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Psychological Functioning of Adolescent Girls at Risk for Breast Cancer: The Role of Disease, Individual, and Family Variables

by

Yolanda G. Korneluk

School of Psychology

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ABSTRACT

In the face of maternal illness, adolescent daughters are thought to be at risk for emotional problems (e.g., Compas et al., 1994; Compas et al., 1996). This may be due to a number of variables, including those related to the functional impact of the disease, perceptions of increased personal risk, or other individual and family influences. To date, however, adolescent daughters of ill mothers remain an understudied population and variables for predicting or explaining adjustment problems in this group have not been thoroughly investigated. The purpose of this study was to examine the disease, family, and individual psychological variables that are related to adolescent girls' adjustment following maternal breast cancer. It was expected that maternal distress and family functioning would moderate the relationship between disease variables and adolescent psychological functioning. The current study included 60 mother-daughter pairs in which the mother was at least 1 year post-treatment for non-metastatic breast cancer. The mean age of mothers in the current sample was 45.4 years, and the average age of daughters was 15.5. Predictor variables examined were: (1) maternal health-related quality of life (HQL, measured with the Short Form - 36; Ware et al., 1993), and adolescent perceptions of (2) disease severity, (3) personal risk for cancer, and (4) breast cancer worries (Severity Perceptions, Risk Perceptions and Worries subscales on the Breast Cancer Survey [BCS], Cappelli et al., 1999). Proposed moderators examined were: (1) family functioning (Family Assessment Measure -III; Skinner et al., 1983), and (2) maternal psychological distress (Symptoms Checklist 90- Revised; Derogatis, 1983). Adolescent psychological adjustment was the outcome variable, and was measured in two ways: (1) adolescent reports on the Youth Self Report (YSR; Achenbach, 1991), and (2) maternal reports

on the Child Behavior Checklist (CBCL; Achenbach, 1991). Some support was provided for the hypothesis that adolescent role functioning moderates the relationship between certain disease-related factors and adolescent psychological adjustment. Specifically, poorer maternal HQL in the presence of greater problems with adolescent functioning within the family was associated with adolescent reports of poorer social competence. When adolescents reported high family functioning, however, no such relationship was observed, suggesting that good family functioning can help to buffer the negative effects maternal illness on adolescent social functioning. Additional analyses suggested that maternal distress levels mediate the significant association between maternal reports of adolescent problems and maternal HQL. In contrast, the relationship between maternal HQL and adolescent self-reports of psychological problems was mediated by family functioning. Results are considered in light of existing research in this area and clinical implications are discussed.

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Psychological Functioning of Adolescent Girls at Risk for Breast Cancer: The Role of Disease, Individual and Family Variables

Each year in Canada, almost 18, 000 new cases of breast cancer are diagnosed and 5,400 women die from this disease. Approximately 5-10% of breast cancer cases have a hereditary component (Hoskins et al., 1995). These familial cases are more likely to occur in women under the age of 50 and are more likely to affect those with adolescent children. Thus, in addition to the significant stress typically experienced by seriously ill patients and their families, adolescent daughters of breast cancer patients must also cope with knowledge of their increased genetic vulnerability to breast cancer. Until recently, research examining the impact of breast cancer has been limited to the study of the patient. As is becoming increasingly clear, however, breast cancer is an illness that affects the entire family system.

The purpose of this study was to examine the disease, individual, and family factors associated with adolescent girls' adjustment to maternal breast cancer. The focus is upon families at risk for a heritable form of the disease. First, a summary of the research on child and adolescent adjustment to parental cancer is presented. The available data suggest several pathways by which adolescent girls may experience increased problems when their mothers are ill. Second, literature from other areas of research is considered in a discussion of the potential contribution to adolescent adjustment of genetic and other disease factors such as personal risk perceptions and health-related quality of life. Following this, methodological issues pertinent to this research area are discussed. Four primary hypotheses are presented.

Review of the Literature:

Impact of Parental Cancer on Adolescent Psychological Functioning

Although speculation about the relationship between parental illness and child and adolescent adjustment is long-standing (e.g., Arnaud, 1957; Power, 1977), empirical investigation into the effects of parental illness has a relatively brief history. Like the research examining psychological correlates of childhood illness (Kazak, 1997), investigation in this area was initially driven by clinical observation and was based on the assumption that parental illness is a qualitatively unique stressor that can compromise normal child development. Earlier efforts in this area compared children of ill parents to normative samples or comparison/control groups (e.g., Armsden & Lewis, 1994; Howes, Hoke, Winterbottom & Delafield, 1994). Using this approach, however, researchers found no obvious deficits in child functioning when parents have cancer, although there is some evidence that a significant subset of children may experience problems when their parents are ill. Following a trajectory similar to that of the childhood illness research, investigators in this area are now beginning to more closely examine the individual, disease and family-level variables associated with adjustment to parental illness.

In this section, research examining child and adolescent adjustment to parental cancer is presented. Studies in the current review were identified through PsycInfo and Medline searches for the years 1985-2000 and were included if they met the following criteria: (a) focused on adjustment of non bereaved children and/or adolescents coping with parental cancer, and (b) included quantitative data (e.g., data from standardized questionnaires, structured interviews, etc.). Using this approach, a total of 11 studies

were identified. For parsimonious presentation, methodological details of these studies are provided in Table 1.

The review begins with a summary of findings from studies comparing children of cancer patients to normative/control groups. This research has been helpful in establishing the importance of individual variables, especially age and gender, in predicting the problems when parents are ill. Taken together, the available data suggest that adolescent daughters of ill mothers are more likely to experience problems than are other children. Questions raised by this line of inquiry are highlighted in subsequent sections that focus on the potential role of maternal distress, family functioning, and disease perceptions in predicting adolescent adjustment to maternal breast cancer.

Overall, studies that have compared children and adolescents of cancer patients to normative and control samples have found no obvious differences in psychological functioning between these groups. For example, Compas and associates (Compas et al., 1994; Compas, Worsham, Ey & Howell, 1996) found that, as a group, symptoms of anxiety and depression were not reported more frequently by children and adolescents an average of 2½ months following a diagnosis of parental cancer. They did, however, observe a greater proportion of children of ill parents who experienced problems in the clinical range of their standardized measures, compared to normative groups. This is consistent with data provided by Howes and associates (1994), who found that a small subset of children of breast cancer patients were evaluated by their mothers as experiencing adjustment difficulties, although overall means were in the normal range.

Closer examination provides information on the variables associated with

adjustment in these samples. Some of the variables that appear to be most important are: the use of self versus observer reports, individual disease appraisals, and the gender and age of the child. For example, a study by Welch, Wadsworth and Compas (1996) found that, although parents did not report elevated levels of child problems, child and adolescent self-reports indicated that a number of participants were experiencing significant emotional strain. Armsden and Lewis (1994) also found that parent and nurse-observer reports did not indicate child problems in a sample of school-aged children coping with maternal breast cancer, whereas child reports did so. Thus the use of self-appraisals in this area of research appears to be essential, and may be especially important when adolescents are studied (Cantwell, Lewinsohn, Rohde, & Seely, 1997).

Available data also suggest that disease appraisals are important in predicting adjustment to illness. Although a number of researchers have predicted that disease severity and prognosis will be associated with child outcome in families with ill parents (e.g., Compas et al., 1994; Armsden & Lewis, 1994), to date, no study has confirmed this relationship. Compas and associates (Compas et al., 1994; Compas et al., 1996) found that neither stage nor prognosis of the parent's cancer was directly related to children's symptoms of anxiety and depression. Only children's *perceptions* of the severity of their experience (as measured with structured interview questions such as "How serious do you think the cancer is at this time", with responses on a 4-point scale) were associated with these problems. Similarly, spouses' and patients' reports of their level of distress were related only to their appraisals of the severity of the illness and not to objective characteristics of the illness.

Disease appraisal may be expected to change with cognitive maturation. Qualitative interview data provided by Christ, Siegal, and Sperber (1994) suggested that, when parent death from cancer is imminent, an adolescent's greater understanding of the situation can result in more adjustment problems than would be observed in younger children. Consistent with this, Compas et al. (1994; Compas et al., 1996) found that the diagnosis of parental cancer was associated with increased problems in adolescent daughters, but not adolescent boys and children of other ages. Compared to these other groups, adolescent girls reported the most symptoms of anxiety and depression. Following this, a small prospective study was conducted with a subgroup of adolescents and young adults from this sample. Mireault and Compas (1996) found that these adolescents reported more symptoms of anxiety and depression than did young adults. These results were observed regardless of whether or not the parent had died from their illness.

Grant and Compas (1995) also provided evidence of one mechanism by which adjustment is compromised in adolescent girls. Their sample included girls and boys between the ages of 11 and 18 who were coping with a variety of parental cancers. Consistent with previous research, overall means on the self-report measure of psychological functioning were in the normal range. Also consistent with other research was the finding that girls whose mothers had cancer reported the highest levels of anxious and depressed symptoms, compared to those whose fathers had cancer or boys with mothers or fathers who were ill. Furthermore, that this relationship was explained (mediated) by adolescent girls' reports of increased family responsibilities following

maternal cancer diagnoses. This suggests that one reason for adolescent daughters' increased distress relative to other groups is that they experience increased pressures relating to household role responsibilities when their mothers are ill.

The results reported by Compas and associates suggest that adolescent daughters who are coping with a maternal illness such as breast cancer patients may be vulnerable to psychological adjustment difficulties. To date, however, only a few studies have attempted to quantitatively examine the specific impact of maternal breast cancer on adolescent girls. Lewis and Hammond (1996) examined the impact of early-stage breast cancer on families with adolescents, and employed multiple informants to test a model derived from stress and coping, developmental, and systems theories. Consistent with results reported by other researchers, Lewis and Hammond (1996) found adolescent girls were at greater risk for problems than were boys. Specifically, they observed that being male was associated with higher levels of self-esteem in this sample, although normative comparisons for the measure of self-esteem were not reported. It is nevertheless also important to know whether observed gender differences were comparable to those also reported in samples from the general population (e.g., Chubb, Fertman, & Ross, 1997; Ohannessian, Lerner, Lerner, & von Eye, 1999; Suesser, 1998, but see DeMello & Imms, 1999).

In the Lewis and Hammond (1996) study, self-esteem was the primary index of adolescent psychological functioning. Although the relationship between more stable traits like self esteem and adjustment to parent illness is clearly worthy of empirical investigation, within the context of research examining the impact of a specific stressor

such as breast cancer, it would also be valuable to consider psychological functioning in broader terms. This might include investigation into current social and academic competence and/or symptoms of depression and anxiety.

In summary, research in the area of parental cancer suggests that adolescent daughters are at heightened risk for adjustment problems both during (Compas et al., 1994; Compas et al., 1996; Grant & Compas, 1995; Welch et al., 1996) and after (Lewis & Hammond, 1996) treatment for maternal cancer. Consistent with recent reviews on adjustment to parental chronic illness (Worsham, Compas, and Ey, 1997; Finney & Miller, 1999; Korneluk & Lee, 1998), studies in this area have suggested that the impact of parental cancer is related to a number of variables, including the age and gender of children within the family, the informant used, and by individual family members' perceptions of the severity and stressfulness of illness. Worsham et al. (1997) also speculated that, in the case of potentially heritable maternal illnesses such as breast cancer, an adolescent girls' reaction might be compounded by an additional awareness of her own susceptibility to the disease. Adolescent daughters of breast cancer patients may also experience other disruptions to normal psychosexual and social development, which might increase their risk for adjustment problems relative to other family members. To date, however, there has been limited research examining these issues.

Taken together, the available data suggest that the prediction of adjustment to maternal breast cancer is likely to be more complex than merely examining functioning in those with and without ill parents. In addition to child age and gender, other variables under investigation in the current wave of empirical research are related to both disease

and family environment variables and include: (1) parent distress levels, (2) family functioning, and (3) perceptions of disease and its impact. The potential contribution of each of these is discussed in the following section.

Table 1

Methodological Details of Research Examining the Impact of Parental cancer on Children and Adolescents

Researchers	Sample Characteristics	Measures
Armsden & Lewis (1994)	Mothers with diabetes (n = 18), nonmetastatic breast cancer (n = 13) or fibrocystic breast disease (n = 17) and their latency[a] aged children (N = 48).	LBC, ZCI, PAIC.
Compas, Worsham, Epping-Jordan, Grant, Mireault, Howell, & Malcarne (1994), and Compas, Worsham, Ey, & Howell (1996)	134 latency-aged (n = 32), adolescent (n = 59), and young adult (n = 43) children of cancer patients (partial sample reported in Compas et al., 1994).	Structured interviews, CDI, RCMAS, CBCL, YSR, BSI.

Table continues...

Table 1, continued

Methodological Details of Research Examining the Impact of Parental cancer on Children and Adolescents

Researchers	Sample Characteristics	Measures
Grant & Compas (1995)	Adolescent children of male and female cancer patients (N = 55).	APES scale, YSR.
Howes, Hoke, Winterbottom & Delafield (1994)	Latency-aged children of breast cancer patients (N =32).	Interview data, CBCL, PAIS, FACES-III.
Lewis, Hammond & Woods (1993)	Families with latency-aged children in which the mother had been diagnosed with breast cancer (N =40).	CES-D, DII, DAS, F-COPES, FACES-III, FPRQ, NSSQ.

Table continues...

Table 1, continued

Methodological Details of Research Examining the Impact of Parental cancer on Children and Adolescents

Researchers	Sample Characteristics	Measures
Lewis & Hammond (1996)	Families with adolescents in which the mother had been diagnosed with early-stage breast cancer (N = 70).	CES-D, DII, DAS, F-COPES, FACES-III, RS, RSEQ.
Lewis, Woods, Hough & Bensley (1989)	Fathers of latency-aged children whose wives had breast cancer (N = 48).	CES-D, DII, DAS, FPRQ, F-COPES, FACES-III.
Mireault & Compas (1996)	17 adolescents and young adult children of cancer patients	Semi-structured interview, YSR, BSI.
Welch, Wadsworth, & Compas (1996)	Families in which one parent had been diagnosed with cancer (N = 76).	CBCL, CDI, RCMAS, YSR.

Table continues...

Table 1, continued

Methodological Details of Research Examining the Impact of Parental cancer on Children and Adolescents

Researchers	Sample Characteristics	Measures
Wellisch, Gritz, Schain, Wang, Siau (1992)	Daughters who had experienced maternal breast cancer before (n = 24) or after (n = 36) the age of 21	Retrospective interview data, BSI, DSFI, WOC.

Note. APES scale – Adolescent Perceived Events Scale; BDI- Beck Depression Inventory; BSI – Brief Symptom Inventory; CAS – Child Assessment Schedule; CBCL - Child Behavior Checklist; CDI – Children's Depression Inventory; CES-D – Center for Epidemiological Studies – Depression Scale; CRI – Coping Responses Inventory; DAS – Dyadic Adjustment Scale; DSFI – Derogatis Sexual Function Inventory; FES – Family Environment Scale; F-Copes – Family Coping Strategies; FPRQ – Family Peer Relationships Questionnaire; HSCL – Hopkins Symptom Checklist; K-SADS – Schedule for Affective Disorders and Schizophrenia, Child Version; LBC – Louisville Behavior Checklist; PAIC – Personality Attribute Inventory for Children;; PAIS – Psychosocial Adjustment to Illness Scale; PCSC – Perceived Confidence Scale for Children; PIC – Personality Inventory for Children; PRS – Parent's Rating Scale of Child's Actual Competence; RCMAS – Revised children's Manifest Anxiety Scale; RS – Relationships Scale; RSEQ – Rosenberg Self-Esteem Questionnaire; NSSQ – Norbeck Social Support Scale; SCL-90-R – Symptom Checklist –90 – Revised; STAIC – State-Trait Anxiety Inventory for Children; WOC – Ways of Coping Checklist; YSR – Youth Self-Report Form; ZCI – Zeitlin Coping Inventory.

[a] refers to children aged 6-12 years.

Maternal Distress

Many women state that the diagnosis of breast cancer is a "turning point" in their lives. Feelings of shock, disbelief, fear, anxiety, and depression can all occur during the course of coping with the illness (Pederson & Valanis, 1988). In addition, both the disease and its prolonged treatment can produce physical side effects (e.g., hair loss, vomiting, pain, appetite changes, and changes to one's appearance) as well as fatigue and mobility restrictions that may necessitate re-allocation of tasks the patient usually performs. Although many women cope well with the diagnosis and treatment of breast cancer, a number of researchers have observed that a subgroup of those with the illness have clinically significant psychiatric symptoms, including major depressive disorder (Duffy, Greenberg, Younger, & Ferraro, 1999; Kash et al., 1992).

It has been well established that maternal psychological problems such as depression can have profound and long-lasting effects upon child functioning (c.f., Lee & Gotlib, 1989; Seifer et al., 1996). Mothers who are depressed have been observed to engage and respond less to their infants (Bettes, 1988), and to display more negative and less task-focused behaviour toward older children (Gordon et al., 1989). In the latter study, chronic stress (relationship, financial, occupational, and/or physical) was also associated with less confirming and less positive behaviour towards children and adolescents aged 8-16 years. Thus, a stressor such as breast cancer, and concomitant depression, can be expected to influence the quality of the parent-child relationship and may result in compromised child/adolescent functioning.

To date the relationship between maternal reactions to breast cancer and child

functioning is unclear. It has been suggested that the emotional impact of the disease upon the patient plays an important role in determining how their children adapt (Lewis, Woods, Hough & Bensley, 1989; Steele, Forehand, & Armistead, 1997). Consistent with this, Armsden and Lewis (1994), and Howes et al. (1994) found that children whose mothers reported greater psychological distress as a result of breast cancer also reported significantly higher levels of child adjustment problems. In another study, however, Lewis and Hammond (1996) reported no direct relationship between maternal depressive symptoms and adolescent reports self-esteem and the quality of the parent relationship. In all of these studies, however, the sample size was not sufficient to achieve adequate statistical power given the number of variables examined.

Biggar and Forehand (1998) investigated the precise role of maternal depression in latency-aged children's adjustment to maternal HIV infection. Specifically, they examined whether maternal depression (a) explains the process through which the presence of maternal HIV affects child adjustment (i.e., acts as a mediator), or (b) accounts for individual differences in adjustment to maternal illness (i.e., acts as a moderator; Holmbeck, 1997; Worsham, Compas, & Ey, 1997). In their sample of 227 African American families (38% of whom had HIV-infected mothers), they observed a moderating (but not mediating) relationship between maternal depressive symptoms (as measured with the depression subscale of the BSI) and child depressive symptoms (measured with the CDI). There was no overall relationship between child and maternal depressive symptoms.

These results must be replicated with other cultural/ethnic groups and with

adolescents coping with other forms of parent illness. Furthermore, the use of the depression subscale of the BSI to measure depressive symptoms may not be appropriate as there are questions about the factor structure of the longer version of this measure (Bonynge, 1993). It is not clear, then, whether this is truly a measure of depressive symptomatology or of some other aspect of psychological distress. Taken together, the results reported by Howes et al. (1994), Lewis and Hammond (1996), and Biggar and Forehand (1998) suggest that, at this time, a more global measure of psychological distress may be most helpful in clarifying the relationship between maternal and child functioning in families coping with breast cancer.

Results from the well-developed literature on adjustment to childhood chronic illness may also inform the current investigation. For example, Cappelli et al. (1988) found that maternal symptoms of anxiety (but not depression) were related to parent reports of behaviour problems in children and adolescents with Cystic Fibrosis (CF). Likewise, Thompson, Gustafsen, Hamlett, and Spock (1992) reported that maternal anxiety was associated with both psychological adjustment problems behaviour in CF patients. As the literature examining the impact of parental illness on child functioning is still in relatively early stages, it might be useful to examine these issues using an index of generalized distress, rather than targeting more specific symptom clusters.

By extension, one can hypothesize that a stressor such as breast cancer will be associated with adjustment problems in adolescents, especially if high levels of parental distress accompany it. In adolescence, breast cancer may further strain parent-child relationships at a time when such relationships may already be vulnerable. Yet, in the

face of significant stress, some families continue to function well and others do not. The manner in which families typically face such challenges may also be important determinants of outcome.

Family Functioning

It has long been recognized that child and family functioning with illness are interrelated in complex ways (Kazak, 1997). To date, however, few researchers have examined family issues in those facing parent illness. Lewis and associates (Issel, Erseck, & Lewis, 1990; Lewis et al., 1989; Lewis and Hammond, 1996; Lewis, Hammond, & Woods, 1993) developed a model of family functioning with parental cancer which emphasizes the role of both individual and family characteristics in adapting to parent illness. The research generated by this model examined the differential impact of maternal breast cancer, fibrocystic breast disease, and diabetes on child adjustment. In one study (Lewis et al., 1989), the father's perception of the well-being of the family was assessed. In this sample, father reports of increased family coping were associated with better marital adjustment and with more frequent communication between fathers and their children. These variables, in turn, were associated with better child adjustment of school-aged children to parent illness, regardless of diagnosis. This suggests that family factors can act as protective or resource factors in families coping with serious illness.

Likewise, in a subsequent investigation adolescent and family adjustment (Lewis et al., 1996), the quality of the parent-child relationship was related to adolescent psychological functioning. This, in turn was predicted by maternal reports of the pressures experienced by the family as a result of the disease. These results indicate that

maternal experiences of the burden of the illness may be important correlates of adolescent perceptions of the parent-child relationship.

Lewis et al. (1993) observed that frequent interaction with the healthy parent, as well as frequent attempts to cope with family problems, were both associated with better functioning in children of breast cancer patients. Similarly, qualitative interview data provided by Issel and associates (1990) indicated that children relied upon their parents and other family members more than on any other source to help them cope with their mother's breast cancer. Among families with adolescents, Lewis and Hammond (1996) found that father reports of increased efforts at coping by family members were associated with increased marital quality and adolescent reports of good parent-child relationships. Family factors were unrelated to adolescent self-esteem in this sample. The importance of having family communication patterns characterized by openness and positive family relationships has been emphasized by a number of authors writing on the topic of parental cancer (Cohen, Dizenhus & Winget, 1977; Pederson &Valanis, 1989; Taylor-Brown, Acheson, & Farber, 1993; Walsh-Burke, 1992).

The role of family functioning in adjustment to childhood chronic diseases may once again provide clues to understanding adjustment to parent illness. Two recent reviews of the literature (Drotar, 1997; Kliewer,1997) have suggested that family factors including cohesion, affection, flexibility, and expressiveness are associated with good psychological *and* physical adjustment in children with chronic illnesses. In contrast, family conflict has consistently been observed to correlate with poor psychological and physical adaptation in these groups. Overall, parent and family functioning appears to

account for 10-15% of the variance in child functioning with parent illness (Drotar, 1997).

It is important to note, however, that the role of family variables may differ between families coping with illness and those that are not. Cohen and associates examined whether family environment plays a moderating role in the relationship between recent stressful life events and psychological distress in able-bodied (Burt, Cohen, & Bjork, 1988) and spina-bifida (Murch & Cohen, 1989) adolescents. Although they found that in both groups family environment did moderate the impact of stressful life events, the specific aspects of the family environment which did so differed slightly between the two groups. Specifically, high levels of perceived independence were associated with greater psychological distress in response to stressful life events in adolescents with spina bifida only.

Although there are specific aspects of spina bifida (e.g., motor and/or sensory impairments) which might preclude broad generalization of findings such as these, the results reported by Cohen et al. highlight an important consideration in conducting research with ill families. In examining the family processes that contribute to adjustment to illness, it may be important to abandon traditional notions of what is considered optimal functioning. Families that are coping with serious illnesses, especially long-term ones, may require different skills in order to maintain the optimal development of family members. Therefore, one must exercise caution when interpreting the strength of family functioning in ill groups with reference to normative samples.

In conclusion, limited research has examined the role of individual and family

variables in adjustment to maternal breast cancer, and few have focused directly on adolescent populations. Nevertheless, data from other sources suggest that parent and family functioning may moderate the impact of parent illness. With respect to disease indices, whereas there is no evidence to suggest that biologic disease variables play a significant role in predicting adolescent adjustment in these families, various data suggest that examination of the functional impact (Lewis & Hammond, 1996) and individual disease appraisals/perceptions (Compas et al., 1994; Compas et al., 1996) may be most useful in understanding the mechanisms at work in this relationship. In the following section, the possible role of perceptions of disease, genetic risk, and the functional impact of breast cancer are further explored.

Disease and Genetic Influences: Perceptions of Illness and Health-Related Quality of Life

It has been somewhat surprising to researchers that subjective appraisals of the seriousness of an illness appear to be better predictors of individual adaptation than are more objective indices such as stage and prognosis. In the best-designed studies, (e.g., Compas et al., 1994; Compas et al., 1996; Lewis et al., 1989; Lewis & Hammond, 1996), objective severity indices were measured, although these were not found to be related to distress levels in the manner predicted. Biological variables may be relatively poor indices because they do not adequately take into account: (a) the individual's perceptions of the illness, and (b) the mobility limitations, fatigue and other inconveniences associated with serious illness. These inconveniences may be important to the adaptational outcomes of the patient and her family.

Within the literature on child adjustment to parental cancer, the role of disease perceptions has been examined only peripherally. Although perceptions of severity appear to play a role, it is not known whether other disease appraisals may as well. In their review of the literature of child adjustment to parent illness, Worsham et al., (1997) emphasized the need for examining heritable versus non-heritable illnesses. Such an approach therefore suggests examining the role of perceptions of personal risk for developing a disease.

The population of adolescent daughters of breast cancer patients provides a unique opportunity for assessing the role of genetic risk. Two breast cancer susceptibility genes, BRCA1 and BRCA2, have recently been cloned. BRCA1 is thought to be a determining factor in the development of the disease in 45% of families with a strong history of breast cancer and 90% of families with a strong history of breast and ovarian cancer (Easten et al., 1993). Women carrying a mutation of the BRCA1 gene are estimated to have an 85-95% cumulative lifetime risk of developing breast cancer, with a median age of onset of 45 years (Easten, Narod, Ford, & Steel, 1994). BRCA2 is associated with a similar level of risk for breast cancer only (Wooster et al., 1995).

Breast cancer susceptibility is inherited in an autosomal-dominant fashion; that is, a woman with an abnormal BRCA1 susceptibility gene has a 50% chance of passing that gene on to her children (Ford et al., 1994). Because heritable breast cancer is associated with earlier age of onset, many of these women have young children. These children are therefore at increased risk for having inherited a mutated version of a breast cancer gene, and may grow up with this knowledge. Although in fact all children in these families are

equally at risk for inheriting a BRCA1/BRCA2 mutation (males can also pass along the gene, and are at increased risk for colon and prostate cancer [Ford et al., 1994]), one may speculate that perceptions of risk will be heightened in adolescent daughters of breast cancer patients who are themselves at a crucial stage of social and sexual development.

The recent introduction of genetic testing for the presence of BRCA1/BRCA2 mutations emphasizes the familial nature of the disease and brings into the forefront issues of prevention and disease detection for those at risk. Health care professionals treating breast cancer patients must therefore address issues of genetic vulnerability with the patient's family, and the primary targets of such interventions are likely to be adolescent daughters. Ritvo and associates (1999) found that concern about one's daughter was the only significant predictor of women's symptoms of depression following genetic ovarian cancer risk assessment. In the current study, one may speculate that maternal distress might also be associated with adolescent perceptions of increased personal risk and adolescent distress. These results further emphasize the need to examine individual and family factors within the framework of research examining hereditary transmission of diseases.

Limited research examining parent perceptions in families in which disorders are genetically transmitted does suggest that the heritability of a disease is associated with child outcome. For example, parents may feel guilty about burdening their children with such a problem (Mack & Berman, 1988; Miller, Bauman, Friedman, & DeCosse, 1987). In a qualitative study of mothers and daughters with scoliosis, Forstenzer and Rowe (1989) reported that maternal guilt was associated with children's non-compliance in

corrective brace-wearing. Mothers who were also affected were more likely to want their daughters to have corrective surgery. Results such as these indicate that genetic risk and disease perceptions may interact with parental variables in determining adjustment to parent illness, but must be examined further.

In recognizing both the importance of the perspective of individuals and families and of the limitations of traditional biological indices of disease characteristics in predicting psychological outcome, measurements of health-related quality of life (HQL) are increasingly being used in health care research. Although there are differing opinions regarding the exact definition of quality of life (Coates, 1993), it is generally agreed that this construct encompasses psychological, physical, mental and social aspects of functioning associated with illness and health (Fallowfield, 1993; Frazer, Brown, & Graves, 1998). The implicit assumption underlying HQL assessment is that: (a) the absence of disease should not be the only criterion in determining the success of a treatment, and (b) preservation of as many areas of functioning as possible will improve both physical and psychological outcomes following treatment for an illness. Information regarding HQL is increasingly being used to direct health care policy. It also provides useful information for clinicians and researchers interested in evaluating the effects of specific treatments and technologies, and in trying to achieve the best possible patient outcomes (Van Hook, Berkman, & Dunkle, 1996).

A recent study by Northouse and associates (1999) examined the HQL of 99 African American women who were an average of 4 years post-treatment for non-metastatic breast cancer. Overall, women in their sample reported a high quality of life.

Women who appraised their illness as more stressful, however, reported significantly lower HQL. Furthermore, family functioning was positively associated with HQL.

A number of women in the Northouse et al. (1999) study reported significant concerns about the impact of their disease on their children. Clearly the impact of the disease on the patient may affect children in the family in both subtle and direct ways. To date, however, only Lewis and Hammond (1996) have examined a construct similar to HQL in the measurement of "illness demands" in families coping with breast cancer. In their research, illness demands relate primarily to psychological and role functioning problems caused by disease (e.g., time taken for physician appointments), but do not directly assess other potentially important physical aspects of HQL such as pain, mobility and fatigue levels.

Illness perceptions and maternal HLQ may be very important to the adolescent daughter of a breast cancer patient. Seeing her mother cope with the illness, she may wonder "Will I get breast cancer?" or she may assume that she is destined to get it. If her mother is still able to function well in many domains of her life, she may view cancer as a challenge with which she can cope with and heightened risk perceptions may not influence her current levels of functioning. The relationships between maternal functioning, family functioning and disease variables will be established at a crucial period in the adolescents' own sexual, physical, and social development.

Methodological Considerations

Taken together, the above data indicate that a number of variables influence how children and adolescents adapt to parental cancer. In addition to individual characteristics

(such as age and gender), the functioning of other family members, the quality of family relationships, and the manner of problem-solving engaged in within the family (e.g., through open communication) are associated with the adjustment of family members to illness. This is consistent with what is known about the adolescent psychosocial functioning in general. For example, a number of researchers have identified adolescent girls as particularly vulnerable to symptoms of depression (e.g., Block, Gjerde, & Block, 1991; Fleming & Offord, 1990; Lewinsohn, Roberts, Seely, Rohde, Gotlib & Hops, 1994). Other risk factors for depression in adolescence include stressful life events (Hammen, Adrian, & Hiroto, 1988; Lewinsohn, Gotlib, & Seely, 1995), parental psychopathology (Fleming & Offord, 1990), low self-esteem and body image (Allgood-Merten, Lewinsohn, & Hops, 1990), lack of social support from family members (Monroe, Bromet, Connel & Steiner, 1986), and family dysfunction (Fleming & Offord, 1990).

In families coping with maternal breast cancer, there is the potential for all of these variables to impact adolescent functioning. Nevertheless, these issues have not yet been examined in a systematic and empirical manner. Methodological limitations of the scant research to date make interpretations of these studies difficult. Most studies are based on small samples. Others have been hampered by the use of retrospective accounts (e.g., Wellisch et al., 1992), or an over-reliance on poorly-validated or qualitative measures (e.g., Issel, Erseck, & Lewis, 1990). The small number of well-designed studies (e.g., Compas et al., 1996) have included a variety of parent diagnoses and children of all ages, making conclusions about the differential impact of maternal breast

cancer on adolescent girls difficult to determine.

Research focusing on a large group of adolescent daughters of breast cancer patients is necessary to address some of the above issues. In light of increasing knowledge about the genetic transmission of breast cancer susceptibility, an examination of high-risk daughters within the context of the family is needed to clarify the importance that genetic vulnerability to illness and risk perception plays in determining psychological adjustment to maternal illness. These issues have not been directly studied prior to the current investigation.

