and I will respect your decision. Your questions and comments are welcome. Ph 33821503 e.coyne@griffith.edu.au PhD Supervisor Associate Professor Judy Wollin Griffith University email j.wollin@griffith.edu.au Please accept in advance my thanks for your assistance.

**Consent Form****What are the strengths and resources the young woman and her family use during therapy for breast cancer?**

I have read the information form and understand that:

- This research is to investigate the young woman and her family's strengths and resources during breast cancer therapy.
- I am being asked to complete a questionnaire on two different occasions.
- You have been given a copy of the Participant Information to keep
- The researchers have agreed not to reveal your identity and personal details if information about this project is published or presented in any public form
- You have had any questions concerning the research answered to your satisfaction
- You understand that if you have any additional questions you can contact the research team
- You understand that you are free to withdraw from the study at any time, without comment or penalty; and
- You understand that you can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 07 3875 5585 (or research-ethics@griffith.edu.au) if you have any concerns about the ethical conduct of this research.

Your consent is implied by the completion and return of the questionnaires.

The purpose of this questionnaire is to explore the strengths and resources, the young family use during the therapy for breast cancer. If at any time during the completion of the questionnaire you feel distress please feel free to discontinue.

PLEASE TICK THE BOX

Personal details

- Patient Family member / support person

Patient breast cancer details

- Surgery
 Chemotherapy
 Radiotherapy

Gender

- Male
 Female

Age in years.....

Family status relationship to patient

- Partner (married) no children
 Partner (married) with children below 10 years
 Partner (married) with children above 10 years
 Single supported by family and close friends

Length of relationship in years

Ethnic origin

- Caucasian / European
- Australian Aboriginal
- Torres Strait Islander
- Asian
- Other

Highest level of education

- Post graduate
- Degree
- Diploma / certificate
- Secondary school

Occupation

- 0 Management / administration
- 1 Professional / Associate professional
- 2 Trade person
- 3 Clerical, sales and service
- 4 Production and transport
- 5 Labourers
- 6 Home duties
- 7 Self-employed
- 8 Unemployed
- 9 Student

Postcode

FHI**Family Hardiness Index**

The purpose of this questionnaire is to measure how you feel that your family works through a stressful situation. Please read through each statement and tick the box, which indicates how much the statement applied to you over the last month.

There are no right or wrong answers. Do not spend too much time on any one statement. PLEASE TICK THE BOX

In our family...

	Questions	False (0)	Mostly false (1)	Mostly true (2)	True (3)
1	Trouble results from mistakes we make				
2	It is not wise to plan ahead and hope because things do not turn out anyway				
3	Our work and efforts are not appreciated no matter how hard we try and work				
4	In the long run, the bad things that happen to us are balanced by the good things that happen to us				
5	We have a sense of being strong even when we face big problems				
6	Many times I feel I can trust that even in difficult times things will work out				
7	While we don't always agree, we can count on each other to stand by us in times of need				
8	We do not feel we can survive if another problems hits us				
9	We believe that things will work out for the better if we work together as a family				
10	Life seems dull and meaningless				
11	We strive together and help each other no matter what				
12	When our family plans activities we try new and exciting things				
13	We listen to each other's problems, hurts and fears				
14	We tend to do the same things over and over...it's boring				
15	We seem to encourage each other to try new things and experiences				
16	It is better to stay at home than go out and do things with others				
17	Being active and learning new things are encouraged				
18	We work together to solve problems				
19	Most of the unhappy things that happen are due to bad luck				
20	We realize our lives are controlled by accidents and luck.				

Permission granted McCubbin, McCubbin, & Thompson, (1991).

F COPES

The purpose of this questionnaire is to measure how you feel that your family works through a stressful situation. Please read through each statement and tick the box, which indicates how much the statement applied to you over the last month.

There are no right or wrong answers. Do not spend too much time on any one statement. PLEASE TICK THE BOX

