DISSERTATION

THE ADOLESCENT EXPERIENCE WITH PARENTAL CANCER: EFFECTS ON ROLES AND RESPONSIBILITIES

Submitted by

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WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR SUPERVISION BY JENNIFER CATHERINE DALY ENTITLED THE ADOLESCENT EXPERIENCE WITH PARENTAL CANCER: EFFECTS ON ROLES AND RESPONSIBILITIES BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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ABSTRACT OF DISSERTATION

THE ADOLESCENT EXPERIENCE WITH PARENTAL CANCER: EFFECTS ON ROLES AND RESPONSIBILITIES

The majority of research to present has examined the experience of the cancer patient. The experience of children in families coping with parental cancer is an area in need of further exploration. Results of research with this population have been somewhat mixed; however, multiple studies have noted that children coping with parental cancer may experience symptoms consistent with anxiety and depression that may vary by the child's age and gender. Changes in household roles and responsibilities subsequent to a diagnosis of parental cancer have been offered as a possible explanation for these gender and age-related differences. Results of a recent study (Daly, 2005) suggested that time/age of the adolescent may be a primary factor in the increase in household roles and responsibilities during adolescence, rather than the presence of parental cancer. The current research further examined the adolescent experience with parental cancer through ethnographic content analysis of narrative responses regarding household roles and responsibilities. This study utilized original data collected at the same time and from the same sample of undergraduate students in introductory psychology classes at Colorado State University as the Daly 2005 study. Results of the qualitative analysis show that differences were reported for the chores performed by adolescents coping with parental cancer and those who were not coping with parental cancer, with adolescents who were coping with parental cancer for longer than three months generally perceiving themselves as more involved with chores. Results also show that adolescents coping with parental cancer linked their experience of chores with their parent's cancer. The results of the present study are discussed in light of the Daly (2005) study's results and the available body of literature on this topic.

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CHAPTER 1

Introduction

"An individual doesn't get cancer, a family does" -Terry Tempest Williams.

Cancer is an illness that significantly affects the individual patient- less apparent is the concomitant influence on the patient's family, particularly when children are involved. A diagnosis of cancer in a parent has been associated with significant negative emotional and behavioral issues for his or her children (Armistead et al., 1995; Armsden & Lewis, 1994; Compas et al., 1994; Hoke, 1997 and Worsham et al., 1997). Some of the issues noted by various researchers include: problematic self-esteem, anxiety, depression, fears about heritability of the disease, hostility and rejection.

The American Cancer Society estimates that there will be approximately 1.4 million new cases of cancer in 2007 across the United States (American Cancer Society, 2007). The most recent data indicates that, on average, over 1,500 people will die each day in 2007 as the result of cancer, totaling 559,650 deaths over the course of the year (American Cancer Society, 2007). The National Cancer Institute estimates that there are about 10.5 million Americans alive now who have dealt with cancer in their lives (as cited in American Cancer Society, 2007). In Colorado alone, it is anticipated that there will be 19,190 new cases of cancer in 2007, with 6,660 deaths from cancer (American Cancer

Society, 2007). Cancer accounts for 1 out of every 4 deaths in the United States and is the second overall leading cause of death, following only heart disease (American Cancer Society, 2007). Cancer is also a disease that disproportionately impacts minorities in terms of both diagnosis and death; for example, African American men have a 38% higher death rate from cancer than White, non-Hispanic men, and African American women have an 17% higher death rate from cancer (American Cancer Society, 2007). The lifetime cancer risk for men is now 1 in 2, and for women, 1 in 3 (American Cancer Society, 2007).

Beyond the experiences of those who have coped with their own diagnoses of cancer, it should be remembered that each of these persons is interpersonally linked with friends, family members, and loved ones, and that each of these individuals may be affected in turn by the patient's illness. Cancer is not always dealt with in a simple, one step treatment; all involved likely adjust and cope not only with the diagnosis but also with the treatment and outcome. Numerous spouses, partners, and children at some point must face the reality of coping with the diagnosis, treatment, and in some cases death of a parent with cancer (Altschuler et al., 1999; Armsden & Lewis, 1993; Worsham et al. 1997). Given the widespread prevalence of cancer in the United States and the resultant number of individuals that it touches, there is a pressing need for research that focuses on the impact that a parental cancer diagnosis has on the children in these families.

The majority of research to present time has focused primarily on the experience of the individual cancer patient, occasionally expanding to include the experience of the patient's romantic partner and spouse. The need for additional studies focusing on the ways in which children cope with the diagnoses of cancer in parents has been suggested by multiple researchers (Altschuler, Dale, & Sass-Booth, 1999; Armsden & Lewis, 1993;

Armsden & Lewis, 1994; Armistead, Klein, & Forehand, 1995; Birenbaum, Yancey, Phillips, Chand, & Huster, 1999; Compas et al., 1994; Graham & George, 1972; Lewis, Ellison, & Woods, 1985; Lewis, 1986; Lewis, Hammond, & Woods; 1993; Worsham, Compas, & Ey, 1997).

Issel, Ersek, and Lewis (1990) is one of the exceptions, applying family systems theory to families' adjustment to cancer diagnoses. Issel et al. (1990) utilized content analysis of interviews and identified four main coping strategies, " ... being *In Her Shoes*, carrying on *Business as Usual*, tapping into *Group Energy*, and putting the mother's illness *On the Table*"; in addition, they reported that the coping of children in these families was significantly facilitated by the adults in their lives (p.8). Lewis and Hammond's (1996) investigation of the family's coping with breast cancer suggests that the illness of a parent impacts the amount of difficulties experienced in their family, inclusive of: depression in mothers, negative marital appraisal by fathers, and poorer quality of parenting for adolescents. Wellisch (1979) and Wellisch, Gritz, Schain, Wang, and Siau (1992), have investigated the potential link between parental cancer and the impact on children. Wellisch (1979) utilized six case studies of adolescents at different times in the illness of the parent; results highlighted the involvement of the adolescent and concomitant impact of the parent's cancer diagnosis. Wellisch et al. (1992) used structured interviews and surveys to examine the characteristics of children coping with parental cancer that may ameliorate or exacerbate the impact of parental illness. While both studies indicated that role shifts in the household were reported by children who coped with parental cancer, neither project showed quantitatively that such a shift had indeed occurred.

Daly (2005) explored this research avenue through a quantitative investigation of changes in childrens' household roles and responsibilities after a parental diagnosis of cancer. Results of this study indicated no significant differences regarding the roles and responsibilities performed by adolescents coping with the diagnosis and treatment of a parent with cancer as compared to same-age peers who were not coping with a parent's cancer over the same time interval. A general pattern of an increase in roles and responsibilities was noted over time for both the cancer and noncancer groups, with some evidence of gender and age differences in the specific roles and responsibilities performed. It was found, however, that individuals handling the impact of parental cancer utilized more psychological coping techniques than did those individuals who were not coping with parental cancer. Given that these results seem inconsistent with past research suggesting a marked role shift for children that occurs with a parental diagnosis of cancer, one question that arises is related to the nature of the methodology used. Daly (2005) used quantitative methods in order to investigate the potential presence of a change in household roles and responsibilities and whether such a change might be related to the coping of children after the diagnosis of a parent with cancer. The majority of previous studies utilized qualitative methods. This methodology may have led to different findings due to the nature of the task required, e.g., in the Daly (2005) study the required task was to specify the amount of time spent on given household roles and responsibilities rather than to explicate one's involvement in household roles and responsibilities as well as other facets of the experience coping with parental cancer.

The current study focuses on analyzing the qualitative components of previously performed quantitative analyses (Daly, 2005). Increasing awareness from both a qualitative and quantitative perspective of the roles and responsibilities and coping in adolescents will help shed needed light on the reasons behind adolescents' difficulties in dealing with parental cancer, as well as point to future directions for interventions with these adolescents.

Children coping with parental cancer

The majority of available research has indicated that parental diagnosis and illness is related to psychological distress, inclusive of depressive symptoms, anxiety symptoms, and maladaptive behaviors in children (Armistead et al., 1995; Armsden & Lewis, 1994; Compas et al., 1994; Hoke, 1997; and Worsham et al., 1997). However, there are several studies that have come to different conclusions. For example, Leedham and Meyerowitz (1999) found that individuals reported negative short-term effects in childhood such as emotional concerns and family problems, yet also noted experiencing some positive changes resulting from the parental illness. In addition, Leedham and Meyerowitz (1999) found that there appeared to be negligible long-term effects of parental cancer related to self-esteem and psychological distress; they added that it was their impression that some long-term subtle, existential changes appear to have taken place that were not picked up by typical measures.

Likewise, Harris and Zakowski (2003) found similar levels of anxiety and depression in both adolescents coping with parental cancer and a control group of adolescents who were not coping with parental cancer; they suggest that reported distress indicated in other studies may simply reflect the distressing nature of the adolescent period of life. The results of Howes, Hoke, Winterbottom, and Delafield (1994), also suggest that most children seem to remain at a healthy level of functioning with the cancer of a parent; they offer multiple hypotheses for these results that are discrepant from most other research, including: children may try to help their parents during time of illness, families' adaptive abilities, and the impact of mother's adjustment to cancer on their perceptions of problems in their children.

