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# Adolescent Daughters' Coping with Maternal Breast Cancer: A Study in a Multicultural Urban Cohort

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## Abstract

The diagnosis of cancer carries a large burden not only on the patient but on their family as well. In this study we specifically examine the effect of a diagnosis of breast cancer on patients' adolescent daughters and the mechanisms used in coping with this stress. We hope that the findings from this study will allow medical practitioners to understand and learn how to assist with the psychosocial and emotional needs of these adolescent daughters so that they may develop optimal coping mechanisms.

**Keywords:** Breast cancer, Daughters, Coping.

## Introduction

The continuum of cancer care includes management of distress and the burden of cancer diagnosis on the patient and their family, including the children. The stress of parental cancer [1,2] and maternal breast cancer specifically has been shown to increase the risk for developing anxiety and depression in adolescents, yet little attention has been paid to their coping needs [3]. Evaluating these skills is a way to build algorithms to help develop a healthy lifestyle and defense mechanisms.

Coping is defined as the voluntary or "conscious volitional effort to regulate emotion, cognition, behavior, physiology, and the environment in response to stressful events or circumstances" [4]. Recently clinicians and researchers claim that coping with cancer affects the patients' mental health as well as their children's. Moreover, a growing number of studies examined the psychological functioning of children whose parents are diagnosed with cancer. Numerous studies reveal that adolescent daughters seemed more at risk than sons for the elevated stress symptoms associated with emotional and behavioral problems 1 to 5 years after the parent's cancer diagnosis. Additionally, ill parents whose mental health worsened were more likely to report on problems in their adolescent offspring.

The adolescent's choice of coping strategies used in response to stressful life events can determine whether the adolescent becomes distressed or adjusts to the stressors. Stressors are defined as "environmental events or chronic conditions that threaten the physical and/or psychological health or well-being of individuals of a particular age in a particular society" [5]. Most models of stress and coping have been developed for adults, and applied to research with children and adolescents. Studies have broadly identified adolescents' responses to stress as either internalizing (withdrawal, anxiety, depression) or externalizing (problems) behaviors. Voluntary coping strategies include problem-solving strategies, acceptance and wishful thinking as examples of the primary, secondary and tertiary dimensions of coping. Involuntary coping responses are identified along engagement and disengagement dimensions and include intrusive thoughts and cognitive interference. More recent studies however, suggest that adolescent coping involves a much broader conceptualization that includes voluntary and controlled efforts to engage with the stressor [4]. This can range from disengagement, such as avoidance, denial, and wishful thinking; primary control coping methods using problem-solving, emotional expression, and emotional regulation, or secondary control coping methods including acceptance, cognitive restructuring, distraction, and positive thinking. These coping dimensions can act as buffers between uncontrollable stressors and poor health outcomes [6,7]. Additionally, family functioning and the maternal-adolescent relationship can impact both stress responses and coping. An adolescents' ability to cope with new and stressful events is enhanced when there is a secure base relationship with his or her mother from which to explore and navigate life. Maternal depression and poor family functioning have been linked to increased behavioral problems in adolescents whose parents have cancer [8]. While maternal breast cancer is an uncontrollable stressor for adolescent daughters and is associated with high levels of anxiety and depression, little is known about the particular coping mechanisms used by the daughters. The purpose of this study was to determine the coping strategies

used by adolescent daughters in response to the stress of their mothers' breast cancer.

## Subjects and Methods

This study design was a cross sectional correlational analysis of mothers and adolescent daughters within the first year of early maternal breast cancer diagnosis. The inclusion criteria included mothers with newly diagnosed, localized breast cancer (Stage I or II) who were either undergoing or completed their treatment and were no more than one year away from their diagnosis; and their adolescent daughters between the ages of 13 and 19. In families where more than one adolescent daughter wanted to participate, all were included. Exclusion criteria included women with other chronic illnesses, and adolescents with disabilities and chronic illnesses, all factors that could confound the analysis.