When we face problems or difficulties in our family, **we respond by:**

	Questions	Strongly disagree (0)	Moderately disagree (1)	Neither agree nor disagree (2)	Moderately agree (3)	Strongly agree (4)
1	Sharing our difficulties with relatives					
2	Seeking encouragement and support from relatives					
3	Knowing we have the power to solve major problems					
4	Seeking information and advice from persons in other families who have faced the same or similar problems					
5	Seeking advice from relatives (grandparents, etc)					
6	Seeking assistance from community agencies and programs designed to help families in our situation					
7	Knowing that we have the strength within our family to solve our problems					
8	Receiving gifts and favours from neighbours (e.g. Food taking mail etc.)					
9	Seeking information and advice from the family doctor					
10	Asking neighbours for favours and assistance					
11	Facing the problems "head-on" and trying to get solution right away					
12	Watching television					
13	Showing that we are strong					
14	Attending church services					
15	Accepting stressful events as a fact of life					
16	Sharing concerns with close friends					
17	Knowing luck plays a big part in how well we are able to solve family problems					
18	Exercising with friends to stay fit and reduce tension					
19	Accepting that difficulties occur unexpectedly					
20	Doing things with relatives (get-togethers, dinner, etc)					
21	Seeking professional counselling and help for family difficulties					
22	Believing we can handle our own problems					
23	Participating in church activities					
24	Defining the family problem in a more positive way so that we do not become too discouraged					
25	Asking relatives how they feel about problems we face					
26	Feeling that no matter what we do to prepare, we will have difficulties handling problems					
27	Seeking advice from a minister					
28	Believing if we wait long enough, the problem will go away					
29	Sharing problems with neighbours					
30	Having faith in God					

Permission granted McCubbin, Olson, & Larsen (1991)

Walsh Family Resilience Framework

The purpose of this questionnaire is to measure how you feel that your family works through a stressful situation. Please read through each statement and tick the box, which indicates how much the statement applied to you over the last month.

There are no right or wrong answers. Do not spend too much time on any one statement. PLEASE TICK THE BOX

	Questions	False (0)	Mostly false (1)	Most ly true (2)	True (3)
1	We can work through our difficulties as a family, rather than separately				
2	When there is a crisis, we try to make sense of the situation				
3	We see problems as a challenge we can manage				
4	We define problems positively to solve them;				
5	We trust things will work out even in difficult times				
6	We encourage one another and support confidence in overcoming difficulties				
7	When facing difficulties we build on our potential				
8	In dealing with problems we are active and persistent				
9	We seize opportunities to change what is possible and we try to accept what can not be changed				
10	When there are problems, we draw on spiritual resources, e.g. faith, prayer, meditation, rituals, religious community				
11	We believe we can learn from difficulties, and can even grow and become better persons				
12	We have faith in a supreme being				
13	We learn from each other's mistakes				
14	We are flexible in dealing with the unexpected				
15	We are open to new ways of dealing with our problems				
16	In times of disruption we are able to provide stability and dependability				
17	In troubled times there is strong leadership to make sure family members are not emotionally or physically hurt				
18	We can trust that family members are committed to support each other through difficulties				
19	We feel good giving time and energy to our family				
20	We have dreams that we want to achieve, and are inspired by others who have succeeded, who are models that we can follow				
21	We can depend upon people in this community				
22	We ask relatives, friend and neighbours for help and assistance				

	Questions	False (0)	Mostly false (1)	Mostly true (2)	True (3)
23	We are able to access community resources, e.g. healthcare, social services				
24	We can ask for clarification if we do not understand each other				
25	We can be honest and direct with each other in our family				
26	We understand communication from other family members				
27	We feel free to express our opinions				
28	We can share many different feelings (e.g. joy, sorrow, anger, fear);				
29	We show love and affection for family members				
30	In stressful times, sharing humour and pleasure help us to cope				
31	We all have input into major family decisions				
32	We discuss things until we reach a resolution				
33	We focus on our goals and take steps to reach them				

Permission granted Walsh 2007

Is there something else which helped your family through this adverse event that has not been described?

Thank you for your time to complete this questionnaire.

Personal interview

If you would like to participate in a personal interview to discuss these issues further please complete the following and the researcher will contact you for an interview at a time convenient for you.

Name

Contact number.....

Convenient time to call.....

Please fold separately to return to researcher.

8.2 Appendix 2 Personal interview consent form



**Information Sheet / Consent form for personal interviews
What are the strengths and resources the young woman and her family
members use during therapy for breast cancer?**

Researcher: Elisabeth Coyne RN, RM, BN, MN (Hons with Dist) PhD (Candidate)

School of Nursing and Midwifery, Logan

Telephone: 07 33821503

Email: e.coyne@griffith.edu.au

Background

The family is acknowledged to form the main source of support for woman after a diagnosis of breast cancer, yet little is known about the family's experience of this support. This study aims to explore the strengths and resources the young woman and her family use during therapy for breast cancer. Your family's experience of breast cancer is extremely important and to explore the strengths and resources you and your family used during your breast cancer trajectory will provide information on how as a family you adjusted for future families. If you are in the age group of 25 to 50 years old with a diagnosis of breast cancer and undergoing curative treatment for your breast cancer (chemotherapy, surgery, radiotherapy). I would like to invite you to participate in this study, to discuss your experience of breast cancer and how your family adjusted during your breast cancer journey.

