DANCING WITH THE ELEPHANT

UNDERSTANDING YOUNG CHILDREN'S KNOWLEDGE OF A PARENTAL ILLNESS

by

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Abstract

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A parental diagnosis of cancer is not a singular entity or static event. It is a complex activity engaged in by the entire family, not merely the afflicted. It is a dance whose steps are dictated by the choices made, both collectively and individually, in the continuous process of making sense of the disease. Yet, often, research conceptualizes the illness as a causative agent or explanatory principle, rather than a specific type of situated knowledge. This oversimplifies the ramifications of the illness across all family members, especially the children.

Within an ecological and family systems frame, the study used narrative theory and methodology to analyze non-narrative data generated by twenty-five (25) preadolescent children participating in the Knowledge Is Power (K.I.P.) program. The K.I.P. program is a two-session structured program for children aged seven to twelve whose parents have been diagnosed with cancer. Group activities consisted of individual and co-constructed charts and group discussions focused on children's existing and desired knowledge. Coping strategies employed for the changes cancer brings to a family were also addressed. The program explored both the individual experiences of these children as well as their collective experience as they attempt to make sense of their parent's illness while coping daily with it.

The application of narrative analysis to this non-narrative data enabled greater access to the levels of meaning which may have been unknown to the children as they lived through the experience and revealed the inadequacy of the information being received from multiple sources. Results indicated a disparity between existing knowledge, which focused on medical statements and overt illness effects and desired knowledge, which reflected a gap in understanding the nature of these changes, their emotional impact and the future ramifications of the illness. Nuanced differences were also found between those considered active copers and those considered avoidant copers (Billings & Moos, 1981) as well as between the private and public story presented.

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> *"Daddy doesn't laugh anymore. Cancer took it away. I wish we could talk about the good times before cancer."*
> *-Participant, male, nine years old*

Cancer in Families

A Story To Be Told

The diagnosis and treatment of cancer present a unique set of challenges for patients and their families. More than an intrapersonal experience, cancer is intimately shared by those within the patient's immediate social circle. This is especially significant for young children whose parents have been diagnosed with the disease. Despite advances in treatment and increased survival rates, a parent's illness elicits the threat of permanent loss of the parent due to death or temporary losses due to the treatment protocol and the realities of the side effects. There may be a disruption in or redistribution of family roles and routines. The overall impact of these events has been shown to have significant psychological and health outcomes for young children and significant ramifications for the family unit.

Yet, despite these delineations and suppositions, studies of the impact of parental cancer on children are, often, reductionistic. While a multitude of factors contribute to the effectiveness of young children's ability to adjust to and cope with their parent's illness, the illness itself is treated as either a causative agent or explanatory principle and the impact on the child is an exercise in recognized behavioral symptomatology. This oversimplifies the ramifications for these children and ignores the story inherent in the experience. A more narrative research approach is necessary to ascertain the meaning children make of their parent’s illness especially with reference to their existing and desired knowledge about the illness and the influence this has on the meanings they make and the overall impact the illness has. Considering their tangential influence and muted voice in the activity of the illness, their stories often go unheard or are relegated to mere footnotes. A stark omission in the current literature is an illumination of their stories as they actively attempt to make meaning of their present circumstances.

Borrowing from Polkinghorne’s (1997) definition of narrative inquiry as qualitative research concerned with knowledge, not as objective truth or a reflection of reality, but, rather, as knowledge as human construction, the active nature of a child’s meaning making through the experience of a parental illness cannot be ignored. It represents an understanding of their evident perspectives on a lived experience and their attempts to make sense of that experience (Padgett, 1998; Ricoeur, 1985). It reflects a specific type of situated meaning (Patterson & Garwick, 1994) that yields a story unexplored in studies which reduce parental illness to a causal or explanatory variable and present childhood impact as one of many outcome variables. Pratt and Fiese (2004) argue that families regularly introduce and support narratives as a way of telling stories that have meaningful effects for individuals and the entire family unit. Moreover, the way such stories are told, or silenced, has significant influence on a child’s emotional state and resilience. Thus, it is not only whether the story is told but also the content and quality of the information within it. This, again, suggests a need to examine levels of knowledge in meaning making and how this contributes to the story being told.

Existing studies which take a more narrative approach to familial illness (Fiese & Wambolt, 2003; Krishna, Bhatti, Chandra, & Juvva, 2005) present stories which continue to ignore the unique voices of children, relying instead on secondary reports from adult family members. As a result, these do not seek to understand what a child specifically knows about the illness as a contributing factor to these other-reports. Given the consuming nature of the illness and its ramifications for all family members, this is a significant oversight and one which warrants exclusive exploration.

Research on childhood bereavement (Kubler-Ross, 1983; Nolen-Hoeksema & Larson, 1999; Silverman, 2000) postulates the psychological benefits of narrating a loss and the significance it plays in the journey through grief. It is arguable, by extension, that given the multiple daily losses experienced by children whose parents are ill, the ability to narrate the meanings associated with the experiences would be no less essential. It is a story waiting, not only to be told, but to be broadcast for the benefit of those voices still unheard.

Given that a parental diagnosis of cancer is not a singular entity or static event, but, rather, a complex activity engaged in by the entire family, the meanings made cannot be reduced to a series of correlational or causal explanations. The experience of parental cancer is a dance whose steps are dictated by the choices made (both collectively and individually) in the continuous process of making meaning of and coping with the disease and the multitude of events associated with it. Every family member, including and especially the children involved, has a story to tell as they struggle to dance with this pervasive “elephant” in their lives that many try to ignore. It is a story largely ignored but essential for an understanding of the full impact of the disease irrespective of its overt or reported manifestations. Only within this more narrative frame can the true meaning of the experience of a parental diagnosis of cancer for children be fully understood.

Cancer and The Family Dynamic

The use of narrative to ascertain children's meaning making with respect to their parent's illness presupposes a more ecological understanding of the experience. Within the past two decades, the conceptualization of child development has shifted from an individualized, passive series of events, to one where a child is understood as an active participant in events and activities that he or she actively co-constructs with others. It has become necessary within this understanding to modify paradigms in the construction of methodologies in order to study significant events in a child's life and truly understand their impact.

Accordingly, interpretations of events are rendered meaningful by those experiencing them, become more privileged than those hypothesized and imposed by researchers (Bronfenbrenner, 1979). Within this more ecological frame, the external experience of a parental diagnosis of cancer and the inevitable familial changes become internalized by the child and impact the meaning made of the illness. It is an active process of transforming the experience through selective patterns of attention, action and response these children undertake as they construct their story (Bronfenbrenner & Ceci, 1994). Arguably, therefore, the meanings made of the experience of a parental diagnosis of cancer are generated through the content of a child's existing knowledge, the recognized gaps therein, which prompt directions in desired knowledge, and the active attempts to reconcile these factors to formulate a salient and meaningful story reflecting the experience of a parental illness.

Cox and Paley (2003) reflect this more contextualized approach to research as one guided by an understanding of the family as an organized system. This is an adaptation of general systems theory which conceptualizes systems and their inherent subsystems as being composed of interrelated and mutually inclusive parts, maintaining a dynamic state of balance or homeostasis (von Bertalanffy, 1968). The systems are categorized by a sense of wholeness and order which postulates that the whole is greater than the sum of its parts. It possesses characteristics that are impossible to understand by merely combining the characteristics of the individual members. When applied to families, this suggests that each subsystem (parental, marital, child, sibling) possesses its own ability to impact and influence every other subsystem as well as the larger system. Family members operate as a set of interdependent units which are continuously maintaining a dynamic level of functioning that balances both constancy and responsiveness. As Boewn (1978) suggests, the condition of one family member influences the conditions of other family members. Within this conceptualization, the family must be viewed as something actively participated in and created through participation, rather than merely belonged to. Thus, the acquisition of parental illness knowledge, in the broader context of experiencing the illness, becomes a proximal process in the dynamic interaction between the child and the altered family environment (Bronfenbrenner & Ceci, 1994). The impact of a parental illness is, therefore, not contained in the static reality of possessing it. Rather, it is determined by the active attempts of all family members to make sense of the event and to construct a reflective story of the experience as lived through the family system.

Family systems, due to their self-organization, are also highly adaptive. As living systems, they are able to adapt to change or challenges on both an individual and subsystem basis. That is, the resulting change in one part of the system becomes associated with changes in all other parts. Parental cancer dynamically impacts the entire familial system through a means of mutual influences. All members of the system are forced to make alterations resulting in a feedback loop of alterations leading to further alterations in a continuous cycle through the progression of the disease. Thus, an understanding of the ramifications of a parental diagnosis of cancer necessitates a shift from a focus solely on the impact it has on the parent/patient or the relationships between this individual and respective members of their close social network. It requires an exploration of the stories of those experiencing the illness within each unique subsystem, such as the children. Their stories are intimately contained within the concentric circles of experience and dynamic fluctuations of the family processes necessitated by the illness.