One type of research related to children's coping with parental cancer has focused specifically on the impact that a terminal illness (and subsequent death) may have on the child. In the cases of those adolescents who must cope with the terminal illness of a parent, studies indicate higher levels of depressive symptoms and other problem behaviors, although the majority did not report severe issues (Berman et al., 1988; Christ, Siegel, & Sperber, 1994). Compas et al., (1994), Pfeffer, Karus, Siegel, & Jiang (2000), and Siegel et al., (1992) suggest that given the overall paucity of literature available on children's coping with parental cancer, this is a specific area that needs additional research and more clearly defined results. For example, Armsden and Lewis (1994) found that children of women with chronic illness reported higher self-esteem than did children of women with a terminal illness of cancer; however, as pointed out in Romer et al. (2002), the children in this research study had mothers who "were considered cured" (pp. 29). Pfeffer et al. (2000) found that children seem to possess a high level of resilience following the death of a parent from cancer, with depression and anxiety levels close to normal 2 to 18 months after the death.

Siegel et al. (1992) reported that the period prior to parental death from terminal illness may be the most critical for assessing the adjustment of children, given that children may already be demonstrating significant distress at that time; however, they noted that the children's experience in this period has not been adequately assessed.

Hilton and Gustavson (2002) took a different perspective; their qualitative interviews with children ranging from age 7 to age 21 suggested that children's coping was impacted both by shielding themselves from aspects of the parent's illness and being shielded by the parents to minimize the impact of the illness. In addition, Siegel et al. (1992) suggested that children may hide or mask distress to protect their parents; as a result of these masking efforts on the parts of the children, parents may not recognize or possess full awareness of their children's adjustment problems. Siegel et al. (1992) also found that children with a terminally ill parent self-reported more symptoms of depression and anxiety, lower self esteem, and higher levels of problem behaviors than children in the community population.

Still, the results of the current studies appear mixed and in need of further clarification. As a clear example of this ambiguity, a review by Osborn (2007) suggests that while children and adolescents may not be at risk for severe psychosocial problems compared to same-age peers, they may still be at higher risk for internalizing problems; she further critiques the nature of the studies done previously on this group, inclusive of: limited sample sizes, limited studies with paternal cancer, use of non-representative comparison groups, and the possibility that current assessment instruments may miss issues that these children are experiencing. Interestingly, a review by Grabiak, Bender, and Pusker (2007) published in the same issue of *Psycho-Oncology* as the Osborn (2007) article disagrees. They conclude that adolescents coping with parental cancer "…are distressed and this distress must be recognized *and* addressed by the parent diagnosed with cancer, family members, health care professionals, and school personnel" (ibid, pp.135).

Although researchers have posited a variety of factors that may influence, positively or negatively, the experience of children coping with parental cancer, the empirical assessment of such factors has been evaluated as inadequate by several researchers (Armistead et al., 1995; Roy, 1990-1991; Welch, Wadsworth, & Compas, 1996). The importance of family functioning is one such factor. Researchers found that the family members seem to cope more with the parents' ability to deal with the illness as a unit than they do with the actual illness; family members' functioning seems to be mainly affected by these coping behaviors rather than the issues related specifically to the physical illness (Lewis et al., 1993). This is echoed by Lewis and Darby (2003), whose study highlighted the relationship between the functioning of parents and the adjustment of the adolescents in families coping with a mother's breast cancer; for example, they reported the presence of more behavioral problems in adolescents when both parents were depressed. Nelson and White (2002) noted that problems in children adjusting to parental cancer during the first year related to poor parental adjustment (in the parent who had cancer) and to low-self-esteem in the child themselves.

The following factors influential in children's coping with parental cancer were summarized by Worsham et al. (1997):

> " ... (1) the type and severity of the parent's disease, (2) whether the disease is acute or chronic in nature, (3) gender of the ill parent and child, (4) age of the child, (5) time of the onset of the parent's illness (prior to child's birth, during childhood, during adolescence), (6) degree of physical impairment in the patient, (7) whether the illness is heritable versus nonheritable, (8) degree of the patient's cognitive impairment and emotional distress related to the illness, and (9) characteristics of treatment ..." (p. 197).

Coping based on age

When comparing the ways in which children cope with psychological stressors and their overall resilience to these stressors, one key aspect is the stage of development of the child. (Compas et al., 1994; Lewis et al., 1985). Surveying the available research across different age ranges of children, it appears that younger children are generally able to cope relatively more effectively than are adolescents. One study indicated that children between the ages of 6 and 10 reported relatively lower levels of distress, anxiety, and depression as compared to adolescents; in fact, the responses of the younger children were not at a level considered to be clinically concerning (Welch et al., 1996). This is supported by other studies suggesting that adolescents have the most difficult time coping psychologically with the cancer of a parent; these studies note higher levels of self-reported anxiety, depression, and stress in adolescents as compared to those reported in children of other ages (Welch et al., 1996; Wellisch et al., 1992; Worsham et al., 1997). Birenbaum et al. (1999) also found that more adolescents reported internalizing behavior problems at a clinically significant level than did children of other ages. Compas, Worsham, Ey, and Howell (1996) found that adolescents tended to utilized problem and emotion focused coping when handling the diagnosis and treatment sequelae of a parent's cancer, associated with more symptoms of anxiety and depression, than did preadolescents. Visser et al (2005) report that the variance in coping on age is also impacted by gender; their study suggested that adolescent girls and boys ages 4-11 experienced relatively more emotional problems, with the adolescent girls also experiencing more behavioral problems.

The seemingly different experiences that children have when coping with the illness of a parent has been explained in various ways. Some researchers posit that in adolescence these children have an increased capability for understanding the meaning and potential ramifications of parental illness; in addition, parents may disclose more information about their illness to an adolescent than they do to a younger child (Altschuler et al., 1999; Adams-Greenly, Beldoch, & Moynihan, 1986; Berman et al., 1988; Compas et al., 1994; Christ et al., 1994). Other explanations attribute the problematic reactions that adolescents experience during the time of parental illness to the conflict between their age-appropriate developmental tasks and goals and the increased needs of their families (Armsden & Lewis, 1993; Armsden & Lewis, 1994; Grant & Compas, 1995; Wellisch, 1979).

This latter explanation suggests that adolescence, a time period when children typically seek increased freedom from their family and experience increased reliance on themselves and same-age peers, is the same period in which the parental diagnosis of cancer would directly block these goals, resulting in less freedom, more time with family members, and less time spent on the adolescent (Adams-Greenly et al., 1986; Lewis et al., 1985; Wellisch et al., 1992). Adams-Greenly et al. (1986) posit that adolescents may be experiencing increased sensitivity to bodily changes in both themselves and other people given their developmental stage; they connect this bodily concern to the process of identity formation that takes place in adolescence. Finally, there is some evidence that perceived heritability of the parent's illness may impact the psychological coping strategies of adolescents; Armsden and Lewis (1993) reported that for a female adolescent coping with an inheritable cancer in the parent (e.g., breast cancer), she " ...

may be forced to accept an unwanted part of the parent as a part of herself" (p. 157). Clinical vignettes as reported by Spira and Kenemore (2000), echoed similar themes of heritability fears, as well as highlighted the girls' resiliency in coping with the impact of parental cancer.

Reactions based on gender

Although both males and females report similar types of symptoms, inclusive of anxiety, depression, and problematic self-esteem, it generally seems that females have a more difficult time coping with parental cancer than do boys, with girls reporting increased severity of anxiety and depression. Female children whose mothers have been diagnosed with cancer report the most severe psychological reactions of all adolescents (Compas et al., 1994; Welch et al., 1996; Worsham et al., 1997). Compas et al. (1994) reported that adolescent girls whose mothers were diagnosed with cancer reported symptoms that were more severe than those reported by boys with either parent ill and by girls with ill fathers. Davey et al. (2005) noted racial and gender differences in their focus groups on coping with parental cancer; they reported that adolescent African American males, African American females, and Caucasian males tended to rely on distraction and maintaining normal routines as coping mechanisms. They found, however, that Caucasian females utilized social support and written expression as means of coping (Davey et al., 2005).

Several explanations have been offered for the seemingly more difficult experience that adolescent girls face in their coping with parental cancer. Lichtman et al. (1985) hypothesized that there may be an increased potential for disruption in the relationship between adolescent daughter and mother relative to the relationship between mother and adolescent son; they remark that one contributing factor may be a fear on the daughter's part of inheriting the mother's cancer. Lichtman et al. (1985) also commented that these daughters may face heightened demands for support; they reported a greater frequency and variety of problems with the adolescent girls, including those of rejection and hostility. In a similar vein, other researchers have commented on the adolescent girls' perceived feelings of vulnerability related to a cancer diagnosis for themselves, leading to maladaptive coping strategies (Compas et al., 1994; Lichtman et al., 1985). These young women may experience problems related to sexual development as well, learning to associate physical changes and development with illness (Wellisch et al., 1992).