The literature reviewed here is also limited by the inconsistency of informants used to measure child and adolescent functioning. Although some researchers used parent and child report data (e.g., Welch et al., 1996), others used parent and observer reports as the primary measure of psychological functioning (e.g., Armsden & Lewis, 1994; Howes et al., 1994). However, Cantwell et al. (1997) recommended the use of adolescent self-report if only one source of data is available. Because parents may be unaware of internalizing problems and because parents and adolescents do not always agree on what is problematic behaviour (Cantwell et al., 1997), multiple informants are thought to provide the best assessment of adolescent problems (Achenbach, Howell, McConaughy, & Stanger, 1995).

Research into the role of family processes must also be further developed. Results from research examining adaptation to childhood chronic illness (c.f., Kliewer, 1997; Wallander & Thompson, 1995), suggest that the examination of family functioning may be helpful in the current line of inquiry. Investigation into family functioning will help

to delineate processes in family coping that are associated with favourable adjustment to parent illness.

Finally, the relationship between disease perceptions, HQL indices and adjustment to parent illness (including breast cancer) must be further studied. Empirical data has provided little evidence to support the hypothesis that objective disease indices predict adjustment in either the patient or her family. Nevertheless, adult-focused studies (e.g., Frazer. Brown, & Graves, 1998; McCaul et al., 1999; Schwartz, 1999) point to HQL as an important correlate of psychological adjustment.

Summary and Hypotheses

There are very limited data in the area of adolescent adjustment to maternal breast cancer. Although it has been hypothesized that adolescent girls are at increased risk for adjustment problems when their mothers have breast cancer, few studies have empirically investigated this hypothesis. It remains to be seen whether some of the results reported in the literature regarding child adjustment to parent illness generalize to the population of adolescent daughters of breast cancer patients. Data from other areas of research suggest that, rather than more objective indices of illness, disease factors such as personal risk perception and maternal health-related quality of life may play an additional role in predicting adolescent adjustment to maternal breast cancer. These issues can be addressed with the examination of larger samples of multiple informants in families coping with maternal breast cancer.

This study was designed to examine the relationship between disease, parent and family factors in predicting adolescent daughters' psychological functioning in families at

risk for a heritable form of breast cancer. It was expected that disease and genetic factors would be associated with adolescent psychological functioning, but that this relationship would be moderated by maternal distress and family functioning levels. Specifically, it was hypothesized that more negative reports of the impact of breast cancer (including perceptions of severity, personal genetic risk, and health-related quality of life experienced by the mother) would be related to poor adolescent psychological functioning in the presence of more problematic functioning and/or greater parent psychological distress. The hypothesized relationship between these variables is depicted in figure 1.

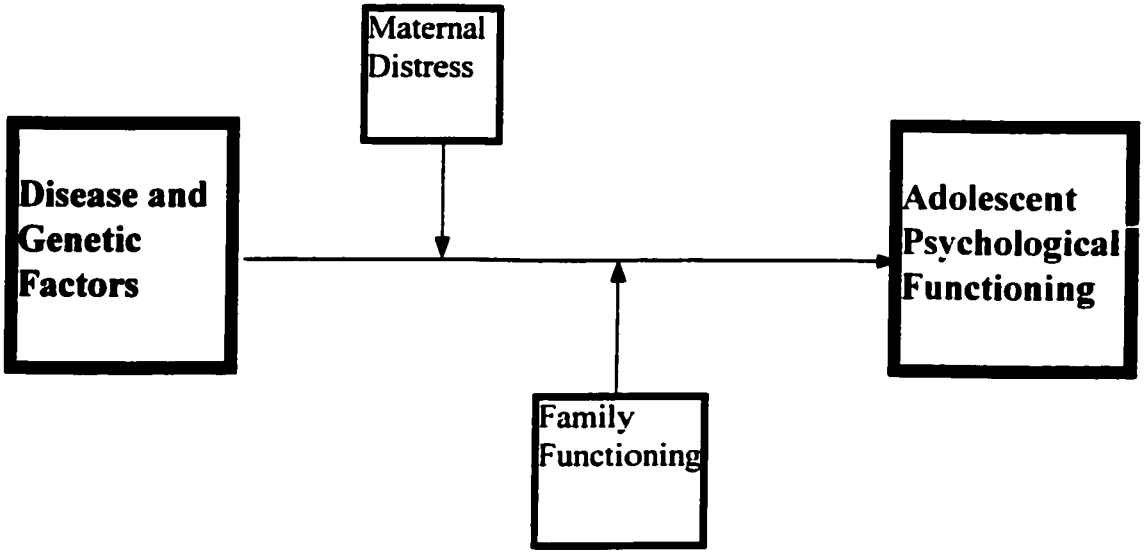

Figure 1. Model of the hypothesized relationship between disease/genetic, parent, family, and adolescent functioning variables in families with maternal breast cancer.

Thus, two sets of primary hypotheses were tested. Because of inconsistencies observed in the research to date (discussed previously) that may be attributed to informant effects, predictors of the two measures of adolescent psychological functioning (mother and adolescent report) were examined separately. Where possible, multiple informants were also used to measure predictor variables and were appropriately matched with outcome measures. Thus the following summary of hypotheses is organized according to informant (See Table 2).

Mother Variables:

1.a) The relationship between maternal HQL and maternal reports of child psychological functioning was expected to be moderated by maternal psychological distress levels such that poorer HQL along with increased distress would be most strongly associated with adolescent adjustment problems.

1.b) The maternal HQL and child psychological functioning relationship was also expected to be moderated by maternal reports of family functioning. Thus, poorer HQL and greater problems in family functioning were expected to be associated with mother reports of adolescent adjustment problems.

Adolescent Variables

With respect to adolescent reports of their own functioning, personal risk perceptions, appraisals of disease severity, and personal breast cancer worries were expected to act as additional variables, along with maternal HQL, in predicting adjustment. As with mother reports, maternal distress and family functioning were expected to moderate the relationship between these variables such that:

2.a) The relationship between disease variables (risk perceptions, severity appraisals, breast cancer worries and maternal HQL) and adolescent reports of psychological adjustment would be moderated by maternal distress. Specifically, the combination of more negative scores on measures of disease variables in the presence of increased maternal distress, was expected to predict adolescent adjustment problems.

2.b). It was also expected that the relationship between disease variables and adolescent reports of their psychological adjustment would be moderated by adolescent reports of family functioning, and specifically, their own functioning within the family. Thus, negative scores on disease-related variables were expected to be most strongly related to adolescent psychological problems in the presence of greater perceived difficulties in family functioning (See Table 2).

Table 2.

Summary of Hypothesized Relationship between Predictors, Proposed Moderators, and Outcome Variables.

Disease Variables (Predictors)	Proposed Moderators	Adolescent Psychological Functioning (outcome)
Hypothesis 1a.		
Maternal Health-Related Quality of Life	Maternal Psychological Distress	Parent Report of Adolescent Competence and Psychological Problems
Hypothesis 1b.		
Maternal Health-Related Quality of Life (HQL)	Maternal Reports of Family Functioning	Parent Report of Adolescent Competence and Psychological Problems
Hypothesis 2a.		
Adolescent perceptions of breast cancer risk, severity and worries or maternal HQL.	Maternal Psychological Distress	Adolescent Self-Report of Competence and Psychological Problems
Hypothesis 2b.		
Adolescent perceptions of breast cancer risk, severity and worries or maternal HQL.	Adolescent Self- Report of Functioning within the Family	Adolescent Self-Report of Competence and Psychological Problems

Method

Participant Characteristics and Inclusion Criteria:

Participants were comprised of 60 mother-adolescent daughter pairs in which the mother was at least one year post - treatment (surgery, chemotherapy, or radiation therapy) for non-metastatic (Stage I or II) breast cancer. The criterion was chosen so that the results would reflect families who have experienced breast cancer from diagnosis through treatment and who are now coping with the threat of re-occurrence. The inclusion of only non-metastatic cancers was selected to provide results pertaining to issues of prevention and risk versus issues of bereavement. Families were included if the mother was diagnosed with breast cancer at 50 years of age or younger. This increases the likelihood that the breast cancer involves a familial or genetic component, as inherited factors are thought to contribute to 25-35% of early-onset cases (Hill, Doyle, McDermott, & O'Higgins, 1997). BRCA1/BRCA2 mutations are associated with breast cancer diagnoses before the age of 50 (Rosenthal & Puck, 1999).

Adolescent daughters were included if they were between the ages of 12-18. This criterion is somewhat restrictive compared to other researchers examining adolescents (e.g., Grant and Compas, 1995; Lewis et al., 1996), who have included those between the ages of 11 and 20. This criterion was selected in the current study to: (a) ensure a relatively homogeneous sample while maintaining sufficient generalizability of results, and (b) to conform to normative sample age-ranges on outcome measures.
Two participants turned 19 between the recruitment and assessment phases of the study. Because their scores did not differ from the rest of the sample on other demographic or

independent variables, dependent variable measures were scored as for 18-year olds and their data were retained.

The 60 mothers were on average 45.4 years of age at the time of participation in the study, and the mean age of daughters was 15.4 years. Almost all of the families (92%) were dual-parent, compared to 86% in Ontario reported by Statistics Canada (1996). The modal education level of mothers was a trade or community college diploma (49%), which is higher than the rate of 23% for men and women over the age of 15 in Ontario (Statistics Canada, 1996). However, this discrepancy may in part reflect the higher average age of women in the current sample. Almost 75% of families reported earning more than $60, 000 per year. Income levels in the current sample are comparable to the average income rate of $71, 530 of dual-earner families with children in Ontario (Statistics Canada, 1998). Thus, it appears that the sample can be considered representative of dual-parent families with children in Ontario. Demographic characteristics of mothers and adolescents are summarized in Tables 3 (continuous data) and 4 (categorical data).

Potential participants were located through medical chart reviews (described later). Treatment and disease information was also collected via self-report. The majority of women reported that their cancer was Stage I (42%) or Stage II (51%) at the time of diagnosis. The mean age of onset was 41.32 years (S.D. = 5.26), and women were on average 31.5 months (2.6 years) post-treatment. Although chart reviews indicated that only women who met the criterion of having been diagnosed with Stage I or Stage II cancer were contacted to participate in the study, three women reported in the survey

Table 3

Demographic Characteristics of Sample – Continuous Data.

Variable	M	SD	N
Maternal Age	45.36	4.69	59
Adolescent Age	15.44	2.29	59

Table 4

Demographic Characteristics of Sample – Categorical Data.

Variable	n	%[a]
Marital Status (mother)		
married	54	92
divorced/single/widowed	5	8
Education (mother)		
high school	13	22
community college	29	49
university bachelor's	8	14
master's degree or higher	9	15
Family Income		
< $20,000	2	4
$20,000-$39,000	5	9
$40,000-$59,000	8	14
$60,000-$79,000	14	25
$80,000-$99,000	15	26
>$100,000	13	23

Note. n (mothers) = 59, n (daughters) = 59.

[a] Percentages reported reflect proportion of respondents to each item on the Breast Cancer Survey.

instruments that they had been diagnosed with Stage III and one with Stage IV disease. Data from these four participants were compared to the rest of the group on all other demographic, independent and dependent variables. Because they did not differ on any other variables, their data was retained in the current study. Likewise, five participants who did not respond to this question were also included in the sample as they did not differ from the rest of the sample on study variables. Treatment characteristics of mothers are provided in Table 5.

Recruitment and procedure:

Focus groups with breast cancer patients, women from the general population, and their adolescent daughters were conducted prior to the commencement of the study (N=16). Participants were consulted about the feasibility and sensitivity of the assessment protocol and measures. The data collection strategy, therefore, was developed with the help of these participants.

Participant recruitment and data collection occurred as part of a larger study examining cancer patients and their families. The following protocol received ethics approval from the participating institutions (See Appendix 1).

Participants were recruited according to a protocol similar to that used in a previous study of adult women (Cappelli et al., 1999). Medical records generated a list of breast cancer patients who met inclusion criteria. The charts of these patients were then examined to confirm the inclusion criteria.

Table 5

Disease and Treatment Characteristics of Women in BC Group

Disease/Treatment Characteristic	n	%[a]
Stage at Diagnosis[b]		
Stage I	22	42
Stage II	27	51
Stage III	3	6
Stage IV	1	2
Lumpectomy	37	65
Mastectomy	23	41
Chemotherapy	39	70
Radiation	50	88
Taking Tamoxifen	15	27

Note. n (mothers) = 59.

[a] Represents percentage of those responding to items on the Breast Cancer Survey.

[b] Five women did not respond to this item.

Although oncologists were invited to remove patient names from the list at their discretion (e.g., if they felt in any way that it was inappropriate to contact the patient), none elected to do so. A letter from the primary investigators of the larger study describing the study and indicating that someone would be in contact within two weeks was then sent to these women (see Appendix 2a). Following this, potential participants were contacted to further describe the study and to invite participation. Due tot he sensitive nature of the subject under investigation, it was felt that mothers should have the option of speaking to their daughters to invite participation. Once daughters agreed to participate, the researcher then contacted the daughter to further explain the study. Families were sent packages containing all pen-and-paper questionnaires in separate envelopes for each participant. At each stage, participants were informed that they could withdraw their consent to participate at any time without repercussion.

A total of 1386 names of women who had been treated at the ORCC and were between the ages of 30-50 at the time of diagnosis were generated via medical records. Individual medical charts were then inspected by the researcher to determine whether the woman met disease stage (Stage I or II) criteria for participation in the study. From this pool of 1386 names, 326 potential participants were identified.

In most cases, data on the gender and age of patient's children were not included in their medical record. Once contacted (as described previously), 166 were determined to be ineligible (no adolescent daughters [90%], language barrier [9%], the cancer had returned [5%], or other reasons [6%]). Fifty-three women did not respond to the introductory letter or three follow-up phone calls, or were not available at the

address/telephone number in their medical record.

A total of 107 women were eligible to participate. Of these, 18 (17%) declined after the introductory letter was mailed to them. Reasons for declining were: (1) being too busy (n= 8), (2) not interested (n= 5), and (3) finding the subject matter too stressful (n= 5). A total of 81 mothers and their daughters agreed to participate in the study (81/107 = 76%). Of these, 21 (21/81 = 26%) dropped out following recruitment or did not complete enough assessment instruments and were therefore not included in the current sample. The final sample was therefore comprised of 60 mother-daughter pairs (60/107 = 56% response rate).

Due to the sensitive nature of the subject matter, it was considered vital that participants receive supportive care if needed. Therefore, any adolescents or families identified through the assessment process as in need of psychological services were offered therapeutic services by Dr. Mario Cappelli (Clinical Psychologist) or Ms. Linda Corsini (Clinical Social Worker) at the ORCC. Participants were also provided with phone numbers of other psychological service agencies/individuals in the Ottawa area and every effort was made to connect participants with appropriate services in a timely fashion. Those requesting genetic counselling services were referred to the Genetics Patient Service Unit at CHEO. During the course of the study, two adolescents reported thoughts of self-harm. These adolescents were contacted and were offered services as described above. Neither elected to follow up on these offers. One mother reported ongoing cancer-related distress and asked to speak to someone. She was referred to LC.

Measures

Disease/Genetic Perceptions.

The Breast Cancer Survey (BCS).

To assess knowledge, risk perception and attitudes about breast cancer prevention, surveillance and treatment, The Breast Cancer Survey (BCS) was developed (Cappelli et al., 1999). Scales were designed to tap constructs included in the Health Belief Model (HBM: Becker & Maiman, 1975). The HBM originated in the public health domain and emphasizes the role of individual perceptions (perceived susceptibility, perceived severity, perceived benefits, and psychological/pragmatic barriers) in compliance with health recommendations. Although adolescent responses on the BCS are the focus of the current study, adolescent and mother versions are available for comparison in Appendices 3a and 3b, respectively. The mother's version was used in previous work by Cappelli et al. (1999). Both the mother and adolescent versions were piloted with focus groups (described earlier) prior to the commencement of the study.

Mother and Adolescent versions of the BCS differ slightly. Appropriate variations in pronouns (e.g., "I" versus "she") and information collected (e.g., about breast cancer history, etc.) were made. For clarity, items/scale descriptions here refer to the Adolescent version, as this is the primary focus of the current study.

The BCS is divided into 8 subscales which assess the following: (1) Personal Risk Factors for Breast Cancer (e.g., age, menstrual history, etc.), (2) Breast Cancer Screening Behaviours (e.g., frequency of breast self-exams), (3) Family and Personal History of Cancer (including Breast Cancer), (4) Knowledge of Breast Cancer, and (5)

Perceived Severity of Breast Cancer (called "Perceptions of Breast Cancer"). These are arranged on a 4-point Likert scale. High scores denote greater perceived severity (5 questions). Subscales 6 and 7 pertain specifically to breast cancer gene testing. Scale 6 assesses: Risk Perceptions (6a) and Breast Cancer Worries (6b), and contains 9 items arranged on a 4-point likert scale. Higher scores indicate greater perceived risk (5 questions) and cancer worries (4 questions). Subscale 7 assesses individual attitudes about Breast Cancer Gene Test Results (e.g., "If a test told me I would probably get breast cancer in the future, I would take an experimental drug to try and prevent it", with responses on a 5-point scale ranging from "Definitely" to "Definitely Not"). Subscale 8 collects demographic and other personal information about the participant. Scales 5, 6a, 6b, and 8 are the focus of the current study.

BCS subscales 5, 6a , and 6b were examined for reliability. Initial computations of Cronbach's alpha yielded coefficients of .63, .79, and .79 for the adolescent versions of the Perceptions of Severity, Risk Perception, and Cancer Worries scales, respectively. Due to inadequate reliability of the Perceptions of Severity subscale, intercorrelations between items and the total subscale score were examined. All items correlated significantly with their total subscale score, except for the item reading "how effective do you think the treatments are for breast cancer" on the Perceptions of Severity Scale. When removed from the scale, alpha coefficient rose from .63 to .71. This item was therefore removed from the scale score and the total Perceptions of Severity Score recalculated for further analyses.

Maternal Health-Related Quality of Life Associated with Breast Cancer.

The Short Form- 36 (SF-36).

The SF-36 is a 36-item questionnaire designed to measure perceptions of health status and outcomes associated with health conditions and medical interventions (Ware, Snow, Kosinski, & Gandek, 1993). The SF-36 measures how a disease or a treatment has affected an individual's ability to function in the world (e.g., whether they are able to perform their job and whether they feel energetic, calm, or nervous). Thirty-three of the items are arranged on 6, 5 or 3-point Likert scales. The remaining three items are in a yes/no format. There are eight multi-item scales (physical functioning, role functioning - physical, bodily pain, general health, vitality, social functioning, role functioning - emotional, and mental health) in addition to a one-item scale which assesses self-evaluated change in health status. The SF-36 takes 5-10 minutes to complete.

The SF-36 has been found to detect differences in health status among several patient groups, including those with a physical versus a mental illness (McHorney, Ware, & Raczek, 1993; McHorney, Ware, Rogers, & Raczek, 1992). Psychometric data were also provided by Garrat, Ruta, Abdalla, Buckingham, & Russel (1993), who analysed responses on the SF-36 of 1317 patients with a variety of conditions. Internal consistency reliability coefficents ranged from .80 on the social functioning scale to .92 on the physical functioning scale. This investigation also identified factors highly consistent with those constructed within the measure. The measure was observed to discriminate between those with and without physical illness.

Because of measurement overlap of study constructs (i.e., with the SCL-90-R), the emotional well-being scale (questions 23-31 and 37-39) were not included in the

analyses. The remaining items on this questionnaire assess primarily physical, social and occupational limitations caused by the disease. An average total score was calculated with the remaining SF-36 items. Cronbach's alpha was computed for the current sample with the abbreviated scale and yielded good reliability at .89. See Appendix 4.

Adolescent Psychological Functioning.

The Child Behavior Checklist (CBCL).

The Child Behavior Checklist (CBCL; Achenbach, 1991) is a 120-item inventory designed obtain parent's reports of the number and degree of child competencies and problems. This is an empirically-developed instrument: items significantly correlated with referrals for social or emotional problems were selected for inclusion on the measure. Two broad dimensions (Competencies and Problem) are assessed. Parents are asked to indicate the presence of 113 behaviours by checking whether they are "not true (as far as you know)", " somewhat or sometimes true", or "very true or often true". The Competencies Scale yields a single dimension score. The Problem Scale yields a total problem score, which is composed of subscales measuring the presence of more specific clusters of behaviours (e.g., aggression, somatic complaints, withdrawn behaviour, etc.). Higher scores (provided in the form of T-scores) indicate that parents perceive their children as having more problematic behaviours. The CBCL takes approximately 15 minutes to complete.

Achenbach (1991) provided normative data, as well as good-to-excellent reliability and validity data in the manual for this instrument. Reliability coefficients reported for the Problem scale include: inter-rater (r = .96), test-retest (r = .89), and

stability (r = .85). Validity data are also provided. The checklist has been found to discriminate between referred and non-referred children. Scores on the CBCL were also found to correlate with scores on other scales designed to measure similar constructs and with DSM-III-R diagnostic criteria. Alpha reliability for the current sample was also computed. Cronbach's alpha coefficients for the Competence and Total Scales were .73 and .87, respectively, thus indicating adequate to good reliability of this measure. See Appendix 5.

Youth Self-Report form of the CBCL (YSR).

The Youth Self-Report form the Child Behavior Checklist (YSR; Achenbach, 1991) is a questionnaire designed to assess 11-18 year-olds' perceptions of their own abilities and problems. The YSR has a parallel format to the CBCL, with Competence and Problem scales. It takes about 15 minutes to complete.

The YSR was normed on a sample of 1415 non-referred youth. The test developer has provided evidence of the instruments' test-retest reliability over a one week period (range r= .83 - .87 for the various scales and subscales). The YSR has also been shown to discriminate between referred and non-referred adolescent samples. For the current sample, Cronbach's alpha was computed for Competence and Total Scales. Although the Total scores showed evidence of the scales' reliability (α = .90), the Competence scale yielded an alpha coefficient of only .69. Because these scores were considered an important focus of the current study, the data were retained in subsequent analyses. See Appendix 6.

Mother-Adolescent Agreement about Problems.

The scoring program for the CBCL and YSR also generates a cross-informant agreement statistic. This compares item-for-item the scores on parent and adolescent reports of adolescent problems to the level of agreement in the normative sample of the two measures, and generates summary statements (below average, average, or above average agreement) for each pair. Cross-informant scores for mothers and adolescents who had experienced breast cancer were computed for comparison against non-ill families in the normative sample. Summary statements were numerically coded (below average agreement = 1, average agreement = 2, and above average agreement = 3). Cross-informant agreement data are presented in the section entitled: "Descriptive Statistics".

Maternal Distress.

Symptom Checklist 90 - Revised (SCL-90-R).

The Symptom Checklist - 90 - Revised (SCL-90-R; Derogatis, 1983) is a 90 item self-report inventory designed to measure current distress levels experienced by adults. Respondents are asked to indicate the extent to which they were distressed by various symptoms in the past seven days, including today. Items are arranged in a 5-point Likert scale ranging from 0 ("not at all") to 4 ("extremely"). The SCL-90-R takes about 15 minutes to complete (See Appendix 7).

The test developer provided normative data for the previous version from a large sample of adult outpatients from psychiatric facilities (Derogatis & Cleary, 1977). Good internal consistency (α = .86) and test-retest reliability (α = .85) were also reported by

Derogatis and Leary (1977). Cronbach's alpha computations for the General Severity Index (GSI) indicated high reliability in the current sample (α = .95).

Family Functioning.

Family Assessment Measure (FAM-III).

The FAM-III is a 134 item self-report questionnaire designed to assess family strengths and problem areas (Skinner, 1984). Items are arranged on a 4-point likert scale ranging from "a" = strongly agree to "d" = strongly disagree. Based on a process model, the FAM-III assesses six areas of family functioning: task accomplishment, role performance, communication, affective involvement, control and values/norms. Higher scores in any of the 6 areas of family functioning indicate greater disturbance in that area.

Reliability and validity data for the FAM-III are provided by Skinner, Stein, and Santa-Barbara (1983). Normative data were collected from a sample of 475 families (n=933 adults and n=502 children) from a variety of socio-economic backgrounds. Internal consistency reliability estimates for the three scales range from .86 for the children who completed the Self-Report Scale to .95 for adults who completed the Dyadic Relationships Scale. The FAM-III was also found to discriminate between families identified as having psychiatric, alcohol, school or major legal problems and those with no such problems. The FAM-III takes 20-40 minutes to complete.

There are General, Self-Report, and Dyadic versions of the FAM-III, all of which measure the 6 constructs. To minimize fatigue, only the General and Self-Report scales of the FAM-III were used in the current study. Grant and Compas (1995) reported that adolescent daughters of ill mothers experienced psychological disturbances as a result of

increased role responsibilities within the family. Accordingly, the total score on the Self-Report version of the FAM-III was used to measure adolescent perceptions of their own functioning within the family (e.g., "My family expects too much of me", and "I do my share of duties in the family".) As a measure of the functioning of the family as a whole, mother reports (total scores) on the General Scale were used (e.g., "The rules in our family don't make sense"). Cronbach's alpha coefficients indicated adequate reliability for both adolescent (α = .91) and mother α =.77) versions. See Appendices 8a and 8b.

Results

Data Analytic Strategy and Sample Size Requirements

Family functioning and maternal distress were proposed as moderators of the relationship between disease/genetic factors and adolescent psychological functioning with maternal breast cancer. A moderating variable is defined as one that "affects the direction and/or strength of a relation between an independent or predictor variable and a dependent or criterion variable" (Baron & Kenny, 1986, pp. 1178). The test for this relationship was completed as outlined by Cohen and Cohen (1983) and Holmbeck (1997), and as demonstrated by Biggar and Forehand (1998), Furhman and Holmbeck (1995), and Murch and Cohen (1989).

The basic strategy for completing this analysis utilizes a hierarchical multiple regression approach in order to test the unique contribution of the interaction term (product) of two independent variables. The following order of entry of variables into the equation is used: *Step 1*: identified covariates; *Step 2*: focal independent variable A; *Step 3:* proposed moderator variable B; and *Step 4:* the interaction term (product) of A and B. This has the effect of statistically testing the unique contribution of the product of the independent variables (interaction) in the prediction of the dependent variable. Where two or more moderators are proposed, analyses are conducted separately for each one (Holmbeck, 1997).

In the current study, data were provided by multiple informants, and there was more than one source for each of the constructs measured. The focal independent variable (disease/genetic factors) was measured with the adolescent and mother responses on the

BCS severity, worry and/or risk perceptions scales and with the mother's responses on the SF-36. Where multiple reports were available (e.g., on the BCS survey or with FAM-III reports), independent variables were matched with outcome informant. For example, adolescent BCS survey items and adolescent FAM – III reports were used in the test of their relationship with YSR scores.

The primary outcome measure is the YSR. In the current study, Competence Scale T-Scores and Total Behaviour Problems T-Scores were included in separate equations as outcome measures. Parent reports of adolescent problems (as measured with the CBCL) constitute the secondary outcome measure. As with the YSR, Competence and Total Problem scale scores on the CBCL were used separately as measures of the dependent variable of adolescent psychological functioning. Taken together, the various combinations of independent and dependent variables yielded 20 planned comparisons. The variables involved in each of these analyses are summarized in Table 6. Bonferroni corrections were conducted to control for the possibility of Type I errors due to multiple comparisons, yielding a critical alpha-level of $p<.003$ for this set of analyses.

Table 6.

Summary of Predictors, Proposed Moderators, and Outcome Variables Included in Planned Comparisons.

Predictor Variable	Proposed Moderator	Outcome Variable
1. Maternal HQL[a]	Maternal distress[b]	Maternal report of adolescent competence[c]
2. Maternal HQL	Maternal reports of family functioning[d]	Maternal report of adolescent competence
3. Maternal HQL	Maternal distress	Maternal report of adolescent total problems[e]
4. Maternal HQL	Maternal reports of family functioning	Maternal report of adolescent total problems
5. Adolescent risk perceptions[f]	Maternal distress	Adolescent self-report of competence[g]
6. Adolescent risk perceptions	Adolescent reports of functioning within the family[h]	Adolescent self- report of competence

Table 6, continued.

Summary of Predictors, Proposed Moderators, and Outcome Variables Included in Planned Comparisons.

Predictor Variable	Proposed Moderator	Outcome Variable
7. Adolescent perceptions of breast cancer severity[i]	Maternal distress	Adolescent self- report of competence
8. Adolescent perceptions of breast cancer severity	Adolescent reports of functioning within the family	Adolescent self- report of competence
9. Adolescent cancer concerns[j]	Maternal distress	Adolescent self- report of competence
10. Adolescent cancer concerns	Adolescent reports of functioning within the family	Adolescent self- report of competence
11. Maternal HQL	Maternal distress	Adolescent self- report of competence
12. Maternal HQL	Adolescent reports of family functioning	Adolescent self- report of competence

Table 6, continued.

Summary of Predictors, Proposed Moderators, and Outcome Variables Included in Planned Comparisons.

Predictor Variable	Proposed Moderator	Outcome Variable
13. Adolescent risk perceptions	Maternal distress	Adolescent self-report of total problems[k]
14. Adolescent risk perceptions	Adolescent reports of functioning within the family	Adolescent self- report of total problems
15. Adolescent perceptions of breast cancer severity	Maternal distress	Adolescent self- report of total problems
16. Adolescent perceptions of breast cancer severity	Adolescent reports of functioning within the family	Adolescent self- report of total problems
17. Adolescent cancer concerns	Maternal distress	Adolescent self- report of total problems

Table 6, continued.

Summary of Predictors, Proposed Moderators, and Outcome Variables Included in Planned Comparisons.

Predictor Variable	Proposed Moderator	Outcome Variable
18. Adolescent cancer concerns	Adolescent reports of family functioning	Adolescent self- report of total problems
19. Maternal HQL	Maternal distress	Adolescent self- report of total problems
20. Maternal HQL	Adolescent reports of family functioning	Adolescent self- report of total problems

[a] Measured with the SF-36.

[b] Measured with the SCL-90-R.

[c] Measured with the CBCL Competence Scale

[d] Measured with the FAM-III General Scale Total Score

[e] Measured with the CBCL Total Problems Scale

[f] Measured with the BCS Risk Perceptions Scale

[g] Measured with the YSR Competence Scale

[h] Measured with the FAM-III Self Report Scale Total Score

[i] Measured with the BCS Severity Perceptions Scale

[j] Measured with the BCS Cancer Concerns Scale

[k] Measured with the YSR Total Problems Scale

Studies of the impact of parental cancer have generally found moderate associations between variables across a wide range of child ages and parent diagnoses (e.g., Compas et al., 1996; Armsden & Lewis, 1994). In this case, one expects to observe a moderate effect size at conventionally acceptable values (i.e., power of .80 and a false-positive error rate of .05). The required sample size was calculated based upon multiple regression analyses for tests of moderating variables with two independent variables. According to Green (1991) and Cohen (1992), a total of 66 families ($n = 50 + 8k$, where k is the number of independent variables) is sufficient to observe a moderate effect. As noted previously, the current sample contains a total of 60 families. However, given the increased homogeneity of the current sample relative to previous studies (see Tables 3-5), and given that the data conformed to the assumptions of the planned statistical analyses (see below), it is fair to hypothesize that more consistent relationships would be observed between study variables. Because a sample of n=30 is needed to observe a large effect size (Cohen, 1992), one can be reasonably confident that the current sample size is sufficient to observe reliable associations between measured constructs.

Preliminary Data Analyses

Prior to analysis, all independent and dependent variables were examined via "screening and cleaning" procedures recommended by Tabachnick and Fidell (1996) using various SPSS –10 programs. All variables were examined for accuracy of data entry, missing values, and fit between their distributions and the assumptions of the analyses chosen. Missing values were observed for the following variables: CBCL total

problem (2 participants) and YSR total problem scales (1 participant). As it represents only 5% of the total sample, in each case the missing values were substituted by the mean of the total sample, as recommended by Tabachnick and Fidell (1996). No data were observed to be skewed or kurtotic, likewise pairwise plots of the variables revealed them to conform to the assumptions of linearity and homoscedasticity. Bivariate correlations between variables showed no evidence of singularity or multicollinearity, except on the correlation between the SCL-90-R depression and SCL-90-R GSI scale scores (r =.92, p<.001), which was dealt with as discussed in the methods section.