According to the Center for Disease Control (2001), more than one in five adults are living with a disability, many of which are associated with chronic health disease. The American Cancer Society (2004) reports that, approximately, one out of every two men and one out of every three women living in the United States will be diagnosed with cancer at some point in their lifetime. As such, the impact of cancer on the family dynamic cannot be minimized. However, the ramifications of the illness have less to do with the actual diagnosis and logistics of treatment and may, ultimately, be mediated through family process variables. Disease creates both practical and emotional demands for all family members. Parental illness, particularly a chronic condition like cancer, causes major stress on the family system and affects the couple's relationship, overall parenting ability, household management, work responsibilities, and social relationships as well as imposes new dynamics of power and control within the larger family system

(Glass, 1985). Parental cancer is an assault on the family system (Giaquinta, 1977). It produces feelings of helplessness, isolation, despair and anger at the changes in family relationships.

In considering these additional circles of illness experience, Compas, Worsham, Epping-Jordan, Grant, Mireault, Howell, and Malcarne (1994) found that patients and their spouses were relatively similar in levels of reported distress surrounding the cancer diagnosis and throughout the progression of the disease. Cancer appears to be an equally significant stressor for patients and spouses. Overall, spouses rate cancer in their partner as a significant stressor and report a number of adverse effects on the marital relationship and family functioning (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Given, Stommel, Given, Osuch, Kurtz, & Kurtz, 1993; Hannur, Gresi-Davis, Harding, & Harfield, 1991; Lewis, Woods, Hough, & Bensley, 1989; Lichtman, Taylor, & Wood, 1987). Greer (1984) cites evidence that illness in one spouse causes an inordinate amount of stress on the healthy spouse. This may be due to the need to provide constant care to the ill spouse (Johnston & Martin, 1992) or the increased illness demands over time (Lewis, Hammond, & Woods, 1993). Such realities are contributing factors in studies (Brazelton, 1989; Register, 1989) which suggest that 75% of married people who develop an illness are eventually divorced. Yet, these demands, which put strain on the marital relationship, also negatively impact all other family members, including children.

Parental cancer impacts all family members, even those with good coping and adaptation (Yeager, Auyang, Brown, Dickinson, Goldstein, Jaffe, McKay, Roche, & Workman, 1999) due to its chronic nature and the continuous life revisions it requires as the disease progresses. Despite evidence that more that 45% of adults presently diagnosed with cancer are alive five years after diagnosis (Boring, Squires, & Tong, 1991), many face a lifetime of after effects including chronic illness, disease and disability. Moreover, there is the threat that the patient (parent) may lose some significant aspect of personal functioning, experience damage to their physical appearance or lose a degree of physical functioning as a result of treatment (Heinrich, Schag, & Ganz, 1984). When this occurs within the context of a family system, it is impossible to focus solely on the consequences for the patient (parent) and deny their impact on the children who are experiencing them in tandem. Beyond the physical and psychological ramifications for those diagnosed are the consequences for those in the patient's intimate social network. As Martocchio (1985) suggests, as the family progresses through the cancer experience, there are constant role changes. More than one-third of families with a parental diagnosis of cancer report a change in familial roles as a result of the disease (ACS, 1979). Many report decreased role functioning in the realms of homemaker, parent, companion and wage earner. In certain cases, there is a role reversal whereby the ill parent becomes the child as the parent is no longer able to fulfill their roles and responsibilities. In a study conducted by Howes, Hoke, Winterbottom, and Delafield (1994), mothers who reported more psychological distress in reaction to their illness also reported lower levels of competence in their children, suggesting that parental perceptions of their illness contribute to their perceptions of their child's behavior and may have important implications in the family dynamic. Lewandowsi and Jones (1998) suggest that the generation of anxiety and altering of communication patterns and relationships as a result of these changes are the hallmarks of familial adjustment to parental cancer. Cancer is an acute, extreme stress that confronts the entire family and requires an assessment, not only of individual responses, but also on the impact of interpersonal and developmental ones. In lieu of medical advances that allow for greater long-term survival, familial ability to cope with the progression of the disease in light of all these factors cannot be minimized. Yet, the impact of parental cancer on the children remains poorly understood as it is relegated to a delineation of causal elements.

There is evidence to suggest that, during times of stress, parent anxiety can have important consequences on their ability to help their children cope (Duffy, 1972; Jay, Ozolins, Elliott, & Caldwell, 1983; Kaplan, Smith, Grobstein, & Flishman, 1973). In an attempt to meet the needs of both patient (parent) and extended family, children's needs can be overlooked and they are left to struggle to make sense of the frightening and confusing experiences they face (Altschuler, Dale, & Sass-Booth, 1999). Given that 40% of those diagnosed will be between 25 and 44 and will most likely be in the process of rearing children (Armistead & Forehand, 1995) and the fact that an estimated 30% of women diagnosed with breast cancer will have one or more school-age or adolescent children still living at home (Lewis & Hammond, 1996), children's voices within this impacted family dynamic cannot be ignored. Overall, investigations of cancer in families have yielded conflicting perceptions. Parental reports indicate that the children experience few behavioral or emotional problems as a result of the cancer diagnosis and progression. However, in these same families, children's self-reports indicate a negative impact of parental cancer on self-esteem and adjustment (Lewis & Deal, 1995; Lewis, Ellison, & Woods, 1993). Developmentally, Compas, et.al (1994) found levels of anxiety and depression highest among adolescents whose parents have cancer. The level of distress varied with degree of relationship between the sex of the ill parent and the sex of the child, while total stress-response symptoms were greatest among young children. Younger children are more likely to engage in intrusive thoughts and emotions or use avoidance as coping mechanisms. In a longitudinal study of fifty-four cancer patients and their families, conducted by Vess, Moreland and Schwebel (1985), the effect of cancer on the family was mediated by the stage in the family cycle at which the reallocation of roles occurred. Families with young children utilized more external resources such as relatives and agencies but also tended to overload the healthy spouse. Families with adolescent children by contrast, expected the adolescent to carry a greater than usual share of the family responsibilities. However, these studies still fail to capture the unique experiences of these children and the meaning they make of these variables. Moreover, delineating childhood as young and adolescent ignores the unique challenges of pre-adolescent children who are no longer comfortable being treated as young children nor completely ready to assume the responsibilities expected by adolescents.

Though seemingly oxymoronic, the ramifications of parental cancer are not always detrimental to the family system. Parental cancer can also alter the family dynamic in positive ways as families struggle to cope with the illness and remain resilient. Problem-solving strategies are often developed according to the length and severity of the illness and each family member’s perception of resources (Johnston & Martin, 1992). Following a parental illness, families have been shown to experience higher degrees of communication, a new family identity no longer defined by the illness, and an ability to redistribute family roles in a way that does not compromise the development of individual family members (Patterson & Garwick, 1984; Reis, Steinglass, & Howe, 1993; Rolland, 1999). Beavers (1982) argued that competent families in which there was a parental illness were more oriented to the present than to future goals and focused on small gains and specific positive events. These families were able to meet individual needs of specific family members without compromising the needs of others by allowing for the expression of negative thoughts and feelings in pro-family ways. According to Radina and Armer (2001) in a study of families in which mothers contracted post-breast cancer lymphedema, there was greater flexibility in modifying daily tasks and a willingness to adopt different roles within the dynamic to compensate. This created better coping resources which carried over into the emotional response to the disease. Similarly, there is evidence to suggest a definite link between family cohesion, adaptability and support and positive adjustment to parental illness and between poor communication, conflict and rigidity and poorer adjustment (Horowitz & Kazak, 1990; Kazak & Barakat, 1997; Kliewer & Lewis, 1995). Such studies present a more multifaceted view of the cancer experience and underscore the need to utilize a more narrative approach to fully present the voices of the children rather than to assume their interpretations according to the dichotomous positive or negative effects. In doing so, much nuance is lost.

What remains salient, however, is that the stress of a parental illness affects the equilibrium and balance of the entire family system. Family responses to a parental diagnosis of cancer necessitate incorporating the cancer and its treatment into the family’s everyday life. This may depend upon the parent’s understanding of their particular cancer and its prognosis (ACS, 2003) and typically involves a shift in focus toward what it is necessary to do in order to live with the disease. This prompts corresponding shifts in the family system. The ill parent may have to make multiple trips to the hospital, their partner may have to take time off work and family routines will be shifted. This has enormous impact on the marital relationship and may compromise children's developmental tasks, producing emotional distress and feelings of stress, fear, guilt, depression and anxiety (Miller, Wilcox, & Soper, 1985) in those we do not always consider full participants in the experience. As Northouse (1991) noted, although children are an integral part of this family system, little attention has been given, specifically, to the impact of cancer on their lives. In the reality of this imposed silence, the elephant thrives.