The mothers who were interested were approached first and provided an email address or telephone number for the researcher to contact their daughters to inquire about their interest in participating.This step provided the adolescent daughters with an opportunity to consider their participation in the study without the added pressure of their mother possibly influencing them. All interviews were conducted in person by the qualified nurse interviewer. Previous research with the breast cancer population has uncovered the importance of the time period from diagnosis through treatment as a critical period of adjustment to the disease by the mothers and their children. Studies with adolescents have emphasized the need to limit research on coping to a particular stressor as each stressor may bring about differences in responses and strategies used [4,5]. This study was approved by the Institutional Review Board of New York University Langone Medical Center, the NYU protocol number 08-072, the study was registered with clinicaltrials.gov NCT 009330088. All records were kept in locked de-identified files.

### Data Collection and Analysis

The mothers completed one demographic data collection and their subjective assessment about how their daughters were coping with the maternal breast cancer diagnosis. The daughters completed the following three questionnaires:

The Youth Risk Behavior Screening Scale (YRBSS) [9] is a self-report scale that measures adolescents' views of their functioning over the past 6 months, rated on a 3-point scale from not true to very or often true. It has been used across studies with adolescents to identify those that have adjusted (low stress response), or present with distress (high stress response) in response to a stressor. Data analysis focused on describing the stress responses that were exhibited.

The Responses to Stress Questionnaire (RSQ) [6] contains 2 sections, with the second section measuring the coping strategies used by adolescents. It consists of 57 items that represent a range of voluntary coping strategies and involuntary responses. Items are rated on a scale from 1 to 4 that indicates the degree to which or frequency with which each strategy was performed by the individual (from "not at all" to "a lot") in response to their mothers' breast cancer diagnosis and treatments. Items for the voluntary coping scales were selected to represent both cognitive and behavioral responses, and items for the involuntary response scales were selected to capture cognitive, behavioral, emotional, and physiological responses. The data from this questionnaire described the types of coping strategies that the adolescent daughters used in response to the stressor of their mother's breast cancer.

The Inventory of Parent and Peer Attachment (IPPA) [10] is a 25-item self-report questionnaire with a five-point ordinal scale that assesses adolescents' perceptions of both the positive and negative affective and cognitive dimensions of their relationships with their parents.

### Results

Seventeen mothers and their 19 adolescent daughters, recruited from New York University Cancer Center and Bellevue Cancer Center, comprised the cohort. The subjects, 19 adolescent girls, ranged from 13-19 years of age, with a mean age of 16 years. Mothers' ages ranged from 41-62 with a mean age of 47 years.

The subjects' racial backgrounds included 10 Caucasian, 5 Hispanic, and 4 African American adolescent girls and their mothers. Three adolescents were in middle school, 14 were in high school, and 2 were in college. Three of the mothers had a grade school education, 4 had a high school education, 7 had a college education, and 3 had completed graduate education. Two pairs of sisters were included in the sample.

The adolescent daughters reported using a range of coping strategies identified in the RSQ that represented both voluntary and involuntary coping strategies (Table 1). These included Primary control engagement coping (problem-solving, emotional regulation and expression); Secondary engagement coping (distraction, positive thinking, cognitive restructuring, acceptance); Disengagement coping (avoidance, denial, wishful thinking); Involuntary engagement (emotional arousal, physiological arousal, impulsive action, intrusive thoughts, rumination); and Involuntary disengagement (emotional numbing, involuntary avoidance, cognitive interference, inaction).

**Table 1:** Responses to Stress Questionnaire (RSQ)

| Coping Strategy Used | Mean Score | Significant Range |
|---|---|---|
| Primary control (PCE) | 30.5 | 33-44 |
| Secondary control (SCE) | 20 | 21-28 |
| Disengagement (DC) | 20.95 | 27-38 |
| Involuntary engagement (IE) | 36.21 | 48-64 |
| Involuntary disengagement (ID) | 27.37 | 36-48 |

The use of secondary engagement strategies ranging from distraction, positive thinking, cognitive restructuring to acceptance were reported as being utilized the most across all subjects. When the individual coping strategies used by each subject were examined by age, the three youngest adolescent girls (< 15 years of age) reported using the secondary engagement strategies less often and the disengagement coping strategies more often than those fifteen and over.