Once case with extreme values on the health-related quality of life index (SF-36) was observed (z = 3.32, p <.001). This univariate outlier was deleted from subsequent analyses, leaving a final sample of 59 families. Mahalanobis distances, Cook's distances and Centered Leverage Values were computed to identify multivariate outliers. No such cases were observed.

Descriptive Statistics.

Descriptive statistics were computed for all primary study variables. On standardized measures, one-sample t-tests were computed to compare the current sample against a standardized mean of 50 (SCL-90-R and FAM-III), or against values observed in a comparable normative sample group (i.e., adolescent girls aged 11-18, as provided in the CBCL and YSR manuals). The SF-36 measure of health-related quality of life was compared to normative values for women under the age of 65 presented by Radosevich, Wetzler and Wilson (1995). Means and standard deviations for the focal study variables and comparisons to normative data (where applicable) are presented in Tables 7 and 8.

Bonferroni adjustments were made to this set of analyses to control for multiple comparisons and yielded a critical p-value of $p<.006$) Using this decision criterion, Competence and Total Problem subscale scores did not differ from those reported by Achenbach (1991). In the current sample, the percentage of mothers reporting problems in the borderline of the clinical range or greater (defined as t-scores less than or equal to 37 on the Competence scales and greater than or equal to 67 on the Problems scales) was 7% (n = 4) for the Competence Scale and 5% (n = 3) for theTotal Problem scale. The proportion of mothers reporting problems in the clinical range did not differ significantly from values reported by Achenbach (1991) for the Competence ($\chi 2 = 1.07$, $p<.30$) or Total Problem ($\chi 2 = 2.11$, $p<.15$) scales. Similarly, 5% (n = 3) of adolescents reported significant problems on the Competence and Total Problem scales. These proportions are comparable to the rates reported by Achenbach (1991) for the Competence ($\chi 2 = .99$, $p<.32$) and Total Problem ($\chi 2 = 3.49$, $p<.06$) scales.

CBCL cross-informant product scores for mothers and adolescents who had experienced breast cancer were computed for comparison against non-ill families in the normative sample. Summary statements provided by the program were numerically coded (below average agreement = 1, average agreement = 2, and above average agreement = 3). A one-sample t-test was computed to compare the mean level of agreement against a value of 2.0 to determine whether the sample of breast cancer patients and daughters differed significantly from normal levels of mother-daughter

agreement. The mean level of mother-daughter agreement did not differ from that observed in the normative sample (t[54) = .00, SD. = .75, p = 1.00).

SCL-90-R scores were compared to standardized values of t=50 for the GSI subscale. Mean subscale scores are reported in Table 7. Overall, breast cancer patients did not differ significantly from the standardized mean on the SCL-90-R. The number of women who reported total distress levels in the borderline of the clinical range or greater was 12% (n=7), indicating that the current sample is similar to the standardization sample.

Likewise, scores on the adolescent and mother FAM-III scales were similar to the standardization sample (See Table 7). Overall, 8% (n = 5) of mothers, and 12% (n=7) of adolescents reported clinically significant problems with family functioning.
Scores on the index of Health-related Quality of Life (SF-36) were compared to a general population sample of people under the age of 65 (Radosevich et al., 1995). Scores on this scale did not differ significantly from those of the normative sample, suggesting that breast cancer patients in the current sample (approximately 3 years post-treatment) were similar to the general population sample in terms of their health related quality of life.

Scores on the BCS Perceptions of Severity, Risk Perceptions, and Cancer Concerns subscales are reported in Table 8. Scores closer to the maximum of 4 on individual items indicate greater perceived severity, risk or concerns. Scores closer to 16 indicate greater total perceived severity, risk and concerns scores on these scales. Overall the scores on these scales suggest that adolescent daughters of breast cancer patients perceive the disease as moderately severe (most item means were in the range of 2.5 – 3.5

out of a maximum of 4). They also perceive themselves to be at increased risk compared to other teens, and display moderate levels of concern about this risk. Items pertaining to the frequency and impact of cancer worries, however, indicate a low level of intrusiveness of cancer-related concerns.

Table 7.

Mean Scores of Participants on Standardized Predictor and Outcome Measures (n=59).

Variable	Mean	SD
CBCL Total Competence T-Score[a]	50.6	8.9
CBCL Total Problems T-Score[a]	46.6	10.6
YSR Total Competence T-Score[a]	50.9	11.3
YSR Total Problems T-Score[a]	50.5	8.4
SCL-90-R General Severity Index[b]	51.3	8.5
FAM-III General Scale Total Score[b]	49.1	8.6
FAM-III Self-Report Scale Total Score[b]	51.3	7.9
SF-36 Total Scores[c]	634.9	146.3

[a] Mean scores compared to normative values provided by Achenbach (1991).
[b] Mean scores compared to a standardized mean of 50.
[c] Mean score compared to the general population value of 658.4 reported by Radosevich et al. (1995).

Table 8.

Mean Disease Perception Scores of Adolescent daughters of breast cancer patients (n = 59).

BCS Item/Scale	Mean	SD
Perceptions of Disease Severity Scale		
how life threatening	3.17	.70
are treatments effective[a]	2.03	.65
how much does BC affect ability to work	2.98	.93
how much does BC affect energy levels	3.33	.89
how much does BC affect leisure activities	2.69	.92
Total Perceptions of Severity	12.17	2.53
Risk Perceptions Scale		
risk of getting BC compared to other teens	3.08	.68
chance of carrying BC gene mutation	2.85	.71
chance of getting other cancer	2.93	.67
chance of getting ovarian cancer	2.14	.58
Total Risk Perceptions Score	10.92	2.25
Cancer-Related Concerns Scale		
worried about own chance of getting BC	2.08	.70
worried about getting any cancer	2.71	.85
how often do you worry about getting BC	1.53	.65

Table 8, continued.

Mean Disease Perception Scores of Adolescent daughters of breast cancer patients (n = 59).

BCS Item/Scale	Mean	SD
do worries affect how you feel each day	1.14	.39
Total Cancer Concerns	10.44	2.46

Note. Responses were rated on a scale ranging from 1 (not at all) to 4 (very much so). Total scores were calculated by summing responses across items (maximum score = 16).

[a] this item was removed from the total scale score before primary analyses to improve alpha reliability.

Correlational Analyses.

Identification of Covariates.

Prior to testing the hypotheses, correlations were computed among demographic variables, proposed moderators (SCL-90-R and FAM-III scores), and outcome measures (CBCL and YSR scores) to identify potential covariates to be included in multiple regression analyses. Disease variables examined were: maternal age at diagnosis, stage at diagnosis, time since treatment, and type of treatment. Potential demographic covariates examined included: maternal age, adolescent age, maternal education, family income, mother's marital status, and presence of siblings in the home. Interrcorrelations between focal study variables and demographic and disease variables are presented in Appendices 9 through 12.

One disease variable, maternal age at diagnosis, was significantly and negatively correlated with CBCL total problem ($r = -.33$, $p<.05$). Therefore, this variable was entered first into all regression analyses predicting CBCL total problem scores to control for that effect.

Demographic correlates of study variables were also observed. Maternal distress was negatively correlated with both education ($r = -.29$, $p<.05$) and family income ($r = -.30$, $p<.05$). Similarly, mother reports of adolescent social competence were significantly correlated with maternal education ($r = -.28$, $p<.05$) and family income ($r = -.29$, $p<.05$). Consequently, these variables were entered first into equations involving SCL-90-R and/or CBCL Competence t-scores where appropriate.

Correlations Between Focal Variables.

Correlations between primary variables are provided in Appendix 13. As indicated on the table, there were a number of significant zero-order correlations observed in the current sample. These associations were almost uniformly in the expected directions. With respect to disease-related variables, maternal HQL was the strongest predictor of both the hypothesized moderators (maternal distress and family functioning), and dependent variables (adolescent and maternal reports of adolescent psychological functioning). Correlations were moderate-to-large in magnitude and ranged from $r = -.27$ ($p<.05$) with the YSR Total Problem Scale to $r = -.63$ ($p<.001$) with the GSI scale of the SCL-90-R.

Overall, adolescent disease perceptions were not correlated with moderating or outcome variables. One unexpected association was observed, however, with the Severity scale of the BCS. Specifically, adolescent perceptions of greater disease severity were associated with increased social competence scores ($r = .36, p <.001$).

Hypothesized moderators were also significantly correlated with outcome variables. Maternal distress levels on the SCL-90-R were moderately-to-highly associated with maternal reports of adolescent Total Problems ($r = .56, p<.001$). Maternal distress was also significantly related to adolescent Total Problem Scale scores on the YSR ($r =.28, p<.05$).

Family functioning was measured in two ways in the current study. Mothers completed reports designed to measure perceptions of whole-family functioning, and adolescents completed a self-report of their own functioning within the family. In the current sample, maternal reports of total family functioning were significantly related to maternal reports of adolescent problems, as measured by the CBCL Total Problem scale. These were unrelated to adolescent reports of

the same problems on the YSR. In contrast, youth reports of their own functioning within the family were significantly correlated with both CBCL scores and YSR scores, although the associations with YSR scores were greater.

Tests of Primary Hypotheses

Multivariate regression analyses were conducted to examine the interactive effects of several disease variables with two proposed moderators: maternal distress and family functioning. The two outcome variables, maternal and youth reports of psychological functioning, were considered conceptually distinct in the design of this study. This assumption was supported by the relatively low, albeit significant, zero-order correlation on Total Problem scores of the CBCL and YSR ($r = .35, p<.001$). Therefore, these variables were analyzed as dependent constructs in separate regression equations.

Similarly, disease variables were conceptualized as distinct in this study. Adolescent disease perceptions measured were: personal risk perceptions, cancer concerns and perceptions of disease severity. Personal risk and cancer concerns were significantly correlated at a low-to-moderate level ($r = .39, p<.001$). None of these variables were related to maternal reports of HQL. These variables were also analyzed separately in tests of moderating hypotheses.

Thus, analyses were conducted separately for YSR and CBCL Competence and Total Problem scores. Results are organized by dependent measure and by moderating variable. Tables 9-12 show moderating analyses using CBCL scores as the outcome variable. Analyses in which YSR scores are the dependent variable are presented in Tables 13-20. For each analysis, predictors were a combination of: (a) previously identified covariates (where applicable), (b) the focal disease-related independent variable (adolescent disease perceptions or maternal HQL), (c)

the hypothesized moderator (SCL-90-R or FAM-III scores), and (d) the interaction (product) of the focal and moderating variables. Bonferroni adjustments were made to control for inflated Type-1 error rate due to multiple comparisons, yielding a critical *p*-value of .006 for the primary analyses.

Tests of Hypotheses 1.a. and 1.b.

Four multiple regression analyses included maternal CBCL competence scores as the criterion variable. In these equations, CBCL competence scores were not significantly predicted by the addition of the focal and moderating variables once education and income were controlled for, thus not supporting the moderating hypotheses as predicted. Results are summarized in Tables 9 and 10.

The CBCL Total Problem Scale scores were also analyzed as criterion variables (See Tables 11 and 12). In both cases, statistically significant *F* -values were observed when the predictors were added to the model at the second step (following covariates). However, no significant interactions were observed, as evidenced by nonsignificant ΔR^2 and β values in the final step. Thus the moderating hypotheses pertaining to these variables were not supported.

Table 9

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting CBCL Total Competence Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.12	3.67*
Maternal Education	1.18	.80	.20	.26*	.19		
Family Income	.81	.46	.23	.29*	.23		
Step 2						.04	1.26
Maternal HQL[a]	-.12	.07	-.23	.47**	-.21		
Maternal Distress[b]	-.17	.15	-.19	.37**	-.15		
Step 3						.02	1.37
Interaction Term	<.01	<.01	-.91	-.26	-.16		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal Self-Report on SF-36. Higher scores indicate better HQL.

[b] Maternal Self-Report on SCL-90-R, GSI scale.

*$p<.05$. **$p<.001$.

Table 10

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting CBCL Total Competence Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.12	3.67*
Maternal Education	1.18	.80	.20	.26*	.19		
Family Income	.81	.46	.23	.29*	.24*		
Step 2						.05	1.61
Maternal HQL[a]	-.01	.06	-.21	-.09	-.21		
Family Functioning[b]	-.20	.14	-.20	-.19	-.19		
Step 3						<.01	.13
Interaction Term	<.01	.01	-.27	-.22	-.05		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self – report on SF-36. Higher scores indicate better HQL.

[b] Maternal self-report on FAM-III, General Scale.

*$p<.05$, **$p<.001$.

Table 11.

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting CBCL Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.11	2.08
Maternal Education	.01	.98	.01	-.04	.01		
Family Income	-.21	.58	-.05	-.13	-.05		
Maternal Age at Diagnosis	-.63	.27	-.30*	-.32*	.30*		
Step 2						.31	13.46**
Maternal HQL	.02	.08	.05	-.30*	.05		
Maternal Distress	.65	.15	.62**	.57**	.51**		
Step 3						<.01	.31
Interaction Term	<.01	.01	.37	-.15	.08		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on SF-36. Higher scores indicate better HQL.

[b] Maternal self-report on SCL-90-R, GSI scale.
*p<.05, **p<.001.

Table 12

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting CBCL Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (Covariates)						.11	7.00*
Maternal Age at Diagnosis	-.67	.25	-.33*	.33*	.33*		
Step 2						.10	3.63*
Maternal HQL[a]	-.14	.07	-.27*	-.29*	-.26*		
Family Functioning[b]	.14	.17	.11	.32*	.11		
Step 3						<.01	.05
Interaction Term	<.01	.01	-.16	-.09	-.03		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on SF-36. Higher scores indicate better HQL.

[b] Maternal self-report on SCL-90-R, GSI scale.

*$p<.05$, **$p<.001$.

Tests of Hypotheses 2.a. and 2.b.

Adolescent self-reports of competence were included as the dependent variable in a total of eight multiple regression equations (See Tables 13-20). Bonferroni adjustments yielded an alpha level of $p<.006$. In these equations, YSR competence scores were significantly predicted by the interaction between maternal HQL and adolescent reports family functioning, as indicated by the significant interaction term shown in Step 2 in Table 20. The equation involving adolescent cancer concerns and family functioning yielded an interaction effect that was significant at alpha = .05, but not at the .006 level (see Table 18). In all other regression equations using the YSR competence scores as the dependent variable, the models including disease and moderating variables were not significant, nor were the interaction terms.

Pictorial representations of the significant interaction are presented in Figure 2. Following Biggar et al. (1998), a median split on the two predictors was used to categorize high and low values of disease and moderator variables with the dependent variable represented on the Y-axis. Figure 2 shows that adolescents who report more problems with family functioning and whose mothers experience a lower health-related quality of life are also likely to report lower levels of social competence. Furthermore, low maternal HQL was not associated with reports of low social competence as long as family functioning was high.

Table 13

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Adolescent Risk Perceptions and Maternal Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.07	1.91
Maternal Education	.59	1.05	.08	.14	.08		
Family Income	.97	.60	.22	.25	.21		
Step 2						.02	.68
Risk Perception[a]	.79	.68	.15	.17	.16		
Maternal Distress[b]	.01	.16	.02	-.08	.02		
Step 3						.00	.00
Interaction Term	<.01	.07	.09	.10	.01		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent perceived risk for breast and other cancers on the BCS Risk Perception total scale score.

[b] Maternal self-report on the SCL-90-R, GSI scale.

*$p<.05$, **$p<.001$.

Table 14

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Adolescent Risk Perceptions and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.08	2.34
Risk Perception[a]	.63	.86	.13	.17	.13		
Family Functioning[b]	-.32	,19	-.23	-.25	-.22		
Step 2						.01	.35
Interaction Term	.05	.09	.64	-.01	.08		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent received risk for breast and other cancers on the BCS Risk Perception total scale score.

[b] Adolescent report on the FAM-III Self-Report Scale.

*$p<.05$, **$p<.001$.

Table 15

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Adolescent Severity Perceptions and Maternal Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.08	2.21
Maternal Education	-.23	.83	-.04	.04	-.04		
Family Income	.97	.47	.24	.25	.25		
Step 2						.03	.89
Severity Perception[a]	.62	.47	.17	.14	.18		
Maternal Distress[b]	.03	.12	.04	-.01	.04		
Step 3						<.01	.24
Interaction Term	-.03	.08	-.77	.08	-.07		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent perceptions of breast cancer severity on the BCS Severity Perception total scale score.

[b] Maternal self-report on the SCL-90-R, GSI scale.
*$p<.05$, **$p<.001$.

Table 16

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Adolescent Severity Perceptions and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.03	.94
Severity Perception[a]	.65	.47	.18	.18	.18		
Family Functioning[b]	<.01	.17	<.-01	.01	<-.01		
Step 2						.01	.79
Interaction Term	.07	.09	1.31	.16	.12		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent perceptions of breast cancer severity, as measured with the BCS Severity Perception total scale score.

[b] Adolescent report on FAM-III Self-Report Scale.

*p<.05, **p<.001.

Table 17

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Adolescent Cancer Concerns and Maternal Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.07	1.91
Maternal Education	.62	1.10	.08	.14	.08		
Family Income	.97	.60	.22	.25	.22		
Step 2						<.01	.12
Cancer Concerns[a]	-.29	.61	-.07	-.03	-.07		
Maternal Distress[b]	<.01	.16	<-.01	-.07	<-.01		
Step 3						.04	2.18
Interaction Term	-.10	.-7	-1.55	-.09	-.20		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent cancer concerns, as measured with the BCS Cancer Concerns total scale score.

[b] Maternal self-report on the SCL-90-R, GSI scale.

*$p<.05$, **$p<.001$.

Table 18

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Adolescent Cancer Concerns and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.06	1.90
Cancer Concerns[a]	-.10	.59	-.02	-.02	-.02		
Family Functioning[b]	-.36	.18	-.25	-.25	-.25		
Step 2						.06	.05*
Interaction Term	-.11	.05	-1.46*	-.20*	-.26*		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent cancer concerns, as measured with the BCS Cancer Concerns total scale score.

[b] Adolescent report on the FAM-III Self-Report Scale.

*$p<.05$, **$p<.001$.

Table 19

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.07	1.91
Maternal Education	.56	1.05	.08	.14	.08		
Family Income	.97	.60	.22	.25	.22		
Step 2						.02	.44
Maternal HQL[a]	.09	.10	.16	.13	.13		
Maternal Distress[b]	.11	.20	.10	-.07	.07		
Step 3						<.01	.05
Interaction Term	<.01	.01	.19	.10	.03		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on the SF-36. Higher scores indicate better HQL.

[b] Maternal self-report on the SCL-90-R, GSI scale.

*p<.05, **p<.001.

Table 20

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Competence Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.07	2.00
Maternal HQL[a]	.04	.08	.08	.13	.08		
Family Functioning[b]	-.33	.19	-.23	-.25	-.23		
Step 2						.22	16.39**
Interaction Term	-.03	.01	2.64**	.06	.48**		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on the SF-36 scale. Higher scores indicate better HQL.

[b] Adolescent report on the FAM-III Self-Report .

*$p<.05$. **$p<.001$.

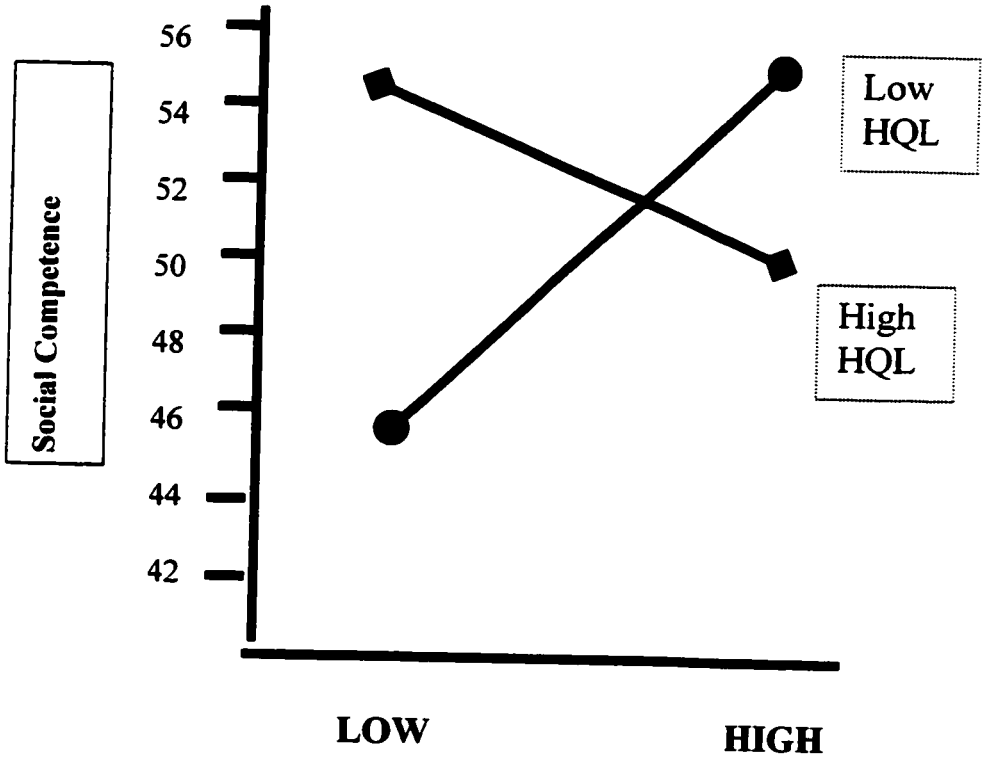

Figure 2. Representation of adolescent self-reports of social competence as a function of maternal health-related quality of life and adolescent reports of family functioning.

Equations involving Total Problem scores as the dependent variable are presented in Tables 21-30. In all cases, the model involving the disease and moderator variables was significant. However, no significant or near-significant interaction terms were observed, as evidenced by non-significant ΔR^2 and β values in the final step of the model. Thus the hypothesized moderating relationship between the variables were not supported.

Summary of Primary Analyses.

In summary, the majority of the hypothesized moderating influences in the relationship between disease and outcome measures were not supported in the current sample. Although as expected, disease, parent psychological and family variables significantly predicted adolescent and mother reports of adolescent psychological functioning, the nature of the relationships was generally not as predicted. The exception to this was observed in the relationship between certain disease factors, adolescent reports of their functioning within the family, and adolescent reports of their own social competence. Specifically, poorer maternal HQL in the presence of greater problems with adolescent role functioning was associated with reports of poorer social competence on the YSR, controlling for maternal education and family income. When adolescents reported high family functioning, however, no such relationship was observed. These analyses support the hypothesis that adolescent role functioning within the family moderates the

influence of maternal HQL and adolescent cancer concerns upon adolescent social competence.

Table 22

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Total Problem Scores from Adolescent Risk Perceptions and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.24	8.65**
Risk Perception[a]	-.15	.45	-.04	-.14	-.05		
Family Functioning[b]	.50	.13	.48**	.49**	.47**		
Step 2						<.01	.10
Interaction Term	-.01	.06	-.31	.19	-.04		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent received risk for breast and other cancers on the BCS Risk Perception scale.

[b] Adolescent report on the FAM-III Self-Report Scale.

*p<.05, **p<.001.

Table 23

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Total Problem Scores from Adolescent Severity Perceptions and Maternal Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						.01	.12
Maternal Education	.78	.77	.14	.07	.14		
Family Income	.10	.43	.03	<-.01	.03		
Step 2						.10	2.90
Severity Perception[a]	1.58	3.52	.49	.13	.06		
Maternal Distress[b]	.51	.87	.66	.26	.08		
Step 3						<.01	.10
Interaction Term	-.02	.07	-.49	.27	-.05		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent perceptions of breast cancer severity on BCS Severity Perception scale.

[b] Maternal self-report on the SCL-90-R, GSI scale.

*p<.05, **p<.001.

Table 24

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Total Problem Scores from Adolescent Severity Perceptions and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.18	6.09*
Severity Perception[a]	.23	.38	.07	.10	.08		
Family Functioning[b]	.46	.13	.42**	.42**	.42**		
Step 2						<.01	<.01
Interaction Term	<.01	.07	-.09	.31	-.01		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent perceptions of breast cancer severity on the BCS Severity Perception scale.

[b] Adolescent report on the FAM-III Self-Report.

*$p<.05$, **$p<.001$.

Table 25

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Total Problem Scores from Adolescent Cancer Concerns and Maternal Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						<.01	.01
Maternal Education	.08	.80	.02	.01	.01		
Family Income	-.07	.46	-.02	-.02	-.02		
Step 2						.13	3.73*
Cancer Concerns[a]	.68	.44	.21	.21	.21		
Maternal Distress[b]	.24	.11	.30*	.28	.29		
Step 3						.01	.38
Interaction Term	-.03	.05	.64	.35	.09		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent cancer concerns on the BCS Cancer Concerns scale.

[b] Maternal self-report on the SCL-90-R, GSI scale.

*p<.05, **p<.001.

Table 26

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Total Problem Scores from Adolescent Cancer Concerns and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.28	10.89**
Cancer Concerns[a]	.69	.38	.21	.21	.24		
Family Functioning[b]	.51	.12	.49**	.49**	.50**		
Step 2						<.01	.10
Interaction Term	-.02	.04	.20	.44**	.04		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent cancer concerns on the BCS Cancer Concerns total score.

[b] Adolescent report on the FAM-III Self-Report Scale.

*p<.05. **p<.001.

Table 27

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1 (covariates)						<.01	.01
Maternal Education	.08	.80	.02	.01	.01		
Family Income	-.06	.46	-.02	-.02	-.02		
Step 2						.10	2.79
Maternal HQL[a]	-.06	.07	-.15	-.27*	-.12		
Maternal Distress[b]	.17	.14	.21	.28*	.17		
Step 3						<.01	.17
Interaction Term	<.01	.01	-.33	-.09	-.06		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on the SF-36 scale. Higher scores indicate better HQL.

[b] Maternal self-report on the SCL-90-R, GSI scale.

*p<.05. **p<.001.

Table 28

Hierarchical Multiple Regression Equations to Test for Moderation, Predicting YSR Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Step 1						.26	9.78**
Maternal HQL[a]	-.06	.05	-.26	-.27	-.18		
Family Functioning[b]	.47	.12	.45**	.49**	.45**		
Step 2						<.01	.16
Interaction Term	<.01	.01	-.26	.02	-.05		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on the SF-36. Higher scores indicate better HQL.

[b] Adolescent report on FAM-III, Self-Report scale.

*p<.05. **p<.001.

Secondary Analyses

The primary analyses indicated that, as predicted, there were a number of significant associations between the variables examined in the current study, although the nature of the relationships were generally not as hypothesized (i.e., very few moderating effects were observed). To further explore the significant associations observed between variables, post hoc analyses were undertaken. Moderating analyses were planned in the current study as recommended by Baron and Kenny (1986) because of the inconsistent relationships between variables observed in the literature to date. However, unexpectedly high correlations between several study variables observed in this sample of breast cancer patients and their daughters suggested that some of the variables may be best described by a mediational model of association (Baron & Kenny, 1986; Holmbeck, 1997).

A moderator variable "is one that affects the relationship between two variables, so that the nature of the impact of the predictor on the criterion varies according to the level or value of the moderator" (Holmbeck, 1997, p. 599). In contrast, a mediator specifies the mechanism by which a given effect occurs (Baron & Kenny, 1986). This is conceptually equivalent to a relationship where the independent variable influences the mediator, which in turn influences the criterion variable.

The test for mediation is similar to that used when conducting a path analysis (Cohen & Cohen, 1983). Baron and Kenny (1986) described the four conditions which must be met for a variable to be considered a mediator. These are: (1) a significant relationship must exist between the predictor and the outcome variables; (2) the predictor and mediator must be significantly associated; (3) the mediator and outcome variables must also be significantly associated, and; (4) the relationship between the predictor and outcome variables must be

reduced to zero (full mediation) or closer to zero (partial mediation) when the mediator is controlled for. An illustrative example of a mediational relationship between HQL, Distress, and Adolescent functioning is provided in Figure 3.

The number and degree of significant zero-order associations between predictor and outcome variables suggested that the variables that were previously hypothesized as moderators might in fact be mediators. Specifically, maternal HQL was observed to be significantly associated with both maternal distress and family functioning, as well as with the outcome measures (CBCL and YSR total problem scores). To maintain the theoretical integrity of the analyses (i.e., to minimize "data-snooping"), secondary analyses were restricted to equations where relationships were previously hypothesized to exist, but were not observed to be associated in the expected manner. Thus, variables were entered into equations with one another if: (1) the predictor and mediator were significantly associated with one another and with the outcome variable (see above criteria for mediation), and (2) they were entered together previously into tests of moderating hypotheses as described in the preceding section. Thus, a total of four tests for mediation relationships were conducted. Previously identified covariates were entered first into multiple regression equations where appropriate and as indicated in Tables 29-32.

Mother Reports of Adolescent Psychological Problems.

With respect to the prediction of CBCL problem scores, analyses were conducted as recommended by Baron and Kenny (1986) and Holmbeck (1997) and as demonstrated by Grant and Compas (1995) and Biggar and Forehand (1998). As shown in Table 29, maternal distress met the criteria for mediational association in the relationship between maternal HQL and

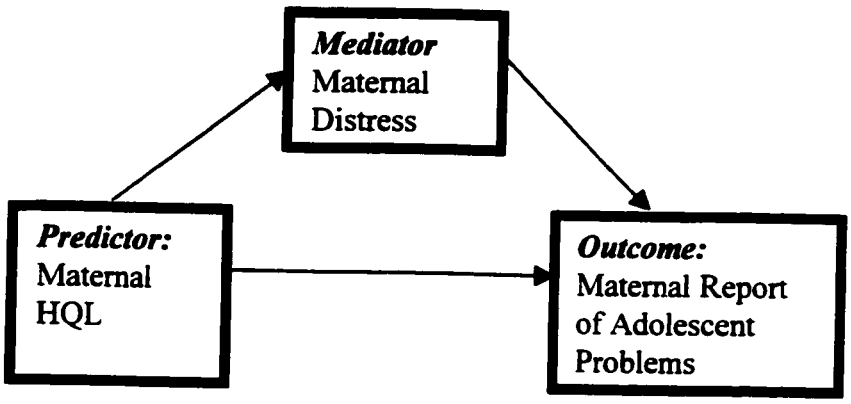

Figure 3. Diagrammatic Representation of the Relationship between Maternal HQL, Maternal Distress, and Maternal Report of Adolescent Problems.

adolescent psychological functioning. First, the relationship between maternal HQL (the independent variable) and the mediator (maternal distress), was found to be significant when controlling for appropriate covariates, $F(1,52) = 32.40$, $p<.001$, $R^2 = .34$. Second, the relationship between the independent variable (HQL) and the dependent variable (CBCL problem scores) was significant, $F(1, 52) = 6.37$, $p<.02$, $R^2 = .10$. Third, the effect of the mediator (maternal distress) on the dependent variable (CBCL problem scores) was significant, $F(1, 52) = 27.37$, $p<.001$. Fourth, the independent variable (HQL) no longer predicted a significant amount of the variance once the mediator was included in the equation, $F(2,51) = .14$, $p<.80$. Thus, the results of these analyses suggest that maternal distress mediates (i.e., explains the variance in) the relationship between maternal HQL and CBCL total problem scores.

Maternal reports of problematic family functioning (MFAM scores) were also significantly associated with both maternal HQL, ($r = -.37$, $p<.001$) and CBCL ($r = .37$, $p<.05$) total problem scores. Thus this variable was also tested as a possible mediator in the HQL-CBCL relationship (See Table 30). Although multiple regression analyses controlling for maternal age at diagnosis confirmed these variables met the criteria for mediation at the first and second steps of the analysis, the inclusion of MFAM to the regression equation predicting CBCL scores from HQL scores did not significantly reduce the unique contribution of HQL to YSR scores. That is, HQL remained a significant predictor in the equation, $F(3,55) = 4.97$, $p<.05$, and MFAM is not a mediator of the relationship between HQL and CBCL problem scores.