What participation in this study involves

Participation in this aspect of the study will involve completion of questionnaires (approximately 20 minutes) on two separate occasions. The first occasion will occur when you are receiving curative treatment for your breast cancer. The treatment may be any treatment from surgery, chemotherapy or radiotherapy. The second occasion will occur when you have finished the curative treatment and may be receiving maintenance treatment.

Consent to participate

Your participation is voluntary and you are not under any obligation to consent to participate in this research. You are, of course, entirely free to discontinue your participation at any time without penalty, or to decline to answer particular questions. Should you feel distressed please contact the free emergency counselling offered by the Cancer Council of Queensland.

Risk

Participation in this research poses no risks as the research asks only to identify the strengths and resources you and your family used during your therapy for breast cancer.

Confidentiality

All information discussed will be treated in the strictest confidence, and the questionnaires will be de-identified. All questionnaires will be stored in a locked filing cabinet in Elisabeth Coyne's office at Griffith University for five years. They will then be destroyed as confidential waste. Only members of the research team will have access to the questionnaires. A report of the general findings from the study will be made available to participants.

Complaints mechanism

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If there are any concerns that you may wish to discuss with me prior to agreeing to enter the study, I would be pleased to talk with you. It is entirely your choice to participate and you are free to withdraw at any time and I will respect your decision. Your questions and comments are welcome. Ph 33821503 e.coyne@griffith.edu.au
PhD Supervisor Associate Professor Judy Wollin Griffith University email j.wollin@griffith.edu.au
Please accept in advance my thanks for your assistance.

**Consent Form****What are the strengths and resources the young woman and her family use during therapy for breast cancer?**

I have read the information form and understand that:

- This research is to investigate the young woman and her family's strengths and resources during breast cancer therapy.
- I am being asked to complete a questionnaire on two different occasions.
- You have been given a copy of the Participant Information to keep
- The researchers have agreed not to reveal your identity and personal details if information about this project is published or presented in any public form
- You have had any questions concerning the research answered to your satisfaction
- You understand that if you have any additional questions you can contact the research team
- You understand that you are free to withdraw from the study at any time, without comment or penalty; and
- You understand that you can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 07 3875 5585 (or research-ethics@griffith.edu.au) if you have any concerns about the ethical conduct of this research.

Signed Date

Researcher Date

8.3 Appendix 3 Walsh Structured Interview Guide

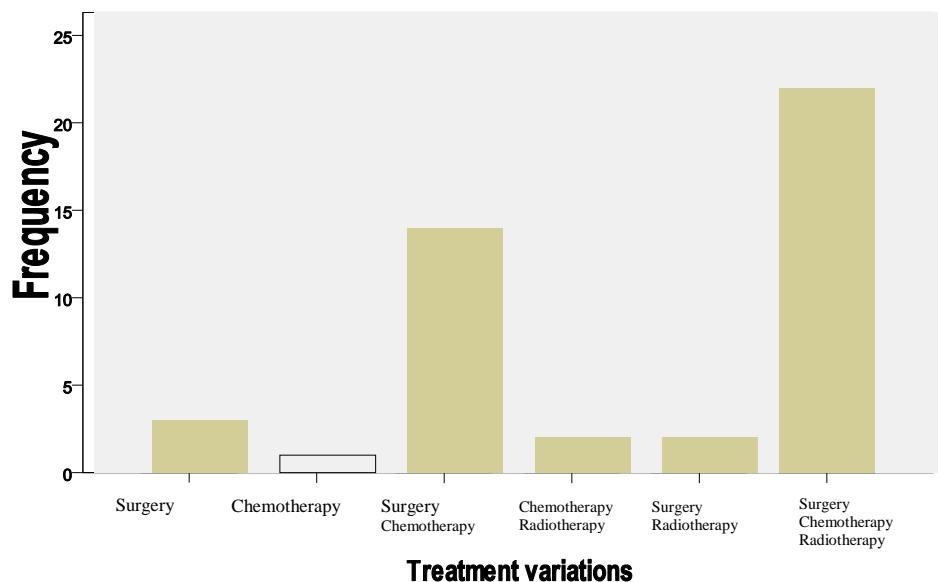
Walsh Family Resilience Framework: Semi-Structured Interview Key	
Family Belief Systems	1 - Make meaning of Crisis, Adversity: How does your family share difficulty, do they see problems as a challenge?
	2 - Positive Outlook: Hope, Confidence, Encouragement, Affirm strengths, & potential; How does your family work through problems?
	3 - Transcendence, Spirituality: Faith, Support, Inspiration Learning, growth, transformation out of adversity. How does your family use spirituality during problems?
Structural / Organizational Processes	4 - Flexibility to adapt; Stability through disruption; Strong leadership: Nurture, guide, & protect. How does your family deal with the unexpected and problems?
	5 - Connectedness—Lifelines for mutual support, models, & mentors. How does your family work together during troubled times?
	6 - Kin, Social, and Economic Resources. Who does your family ask for help from?
Communication / Problem- Solving Processes	7 - Clear information, consistent messages. How does your family maintain open communication with each other?
	8 - Open Emotional Expression; joy and sorrow; humour in midst of suffering. How does your family share emotional expression?
	9 - Collaborative Problem-solving; become more resourceful, proactive. When working through problems how does your family problem solve?