In Summary

Given the current shift in the perception of child development from an individualized, passive series of events to a more active, mutually influential and ecological one, the understanding of the essence of the family must be altered. No longer an encompassing entity one is merely a part of, the family becomes a dynamic system participated in equally by all members. The dynamic and interdependent nature of this family system, presupposes that the actions of any one member have consequences for the lives of all the other member of the system. They are intimately linked in ways that mutually propel the system and, at times, definitively alter it.

Within this conceptualization, a parental diagnosis of cancer presents challenges for all family members by impacting all familial systems including the couple's relationship, parenting issues, household management, work responsibilities and social relationships. In the context of Bronfenbrenner's ecological approach this translates into an impact within the microsystem of the family reflecting the effects experienced in the outwardly concentric meso- and ecosystems. Thus, the story of a child's experience of their parent’s illness is an expression of the meanings made in the negotiation of these environments.

Further, considering statistics which suggest that one out of every three women in the United States will be diagnosed with cancer at some point in their lives and that 30% of these will have one or more school-aged or adolescent children living at home as well as the fact that 40% of those diagnosed with cancer, regardless of gender, will be between the ages of twenty-five and forty-four and will most likely be in the process of raising children, the role of children in the family dynamic of a parental cancer diagnosis cannot be ignored. A significant number of children will be faced with the dilemma of how to make meaning of the experience and their dramatic change in circumstances. Given the chronic, rather than terminal nature of the illness (prompted by advances in medical treatment), constant negotiation and renegotiation of the various aspects of family dynamics such as roles, responsibilities, relationships, expectations, activity patterns, and so on is required. This especially affects children who, at times, are treated by both researchers and family members as of tangential interest for research into the experience. Despite such social assumptions, the stories constructed by children as they give meaning to the parental illness and their experience of it, though as yet unheard, are of great relevance.

The Impact of Parental Cancer on Children

Parental illness as a negative life event has been rated as requiring more readjustment for children than repeating a grade in school, parental loss of employment, or the death of a grandparent (Coddington, 1972; Monaghan, Robinson, & Dodge, 1979). However, in a review of the available literature, Faulkner and Davey (2002) noted a scarcity of articles focusing solely on the impact of parental cancer on children and adolescents. Little empirical data on children's coping near the time of parental diagnosis is available, despite research that demonstrates children's perceptions of the seriousness and stressfulness of their parent's cancer appear to be accurate (Compas, Worsham, Ey, & Howell, 1996) irrespective of stage or prognosis. Most studies on cancer in families discuss the impact of cancer on the patient, the spouse of the patient or on a family when there is a child diagnosed with the disease. Yet, children whose parents are diagnosed with cancer are faced with significant psychosocial stress from a combination of factors including the emotional distress of their ill parent and any disruption in the parent/child relationship or marital relationship. Further, they must cope with the threat of the loss of a parent, decreased parental availability, increased household responsibility, changing schedules and routines and the potential depletion of financial resources (Armistead, Klein, & Forehand, 1995). These factors put them at risk for greater physical complaints, increased family conflicts and less family cohesion (Veach, 1999) and are reflected in self-reports of moderate to high levels of emotional distress in children and adolescents (Compas, et.al., 1994).

In a review of the literature on children's adjustment to parental illness, Korneluk and Lee (1998) reported contradictory findings. Some investigators found children of chronically and terminally ill parents to exhibit moderate distress and maladjustment (Worsham, Compas, & Ey, 1997) as well as psychological problems, including anxiety, depression, academic and behavior problems (Armsden & Lewis, 1994; Compas et. al., 1994; Lewis, Hammond, & Woods, 1993; Lewis, et.al., 1989). Such studies report more clinically significant symptoms (Korneluk & Lee, 1998) including evidence that children with chronically ill parents resembled the children of mentally ill parents on measures of behavioral, emotional and academic functioning (Anderson & Hammen, 1993; Conrad & Hammen, 1993; Hammen, Gordon, Burge, Adrian, Jaenicke, & Hiroto, 1987; Hirsch, Moos, & Reischl, 1985; Lee & Gotlib, 1989).

Other studies delineating the effects of parental cancer on children reported no elevated risk (Howes, et. al., 1994; Wellisch, Gritz, Schain, Wang, & Siau, 1991) or serious child problems reported by parents recently diagnosed with cancer (Brown, Fuemmeler, Anderson, Jamieson, Simonian, Kneuper, & Brescia, 2007; Howes, et.al., 1994; Welch, Wadsworth, & Compas, 1996). That is, most children of ill parents did not score in the clinical range for anxiety or depression. This was echoed in one of the first reports on the impact of cancer on children (Cancer Cares, 1977). Among the forty-seven children who evidenced no behavioral problems before the illness, only 36% demonstrated behavioral problems after the diagnosis. Compas, et.al. (1996) suggest that these discrepancies may be related to each child’s perception of the stressfulness of their experience. Normal responses to parental cancer become pathological when behavior changes are extreme or their duration seems excessive.

As was argued previously, parental cancer disrupts children’s psychological adjustment primarily by disrupting family dynamics. It can mean the threat of parental loss, either temporarily through disease symptomatology or treatment, or permanently through death (Grant & Compas, 1995; Lewis, 1990; Siegel, Mesagno, Karus, Christ, Banks, & Moynihan, 1992). Children are expected to deal with a disruption in family roles and routines. Parental cancer can cause a depressed mood in both the afflicted parent and his or her spouse (Cunningham, Edmonds, & Williams, 1999; Gilbar, 1998;

Leedham & Meyerowitz, 1999; Lewis, 1986; Lewis & Hammond, 1996) leading to less psychological availability, communication, direct supervision or consistence in discipline and initiative as well as increased hostility, irritability and coerciveness (Armsden & Lewis, 1994; Christ, Siegel, & Sperber, 1994; Compas, et.al., 1994; Garber & Robinson, 1997; Garber, Robinson, & Valentiner, 1997) . Moreover, even in the absence of comorbid parental depression, parental cancer may lead to parental inaccessibility due to treatments demands or as a result of parental preoccupation with the illness. This sense of physical or emotional unavailability may be perceived as withdrawal by the child and has been linked to impaired adaptability in behavior, social relations and self-esteem (Faulkner & Davey, 2002). Similarly, marital tension produced by parental illness can produce adjustment difficulties in children through more frequent punishment (Jew & Green, 1996; Lewis & Deal, 1995), increased anxiety or the perception that they (children) are unloved or unvalued (Compas, et.al., 1996; Garber & Robinson, 1997; Garber, et.al., 1997; Lewis & Hammond, 1996). While this is more of a concern for younger children, in reference to child care, older children will test their independence in reaction to the changes in circumstance or feel compelled to compensate for their parent's inability to maintain the family routines.

Due to a comparatively limited field of social experiences, children do not respond to the cancer diagnosis in the same way as the adults in the family. Johnston, Martin, Martin, and Gumaer (1992) and Armsden and Lewis (1993) found that younger children had more difficulty conceptualizing the illness, were more likely to express anxiety about the day-to-day changes in their lives and possessed greater fear, loneliness, anger and uncertainty about the future than older children. Younger children may be concerned with cancer being a contagious disease, promoting a fear that the other parent or other family members will contract it, or they may hold the belief that cancer is always fatal (ACS, 2003). Fearing that they will burden their parents with their concerns, children may react by withdrawing emotionally. This points to noted discrepancies between parent and child-reports of adjustment to parental illness. These children were also more likely to report internalizing problems as a result of the illness than were their parents (Achenbach, 1991). In an effort to spare their parents further distress, they conceal their own distress. As Bearison (1991a) presents, there exists a conspiracy of silence within such exchanges and the voice of the child is muted. Many children also ruminate on how their actions may have caused their parent's cancer and how they could have prevented it from happening (Finch & Daugherty, 1993; Yule, 1992; Yule, Bruggencate, & Joseph, 1994). This elicits an experience of guilt that, often, goes unexpressed and exists as a form of magical thinking stemming from an egocentric worldview. For many children this is a common experience at some point during the cancer diagnosis and treatment. At times, the emotional impact on young children may be more behaviorally than verbally expressed. For example, a dependent child may become more dependent, a pessimistic child may develop increased negative life ascriptions, or an aggressive child may increase their confrontational behavior to demand attention for themselves (ACS, 2003).

In older children, the impact of parental cancer is focused more on the perception of changes in long-term responsibilities and consequences. That is, older children may be more equipped to contribute significantly to the care of their ill parent. Although Aldridge and Becker (1993) found this to be initially valuable in developing self-confidence, over the progression of the disease it becomes overwhelming as it challenges the child's sense of personal control. Among adolescent daughters, for example, the increased stress of greater caretaking responsibility led to a perception of personal vulnerability to cancer or the use of maladaptive coping strategies (Compas, Worsham, & Ey, 1989). This suggests that older children may be as unable to cope with the threats, associated with parental cancer, to the family system as are their younger counterparts. The developmental tasks of older children are often compromised and masked by adult responsibilities and the status and reinforcement received from them (Johnston & Martin, 1992). Yet, once again, the dichotomy of younger and older children oversimplifies the age-related issues and ignores the population of children who exist between the two realms.