Table 29

Hierarchical Multiple Regression Equations to Test for Mediation Predicting CBCL Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Mediation Step 1: Dependent Variable = Maternal Distress[a]							
Block 1 (covariates)						.11	2.07
Maternal age at diagnosis	-.12	.26	-.06	-.12	-.06		
Maternal education	-1.8	.94	-.25	-.29	-.25		
Family income	-.45	.55	-.11	-.20	-.11		
Block 2						.34	32.40**
Maternal HQL[b]	-.31	.05	-.60**	-.63**	-.62**		
Mediation Step 2: Dependent Variable = CBCL Total Problem Score							
Block 1 (covariates)						.11	2.08
Maternal age at diagnosis	-.63	.27	-.31*	-.32*	-.30*		
Maternal education	.07	.10	.07	-.04	-.01		
Family income		-.21	.58	-.05	-.13	-.05	
Block 2						.09	6.37*
Maternal HQL	-.17	.07	-.32*	-.30*	-.33*		

Table continues...

Table 57, continued.

Hierarchical Multiple Regression Equations to Test for Mediation Predicting CBCL Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Mediation Steps 3 & 4: Dependent Variable = CBCL Total Problem Score							
Block 1 (Covariates)						.11	2.08
Maternal age at diagnosis	-.63	.27	-.31*	-.32	-.30		
Maternal education	.06	.98	.01	-.04	.01		
Family income	-.21	.58	-.05	-.13	-.05		
Block 2						.31	13.46**
Maternal HQL	.03	.08	.05	-.30*	.05		
Maternal distress	.65	.15	.62**	.57**	.52**		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on the SCL-90-R. GSI scale.

[b] Maternal self-report on the SF-36. Higher scores indicate better HQL.

*$p<.05$. **$p<.001$.

Table 30

Hierarchical Multiple Regression Equations to Test for Mediation Predicting CBCL Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Mediation Step 1: Dependent Variable = Family Functioning[a]							
Block 1 (covariates)						.12	7.71*
Maternal age at diagnosis	-.57	.20	-.35*	-.35*	-.35*		
Block 2						.15	11.42**
Maternal HQL[b]	-.17	.05	-.39**	-.37*	-.41**		
Mediation Step 2: Dependent Variable = CBCL Total Problem Score							
Block 1 (covariates)						.11	7.00*
Maternal age at diagnosis	-.67	.25	-.33*	-.33*	-.33*		
Block 2						.08	6.63*
Maternal HQL	-.17	.07	-.31*	-.29*	-.33*		
Mediation Steps 3 & 4: Dependent Variable = CBCL Total Problem Score							
Block 1 (Covariates)						.11	7.00*
Maternal age at diagnosis	-.67	.25	-.33*	-.33*	-.33*		
Block 2						.10	3.63*
Maternal HQL	-.14	.07	-.26*	-.29*	-.26*		
Family functioning	.14	.17	.12	.32*	.11		

Table 30, continued.

Hierarchical Multiple Regression Equations to Test for Mediation Predicting CBCL Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal report.

[b] Maternal self-report. Higher scores indicate better HQL.

*$p<.05$, **$p<.001$.

Adolescent Self-Report of Psychological Problems.

Similar analyses were conducted to test whether maternal distress and adolescent reports of their own functioning within the family mediate the relationship between HQL and YSR scores. With respect to maternal distress, the relationships between this variable (the mediator) and maternal HQL, $F(1,52) = 31.75, p<.001$, $R^2 = .62$, as well between the mediator and YSR scores, $F(1,57) = 4.35, p<.05$, $R^2 = .27$, were significant, thus fulfilling criteria for steps 1 and 2 of the analysis. However, when maternal distress was added to the regression equation predicting YSR scores from HQL scores, neither the independent nor mediating variable contributed uniquely to the equation when controlling for covariates. Thus, maternal distress is not a mediator of the relationship between maternal HQL and adolescent reports of their own functioning (See Table 31).

Adolescent reports of family functioning (AFAM) were then tested as a mediator in the HQL-YSR relationship. As shown in Table 32, HQL and AFAM scores were associated at a level that approached significance, $F(1,57) = 3.29, p=.07$, $R^2 = .23$. HQL and YSR were also significantly related, $F(1,57) = 4.35, p<.05$, $R^2 = .27$, thus fulfilling criteria for the 1st and 2nd steps of the analysis. Third, the effect of AFAM on YSR scores was significant when controlling for HQL, $F(2,56) = 9.96, p<.001$. Fourth, the association between HQL and YSR scores dropped to nonsignificance when AFAM was added to the regression equation, $F(2,56) = 1.88, p = .18$. Therefore these analyses support the hypothesis that AFAM mediates the relationship between HQL and YSR scores.

Table 31

Hierarchical Multiple Regression Equations to Test for Mediation Predicting YSR Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Mediation Step 1: Dependent Variable = Maternal Distress[a]							
Block 1 (covariates)						.10	3.05
Maternal education	-1.77	.93	-.26	-.29*	-.25		
Family income	-.51	.53	-.13	-.20	-.13		
Block 2						.34	31.75**
Maternal HQL[b]	-.31	.05	-.59**	.63**	-.61**		
Mediation Step 2: Dependent Variable = YSR Total Problem Score[c]							
Block 1 (covariates)						<.01	.01
Maternal education	.08	.80	.02	.01	.01		
Family income	-.06	.46	-.02	-.02	-.02		
Block 2						.07	4.07*
Maternal HQL	-.11	.06	-.27*	-.26*	-.27*		

Table continues...

Table 31, continued.

Hierarchical Multiple Regression Equations to Test for Mediation Predicting YSR Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Distress.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Mediation Steps 3 & 4: Dependent Variable = YSR Total Problem Score							
Block 1 (Covariates)						<.01	.01
Maternal education	.08	.80	.02	.01	.01		
Family income	-.06	.46	-.02	-.02	-.02		
Block 2						.10	2.79
Maternal HQL	-.06	.07	-.15	-.26	-.12		
Maternal distress	.17	.14	.21	.28	.17		

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; *r* = zero-order correlation with dependent variable, *pr* = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Maternal self-report on the SCL-90-R, GSI scale.

[b] Maternal self-report on the SF-36. Higher scores indicate better HQL.

*p<.05, **p<.001.

Table 32

Hierarchical Multiple Regression Equations to Test for Mediation Predicting YSR Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Variable	B	SE B	β	*r*	*pr*	ΔR^2	F(cha)
Mediation Step 1: Dependent Variable = Family Functioning[a]							
Block 1						.06	3.29†
Maternal HQL[b]	-.09	.05	-.23†	-.23†	-.23†		
Mediation Step 2: Dependent Variable = YSR Total Problem Score							
Block 1						.07	4.35*
Maternal HQL	-.11	.05	-.27*	-.27*	-.27*		
Mediation Steps 3 & 4: Dependent Variable = YSR Total Problem Score							
Block 1						.26	9.96**
Maternal HQL	-.06	.05	-.16	-.27	-.18		
Family functioning	.47	.12	.25*	.49**	.45**		

Table continues...

Table 32, continued.

Hierarchical Multiple Regression Equations to Test for Mediation Predicting YSR Total Problem Scores from Maternal Health-Related Quality of Life (HQL) and Family Functioning.

Note. B = unstandardized beta-coefficient for variable at entry into equation; β = standardized beta-coefficient for variable at entry into equation; r = zero-order correlation with dependent variable, pr = partial correlation with dependent variable, controlling for other variables in step; ΔR^2 = change in R^2 at entry; F value is that associated with change in R^2 at entry.

[a] Adolescent report on the FAM-III Self Report Scale.

[b] Maternal self-report on the SF-36. Higher scores indicate better HQL.

*p<.05. **p<.001.

† p = .07

Summary of Secondary Analyses.

Maternal Health-Related Quality of Life (HQL) was significantly associated both with other predictors and with the criterion variables in the current study. Furthermore, the nature of zero-order correlations suggested that previously hypothesized moderating variables might act in a mediational manner in the current sample. Therefore, a limited number of multiple regression analyses were conducted to further examine the nature of the relationship between study variables. These analyses suggested that maternal distress levels mediate the relationship between maternal HQL and maternal reports of adolescent problems. The relationship between maternal HQL and adolescent reports of their own problems (YSR) appears to be mediated by adolescent self-reports of functioning within the family.

Discussion

Qualitative and quantitative data from a variety of sources have suggested that adolescent daughters of breast cancer patients are at increased risk for psychological problems both during and after their mothers' illness. A variety of plausible mechanisms have been posited to explain this, including speculation on the role of increased personal vulnerability to the disease, increased responsibilities as a result of maternal illness, and other individual and family factors. To date, however there has been no substantive investigation into the unique correlates of adjustment in this population. The current study therefore was an attempt to clarify previous findings by more closely examining some of the disease, family and individual factors associated with adjustment in adolescent daughters of breast cancer patients. Results are briefly summarized below. Following this, findings are reviewed in light of existing research in the areas of: (1) disease appraisals and health-related quality of life (HQL), (2) maternal distress, and (3) family functioning. Limitations of this study and directions for future research are then considered. Finally, clinical implications are discussed.

Data were collected an average of 2 ½ years post-diagnosis for non-metastatic breast cancer. Overall, the data are consistent with previous research examining children and adolescent adjustment to parent illness. As a group, this sample of mothers and their adolescent daughters were functioning as well as normative samples on measures of maternal distress, family functioning, and adolescent psychological functioning. Like other mothers and daughters, those in the current sample displayed fairly low levels of agreement about the nature of adolescent problems.

Responses on the Breast Cancer Survey indicated that adolescent daughters of breast cancer patients view the disease as serious, see themselves as at risk, and report moderate levels of concern about the disease. Although girls did not report that thoughts of the disease interfered with their daily lives, the results nevertheless suggest that issues of personal risk are salient for daughters of breast cancer survivors.

Approximately 2 ½ years post-diagnosis, mothers in our sample were enjoying HQL comparable to that reported by healthy women in the general population. As predicted, however, women who experienced poorer HQL were more likely to report higher levels of distress and more problems with family and adolescent psychological functioning. Poorer maternal HQL was also associated with adolescent reports of increased psychological problems.

Maternal distress and family functioning were proposed as moderators of the relationship between disease factors (HQL, adolescent perceptions of risk and disease severity, and cancer concerns) and adolescent functioning. These hypotheses were formulated based upon the literature in the area of child and adolescent adjustment to parent illness, in which inconsistent relationships between these or similar constructs have been observed (Holmbeck, 1997). In the current study, it was expected that negative appraisals of the disease would be associated with adolescent psychological problems in the presence of increased maternal distress and more problematic family functioning.

Although significant relationships were observed in the predicted direction, overall the data did not support the hypothesized moderating role of maternal distress. With respect to family functioning, however, results supported the hypothesis that adolescent reports of their own functioning within the family moderate the relationship between maternal HQL and

adolescent reports of their social competence. Specifically, adolescents who reported more problems with family functioning and whose mothers experienced poorer HQL were more likely to report lower competence levels on the YSR. Moderating relationships were not observed when mother reports of family functioning or adolescent problems and competencies, nor when adolescent reports of psychological symptoms (e.g., symptoms of anxiety, depression, attention problems, etc.) were investigated.

Further analyses indicated that, rather than acting as moderators, maternal distress and family functioning acted as mediators (i.e., explained the variance) in the relationship between disease factors and adolescent psychological problems. HQL was significantly associated both with adolescent and maternal reports of adolescent symptoms. This relationship was mediated by different variables, however, depending upon the informant surveyed. Specifically, results suggested that maternal distress levels explain the association between HQL and maternal reports of adolescent functioning (on the CBCL), but do not explain the significant association between HQL and adolescent reports of psychological adjustment (on the YSR). In contrast, the critical variable in predicting adolescent reports of problems was adolescent reports of their own functioning within the family.

The Role of Disease Appraisal and HQL

The results of the current study are consistent with those in the pediatric and adult illness literatures in their demonstration of the relatively poor predictability of psychological outcomes based on objective disease characteristics. In the current investigation, biological disease indices such as stage of cancer and treatment variables were not correlated with maternal or adolescent psychological functioning measures. This is consistent with results reported by Compas and

associates (Compas et al., 1994; Compas et al., 1996), Lewis and Hammond (1996), and with those reported in the literature on adjustment to childhood illness (DeMaso et al., 1991; Hurtig, Keopke, & Park, 1989; Murch & Cohen, 1988) and patient adjustment to breast cancer (Northouse et al., 1999).

Only one disease-related variable, maternal age at diagnosis, was negatively related to Total Problem and Externalizing scores on the CBCL. In this sample of adolescents and their mothers, this finding may be explained in several ways. First, women who were younger at diagnosis may have experienced greater disruptions to their career and family lives. If this were the case, however, one would expect that maternal age (and not just age at diagnosis) would also be negatively related to adjustment, which was not observed in the current sample. A second explanation is that age of diagnosis is a variable that reflects the length of time that a family has been coping with the threat of illness. However, because length of time since treatment was not associated with outcome measures, this explanation is also not entirely consistent with the data. Third, children who were younger when their parents were diagnosed may have been more negatively affected by the diagnosis. As discussed previously, however, this explanation is inconsistent with the bulk of findings in the literature to date. Nevertheless, further research must therefore attempt to replicate and clarify this association.

Taken together, however, the results of this study indicate that perceptions of breast cancer and its impact are most useful in predicting adjustment to illness for patients and their families. The SF-36, as a self-report instrument, can be considered a measure of illness appraisal which includes both objective (e.g., how much has the mother's health limited her ability of walk several blocks, bathe and dress herself, etc.) and subjective (e.g., how much pain, fatigue, etc.,

has she recently experienced) components. Women with poorer HQL were more likely to experience increased psychological distress in the current study. This is consistent with results reported in adult-focused literature which have repeatedly demonstrated a link between the ability to carry out daily activities and patient distress (e.g., Davis et al., Northouse et al., 1998; Walker et al., 1999).

Until now, few researchers in this area have examined patient HQL as a predictor of adjustment to parent illness. Only Lewis and Hammond (1996) looked at a similar construct, the "demands of illness" (Haberman, Woods & Packard, 1990). This construct, however, is limited to the practical demands of an illness such as time taken for doctors' appointments, etc., and does not include other potential components of HQL such as appraisals of pain and fatigue levels. Whereas in the Lewis and Hammond (1996) study, illness demands were not related to maternal depression, in the current sample HQL was negatively correlated with maternal psychological distress. In fact the two measures shared 44% of the variance in scores, even though scales directly related to emotional adjustment were removed from the HQL questionnaire. This underscores the need to evaluate patient perceptions of the impact of illness in future studies examining family coping with illness.

Adolescent perceptions of disease severity were also measured. Contrary to expectation, however, they were not predictive of adolescent psychological functioning. These results contrast with those reported by Compas and associates (Compas et al., 1994; Compas et al., 1996), who found that child and adolescents who appraised their parents' illness as more severe experienced more symptoms of distress. Two explanations may be offered for this discrepancy. First, Compas et al. interviewed participants approximately two months post-diagnosis, when the

parent was still undergoing treatment. As such, disruptions to the daily life of the family caused by the disease would likely be greater. Second, participants in the Compas et al. study were asked to rate the severity of the cancer "at this time". In constrast, adolescents in the current study were asked to rate the severity of the disease in general and after their mothers had finished treatment.

Given their increased biological vulnerability, however, it was expected that adolescent perceptions of heightened personal risk would be associated with psychological distress (Worsham et al., 1997). It is especially important to investigate the impact of personal risk perceptions and biological vulnerability to breast cancer given the recent introduction of genetic testing for BRCA1 and BRCA2 genes (Easten et al., 1993). This issue has become a topic of debate amongst medical ethicists (Werz, Fanos, & Reilly, 1994) and genetic counselors (Elger & Harding, 2000). The key question centers around deciding whether knowing that one carries a breast cancer susceptibility gene will lead to unmanageable psychological distress for an adolescent, or whether knowing this risk will help initiate prevention or early detection strategies. Unlike with adult samples, however (Gilbar & Borvik, 1998; Zakowski et al, 1997), in this study adolescent risk perceptions were generally not associated with adolescent psychological symptoms.

Despite reporting perceptions of increased personal risk, overall this sample of adolescent girls was doing well and results suggest that they were not significantly affected by this perceived risk. Two explanations may be offered for this finding. First, as is observed with respect to adolescent risk-taking behaviours such as engaging in unprotected intercourse or using illicit substances, the young women in this sample may have felt themselves to be invulnerable

(a "personal fable", Elkind, 1967; Thornburg, 1982). An alternative explanation is that adolescent girls in the current sample are resilient in the face of the knowledge of their increased personal risk. If this is so, it is important to explore with future research exactly *how* these young women are able to adapt to their heightened risk for breast cancer.

More proximal causes such as currently or recently experienced stressors may be better predictors of adolescent adjustment at a particular time. Consistent with this, Compas, Howell, Phares, Williams, and Giunta (1989) found that recently-experienced stressful events were the best predictors of adolescent self-reports of problems on the YSR, controlling for previous levels of distress. Personal risk perceptions may therefore take on greater significance at the time of diagnosis, when the mother dies from the illness, or in adulthood when issues of prevention and early detection become more salient (Gilbar, 1998).

The Role of Maternal Distress

Results of this study are consistent with the hypothesis that maternal HQL is related to adolescent daughters' adjustment through maternal distress and family functioning. Furthermore, they suggest that the role of each may vary by informant. Results pertaining to each of the proposed moderators, maternal distress and family functioning, are considered in turn below.

Maternal distress was expected to moderate the relationship between disease factors and adolescent adjustment such that heightened maternal distress in combination with more negative disease appraisals would best predict adolescent psychological functioning. This hypothesis was derived in part from research by Biggar and Forehand (1998), who found that maternal depressive symptoms moderated the relationship between disease status (HIV positive versus

HIV negative) and child depressive symptoms in an African American sample. In contrast, maternal distress mediated the relationship between disease factors and adolescent distress in the current sample.

Two explanations may be offered for these discrepant findings. First, differences in samples (African American versus primarily Caucasian, child versus adolescent groups) and/or disease characteristics (HIV versus breast cancer) between these studies may explain observed differences. Second, although the current study was designed to measure similar variables to those in the Biggar and Forehand study, it is possible that differences in the underlying constructs measured in the two studies differed. For example, whereas in the current study a number of different subjective disease experiences were measured, in the Biggar and Forehand study, the disease predictor was dichotomous (presence versus absence of HIV). Furthermore, whereas the current study employed a broad definition of psychological distress and adjustment, Biggar and Forehand targeted maternal and child depressive symptoms. Because most variables can be conceptualized as both mediators and moderators, depending upon other variables in the model (Holmbeck, 1997), it is possible that the current results reflect this statistical condition.

Biggar and Forehand also found significant differences between the HIV group and the non-illness control group on outcome measures. In contrast, the current sample of adolescent daughters of breast cancer patients did not differ from normative groups on measures of psychological functioning. Whereas in this study measures were completed post treatment for non-metastatic illness, women in the Biggar and Forehand study were experiencing symptoms of AIDS. In this way, the currently-experienced manifestations of the disease and/or awareness of the fatality of AIDS may explain differences observed in this study.

In the current sample, mother and adolescent appraisals of the threat of breast cancer had no doubt receded since termination of treatment for the disease. Consistent with this, Rolland (1999) emphasized the importance of considering not only individual developmental factors, but also those associated with practical and emotional demands that vary over the course of the disorder. Thus, changes in disease-related functioning experienced by the patient may have direct effects on family members' adjustment scores. Consistent with this interpretation, Thomas, Forehand and Neighbors (1995) found that increased symptoms of maternal depression across one year predicted teacher reports of increased problems and lower social competence in adolescents, above that which was predicted by initial levels of depressed mood.

In the current study, the SCL-90-R GSI scale was chosen as a measure of generalized maternal distress. Although others have targeted maternal depression (e.g., Biggar & Forehand, 1998; Lewis and Hammond, 1996), the results of this and previous studies demonstrate the utility of including a broader definition of distress. Whereas Lewis and Hammond (1996) did not find an association between maternal depression and adolescent self-esteem in families coping with breast cancer, GSI scores in the current study were significantly associated with maternal and adolescent reports of global adolescent adjustment. This is consistent with results reported by Lee and Gotlib (1989) and Dickstein et al. (1998), who found that nonspecific indicators of maternal psychopathology were more strongly related to child adjustment than were specific diagnostic categories.

Although causal inferences based on correlational data must be made with caution, the results of this study are nevertheless consistent with the hypothesis that subjective maternal experiences of distress influence her appraisal of her daughter's adjustment. In the current study,

maternal GSI scores explained the variance (mediated) the relationship between maternal reports of HQL and maternal reports of adolescent psychological functioning. At the zero-order level, GSI scores predicted 31% of the variance in CBCL scores. These results are consistent with those reported by Compas and associates (1989), who found that GSI scores were significantly associated with CBCL scores.

In contrast to previous findings (Compas et al., 1989), GSI scores were also significantly correlated with YSR scores in the current sample. Unlike the relationship between HQL, GSI and CBCL scores, however, maternal distress did not mediate the relationship between HQL and YSR scores. Although significant, YSR and GSI scores shared only 8% overlap in variance. Instead, adolescent reports of their own functioning were best explained by other family-level variables, discussed below.

The Role of Family Functioning

Adolescent reports of their functioning within the family were measured with the self-report version of the FAM-III (AFAM). As discussed in the methods section, whereas the General version, completed by mothers (MFAM) assesses maternal perceptions of the family as a whole (e.g., "we spend too much time arguing about what our problems are", "when problems come up, we try different ways to solve them", "we tell each other about things that bother us"), the AFAM was designed to tap adolescent perceptions of how she functions relative to others and the unit as a whole. Examples of items on the AFAM are: " My family knows what I mean when I say something", "when my family has a problem, I have to solve it", and "I'm not as responsible as I should be in the family". Thus, this version appears to measure the adolescent's feelings of being loved, understood and appreciated in the family, and also includes a component

of role functioning. In this way, the AFAM resembles the "family responsibilities and role strain" construct measured by the APES (Adolescent Perceived Event Scale; Compas, Davis, Forsythe & Wagner, 1987).

As predicted, AFAM scores moderated the relationship between certain disease factors and adolescent self-reports of their competence on the YSR. The YSR Competence scale assesses adolescents' participation in extracurricular activities, number of friends, and academic performance relative to other girls her age. The analyses reported here indicate that poor maternal HQL in the presence of increased problems with family functioning significantly predicted poorer total competence scores on the YSR. Neither HQL nor AFAM scores alone predicted competence scores.

One explanation for these findings is that adolescents were able to engage in fewer social and extracurricular activities because of greater role responsibilities resulting from poorer maternal HQL. Consistent with this interpretation, adolescent girls have reported high rates of role strain (Bird & Harris, 1990), which has also been associated with adolescent adjustment to parental cancer (Grant & Compas, 1995). Viewed another way, these findings point to healthy adolescent role functioning as a protective factor against adjustment problems when mothers have health-related problems.

Secondary analyses also indicated an important role for adolescent reports of functioning within the family in predicting psychological symptoms. Rather than acting in a moderating fashion, these analyses supported the hypothesis that AFAM scores mediated the significant relationship between maternal HQL and Total Problem scores on the YSR. Although the datae are consistent with the hypothesis that adolescent perceptions of role functioning problems cause

adolescent adjustment problems (Baron & Kenny, 1986; Holmbeck, 1997), it must be emphasized that the data reported here were collected at one point in time and are correlational in nature. Thus no causal inferences can be made. For example, although it was assumed that maternal HQL problems would influence family functioning (which in turn would influence adolescent adjustment), it is possible that the reverse is true. These issues may be addressed with longitudinal studies.

When other reports of family functioning and adolescent adjustment were considered, however, the relationship between HQL and adolescent functioning was not observed. Specifically, when maternal reports of general family functioning were added to the equation predicting CBCL Total Problems scores from HQL, HQL remained a significant predictor. As discussed previously, maternal distress rather than family functioning accounted for the variance in CBCL scores predicted by HQL. Again, this underscores the assertion that psychological outcomes are likely to be highly influenced by the perceptions of individual informants.

Overall, these results are consistent with previous research that has provided evidence for family factors as important predictors of child and adolescent adjustment (e.g., Cappelli et al., 1989; Furhman & Holmbeck, 1995; Murch & Cohen, 1989). However, the precise role of family functioning in families coping with illness remains unclear. Whereas Furhman and Holmbeck (1995) and Murch and Cohen (1989) observed that family environment factors moderated the impact of stressful events (Murch & Cohen, 1989) and emotional autonomy (Furhman & Holmbeck, 1995) on emotional adjustment, the current results and those reported elsewhere suggest that family-level variables play a mediational role in predicting adolescent girls' adjustment when parents are ill.

As discussed previously, these discrepancies may be explained from a statistical standpoint, and thus related to which variables are proposed as moderators/mediators relative to others in the model (Holmbeck, 1997). A second possibility is that methodological differences exist between studies finding moderating versus mediating effects. Specifically, both Grant and Compas (1995) and the current study used adolescent self-reports of their own role functioning in the family. In contrast, Furhman and Holmbeck (1995) and Murch and Cohen (1989) used adolescent reports of the family environment in general. It seems plausible that adolescent self-reports of psychological problems share greater variance with adolescent perceptions of their own role functioning than with assessments whole-family functioning.

This raises a general issue in the literature examining the relationship between family functioning and individual psychological adjustment. Specifically, in the research reviewed here, family functioning is defined and measured in a variety of ways. Although there are several commonly-used family measures such as the FACES (Olsen et al., 1983), F-COPES (McCubbin, Larsen & Olsen, 1982), FAD (Epstein, Baldwin & Bishop, 1982), and FES (Moos & Moos, 1981), it is unclear how these measures might overlap and what essential components of family functioning might be. Although results from the pediatric and adult literature have emphasized family process variables such as communication (Mesters et al., 1997; Hilton, 1994) and cohesion (Drotar, 1997), many have also observed weak or inconsistent associations between specific family qualities and individual outcomes (Davis, Brown, Bakeman & Cambell, 1998; Lewis and Hammond, 1996; Lewis et al., 1989).

Furthermore, the distinction between family functioning and family coping bears clarification. In the Lewis and Hammond (1996) study of adolescent adjustment to maternal

breast cancer, for example, both family functioning (FACES-II) and family coping (F-COPES) were measured as predictors of other variables in the model. It is unclear, however, how family functioning is qualitatively different from family coping. Consistent with this, Lewis and Hammond (1996) found that family coping was correlated with family functioning at the $p<.001$ level. Thus, future psychometric research must aim to clarify these conceptual inconsistencies (Kazak, 1997).

Limitations of this Study and Directions for Future Research

This study included the largest number of adolescent daughters of breast cancer patients studied to date, and has provided some evidence of the mechanisms for explaining adjustment in this population. Examination of disease perceptions and maternal HQL has helped to clarify some issues raised in previous research and will provide interesting avenues for future research. The inclusion of multiple informants of similar constructs has likewise shed light upon certain methodology-based discrepancies observed in previous research. Nevertheless, there are a number of limitations to the current study that require discussion. These will be outlined in the following section, which includes several suggestions for building on these findings via future research.

Mothers were included in the current study if they were post-treatment for early-stage breast cancer. This criterion was selected in order to examine the correlates of risk appraisal in adolescent girls without the potential confound of anticipated bereavement. The selection of participants based on these criteria, however, necessarily limits the generalizability of results. Thus it is possible that the relationships between maternal HQL and other study variables was attenuated because mothers were generally enjoying good physical, occupational, and social

quality of life.

Inclusion criteria for the current study included restricting participants to those diagnosed with Stage I or Stage II (i.e., less severe) disease. Although this criterion was selected in order to increase the homogeneity of the sample, it also limits generalizability of the findings. Women with more advanced stages of cancer might differ from those in the current sample in a number of important ways, including their attitudes towards health care behaviours, for example with respect to their vigilance about having regular mammograms and breast examination habits.

The sample included here, although representative of families in Ontario, was largely Caucasian, dual income, and of high SES. Thus, the results may not be generalizable to families living in other ethnic, economic, and/or geographical contexts. Although recent studies have targeted African Americans coping with illness (e.g., Biggar & Forehand, 1998; Northouse et al., 1999), efforts must also be directed toward examining these issues in Canadian minority groups.

A dropout rate of 36% (21/81 families) was observed in the current study and must also be considered a limitation of this research. Although data were not collected regarding reasons for dropping out, it is possible that the length of the questionnaire package (all measures were full, rather than abbreviated, versions) might have contributed to the attrition rate. Alternately, participants may have found the questions asked too personal, especially those on the BCS. Although other data indicate that this sample is representative of families in Ontario, the attrition rate of this study further limits the generalizability of findings.

Compared to other studies (e.g., Grant and Compas, 1995; Lewis et al., 1996) which have included adolescent between the ages of 11-20, this study employed a relatively restricted

age range of 12-18. This criterion was selected in order to conform to age ranges for norms on outcome measures, and also to ensure a relatively homogeneous sample while maintaining sufficient generalizability of results. Although predictor and outcome measures did not covary with adolescent age, there are nevertheless good reasons to hypothesize that differences might be observed in younger versus older adolescent girls on other constructs. Given that formal adult thought does not appear until around the age of 15 or so (e.g., Piaget, 1972), the association between cognitive, emotional and behavioural variables in younger adolescents may be different than that observed for older girls. Variables not measured in this study (e.g., in the area of attitudes toward risk-management and preventive behaviour in high-risk girls) might therefore reflect developmental differences and this is an important consideration for future research.

Informant effects were clearly observed in this study. That is, mothers and daughters displayed a low level of agreement about adolescent problems, and maternal versus adolescent perceptions of family-level variables predicted different outcomes. Given these findings, it would be interesting had *all* constructs been measured with multiple informants. In this case, one might expect adolescent appraisals of maternal HQL or distress to be more strongly associated with other adolescent measures. Although HQL and distress measures included here do not provide norms for observer reports, the results of this study underscore the importance of assessing multiple perspectives on all study constructs.

Related to this, a significant limitation of this study is the exclusion of fathers and other children in the family. With respect to fathers, evidence from a variety of research areas indicates that (a) spouses of cancer patients experience significant distress and cancer may disrupt the marital relationship (Northouse & Peters-Golden, 1993), and (b) children of fathers

experiencing distress are at greater risk for adjustment difficulties (Compas, Howell, Phares, Williams & Ledoux, 1989; Phares & Compas, 1992). Fathers were originally targeted for inclusion in the study and would have been included had there been sufficient numbers to achieve adequate statistical power. However, only nine fathers agreed to participate, and only five survey packages were returned during the course of data collection. Although this is consistent with results reported by Hops and Seely (1992), who found that fathers were significantly less likely to participate in family research, Phares (1995) did not observe any differences in participation rates of mothers versus fathers of college students.

The low participation rate of fathers in this study may be explained by the nature of the topic under investigation, and also because of the recruitment strategy used. Specifically, fathers may have viewed the topic of breast cancer, especially as it applies to their adolescent daughter's risk, as an uncomfortable topic or too far-removed from their own sphere of influence as parents. Furthermore, ethical concerns prevented the direct recruitment of fathers, and thus mothers were approached first for participation in this research. Had fathers been directly recruited, however, participation rates would likely have been higher (Phares, 1995). The importance of examining the unique perspectives and strengths provided by fathers in families experiencing maternal breast cancer cannot be overstated and efforts must be directed towards their inclusion in future research.

Although this study was helpful in clarifying the role of maternal distress and family functioning in adolescent adjustment following maternal breast cancer, there are likely numerous other important variables. In addition to father variables, couple (Northouse, Dorris, Charron-Moore, 1995), and sibling (Gordon-Walker, Johnson, Manion, & Cloutier, 1996) relationships

add to the complex constellation of family-level influences in those coping with illness. Furthermore, although the relationship between maternal distress and family functioning was not examined in this study, maternal psychological problems have been associated with poorer family functioning (e.g., Dickstein et al., 1998), and this relationship must be further investigated.

Taken together, the results of this and other studies provide several important avenues for future research. First and foremost, research in this area should strive to be developmentally-based, and should also be conducted from a competency-oriented systemic framework. This includes using multiple informants and multiple perspectives on similar constructs. Given that the majority of studies suggest that most families adjust to illness quite well, investigators must continue to identify those at greatest risk for problems, but must also describe normative adaptation and stress-buffering individual, spousal and child factors.