Household responsibilities

Shifts in roles and household responsibilities that may occur after a parental diagnosis has also been offered as a reason for the different age and gender-related experiences of children. For example, after a parental diagnosis of cancer, an adolescent girl may take on a heightened amount of household responsibilities than prior to the illness; likewise, an older child or adolescent would likely take on more responsibilities than a younger child in the same family. Numerous researchers have commented on the added stress that adolescent girls experience as the result of shouldering proportionately more of the household burdens and of moving into a different familial role (Adams-Greenly et al., 1986; Compas et al, 1994; Grant & Compas, 1995; Lewis et al., 1985; Welch et al., 1996; Wellisch, 1979; Wellisch et al., 1992; Worsham et al., 1997). This is supported by Grant and Compas (1995), who reported that adolescent girls whose mothers were diagnosed with cancer experienced, " … more stressful events related to increased family responsibilities than girls whose fathers were ill or boys, and these family responsibilities accounted for the higher occurrence of anxious-depressed symptoms in these girls" (p. 1019). However, these suppositions are not without detactors.

For example, Issel et al. (1990) found that while 23% of younger children discussed household responsibilities in their experience with parental cancer, only 9% of the older children did so. Complicating this further, other researchers note that reports made by parents regarding the functioning of their children may not be congruent with the dysfunction found in self-reports of adolescent girls, with the dysfunction found in the self-reports absent from parental reports (Armsden & Lewis, 1994; Welch et al., 1996; Worsham et al., 1997). As such, Welch et al. (1996) highlighted the importance of gaining the report from the adolescents themselves in order to most accurately assess their level of functioning. The impact of raters is also supported by Visser, Huizinga, Hoekstra, Van Der Graaf, Klip, Pras, and Weebers (2005), who note that while the reports of adolescents and their mothers are relatively consistent, that the reports of fathers suggest the presence of relatively fewer problems.

Despite the positing of changes in household roles and responsibilities as a contributing factor in different age and sex related experiences, the majority of research in this area has neither examined whether such a change in roles or responsibilities actually occurs nor examined the reasons that might exist behind such potential changes. For example, the research of Vess, Moreland, and Schwebel (1985) assessed the ways in which the roles in a household were assigned and noted the importance of effectively reallocating roles in the context of parental cancer; however, they did not examine gender differences within role allocation.

An exception to this pattern is Daly (2005), in which the potential change in household roles and responsibilities occurring after the diagnosis of parental cancer and these changes link with family coping were assessed with both gender of the parent and gender of the adolescent included as variables. A retrospective design was utilized to investigate whether a significant difference exists between the number of self-reported responsibilities and roles and coping strategies of male and female adolescents before and after a parental diagnosis of cancer. This study included a comparison group of individuals who had not coped with parental cancer in order to rule out changes in chores that may occur due to the simple maturation of the adolescent. No main effect for parental cancer was observed. For several categories of chores (e.g., Food, Clothes), a main effect of time was found, suggesting that adolescents performed more chores related to these categories at age 17 than at age 12. In other categories of chores (e.g., Yardwork), a main effect for gender of the adolescent was found. Only two interactions were noted that suggested involvement of parental cancer. For example, in yardwork-related chores, an increase over time was reported for participants with a male parental figure diagnosed with cancer, and a slight decrease over time was reported for participants with a female diagnosed with cancer. Exploratory analyses on the household roles and responsibilities completed during treatment of parental cancer suggested that adolescents coping with parental cancer performed a similar amount of chores during treatment as they did at age 17. However, as no main effect was found for parental cancer, they performed the same amount of chores as did adolescents not coping with parental cancer.

The Present Study

The present research seeks to complement the Daly (2005) study that investigated whether there was a significant difference between number of self-reported responsibilities and roles of both male and female adolescents before and after a parental diagnosis of cancer. Given that the results of the Daly (2005) study varied from earlier research, it is crucial to assess the reasons for this divergence. The present study uses a qualitative analysis of the narrative responses given by the Daly (2005) participants regarding household roles and responsibilities. Research questions for the current study include: 1) Are there qualitative differences in household roles and responsibilities between the responses of individuals who coped with parental cancer and those who did not cope with parental cancer? 2) Is the lack of quantitative differences in terms of household roles and responsibilities between those reported by individuals who coped with parental cancer and individuals who did not cope with parental cancer reflected in their qualitative responses to queries regarding their experience of household roles and responsibilities? 3) Do the qualitative responses given by participants vary related to the presence or absence of parental cancer? 4) If differences exist between responses to qualitative and quantitative assessments, to what might we attribute this?

CHAPTER II

Method

Research Data

The proposed study was performed on previously collected data from Daly (2005). The methodology presented below gives a description of that prior study.

Preliminary Work

Creation of a measure. Before the Daly (2005) study began, a measure of household roles and responsibilities was created. The author generated an initial list of items that might be included on the measure, based on items that were observed in measures that seemed related. The author, with assistance from co-workers who were parents in families, then created numerous additional items. All items, both those from the initial list and those generated subsequently, were then combined into a final list of items for the Household Roles and Responsibilities measure (Appendix A). The Household Roles and Responsibilities measure is, at the basic level, a checklist of behaviors. As a result, the primary concern with this measure is with content validity. The various roles and responsibilities on this measure were categorized into six general areas of household work: Food, Housework, Clothes, Family, General, and Yardwork. At the end of this measure, the author included two open-ended questions. The first open-ended question requested information regarding roles/responsibilities not specifically listed on the measure that the participant might have also performed. The

The second open ended question asked participants to comment in narrative form on their perceived experience of household roles and responsibilities.

Research Study

Participants. This research study utilized as participants those individuals who were randomly selected from the overall pool of students enrolled in an undergraduate class in psychology (PY100) at Colorado State University. Participation in this study granted research credit to students. This study drew from the students enrolled during the Fall 2004 and Spring 2005 semesters; the number of participants were subsequently restricted by the number of students who met the inclusion/exclusion criteria of this study. Equal numbers of male and female students were selected, and participants of all ethnicities were accepted. All participants were required to be over the age of eighteen; this was necessitated by the sensitive nature of this study related to family dynamics, in order that parental consent not be required.

Two groups of participants were selected and asked to participate in this study. The first group had either a parent or parental figure diagnosed with cancer when the participant was between the ages of 12 and 17; the gender of the person diagnosed, and their relationship to the participant were subsequently utilized as exclusion criteria (Daly, 2005). The second group of participants was a comparison group, comprised of individuals who did not have a parent or parental figure diagnosed with cancer when the participant was between the ages of 12 and 17. In order to determine those students who met criteria, a screening form entitled "Student Questionnaire" was utilized in all General Psychology classes in both the Fall 2004 and Spring 2005 semesters. (Appendix C). Based on the responses on this form, those potential subjects who met the initial criteria were contacted by phone and asked to participate in the study. An equal number of potential participants from the General Psychology population who did not meet the initial criteria were then selected, contacted by phone, and asked to participate.

One hundred and thirty-five individuals, 68 females and 67 males, participated in this study and provided data for analysis over the course of the Fall 2004 and Spring 2005 semesters (Daly, 2005). All participants were randomly selected from the pool of potential participants through the generation by computer of randomly assigned numbers given to each potential participant. Of these 135 participants, the majority (116) self-identified as Caucasian, with less than 18 total participants who self-identified as African-American, Asian, Hispanic, Indian, or multiracial.

Sixty-five individuals comprised the group without parental figures diagnosed with cancer, and 70 individuals comprised the group with parental figures diagnosed with cancer. Of the 36 female participants who had a parent diagnosed with cancer, 17 had a mother diagnosed with cancer, 16 had a father diagnosed with cancer, 1 had a stepfather diagnosed with cancer, 1 had a grandparent diagnosed with cancer, and 1 had another parental figure (family friend) diagnosed with cancer. Of the 34 male participants who had a parent diagnosed with cancer, 17 had a mother diagnosed with cancer, 13 had a father diagnosed with cancer, 2 had a stepfather diagnosed with cancer, and 2 had a grandparent diagnosed with cancer. The mean age at the time of parental diagnosis was 14.51 years old, and the mean length of time these individuals reported being affected by parental cancer was 16.84 months after time of diagnosis. The reported severity of diagnosis was a mean of 3.49 on a 1 (Outpatient) to 7 (Terminal) point scale (SD=1.74) and the reported degree to which the family was affected by parental cancer had a mean of 4.34 on a 1 (Not at all) to 7 (Severely) point scale (SD=1.75). Types of parental cancer as reported by participants may be seen in Table 2.1 at the end of this chapter.

Measures and instruments

Three assessment instruments were utilized in this study; this included the Household Roles and Responsibilities measure (Appendix A), F-COPES (McCubbin et al., 1981, used with permission), and a demographic form (Appendix B).