8.4 Appendix 4 Treatment variations

Presentation of Treatment Variations Phase 1 and Phase 2

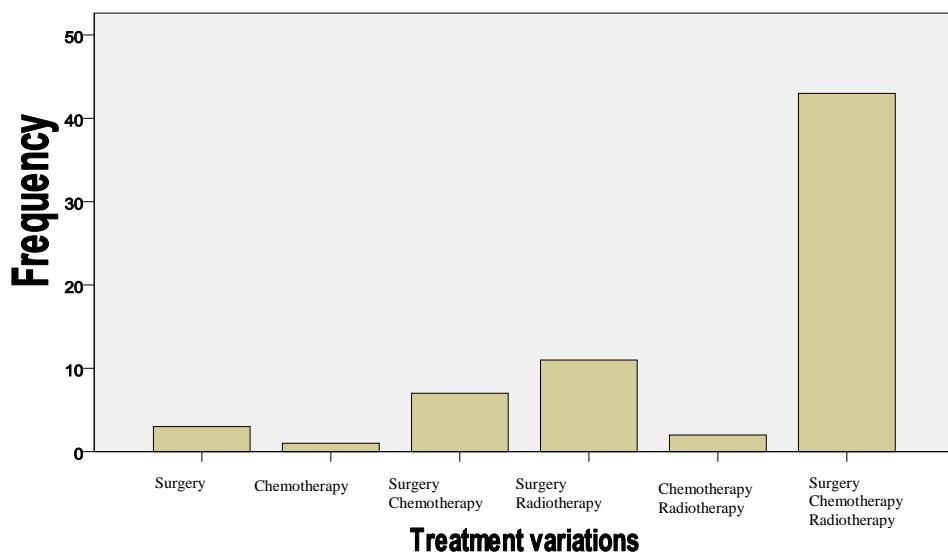
Phase 1 Treatment variations

Phase 1



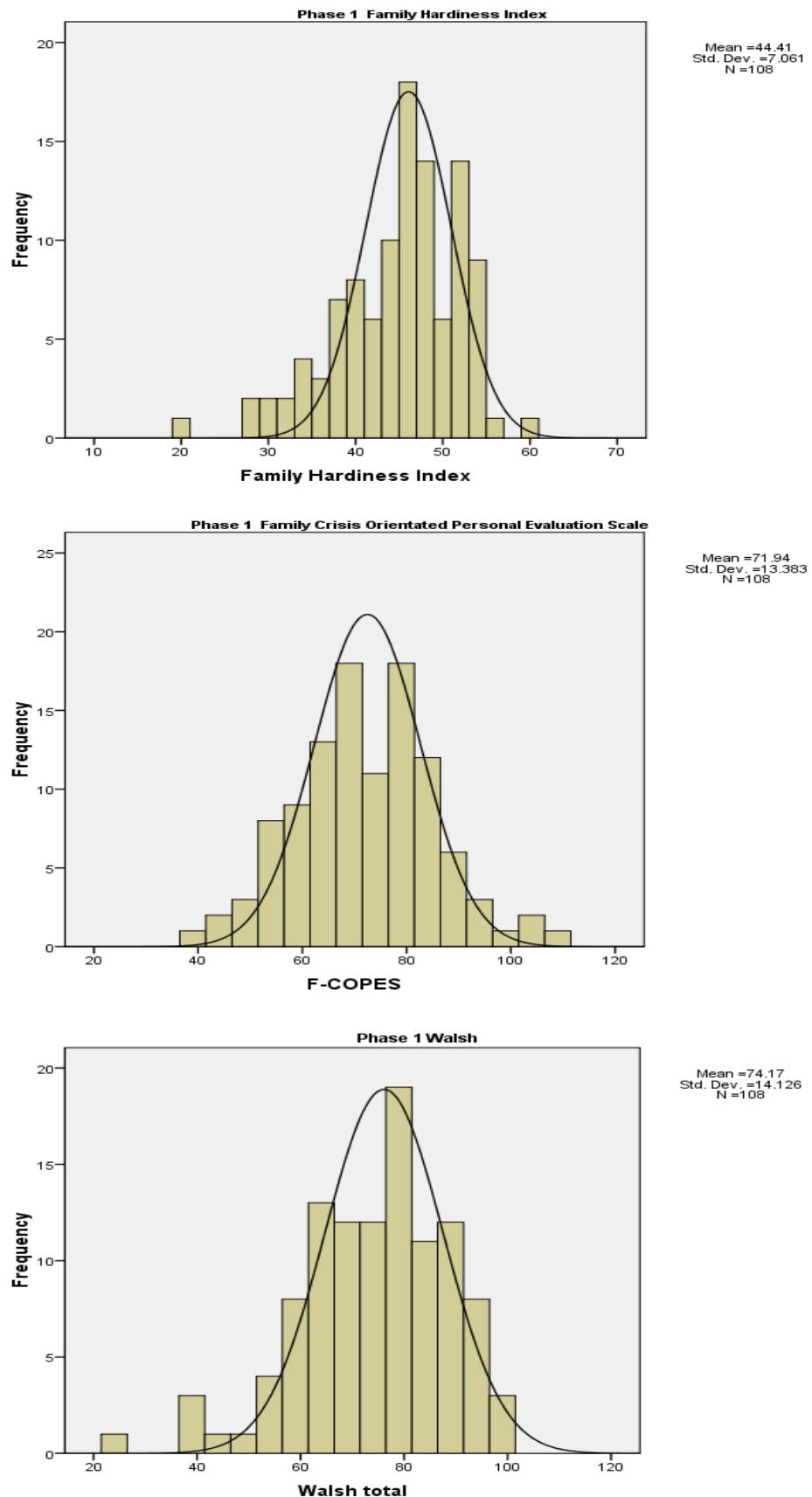
Phase 2 Treatment variations

Phase 2

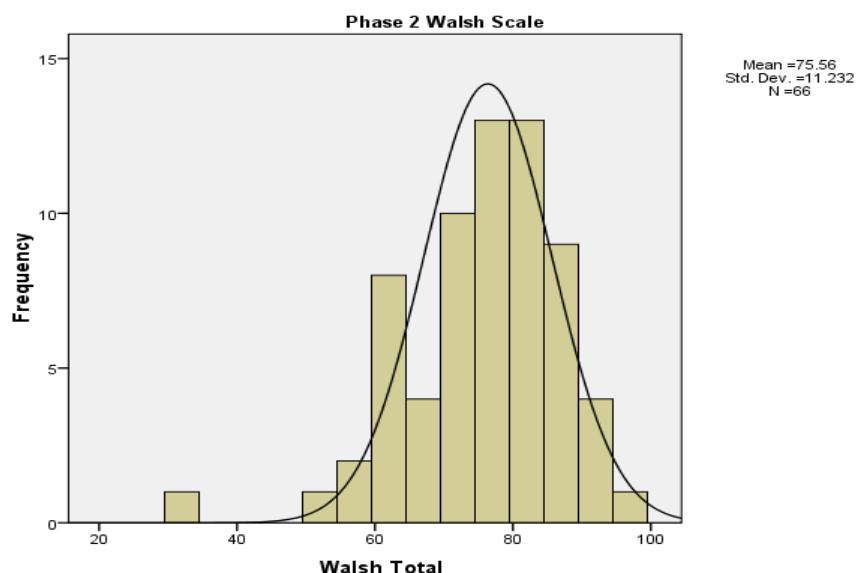
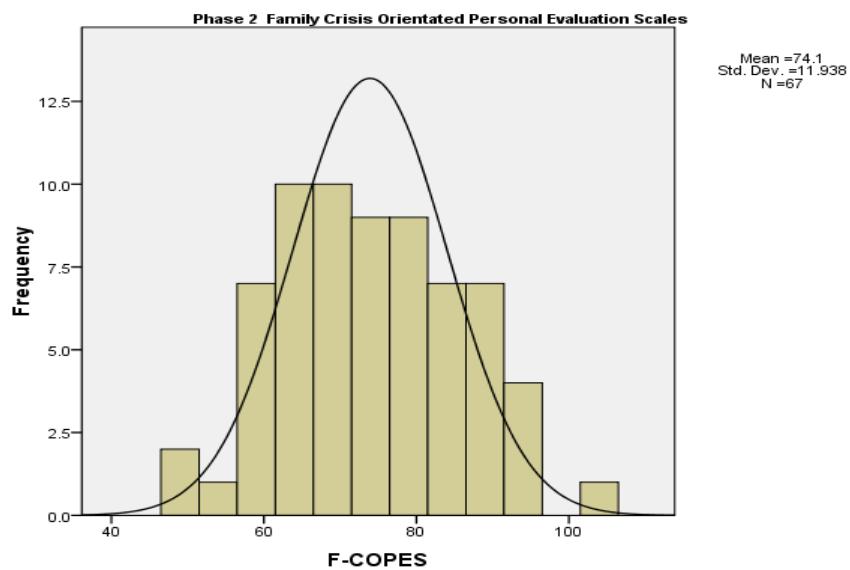
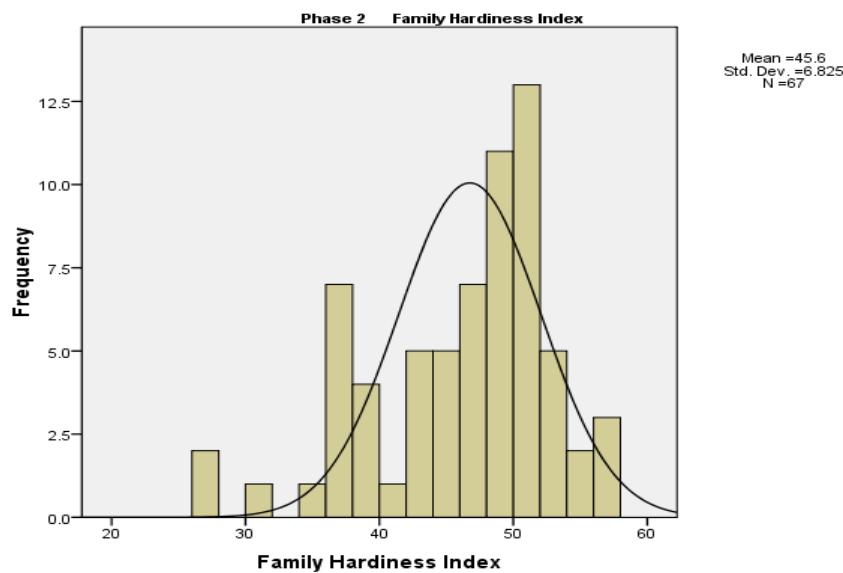


8.5 Appendix 5 Presentation of Normality Phase 1, Phase 2

Presentation of Normality Phase 1



Presentation of Normality Phase 2



8.6 Appendix 6 Factor analysis of Walsh scale

Exploratory Factor Analysis Walsh

	Components				
	1	2	3	4	5
Communication					
Q29 show love and affection	.790				