Second, further investigation that more closely examines the role of individual disease appraisals is likely to yield important results. The current study suggests that HQL is perhaps the most significant disease-related predictor of family members' adjustment, but few other studies in the area of parent illness have measures this construct. This is therefore a fruitful topic for future research and may help to link the currently disparate literatures on patient and family adjustment to illness.

Third, family-level factors must be investigated with greater care, both from theoretical and methodological perspectives. Greater clarity is needed in defining terms such as family functioning versus family coping, and differentiation between these constructs and other family factors (e.g., marital and other dyadic relationships) would also be helpful. This will help to

delineate which family-level factors are most important to target for intervention.

Finally, ongoing search for causal mechanisms, moderators, and mediators is essential and more complex model-building is needed to accurately capture the subtle forces at work in families experiencing illness. That said, complex models proposed to date have proven difficult to test because of problems achieving adequate statistical power (e.g., studies by the Lewis group), or because of difficulty in operationalizing and testing constructs (e.g., Rolland's work). Thus, although it is essential that research in this area address the complexity of associations between multiple factors, studies in the near future should first focus on clarifying relationships between key variables in a rigorous empirical manner.

Clinical Implications

The results of this research have a number of implications for health care professionals working with cancer patients and their families. First, individual perceptions are important and the impact of disease may be viewed differently by various family members. With respect to adolescent adjustment to parent illness, the current results are consistent with others in suggesting that the best way to find out how an adolescent is functioning is to ask her. The results reported here indicate that a parent's own distress about the impact of an illness may influence her perceptions of her daughters' functioning (see also King et al., 2000). However, although some adolescent girls may experience significant immediate and long-term problems as a result of their mothers' illness, parents may nevertheless be reassured that most function as well as others their age after treatment for maternal breast cancer is finished.

Second, consistent with research in patient adjustment to illness, the current study underscores the value of designing interventions to improve HQL. HQL was associated with

maternal distress and adolescent self- reports of functioning within the family, both of which were in turn related to adolescent psychological functioning. This suggests that attention to issues of HQL is likely to have benefits for the patient and her family.

Third, maternal distress and adolescent role functioning mediated the relationship between maternal and adolescent reports of adjustment problems, respectively. Thus, clinicians working with cancer patients and their families must be attuned to the level of distress experienced by the patient, and to the extent to which normal family functioning is compromised during and following illness. Conversely, the moderating analyses reported herein suggest that positive family relationships are likely to act as buffers to the stress caused by a breast cancer diagnosis. As such, interventions must be designed to include the whole family.

In conclusion, this study has added to the literature on adjustment to parent illness by examining individual, family, and disease factors associated with adjustment in adolescent daughters of breast cancer patients. Consistent with previous research, the current study suggests that maternal distress and family functioning are important predictors of adolescent adjustment, and that the association between these variables differs according to informant. These results also add to the existing literature in their implication of maternal health-related quality of life as an important disease-related predictor of adolescent adjustment. Future research must continue the search for moderators, mediators, and other causal processes in order to more accurately describe the complex nature of adolescent adaptation to maternal breast cancer.

REFERENCES

Achenbach, T.M. (1991). Integrative guide for the 1991 CBCL/4-19, YSR and TRF profiles. Burlington, VT: University of Vermont, Department of Psychiatry.

Achenbach, T.M., Howell, C.T., McConaughy, S.H., & Stanger, C.(1995). Six-year predictors of problems in a national sample of children and youth: II. Signs of disturbance. Journal of the American Academy of Child and Adolescent Psychiatry, 34 (4), 488-498.

Adams-Greenly, M., Beldoch, N., & Moynihan, R. (1986). Helping adolescents whose parents have cancer. Seminars in Oncology, 2, 113-138.

Allgood-Merton, B., Lewinsohn, P.M., & Hops, H.(1990). Sex differences and adolescent depression. Journal of Abnormal Psychology, 99, 55-63.

Antonovsky, A., (1979). Health, Stress, and Coping. San Francisco: Jossey-Bass.

Armistead, L., Klein, K., & Forehand, R. (1995). Parent physical illness and child functioning. Clinical Psychology Review, 15; 409-422.

Baider, L., & Kaplan DeNour, A. (1984). Adjustment to cancer: who is the patient – the husband or the wife? Israel Journal of Medical Science, 24, 631-636.

Baron, R.M., & Kenny, D. A. (1986). The moderator-mediator distinction in social psychological research: Conceptual, strategic, and statistical considerations. Journal of Personality and Social Psychology, 51 (6), 1173-1182.

Bettes, B.A. (1988). Maternal depression and motherese: Temporal and intonational features. Child Development, 59, 1089- 1096.

Biggar, H., & Forehand, R. (1998). The relationship between maternal HIV status and child depressive symptoms: Do maternal depressive symptoms play a role? Behavior

Therapy,29, 409-422.

Bird, G. W., & Harris, R. L. (1990). A comparison of role strain and coping strategies by gender and family structure among early adolescents. Journal of Early Adolescence, 10(2), 141-158.

Block, J. Gjerde, P.F. & Block, J. H. (1991). Personality antecedents of depressive tendencies in 18-year-olds. Journal of Personality and Social Psychology, 60, 726-738.

Bonynge, E.R. (1993). Unidimensionality of SCL-90-R scales in adults and adolescent crisis samples. Journal of Clinical Psychology, 49, 212-215.

Bucklew, S.P., Burk, J. P., Brownlee-Duffeck, M., & Frank, R.G. (1988). Cognitive and somatic aspects of depression among a rehabilitation sample: Reliability and validity of SCL-90-R research scales. Rehabilitation Psychology, 33, 67-74.

Cantwell, D.P., Lewinsohn, P. M., Rohde, P., & Seely, J. R. (1997). Correspondence between adolescent report and parent report of psychiatric diagnostic data. Journal of the American Academy of Child and Adolescent Psychiatry, 36, 610-619.

Cappelli, M., McGrath, P., MacDonald, N. E., Boland, M., Fried, P., and Katsanis, J. (1988). Parent, family and disease factors as predictors of psychosocial functioning in children with cystic fibrosis. Canadian Journal of Behavioural Science, 20, 413-423.

Cappelli, M., Surh, L., Humphreys, L., Verma, S., Logan, D., Hunter, A., & Allanson, J. (1999). Psychological and social determinants of women's decisions to undergo genetic counseling and testing for breast cancer. Clinical Genetics, 55, 419-431.

Christ, G.H., Seigal, K., & Sperber, D. (1994). Impact of parental terminal cancer on adolescents. American Journal of Orthopsychiatry, 64, 604-613.

Chubb, N.H., Fertman, C. I., & Ross, J.L. (1997). Adolescent self-esteem and locus of control: A longitudinal study of gender and age differences. Adolescence, 32(125), 113-129.

Cohen, J. (1992). A power primer. Psychological Bulletin, 112, 155-159.

Cohen, J., & Cohen, P. (1983). Applied multiple regression/correlation analysis for the behavioral sciences (2nd ed.) Hillsdale, N.J: Erlbaum.

Compas, B.E., Davis, G.E., Forsythe, C.J., & Wagner, B.M. (1987). Assessment of major and daily stressful events during adolescence: The Adolescent Perceived Events Scale. Journal of Consulting and Clinical Psychology, 55, 534-541.

Compas, B. E., Howell, D. C., Phares, B., Williams, R., & Giunta, C.T. (1989). Risk factors for emotional/behavioral problems in young adolescents: A prospective analysis of adolescent and parental stress and symptoms. Journal of Consulting and Clinical Psychology, 57(6), 732-740.

Compas, B.E., Worsham, N. L., Epping-Jordan, J. E., Grant, K. E., Mireault, G., Howell, D.C. & Malcarne, V.L. (1994). When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. Health Psychology, 13, 507-515.

Compas, B.E., Worsham, N.L, Ey, S. & Howell, D.C. (1996). When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patient. Health Psychology, 15, 167-175.

Colditz, G.A., Willett, W.C. & Hunter, D.J. (1993). Family history, age and risk of breast cancer. Journal of the American Medical Association, 270, 338-343.

Davis, C.C., Brown, R. T., Bakeman, R., & Campbell, R. (1998). Psychological adaptation and adjustment of mothers of children with congenital heart disease: Stress, coping

and family functioning. Journal of Pediatric Psychology, 23 (4), 219-228.

DeMaso, D. R., Campis, L.K., Wypij, D., Bertram, S., Lipshitz, M., & Freed, M. (1991). The impact of maternal perceptions and medical severity on the adjustment of children with congenital heart disease. Journal of Pediatric Psychology, 16, 1370149.

DeMello, L. R., & Imms, T. (1999). Self-esteem, locus of control and coping styles and their relationship to school attitudes of adolescents. Psychological Studies, 44 (1-2), 24-34.

Derogatis, L. R. (1983). SCL-90-R: administration, scoring and procedures manual-II. Towson, MD: Clinical Psychometric Research.

Derogatis, L. R. & Leary, P. A. (1977). Factorial invariance across gender for the primary symptom dimensions of the SCL-90. British Journal of Social and Clinical Psychology, 16, 347-356.

Derogatis, L. R. & Lopes, M. C.(1983). Psychosocial Adjustment to Illness Scale (PAIS and PAIS-SR): scoring, procedures, and administration manual - I. Baltimore, MD: Clinical Psychometric Research.

Dickstein, S., Seifer, R., Hayden L. C., Schiller, M., Sameroff, A.J., Keitner, G., Miller, I., Rasmussen, S., Matzko, M., & Magee, K.D. (1998). Levels of family assessment: II. Impact of maternal psychopathology on family functioning. Journal of Family Psychology, 12 (1), 23-40.

Duffy, L.S., Greenberg, D.B., Younger, J., & Ferraro, M.G. (1999). Iatrogenic acute estrogen deficiency and psychiatric syndromes in breast cancer patients. Psychosomatics, 40(4), 304-308.

Easten, D.F., Bishop, D.T., Ford., D., Crockford, G.P., and the Breast Cancer Risk

Consortium (1993). Genetic linkage analysis in familial breast and ovarian cancer: Results from 241 families. American Journal of Human Genetics, 52, 687-701.

Easten, D.F., Narod, S.A., Ford, D., Steel, M. (1994) The genetic epidemiology of BRCA1. Lancet 344: 761.

Elger, B. S., & Harding, T. W. (2000). Testing adolescents for a hereditary breast cancer gene (BRCA1): Respecting their autonomy is in their best interest. Archives of Pediatric and Adolescent Medicine, 154, 113-119.

Elkind, D. (1967). Egocentrism in adolescence. Child Development, 38, 1025-1034.

Elstein, A.S., Holzman, G.B., Ravitch, M.M., et al. (1986). Comparison of physicians' decisions regarding estrogen replacement therapy for menopausal women and decisions derived from a decision analytic model. American Journal of Medicine, 80, 246-258.

Epstein, N.B., Baldwin, L.M., & Bishop, D. S. (1981). McMaster Clinical Rating Scale. Brown/Butler Family Research Program. Providence, RI.

Fallowfield, L. J.(1993). Quality of life measurement in breast cancer. Journal of the Royal Society of Medicine, 86, 10-12.

Fallowfield, L.J. & Hall, A. (1991). Psychosocial and sexual impact of diagnosis and treatment of breast cancer. British Medical Bulletin, 47, 338-399.

Finney, J. W., & Miller, K. M. (1999). Children of parents with medical illness. In Silverman, W.K., & Ollendick, T. H. (Eds). Developmental issues in the clinical treatment of children. Boston, MA: Allyn & Bacon, Inc. (pp. 433-442).

Fleming, J. E., & Offord, D. R. (1990). Epidemiology of childhood depressive disorders: A critical review. Journal of the American Academy of Child and Adolescent Psychiatry, 29,

571-580.

Ford, D., Easten, D.F., Bishop, D.T., Narod, S.A., Goldar, D.E. and the Breast Cancer Risk Consortium (1994) Risk of cancer in BRCA1 mutation carriers. Lancet. 344, 692-695.

Frazer, G. H., Brown, C. H., Graves, T. K. (1998). Assessment of quality of life indicators among selected patients in a community cancer center. Issues in Mental Health Nursing, 19, 241-262.

Furhman, T. & Holmbeck, G.N. (1995). A contextual-moderator analysis of emotional autonomy and adjustment in adolescence. Child Development, 66, 793-811.

Garrat, A.M., Ruta, D., A., Abdalla, M.I., Buckingham, J.K., & Russel, I.T. (1993). The SF 36 health survey questionnaire: An outcome measure suitable for routine use within the NHS? British Medical Journal, 306, 1440-1444.

Gilbar, O. (1998) Coping with threat: Implications for women with a family history of breast cancer. Psychosomatics, 39(4), 329-339.

Gilbar, O. & Borovik, R. (1998). How daughters of women with breast cancer cope with the threat of illness. Behavioral Medicine, 24, 115-121.

Gordon, D., Burge, D., Hammen, C., Adrian, C., Jaenicke, C., & Hiroto, D. (1989). Observations of interactions of depressed women with their children. American Journal of Psychiatry, 146, 50-55.

Gordon-Walker, J., Johnson, S., Manion, I., & Cloutier, P. (1996). Emotionally-focused marital intervention for couples of with chronically ill children. Journal of Consulting and Clinical Psychology, 64, 1029-1036.

Grant, K. E., & Compas, B.E. (1995). Stress and anxious-depressed symptoms among

adolescents: Searching for mechanisms of risk. Journal of Consulting and Clinical Psychology, 63, 1051-1021.

Haberman, M. R., Woods, N. F., & Packard, N.J. (1990). Demands of chronic illness: Reliability and validity assessment of a demands of illness inventory. Holistic Nursing Practice, 5, 25-35.

Hammen, D. (1997). Children of depressed parents: The stress context. In S.A. Wolchik & I. N. Sandler (eds.) Handbook of children's coping: Linking theory and intervention (pp. 131-157). New York: Plenum.

Hammen, C., Adrian, C., & Hiroto, D. (1988). A longitudinal test of the attributional vulnerability model in children at risk for depression. British Journal of Clinical Psychology, 27, 37-46.

Heckerling, P., Verp, M., & Hadro, T. (1994). Preferences of pregnant women for amniocentiesis or chorionic villus sampling for prenatal testing: Comparison of patients' choices and those of a decision-analytic model. Journal of Clinical Epidemiology, 47, 1215-1228.

Hill, A.D., Doyle, J.M. McDermott, E.W., & O'Higgins, N.J. (1997). Hereditary breast cancer. British Journal of Surgery, 84(10), 1334-1339.

Hilton, B. A. (1994). Family communication patterns in coping with early breast cancer. Western Journal of Nursing Research, 16(4), 366-391.

Holcomb, W.R., Adams, N. A., & Ponder, H. M. (1983). Factor structure of the Symptom Checklist - 90 with acute psychiatric inpatients. Journal of Consulting and Clinical Psychology, 51, 535-538.

Holmbeck, G. (1997). Toward terminological, conceptual, and statistical clarity in the

study of mediators and moderators: Examples from the child-clinical and pediatric psychology literature. Journal of Consulting and Clinical Psychology, 65, 599-610.

Hops, H. & Seely, J.R. (1992). Parent participation in studies of family interaction: Methodological and substantive considerations. Behavioral Assessment, 14, 229-243.

Howes, M.J., Hoke, L., Winterbottom, M., & Delafield, D. (1994). Psychosocial effects of breast cancer on the patient's children. Journal of Psychosocial Oncology, 12, 1-21.

Hurtig, A.L., Keopke, D., & Park, K.B. (1989). Relation between severity of chronic illness and adjustment in children and adolescents with sickle cell disease. Journal of Pediatric Psychology, 14(1), 117-132.

Issel, L.M.,Erseck, M., & Lewis, F.M. (1990). How children cope with mother's breast cancer. Oncology Nursing Forum, 17, 5-13.

Janz, N.K., & Becker, M.H. (1984). The health belief model: A decade later. Health Education Quarterly, 11, 1-47.

Kash, K.M., Holland, J. C., & Halper, M. S., & Miller, D.G. (1992). Psychological distress and surveillance behaviours of women with a family history of breast cancer. Journal of the National Cancer Institute, 84: 24-30.

Kelley, S.M.. Sikka, A., & Venkatesan, S. (1997). A review of reseach on parental disability: Implications for research and counseling practice. Rehabilitation Counseling Bulletin, 41(2), 105-121.

King, W. J.. Schlieper, A., Birdi. N., Cappelli, M., Korneluk, Y., & Rowe, P. (2000). The effect of Kawasaki disease on cognition and behaviour. Archives of Pediatrics and Adolescent Medicine, 154, 463-468.

Kliewer, W. (1997). Children's coping with chronic illness. In S.A. Wolchick & I. N. Sandler (eds.) Handbook of children's coping: Linking theory and intervention (pp. 275-300). New York: Plenum.

Korneluk, Y.G., & Lee, C. M. (1998). Children's adjustment to parental physical illness. Clinical Child and Family Psychology Review, 1(3), 179-193.

Kovacks, M. (1981). Rating scales to assess depression in school-aged children. Acta Paedopsychiatrica, 46, 305-315.

Lee, C.M., & Gotlib, I.H. (1989). Maternal depression and child adjustment: A longitudinal analysis. Journal of Abnormal Psychology, 98, 75-85.

Lewinsohn, P. M., Roberts, R.E., Seely, J. R., Rohde, R., Gotlib, I. H., & Hops, H. (1994). Adolescent psychopathology, II: Psychosocial risk factors for depression. Journal of Abnormal Psychology, 103, 302-315.

Lewinsohn, P. M., Gotlib, I. H., & Seely, J. R. (1995). Adolescent psychopathology: IV. Specificity of psychosocial risk factors for depression and substance abuse in older adolescents. Journal of the American Academy of Child and Adolescent Psychiatry, 34, 1221-1229.

Lewis, F.M. (1998). Family-level services in oncology nursing: Facts, fallout and realities revisited. Oncology Nursing Forum, 25 (8), 1378-1388.

Lewis, F. M., & Hammond, M. A. (1996). The father's mother's, and adolescent's functioning with breast cancer. Family Relations, 45, 456-465.

Lewis, F.M., Hammond, M.A., & Woods, N.F. (1993). The family's functioning with newly-diagnosed breast cancer in the mother: The development of an explanatory model. Journal of Behavioral Medicine, 16, 351-370.

Lewis, F.M., Woods, N.F., Hough, E.E., & Bensley, L. S. (1989). The family's functioning with chronic illness in the mother: The spouse's perspective. Social Science Medicine, 29, 1261-1269.

Lichtman, R.R., Taylor, S.E., Wood, J. V., Bluming, A.Z., Dosik, G.M., & Leibowitz, R.L. (1984). Relationships with children after breast cancer: The mother-daughter relationship at risk. Journal of Psychosocial Oncology, 2 (3/4), 1-19.

Lipman, R. S., Covi, L., & Shapiro, A.K. (1977). The Hopkins Symptom Checklist (HSCL): Factors derived from the HSCL. Psychopharmacology Bulletin, 13, 43-45.

Marshall, E. (1993). Search for a killer: Focus shifts from fat to hormones. Science, 259, 618-621.

McCaul, L. D., Sandgren, A.K., King, B., O'Donnel, S., Branstetter, A., & Foreman, G. (1999). Coping and adjustment to breast cancer. Psycho-Oncology, 8, 230-236.

McCubbin, H.I., Larsen, A. S., & Olson, D.H.(1982). F-COPES. In D. Olson, H.I., McCubbin, H. Barnes, A. Larsen, M. Muxen, & M. Wilson (Eds.), Families: What makes them work. (pp. 206-261). Beverly Hills, CA: Sage.

Mesters, I., van den Borne, H., McCormick, L., Pruyn, J., de Boer, M., & Imbos, T. (1997). Openness to discuss cancer in the nuclear family: Scale development, and validation. Psychosomatic Medicine, 59, 269-279.

Mireault, G.C., & Compas, B.E. (1996). A prospective study of coping and adjustment before and after a parent's death from cancer. Journal of Psychosocial Oncology, 14, 95-118.

Monroe, S. M., Bromet, E. J., Connel, M.M., & Steiner, S.C. (1986). Social support, life events, and depressive symptoms: A 1-year prospective study. Journal of Consulting and

Clinical Psychology, 54, 424-431.

Moos, R., & Moos, B. (1981). Family Environment Scale manual. Palo Alto, CA: Consulting Psychologists Press.

Murch, R.L., & Cohen, L.H. (1989). Relationships among life stress, perceived family environment, and the psychological distress of spina bifida adolescents. Journal of Pediatric Psychology, 14, 193-214.

National Cancer Institute. Breast Cancer Prevention Trial shows major benefit, some risk (Web site news release). Available: http://cancertrials.nci.nih.gov (Accessed May 1998).

Nguyen, T.D., Attkisson, C.C., & Stegner, B.L. (1983). Assessment of patient satisfaction: Development and refinement of a service evaluation questionnaire. Evaluation and Program Planning, 6, 299-314.

Northouse, L., L., Caffey, M., Deichelbohrer, L., Schmidt, L., Guziatek-Trojniak, L., West, S., Kershaw, T., & Mood, D. (1999). The quality of life of African American women with breast cancer. Research in Nursing & Health, 22, 449-460.

Northouse, L. L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. Social Science in Medicine, 41(1), 69-76.

Northouse, L. & Peters-Golden, H. (1993). Cancer and the family: Strategies to assist spouses. Seminars in Oncology Nursing, 9 (2), 74-82.

Ohannessian, C. M., Lerner, R.M., Lerner, J. V., von Eye, A. (1999). Does self-competence predict gender differences in adolescent depression and anxiety? Journal of Adolescence, 22 (3), 397-411.

Olson, D. H., McCubbin, H. I., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1983).

Families: What makes them work? Beverly Hills: Sage.

Parish, T.S., & Taylor, J. (1978). The Personal Attribute Inventory for Children: A report on its validity and reliability as a self-concept scale. Educational and Psychological Measurement, 38, 565-569.

Pederson, L.M., & Valanis, B.G. (1988). The effects of breast cancer on the family: A review of the literature. Journal of Psychosocial Oncology, 6, 95-118.

Phares, V. (1995). Fathers' and mothers' participation in research. Adolescence, 30 (119), 593-602.

Phares, V., & Compas, B.E. (1992). The role of fathers in child and adolescent psychopathology: Make room for daddy. Psychological Bulletin, 111, 387-412.

Piaget, J. (1972) Intellectual evolution from adolescent to adulthood. Human Development, 15, 1-12.

Pliskin, J. S., Shepar, D.S., & Weinstein,, M.C. (1980). Utility functions for life-years and health status. Operations Research, 28 (1), 206-204.

Radosevich, D.M., Wetzler, H., & Wilson, S.M. (1995). Health Status Questionnaire (HSQ) 2.0: Scoring Comparisons and Reference Data. Bloomington, MN: Health Outcomes Institute.

Rauter, U.K, Leonard, C.E., & Swett, C.P. (1996). SCL-90-R factor structure in an acute, involuntary, adult psychiatric inpatient sample. Journal of Clinical Psychology, 52, 625-629.

Reynolds, C.R., & Richmond, B.O. (1987). What I think and feel: A revised measure of children's manifest anxiety. Journal of Abnormal Child Psychology, 6, 271-280.

Ritvo, P., Robinson, G., Irvine, J., Brown, L., Murphy, K.J., Stewart, D.S., Styra, R.,

Wang, C., Mullen, M., Cole, D., Rosen, B. (1999). A longitudinal study of psychological adjustment to familial genetic risk assessment for ovarian cancer. Gynecological Oncology; 74 (3); 331-337.

Rolland, J. S. (1999). Parental illness and disability: A family systems framework. Journal of Family Therapy, 21, 242-266.

Rosenstock, I.M. (1974). The health belief model and preventive health behavior. Health Education Monographs, 2, 354-386.

Rosenthal, T. C., & Puck, S. M. (1999). Screening for genetic risk of breast cancer. American Family Physician, 59(1), 99-104.

Schwartz, A. (1999). Fatigue mediates the effects of exercise on quality of life. Quality of Life Research, 8, 529-538.

Schwartzweld, J., Weisenberg, M., & Solomon, Z. (1991). Factor invariance of SCL-90-R: The case of combat stress reaction. Psychological Assessment: A Journal of Consulting and Clinical Psychology, 3, 385-390.

Seifer, R., Sameroff, A.J., Dickstein, S., Keitner, G., Miller, I., Rasmussen, S., & Hayden, L.C. (1996). Parental psychopathology, multiple contextual risks, and one-year outcomes in children. Journal of Clinical Child Psychology, 25, 423-435.

Skinner, H.A., Steinhauer, P.D., & Santa-Barbara, J. (1983). The family assessment measure. Canadian Journal of Community Mental Health, 2, 91-105.

Statistics Canada (1996). 1996 Census data: Canada at a glance: Families, households and housing [on-line]. Website. Available: http//www.statcan.ca (Accessed June, 2000).

Steele, R. G., Forehand, R., & Armistead, L. (1997). The role of family processes and

coping strategies in the relationship between parental chronic illness and childhood internalizing problems. Journal of Abnormal Child Psychology, 25, 83-94.

Suesser, K. (1998). Explaining the emergence of gender differences in depression during adolescence: The role of personality characteristics and mixed-sex interactions. Dissertation Abstracts International: Section B: the Sciences & Engineering, 58 (11-B), 6248.

Tabachnick B.G. & Fidell. L. (1996). Using Multivariate Statistics (3rd edition). HarperCollins College Publishers: New York.

Taylor-Brown, J., Acheson, A., & Farber, J.M. (1993). Kids can cope: A group intervention for children whose parents have cancer. Journal of Psychosocial Oncology, 11, 41-53.

Taylor, S.E., Lichtman. R. R., Wood, J. V., Bluming, A.Z., Dosik, G.M., & Leibowitz, M.L.S. (1985). Illness-related and treatment-related factors in psychological adjustment to breast cancer. Cancer, 55, 2506-2513.

Thomas, A.M., Forehand, R., & Neighbors, B. (1995). Change in maternal depressive mood: Unique contributions to adolescent functioning over time. Adolescence, 30 (117), 43-52.

Thompson. R. J., Gustafson, K. E., Hamlett, K. W., & Spock, A. (1992). Psychological adjustment of children with cystic fibrosis: The role of child cognitive processes and maternal adjustment. Journal of Pediatric Psychology, 17, 741-755.

Thornburg. H.D. (1982). Development in adolescence(2nd edition); pp. 82-114. Monterey, CA: Brooks-Cole

Van Hook. M.P., Berkman. B., & Dunkle, R. (1996). Assessment tools for general health care settings: PRIME-MD, OARS, and SF-36. Health and Social Work, 21, 230-234.

Wallander, J. L., & Thompson, R. J. (1995). Psychosocial adjustment of children with chronic conditions. In D. K. Routh (ed.) Handbook of pediatric psychology., pp. 124-141. New York: Guilford.

Walsh-Burke, K. (1992). Family communication and coping with cancer: Impact of the We-Can Weekend. Journal of Psychosocial Oncology, 10, 63-81.

Weissmam, M. M., Myers, J. K., & Thompson, W. D. (1981). Depression and its treatment in a US urban community – 1975-1976. Archives of General Psychiatry, 38(4), 417-421.

Welch, A.S., Wadsworth, M., & Compas, B.E. (1996). Adjustment of children and adolescents to parental cancer: Parents and children's perspectives. Cancer, 77, 1409-1418.

Wellisch, D.K., Gritz, E.R., Schain, W., Wang, H., & Siau, J. (1992). Psychological functioning of daughters of breast cancer patients. Part II: Characterizing the distressed daughter of the breast cancer patient. Psychosomatics, 33, 171-179.

Wertz, D. C., Fanos, J.H., & Reilly, P. R. (1994). Genetic testing for children and adolescents: Who decides? Journal of the American Medical Association, 272, 875-881.

Woody, S.R., Steketee, G., & Chambliss, D.L. (1995). The usefulness of the obsessive-compulsive scale of the SCL-90-R. Behaviour Research and Therapy, 33, 607-611.

Wooster, R., Bignell, G., Lancaster, J., et al. (1995). Identification of the breast cancer susceptibility gene BRCA2. Nature, 378, 789-791.

Worsham, N.L., Compas, B.E., & Ey, S. (1997). Children's coping with parental illness. In S.A. Wolchik & I. N. Sandler (eds.) Handbook of children's coping: Linking theory and intervention (pp. 195-213). New York: Plenum.

Zakowski. S. G., Valdimarsdottir, H. B., Bovbjer, D. H., Borgen, P., Holland, J., Kash, K., Miller, D., Mitnick, J., Osborner, M., Van Zee, K. (1997). Predictors of intrusive thoughts and avoidance in women with family histories of breast cancer. Annals of Behavioral Medicine, 19(4), 362-369.

APPENDIX 1: Ethics Approval Certificate

APPENDIX 1

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario
401 SMYTH. OTTAWA, ONT. K1H 8L1 TELEPHONE (613) 737-7600

July 29, 1998

Dr. Mario Cappelli
Psychology
CHEO INTRA

Re: Proposal 98/30E - Assessing the Psychological Functioning and Health Care Choices of Adolescent Daughters of Breast Cancer Patients

Dear Dr. Cappelli:

Thank you for your letter of July 15, 1998, regarding the above-mentioned proposal, incorporating the changes/additions recommended by the Research Ethics Committee at the July 8, 1998 meeting.

Please accept this letter as written approval from CHEO's Research Ethics Committee for the above-mentioned proposal.

It is your obligation to notify the REC prior to the institution of any modifications to this study, or any adverse events which may occur during the course of this study.

To ensure that the REC is kept informed of the progress of clinical studies, we request a yearly progress report from each investigator.

Kindly refer to the above-mentioned Proposal Number in any future correspondence.

Sincerely,

D. Palframan, M.D., F.R.C.P. (C)
Chair
Research Ethics Committee

/rw

APPENDIX 2: Letter from Principal Investigators and Consent Forms

OTTAWA REGIONAL CANCER CENTRE
We care for life

CENTRE RÉGIONAL DE CANCÉROLOGIE D'OTTAWA
Le cancer parlons-en

CIVIC DIVISION
190 Melrose Avenue
Ottawa, ON K1Y 4K7
CANADA
(613) 737-7700

GENERAL DIVISION
501 Smyth Road
Ottawa, ON K1H 8L6
CANADA
(613) 737-7700

APPENDIX 2

March 19, 1998

Dear

I am writing to invite you to participate in a research study that examines the impact of breast cancer on families, particularly the adolescent daughters of women who have breast cancer. We would like to learn about how daughters cope with maternal breast cancer, and what their perceptions and feelings are with respect to the disease.

This research will also examine the attitudes of women and their family members toward genetic testing. As you may be aware, a small proportion of breast cancer patients (5%) may carry an inherited gene which causes a high risk for the development of breast cancer in family members. For some time now, a blood test to determine whether or not the breast cancer gene is present in a particular woman has been available. We would like to know how women and their daughters feel about this test so that when widespread testing is instituted, it is done in as correct a manner as possible.

The research involves filling out a survey package and being interviewed by a trained research associate. The process should not inconvenience you and the information gathered will be most helpful. All data collected will be kept totally confidential.

A research associate will be contacting you by telephone to ask if you are interested in participating in the study. Your decision to take part in this study will not in any way affect your care at the Ottawa Regional Cancer Centre. Your participation is entirely voluntary and you may withdraw at any time.

If you have any questions, please feel free to contact me at (613) 737-7700 ext. 6747 or leave a message at (613) 738-3904 and a research associate will return your call.

Yours sincerely,

(Medical Oncologist)

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario

401 SMYTH. OTTAWA. ONT K1H 8L1 TELEPHONE (613) 737-7600

Dr. Mario Cappelli
Psychology
CHEO

Dr. Shailendra Verma
Oncology
ORCC

Dr. E. Tomiak
Oncology
ORCC

C. Segrasse
Clinical Services
WBHC

L. Corsini
Social Work
ORCC

L. Humphreys
M. Walker
Research Assistants

ASSESSING THE PSYCHOLOGICAL FUNCTIONING AND HEALTH CARE CHOICES OF ADOLESCENT DAUGHTERS OF BREAST CANCER PATIENTS

Consent Form - BC Group - Mothers

Introductory Letter to Participants

The purpose of our research is to learn about how family members, particularly adolescent girls, cope with having breast cancer in the family. We would like to learn about your opinions and feelings toward breast cancer and its risks. We would also like to know what your thoughts are about genetic testing for breast cancer. The new gene test will be able to tell some people if they are at greater risk for developing breast cancer, before the cancer has occurred. *You do not have to undergo genetic testing for this study*; we would simply like to know your opinions about the test.