The Household Roles and Responsibilities Measure. The household roles and responsibilities measure as designed specifically for the Daly (2005) study consisted of several sections. Participants first completed a yes/no checklist assessing their participation in different roles and responsibilities. Next, if participants indicated that they participated in a given role/responsibility, they then estimated the number of minutes per week and percent of time that they spent on that particular role/responsibility. Given the focus of the study, participants were also asked to estimate the amount of time in minutes per week that each task was performed by anyone else in the household, e.g., other parent, siblings, or grandparents. Each participant filled out two to three Household Roles and Responsibilities Measures; those in the experimental group filled out three and those in the comparison group filled out 2. The first was marked “Age 12” for both the experimental group and the comparison group. The second was marked “During Treatment” for the experimental group; this copy was not filled out by the comparison group. The third was labeled “Age 17” for both the experimental group and the comparison group. Each of these measures was scored by summing the number of minutes per week spent on tasks within the six categories of roles/responsibilities. As a result, there were 6 scores for participants on each Household Roles and Responsibilities measure, with the each score the summation of time spent in chores within a general category. The measure concluded with two open-ended questions: the first question asked: "Were there any other household roles/responsibilities that you spent time in; if so, what were they?' The second question asked: "How would you describe your participation in household responsibilities? (For example- They were chores that my parents assigned to me and I feel I helped out a lot around the house; I didn't usually do any chores unless I had to; I wasn't assigned any chores but I did _____ anyways)."

F-COPES. The second measure used in this study was the F-COPES (McCubbin et al., 1981). The F-COPES (McCubbin et al., 1981) is a 30 item, self-report survey that asks participants about their family's participation in given strategies, both internal and external, used to cope with crises. Participants are asked to indicate their perceptions regarding their family's use of 30 different coping strategies, on a five point scale from strongly agree to strongly disagree. The reliability estimates for the scales on the F-COPES (McCubbin et al., 1981) are:

> "acquiring social support, .83, reframing, .82, seeking spiritual support, .80, mobilizing family to acquire and accept help, .71, passive appraisal, .63, and total scale, .86" (p. 480). The final scale's test-retest reliability is: "acquiring social support, .78, reframing, .61, seeking spiritual support, .95, mobilizing family to acquire and accept help, .78, passive appraisal, .75, and total scale, .81" (McCubbin et al., 1981, p.480).

The total score for the questions within each factor, as determined by factor analysis, were used for the purposes of analysis.

An exploratory factor analysis using four, five, and six factors models as possible solutions were then examined. A rotated component matrix with a cut-off level of .4 was used to indicate significance. It was determined that five items did not meet this significance level; they were not included in scoring. Although the *a priori* model was five factor, results of the factor analysis suggested that a four factor model fit the current data best. In the latter model, items had minimal significance or overlap on multiple factors. This model was subsequently used when computing subscales for this measure. "Factor 1 could best be described as "Seeking spiritual support," as indicated in the original five factor model (McCubbin et al., 1981, p. 479). Factor 2 was characterized as "Reframing," again as indicated in the original five factor model (McCubbin et al., 1981, p. 479). Factor 3 was comprised of questions from the factors of both "Acquiring social support," and "Mobilizing family to acquire and accept help," in the original model, and Factor 4 was comprised of questions from "Acquiring social support" (McCubbin et al., 1981, p. 479)" (Daly, 2005, pp.18-19). The *a priori* fifth factor did not include any questions demonstrated to be significant, and as a result was dropped.

Demographic Form. The demographic form (Appendix B) requested anonymous information for each participant, inclusive of age, gender, ethnicity, age of student at time of diagnosis of parent/parental figure, gender of person diagnosed with cancer, relationship of the student to the person diagnosed, and specific diagnosis and outcome of the person's cancer. Family composition, including presence/absence of a second parent, participant's birth order, age and sex of other siblings, and presence/absence of additional household help and parental figures were also assessed (Daly, 2005). Participants were asked to indicate their subjective appraisals of the severity of the parent/parental figure's diagnosis on a seven point scale ranging from "Outpatient (1)" to "Terminal (7)," the severity of how their family was affected by the diagnosis on a seven point scale from "Not at all (1)" to "Severely (7)," and the length of time their family was affected by the diagnosis.

Design and Procedure

Early in the Fall 2004 and Spring 2005 semesters, all students present in the general psychology class were asked to fill out a screening questionnaire (Appendix C). This screening form asked students to indicate their name and whether they had a parent or parental figure diagnosed with cancer. If students indicated that they had a parent or parental figure diagnosed with cancer, they were also asked to indicate the gender of the person diagnosed, their relationship to the person diagnosed, their age at time of diagnosis, and their contact information. Students were informed of the purpose of the forms and were told that they would be contacted for participation if they met the criteria for the study. Using the screening questionnaire, the author determined which students who met the inclusion criteria. These students were then contacted by phone and asked to participate in the study for research credit. Once students agreed to participate, they were registered online.

Participants met with a research assistant in a classroom on Colorado State University's campus. Students were given two informed consent forms by the research assistant, (Appendix D); one form was turned in immediately to the research assistant, and the other was kept by the student (Daly, 2005). Upon turning in the consent form, students then received the research packet in a sealed manila envelope, which included: the demographic form, three Household Roles and Responsibilities measures, and the F-COPES measure (McCubbin et al., 1981), labeled "Coping Survey". Students filled out the appropriate forms and turned them in to the research assistant (Daly, 2005). At the end of the study, all students were given referral information to Colorado State University's Counseling Center; this was done in the event that filling out the survey might bring out any feelings or issues that the student would like to discuss with a mental health professional.

Table 2.1

Descriptives of Gender and Cancer

Type of Cancer	Number reported
Breast	15*
Colon	4
Lung	4*
Bladder	2
Esophageal	1
Testicular	1
Prostate	2
Liver	2
Cervical	5
Lymphoma	2**
Unknown	2
Ovarian	1
Leukemia	1
Lip	1
Brain cancer unspecified	1
Multiple Myeloma	1
Glioblastoma	1
Basal cell Carcinoma	3
Melanoma	8**
Skin cancer unspecified	15

* One participant reported both lung and breast cancer

**One participant reported both lymphoma and malignant melanoma

CHAPTER III

Analysis

In order to investigate the qualitative results from this study, an interpretive and descriptive qualitative analysis was performed. This analysis was completed on the two narrative statements at the end of each Household Roles and Responsibilities measures; this provided approximately four to six qualitative responses for each participant in the study. The investigator used an ethnographic content analysis as the major method, as explained in Altheide (1987). This particular method calls for an inductive coding strategy, an approach that focuses on the emergence of themes and codes from the data itself, rather than applying preconceived ideas to the data (Merriam et al., 2002).

The investigator coded all narrative passages for all participants, ensuring the most reliable and valid codification of the qualitative data. With this type of strategy, ethnographic content analysis, inter-rater reliability is less critical and reliability may be achieved through the use of a single code (Altheide, 1987). Given that there was no pre-set coding system utilized, it was necessary for the investigator to make explicit her position on the data and also to address any potential biases. As a result, the results section opens with the investigator's description of the data and her preconceived beliefs regarding the data. Next, the investigator utilized a constant comparative strategy, in which categories are built from comparing each piece of data to all others, to induce the coding system. The results of this qualitative analysis are subsequently discussed in light of the previous quantitative results in order to ascertain any differences that may exist and hypothesize avenues for future research. Throughout the coding process, memos were written as related to aspects of coding as well as to the overall research design; this provided an avenue for the investigator to note ideas and connections between concepts (Pandit, 1996).

The procedure for this type of data analysis came from Corbin and Strauss (1990). In Corbin and Strauss' (1990) identified procedure, the specific steps of coding include: open, axial, and selective coding. The open coding phase is the "interpretive process by which data is broken down analytically" (Corbin and Strauss, 1990, pp.12). The investigator looked within the text for units of information and attached a coding name to each unit. This phase of coding was continued until saturation, the point at which new information no longer provided additional awareness or knowledge. Constant comparison was made between the data and the codes, with additional codes generated if indicated by the analysis. Next is the axial coding phase, in which the investigator examined the open codes and arranged them into categories, with the more global categories induced from the open codes. Finally, in the selective coding phase, the categories were connected within an integrated framework, with all "categories unified around a "core" category" (Corbin and Strauss, 1990, pp.14).

In terms of trustworthiness strategies, which are the strategies in the qualitative research tradition that are comparable to validity and reliability in the quantitative research tradition, the primary investigator applied two strategies, those of peer examination and of keeping a reflective journal. According to Creswell (1998), peer review supplies a check of the research process in a similar way as does inter-rater reliability. The investigator met on a regular basis with a peer experienced in qualitative research to discuss aspects of the research, coding, and interpretation process of this project. To aid with credibility, the investigator also commented on her personal experience of the research process throughout the procedures of coding and interpretation in a reflective journal.