Q26 understand communication	.767				
Q27 feel free to express options	.754				
Q28 share different feelings	.740				
Q25 honest and direct with each other	.736				
Q18 trust family members to support	.725				
Q31 input into family decisions	.673	.352			
Q32 discuss things	.658	.401			
Q6 encourage and support each other	.634	.342			
Q19 feel good giving time	.594		.333		
Q30 share humour	.592				
Q17 strong leadership	.564	.329		.336	
Q33 focus on goals	.534	.314		.409	
Q16 provide stability and dependability	.477	.472			.302
Challenge					
Q3 problems as challenge	.321	.782			
Q4 define problems positively		.695			
Q5 trust things will work out		.632			
Q2 make sense of crisis	.491	.559			
Q1 work difficulties as family	.537	.540			
Q9 opportunities to change	.471	.521	.371		
Q11 learn from difficulties		.514	.482		
Q8 active with problems	.361	.420		.364	
Resources					
Q23 access community resources			.731		
Q22 ask relatives and friends for help			.672		
Q21 depend upon community			.622		
Q24 ask for clarification	.311	.462	.606		
Family flexibility					
Q20 dreams to achieve				.402	.699
Q14 flexible in dealing with unexpected	.457	.349			.585
Q13 learn from mistakes		.363	.355		.510
Q15 open to new ways	.428	.333			.483
Q 17 facing difficulties build on potential	.387	.395	.337		.430
Spiritual support					
Q12 faith in supreme being					.946
Q10 spiritual resources					.900