This study is conducted through the Children's Hospital of Eastern Ontario, the Ottawa Regional Cancer Centre and the Ottawa Regional Women's Breast Health Centre. Your part in the study is to complete a survey package at home and to participate in an interview to be arranged at your convenience. The survey package will take approximately 90 minutes to fill out and the interview will last approximately 30 minutes. You do not have to complete the survey all at once; feel free to fill it out at your leisure.

All information will be kept confidential. You do not have to participate in this study. If you agree to participate, you can withdraw from the study at any time. Your decision will not affect care received at the Children's Hospital of Eastern Ontario or at the Ottawa Regional Cancer Centre.

If you have any questions, please feel free to phone Melanie Walker or Lauren Humphreys at (613) 738-3904.

Sincerely,

Dr. Shailendra Verma
Medical Oncologist,
Ottawa Regional Cancer Centre

Dr. Mario Cappelli
Clinical Psychologist,
Children's Hospital of Eastern Ontario

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario
401 SMYTH, OTTAWA, ONT K1H 8L1 TELEPHONE (613) 737-7600

Dr. Mario Cappelli
Psychology
CHEO

Dr. Shailendra Verma
Oncology
ORCC

Dr. E. Torniak
Oncology
ORCC

C. Degrasse
Clinical Services
WBHC

L. Corsini
Social Work
ORCC

L. Humphreys
M. Walker
Research Assistants

ASSESSING THE PSYCHOLOGICAL FUNCTIONING AND HEALTH CARE CHOICES OF ADOLESCENT DAUGHTERS OF BREAST CANCER PATIENTS

Consent Form - BC group - Daughters

Introductory Letter to Participants

The purpose of our research is to learn about how people like yourself and other family members cope with having breast cancer in the family. We are inviting you to participate in our study, as a young woman whose mother has been diagnosed with breast cancer. We would like to know what your opinions and feelings are about breast cancer and its risks. We would also like to learn about your thoughts on the new breast cancer gene test. This test will be able to tell some people if they are at greater risk for developing breast cancer, before the cancer has occurred. *You will not be required to have the new gene test for this study*; we would simply like to know your opinions about the test.

This study is conducted through the Children's Hospital of Eastern Ontario, the Ottawa Regional Cancer Centre and the Ottawa Regional Women's Breast Health Centre. Your part in the study is to complete a survey package at home and to participate in an interview to be arranged at your convenience. The survey package will take approximately 90 minutes to fill out and the interview will last approximately 30 minutes. You do not have to complete the survey all at once; feel free to fill it out at your leisure.

All information will be kept confidential. You do not have to participate in this study. If you agree to participate, you can withdraw from the study at any time. Your decision will not affect care received at the Children's Hospital of Eastern Ontario or at the Ottawa Regional Cancer Centre.

If you have any questions, please feel free to phone Melanie Walker or Lauren Humphreys at (613) 738-3904.

Sincerely,

Dr. Shailendra Verma
Medical Oncologist,
Ottawa Regional Cancer Centre

Dr. Mario Cappelli
Clinical Psychologist,
Children's Hospital of Eastern Ontario

APPENDIX 3a: Breast Cancer Survey – Adolescent Version (BCS-A)

October, 1998

Number _____

APPENDIX 3A

BREAST CANCER SURVEY

ADOLESCENT VERSION

This questionnaire is part of a research project to improve our understanding of breast cancer that is inherited.

A collaborative study between the Children's Hospital of Eastern Ontario and the Ottawa Regional Cancer Centre

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For information:

Breast Cancer Gene Study
Children's Hospital of Eastern Ontario
Research Institute, Rm 224
401 Smyth Road
Ottawa, Ontario K1H 8L1
Telephone: (613) 738-3904

BREAST CANCER SURVEY

We are interested in learning about people's opinions about breast cancer, its prevention, and its treatment. By completing this questionnaire, you will help us to better understand people's views about this illness and to improve our service in the future.

All of your responses will be kept strictly confidential. Your name will not appear with any of the responses that you give.

Before you begin,
remember that you do not have to answer any questions you would rather not answer.

Thank you.

I. PERSONAL RISK FACTORS FOR BREAST CANCER

Please check(✓) the right box or fill in the blank line.

1. Have you started your menstrual periods yet? ☐ YES ☐ NO
2. If YES, how old were you when you had your first period? _____ (years old)
3. a) Have you ever taken (or are you currently taking) birth control pills? ☐ YES ☐ NO

   b) If YES, indicate which years you took birth control pills:

   1. From 19____ to 19____
   2. From 19____ to 19____
   3. From 19____ to 19____
   4. From 19____ to 19____

4. a) Are you or have you ever been a smoker? ☐ YES ☐ NO

   b) If YES,

   What year did you start? 19____

   How many cigarettes per day? _____

   If you have quit smoking, what year did you stop? 19____

5. a) How tall are you? _____ feet and _____ inches

   b) How much do you weigh now? _____ pounds

   c) What is the most you have ever weighed (excluding pregnancy)? _____ pounds

6. a) Do you drink alcoholic beverages? ☐ YES ☐ NO

   b) If YES, on average, how many alcoholic drinks do you have per month? *(check only <u>one</u> box)*

   ☐ 1-3 ☐ 10-14 ☐ 21-29

   ☐ 4-9 ☐ 15-20 ☐ 30 or more

II. BREAST CANCER SCREENING

The following questions refer to different breast screening methods. Please check(✓) the right box or fill in the blank line.

7. a) Have you ever done a self-examination of your breasts (Breast Self-Exam)?

   ☐ YES ☐ NO ☐ I don't know how

   b) If YES,

   How often did you perform a breast self-exam in the past year? *(check only <u>one</u> box)*

   ☐ Once a month ☐ Twice a year

   ☐ Once every two months ☐ Once a year

c) If YES,

Who taught you to do breast self-exam:

- ☐ Health Teacher
- ☐ Doctor
- ☐ Nurse
- ☐ Pamphlet
- ☐ Other (*please specify*): _____

8. a) Have you ever had a breast biopsy?

☐ YES ☐ NO ☐ I don't know what a biopsy is

b) If YES,

How old were you when you had your first biopsy? _____years

How old were you when you had your last biopsy? _____years

How many breast biopsies have you had? _____

III. *FAMILY HISTORY OF CANCER*

The following are some general questions about cancer and your family. Please check (✓) the right box or fill in the blank line.

Are you adopted?

☐ YES ☐ NO

If yes, please skip to question 16.

9. a) Does cancer run your family (i.e., more than 2 blood relatives have or had cancer)?

☐ YES ☐ NO

b) If YES,

How old were you when you found out that cancer runs in your family?_____years

10. a) Does anyone in your family (immediate or extended) have breast and/or ovarian cancer?

☐ YES ☐ NO ☐ Don't know

b) If YES, please list which family members were told they have breast and/or ovarian cancer.

_____ _____

_____ _____

_____ _____

11.a) Have any members of your immediate family (grandparents, parents, brothers, sisters, children) ever been treated for other types of cancer?

□ YES □ NO *(go to question 12)* □ Don't know

b) If YES, please list which family member(s) and type of cancer.

_____ _____

_____ _____

_____ _____

12. a) Have you ever had any type of cancer?

□ YES □ NO □ UNSURE

b) If YES,

I. What type of cancer did you / do you have? _____

II. How old were you when you were first told you had cancer? _____ years old

III. What, if any, treatments were you or are you undergoing?

□ chemotherapy □ radiation □ other (specify) _____

IV. If you have finished treatments, how long ago was your last one? _____

V. What is your current condition? □ perfectly healthy □ disease free □ in remission

□ in treatment □ other (specify) _____

VI. Are you concerned about your future health? □ not at all □ a little □ moderately so □ very much

Please explain _____

V. KNOWLEDGE OF BREAST CANCER

The following questions refer to breast cancer and cancer in general. We are interested in learning how much people know about cancer. Do not be concerned if you are not sure of the correct answers. It is helpful for us to know both what people know and what they do not know.

For each question, choose the single best answer. (For each question, circle one letter only).

13. How many women will develop breast cancer in Canada?

    a. 1% (1 out of 100 women)
    b. 5% (5 out of 100 women)
    c. 10% (10 out of 100 women)
    d. 25% (25 out of 100 women)
    e. 50% (50 out of 100 women)
    f. Don't know

14. *For each of the following statements, please indicate which ones are "true", "false" or if you are "unsure".*

a) The older you are, the more likely you are to get breast cancer.	☐ True	☐ False	☐ Unsure
b) Women are more likely to get cancer than men.	☐ True	☐ False	☐ Unsure
c) If one of your parents has cancer, then you will get cancer.	☐ True	☐ False	☐ Unsure
d) Gene testing for inherited types of cancer can tell whether or not you will get cancer.	☐ True	☐ False	☐ Unsure

V. PERCEPTIONS OF BREAST CANCER

For each of the following statements, please indicate your opinion.

15. *For each of the following statements, please indicate your opinion.*

a) In your opinion, how life threatening is breast cancer?	1 Very threatening	2 Moderately threatening	3 Somewhat threatening	4 not at all threatening
b) In your opinion, how effective are the treatments for breast cancer?	1 Not at all effective	2 Somewhat effective	3 Moderately effective	4 Very effective
c) In your opinion, how much does breast cancer affect the patient's ability to do their usual work activities (e.g. housework, go to work outside the home, etc.)?	1 Very much	2 Moderately	3 Somewhat	4 Not at all
d) In your opinion, how much does breast cancer affect the patient's energy levels?	1 Very much	2 Moderately	3 Somewhat	4 Not at all
e) In your opinion, how much does breast cancer affect the patient's ability to do her usual leisure activities (e.g. go out with friends and family, have hobbies, etc.)?	1 Very much	2 Moderately	3 Somewhat	4 Not at all

Breast Cancer Gene Test

There is a new gene test that can identify some women who are at greater risk for breast cancer, before cancer occurs.

This new test can find changes (mutations) in specific genes (BRCA1 and BRCA2) which lead to an increased risk of developing breast cancer. The test uses a small blood sample.

We know that genes can be passed from parent to child (i.e., inherited). Therefore some, but not all, children may inherit a breast cancer gene with a mutation that leads to an increased risk of developing breast cancer.

Other cancer genes will be discovered but until then the breast cancer gene test will first look at BRCA1 and BRCA2 gene mutations.

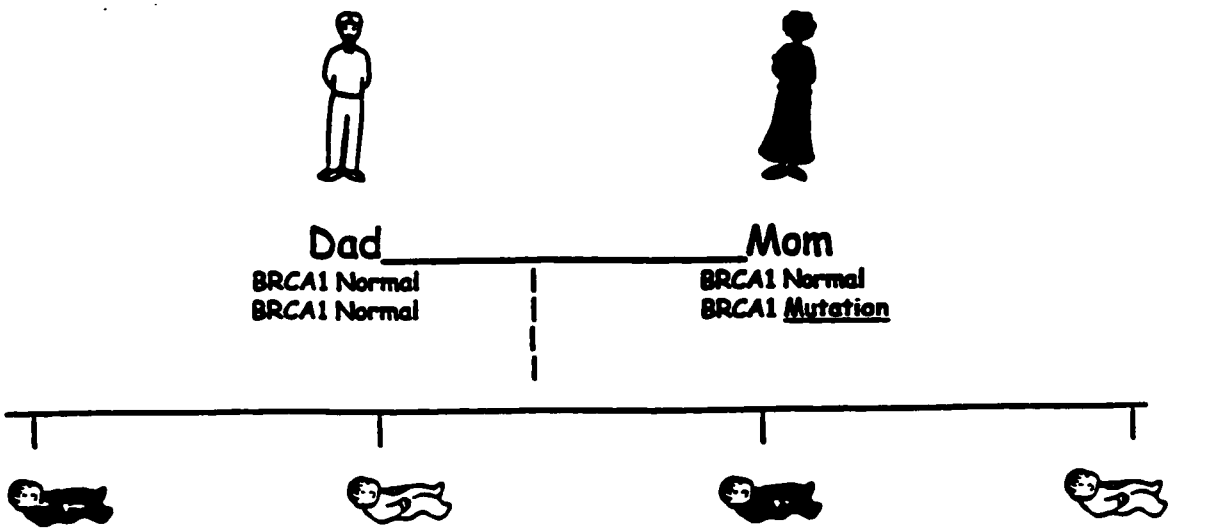
On the following white pages is some information about BRCA1/BRCA2 gene testing, breast cancer treatments and prevention and a glossary of medical terms. You may use this information as a reference while completing the remainder of the questionnaire. However, PLEASE DO NOT GO BACK AND CHANGE ANY OF YOUR ANSWERS ON THE QUESTIONNAIRE UP TO THIS POINT.

BREAST CANCER INFORMATION SHEET

An average woman has about a 10% chance of developing breast cancer in her lifetime. In other words 1 women out of 10 will develop breast cancer at some time in her life.

The majority of breast cancer is sporadic, which means it happens by chance. But some breast cancers are caused by a change or mutation in a gene called the BRCA1 or BRCA2 gene. Genes are tiny structures that are found in chromosomes. Genes give us characteristics like eye colour and hair colour. We inherit genes from both our parents, which is why we sometimes have features that are similar to our mother and father. The percentage of breast cancer that occurs due to the inheritance of a mutation on the BRCA1/ BRCA2 gene is approximately 5-10%. This means that out of 100 women who have breast cancer, approximately 5-10 women developed breast cancer due to a change in the BRCA1/ BRCA2 gene.

Inheritance of a Mutated BRCA1/ BRCA2 Gene:
Everyone has two BRCA1/ BRCA2 genes. We receive one from our mother and one from our father. A person can inherit a mutated or changed BRCA1/ BRCA2 gene from either parent. If one of the parents has the mutated gene, each of their children has a 50% chance of inheriting the mutated version of the gene.



Inheriting a BRCA1 / BRCA2 mutation does not necessarily mean that you will develop breast cancer. What it means is that your chance of developing breast cancer increases to approximately 80% over your lifetime. In other words, 8 out of 10 women who have a mutated BRCA1/ BRCA2 gene will develop breast cancer at some time in their life.

If you have not inherited the BRCA1/ BRCA2 mutation, your risk of developing breast cancer is the same as the general population, which is approximately 10% (or 1 in 10).

Genetic Testing:
There is a genetic test for breast cancer which is still in the research stage. For the genetic test, a blood sample is taken and DNA is removed and looked over to see if there is a mutation on the BRCA1/ BRCA2 gene. This test tells whether or not you have inherited a BRCA1 or BRCA2 mutation. This will then tell you if your risks of developing breast cancer are increased from 10% to 80%.

Breast Cancer Detection:
There are ways in which you can monitor yourself for the possible development of breast cancer. Early detection can greatly increase your chances of survival. Ways of monitoring for breast cancer are: 1)performing self breast exams on a monthly basis, 2) having your physician examine your breasts 3) by having mammograms.

Breast Cancer Prevention:
There are a number of things that might help to prevent breast cancer in some people. Nutrition and lifestyle choices, such as not smoking and eating a healthy, well balanced diet, can help to reduce your risk of developing breast cancer. Occasionally, women at high risk for developing breast cancer will chose to have their breasts removed even though they do not have cancer in hopes of preventing it. Some women at risk may choose to take medications to further reduce their risk of developing breast cancer.

Treatments for Breast Cancer:
If breast cancer is detected early and the tumour is small, a lumpectomy (to remove the cancer) and radiation (to kill any remaining cancer cells) may be given. More severe forms of breast cancer might require 1) single mastectomy (removal of the entire breast), 2) double mastectomy (removal of both breasts) 3) hormone therapy and 4) chemotherapy (drug therapy).

GLOSSARY

Biopsy: Test for breast cancer which includes removal of a tissue sample from the breast for examination.

BRCA1/ BRCA2 Gene: A gene that produces a protein which is important for preventing cancer in normal breast tissue cells. Changes/ mutations in the BRCA1/ BRCA2 gene mean that this protein is no longer produced. Mutations of the BRCA1/ BRCA2 gene result in an increased chance of developing breast cancer to up to 80% over one's lifetime.

Breast cancer: Uncontrolled cell multiplication that results in a tumour in the breast.

Cancer: Uncontrolled cell multiplication that results in a tumour.

Chemoprevention: The use of chemotherapy even when there is no cancer. This is occasionally performed on women who have a high risk of developing breast cancer.

Chemotherapy: The use of systemic drugs (drugs which effect the whole body) that kill the cancer cells. It kills tumour cells by interfering with some of the steps involved with cell division.

Chromosomes: Microscopic structures found in each cell of the body, which carry genes. Normally, we all have 23 pairs of chromosomes. One member of each pair is inherited from our mother and one from our father.

DNA: Deoxyribonucleic Acid: This is the material which genes are made of.

Genes: Very small structures that are found in chromosomes. They determine or influence a person's physical and chemical characteristics (e.g. the colour of your skin, eyes, hair, your height, etc.). They tell the body how to grow and work.

Inheritance: The passing of genetic qualities from parents to their children.

Lumpectomy: Removal of a cancerous tumour, along with some lymph nodes and perhaps some of the healthy breast tissue around the tumour.

Lymph Nodes: Glands that are part of the body's defence system against infection.

Mammogram: A way of taking a picture of the inside of the breast to look for cancerous cells. This is done by using a low-dose X-ray.

Mastectomy: Removal of the whole breast. Double mastectomy (also called bilateral mastectomy) is the removal of both breasts.

Mutation: A change in a gene. For example, if someone has an altered BRCA1 or BRCA2 gene, they have a higher risk of developing breast cancer.

Radiation: Ionizing radiation is used in treating breast cancer by killing tumour cells.

Tumour: An abnormal mass of tissue caused by cells multiplying uncontrollably.

X-ray: A "photograph" of a body part (e.g., the breast) taken using electromagnetic radiation to mark the film.

VI. YOUR RISK AND THE BREAST CANCER GENE TEST

16.a) Compared to other teens, what do you believe is your chance of getting breast cancer?

1 Less | 2 The same | 3 A little higher | 4 Much higher

b) What do you think is the likelihood of your carrying a breast cancer gene mutation?

1 Not at all | 2 A little | 3 Somewhat | 4 Very likely

c) What do you think your chance is of getting any kind of cancer?

1 No chance | 2 Small chance | 3 Moderate chance | 4 Strong chance

d) What do you think your chance is of getting ovarian cancer (cancer of the ovaries)?

1 No chance | 2 Small chance | 3 Moderate chance | 4 Strong chance

17.a) How concerned are you about your chance of getting breast cancer?

1 Not at all | 2 Somewhat concerned | 3 Moderately concerned | 4 Very concerned

b) How concerned are you about your chance of getting any kind of cancer?

1 Not at all | 2 Somewhat concerned | 3 Moderately concerned | 4 Very concerned

c) How often do you worry about your chance of getting breast cancer?

1 Rarely or never | 2 Sometimes | 3 Often | 4 All the time

d) How much do worries about breast cancer affect the way you feel from day to day?

1 Not at all | 2 Somewhat | 3 A fair bit | 4 Very much

e) How often do worries about breast cancer get in the way of your ability to carry out daily activities?

1 Rarely or never | 2 Sometimes | 3 Often | 4 All the time

8.a) Before today, have you heard about the new type of gene testing (like BRCA1) for breast cancer?

□ YES □ NO

b) If YES, who told you about the gene test? _____

19. Would you take a test which could tell you if you have a high risk (80-90%) of getting breast cancer?

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

VII. BREAST CANCER GENE TEST RESULTS

For each of the following statements, indicate your response by circling the appropriate number.

20. If a test told me I would probably get breast cancer in the future, I would keep the test results to myself.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

21. If a test told me I would probably get breast cancer in the future, I would put the test results out of my mind.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

22. If a test told me I would probably get breast cancer in the future, I would tell my family about my test results.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

23. If a test told me I would probably get breast cancer in the future, I would tell my friends about my test results.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

24. If a test told me I would probably get breast cancer in the future, I would take an experimental drug to try and prevent it.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

25. If a test told me I would probably get breast cancer in the future, I would get surgery (have both breasts removed) to try and prevent it.

1 Definitely | 2 Probably | 3 Not Sure | 4 Probably Not | 5 Definitely Not

26. If a test told me I would probably get breast cancer in the future, it would affect my decisions about dating and having long-term relationships.

1 Definitely | 2 Probably | 3 Not Sure | 4 Probably Not | 5 Definitely Not

27. My mother wants me to have the new gene test for breast cancer.

1 Strongly Agree | 2 Agree | 3 Neutral | 4 Disagree | 5 Strongly Disagree | 6 Not sure

28. My father wants me to have the new gene test for breast cancer.

1 Strongly Agree | 2 Agree | 3 Neutral | 4 Disagree | 5 Strongly Disagree | 6 Not sure

29. Having the new gene test would help me make decisions about changing my lifestyle to try and prevent cancer (e.g. changing my diet, exercising more, etc.).

1 Strongly Agree | 2 Agree | 3 Neutral | 4 Disagree | 5 Strongly Disagree

30. Having the new gene test would help me make decisions about screening (doing monthly breast self-exams, regular check-ups with my doctor, etc.)

1 Strongly Agree | 2 Agree | 3 Neutral | 4 Disagree | 5 Strongly Disagree

31. Having the new gene test and finding out I am *not at high risk* for developing breast cancer would make me feel relieved.

1 Strongly Agree | 2 Agree | 3 Neutral | 4 Disagree | 5 Strongly Disagree

32. Having the new gene test and finding out I *am at high risk* for developing breast cancer would make me feel very upset and anxious.

1 Strongly Agree | 2 Agree | 3 Neutral | 4 Disagree | 5 Strongly Disagree

33. Taking the new gene test would make me worry too much.

1 Strongly Agree | 2 Agree | 3 Neutral | 4 Disagree | 5 Strongly Disagree

34. It's better not to get gene testing because it's better not to know.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

35. It's better not to get gene testing because the gene test is too much trouble.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

36. I believe that the new gene test is not necessary for me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

37. It's better not to get gene testing because it's better to let nature take its course.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

VIII. GENERAL INFORMATION - TELL US A BIT ABOUT YOURSELF

Please check (✓) the right box or fill in the blank line.

38. Date of birth: _____/_____/_____
month day year

39. Do you have any brothers and/or sisters?

No ☐
Yes ☐

Name _____
Age _____
Name _____
Age _____
Name _____
Age _____
Name _____
Age _____

40. What grade are you in at school? *(check only one box)*

☐ 9
☐ 10
☐ 11
☐ 12
☐ 13
☐ Other _____

41. How are you doing in school? *(check only one box)*

☐ A average
☐ B average
☐ C average
☐ D average
☐ Lower_____

42. Are you planning on going to:

a) college? ☐ yes ☐ no

b) university? ☐ yes ☐ no

c) work after finishing high school? ☐ yes ☐ no

d) other_____

43. What would you like to do eventually as a career?

_____

44. Please list:

a) your hobbies / extracurricular activities:_____

_____

b) any clubs / organizations to which you belong:_____

_____

c) any jobs or volunteer positions you may have:_____

_____

45. What language do you speak most often at home? *(check only <u>one</u> box)*

☐ English ☐ French ☐ Both

☐ Other _____

46. What is your religion? *(check only <u>one</u> box)*

☐ Roman Catholic ☐ Protestant ☐ Hindu

☐ Jewish ☐ Muslim ☐ No religious preference

☐ Other: _____

47. How often do you attend religious services? *(check only <u>one</u> box)*

☐ Never ☐ Less than once a year ☐ Once a year

☐ Several times a year ☐ Once a month ☐ Every week

APPENDIX 3b: Breast Cancer Survey – Mother Version (BCS-M)

October, 1998

Number _____

APPENDIX 3B

BREAST CANCER SURVEY

MOTHERS' VERSION

This questionnaire is part of a research project to improve our understanding of breast cancer that is inherited.

A collaborative study between the Children's Hospital of Eastern Ontario and the Ottawa Regional Cancer Centre

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For information:

Breast Cancer Gene Study
Children's Hospital of Eastern Ontario
Research Institute, Rm 224
401 Smyth Road
Ottawa, Ontario K1H 8L1
Telephone: (613) 738-3904

BREAST CANCER SURVEY

We are interested in learning about people's opinions about breast cancer, its prevention, and its treatment. By completing this questionnaire, you will help us to better understand people's views about this illness and to improve our service in the future.

All of your responses will be kept strictly confidential. Your name will not appear with any of the responses that you give.

Before you begin,
remember that you do not have to answer any questions you would rather not answer.

Thank you.

I. PERSONAL RISK FACTORS FOR BREAST CANCER

Please check(✓) the right box or fill in the blank line.

1. How old were you when you had your first menstrual period? _____ (years old)

2. a) Have your periods stopped? ☐ YES ☐ NO

   b) If YES, your periods stopped because of: *(check only <u>one</u> box)*

   ☐ natural menopause (change of life)

   ☐ a hysterectomy (uterus and/or ovaries removed)

   ☐ medication that stopped your periods

   ☐ Other (please specify): _____

   c) How old were you when your periods stopped? _____ (years old)

3. a) Have you ever taken (or are you currently taking) hormone replacement therapy for menopause?

   ☐ YES ☐ NO

   b) If YES, what year did you start taking hormone replacement therapy? 19_____

4. a) Have you ever taken (or are you currently taking) birth control pills? ☐ YES ☐ NO

   b) If YES, indicate which years you took birth control pills:

   1. From 19_____ to 19_____
   2. From 19_____ to 19_____
   3. From 19_____ to 19_____
   4. From 19_____ to 19_____

5. a) Are you or have you ever been a smoker? ☐ YES ☐ NO

   b) If YES,

   What year did you start? 19_____

   How many cigarettes per day? _____

   If you have quit smoking, what year did you stop? 19_____

6. a) How tall are you? _____feet and _____inches

   b) How much do you weigh now? _____ pounds

   c) What is the most you have ever weighed (excluding pregnancy)? _____pounds

7. a) Do you drink alcoholic beverages? ☐ YES ☐ NO

   b) If YES, on average, how many alcoholic drinks do you have per month? *(check only <u>one</u> box)*

   ☐ 1-3 ☐ 10-14 ☐ 21-29

   ☐ 4-9 ☐ 15-20 ☐ 30 or more

II. BREAST CANCER SCREENING

The following questions refer to different breast screening methods. Please check(✓) the right box or fill in the blank line.

8. a) Have you ever had a mammogram?

   ☐ YES ☐ NO ☐ I don't know what a mammogram is

   b) If YES,

   How old were you when you had your first mammogram? _____years
   How old were you when you had your last mammogram? _____years
   How many mammograms have you had in your lifetime? _____

9. a) Have you ever done a self-examination of your own breasts (Breast Self-Exam)?

   ☐ YES ☐ NO ☐ I don't know how

   b) If YES,

   How often did you perform a breast self-exam in the past year? *(check only <u>one</u> box)*

   ☐ Once a month
   ☐ Once every two months
   ☐ Twice a year
   ☐ Once a year

   c) If YES,

   Who taught you to do breast self-exam:

   ☐ Doctor
   ☐ Nurse
   ☐ Pamphlet
   ☐ Other (*please specify*): _____

10. a) Have you ever had a breast biopsy?

    ☐ YES ☐ NO ☐ I don't know what a biopsy is

    b) If YES,

    How old were you when you had your first biopsy? _____years
    How old were you when you had your last biopsy? _____years
    How many breast biopsies have you had? _____

III. FAMILY HISTORY OF CANCER

The following are some general questions about cancer and your family. Please check (✓) the right box or fill in the blank line.

10.(c) **Are you adopted?**

☐ YES ☐ NO

If yes, please skip to question 16.

11. a) **Does cancer run your family (i.e., more than 2 blood relatives have or had cancer)?**

☐ YES ☐ NO

b) **If YES,**

How old were you when you found out that cancer runs in your family?_____years

12. a) **Does anyone in your family (immediate or extended) have breast and/or ovarian cancer?**

☐ YES ☐ NO ☐ Don't know

b) **If YES, please indicate which family member was told they have breast and/or ovarian cancer, whether the cancer was in one or both breasts and their age when they were told when they had cancer.**
(You may check more than one box)

Family Member	Breast Cancer		Ovarian Cancer	Age of relative when cancer found
	One Breast	Both Breasts		
Grandmother	☐	☐	☐	_____years
Mother	☐	☐	☐	_____years
Aunt	☐	☐	☐	_____years
Sister	☐	☐	☐	_____years
Cousin	☐	☐	☐	_____years
Other (please specify): _____	☐	☐	☐	_____years

13.a) Has a male member(s) of your family been diagnosed with prostate cancer?

□ YES □ NO □ Don't know

b) If YES,

Please indicate your relationship to this relative and when they were told they had prostate cancer.

Relationship (e.g., my brother, my uncle, etc...)	Age of relative when cancer found
_____	_____years
_____	_____years

14.a) Has a member(s) of your immediate family (grandparents, parents, brothers, sisters, children) ever been treated for other types of cancer?

□ YES □ NO *(go to question 15)* □ Don't know

b) If YES, which family member(s)?

Family Member (e.g. Grandmother)	Type of Cancer	Family member's age when told he or she had cancer
_____	_____	_____years
_____	_____	_____years
_____	_____	_____years
_____	_____	_____years

15.a) Have you ever had any type of cancer?

□ YES □ NO □ UNSURE

b) If YES,

I. What type of cancer did you / do you have? _____

II. How old were you when you were first diagnosed with cancer? _____years old

III. What stage was your cancer when it was first diagnosed? □ I □ II □ III □ IV

IV. Were nodes involved? □ YES □ NO

V. What, if any, treatments were you or are you undergoing? □ lumpectomy □ mastectomy

□ chemotherapy □ radiation □ other (specify) _____

VI. If you have finished treatments, how long ago was your last one? _____

VII. What is your current condition? □ perfectly healthy □ disease free □ in remission

□ in treatment □ other (specify) _____

VIII. Are you concerned about your future health? □ very much □ moderately so □ a little □ not at all

Please explain _____

IV. KNOWLEDGE OF BREAST CANCER

The following questions, refer to breast cancer and cancer in general.

For each question, choose the single best answer. (For each question, circle one letter only).

16. How many women will develop breast cancer in Canada?

    a. 1% (1 out of 100 women)
    b. 5% (5 out of 100 women)
    c. 10% (10 out of 100 women)
    d. 25% (25 out of 100 women)
    e. 50% (50 out of 100 women)
    f. Don't know

17. *For each of the following statements, please indicate which ones are "true", "false" or if you are "unsure".*

a) The risk or chance of getting breast cancer increases with age.	☐ True	☐ False	☐ Unsure
b) Women are more likely to get cancer than men.	☐ True	☐ False	☐ Unsure
c) If one of your parents has cancer, then you will get cancer.	☐ True	☐ False	☐ Unsure
d) Gene testing for inherited types of cancer can tell whether or not the tested person will get cancer.	☐ True	☐ False	☐ Unsure

V. PERCEPTIONS OF BREAST CANCER

18. *For each of the following statements, please indicate your opinion.*

a) In your opinion, how life threatening is breast cancer?	1 Very threatening	2 Moderately threatening	3 Somewhat threatening	4 Not at all threatening
b) In your opinion, how effective are the treatments for breast cancer?	1 Not at all effective	2 Somewhat effective	3 Moderately effective	4 Very effective
c) In your opinion, how much does breast cancer affect the patient's ability to do her usual work activities (e.g. housework, go to work outside the home, etc.)?	1 Very much	2 Moderately	3 Somewhat	4 Not at all
d) In your opinion, how much does breast cancer affect the patient's energy levels?	1 Very much	2 Moderately	3 Somewhat	4 Not at all
e) In your opinion, how much does breast cancer affect the patient's ability to do her usual leisure activities (e.g. go out with friends and family, have hobbies, etc.)?	1 Very much	2 Moderately	3 Somewhat	4 Not at all

19. Please share your beliefs.

a) In your opinion, what is the best method of preventing breast cancer? _____

b) In your opinion, what factors determine how curable breast cancer is? _____

20. What advice would you give young women regarding breast cancer detection, prevention, and treatment?

Please turn to next page.....