Beyond developmental concerns, studies of the impact of a parental diagnosis of cancer suggest that gender may play a role in the impact of parental cancer on children. Wagner and Compas (1990) argue that the psychological distress of daughters is greater than that of sons. They cite evidence to suggest that girls perceive events affecting a member of their family as more stressful than boys. However, such self-reports must be considered along with evidence that, generally, girls more spontaneously voice what they feel about the cancer, while boys are more likely to act out behaviorally (Altschuler, 1993; Dale & Altschuler, 1997; Parker, 1993). This dichotomy is also evident with respect to the nature of the parent-child relationship. Steele, Forehand and Armistead (1987) found that mother/child relationships were twice as problematic as father/child relationships in reference to parental cancer. In a study conducted by Levinson (2000) girls with a more conflict-ridden relationship with their ill mothers, marked by anger and the perception of a retaliatory parental response, reported that their mother was not dealing well emotionally with her cancer and had personal concerns about having caused the cancer. Thus, when the mother/child relationship is compromised, the child appears to be at greater risk for adjustment problems. However, studies also suggest that this may be qualified through the relationship with the healthy parent (Lewis, et.al., 1989). A positive relationship with the healthy parent may buffer the effects of a strained maternal relationship. Within the family system, the quality of the relationship always takes precedence over the nature of it. Yet, there is little research to explore such factual statements in a way that goes beyond the simplistically reductionistic views about gender differences.

There is also evidence to support the theory that the gender of the child is not as important as the symmetry between the gender of the parent and the gender of the child. That is, findings by Compas, et.al. (1994) found higher levels of distress among daughters whose mothers had breast cancer and among sons whose fathers had cancer. This was confirmed by a study of the children of breast cancer patients conducted by Brown, et.al. (2007). They found that in such a situation daughters showed significantly more depressive symptoms than sons. However, Gilligan (1982) and Goldner (1985) argue that the gender differences expressed by children in families with parental cancer are rooted less in the gender of the parent and more in differences in familial expectations toward male and female children. This is best reflected in the differences in the care they are expected to provide to the ill parent (with daughters expected to provide significantly more) or in their ways of showing distress (daughters verbally; sons behaviorally). However, as with the influence of parental cancer on the family dynamic, there is also evidence of gender differences in the processes leading to resilience. Girls, because of their early maturity, tend to respond to life events with greater autonomy and competence (Johnston & Martin, 1992). That is, the addition of extra family responsibilities seems to have a maturing effect on them especially in the presence of external emotional support. In contrast, resilient boys were found to require more structure. Yet, each reality ignores the subtle factors that may contribute to the use of one strategy over another or the reality of using both stereotypical and resilient techniques interchangeably through the process of a child's making sense of their experiences.

In view of a child's need for safety and security and the fact that they look to their parents to provide for all their basic physical and emotional needs, the issue of who will care for them when their parent is feeling sick or requires more aggressive treatment is paramount. Children often appear more anxious when their parent must be hospitalized and react with anger and frustration to the restrictions on everyday life parental hospitalization entails (Forbes, 1997; Worley, 1999). Many parents report children as upset or embarrassed by the physical changes that may accompany treatment (ACS, 2003). Even when prepared verbally for what may happen, it is still traumatic to witness, as it is a physical reminder of the encompassing changes parental cancer brings.

Children often cling to the patterns and routines of their life before their parent became ill. They are challenged to navigate the disease such that it will not consume their lives. Many of these challenges can be mediated by an effective external support network and the maintenance of important activities that have nothing to do with the illness, such as informing the child's school about the illness. While it is not necessary to provide all the details, this becomes, in many instances, an invaluable resource if and when behavioral issues arise. Clinical evidence (Altschuler, et.al., 1999) suggests that some children thrive in school at such times as they see it as a safe haven from the illness. Still, others have difficulty relating academically and with peers. Several studies have explored the emotional difficulties children whose parents have cancer experience in school (Deasy-Spinetta, 1981; Waechter, 1987). They highlight the loneliness and sense of being different these children may experience as they face life events their peers have no frame of reference for. Academically, there are problems with punctuality, attendance, homework and coursework and anxiety about situations going on at home while they are not there, such as financial concerns (Rendall, 1998).

Despite an ample amount of literature delineating the negative impact parental cancer has on child development, Cummings and Davies (1994) caution against the tendency to pathologize children's situations and responses related to parental cancer. The mere presence of a parental illness does not, inevitably, lead to adjustment difficulties. Further, not all children experience long-term problems and many demonstrate considerable emotional growth as well as an increase in sensitivity as a result of having to cope with their parent's cancer (Beardslea, 1989; Blechman & Delamater, 1993; Garmezy & Masten, 1994; Jenkins & Smith, 1990; Roy, 1990;). Werner and Smith (1982) found that resilient children were those with a positive social orientation, sense of autonomy, sex-appropriate behaviors and the ability to process information. These children were also able to solicit support when needed. Moreover, there is substantial evidence that parental illness can lead to a more cohesive parent-child relationship as well as a sense of accomplishment in the child (Glass, 1985; Greer, 1984). Forbes (1997) and Worley (1999) cite parental reports that their children are more caring and understanding towards others, particularly those who are unwell, as a result of the disease. Similarly, Conrad and Hammen (1993) cite increases in child self-esteem as evidenced by more reported friendships and higher academic performance as a protective factor for children. Gottman, Katz, and Gottman (1997) highlight the role of emotional scaffolding by parents who have integrated the illness experience and are prepared for the strong emotions expressed by their children as necessary for positive adjustment. However, such scaffolding cannot happen in the absence of communication and open discussion about the illness.

Yet, despite the ample evidence suggesting its profound impact upon them, Delengowski (1993) continues to argue that children are the hidden victims of the tragedy of cancer. She notes that they are often the recipients of misdirected anger as their parents try to cope with the disease or are emotionally neglected because of the perception that they are too young to understand. Overall, however, emotional reaction to the news that a parent has cancer will depend on a multitude of factors including the child's age, personality, relationship to the parent, how the information is presented, the severity, phase, prognosis of and incapacitation caused by the illness and the child's previous experience with illness, trauma and loss (Lee & Dwyer, 1995; Rolland, 1994). As most of the available research adopts checklists which explore internalizing and externalizing symptoms in children, there is a focus on the extent to which children are symptomatic as a result of their parent's illness rather than the ways the illness is associated with the trajectory of developmental tasks or the mechanisms that facilitate positive adjustment. It is therefore necessary to understand the factors contributing to the psychological resilience of such children. One such, yet unexplored, protective factor may be the quality of the information a child possesses regarding their parent's cancer and the means through which this information was accumulated.

In Summary

In conceptualizing the impact of parental cancer on children, it is essential to note that research by Compas, et.al. (1994) has demonstrated that children accurately perceive the seriousness and stressfulness of their parent's illness. However, because they frequently lack a voice in this familial experience, they exist within a hidden transcript of experience and the passé public persona that they live in blissful ignorance. As a result, children are forced to "dance" to uncertain steps with an unknown and ominous partner. The outcome of their negotiation within this reality has yielded contradictory findings.

Some studies find moderate distress and maladjustment among children whose parents have cancer (Worsham, et.al., 1997) and psychological problems including anxiety, depression and academic or behavioral problems that run from moderate to severe (Armsden & Lewis, 1994; Lewis, et.al., 1993; Lewis, et.al., 1989). However, an equivalent group of studies report no elevated risk (Howes, et.al., 1994; Wellisch, et.al., 1991) or serious problems as reported by parents recently diagnosed with cancer (Brown, et.al., 2007; Howes, et.al., 1994; Welch, et.al., 1996). Most children of ill parents did not score in the clinical range for anxiety or depression. Further, these same studies indicate that some families even report positive outcomes from the diagnosis including greater family communication, a new family identity and an increasingly efficient ability to redistribute roles.

Overall, however, the impact of parental diagnosis on the children in the family is mediated through a multitude of factors, including child's age, personality, relationship to the parent, how the information was presented and parent’s incapacitation caused by the illness as well as the child’s previous experience with illness, trauma and loss. Yet, despite the multitude of variables that contribute to a child’s making meaning of and adjustment to the experience of a parental illness, there remains the unexplored factor of the quality of the information the child already possesses about the illness and how this information is perceived by the child.