The adolescent girls reported their response to stress on the YRBSS in terms of the presence of anxiety, depression, and problem behaviors (Table 2). While all of the daughters reported feeling "shocked and upset" in hearing the diagnosis, their responses on the YRBSS were well outside the clinical range and indicated positive overall adjustment to their lives as adolescents.

**Table 2:** Youth Risk Behavior Screening Scale (YRBSS) scoring results

| | Anxiety depressed | Withdrawn depressed | Somatic complaints | Social problems | Thought problems | Attention Problems | Rule Breaking Behaviors | Aggressive behaviors | Other problems |
|---|---|---|---|---|---|---|---|---|---|
| **Mean** | 6.47 | 4.58 | 5.32 | 3.79 | 4.53 | 5.84 | 4.26 | 6.53 | 5.32 |
| **Significant Range** | 15-26 | 10-16 | 12-20 | 10-22 | 13-25 | 12-16 | 14-30 | 16-34 | 2 |

A content analysis of the open-ended questions on both the RSQ and YRBSS indicated that the adolescent daughters reported helping out with more household tasks like cleaning and cooking(Table 3). Many had to look after their younger siblings, and some reported having to delay or quit college.When probed further about these responses all of the participants stated that they gladly engaged in these increased tasks—"anything to help out their mothers". The adolescent daughters indicated that their coping mechanisms included open communication within the family and just spending time talking with their mothers; being positive and calm around their mothers; and, just "hanging out" (watching television and listening to music) more with their mothers.Many prayed that their mothers would get better. Several identified a teacher or other adult with whom they could confide. They also liked hanging out with friends when they could, with the three younger daughters (<15 years) enjoying the routines of school and their activities.

The mother-daughter relationship as measured by the IPPA indicated that all adolescent girls reported a positive relationship with their mothers overall. While they responded that their mothers respected them and did a good job as a mother, half of the adolescent daughters also noted that their mothers did not always know when the daughters were upset or dealing with an issue. They did not always tell their mothers about their problems or troubles, even when they felt they needed to. The mothers all stated that they felt their daughters were reacting to their breast cancer diagnosis with increased anxiety. Some of the daughters reportedly presented with decreased school performance, while others seemed quieter to their mothers.

## Discussion

The study findings indicated a broad range of coping strategies used by the adolescent daughters that included problem-solving strategies, acceptance and wishful thinking as examples of the primary, secondary and tertiary dimensions of coping; and involuntary coping responses that at times included intrusive thoughts and cognitive interference. Although the sample size was small, the use of the multidimensional model of adolescent coping with the stress of maternal breast cancer did provide insights into both the model and the strategies used. The model guided the inquiry to look differently at adolescent coping with the RSQ uncovering some unique coping strategies with targeted questions. A 2008 Dutch study examined a sample of 117 daughters [11] whose parents had various types of cancer and used the Child Behavior Checklist (CBLT) and YRBSS internalizing and externalizing scales that identified their internal mental states and problems experienced. While the findings demonstrated that adolescent daughters had higher internalizing problems and clinically elevated scores, there was no indication of what coping strategies contributed to their lack of functioning as a result of their response to parental cancer. In their 2008 study, Edwards et al. also focused on stress responses (using the CBLT, YRBSS and Child Impact of Events Scale) rather than coping strategies used [12]. Although not displayed in our study, many of the children of cancer patients negatively cope with their parent's diagnosis by becoming clinically depressed and anxious and at times turning to substance abuse [13]. In a review of literature on the impact of parental cancer on adolescents [1], adolescent ways of coping across studies was conceptualized and reported using Lazarus'