Breast Cancer Gene Test

There is a **new gene test** that can identify some women who are at greater risk for breast cancer, before cancer occurs.

This new test can find changes (mutations) in specific genes (BRCA1 and BRCA2) which lead to an increased risk of developing breast cancer. The test uses a small blood sample.

We know that genes can be passed from parent to child (i.e., inherited). Therefore some, but not all, children may inherit a breast cancer gene with a mutation that leads to an increased risk of developing breast cancer.

Other cancer genes will be discovered but until then the breast cancer gene test will first look at BRCA1 and BRCA2 gene mutations.

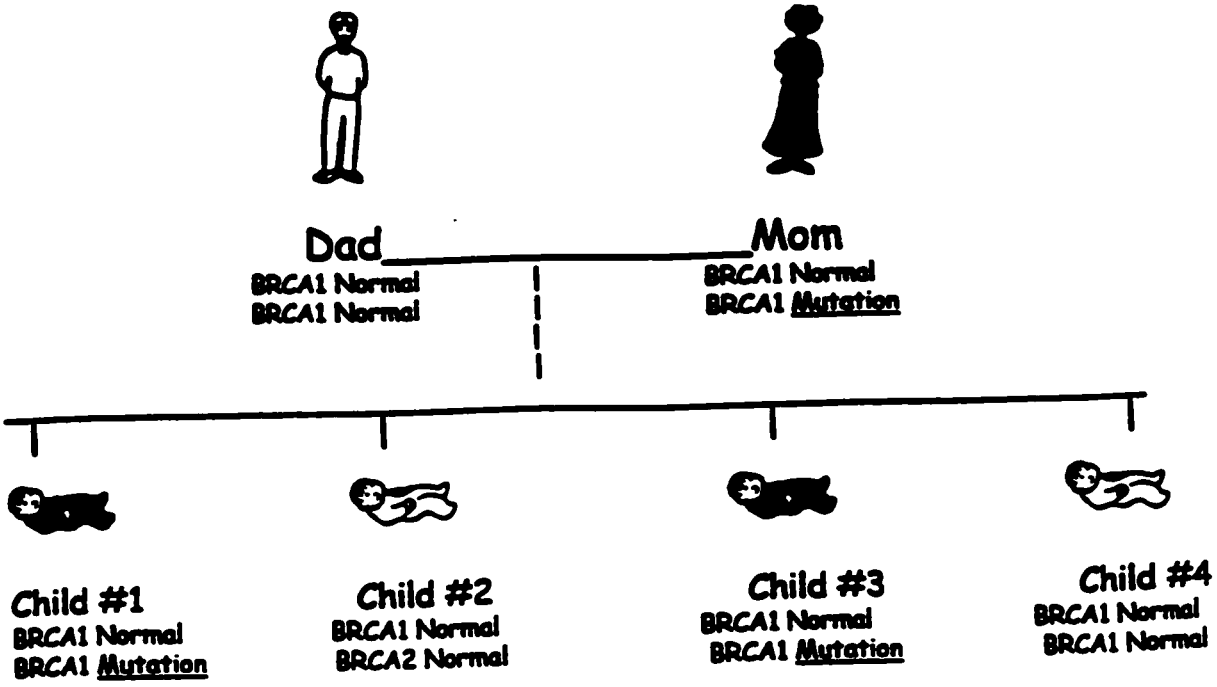
On the following white pages is some information about BRCA1/BRCA2 gene testing, breast cancer treatments and prevention and a glossary of medical terms. You may use this information as a reference while completing the remainder of the questionnaire. However, PLEASE **DO NOT** GO BACK AND CHANGE ANY OF YOUR ANSWERS ON THE QUESTIONNAIRE UP TO THIS POINT.

BREAST CANCER INFORMATION SHEET

An average woman has about a 10% chance of developing breast cancer in her lifetime. In other words 1 women out of 10 will develop breast cancer at some time in her life.

The majority of breast cancer is sporadic, which means it happens by chance. But some breast cancers are caused by a change or mutation in a gene called the BRCA1 or BRCA2 gene. Genes are tiny structures that are found in chromosomes. Genes give us characteristics like eye colour and hair colour. We inherit genes from both our parents, which is why we sometimes have features that are similar to our mother and father. The percentage of breast cancer that occurs due to the inheritance of a mutation on the BRCA1/ BRCA2 gene is approximately 5-10%. This means that out of 100 women who have breast cancer, approximately 5-10 women developed breast cancer due to a change in the BRCA1/ BRCA2 gene.

Inheritance of a Mutated BRCA1/ BRCA2 Gene:
Everyone has two BRCA1/ BRCA2 genes. We receive one from our mother and one from our father. A person can inherit a mutated or changed BRCA1/ BRCA2 gene from either parent. If one of the parents has the mutated gene, each of their children has a 50% chance of inheriting the mutated version of the gene.



Inheriting a BRCA1 / BRCA2 mutation does not necessarily mean that you will develop breast cancer. What it means is that your chance of developing breast cancer increases to approximately 80% over your lifetime. In other words, 8 out of 10 women who have a mutated BRCA1/ BRCA2 gene will develop breast cancer at some time in their life.

If you have not inherited the BRCA1/ BRCA2 mutation, your risk of developing breast cancer is the same as the general population, which is approximately 10% (or 1 in 10).

Genetic Testing:
There is a genetic test for breast cancer which is still in the research stage. For the genetic test, a blood sample is taken and DNA is removed and looked over to see if there is a mutation on the BRCA1/ BRCA2 gene. This test tells whether or not you have inherited a BRCA1 or BRCA2 mutation. This will then tell you if your risks of developing breast cancer are increased from 10% to 80%.

Breast Cancer Detection:
There are ways in which you can monitor yourself for the possible development of breast cancer. Early detection can greatly increase your chances of survival. Ways of monitoring for breast cancer are: 1)performing self breast exams on a monthly basis, 2) having your physician examine your breasts 3) by having mammograms.

Breast Cancer Prevention:
There are a number of things that might help to prevent breast cancer in some people. Nutrition and lifestyle choices, such as not smoking and eating a healthy, well balanced diet, can help to reduce your risk of developing breast cancer. Occasionally, women at high risk for developing breast cancer will chose to have their breasts removed even though they do not have cancer in hopes of preventing it. Some women at risk may choose to take medications to further reduce their risk of developing breast cancer.

Treatments for Breast Cancer:
If breast cancer is detected early and the tumour is small, a lumpectomy (to remove the cancer) and radiation (to kill any remaining cancer cells) may be given. More severe forms of breast cancer might require 1) single mastectomy (removal of the entire breast), 2) double mastectomy (removal of both breasts) 3) hormone therapy and 4) chemotherapy (drug therapy).

GLOSSARY

Biopsy: Test for breast cancer which includes removal of a tissue sample from the breast for examination.

BRCA1/ BRCA2 Gene: A gene that produces a protein which is important for preventing cancer in normal breast tissue cells. Changes/ mutations in the BRCA1/ BRCA2 gene mean that this protein is no longer produced. Mutations of the BRCA1/ BRCA2 gene result in an increased chance of developing breast cancer to up to 80% over one's lifetime.

Breast cancer: Uncontrolled cell multiplication that results in a tumour in the breast.

Cancer: Uncontrolled cell multiplication that results in a tumour.

Chemoprevention: The use of chemotherapy even when there is no cancer. This is occasionally performed on women who have a high risk of developing breast cancer.

Chemotherapy: The use of systemic drugs (drugs which effect the whole body) that kill the cancer cells. It kills tumour cells by interfering with some of the steps involved with cell division.

Chromosomes: Microscopic structures found in each cell of the body, which carry genes. Normally, we all have 23 pairs of chromosomes. One member of each pair is inherited from our mother and one from our father.

DNA: Deoxyribonucleic Acid: This is the material which genes are made of.

Genes: Very small structures that are found in chromosomes. They determine or influence a person's physical and chemical characteristics (e.g. the colour of your skin, eyes, hair, your height, etc.). They tell the body how to grow and work.

Inheritance: The passing of genetic qualities from parents to their children.

Lumpectomy: Removal of a cancerous tumour, along with some lymph nodes and perhaps some of the healthy breast tissue around the tumour.

Lymph Nodes: Glands that are part of the body's defence system against infection.

Mammogram: A way of taking a picture of the inside of the breast to look for cancerous cells. This is done by using a low-dose X-ray.

Mastectomy: Removal of the whole breast. Double mastectomy (also called bilateral mastectomy) is the removal of both breasts.

Mutation: A change in a gene. For example, if someone has an altered BRCA1 or BRCA2 gene, they have a higher risk of developing breast cancer.

Radiation: Ionizing radiation is used in treating breast cancer by killing tumour cells.

Tumour: An abnormal mass of tissue caused by cells multiplying uncontrollably.

X-ray: A "photograph" of a body part (e.g., the breast) taken using electromagnetic radiation to mark the film.

VI. YOUR RISK AND THE BREAST CANCER GENE TEST

21. a) Compared to other women, what do you believe is your chance of getting breast cancer?

1	2	3	4
Less	The same	A little higher	Much higher

b) What do you think is the likelihood of your carrying a breast cancer gene mutation?

1	2	3	4
Not at all	A little	Somewhat	Very likely

c) What do you think your chance is of getting any kind of cancer?

1	2	3	4
No chance	Small chance	Moderate chance	Strong chance

d) What do you think your chance is of getting ovarian cancer (cancer of the ovaries)?

1	2	3	4
No chance	Small chance	Moderate chance	Strong chance

22. a). How concerned are you about your chance of getting breast cancer?

1	2	3	4
Not at all	Somewhat concerned	Moderately concerned	Very concerned

b). How concerned are you about your chance of getting any kind of cancer?

1	2	3	4
Not at all	Somewhat concerned	Moderately concerned	Very concerned

c). How often do you worry about your chance of getting breast cancer?

1	2	3	4
Rarely or never	Sometimes	Often	All the time

d). How much do worries about breast cancer affect the way you feel from day to day?

1	2	3	4
Not at all	Somewhat	A fair bit	Very much

e). How often do worries about breast cancer get in the way of your ability to carry out daily activities?

1	2	3	4
Rarely or never	Sometimes	Often	All the time

23. How concerned are you about <u>your child(ren)</u> or future child(ren) getting breast cancer?

1	2	3	4	5
Not at all Concerned	Slightly Concerned	Neutral	Moderately Concerned	Very Concerned

24.a) Before today, have you heard about the new type of gene testing (like BRCA1) for breast cancer?

□ YES □ NO

b) If YES, who told you about the gene test? _____

25. Would you take a test which could tell you if you have a high risk (80-90%) of getting breast cancer?

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

VII. BREAST CANCER GENE TEST RESULTS

For each of the following statements, indicate your response by circling the appropriate number.

26. If a test told me I would probably get breast cancer in the future, I would keep the test results to myself.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

27. If a test told me I would probably get breast cancer in the future, I would put the test results out of my mind.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

28. If a test told me I would probably get breast cancer in the future, I would tell my family about my test results.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

29. If a test told me I would probably get breast cancer in the future, I would tell my friends about my test results.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

30. If a test told me I would probably get breast cancer in the future, I would take an experimental drug to try and prevent it.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

31. If a test told me I would probably get breast cancer in the future, I would get surgery (have both breasts removed) to try and prevent it.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

32. If a test told me I would probably get breast cancer in the future, it would affect my decisions about having long-term relationships.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

33. My spouse wants me to have the new gene test for breast cancer.

1	2	3	4	5	6
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not sure

34. Having the new gene test would help me make decisions about changing my lifestyle to try and prevent cancer (e.g. changing my diet, exercising more, etc.)

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

35. Having the new gene test would help me make decisions about screening (doing monthly breast self-exams, regular check-ups with my doctor, etc.)

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

36. Having the new gene test and finding out I am *not at high risk* for developing breast cancer would make me feel relieved.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

37. Having the new gene test and finding out I *am at high risk* for developing breast cancer would make me feel very upset and anxious.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

38. Taking the new gene test would make me worry too much.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

39. It's better not to get gene testing because its better not to know.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

40. It's better not to get gene testing because the gene test is too much trouble.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

41. I believe that the new gene test is not necessary for me.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

42. It's better not to get gene testing because it's better to let nature take its course.

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

43. I would encourage my immediate family (e.g., Mother or Sister) to be tested.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

44. I would encourage my relatives to be tested.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

45. I would encourage my older children to be tested.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

46. I would encourage my friends to be tested.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

47. I would tell my family doctor about my test results.

1	2	3	4	5
Definitely	Probably	Not Sure	Probably Not	Definitely Not

48. **Here are some reasons to take, or not to take, the new gene test for breast cancer. We would like to know <u>your</u> opinion.**
Please indicate how much you agree or disagree with each of the following statements:

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
a.	I am concerned about my relatives' risk of getting breast cancer.	1	2	3	4	5
b.	I am concerned about my children's risk of getting breast cancer.	1	2	3	4	5
c.	My other relatives want to know if they have a greater risk to get breast cancer.	1	2	3	4	5
d.	The results of the new gene test will help me to make decisions about having children.	1	2	3	4	5
e.	The results of the new gene test will help me make better career choices.	1	2	3	4	5
f.	The results of the new gene test will help me make plans for retirement.	1	2	3	4	5
g.	The result of the new gene test will help me make decisions about life and disability insurance.	1	2	3	4	5
h.	My doctor wants me to be tested	1	2	3	4	5
i.	I would get the new gene test to help cancer research.	1	2	3	4	5
j.	The new gene test will help me make decisions about treatments for breast cancer.	1	2	3	4	5
k.	I am concerned about my children passing on a possible cancer susceptibility gene to their children (my grandchildren).	1	2	3	4	5

49. For each situation, indicate how much it would influence your choice to be tested for a breast cancer gene.

	Very Likely	Likely	Neutral	Unlikely	Very Unlikely
a) Having breast cancer	1	2	3	4	5
b) Family History of breast cancer	1	2	3	4	5
c) Family History of any cancer	1	2	3	4	5
d) Marriage	1	2	3	4	5
e) Pregnancy	1	2	3	4	5

50. If you decide to take the new gene test for breast cancer, how much time would you be willing to travel to be tested? *(check only <u>one</u> box)*

- ☐ Up to 15 minutes
- ☐ Up to 30 minutes
- ☐ Up to 45 minutes
- ☐ Up to 1 hour
- ☐ Up to 1 ½ hours
- ☐ Up to 2 hours
- ☐ Over 2 hours

51. If you decide to take the new gene test for breast cancer, would any of the following reasons stop you from getting tested. *(check "yes" or "no" for each statement)*

a) Finding out where to go for testing	☐ YES	☐ NO
b) Taking time off work	☐ YES	☐ NO
c) Transportation to the blood lab (testing site)	☐ YES	☐ NO
d) Parking costs at the blood lab (testing site)	☐ YES	☐ NO
e) Finding a babysitter while I am being tested	☐ YES	☐ NO
f) Spending 1 hour receiving information about the test before being tested	☐ YES	☐ NO

VIII. GENERAL INFORMATION - TELL US A BIT ABOUT YOURSELF

Please check (✓) the right box or fill in the blank line.

52. Date of birth: _____/_____/_____
month day year

53. What is your postal code? _____

54. What is the highest level of education that you are completing or have completed? *(check only one box)*

- ☐ Less than high school
- ☐ Completed high school
- ☐ Certificate/diploma
- ☐ Community college diploma or degree
- ☐ University Bachelors degree
- ☐ University Masters degree
- ☐ University Doctorate
- ☐ Post Doctoral Training

55. What language do you speak most often at home? *(check only one box)*

- ☐ English ☐ French ☐ Both
- ☐ Other _____

56. What is your religion? *(check only one box)*

- ☐ Roman Catholic ☐ Protestant ☐ Hindu
- ☐ Jewish ☐ Muslim ☐ No religious preference
- ☐ Other: _____

57. How often do you attend religious services? *(check only one box)*

- ☐ Never ☐ Less than once a year ☐ Once a year
- ☐ Several times a year ☐ Once a month ☐ Every week

58. What is your current marital status? *(check only one box)*

- ☐ Single ☐ Married or Common-law
- ☐ Separated ☐ Divorced ☐ Widowed

59. Which of the following best describes your living arrangement? *(check only one box)*

- ☐ Live alone
- ☐ Live with spouse, family or friends

60. (a) For all your pregnancies please indicate the following information: *(check correct box and write year)*

	Sex (M= Male or F = Female)		Year Born	Breast fed?		Currently Living With You?	
1.	☐ M	☐ F	19____	☐ Yes	☐ No	☐ Yes	☐ No
2.	☐ M	☐ F	19____	☐ Yes	☐ No	☐ Yes	☐ No
3.	☐ M	☐ F	19____	☐ Yes	☐ No	☐ Yes	☐ No
4.	☐ M	☐ F	19____	☐ Yes	☐ No	☐ Yes	☐ No
5.	☐ M	☐ F	19____	☐ Yes	☐ No	☐ Yes	☐ No

(b) Have you had any miscarriages? ☐ Yes ☐ No How many? _____

61. Are you planning to have children in the next two years? *(check only one box)*

☐ YES ☐ NO ☐ UNCERTAIN

62. (a) What is your main occupation?

- ☐ Looking for work
- ☐ Student
- ☐ Retired
- ☐ Homemaker
- ☐ Self-employed
- ☐ Currently employed as: _____
- ☐ Other (please specify): _____

(b) Number of hours worked per week? _____

63. What is your family income per year? *(check only one box)*
(If married or common-law, state the combined income of you and your partner).

- ☐ Under $10,000
- ☐ $10,000 to 19,999
- ☐ $20,000 to 29,999
- ☐ $30,000 to 39,999
- ☐ $40,000 to 49,999
- ☐ $50,000 to 59,999
- ☐ $60,000 to 69,999
- ☐ $70,000 to 79,999
- ☐ $80,000 to 89,999
- ☐ $90,000 to 99,999
- ☐ $100,000 or above

APPENDIX 4: The Health Status Questionnaire (SF-36)

Health Status Questionnaire SF-36

1) In general, would you say your health is:

(*circle one number*)

Excellent.....1
Very good.....2
Good.....3
Fair.....4
Poor.....5

2) Compared to one year ago, how would you rate your health in general now?

(*circle one number*)

Much better now than one year ago.....1
Somewhat better now than one year ago.....2
About the same.....3
Somewhat worse now than one year ago.....4
Much worse now than one year ago.....5

The following items are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

(*circle one number on each line*)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5) Lifting or carrying groceries	1	2	3
6) Climbing several flights of stairs	1	2	3
7) Climbing one flight of stairs	1	2	3
8) Bending, kneeling, or stooping	1	2	3
9) Walking more than a mile	1	2	3
10) Walking several blocks	1	2	3
11) Walking one block	1	2	3
12) Bathing or dressing yourself	1	2	3

During the past 4 weeks. have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	(*circle one number on each line*) Yes	No
13) Cut down the amount of time you spend on work or other activities	1	2
14) Accomplished less than you would like	1	2
15) Were limited in the kind of work or other activities	1	2
16)Had difficulty, performing the work or other activities (for example, it took extra effort)	1	2

During the past 4 weeks. have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	(*circle one number on each line*) Yes	No
17) Cut down the amount of time you spent on work or other activities	1	2
18)Accomplished less than you would like	1	2
19) Didn't do work or other activities as carefully as usual	1	2

20) During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(*circle one number*)

Not at all.....1
Slightly.....2
Moderately.....3
Quite a bit.....4
Extremely.....5

21) How much bodily pain have you had during the past 4 weeks?

(*circle one number*)

Not at all.....1
Slightly.....2
Moderately.....3
Quite a bit.....4
Extremely.....5

22) During the past 4 weeks how much did pain interfere with your normal work (including both work outside the home and housework)?

(*circle one number*)

Not at all.....1
Slightly.....2
Moderately.....3
Quite a bit.....4
Extremely.....5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

(circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23) Did you feel full of pep or energy?.....	1	2	3	4	5	6
24) Have you been a very nervous person?.....	1	2	3	4	5	6
25) Have you felt so down in the dumps that nothing could cheer you up?.....	1	2	3	4	5	6
26) Have you felt calm and peaceful?.....	1	2	3	4	5	6
27) Did you have a lot of energy?.....	1	2	3	4	5	6
28) Have you felt down-hearted and blue?.....	1	2	3	4	5	6
29) Did you feel worn out?.....	1	2	3	4	5	6
30) Have you been a happy person?.....	1	2	3	4	5	6
31) Did you feel tired?.....	1	2	3	4	5	6

32) During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your socials activities (like visiting with friends, relatives, etc.)?

(circle one number)

All of the time.....1
Most of the time.....2
Some of the time.....3
A little of the time.....4
None of the time.....5

How TRUE or FALSE is each of the following statements for you?

(*circle one number on each line*)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33) I seem to get sick a little easier than other people.....1	1	2	3	4	5
34) I am as healthy as anybody I know.....1	1	2	3	4	5
35) I expect my health to get worse.....1	1	2	3	4	5
36) My health is excellent.....1	1	2	3	4	5

Please answer YES or NO for each question by circling "1" or "2" on each line.

	(*circle one number*) Yes	No
37) In the past year, have you had 2 weeks or more during which you felt sad, blue, or depressed; or when you lost all interest or pleasure in things that you usually cared about or enjoyed?.....1	1	2
38) Have you had 2 years or more in your life when you were depressed or sad most days, even if you felt okay sometimes?.....1	1	2
39) Have you felt depressed or sad much of the time in the past year?.....1	1	2

APPENDIX 5: The Child Behavior Checklist (CBCL)

CHILD BEHAVIOR CHECKLIST FOR AGES 4-18

Please Print

CHILD'S FULL NAME: FIRST MIDDLE LAST

SEX: ☐ Boy ☐ Girl

AGE

ETHNIC GROUP OR RACE

TODAY'S DATE: Mo. ____ Date ____ Yr. ____

CHILD'S BIRTHDATE: Mo. ____ Date ____ Yr. ____

GRADE IN SCHOOL: ____

NOT ATTENDING SCHOOL ☐

Please fill out this form to reflect your view of the child's behavior even if other people might not agree. Feel free to print additional comments beside each item and in the spaces provided on page 2.

PARENTS' USUAL TYPE OF WORK, even if not working now. (e.g., for mother: sales clerk, assembler, high school teacher; for father: auto mechanic, shoe salesman, army sergeant.)

FATHER'S TYPE OF WORK: ____

MOTHER'S TYPE OF WORK: ____

THIS FORM FILLED OUT BY:

☐ Mother (full name) ____

☐ Father (full name) ____

☐ Other (full name) & relationship to child: ____

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do?		
	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average
a. ____	☐	☐	☐	☐	☐	☐	☐
b. ____	☐	☐	☐	☐	☐	☐	☐
c. ____	☐	☐	☐	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, singing, etc. (Do not include listening to radio or TV.)

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				Compared to others of the same age, how well does he/she do?		
	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average
a. ____	☐	☐	☐	☐	☐	☐	☐
b. ____	☐	☐	☐	☐	☐	☐	☐
c. ____	☐	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

	Compared to others of the same age, how active is he/she in each?			
	Don't Know	Less Active	Average	More Active
a. ____	☐	☐	☐	☐
b. ____	☐	☐	☐	☐
c. ____	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

	Compared to others of the same age, how well does he/she carry them out?			
	Don't Know	Below Average	Average	Above Average
a. ____	☐	☐	☐	☐
b. ____	☐	☐	☐	☐
c. ____	☐	☐	☐	☐

Please Print

V. 1. About how many close friends does your child have? (Do *not* include brothers & sisters) ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week does your child do things with any friends outside of regular school hours? (Do *not* include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

VI. Compared to others of his/her age, how well does your child:

	Worse	About Average	Better	
a. Get along with his/her brothers & sisters?	☐	☐	☐	☐ Has no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Behave with his/her parents?	☐	☐	☐	
d. Play and work alone?	☐	☐	☐	

VII. 1. For ages 6 and older—performance in academic subjects. ☐ Does not attend school because _____

Check a box for each subject that child takes	Failing	Below Average	Average	Above Average
a. Reading, English, or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
Other academic subjects—for example: computer courses, foreign language, business. Do *not* include gym, shop, driver's ed., etc. e. _____	☐	☐	☐	☐
f. _____	☐	☐	☐	☐
g. _____	☐	☐	☐	☐

2. Does your child receive special remedial services or attend a special class or special school? ☐ No ☐ Yes—kind of services, class, or school:

3. Has your child repeated any grades? ☐ No ☐ Yes—grades and reasons:

4. Has your child had any academic or other problems in school? ☐ No ☐ Yes—please describe:

When did these problems start?

Have these problems ended? ☐ No ☐ Yes—when?

Does your child have any illness or disability (either physical or mental)? ☐ No ☐ Yes—please describe:

What concerns you most about your child?

Please describe the best things about your child:

Below is a list of items that describe children and youth. For each item that describes your child ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of your child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of your child. If the item is ***not true*** of your child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to your child.

Please Print

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 1. Acts too young for his/her age
0 1 2 2. Allergy (describe): _____
_____
0 1 2 3. Argues a lot
0 1 2 4. Asthma
0 1 2 5. Behaves like opposite sex
0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): _____
_____
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Cruel to animals
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Day-dreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys things belonging to his/her family or others
0 1 2 22. Disobedient at home
0 1 2 23. Disobedient at school
0 1 2 24. Doesn't eat well
0 1 2 25. Doesn't get along with other kids
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Eats or drinks things that are not food — ***don't*** include sweets (describe): _____
_____
0 1 2 29. Fears certain animals, situations, or places, other than school (describe): _____
_____
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do somethir bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves hir
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trout
0 1 2 40. Hears sounds or voices that aren't ther (describe): _____
_____
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describ
_____
_____
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired
0 1 2 55. Overweight

56. Physical problems ***without known medical cause:***

0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses) (describe): _____
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches or cramps
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): _____
_____

Please Print

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 57. Physically attacks people
0 1 2 58. Picks nose, skin, or other parts of body (describe): _____

_____

0 1 2 59. Plays with own sex parts in public
0 1 2 60. Plays with own sex parts too much

0 1 2 61. Poor school work
0 1 2 62. Poorly coordinated or clumsy

0 1 2 63. Prefers being with older kids
0 1 2 64. Prefers being with younger kids

0 1 2 65. Refuses to talk
0 1 2 66. Repeats certain acts over and over; compulsions (describe): _____

_____

0 1 2 67. Runs away from home
0 1 2 68. Screams a lot

0 1 2 69. Secretive, keeps things to self
0 1 2 70. Sees things that aren't there (describe):

_____

_____

0 1 2 71. Self-conscious or easily embarrassed
0 1 2 72. Sets fires

0 1 2 73. Sexual problems (describe): _____

_____

_____

0 1 2 74. Showing off or clowning

0 1 2 75. Shy or timid
0 1 2 76. Sleeps less than most kids

0 1 2 77. Sleeps more than most kids during day and/or night (describe): _____

_____

0 1 2 78. Smears or plays with bowel movements

0 1 2 79. Speech problem (describe): _____

_____

0 1 2 80. Stares blankly

0 1 2 81. Steals at home
0 1 2 82. Steals outside the home

0 1 2 83. Stores up things he/she doesn't need (describe): _____

_____

0 1 2 84. Strange behavior (describe): _____

_____

0 1 2 85. Strange ideas (describe): _____

_____

0 1 2 86. Stubborn, sullen, or irritable

0 1 2 87. Sudden changes in mood or feelings
0 1 2 88. Sulks a lot

0 1 2 89. Suspicious
0 1 2 90. Swearing or obscene language

0 1 2 91. Talks about killing self
0 1 2 92. Talks or walks in sleep (describe): _____

_____

0 1 2 93. Talks too much
0 1 2 94. Teases a lot

0 1 2 95. Temper tantrums or hot temper
0 1 2 96. Thinks about sex too much

0 1 2 97. Threatens people
0 1 2 98. Thumb-sucking

0 1 2 99. Too concerned with neatness or cleanliness
0 1 2 100. Trouble sleeping (describe): _____

_____

0 1 2 101. Truancy, skips school
0 1 2 102. Underactive, slow moving, or lacks energy

0 1 2 103. Unhappy, sad, or depressed
0 1 2 104. Unusually loud

0 1 2 105. Uses alcohol or drugs for nonmedical purposes (describe): _____

_____

0 1 2 106. Vandalism

0 1 2 107. Wets self during the day
0 1 2 108. Wets the bed

0 1 2 109. Whining
0 1 2 110. Wishes to be of opposite sex

0 1 2 111. Withdrawn, doesn't get involved with others
0 1 2 112. Worries

113. Please write in any problems your child has that were not listed above:

0 1 2 _____

0 1 2 _____

0 1 2

APPENDIX 6: The Youth Self-Report Form (YSR)

YOUTH SELF-REPORT FOR AGES 11–18

Please Print

YOUR FULL NAME: FIRST MIDDLE LAST

YOUR SEX: ☐ Boy ☐ Girl

YOUR AGE

ETHNIC GROUP OR RACE

TODAY'S DATE: Mo. ____ Date ____ Yr. ____

YOUR BIRTHDATE: Mo. ____ Date ____ Yr. ____

GRADE IN SCHOOL ____

NOT ATTENDING SCHOOL ☐

IF YOU ARE WORKING, PLEASE STATE YOUR TYPE OF WORK:

PARENTS' USUAL TYPE OF WORK, even if not working now (Please be specific—for example, auto mechanic, high school teacher, homemaker, laborer, salesperson, accountant, army sergeant.)

FATHER'S TYPE OF WORK: ____

MOTHER'S TYPE OF WORK: ____

Please fill out this form to reflect your views, even if other people might not agree. Feel free to print additional comments beside each item and in the spaces provided on pages 2 and 4.

I. Please list the sports you most like to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

a. ____

b. ____

c. ____

Compared to others of your age, about how much time do you spend in each?

	Less Than Average	Average	More Than Average
a.	☐	☐	☐
b.	☐	☐	☐
c.	☐	☐	☐

Compared to others of your age, how well do you do each one?

	Below Average	Average	Above Average
a.	☐	☐	☐
b.	☐	☐	☐
c.	☐	☐	☐

II. Please list your favorite hobbies, activities, and games, other than sports. For example: cards, books, piano, cars, crafts, etc. (Do *not* include listening to radio or TV.)

☐ None

a. ____

b. ____

c. ____

Compared to others of your age, about how much time do you spend in each?

	Less Than Average	Average	More Than Average
a.	☐	☐	☐
b.	☐	☐	☐
c.	☐	☐	☐

Compared to others of yo how well do you do each one?

	Below Average	Average	Above Average
a.	☐	☐	☐
b.	☐	☐	☐
c.	☐	☐	☐

III. Please list any organizations, clubs, teams or groups you belong to.

☐ None

a. ____

b. ____

c. ____

Compared to others of your age, how active are you in each?

	Less Active	Average	More Active
a.	☐	☐	☐
b.	☐	☐	☐
c.	☐	☐	☐

IV. Please list any jobs or chores you have. For example: paper route, babysitting, making bed, working in store, etc. (Include *both* paid and unpaid jobs and chores.)

☐ None

a. ____

b. ____

c. ____

Compared to others of your age, how well do you carry them out?

	Below Average	Average	Above Average
a.	☐	☐	☐
b.	☐	☐	☐
c.	☐	☐	☐

Please Print

V. 1. About how many close friends do you have? ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more
(Do *not* include brothers & sisters)

2. About how many times a week do you do things with any friends outside of regular school hours? ☐ less than 1 ☐ 1 or 2 ☐ 3 or more
(Do *not* include brothers & sisters)

VI. Compared to others of your age, how well do you:

	Worse	About the same	Better	
a. Get along with your brothers & sisters?	☐	☐	☐	☐ I have no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Get along with your parents?	☐	☐	☐	
d. Do things by yourself?	☐	☐	☐	

VII. Performance in academic subjects. ☐ I do not attend school because _____

Check a box for each subject that you take

	Failing	Below Average	Average	Above Average
a. English or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
Other academic subjects—for example: computer courses, foreign language, business. Do *not* include gym, shop, driver's ed., etc. e. _____	☐	☐	☐	☐
f. _____	☐	☐	☐	☐
g. _____	☐	☐	☐	☐

Do you have any illness, disability, or handicap? ☐ No ☐ Yes—please describe:

Please describe any concerns or problems you have about school:

Please describe any other concerns you have:

Please describe the best things about yourself:

Below is a list of items that describe kids. For each item that describes you *now or within the past 6 months*, please circle the 2. *very true or often true* of you. Circle the *1* if the item is *somewhat or sometimes true* of you. If the item is *not true* of you, circle the 0.