CHAPTER IV

Results

As noted previously in the Analysis section, a critical component of qualitative research is that of clarifying the investigator's position on the data, inclusive of her early thoughts and potential hypotheses. The current research project had in many ways begun several years earlier with the inception of my thesis research. I had long been interested in health psychology and in looking for research topics for my thesis, discovered an apparent gap in the literature- the experience of children coping with parental cancer. This topic was investigated in a quantitative way through my thesis project, which sought to determine whether there were quantitative differences between the household roles and responsibilities performed by adolescents who coped with parental cancer and those who did not cope with parental cancer.

Much to my surprise, the results of this thesis research contrasted sharply with what I had expected based on the majority of available literature. While the results of my research suggested that there were no clear differences between the roles and responsibilities performed by adolescents coping with parental cancer and those who were not coping with parental cancer, the literature had suggested strongly that this was a potential explanation for the gender and coping differences observed, particularly in the cases of adolescent girls coping with parental cancer (Adams-Greenly et al., 1986; Compas et al, 1994; Grant & Compas, 1995; Lewis et al., 1985; Welch et al., 1996; Wellisch, 1979; Wellisch et al., 1992; Worsham et al., 1997). Even in the early stages of my thesis research, the topic of parental cancer appeared to be subjectively important to potential participants. For example, when I passed out the initial screening forms to students in the Introduction to Psychology classes, after briefly explaining my thesis project, one student explicitly thanked me for conducting this research. As my research assistant worked on recruiting participants, we noticed that nearly all the participants who had coped with parental cancer agreed to participate in this study, whereas it was more difficult to find participants who had not dealt with parental cancer who would participate. My curiosity piqued after my thesis research, I decided to continue investigating this topic through my dissertation research in order to clarify the apparent discrepancy between the results of my thesis and the body of literature.

At the inception of my dissertation research, I wondered whether there might be differences in the qualitative responses by participants coping with parental cancer as compared to the responses given by those individuals who were not coping with parental cancer. I was also curious about whether there might be differences in attributions that participants made about the reasons they had for completing their chores; for example, whether participants coping with parental cancer attributed their participation in chores to having a parent with cancer, while the participants who did not have a parent with cancer perhaps attributed their participation in chores to the natural process of adding chores as they grew older. There seemed to be richness to the qualitative data that might address these early thoughts and subsequently round out the quantitative work previously completed.

I felt eager to begin working with a qualitative approach to analysis, and completed a graduate level independent study course in order to better prepare myself for working in this research tradition. The process of this project has been exciting, frustrating, yet always interesting. It has ultimately been one that has been much more involved and engaging than my quantitative research. Given the process component to the qualitative research tradition, my experience in this research project was also impacted for several months during the time when I was doing data entry, as my own father was diagnosed with prostate cancer. During that time, I consulted with my advisor and decided to take some time away from the project in order to take care of myself and my family, and to minimize the potential impact that this might have on the coding process. Happily, my father is doing well, and I returned to the project after several months away re-energized and excited to continue.

Below are the main themes that I've found through my analysis of this data; given the number of participants and overall number of open codes, I've focused this description on the results that were most prominent or significant, and have used quotations from the project to highlight and elucidate themes. As noted earlier, 135 students participated in this study, contributing approximately 557 responses that were coded in the manner described in the previous section. Approximately 489 open codes were initially generated from this pool of data, with the results collapsed into the four overall codes described below: chores performed, additional chores performed, reasons for completing chores, and reasons for not completing chores. In the Discussion section, I connect the results of this research to the previous quantitative research in light of the research questions.

Different chores?

The broadest question to be explored within the context of this project was that of whether there were differences in the qualitative responses given by those participants who coped with parental cancer and those participants who had not coped with parental cancer. This analysis focused on the second question, "How would you describe your participation in household responsibilities? (For example- They were chores that my parents assigned to me and I feel I helped out a lot around the house; I didn't usually do any chores unless I had to; I wasn't assigned any chores, but I usually did _______ on my own anyways) "

In examining the qualitative responses to the second question given by participants who coped with parental cancer and those who did not, the number of codes in the global category of chores was higher for those participants who coped with parental cancer as compared to those who did not cope with parental cancer. Participants who coped with parental cancer reported more involvement in several specific areas of chores than did those participants who did not cope with parental cancer.

Two of these specific areas were chores of cleaning and chores related to food. Both were reflected more strongly for participants coping with parental cancer than for those not coping with parental cancer, at double or more the frequency. Chores related to cleaning ranged from chores specific to the participant, such as cleaning their own room, making their own bed, to more global cleaning chores, such as cleaning the kitchen, or cleaning that was non-specifically focused. Participants made statements such as "Clean and vacuum my own room and sometimes other rooms," or "took care of my own room." Participants coping with parental cancer also more often reported involvement in chores related to themselves or to caring for themselves, interestingly, as compared to those individuals not coping with parental cancer. Regarding chores related to food, participants coping with parental cancer reported more involvement in providing food for themselves and their families, including such statements as "cooking for myself," and "cooking for myself and others when they were around and interested," or "making everyone breakfast," as compared to those individuals who were not coping with parental cancer. One participant specifically talked about part of their responsibilities within their family as "providing comfort food." In contrast, responses from the participants not coping with parental cancer referred briefly and simply to "cooking" or "made dinner." Other frequent responses related to performing chores included general housework and chores related to one's self, in which participants coping with parental cancer also more often reported involvement as compared to participants who were not coping with parental cancer.

One area within the overall code of chores that showed a dramatic difference between the parental cancer and the non parental cancer groups was that of the chore of helping with others' responsibilities. Chores that were categorized under this code were chores where participants indicated that they helped out with tasks usually performed by another family member. Again, nearly double the participants coping with parental cancer reported involvement in these chores as compared to the participants who did not cope with parental cancer. Participants made statements such as "I always tried to help out my mom as much as I could," "I filled in for my mom," and "had to do more of my mom's regular chores." Interestingly, no references were made to filling in specifically for their father's roles. In comparison, while participants not coping with parental cancer also reported helping out with other individual's responsibilities, the responsibilities that they assisted with were exclusively those of their siblings, rather than those of their parents, as seen in the group related to parental cancer. In general, participants who were coping with parental cancer also talked about "helping out" at more than double the rate of those individuals who did not cope with parental cancer.

The only exceptions to this general pattern occurred with regards to chores related to caring for siblings. Participants who did not cope with parental cancer more often reported involvement with caring for their siblings as a chore than did participants coping with parental cancer. For example, participants wrote statements that referred to generally taking care of their siblings, such as "I took care of my brothers," or "babysitting." Other participants also made statements that referred to caring for their brothers and sisters in a specific context, for example, "I usually helped my brother with homework," or "helped my sister with schoolwork."

A secondary analysis explored the possibility that the amount of chores performed by participants coping with cancer might vary by the length of time their family was affected by the cancer. Regarding this question of whether differences existed in the qualitative responses given by those participants who coped with parental cancer of different severities, results suggested that the general pattern of results as described above holds true for those participants who coped with parental cancer for over three months. Those individuals who coped with parental cancer for less than or equal to three months, suggesting briefer interventions and treatment, had in general fewer responses. As such, in all categories of chores as elucidated above, individuals who coped with parental cancer for less than three months reported relatively less involvement in these chores as compared to individuals who had not coped with parental cancer.

Any Additional Chores?

In the course of completing the open-ended questions, participants were invited to respond to the first question, "Were there any other household roles/responsibilities that you spent time in; if so, what were they?" In general, participants who coped with parental cancer and participants who had not coped with parental cancer reported fairly similar involvement in additional chores, with no outstanding differences between the groups. The additional chores that participants noted participating in included tasks such as: assisting with family parties, shoveling snow or snow-blowing, fixing the computer, and bringing in wood.

There were a few exceptions to this general pattern, however. Participants who had coped with parental cancer generally indicated that they did *not* participate in any additional chores (besides those mentioned on the Household Roles and Responsibilities forms) more frequently as compared to individuals who were not coping with parental cancer. Seemingly incongruously, participants who had coped with parental cancer also did report participation in additional chores; they more often reported chores related to schoolwork, perceiving their involvement in academics as an extra task more often than did participants who were not coping with parental cancer. For example, one participant wrote, "I had to study for certain amounts of time when I was 12, usually a certain hour set aside at night." Similarly, participants coping with cancer also more often reported additional roles and additional chores related to providing food as compared to participants who did not cope with parental cancer. While not a frequent code, it is worthwhile to note that several participants coping with parental cancer did specifically comment on caring for their parent as an additional chore. For example, one participant noted additional chores of, "helping her walk, bathing her, feeding her, regulating her sodium intake," suggesting participation in direct care of the parent who was coping with cancer. This code of caring for one's parent was not present at all in the responses from individuals who had not coped with parental cancer.