**Table 3:** Adolescent stress and coping with maternal breast cancer

| | Significant range | Mean | Standard Deviation | Median |
|---|---|---|---|---|
| **Anxiety-depression (YRBSS)** | 15-26 | 6.47 | 4.94 | 5.00 |
| **Withdrawn-depressed (YRBSS)** | 10-16 | 4.58 | 2.57 | 5.00 |
| **Somatic complaints (YRBSS)** | 12-20 | 5.32 | 4.36 | 4.00 |
| **Social problems (YRBSS)** | 10-22 | 3.79 | 4.30 | 2.00 |
| **Thought problems (YRBSS)** | 13-25 | 4.53 | 2.27 | 4.00 |
| **Attention problems (YRBSS)** | 12-16 | 5.84 | 2.27 | 4.00 |
| **Rule-breaking behavior (YRBSS)** | 14-30 | 4.26 | 4.34 | 3.00 |
| **Aggressive behavior (YRBSS)** | 16-34 | 6.53 | 5.02 | 5.00 |
| **Primary control engagement coping (RSQ)** | 33-44 | 30.05 | 6.84 | 31.00 |
| **Secondary control engagement coping (RSQ)** | 20-28 | 20.00 | 3.89 | 20.00 |
| **Disengagement coping (RSQ)** | 27-36 | 20.95 | 5.25 | 21.00 |
| **Involuntary engagement coping (RSQ)** | 48-64 | 36.21 | 8.94 | 36.00 |
| **Involuntary disengagement coping (RSQ)** | 36-48 | 27.37 | 8.04 | 29.00 |

YRBSS - Youth Risk Behavior Screening Scale; RSQ - Responses to Stress Questionnaire

problem and emotion-focused coping indicating a narrower inquiry into, and view of coping than the current study's multi-dimensional model. Garcia et al, in a review of the literature on coping during adolescence analyzed 59 articles measuring coping with original data and primarily targeting adolescents [14]. Her review demonstrated that fewer than half included a definition of coping, many in the context of stress responses, and with variations in the models used to guide their inquiry. Her Many studies again used the dichotomy of either problem- or emotion-based coping to describe their results. In light of the increased anxiety and potential for mental health problems experienced by this population, interventions that are target coping strategies are warranted. Clearly more research is needed using a broader conceptualization and measure of coping in adolescence.

The mothers and adolescent daughters that came forward to participate in the study were enthusiastic about the study, and many verbalized a need to both discuss their feelings and contribute to any programs that might target adolescent children when parents were diagnosed with cancer. Some of the mothers similarly wished that their daughters had a forum to communicate their feelings within, as they thought that perhaps they were shielding the mothers from any further worries. In fact this was supported in the data from the IPPA where half of the daughters reported not being able to share their concerns with their mothers when they needed to. Recent evidence has emerged that mothers experiencing breast cancer often are not as aware of their adolescents' and daughters' needs because of their own fatigue and need to focus on their treatments [15]. The changes adolescents report in their lives as a result of their parental cancer contribute to increased anxiety and depression [3]. Yet despite these feelings, this cohort of adolescent daughters in the present study reported overall adjustment possibly related to the specific coping strategies used. In particular, the secondary coping strategies of distraction, positive thinking, cognitive restructuring, and acceptance were reported as being utilized the most across all subjects. Additionally it was clear from the IPPA that the positive mother-daughter relationships were strength in this group of subjects that could have also contributed to their positive adjustment.

The study had originally targeted a sample of 90 adolescent daughters to meet the power requirements for analysis of coping strategies used by stress response category, by age, and by maternal-adolescent relationship. Twenty-eight mothers were first recruited and gave their consent for their daughters' participation; one mother became ineligible because of advanced disease; three moved out of the catchment area; and four had daughters who did not attend the scheduled appointments for data collection despite their consent via telephone.