Coping with Parental Cancer

Issue of Stress and Coping in Childhood

A parental diagnosis of cancer, arguably, creates a stressful life situation for the children involved and requires a unique set of skills and strategies to cope with emerging changes across multiple areas of existence. Yet, in conceptualizing stress during childhood, research often presents the experience as either an objective documentation of a specific occurrence and its effects, irrespective of the potential confound of cognitive appraisal (Brown & Harris, 1989; Cohen, et.al., 1995; Dohrenwend & Shrout, 1985; Holmes & Rahe, 1967) or focuses on the relationship between environment and an individual's cognitive appraisal of the event as one which presents a type of challenge, threat, harm or loss (Lazarus & Folkman, 1984). Such approaches continue the reductionistic view present in studies of the impact of parental cancer on children. Childhood stress is within the situation or within the individual and must be coped with either by either relying on stable personality traits or altering the environment. In parental cancer populations, neither possibility presents a viable option. Further, this ignores the fluid strategies employed by children as they actively cope with an ever changing disease and views coping skills as something a child inherently possesses rather than something they employ in specific contexts. Similarly, it establishes a dichotomy, whereby certain strategies are better than others; once again pathologizing aspects of the experience. Little credence is given to how the choice of certain coping strategies may impact the stories children tell about their experience or the meanings that they make.

Traditional research on coping in childhood postulates coping strategies in accord with those outlined by Billings and Moos (1981). In a guide to research on stress with children, they compared active coping strategies, which behaviorally or cognitively affect the stressor, with avoidant strategies which draw attention away from the stressor. In research examining developmental changes and stabilities in active and avoidant coping in childhood and adolescence (Altschuler & Rubel, 1989; Band, 1990; Band & Weisz, 1988; Compas, Malcarne & Fondacaro, 1988; Curry & Russ, 1985; Ryan, 1989; Wertlieb, Weigel, & Feldstein, 1987), younger children tended to employ more avoidant coping strategies. They created a sense of order by ritualizing routines and developing relatively absolute mental structures of reality (Johnston & Martin, 1992). Further, Beavers (1982) suggests that their more avoidant coping style manifests itself in acting-out behavior, poor school performance, social withdrawal, sexual promiscuity or substance abuse. Older children, by contrast, were able to understand and identify with parental illness and the problems arising from it. They employed more cognitive restructuring and emotional regulation (Stark, et.al., 1989). Thus, as children develop from preschool years to adolescence, their coping strategies change to include an increased use of more specific active coping strategies (Fields & Prinz, 1997). However, these age-related changes explain little about the reasons for the choices made or how the choice of a specific coping strategy frames the story of the stress.

The choice of any given coping strategy may have less to do with age-related changes and more to do with the process of engaging in and deriving meaning from the stressful experiences. In a study by Forsythe and Compas (1987), the use of active coping strategies resulted in lower levels of psychological distress only in events perceived as controllable, of which parental cancer is not one. This suggests that the use and efficacy of different coping strategies employed by children is related not only to the objective characteristics of the event and the age of the child, but also to the child's appraisal of their control over the course of the stressor (Folkman, 1984; Thompson, et.al., 1993). In cases of parental cancer, the severity of the parent's disease is an important factor. Parental cancer is a relatively uncontrollable event for children and offers them little ability to exert personal control (Weisz, McCabe & Dennig, 1994), a fact which does not differ across age groups. This perception that their parent's cancer is controlled by external factors was found to constrain the types of coping strategies children employed, resulting in a limited use of active coping (Compas, et.al., 1996) and, as a result, greater psychological distress. However, fail to provide evidence of the information inherent in the perception of a situation as stressful. Specific knowledge of the event is overlooked and may have important implications in the choice of one coping strategy over another and the meanings derived, therein.

In the absence of a more narrative approach to coping, whereby process variables are considered above outcome measures, the use of a singular coping strategy remains linked to the child or the event. There is limited reference to the child within the event and the dynamic interaction between these factors. For example, Grant, et.al. (2003) argued that as cognitive appraisals change developmentally, so do the mediating and moderating processes involved in those appraisals. In this more transactional approach, aspects of coping must be examined both across time and within specific situations (Compas, et.al., 1988). Elements within family relationships, thus, have the ability to influence the perception and subsequent response to an event as stressful. As was postulated in the family systems research, it is the elements of the system and how they adapt to the event that may make the difference in outcome. Thus, it seems more important to examine coping efforts aimed at a particular event, within the context of it unfolding, than to assess a global pediatric coping style.

In an effort to address this need to contextualize coping, research has employed the categories outline by Billings and Moos (1981) to suggest an explanation for the nature of the psychological impact of parental cancer on children. Active coping strategies such as problem-solving and monitoring were found to be related to better functioning when compared with less active or avoidant strategies such as distraction (Compas, et.al., 1988; Endler & Parker, 1990). This preferential approach across strategies was also present in a study conducted by Steele, Forehand and Armistead (1997). They found increased use of avoidant strategies in response to a parental cancer diagnosis predicted more internalizing problems in children. A sustained reliance on such a strategy was found to impede individual confrontation with and overcoming of the stressor, resulting in psychological dysfunction. Similarly, research by Compas, et.al. (1996) revealed that the use of avoidant coping strategies in response to a parental diagnosis of cancer was ineffective in managing the child’s emotional distress. It was related to more avoidant thoughts and more symptoms of anxiety and depression. Thus, the use of avoidant coping strategies, initially employed as an attempt to disengage from the stress, in reality, exacerbated it. Such approaches, however, view coping strategies as factorial variables with inevitable, often pathologizing, outcomes without attempting to understand how the choice of a particular strategy influences the meanings made through the experience.

Further, there is limited research on children’s coping at the time of diagnosis, as many studies were conducted several months or years after the initial diagnosis. The motivations for the strategies children choose to employ remain unexplored, as most studies focus only on self-reports of strategies used and measure specific outcomes. Coping strategies are treated as factorial variables and subject to statistical analyses. When considering evidence that, in any given situation, children will employ multiple strategies in response to stress (Forsyth & Compas, 1987; Frydenberg & Lewis, 1994), there is growing interest in the variables, underlying the specific coping strategies (Issel, Erseck, & Lewis, 1990; Northouse, 1984; Pederson & Valanis, 1988). What is necessary is the conceptualization of coping as a narrative category which influences the nature of the story told rather than presupposes an inevitable behavioral outcome. Within this more active conception of coping as a strategy, rather than a trait, child's level of knowledge about their parent's illness and the means through which this information was ascertained become more dynamic aspects of the experience. The meanings children make and the coping strategies they use fluidly move through the experience, changed by and changing the nature of the information available as the disease progresses. This remains an unexplored approach to coping, especially with respect to a parental diagnosis of cancer.

In Summary

While exposure to stressful life events, such as a parental diagnosis of cancer, has enormous impact on the well-being of children in multiple areas of functioning, attempting to study stress in childhood is plagued by the lack of a theoretical conceptualization of stress or one that is operationalized to include an acknowledgment of the environmental conditions that may mediate the cognitive appraisal of an event as stressful. Moreover, there currently exists a divide between the dominant theoretical conceptualizations of stress in childhood and the methods employed to study them. In a literature review conducted by Grant, et.al. (2004), more than fifteen hundred empirical investigations were reported, within the last fifteen years, focused on the relation between stressors and psychological symptoms among youth. This postulates the presumption that certain coping strategies are better than others and are related to better psychological functioning. There is little focus on the reasons behind the choice of strategies or how these strategies work through what children understand about the situation as it is progressing.

This necessitates a conceptualization of coping which moves beyond self-reports and behavioral outcomes devoid of explanations. Such dichotomous and, often, pathologizing, conceptualizations negate the story inherent in the activity of coping. In order to fully understand the choice of a specific coping strategy in response to an event, it is necessary to reconceptualize coping strategies as narrative categories rather than factorial variables. Coping strategies influence the nature of the story told and the quality of the information a child possesses about the experience. In studies of parental cancer, an understanding of the specific protective and detrimental types of information children possess may serve to inform approaches to coping with the disease both within and across families. Therefore, the role of existing and desired information as children actively seek to cope and make meaning of the experience of parental cancer cannot be ignored.

The Role of Information

Young children understand, through their parents, what is happening in their world, especially when a parent is stricken with disease. If information about the disease and its ramifications is not directly communicated from parents it is plausible that children will overhear telephone conversations, obtain information from the Internet, from friends and television, or react to the anxiety and worry they notice in their parents. Parental cancer brings notable changes in both the ill parent and the family dynamic. Cancer is an impossible secret to keep.

Although there is little evidence to support the hypothesis that families with an ill member always exhibit poorer family functioning (Kazak & Barakat, 1997), there is growing evidence for the beneficial role of information and communication in positive adjustment (Horowitz & Kazak, 1990; Kazak & Barakat, 1997; Kliewer & Lewis, 1995). A study reported by Rait and Lederberg (1989) noted that children who had information about their parent's illness exhibited less anxiety than those who lacked such information. Similarly, according to the American Cancer Society (2003), to promote effective coping, it is essential to provide accurate information in such a way that children are able to understand and prepare themselves for the changes that will happen in the family. Children whose mothers provided them with greater information about their disease were more likely to actively explore situations than those who were, solely, provided with verbal reassurance (Blout, Corbin, Sturges, Wolfe, Prater, & James, 1989). Delengowski (1993) supports the importance of education, especially during the treatment phase of the disease. In an article directed at health care practitioners, she stressed honest and concise information directed at the entire family system in both verbal and written form. When children are presented with information they consider too vague they may question whether they are being told the truth (ACS, 2003).