Secondary analysis investigated whether this pattern of responses held true for participants who coped with parental cancer for varying lengths of time. In general, participants who coped with parental cancer for less than or equal to three months had fewer overall responses, and did not demonstrate the pattern of results as seen above. Individuals who coped with parental cancer for over three months demonstrated very similar results to those who had not coped with parental cancer. Marked difference between those who coped with parental cancer for over three months and those who had not coped with parental cancer occurred regarding: performing no additional chores, and additional chores related to studying and working. Participants who coped with parental cancer for longer than three months more often reported involvement in these chores. Of note, all responses regarding caring for parents as an additional chore were given by participants who dealt with parental cancer for longer than three months.

Why Complete Chores?

Another theme that arose from the data over the course of analysis was participant's spontaneous reports of the various reasons behind their performance of chores, without being specifically asked about their motivation for chore completion. While the frequency of these responses were lower than those of the prior two categories, they appeared as a distinct group of responses. These reasons ranged widely from internal motivations to external motivations; for example, from perceiving chores as a natural occurrence that they would participate in to being externally rewarded for chores through allowance, or "star charts." Participants who were coping with parental cancer more frequently commented about both internal and external motivations for chores than did the participants who had not coped with parental cancer. One striking difference that arose between the parental cancer and the no parental cancer groups was the much higher report of self-motivated chores with the parental cancer group. These participants talked about chores that "I assigned myself," commenting that "I usually did a lot without being asked," and saying, "I also did chores that I wasn't asked to do." Both groups reported reasons of age or ability, for example, noting "because I could do more things, such as drive myself" as a frequent reason for completing chores. Participants in both groups also referred to enforcement of chores as frequent reasons for completion of chores, noting that they were "made" to do chores, or "they made sure I got them done."

Participants coping with parental cancer also commented more frequently about completing chores due to perceiving a need for those chores to be completed. These participants wrote statements such as, "If Mom or Dad needed help around the house I would do it," and commented that, "{they} took the initiative to do something when it needed to be done." Another specific motivator within the overall category of chore completion was that of helping others as a primary reason for the completion of chores. Participants who were coping with parental cancer wrote more comments about specifically helping their mothers, whereas the participants who had not coped with parental cancer made more statements about helping out both of their parents rather than just their mother. This appears to tie in neatly in with a theme to be discussed later, that of the differences observed specifically related to parental cancer and gender.

Looking within the responses of participants who coped with parental cancer, those individuals who coped with cancer for less than or equal to three months had fewer overall responses. As such, the results as described above are not reflected in this group. The overall pattern of responses regarding chore completion, however, does hold consistently true for the participants who coped with parental cancer for longer than three months.

Along with participant's comments about the reasons behind their completion of chores, participants also spontaneously wrote statements about their positive perceptions of themselves related to chores. Both those individuals who had coped with parental cancer and those participants who had not coped with parental cancer perceived themselves as helpful at about the same frequency. A key difference occurred in that individuals who were coping with parental cancer for longer than three months wrote more frequently about perceiving themselves as doing their fair share around the house. For example, participants who coped with parental cancer made statements such as, "doing my part in house," and "try and pull my own weight," and more often noted helping their family as a reason for completing chores. Participants who had not coped with parental cancer, or who had coped with parental cancer for less than or equal to three months did not report any comments about doing their fair share of chores.

Why Not Complete Chores?

In a similar manner as they had reported the reasons why they completed chores, multiple participants also spontaneously reported why they had failed to complete chores, or had decided not to complete chores. Again, while the frequency of these responses were lower than those of the first two categories, they appeared as a distinct group of responses that paralleled the positive perceptions category. Interestingly, the parental cancer group more frequently talked about failing to complete chores as compared to the group not coping with parental cancer, just as they had more frequently commented on the reasons why they had completed chores. The primary reason that participants coping with parental cancer noted was that of the involvement in other people in the household related to chores. Those participants who had coped with parental cancer and those who had not coped with parental cancer made similar statements about the presence of family members, siblings, and professional household workers that would either complete their chores or help out so that the participant himself or herself no longer needed to complete the chore or participate in that aspect of household work.

Investigating the potential differences in responses related to the length of time individuals coped with parental cancer, in general, participants who coped with parental cancer for less than or equal to three months had fewer responses. As a result, the pattern of results as described above is not demonstrated for this group of participants. However, the pattern of responses does remain consistent for those individuals who coped with parental cancer for more than three months.

Along with participant's comments about the positive qualities within themselves or about their participation in household chores, participants also noted negative qualities about themselves related to chores. Participants who coped with parental cancer and participants who did not cope with parental cancer overall made similar numbers of these statements; both groups generally made fewer references to negative perceptions of themselves as compared to positive perceptions of themselves. Participants who coped with parental cancer for less than or equal to three months made fewer references to negative perceptions of themselves than did those participants who had not coped with parental cancer and those participants who coped with parental cancer longer than three months.

Parental Cancer and Gender

In addition to participant's comments about chores in general, a theme arose from the coding in which a subset of participants wrote specifically about their parent's cancer diagnosis, treatment, and/or outcome. In general, these responses were fewer in number. Participants tended to utilize aspects of their parents' cancer diagnosis as a time marker, referring to before diagnosis, after surgery or treatment, or the time when their mother or father became increasingly ill. Parental cancer appeared to be an event that shaped these participant's recollections, a singular event that their memories of chores were tied around. In general, both male and female participants more often referred explicitly to the presence of maternal cancer as compared to the presence of paternal cancer. Interestingly, while both maternal and paternal cancer were used primarily as time markers, as indicated above, several male participants who coped with maternal cancer also made comments about their mother's experience of cancer; these more process oriented statements were completely absent from the codes present for father's experience of cancer. These comments reflected participant's thoughts about how their mother viewed the cancer diagnosis and impact of treatment; for example, participants commented "my mom tried not to let the cancer affect her," or "she never wanted to be taken care of, just cared for," or "it seemed she didn't want to be helpless so she did a lot herself," in general, noting the belief that their mothers wanted to continue their roles in the households. The gender differences observed in these responses suggest that male participants may view the cancer of a mother in some way differently than that of the cancer of a father. Again, these themes was not explicitly asked of participants, but arose from the participant's open qualitative responses.

Regarding chores and parental cancer, participants reported viewing their chores differently when their parents had cancer, for example, "I did them [chores] a lot more diligently when I learned my mom had cancer" or completing chores, "mostly to help out my dad so he didn't have to worry about it when he got home." Female participants and male participants explicitly noted the diagnosis or impact of treatment as a factor in changes in chores at a similar frequency. For example, they wrote statements such as, "b/c my mom was always in bed sick," and "when my mom had to be in bed a lot." Slightly more comments about their chores were made by those who coped with maternal cancer as compared to those who coped with paternal cancer. While not a frequent code, participants coping with maternal parental cancer commented as well on the increase in chores by their fathers; the parallel of increased chores by mothers during paternal parental cancer was not reported.

CHAPTER V

Discussion

Both the current study and the prior study that it draws from were predicated by the observation of multiple researchers that there exists a lack of research available that explores and clarifies the experience of children coping with parental cancer (Altschuler et al., 1999; Armistead et al., 1995; Armsden & Lewis, 1993; Armsden & Lewis, 1994; Birenbaum et al., 1999; Compas et al., 1994; Graham & George, 1972; Lewis et al., 1985; Lewis et al., 1993; Worsham et al., 1997). While there had been many studies investigating the experience of the parent/patient themselves, fewer studies had addressed the needs or feelings of either the children or spouses in these families (with even relatively less attention focused on the experiences of the children as compared to the experiences of the spouses). Those studies that had been completed had produced a mixed body of conclusions.

Previous research had hypothesized that a reason behind the difficulty that adolescents, especially adolescent girls have coping with parental cancer might be due to alterations in household roles and responsibilities subsequent to parental cancer (Adams-Greenly et al., 1986; Compas et al, 1994; Grant & Compas, 1995; Wellisch, 1979). Few studies had demonstrated that such a change or shift actually occurs with the diagnosis of a parent with cancer. However, multiple studies have reported that a parental diagnosis or illness has been linked to symptoms of anxiety, depression, and maladaptive behaviors in children in those families (Armistead et al., 1995; Armsden & Lewis, 1994; Compas et al., 1994; Hoke, 1997 and Worsham et al., 1997). The Daly (2005) study sought to address this gap in the body of research; however, the data from this study found no clear differences between the chores performed by adolescents coping with parental cancer and those performed by adolescents who had not coped with parental cancer. Instead, the results of this study pointed more towards gender and age-related differences in the performance of chores in both adolescents coping with parental cancer and adolescents not coping with parental cancer. Research would have suggested that adolescent girls experience increased stress secondary to increasing chores and responsibilities around the home and shifting roles (Adams-Greenly et al., 1986; Compas et al, 1994; Grant & Compas, 1995; Lewis et al., 1985; Welch et al., 1996; Wellisch, 1979; Wellisch et al., 1992; Worsham et al., 1997). Given that the results of the Daly study were discrepant from what would have been expected based on most of the previous research, the current research study investigated the qualitative responses of participants to determine if differences might be reflected in the qualitative responses that had not been demonstrated in the quantitative responses.