Please Print 0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 1. I act too young for my age
0 1 2 2. I have an allergy (describe): _____

0 1 2 3. I argue a lot
0 1 2 4. I have asthma
0 1 2 5. I act like the opposite sex
0 1 2 6. I like animals
0 1 2 7. I brag
0 1 2 8. I have trouble concentrating or paying attention
0 1 2 9. I can't get my mind off certain thoughts (describe): _____

0 1 2 10. I have trouble sitting still
0 1 2 11. I'm too dependent on adults
0 1 2 12. I feel lonely
0 1 2 13. I feel confused or in a fog
0 1 2 14. I cry a lot
0 1 2 15. I am pretty honest
0 1 2 16. I am mean to others
0 1 2 17. I daydream a lot
0 1 2 18. I deliberately try to hurt or kill myself
0 1 2 19. I try to get a lot of attention
0 1 2 20. I destroy my own things
0 1 2 21. I destroy things belonging to others
0 1 2 22. I disobey my parents
0 1 2 23. I disobey at school
0 1 2 24. I don't eat as well as I should
0 1 2 25. I don't get along with other kids
0 1 2 26. I don't feel guilty after doing something I shouldn't
0 1 2 27. I am jealous of others
0 1 2 28. I am willing to help others when they need help
0 1 2 29. I am afraid of certain animals, situations, or places, other than school (describe): _____

0 1 2 30. I am afraid of going to school
0 1 2 31. I am afraid I might think or do something bad
0 1 2 32. I feel that I have to be perfect
0 1 2 33. I feel that no one loves me
0 1 2 34. I feel that others are out to get me
0 1 2 35. I feel worthless or inferior
0 1 2 36. I accidentally get hurt a lot
0 1 2 37. I get in many fights
0 1 2 38. I get teased a lot
0 1 2 39. I hang around with kids who get in trouble

0 1 2 40. I hear sounds or voices that other people think aren't there (describe): _____

0 1 2 41. I act without stopping to think
0 1 2 42. I would rather be alone than with others
0 1 2 43. I lie or cheat
0 1 2 44. I bite my fingernails
0 1 2 45. I am nervous or tense
0 1 2 46. Parts of my body twitch or make nervous movements (describe): _____

0 1 2 47. I have nightmares
0 1 2 48. I am not liked by other kids
0 1 2 49. I can do certain things better than most kids
0 1 2 50. I am too fearful or anxious
0 1 2 51. I feel dizzy
0 1 2 52. I feel too guilty
0 1 2 53. I eat too much
0 1 2 54. I feel overtired
0 1 2 55. I am overweight
56. Physical problems without known medical cause:
0 1 2 a. Aches or pains (not stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feel sick
0 1 2 d. Problems with eyes (not if corrected by glasses) (describe): _____
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches or cramps
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): _____

0 1 2 57. I physically attack people
0 1 2 58. I pick my skin or other parts of my body (describe): _____

0 1 2 59. I can be pretty friendly
0 1 2 60. I like to try new things
0 1 2 61. My school work is poor
0 1 2 62. I am poorly coordinated or clumsy
0 1 2 63. I would rather be with older kids than with kids my own age

Please see other

0 = Not True 1 = Somewhat or Sometimes True 2 = Very True or Often

0 1 2 64. I would rather be with younger kids than with kids my own age
0 1 2 65. I refuse to talk
0 1 2 66. I repeat certain acts over and over (describe): _____

0 1 2 67. I run away from home
0 1 2 68. I scream a lot
0 1 2 69. I am secretive or keep things to myself
0 1 2 70. I see things that other people think aren't there (describe): _____

0 1 2 71. I am self-conscious or easily embarrassed
0 1 2 72. I set fires
0 1 2 73. I can work well with my hands
0 1 2 74. I show off or clown
0 1 2 75. I am shy
0 1 2 76. I sleep less than most kids
0 1 2 77. I sleep more than most kids during day and/or night (describe): _____

0 1 2 78. I have a good imagination
0 1 2 79. I have a speech problem (describe): _____

0 1 2 80. I stand up for my rights
0 1 2 81. I steal at home
0 1 2 82. I steal from places other than home

0 1 2 83. I store up things I don't need (describe): _____

0 1 2 84. I do things other people think are strange (describe): _____

0 1 2 85. I have thoughts that other people would think are strange (describe): _____

0 1 2 86. I am stubborn
0 1 2 87. My moods or feelings change suddenly
0 1 2 88. I enjoy being with other people
0 1 2 89. I am suspicious
0 1 2 90. I swear or use dirty language
0 1 2 91. I think about killing myself
0 1 2 92. I like to make others laugh
0 1 2 93. I talk too much
0 1 2 94. I tease others a lot
0 1 2 95. I have a hot temper
0 1 2 96. I think about sex too much
0 1 2 97. I threaten to hurt people
0 1 2 98. I like to help others
0 1 2 99. I am too concerned about being neat or clean

0 1 2 100. I have trouble sleeping (describe): _____

0 1 2 101. I cut classes or skip school
0 1 2 102. I don't have much energy
0 1 2 103. I am unhappy, sad, or depressed
0 1 2 104. I am louder than other kids
0 1 2 105. I use alcohol or drugs for nonmedical purposes (describe): _____

0 1 2 106. I try to be fair to others
0 1 2 107. I enjoy a good joke
0 1 2 108. I like to take life easy
0 1 2 109. I try to help other people when I can
0 1 2 110. I wish I were of the opposite sex
0 1 2 111. I keep from getting involved with others
0 1 2 112. I worry a lot

Please write down anything else that describes your feelings, behavior, or interests

PLEASE BE SURE YOU HAVE ANSWERED ALL

APPENDIX 7: The Symptom Checklist 90 – Revised (SCL-90-R)

APPENDIX 7

SCL-90-R®

Symptom Checklist-90-R

Leonard R. Derogatis, PhD

Last Name First MI

ID Number

Age Gender Test Date

DIRECTIONS:

1. Print your name, identification number, age, gender, and testing date in the area on the left side of this page.
2. Use a lead pencil only and make a dark mari when responding to the items on pages 2 and 3.
3. If you want to change an answer, erase carefully and then fill in your new choice.
4. Do not make any marks outside the circles.

COPY

INSTRUCTIONS:
Below is a list of problems people sometimes have. Please read each one carefully, and blacken the circle that best describes HOW MUCH THAT PROBLEM HAS DISTRESSED OR BOTHERED YOU DURING THE PAST 7 DAYS, INCLUDING TODAY. Blacken the circle for only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example before beginning, and if you have any questions please ask them now.

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
EXAMPLE					
HOW MUCH WERE YOU DISTRESSED BY:					
11 Backaches	0	1	2	●	4

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	HOW MUCH WERE YOU DISTRESSED BY:
1	●	1	2	3	4	Headaches
2	●	1	2	3	4	Nervousness or shakiness inside
3	●	1	2	3	4	Repeated unpleasant thoughts that won't leave your mind
4	●	1	2	3	4	Faintness or dizziness
5	●	1	2	3	4	Loss of sexual interest or pleasure
6	●	1	2	3	4	Feeling critical of others
7	●	1	2	3	4	The idea that someone else can control your thoughts
8	●	1	2	3	4	Feeling others are to blame for most of your troubles
9	●	1	2	3	4	Trouble remembering things
10	●	1	2	3	4	Worried about sloppiness or carelessness
11	●	1	2	3	4	Feeling easily annoyed or irritated
12	●	1	2	3	4	Pains in heart or chest
13	●	1	2	3	4	Feeling afraid in open spaces or on the streets
14	●	1	2	3	4	Feeling low in energy or slowed down
15	●	1	2	3	4	Thoughts of ending your life
16	●	1	2	3	4	Hearing voices that other people do not hear
17	●	1	2	3	4	Trembling
18	●	1	2	3	4	Feeling that most people cannot be trusted
19	●	1	2	3	4	Poor appetite
20	●	1	2	3	4	Crying easily
21	●	1	2	3	4	Feeling shy or uneasy with the opposite sex
22	●	1	2	3	4	Feelings of being trapped or caught
23	●	1	2	3	4	Suddenly scared for no reason
24	●	1	2	3	4	Temper outbursts that you could not control
25	●	1	2	3	4	Feeling afraid to go out of your house alone
26	●	1	2	3	4	Blaming yourself for things
27	●	1	2	3	4	Pains in lower back
28	●	1	2	3	4	Feeling blocked in getting things done
29	●	1	2	3	4	Feeling lonely
30	●	1	2	3	4	Feeling blue
31	●	1	2	3	4	Worrying too much about things
32	●	1	2	3	4	Feeling no interest in things
33	●	1	2	3	4	Feeling fearful
34	●	1	2	3	4	Your feelings being easily hurt
35	●	1	2	3	4	Other people being aware of your private thoughts
36	●	1	2	3	4	Feeling others do not understand you or are unsympathetic
37	●	1	2	3	4	Feeling that people are unfriendly or dislike you

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY	HOW MUCH WERE YOU DISTRESSED BY:
38	0	1	2	3	4	Having to do things very slowly to insure correctness
39	0	1	2	3	4	Heart pounding or racing
40	0	1	2	3	4	Nausea or upset stomach
41	0	1	2	3	4	Feeling inferior to others
42	0	1	2	3	4	Soreness of your muscles
43	0	1	2	3	4	Feeling that you are watched or talked about by others
44	0	1	2	3	4	Trouble falling asleep
45	0	1	2	3	4	Having to check and double-check what you do
46	0	1	2	3	4	Difficulty making decisions
47	0	1	2	3	4	Feeling afraid to travel on buses, subways, or trains
48	0	1	2	3	4	Trouble getting your breath
49	0	1	2	3	4	Hot or cold spells
50	0	1	2	3	4	Having to avoid certain things, places, or activities because they frighten you
51	0	1	2	3	4	Your mind going blank
52	0	1	2	3	4	Numbness or tingling in parts of your body
53	0	1	2	3	4	A lump in your throat
54	0	1	2	3	4	Feeling hopeless about the future
55	0	1	2	3	4	Trouble concentrating
56	0	1	2	3	4	Feeling weak in parts of your body
57	0	1	2	3	4	Feeling tense or keyed up
58	0	1	2	3	4	Heavy feelings in your arms or legs
59	0	1	2	3	4	Thoughts of death or dying
60	0	1	2	3	4	Overeating
61	0	1	2	3	4	Feeling uneasy when people are watching or talking about you
62	0	1	2	3	4	Having thoughts that are not your own
63	0	1	2	3	4	Having urges to beat, injure, or harm someone
64	0	1	2	3	4	Awakening in the early morning
65	0	1	2	3	4	Having to repeat the same actions such as touching, counting, or washing
66	0	1	2	3	4	Sleep that is restless or disturbed
67	0	1	2	3	4	Having urges to break or smash things
68	0	1	2	3	4	Having ideas or beliefs that others do not share
69	0	1	2	3	4	Feeling very self-conscious with others
70	0	1	2	3	4	Feeling uneasy in crowds, such as shopping or at a movie
71	0	1	2	3	4	Feeling everything is an effort
72	0	1	2	3	4	Spells of terror or panic
73	0	1	2	3	4	Feeling uncomfortable about eating or drinking in public
74	0	1	2	3	4	Getting into frequent arguments
75	0	1	2	3	4	Feeling nervous when you are left alone
76	0	1	2	3	4	Others not giving you proper credit for your achievements
77	0	1	2	3	4	Feeling lonely even when you are with people
78	0	1	2	3	4	Feeling so restless you couldn't sit still
79	0	1	2	3	4	Feelings of worthlessness
80	0	1	2	3	4	The feeling that something bad is going to happen to you
81	0	1	2	3	4	Shouting or throwing things
82	0	1	2	3	4	Feeling afraid you will faint in public
83	0	1	2	3	4	Feeling that people will take advantage of you if you let them
84	0	1	2	3	4	Having thoughts about sex that bother you a lot
85	0	1	2	3	4	The idea that you should be punished for your sins
86	0	1	2	3	4	Thoughts and images of a frightening nature
87	0	1	2	3	4	The idea that something serious is wrong with your body
88	0	1	2	3	4	Never feeling close to another person
89	0	1	2	3	4	Feelings of guilt
90	0	1	2	3	4	The idea that something is wrong with your mind

APPENDIX 8a: The Family Assessment Measure – III- General Form (MFAM)

APPENDIX 8A

Family Assessment Measure

General Scale

Directions

On the following pages you will find 50 statements about your family as a whole. Please read each statement carefully and decide how well the statement describes your family. Then, make your response beside the statement number on the same answer sheet.

- If you STRONGLY AGREE with the statement then circle the letter "A"
- If you AGREE with the statement then circle the letter "B"
- If you DISAGREE with the statement then circle the letter "C"
- If you STRONGLY DISAGREE with the statement then circle the letter "D".

Please circle only one letter (response) for each statement. Answer every statement, even if you are not completely sure of your answer.

Family Assessment Measure - General Scale

		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	We spend too much time arguing about what our problems are.	A	B	C	D
2.	Family duties are fairly shared.	A	B	C	D
3.	When I ask someone to explain what they mean, I get a straight answer.	A	B	C	D
4.	When someone in our family is upset, we don't know if they are angry, sad, scared or what.	A	B	C	D
5.	We are as well adjusted as any family could possibly be.	A	B	C	D
6.	You don't get a chance to be an individual in our family.	A	B	C	D
7.	When I ask why we have certain rules, I don't get a good answer.	A	B	C	D
8.	We have the same views on what is right and wrong.	A	B	C	D
9.	I don't see how any family could get along better than ours.	A	B	C	D
10.	Some days we are more easily annoyed than on others.	A	B	C	D
11.	When problems come up, we try different ways of solving them.	A	B	C	D
12.	My family expects me to do more than my share.	A	B	C	D
13.	We argue about who said what in our family.	A	B	C	D
14.	We tell each other about things that bother us.	A	B	C	D
15.	My family could be happier than it is.	A	B	C	D
16.	We feel loved in our family.	A	B	C	D
17.	When you do something wrong in our family, you don't know what to expect.	A	B	C	D
18.	It's hard to tell what the rules are in our family.	A	B	C	D
19.	I don't think any family could possibly be happier than mine.	A	B	C	D

	Strongly Agree	Agree	Disagree	Strongly Disagree
20. Sometimes we are unfair to each other.	A	B	C	D
21. We never let things pile up until they are more than we can handle.	A	B	C	D
22. We agree about who should do what in our family.	A	B	C	D
23. I never know what's going on in our family.	A	B	C	D
24. I can let my family know what is bothering me.	A	B	C	D
25. We never get angry in our family.	A	B	C	D
26. My family tries to run my life.	A	B	C	D
27. If we do something wrong, we don't get a chance to explain.	A	B	C	D
28. We argue about how much freedom we should have to make our own decisions.	A	B	C	D
29. My family and I understand each other completely.	A	B	C	D
30. We sometimes hurt each others feelings.	A	B	C	D
31. When things aren't going well it takes too long to work them out.	A	B	C	D
32. We can't rely on family members to do their part.	A	B	C	D
33. We take the time to listen to each other.	A	B	C	D
34. When someone is upset, we don't find out until much later.	A	B	C	D
35. Sometimes we avoid each other.	A	B	C	D
36. We feel close to each other.	A	B	C	D
37. Punishments are fair in our family.	A	B	C	D
38. The rules in our family don't make sense.	A	B	C	D
39. Some things about my family don't entirely please me.	A	B	C	D

	Strongly Agree	Agree	Disagree	Strongly Disagree
40. We never get upset with each other.	A	B	C	D
41. We deal with our problems even when they're serious.	A	B	C	D
42. One family member always tries to be the centre of attention.	A	B	C	D
43. My family lets me have my say, even if they disagree.	A	B	C	D
44. When our family gets upset, we take too long to get over it.	A	B	C	D
45. We always admit our mistakes without trying to hide anything.	A	B	C	D
46. We don't really trust each other.	A	B	C	D
47. We hardly ever do what is expected of us without being told.	A	B	C	D
48. We are free to say what we think in our family.	A	B	C	D
49. My family is not a perfect success.	A	B	C	D
50. We have never let down another family member in any way.	A	B	C	D

APPENDIX 8b: The Family Assessment Measure – III –Self Report Form (AFAM)

APPENDIX 8B

Family Assessment Measure

Self-Rating Scale

Directions

On the following pages you will find 42 statements about how you are functioning in the family. Please read each statement carefully and decide how well the statement describes you. Then, make your response beside the statement number on the same answer sheet.

- If you STRONGLY AGREE with the statement then circle the letter "A"
- If you AGREE with the statement then circle the letter "B"
- If you DISAGREE with the statement then circle the letter "C"
- If you STRONGLY DISAGREE with the statement then circle the letter "D".

Please circle only one letter (response) for each statement. Answer every statement, even if you are not completely sure of your answer.

Family Assessment Measure - Self-Rating Scale

		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	My family and I usually see our problems the same way.	A	B	C	D
2.	My family expects too much of me.	A	B	C	D
3.	My family knows what I mean when I say something.	A	B	C	D
4.	When I'm upset, my family knows what's bothering me.	A	B	C	D
5.	My family doesn't care about me.	A	B	C	D
6.	When someone in the family makes a mistake, I don't make a big deal of it.	A	B	C	D
7.	I argue a lot with my family about the importance of religion.	A	B	C	D
8.	When my family has a problem, I have to solve it.	A	B	C	D
9.	I do my share of duties in the family.	A	B	C	D
10.	I often don't understand what other family members are saying.	A	B	C	D
11.	If someone in the family has upset me, I keep it to myself.	A	B	C	D
12.	I stay out of other family members' business.	A	B	C	D
13.	I get angry when others in the family don't do what I want.	A	B	C	D
14.	I think education is much more important then my family does.	A	B	C	D
15.	I have trouble accepting someone else's answer to a family problem.	A	B	C	D
16.	What I expect of the rest of the family is fair.	A	B	C	D
17.	If I'm upset with another family member, I let someone else tell them about it.	A	B	C	D
18.	When I'm upset, I get over it quickly.	A	B	C	D
19.	My family doesn't let me be myself.	A	B	C	D

	Strongly Agree	Agree	Disagree	Strongly Disagree
20. My family knows what to expect from me.	A	B	C	D
21. My family and I have the same views about what is right and wrong.	A	B	C	D
22. I keep on trying when things don't work out in the family.	A	B	C	D
23. I am tired of being blamed for family problems.	A	B	C	D
24. Often I don't say what I would like to because I can't find the words.	A	B	C	D
25. I am able to let others in the family know how I really feel.	A	B	C	D
26. I really care about my family.	A	B	C	D
27. I'm not as responsible as I should be in the family.	A	B	C	D
28. My family and I have the same views about being successful.	A	B	C	D
29. When problems come up in my family, I let other people solve them.	A	B	C	D
30. My family complains that I always try to be the centre of attention.	A	B	C	D
31. I'm available when others want to talk to me.	A	B	C	D
32. I take it out on my family when I'm upset.	A	B	C	D
33. I know I can count on the rest of my family.	A	B	C	D
34. I don't need to be reminded what I have to do in the family.	A	B	C	D
35. I argue with my family about how to spend my spare time.	A	B	C	D
36. My family can depend on me in a crisis.	A	B	C	D
37. I never argue about who should do what in our family.	A	B	C	D
38. I listen to what other family members have to say, even when I disagree.	A	B	C	D
39. When I'm with my family, I get too upset too easily.	A	B	C	D
40. I worry too much about the rest of my family.	A	B	C	D
41. I always get my way in our family.	A	B	C	D
42. My family leaves it to me to decide what's right and wrong.	A	B	C	D

APPENDIX 9

Interrcorrelations between demographic characteristics and maternal and adolescent reports of adolescent functioning

Appendix 9

Intercorrelations Between Demographic Characteristics and Maternal and Adolescent Reports of Adolescent Functioning

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
							Participants (N = 59)							
1. Maternal Age	--	.16	.30*	.07	.46**	.01	.13	-.09	-.22	-.24	.16	.18	.04	.11
2. Maternal Education[a]	--	--	.29*	-.24	-.01	-.07	.29*	.06	-.03	-.05	.17	.11	-.03	-.01
3. Family Income	--	--	--	.07	-.10	.12	.29*	-.01	-.02	-.13	.25	.06	-.02	-.02
4. Marital Status[b]	--	--	--	--	.00	.04	-.16	.03	.18	.14	-.19	-.17	-.02	-.08
5. Adolescent Age	--	--	--	--	--	-.01	.03	-.04	-.17	-.14	-.15	.22	.09	.18
6. Number of siblings		--	--	--	--	--	.16	.05	-.13	-.10	-.09	-.17	-.16	-.17
7. Maternal Report of Adolescent Competence[c]	--	--	--	--	--	--	--	-.04	-.22	-.20	.49**	.14	-.03	-.02
8. Maternal Report of Adolescent Internalizing Problems[d]	--	--	--	--	--	--	--	--	.50**	.79**	-.16	.27*	.13	.30*
9. Maternal Reports of Adolescent Externalizing Problems[e]	--	--	--	--	--	--	--	--	--	.87**	-.23	.09	.44**	.31

Appendix 9, continued.

Intercorrelations Between Demographic Characteristics and Maternal and Adolescent Reports of Adolescent Functioning.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Participants (N = 59)														
10. Maternal Report of Adolescent Total Problems[f]	--	--	--	--	--	--	--	--	--	--	-.28*	.16	.34**	.35**
11. Adolescent Self-Report of Competence[g]	--	--	--	--	--	--	--	--	--	--	--	-.14	-.30*	-.30*
12. Adolescent Self-Report of Internalizing Problems[h]	--	--	--	--	--	--	--	--	--	--	--	--	.50**	.84**
13. Adolescent Self-Report of Externalizing Problems[i]	--	--	--	--	--	--	--	--	--	--	--	--	--	.82**
14. Adolescent Self-Report of Total Problems[j]	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Appendix 9, continued.

Intercorrelations Between Demographic Characteristics and Maternal and Adolescent Reports of Adolescent Functioning.

---

[a]Measured on a 4-point scale ranging from 1 (high school) to 4 (master's degree or higher).

[b]Measured on a 2-point scale: 0 (single, no partner residing in household), 1 (married/cohabiting with partner).

[c]Measured with the CBCL Total Competence Scale T-score.

[d]Measured with the CBCL Internalizing Scale Score

[e]Measured with the CBCL Externalizing Scale Score

[f]Measured with the CBCL Total Scale Score

[g]Measured with the YSR Total Competence Scale Score

[h]Measured with the YSR Internalizing Scale Score

[i]Measured with the YSR Externalizing Scale Score

[j]Measured with the YSR Total Scale Score

* $p<.05$, ** $p<.001$

APPENDIX 10

Intercorrelations between demographic characteristics and proposed moderators (maternal distress and family functioning).

Appendix 10

Intercorrelations Between Demographic Characteristics and Proposed Moderators (Maternal Distress and Family Functioning)

Variable	1	2	3	4	5	6	7	8	9
	Participants (N = 59)								
1. Maternal Age	--	.16	.30*	.07	.46**	.01	.13	-.09	-.22
2. Maternal Education[a]	--	--	.29*	-.24	-.01	-.07	.29*	.06	-.03
3. Family Income	--	--	--	.07	-.10	.12	.29*	-.01	-.02
4. Marital Status[b]	--	--	--	--	.00	.04	-.16	.03	.18
5. Adolescent Age	--	--	--	--	--	-.01	.03	-.04	-.17
6. Number of siblings	--	--	--	--	--	--	.12	.05	-.20
7. Maternal Distress[c]	--	--	--	--	--	--	--	.47**	.33**
8. Maternal Reports of Family Functioning[d]	--	--	--	--	--	--	--	--	.43**
9. Adolescent Reports[e] of Functioning within the family	--	--	--	--	--	--	--	--	--

Table continues...

Appendix 10, continued.

Intercorrelations Between Demographic Characteristics and Proposed Moderators (Maternal Distress and Family Functioning)

---

[a]Measured on a 4-point scale ranging from 1 (high school) to 4 (master's degree or higher).

[b]Measured on a 2-point scale: 0 (single, no partner residing in household), 1 (married/cohabiting with partner).

[c]Measured with the SCL-90-R GSI Scale.

[d]Measured with the Family Assessment Measure – General Scale.

[e]Measured with the Family Assessment Measure – Self-Report Scale.

* $p<.05$

** $p<.001$.

APPENDIX 11

Intercorrelations between breast cancer characteristics and maternal and adolescent reports of adolescent functioning

Appendix 11.

Intercorrelations Between Breast Cancer Characteristics and Maternal and Adolescent Reports of Adolescent Functioning

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
							Participants (N = 59)								
1. Maternal Age at Diagnosis	--	-.12	-.25	-.10	.09	.23	-.15	.16	-.15	-.26*	-.33*	.26	.19	.04	.10
2. Stage at Diagnosis[a]	--	--	.04	.42**	-.49**	-.53**	.27	.10	.00	.07	.06	.14	.19	.02	.09
3. Time Since Treatment[b]	--	--	--	-.04	.07	-.03	.01	-.02	.11	.14	.11	-.23	..06	.05	.07
4. Lumpectomy[c]	--	--	--	--	-.74**	-.41**	.51**	-.19	-.14	-.05	-.09	-.02	.08	-.02	.02
5. Mastectomy[c]	--	--	--	--	--	.56**	-.34**	-.02	-.01	-.06	-.01	-.05	-.21	-.11	-.12
6. Chemotherapy[c]	--	--	--	--	--	--	-.25	-.13	-.17	-.13	-.18	-.22	.03	.15	.09
7. Radiation[c]	--	--	--	--	--	--	--	-.22	.05	.10	.12	-.15	-.10	.09	.03
8. Maternal Report of Adolescent Competence[d]	--	--	--	--	--	--	--	--	-.04	-.22	-.20	.49**	.14	-.03	-.02
9. Maternal Report of Adolescent Internalizing Problems[e]	--	--	--	--	--	--	--	--	--	.50**	.79**	-.16	.27*	.13	.30*

Appendix 11, continued

Intercorrelations Between Breast Cancer Characteristics and Maternal and Adolescent Reports of Adolescent Functioning

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
						Participants (N = 59)									
10. Maternal Reports of Adolescent Externalizing Problems[f]	--	--	--	--	--	--	--	--	--	--	87**	-.23	.09	.44**	.31
11. Maternal Report of Adolescent Total Problems[g]	--	--	--	--	--	--	--	--	--	--	--	-.28*	.16	.34**	.35**
12. Adolescent Self-Report of Competence[h]	--	--	--	--	--	--	--	--	--	--	--	--	-.14	-.30*	-.30*
13. Adolescent Self-Report of Internalizing Problems[i]	-	--	--	--	--	--	--	--	--	--	--	--	--	.50**	.84**
14. Adolescent Self-Report of Externalizing Problems[j]	-	--	--	--	--	--	--	--	--	--	--	--	--	--	.82**
15. Adolescent Self-Report of Total Problems[k]		--	--	--	--	--	--	--	--	--	--	--	--	--	--

Appendix 11, continued.

Intercorrelations Between Breast Cancer Characteristics and Maternal and Adolescent Reports of Adolescent Functioning

[a]Measured on a 4-point scale ranging from 1 (Stage I) to 4 (Stage IV).

[b]Measured in months.

[c] 0 = No, 1 = Yes.

[d]Measured with the CBCL Total Competence Scale T-score.

[e]Measured with the CBCL Internalizing Scale Score

[f]Measured with the CBCL Externalizing Scale Score

[g]Measured with the CBCL Total Scale Score

[h]Measured with the YSR Total Competence Scale Score

[i]Measured with the YSR Internalizing Scale Score

[j]Measured with the YSR Externalizing Scale Score

[k]Measured with the YSR Total Scale Score

* $p<.05$, ** $p<.001$

APPENDIX 12

Intercorrelations between breast cancer characteristics and proposed moderators (maternal distress and family functioning).

Appendix 12.

Intercorrelations Between Breast Cancer Characteristics and Proposed Moderators (Maternal Distress and Family Functioning)

Variable	1	2	3	4	5	6	7	8	9	10
					Participants (N = 59)					
1. Maternal Age at Diagnosis	--	-.12	-.25	-.10	.09	.23	-.15	-.11	-.15	-.06
2. Stage at Diagnosis[a]	--	--	.04	.42**	-.49**	-.53**	.27	.06	.20	.26
3. Time Since Treatment[b]	--	--	--	-.04	.07	-.03	.01	-.14	.18	.09
4. Lumpectomy[c]	--	--	--	--	-.74**	-.41**	.51**	.06	.02	-.22
5. Mastectomy[c]	--	--	--	--	--	.56**	-.34**	-.02	-.05	-.03
6. Chemotherapy[c]	--	--	--	--	--	--	-.25	-.03	-.14	.01
7. Radiation[c]	--	--	--	--	--	--	--	.00	.04	-.17
8. Maternal Distress[d]	--	--	--	--	--	--	--	--	.47**	.33**
9. Maternal Reports of Family Functioninge	--	--	--	--	--	--	--	--	--	.43**
10. Adolescent Reports[f] of Functioning within the family	--	--	--	--	--	--	--	--	--	--

Appendix 12, continued.

Intercorrelations Between Breast Cancer Characteristics and Proposed Moderators (Maternal Distress and Family Functioning)

---

[a]Measured on a 4-point scale ranging from 1 (Stage I) to 4 (Stage IV).

[b]Measured in months.

[c] 0 = No, 1 = Yes.

[d]Measured with the SCL-90-R GSI Scale.

[e]Measured with the Family Assessment Measure – General Scale.

[f]Measured with the Family Assessment Measure – Self-Report Scale.

* $p<.05$

** $p<.001$

APPENDIX 13

Intercorrelations between primary study variables

Appendix 13

Intercorrelations Between Primary Study Variables.

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Adolescent Risk Perceptions[a]	--	.39**	.07	.05	-.18	-.06	-.21	.28*	-.23	.17	-.14
2. Adolescent Cancer Concerns[b]	--	--	.14	-.08	-.01	-.03	-.16	.15	.13	-.02	.15
3. Adolescent Severity Perceptions[c]	--	--	--	-.15	-.20	-.05	.05	.08	-.08	.36**	.10
4. Maternal Health-Related Quality of Life[d]	--	--	--	--	-.67**	-.37**	-.23	-.09	.29*	.13	-.27*
5. Maternal Distress[e]	--	--	--	--	--	.47**	.33*	-.13	.56**	-.08	.28*
6. Maternal Reports of Family Functioning[f]	--	--	--	--	--	--	.44**	-.17	.37*	-.28*	.04
7. Adolescent Reports of Functioning Within the Family[g]	--	--	--	--	--	--	--	-.05	.29*	-.25	.49**
8. Maternal Report of Adolescent Competence[h]	--	--	--	--	--	--	--	--	-.20	.49**	-.02

Appendix 13, continued.

Intercorrelations Between Primary Study Variables.

Variable	1	2	3	4	5	6	7	8	9	10	11
9. Maternal Report of Adolescent Total Problems[k]	--	--	--	--	--	--	--	--	--	-.28*	.35**
10. Adolescent Self-Report of Competence[l]	--	--	--	--	--	--	--	--	--	--	-.30*
11. Adolescent Self-Report of Total Problems[o]	--	--	--	--	--	--	--	--	--	--	--

[a] Measured with the Breast Cancer Survey – Risk Perceptions Subscale
[b] Measured with the Breast Cancer Survey – Cancer Concerns Subscale
[c] Measured with the Breast Cancer Survey – Perceptions of Severity Subscale
[d] Measured with the Short Form -36
[e] Measured with the Symptom Checklist –90-R, GSI scale
[f] Measured with the Family Assessment Measure – General Scale, Total Score
[g] Measured with the Family Assessment Measure – Self-Report Scale, Total Score
[h] Measured with the CBCL Total Competence Scale T-Score
[i] Measured with the CBCL Total Scale T-Score
[j] Measured with the YSR Competence Scale T-Score
[k] Measured with the YSR Total Scale T-Score

* $p<.05$, ** $p<.001$