This is echoed in studies of children who are, themselves, ill. Bearison (1991a) reports that simplifying or "down-speaking" complex medical procedures and physiological processes when speaking to children often confuses them, raises unspoken fears about the uncertainties of their condition, and inhibit them from seeking information and advice in their struggle to make sense of the experience of being sick. The same can be said for the children whose parents have cancer. Therefore, parents and children must learn to communicate about the illness in developmentally appropriate ways which will alleviate the fears and anxieties children may have about their parent's cancer (Faulkner and Davey, 2002). This also corresponds to a need for developmentally appropriate materials, in the form of media presentations and Internet exposure, to supplement direct family-directed information. In situations where it is impossible to shield children from stressful life experiences, it is necessary to provide them with the tools they need to cope.

Children may incorrectly assume that what is happening is too terrible to discuss and feel isolated from the family. They will usually imagine the worst if they are not included in what is happening. Many young children attribute something they did or didn't do as the cause of their parent's illness. That is, children specifically seek out causal information in the effort to understand illness (Kalish, 1996).

In order to prevent misattributions, children need to be able to sort out the information they obtain, often from multiple sources, so as to understand what pertains, specifically, to their situation. This requires, minimally, direct communication about the type of cancer their parent has been diagnosed with, the part of the body it is in, what will happen with treatment, how their lives will be affected and may include a developmentally appropriate biological explanation of the body's response to cancer and the possibility that it can travel to other parts of the body so that children understand the need for treatment and the changes it brings. The American Cancer Society (2003) recommends that children understand some basic terms about the illness such as biopsy, malignant, metastasis, remission, relapse, prognosis, tumor and oncologist as well as some basic terms about treatment such as biological therapy, chemotherapy, clinical trials, protocol, radiation therapy, side effects and surgery. However, knowledge and information need not be technical medical terminology or advanced understanding of treatment procedures. Effective coping with parental illness has been shown to involve information on parental absence (how long the parent will be in the hospital, what is going to happen there, whether they can visit or call), level of increased responsibility, changes in routine (who will take care of them when their parent is absent), changes in mood of both the ill and healthy parent, changes in the relationship between the parents and worries about parental death (Compas, Banez, Malcarne, & Worsham, 1991; Fields & Prinz, 1997).

In clinical articles designed to help parents communicate with their children about their illness (Cunningham, et.al., 1999; Leedham & Meyerowitz, 1999; Veach, 1999) recommendations were made for parental explanations that their cancer is not contagious, removal of any blame that the young child may have caused the illness, contact during hospital stays to reassure love and concern, honest answers to questions, preparation for the side effects of treatment and recognition of children who are overburdened by responsibility. To assuage fears, the American Cancer Society(2003) further recommends parents schedule a visit to the hospital in advance to provide a concrete image of the parent’s experience. This is enhanced when a health care provider is available to explain the equipment and procedures. These elements of effective parental support were found to be beneficial for positive outcomes in children of cancer patients.

The more honest family members can be with one another, the greater the benefits for all family members and their interrelationships. Lewis, et.al. (1989) reported that family coping (in situations related to parental cancer) characterized by frequent feedback, reflection, and discussion about the illness were associated with better marital adjustment and greater communication between fathers and children. Harpham (1997) argued that children should be given truthful information when they need it in order to cope effectively. Children who are included in discussing the experience of the disease in a way that provides them with truthful information in manageable doses experience less anxiety than children whose parents are evasive. Further, by applying information gained in studies with ill children, Korneluk and Lee (1998) found that children who are involved in discussions about their parent's cancer show more immediate distress, but also have the opportunity to learn from their parent's coping and fare better in the long term. That is, parents who attempt to shield their children from awareness of their illness may, inadvertently, deprive the child of opportunities to model coping strategies.

There is a need to explore the processes and underlying protective/vulnerability factors associated with adjustment to parental cancer and its impact on the mental health of the children. Yet, the majority of existing research assumes the nature of such variables by either making recommendations based on other-reports of what children need or reducing child-reports to singular causal elements largely without nuanced explanations or a consideration of the meanings associated with these expressed variables. Missing are the explicit voices of the children in these life circumstances as a way to expand upon the supposed symptomatic impact of the information.

When children feel included in the process of the illness, via a greater understanding of it, they feel more central members of the family dynamic. Such factors may moderate the outcomes experienced in response to a parental diagnosis of and treatment for cancer. Moreover, the American Cancer Society (2003) cautions against allowing information to be transmitted to children from a third party. That is, when children learn about their parent's cancer from someone outside the immediate family, it can decrease their trust in the parent. Therefore, an understanding not of not only what is known, but how it has come to be known may be very telling with regard to how children are coping with the disease. Further, as many types of cancer are becoming more chronic diseases, not, necessarily, terminal ones (ACS, 2003), it is helpful to provide young children with the balanced point of view that cancer is a serious, but not a hopeless illness. Thus, the focus of both child and, overall familial adaptation becomes how to live with the illness (Boewn, 1978). This can only be accomplished with a full awareness of all points of view, including those of the children. In this way there is greater assurance that everyone is living and coping with the same disease. However, to date, no study has directly explored the role of children's actual and desired knowledge level in their adjustment to a parental diagnosis of and treatment for cancer. Even rarer is such a consideration as it is generated by the children and explored qualitatively so as to present the complete experience of a parental diagnosis of cancer and what is necessary to cope effectively with that reality.

Only one study could be found which included information level as a component of the meaning a child makes of their parent's illness. In a study of children in England whose parents were diagnosed with Inflammatory Bowel Disease, Mukherjee, Sloper, &

Lewin (2002) found that variation in age did not explain differences in understanding about their parent's illness. Although there was little consensus regarding accurate perceptions of illness severity, most of the children recognized the benefits of treatment and the social restrictions it brings. Further, most children expressed a desire for more information about their parents health and medical treatment. Potential avenues for acquisition included written information and the opportunity to talk with the health care professionals caring for their parents about the disease. Talking to friend was a limited option for social reasons. However, the children studied were reluctant to speak directly to the parent as it was deemed personally upsetting or embarrassing for either the child or parent. Similarly, there was a greater desire not to add to their parent's worries by asking questions or bringing up sensitive topics. As a result, children felt lacking in information about their parent's health and treatment as well as in the opportunity to connect with other children in similar situations. Although information was shown to be important in the meanings children associate with their parent's illness, the study focused solely on desired information with no link being made between meaning and actual knowledge about the disease or a consideration of overall knowledge level (existing and desired), avenues of information transmission or the reactions to the familial changes cancer brings. These additional variables contribute not only to the meaning children are able to make of the experience of their parent's cancer but may also have an impact on the ways in which they cope with the disease and the additional resources they possess or wish to possess for external support.

In Summary

Behavioral measurements of coping with a parental illness only begin to tell the story. Deeper than these assessments are the catalytic influences that precede the adoption of one coping strategy over another. One such unexplored variable is the role of illness knowledge in the ability to make meaning of the experience.

Evidence suggests that providing children with a certain amount of information in developmentally appropriate ways (without “talking down” to them) is beneficial for positive adjustment (ACS, 2002; Kazak & Barakat, 1997). It has been argued to help children understand and prepare for the changes that will occur within the family. At minimum, the American Cancer Society (2002) recommends discussing the type of cancer, where it is, what will happen during treatment and how it will affect the family. Failure to provide information “for the child’s own good” often results in the opposite result. Children may assume what is happening is too terrible to discuss and may experience increased stress.

Likewise, children whose parents have been diagnosed with an illness such as cancer will typically seek out information on their own in an effort to understand what is happening (Kalish, 1996). Therefore, involvement in discussions about a parent’s cancer, while initially causing more immediate distress, also represent unique opportunities to learn from a parent’s coping style (Korneluk & Lee, 1998). This can have important long-term benefits in the ongoing adjustment to the illness.

Children’s Knowledge of Illness

Although knowledge has been linked to more effective coping, children’s concept of illness is not a universal construct. The form and content of the acquisition can vary greatly. That is, children of different ages understand the causes and consequences of illness differently. Moreover, differing experiences with illness-related concepts can alter the developmental trajectory. Thus, research on children’s concepts of health and illness has been dominated by two distinct theories: developmental and functionalist approaches.