The present study investigated four primary research questions: 1) Are there qualitative differences in household roles and responsibilities between the responses of individuals who coped with parental cancer and those who did not cope with parental cancer? 2) Is the lack of quantitative differences in terms of household roles and responsibilities between those reported by individuals who coped with parental cancer and individuals who did not cope with parental cancer reflected in their qualitative responses to queries regarding their experience of household roles and responsibilities?

3) Do the qualitative responses given by participants vary related to the presence or absence of parental cancer? 4) If differences exist between responses to qualitative and quantitative assessments, to what might we attribute this?

Are there qualitative differences in household roles and responsibilities between the responses of individuals who coped with parental cancer and those who did not cope with parental cancer?

In general, the results of this qualitative research suggest that regarding question one, there do appear to be important qualitative differences in the household roles and responsibilities between individuals who coped with parental cancer for longer than three months and those individuals who did not cope with parental cancer. These differences include: increased involvement in chores typically performed by another family member, chores related to cleaning, chores related to food, chores related to housework, and chores related to self-care were all reported more frequently by those who had coped with parental cancer as compared to those who had not coped with parental cancer. Individuals who had not coped with parental cancer more often reported involvement in caring for their siblings as compared with individual who had coped with parental cancer. Differences were also observed related to additional chores performed, with participants who had coped with parental cancer reporting additional involvement in tasks such as schoolwork and caring for others. This pattern was not observed in the responses of those individuals who did not cope with parental cancer. However, individuals coping with parental cancer also more often reported that they did not have involvement in additional chores, as compared to those participants not coping with parental cancer. Overall, these results do seem to suggest that those adolescents coping with parental cancer may perceive themselves as generally more involved in chores when compared to adolescents who are not coping with parental cancer and that the tasks which they were involved in were addressed in the Household Roles and Responsibilities.

Is the lack of quantitative differences in terms of household roles and responsibilities between those reported by individuals who coped with parental cancer and individuals who did not cope with parental cancer reflected in their qualitative responses to queries regarding their experience of household roles and responsibilities?

Regarding question two, the lack of quantitative differences in terms of the household roles and responsibilities between individuals who had coped with parental cancer and those individuals who had not coped with parental cancer was not consistently reflected in their qualitative responses. As noted above, participants who coped with parental cancer for longer than three months did more frequently report involvement in certain categories of chores and in additional chores performed, as well as more frequently reporting no involvement in additional chores. Differences were also observed with regards to participant's comments about the reason that they completed chores or did not complete chores between the participants who coped with parental cancer and the participants who had not coped with parental cancer. However, there were also many areas of similarities in the responses between the two groups.

Do the qualitative responses given by participants vary related to the presence or absence of parental cancer?

This lack of overall consistency in the amounts and types of chores performed by participants, as well as the duration of time participants coped with parental cancer may again have masked the potential for quantitative differences. As a result, regarding question three, the responses by participants do seem to vary dependent on the presence or absence of parental cancer, by the gender of the parental cancer, and most clearly, by the length of time that they coped with parental cancer. Multiple participants explicitly referred to their parent's cancer. Some participants specifically talked about their experience with their parent's diagnosis, treatment, or outcome of their cancer. Likewise, responses also varied dependent on whether it was maternal cancer or paternal cancer, with some codes completely absent from the responses concerning paternal cancer as compared to the responses concerning maternal cancer. These responses suggest that participants who coped with parental cancer appeared to make a connection between the chores that they were performing and the illness of their parent, and in a few instances, linking their performance of a chore or increase in their chores directly to their parent's cancer. For those participants who coped with parental cancer for less than or equal to three months, the impact of parental cancer on chores appears to be minimal, as demonstrated by the fewer responses and less reporting of involvement in chores as compared to the participants who coped with parental cancer for longer than three months.

If differences exist between responses to qualitative and quantitative assessments, to what might we attribute this?

Regarding question four, which asked about the attributions that might be made for the differences between the qualitative and quantitative responses, there appear to be multiple possibilities. In general, the qualitative differences between the responses for those participants who coped with parental cancer for more than three months and the responses for those participants who had not coped with parental cancer appear somewhat more consistent with what might be expected based on the body of literature suggesting that parental cancer significantly impacts the children in families, as compared to the lack of differences observed in the quantitative research which was at odds with the previous research. One reason for this might be that as this was a retrospective study, the specificity of identifying the exact chores (and amount of time spent in these chores) performed by oneself would certainly be greater as compared to giving general comments about one's perception regarding these chores. While the quantitative estimates may have masked the possibility of differences between the roles and responsibilities performed by those individuals who coped with parental cancer and those individuals who did not cope with parental cancer, these differences might still be reflected in the qualitative results, as indicated in the current study. Similarly, as participants coping with parental cancer for more than three months more often both reported involvement in chores and involvement in no additional chores, potential differences between the cancer group and the non-cancer group may have been masked.

The differences observed between the results of the previous quantitative study and current qualitative study might also be attributed to the very nature of qualitative and quantitative research. As noted above, themes arose from the qualitative data that were not specifically asked of participants, such as the reason for completing chores, their reasons for failing to complete chores, and their positive and negative perceptions of themselves. These qualitative differences suggest that adolescents coping with parental cancer and those not coping with parental cancer may make different attributions for the reasons that they are performing (or not performing) their chores. The qualitative study also examined the variation of responses within the group who coped with parental cancer.

While the overall quantitative amount of the chores they perform may not be significantly different whether they are coping with parental cancer or are not coping with parental cancer, the reasons that they believe they are doing the chores may potentially vary quite a bit. The prevalence of assignment of chores and self-motivated chores also speaks to a potential reason why the lack of quantitative differences may have occurred; it again may be less about the number of chores that participants performed and more about the motivation for performing these chores- whether they were assigned, or whether they were something that participants felt they wanted to do on their own. Participants who were coping with parental cancer for more than three months perceived themselves as doing chores of their own volition at a markedly higher frequency than those who were not coping with parental cancer; this may suggest that participants coping with parental cancer for more than three months were presented with a situation in which there was the possibility to perform chores on their own due to the absence of a parent in the household labor. In contrast, those individuals who coped with parental cancer for less than or equal to three months did not encounter the same gap or absence of a parent's involvement in the household work.

Taking a wider perspective, what do the results of this study suggest? This project's results are particularly strengthened by the large number of participants, the inclusion of both paternal and maternal cancers, the range of cancers investigated, the length of time impacted by cancer, and the use of a comparison group. The differences in the results between this project and its origin clearly delineates the importance of obtaining both qualitative and quantitative data when investigating an experiential topic, in order to strengthen each component and allow comparisons to be made between them. The results suggest that there exist some potential differences in the ways that adolescents who are coping with parental cancer and those adolescents who are not coping with parental cancer view their household responsibilities. As a result, addressing the chores that a child or adolescent has may be a way for parents to intervene with their children during the time of parental cancer, being aware that their children may simply take more upon themselves in the household (particularly with longer treatment/intervention of parental cancer), or that they may also be assigned chores due to the changes in the parental chore-load. It is possible that the ongoing involvement in additional chores and the attribution made for them may combine to create additional difficulties coping. In addition, parents can be increasingly cognizant that children may have perceptions about their parent's coping with parental cancer that may also impact their chore performance, for example, perceiving that their parent wants to continue their chores as normal; this may be particularly the case in maternal cancer and male adolescents, based on the results of this study. That said, there were also many similarities in the responses between participants who were coping with parental cancer and those who were not coping with parental cancer, suggesting that in many ways these groups' experiences of chores is relatively similar.

Limitations of the current study include the largely White, non-Hispanic and relatively well educated population of this study, which attended a singled university in a single area of the country. As a result, the generalizability of these findings to the overall United States population as well as to individuals of diverse backgrounds may be somewhat limited. Although there was a high number of participants and a large data pool, particularly for a qualitative project, this study could be improved by asking additional questions of its participants in order to add greater depth and understanding to the way that the participants perceived their experience with household roles and responsibilities, whether it occurred in the context of parental cancer or not. Another limitation to the current research includes that this was a retrospective study, and may not necessarily accurately reflect the exact perceptions that participants had at the time that it refers to, but instead are viewed subjectively through participant's thoughts about their past. As a result, some responses may reflect a more adult awareness than that which would have been observed had the data been collected at the time of the participant's experience.

Research that explores the nature of a child or adolescent's experience with cancer continues to be important, particularly when placed in the overall context of the prevalence of cancer in the United States. Looking at the number of individuals newly diagnosed with or currently coping with a diagnosis of cancer would suggest that children who are coping with the cancer of a parent is not altogether an uncommon experience. Areas of continued research in this vein may expand focus to include the emotional dynamics and interplay within a household, or "emotional labor," as identified by Hochschild (1983), rather than structured household tasks as examined in this study. While the previous research is somewhat mixed, much of it has shown that these children may have difficulties coping and may experience symptoms consistent with anxiety and depression (Welch et al., 1996; Wellisch et al., 1992; Worsham et al., 1997). As a result, it is critical to continue investigating the reasons behind their experience in order to most effectively provide support for them in the time of familial stress, to provide the most efficacious interventions to ameliorate symptoms of psychological distress, and to educate not only their families but also their healthcare providers to better assist the entire familial system during times of parental cancer.