## Conclusions

The study evaluating the mechanisms of coping of adolescents daughters of women with new diagnosis of breast cancer in a sample of multicultural and multilingual women representing urban population of NYC brings important insights in planning distress management for women and their families, in this case their adolescent daughters when faced with new cancer diagnosis. Adolescent daughters whose mothers had breast cancer in this study reported using a broad range of coping strategies that previous research has not identified in this population. While the limitations of the small sample does not allow to generalize all these findings, the study is clearly indicating that more research as well as capitalizing on these coping skills for adolescent daughters in order to manage their and their parents distress to cancer diagnosis. Interventions that target adolescent coping can be developed and tested using this broader view of both stressors experienced and strategies used to deal with maternal breast cancer, and parental cancer in general. The study findings further confirm the strength of positive adolescent-maternal relationships on the adolescent daughters coping with the stress of their mothers' breast cancer. Both mothers and daughters approached in this study welcomed the opportunity to discuss their feelings and engage in this research. The stress and resulting mental health issues that can arise for these daughters warrant further research and a commitment to serve this vulnerable population. Coping with the stress of parental diagnosis and maintaining emotional health is also critical to help the young generation to pay special attention to health habits, health education, prevention strategies and management of risk. The results of this study represent the experience of the investigators and emphasize the importance of providing access to distress management to the families of cancer patients with psychological, social, and emotional support.

## References

1. Grabiak BR, Bender CM, Puskar KR. The impact of parental cancer on the adolescent: An analysis of the literature. Psychooncology. 2007; 16(2):127-137.
2. Visser A, Huizinga GA, Hoekstra HJ, van der Graaf WT, Klip EC, Pras E, et al. Emotional and behavioral functioning of children of a parent with cancer: a cross-informant perspective. Psychooncology. 2005; 14(9):746-758.
3. Kristjanson LJ, Chalmers KI, Woodgate R. Information and support needs of adolescent children of women with breast cancer. OncolNurs Forum. 2004; 31(1):111-118.
4. Compas BE, Connor-Smith JK, Saltzman H, Thomsen AH, Wadsworth ME. Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research. Psychol Bull. 2001; 127(1):87-127.
5. Grant KE, Compas BE, Thurm AE, McMahon SD, Gipson PY. Stressors and child and adolescent psychopathology: measurement issues and prospective effects. J Clin Child Adolesc Psychol. 2004; 33(2):412-425.
6. Connor-Smith JK, Compas BE, Wadsworth ME, Thomsen AH, Saltzman H. Responses to stress in adolescence: measurement of coping and involuntary stress responses. J Consult Clin Psychol.. 2000; 68(6):976-92.
7. Wadsworth ME, Raviv T, Compas BE, Connor-Smith JK. Parent and adolescent responses to poverty-related stress: tests of mediated and moderated coping models. Journal of Child and Family Studies. 2005; 14(2):283-298.
8. Lewis FM, Darby EL. Adolescent adjustment and maternal breast cancer: a test of the "faucet" hypothesis. Journal of Psychosocial Oncology. 2003; 21(4):81-104.
9. Achenbach TM. Manual for the Youth Self-Report and 1991 Profile. Burlington, VT: University of Vermont, Department of Psychiatry.
10. Armsden GC, Greenberg MT. The inventory of parent and peer attachment: Individual differences and their relationship to psychological well-being in adolescence. J Youth Adolesc. 1987; 16(5):427-454.doi: 10.1007/BF02202939.

11. Gazendam-Donofrio SM, Hoekstra HJ, van der Graaf WT, Pras E, Visse A, Huizinga GA, et al. Quality of life of parents with children living at home: when one parent has cancer. Support Care Cancer. 2008; 16(2):133–141.doi: 10.1007/s00520-007-0299-7.

12. Edwards L, Watson M, St James-Roberts I, Ashley S, Tilney C, Brougham B, et al. Adolescent's stress responses and psychological functioning when a parent has early breast cancer. Psychooncology. 2008; 17(10):1039-1047.doi: 10.1002/pon.1323.

13. Costas-Muniz R. Hispanic adolescents coping with parental cancer. Support Care Cancer. 2012; 20(2):413-417.doi: 10.1007/s00520-011-1283-9.

14. Garcia C. Conceptualization and measurement of coping during adolescence: a review of the literature. J NursScholarsh.. 2010; 42(2):166-185.doi: 10.1111/j.1547-5069.2009.01327.x.

15. Clemmens DA. The significance of motherhood for adolescents whose mothers have breast cancer. OncolNurs Forum. 2009; 36(5):571-577.doi: 10.1188/09.ONF.571-577.