Traditional Developmental Approaches

Early studies of children’s conceptualizations of illness (Brewster, 1982; Brodie, 1974; Kister & Patterson, 1980) were Freudian, rather than Piagetian-based. They focused on interpretations of illness as punishment and the tendency of (young) children to self-blame (Beverly, 1936; Jensen, 1955; Langford, 1948). It was suggested that this conceptualization of illness was referential to parental admonitions about rule breaking and proper dress (Beverly, 1936; Langford, 1948). More recent studies (Brewster, 1982; Perrin & Gerrity, 1981; Simeonsson, Buckley, & Monson, 1979) have also considered illness-as-punishment as a component in children’s knowledge of illness. Kister and Patterson (1980) reported that kindergarten and first graders were more likely than fourth grade students to think a cold, toothache or scraped knee were the result of misbehavior. However, the prevalence of results in these studies may be skewed with respect to how the data was collected. While Gratz and Pilivan (1984) reported that 71% of kindergarten students believed that illness was caused by personal misbehavior, this result was not replicated when misbehavior was presented as one of many causal attributions (Hergenrather & Rabinowitz, 1991). Moreover, despite evidence to suggest that, in the absence of concrete causes, about half of the children with cancer were found to have constructed their own causal attributions which may or may not have been rational (Bearison, Sadow, Granowetter, & Winkel, 1993) these attributions were not, necessarily, related to self-blame.   This suggests that a psychoanalytic approach to understanding developmental changes in illness conceptualization may ignore the depth and breadth of understanding.

Currently, traditional research postulates age-related qualitative changes in children's concepts of health and illness and interprets these changes within a Piagetian framework (Brewster, 1982; Gratz & Pilivian, 1984; Kister & Patterson, 1980; Perrin & Gerrity, 1981). This research centers around the qualitatively different and invariant sequence of stages denoting the development of logical reasoning about causality and the ability to differentiate between self and other (Laurendeau & Pinard, 1962; Piaget, 1952; Werner, 1948). It postulates an increasingly biological understanding of illness and injuries (Williams & Binnie, 2002). Categories of reasoning range from the most rudimentary conception of phenomenism characteristic of preoperational thinking, where there is no clear differentiation between cause and effect, to the most sophisticated psychophysiological concepts, characteristics of formal operational thought, where there exists the integration of multiple causes and effects (Bibace & Walsh, 1979; 1980; 1981).

From this perspective, it is generally accepted that concepts of illness presented by preoperational children are undifferentiated, logically circular and superstitious (Bibace & Walsh, 1980; Brewster, 1982; Perrin & Gerrity, 1981; Redpath & Rogers, 1984; Simeonsson, et. al., 1979). They are based primarily, if not exclusively, on obvious features where illness is a characteristic set of symptoms and being sick is the experience of some physical (e.g. runny nose), psychological (e.g. pain) or social (e.g. not going to school) effects (Kalish, 1996). Children younger than seven years old are presumed to be incapable of the cognitive competence necessary to reason theoretically about illness processes such as contamination and contagion (Bibace & Walsh, 1980; Brewster, 1982; Gratz & Pilivan, 1984; Kister & Patterson, 1980; Perrin & Gerrity, 1981). According to such postulations, discussions of medical procedures and their efficacy with five-year old children are most developmentally appropriate when they are focused on the observable, external events they will experience (Bibace & Walsh, 1981) rather than on issues of illness causation. The sources of symptoms are not understood and are, often, ascribed to such phenomenalistic processes as immanent justice (Bibace & Walsh, 1980; Perrin & Gerrity, 1981) or are relegated to a single cause for all illness (Hergenrather & Rabinowitz, 1991). Their lack of abstract reasoning represents a qualitative difference in their knowing. Neuhauser, Amsterdam, Hines, & Steward (1978) reported that children's explanations of visible, external conditions, such as cuts, were more logical than their statements about internal conditions. As a result, few children were able to describe the process of recovery in internal illnesses as opposed to external ones.

Concrete operational children conceptualize illness in ways that are more specific and related to common ideas about illness in a limited univariate manner (Bibace & Walsh, 1980; Perrin & Gerrity, 1981). Formal operational children seem to understand generalized principles of infection, health maintenance and treatment (Bibace & Walsh, 1980; Brewster, 1982; Simeonsson, et.al., 1979). Further, Natapoff (1978) found that first, fourth, and seventh graders were more likely to describe health as a positive consequence rather than a lack of illness. Only older children were able to comprehend that a person could be, simultaneously sick and healthy. Symptoms are considered evidential rather than definitive such that the causes of the symptoms begin to be considered. In younger children, such a consideration of symtomatology is absent.

In one of the earliest studies of this developmental understanding of illness, Bibace and Walsh (1981) distinguished six types of formal illness explanations corresponding to the prelogical, concrete logical and formal/abstract logical periods of cognitive development. Similarly, consistent with Piaget's (1930) clinical method, responses were elicited without directive probing. Their findings indicate the attempt by children in this age range (four to eleven years) to assimilate the experience of their own or other's illness into their cognitive schemes. In younger children there was a higher prevalence of phenomenism where illness is understood as an external concrete phenomenon which is spatially and temporally remote from the conditions of the illness, such as from God. Contagion-type explanations where illness is caused by people or objects proximate to, but not in direct contact with the child, were found in 54% of four-year old children, but were absent in the older populations. However, in accord with research by Hergenrather and Rabinowitz (1991), contagion was conceptualized in terms of proximity (someone near them) rather than infection transmission. Contamination-type explanations where illness is caused by people, objects or actions that are external to the child and are transmitted by physical contact or harmful action such as getting a cold from not wearing a hat outside, were present in 38% of four-year olds, 63% of seven-year olds and 54% of eleven year olds. There were internalization-type explanations offered where illness is understood as a process of internalizing the illness through swallowing or inhaling the germ. Physiological-type explanations where illness is understood as the malfunctioning of an internal physiological organ or process and is explained by a sequence of events such as a virus, were present in 8% of seven year olds and 34% of eleven year olds. Psychophysiological-type explanations where the child can conceptualize the physiology but also considers the thoughts and feelings of the ill such as the ramification of having a heart attack, are only given by eleven year olds.

These findings have subsequently been replicated in studies by Potter and Roberts (1984) and Young, McMurray, Rothbery, and Emery (1987). As children develop cognitively, their understanding of illness becomes more complex, more related to internal body cues, more differentiated in terms of specifics, symptoms and causes and more dependent on process (causal) types of relationships. Further, they begin to understand illness as less of a chance occurrence and develop a greater sense of control over illness due to an increased reliance on internal cues (Beales, Lennox-Holt, Keen, & Mellor, 1983; Campbell, 1975; Hergenrather & Rabinowitz, 1991; Kister & Patterson, 1980; Neuhauser, et.al., 1979; Perrin & Gerrity, 1981; Perrin & Perrin, 1983; Redpath & Rogers, 1984). That is, younger children discuss illness in terms of external, egocentric aspects such as symptoms while older children describe illness as an internal process (Bibace & Walsh, 1980). There is also a tendency for older children to discuss illness with greater specificity and consistency with scientific and prevailing cultural beliefs (Simeonsson, et.al., 1979). Brewster (1982) found that the majority of seven to ten year olds believed all illnesses were caused by germs and that the individual bore no responsibility for becoming ill. Similarly, in reference to contagions, most seven to eleven year olds believe all illnesses, including scraped knees and toothaches were contagious (Bibace & Walsh, 1980; Kister & Patterson, 1980). Similarly, Gratz and Pilivian (1984) reported that 58% of kindergarten students and 88% of fourth and fifth grade students believed all illnesses were contagious.

Redpath and Rogers (1984) note that preschoolers use restrictions on activity to describe the nature of illness. Further, Perrin and Gerrity (1981) report that kindergarten and second grade students understood personal illness only when illness had a behavioral impact such as having to stay in bed. As a result, health was defined as a state facilitating certain behaviors such as the ability to play with friends or go outside (Natapoff, 1982). These ideas about behavior also impacted conceptions of medical treatment. Brewster (1982) reported treatment as punishment in a study of five to seven year olds. This was replicated by Perrin and Gerrity (1981) who argued that, within this same age group, recovery was postulated as the direct result of having adhered to certain social rules about proper behavior. By age nine, however, studies suggest that children’s concept of illness causality include ideas about the correlation between symptoms and the experience of illness (Beales, et.al., 1983; Neuhauser, et.al., 1978; Perrin & Gerrity, 1981), contagion and infection (Brewster, 1982; Simeonsson, et.al., 1979), the malfunction of internal organs or systems (Beales, et.al., 1983; Bibace & Walsh, 1980; Perrin & Gerrity, 1981), behaviors, attitudes and feelings (Bibace & Walsh, 1980; Campbell, 1975) and the role of the body, medications and other treatments in recovery (Brewster, 1982; Perrin & Gerrity, 1981). Health care professionals, as a result, are often confronted with young children with irrational ideas about illness and bodily functions and adolescents who are concerned with factors that are irrelevant or contradictory to health-related concerns, such as body image (Bearison, 1998).