Extraction Method: Principal Component Analysis

Rotation Method: Varimax with Kaiser Normalization Rotation converged in 5 iterations

8.7 Appendix 7 Family group analysis

Presentation of Means, treatment groups and age groups

**Participant number

1	1 or 2	1 to 4	
Family number	Women with breast cancer Family member	1 2	Family member number

*Treatment code 1 = combination of surgery, chemotherapy and radiotherapy

*Treatment code 2 = completed surgery, chemotherapy and radiotherapy

FHI maximum scores 60

F-COPES maximum scores 118

Walsh maximum scores 99

		Phase 1			Phase 2				
Family group	Participant Number**	FHI	F-COPES	Walsh	FHI	F-COPES	Walsh	Treatment*	Age groups
2	21	48	62	75	42	62	62	31-40	
	221	45	61	69	.	.	.	31-40	
Mean		47	62	72	42	62	62	1	
3	31	44	76	81	50	75	84	41-50	
	321	39	62	52	44	52	67	0-30	
	322	43	47	62	30	51	32	41-50	
Mean		42	62	65	41	59	61	2	
4	41	53	75	88	.	.	.	31-40	
	421	45	71	90	.	.	.	0-30	
	422	51	82	92	.	.	.	0-30	
	423	56	80	88	45	73	88	61-90	
Mean		51	77	90	45	73	88	2	
5	51	44	81	69	50	88	85	41-50	
	521	46	86	78	50	91	83	0-30	
	522	38	83	61	.	.	.	51-60	
Mean		43	83	69	50	90	84	2	
6	61	48	65	77	55	73	82	41-50	
	621	44	68	76	48	64	74	41-50	
	622	49	67	71	37	49	53	0-30	
Mean		47	67	75	47	62	70	2	
7	71	43	58	81	47	59	82	31-40	
	721	46	50	65	.	.	.	31-40	
	722	45	68	59	.	.	.	61-90	
Mean		45	59	68	47	59	82	1	
8	81	41	80	82	56	93	85	41-50	
	821	51	72	92	50	78	94	0-30	

	822	51	77	74	50	82	76	0-30
Mean		48	76	83	52	84	85	1
9	91	47	48	78	51	62	.	31-40
	921	42	.	.	46	57	81	31-40
	922	46	66	89	.	.	.	41-50
Mean		45	57	84	49	60	81	2
10	101	48	79	93	48	75	78	41-50
	1021	47	83	95	48	77	91	51-60
Mean		48	81	94	48	76	85	2
11	111	31-40
	1121	45	82	80	52	86	76	61-90
	1122	54	71	74	.	.	.	31-40
Mean		50	77	77	52	86	76	1
12	121	45	88	86	.	.	.	41-50
	1221	40	69	61	48	87	74	41-50
	1222	45	77	81	.	.	.	0-30
Mean	854.67	43	78	76	48	87	74	2
15	151	34	54	41	.	.	.	41-50
	1521	50	76	68	44	68	75	41-50
Mean		42	65	55	44	68	75	2
16	161	27	55	38	.	.	.	41-50
	1621	35	39	66	.	.	.	0-30
	1622	39	57	65	.	.	.	41-50
Mean		34	50	56				2
19	191	47	111	92	57	106	96	41-50
	1921	50	77	87	57	94	88	41-50
	1922	54	93	84	51	84	88	61-90
Mean		50	94	88	55	95	91	2
21	211	38	63	77	44	66	75	41-50
	2121	52	77	73	47	68	58	51-60
Mean		45	70	75	46	67	67	2
21	221	52	104	99	.	.	.	31-40
	2221	46	102	98	.	.	.	51-60
Mean		49	103	99				1
24	241	52	80	86	45	82	84	41-50
	2424	46	70	81	.	.	.	31-40
	2422	43	70	63	52	73	75	31-40
	2421	54	87	88	54	80	89	31-40
	2423	53	86	80	.	.	.	61-90
Mean		50	79	80	50	78	83	2
28	281	45	64	70	46	61	71	41-50
	2821	51	85	91	.	.	.	61-90