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Appendix A

Household Roles and Responsibilities Measure

Role/Responsibility	Did you participate in this activity?	If yes, How many minutes/week?	What percent of time Did you spend? (eg: 30%, 75%)	Who else spent time on This activity? (Indicate who)	How many minutes/week Did they spend?
Food					
Grocery shopping	___ Yes ___ No	________	________	________	________
Preparing breakfast	___ Yes ___ No	________	________	________	________
Preparing lunch	___ Yes ___ No	________	________	________	________
Preparing dinner	___ Yes ___ No	________	________	________	________
Setting/clearing the table	___ Yes ___ No	________	________	________	________
Making snacks/treats	___ Yes ___ No	________	________	________	________
Washing the dishes	___ Yes ___ No	________	________	________	________
Cleaning the Kitchen	___ Yes ___ No	________	________	________	________
Housework					
Cleaning the main rooms	___ Yes ___ No	________	________	________	________
Vacuuming	___ Yes ___ No	________	________	________	________
Picking up toys	___ Yes ___ No	________	________	________	________
Washing the floors	___ Yes ___ No	________	________	________	________
Making the beds	___ Yes ___ No	________	________	________	________
Changing the linens	___ Yes ___ No	________	________	________	________
Washing the windows	___ Yes ___ No	________	________	________	________
Taking out the garbage	___ Yes ___ No	________	________	________	________
Dusting	___ Yes ___ No	________	________	________	________
Sweeping	___ Yes ___ No	________	________	________	________

Role/Responsibility	Did you participate in this activity?	If yes, How many minutes/week?	What percent of time Did you spend? (eg: 30%, 75%)	Who else spent time on This activity?	How many minutes/week Did they spend?
Clothes					
Shopping for clothes	___ Yes ___ No	______	______	______	______
Sewing tears/buttons	___ Yes ___ No	______	______	______	______
Sorting laundry	___ Yes ___ No	______	______	______	______
Washing the clothes	___ Yes ___ No	______	______	______	______
Folding/hanging up clothes	___ Yes ___ No	______	______	______	______
Ironing	___ Yes ___ No	______	______	______	______
Family					
Getting siblings ready for school	___ Yes ___ No	______	______	______	______
Babysitting siblings	___ Yes ___ No	______	______	______	______
Driving siblings	___ Yes ___ No	______	______	______	______
Helping siblings with homework	___ Yes ___ No	______	______	______	______
Planning activities	___ Yes ___ No	______	______	______	______
Playing with younger siblings	___ Yes ___ No	______	______	______	______
Caring for sick family members	___ Yes ___ No	______	______	______	______
Putting siblings to bed	___ Yes ___ No	______	______	______	______
General					
Running errands	___ Yes ___ No	______	______	______	______
Making household repairs	___ Yes ___ No	______	______	______	______
Taking care of pets	___ Yes ___ No	______	______	______	______
Cleaning up after pets	___ Yes ___ No	______	______	______	______
Yardwork					
Mowing the lawn	___ Yes ___ No	______	______	______	______
Weeding	___ Yes ___ No	______	______	______	______
Gardening	___ Yes ___ No	______	______	______	______
Watering the lawn/flowers	___ Yes ___ No	______	______	______	______
Raking leaves	___ Yes ___ No	______	______	______	______

Were there any other household roles/responsibilities that you spent time in; if so, what were they?

How would you describe your participation in household responsibilities? (For example- They were chores that my parents assigned to me and I feel I helped out a lot around the house; I didn't usually do any chores unless I had to; I wasn't assigned any chores, but I usually did _______ on my own anyways).

Appendix B

Demographic Form

1. Age? _____

2. Gender? ______________

3. Ethnicity? ____________

4. Have you had a parent/parental figure who you lived with diagnosed with cancer?______________

If **no**, you may skip the rest of the questions on this form. Please fill out the Household Role and Responsibility forms labeled **Age 12** and **Age 17**, and the **Coping Survey**.

If **yes**, please continue with questions 5-15. Then, please fill out **all three** Household Role and Responsibility forms and the **Coping Survey**.

5. What was your age at the time your parent/parental figure was diagnosed? ______

6. What was the gender of the person diagnosed? __________

7. If not your parent, what is your relationship to the person diagnosed? __________

8. What was their specific cancer diagnosis? ___________

9. Please indicate the severity of their diagnosis:

1 2 3 4 5 6 7

Outpatient Inpatient Terminal

10. What was the outcome of their cancer? _____________

11. Length of time your family was affected? ____________

12. Please indicate how severely your family was affected

1 2 3 4 5 6 7

Not at all Moderately Severely

13. Was there a second parent/parental figure in your family? If so, what was your relationship to them? ___________

14. Do you have siblings? If so, please list the gender and ages of all at time of diagnosis, including self

15. Were there any additional household help or parental figures in your household? (If so, please list gender and relationship(s))

Appendix C

Student Questionnaire

Thank you for your assistance in filling out this student questionnaire. It is for a graduate thesis study. You will be contacted and invited to participate if you meet the criteria for this study. Participation in this study will count towards the research requirements of this class.

1. Name: __________________
2. Have you had a parent/parental figure diagnosed with cancer? _________
3. What is the gender of the person who was diagnosed? ___________
4. What is your relationship with the person who was diagnosed? ______________
5. How old were you when they were diagnosed? ____________
6. Contact information:
    a. Telephone number ___________________________
    b. Email address _____________________________

Appendix D

COLORADO STATE UNIVERSITY
INFORMED CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

TITLE OF PROJECT: Adolescent Coping with Parental Cancer: Shifts in Household Roles and Responsibilities
NAME OF PRINCIPAL INVESTIGATOR: Kathy Rickard, Ph.D.
NAME OF CO-INVESTIGATOR: Jennifer C. Daly, B.S.
CONTACT NAME AND PHONE NUMBER FOR QUESTIONS/PROBLEMS: Jennifer C. Daly, (970) 491-3788

PURPOSE OF THE RESEARCH:
This study involves survey research looking at the shifts in household roles and responsibilities that may occur after the diagnosis of a parent/parental figure with cancer, as well as family participation in coping strategies.

PROCEDURES/MEASURES TO BE USED:
You will first fill out a basic questionnaire form in your PY100 class. If you meet the criteria, you will be contacted and asked to participate in the study. At the time of the study, you will receive a research packet, which includes an anonymous demographic form, several Household Roles and Responsibilities measures, and Coping Survey. The demographic form will ask for information similar to the initial questionnaire form. The Household Roles and Responsibilities measures will ask you to check off household roles and responsibilities that you participated in, and to estimate the amount of time you and others spent in them. The Coping Survey will ask you to indicate your family's use of various coping strategies. Your name will not appear on the demographic form, Household Roles and Responsibilities forms, or Coping Survey form. Your participation will take about a half hour to forty minutes. Participation in this study will be worth two out of the research credits required by Colorado State University

RISKS INHERENT IN THE PROCEDURES:
There may be minimal psychological distress. However, if you would like to speak to a mental health professional about any feelings that you might have after completing this study, please contact the University Counseling Center at 970-491-6053, or stop by Monday through Friday from 8:00 a.m. to 5:00 p.m. All students, as part of their fees, are eligible for 5 free sessions per semester at the University Counseling Center.
It is not possible to identify all potential risks in research procedures, but the researchers have taken reasonable safeguards to minimize any known and potential, but unknown, risks.

BENEFITS:
There are no known benefits to participating in this study; however, we hope that you will gain increased self-awareness for the roles and responsibilities in which you may have participated. We also hope that that this study will also benefit doctors and counselors working with the families of cancer patients, in that they may better be able to advise of potential role shifts that may occur.

CONFIDENTIALITY: Your responses on the demographic form, Household Roles and Responsibilities measures, and Coping Survey are completely anonymous. Your name is not present on any of these forms. Your informed consent form with your name and signature cannot be linked back to these forms in any way, as they are turned in separately. Your initial student questionnaire forms will be kept confidential, and will be kept separately from both the test measures and demographic forms. In addition, there will be no recorded list of the students who participated in the study relative to those participants who initially met criteria and were asked to participate- we will not know the names of those students who participated.

LIABILITY:
The Colorado Governmental Immunity Act determines and may limit Colorado State University's legal responsibility if an injury happens because of this study. Claims against the University must be filed within 180 days of the injury.

Questions about participants' rights may be directed to Celia S. Walker at (970) 491-1563.

PARTICIPATION:
Your participation in this research is voluntary. If you decide not to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

Your signature acknowledges that you have read the information stated and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing 2 pages.

____
Participant name (printed)

_________________________ ____________________
Participant signature Date

_________________________ ____________________
Witness to signature (project staff) Date

Page 2 of 2 Participant's initials ______ Date______