	2822	53	87	85	49	79	82	41-50
Mean		50	79	82	48	70	77	2
30	301	43	81	65	42	91	85	41-50
	3021	42	66	57	40	91	91	41-50
Mean		43	74	61	41	91	88	2 3.00
31	31311	48	63	92	.	.	.	41-50
	3121	46	67	87	.	.	.	0-30
Mean		47	65	90				2
33	331	39	55	45	.	.	.	41-50
	3321	34	44	52	.	.	.	41-50
	3322	53	79	97	.	.	.	31-40
Mean		42	59	65				1
	371	37	61	62	36	66	57	41-50
	3721	37	61	65	.	.	.	41-50
Mean		37	61	64	36	66	57	1
38	381	38	52	62	.	.	.	41-50
	3821	38	46	59	.	.	.	41-50
Mean		38	49	61				1
39	391	.	53	55	48	68	69	41-50
	3921	47	76	74	46	68	64	41-50
	3922	51	74	75	47	81	81	61-90
Mean		49	68	68	47	72	71	2
41	411	42	70	88	.	.	.	41-50
	4121	39	61	81	.	.	.	51-60
Mean		41	66	85				2
43	431	46	89	77	48	92	81	31-40
	4321	46	87	78	48	89	79	41-50
	4322	53	95	88	53	93	84	61-90
Mean		48	90	81	50	91	81	1
44	441	45	67	78	50	59	70	41-50
	4421	54	74	80	51	61	75	61-90
	4422	47	63	77	48	79	72	41-50
Mean		49	68	78	50	66	72	1
49	491	39	85	71	37	78	69	41-50
	4921	41	72	64	46	78	77	41-50
	4922	40	67	60	36	65	62	0-30
	4923	46	77	74	39	84	86	61-90
Mean		42	75	67	40	76	74	2
54	541	42	86	68	.	.	.	41-50
	5421	44	67	65	.	.	.	41-50
	5422	45	68	67	.	.	.	61-90
Mean		44	74	67				1

55	551	47	71	86	.	.	.	0-30
	5521	50	82	75	50	82	80	61-90
	5522	51	70	86	48	81	80	51-60
	5523	52	73	85	.	.	.	61-90
Mean		50	74	83	49	82	80	2
62	621	36	65	62	50	61	63	41-50
	6221	50	89	77	27	70	60	51-60
	6222	28	70	69	27	70	60	61-90
Mean		38	75	69	35	67	61	1
63	631	30	57	50	38	71	72	41-50
	6321	34	66	61	34	73	60	41-50
	6322	39	78	83	37	65	71	61-90
	6323	47	92	83	37	65	70	61-90
Mean		38	73	69	37	69	68	2
65	651	44	73	69	43	75	80	41-50
	6521	47	79	79	51	90	92	51-60
Mean		46	76	74	47	83	86	2
66	661	51	75	76	49	75	77	41-50
	6621	52	58	73	51	64	77	41-50
Mean		52	67	75	50	70	77	1
68	681	31	77	70	.	.	.	41-50
	6821	33	56	39	.	.	.	0-30
Mean		32	67	55				1 2.00
70	701	47	77	83	42	67	76	41-50
	7021	47	53	74	53	60	73	41-50
Mean		47	65	79	48	64	75	1

8.8 Appendix 8 Breast Cancer research leaflet.



Princess Alexandra Hospital
Health Service District

Inviting: Young women (under 50) with breast cancer

Researchers in the School of Nursing and Midwifery at Griffith University are calling for volunteers to participate in a study exploring the strengths and resources young women and their family members use during breast cancer therapy.

One in four of the women diagnosed with breast cancer are under the age of fifty years. This diagnosis will subsequently influence the women's family and support people, yet little is known about how they cope with this experience.

The aim of this research is to explore your experience thus providing increased information for health professionals caring for future families with breast cancer.

To participate in the study, you will be required to complete a questionnaire about the strengths (communication, leadership, coping styles) and resources (family, extended family neighbours and health professional) you have been using during the breast cancer treatment period. The questionnaire takes approximately 20 minutes to complete.

You may be a suitable participant if you:

- have been diagnosed with breast cancer
- are under 50 years of age
- are in the treatment phase (surgery, chemotherapy, radiotherapy)
- have family members willing to participate

For further information, please contact:

Ms Elisabeth Coyne (RN RM BN MN)
PhD student
Telephone: 07 3382 1503 0403021699
Email: e.coyne@griffith.edu.au

This study has been reviewed and approved by the Princess Alexandra Hospital and Health Service District Human Research Ethics Committee and the Griffith University Human Research Ethics Committee.

8.9 Appendix 9 Thankyou card.



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