Though never completely paralleling the more basic type, as children acquire more knowledge, the concepts that frame their understanding about the consequences of illness are transformed. Accordingly, children's conceptions of illness causality follow a developmental progression paralleling the increasing sophistication of general cognitive abilities, moving from circular, egocentric reasoning where there is a tendency to somatasize emotional experiences due to an inability to separate their (the child's) body from that of the patient, to more consistent, abstract logical thinking pertaining to the concerns faced by the patient (Kury & Rodrigue, 1995). In a study by Banks (1990) the efficacy of a developmental approach to knowledge of illness was tested. Through a drawing activity which asked children to concretely represent a germ and discuss illness causality, older children were not significantly more likely to give reasons based on personal actions or responsibility for illness. For example, older children described the symptoms of a cold and the specific sensory properties associated with taking medicine while younger children described colds as "being sick" and the necessity of taking medicine to "feel better". However, the progression of germ images did correspond to traditional developmental descriptions. That is, interview questions about germs progressed from identifying germs as bad to more biologically accurate answers.

However, despite the logic of these arguments, cognitive developmental explanations cannot fully account for the role of exposure to and experience with an illness. In a study by Kalish (1996), preschoolers' level of understanding of illness was not limited to symptoms or obvious features. Children were able to take into account the causes of underlying, observable symptoms and indicated that not all illnesses were contagious or caused in the same way. As Wohlwill (1973) suggests, cognitive development is considered as seemingly independent from specific knowledge about health or illness. As most studies were conducted using arbitrary, decontextualized illnesses such as AIDS (Bank, 1990; Kalish, 1996; Osborne, Kistner, & Helgemo, 1993) or obesity (Johnson, et.al., 1994), the effects of the child's environment were not considered. Moreover, a lack of consensus regarding reliable criteria for determining which behaviors indicate which type of operational thought in the domain of illness knowledge and the confusion of domain-general inferential abilities with knowledge in the specific domain (Hergenrather & Rabinowitz, 1991) limits the applicability of traditional developmental approaches. That is, developmental approaches do not consider the logic behind these assumptions or the reasons for the differing types of knowledge children may possess.

In Summary

Traditional developmental research of children's general illness knowledge focuses on age-related, qualitative changes in understanding. These typically are encompassed within either a Freudian framework, where illness is thought of as punishment and children engage in self-blame (Brewster, 1982; Brodie, 1974; Kister & Patterson, 1980) or a Piagetian framework, where concepts of illness develop from rudimentary conceptions without cause and effect to phenomenistic ones with multiple causes (Gratz & Pillivian, 1984; Brewster, 1982). These age-related changes in cognition move illness from being encased in circular, egocentric reasoning, with illness as a set of symptoms, to consistent abstract logical thinking with an increasing ability to comprehend generalized principals of infection, health maintenance and treatment. However, these studies fail to account for experiences with and exposure to actual illness and focus, rather, on more global illnesses such as colds or more remote illnesses such as AIDS (Williams & Binnie, 2002; Kalish, 1996).

Functionalist Approaches

Alternative functionalist theories (Eiser, 1989) place more emphasis on the role of experience and do not assume such a structural restriction on children's cognition. Their concerns are not hypothetical or arbitrary and their knowledge continually needs to be adjusted to meet the demands of their subjective experience. Repeated experience and education may lead to more advanced reasoning regardless of age level. Studies suggest that a series of domain-specific experiences may serve to modify the cognitive framework of understanding illness causes and effects allowing children to construct coherent theories of disease (Carey, 1985; Keil, 1989; Sigelman, Maddock, Epstein & Carpenter, 1993). These studies have mainly focused on children with illness whose more sophisticated illness concepts are due to more frequent personal contact with aspects of the disease including greater opportunity for medical education and discussion regarding illness etiology. However, they have produced conflicting findings.

Williams (1978) found that hospitalized children had a better understanding of illness causality. Pediatric patients often appear unusually savvy and knowledgeable about medical procedures and illness. Their active struggle to make sense of their illness has contributed to a more sophisticated understanding of complex medical procedures and medication effects (Bearison, 1991a; Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969; Bluebond-Langner, 1978). In a study of pediatric asthma patients by McQuaid, Howard, Kopel, Rosenblum, and Bibace (2002), this increased conceptualization was due to the child's priming for observation of cause-and-effect associations, leading to more frequent use of preventive strategies for asthma management. Similarly, Sanger, Sandler & Perrin (1988) found that children who perceived greater control over their health had a more sophisticated understanding of disease. Thus, the level of abstract reasoning needed for a child to think of illness management in terms of prevention may have nothing to do with their chronological age. An ill child’s ability to recognize and understand the clinical implications of their symptoms depends on factors beyond their level of cognitive development. These include their methods of coping, sense of self-efficacy and level of anxiety (Fritz, Spirito, & Young, 1994).

In contrast to these findings, however, Brodie (1978) argued that children who are ill were more likely than healthy children to describe illness as a consequence of doing something wrong. Healthy children also scored higher, in general, on illness concept questions and expressed significantly more internal locus of control beliefs than children with chronic illness (Sayer, Willett, & Perrin, 1993). Health controls were also found to have higher concepts of illness regarding common experiences such as colds when compared with those they have not personally experienced (Johnson, Schofeld, Siegel, Krasnovsky, Boyce, Saliba, Boyce, & Perrin, 1994). In certain cases, previous medical experience has been shown to lead to less mature illness concepts (Peterson & Harbeck, 1988) suggesting that, in certain cases, the stressful nature of the illness for children causes them to think even less about illness in general. Subsequently, the developmental disruptions caused by illness and hospitalization, may retard illness conceptualization as well (Myers-Vando, Steward, Folkins, & Hines, 1979).

Bearison (1998) argues that, overall, more recent approaches to illness knowledge in children have displayed a greater appreciation that the children's experiences in specific domains often result in striking developmental changes irrespective of those predicted by their basic cognitive processes. One such approach to this is the use of script knowledge to study children's understanding of their medical problems and treatment. Script knowledge in cognitive psychology refers to a child's knowledge of recurring social events and is organized around schematic representations of generalized and temporal sequences of socially contexted activities leading to the attainment of particular goals (Mandler, 1983; Nelson, 1986; Schank & Ableson, 1977). The "What happens when….." questions that are typically used in this type of research target conceptual knowledge in its direct experience and yield more differentiated information (Bearison, 1998). In a study conducted by Bearison and Pacifici (1989) on script knowledge for outpatient chemotherapy in pediatric populations, while all children, including those as young as four, presented scripts that were temporally sequenced, the scripts of older children contained more procedure-related events and were presented with greater consistency across time, topic and subjects. However, by age seven, scripts are well established and there is less of a gap between the recall and organization of knowledge between younger and older groups. Discrepancies between age groups have been explained through differences in episodic memory such that three year olds provide less information in response to open-ended questions regarding the components of a routine physical examination (Baker-Ward, Gordon, Ornstein, Larus, & Clubb, 1993; Clubb, Nida, Merritt, & Ornstein, 1993) than older children. Similarly, these studies found more forgetting among three year olds than seven year olds. However, this may have been due to the level of severity of the event in question. In a study of the more aversive voiding cystourethrogram (VCUG) procedure, Merritt, Ornstein, and Spicker (1994) found that 88% of three to seven year olds were able to recall the elements of the procedure accurately both immediately and six weeks post-procedure. After testing cortisol levels for biological stress reaction, they concluded that the perception of stress by the child contributed to their recall more than their physical stress reaction to the procedure. This has important implications in situations where the illness is not the child's.

To date, however, research has not sufficiently documented children's illness concepts as a function of their previous medical experience mediated by illness duration, frequency of hospitalization and degree of life threat. Even rarer are those studies of indirect experience with illness in the form of a parental diagnosis over which children have no control and the accompanying influence of perceived stress in situations where there is minimal transmission or discussion of information.

In Summary

In contrast to more traditional developmental approaches, functionalist theories emphasize the role of experience with illness without the structural restrictions on cognition. They are based on the premise that the more experience one has with illness, the more advanced one's reasoning will be. As a result, children modify their cognitive framework, irrespective of age, to fit their experience. However, these studies tend to focus on children who are, themselves, ill (Bearison & Pacifici, 1989; Sayer, et.al., 1993) and utilize script knowledge and perceptions of control within the situation.

Thus, the dichotomous choices presented by both traditional and functionalist approaches to children's illness knowledge severely restrict the stories told. Moreover, they do not allow for a study of indirect experiences with illness such as those presented by a parental diagnosis of cancer. A story yet to be told is that of a child's experience with an illness without personal control and within which information transmission may be minimal.

The Present Study

Study Rationale

Levels of coping in response to a parental illness such as cancer may be mediated through the depth of the child's knowledge about the disease and the misconceptions they hold. That is, before one can analyze how the disease affects the child, it seems essential to ascertain what the child knows about the disease. To date, most studies of concepts of illness, in terms of Piagetian stages, have focused either on global illnesses such as colds or remote illnesses such as AIDS in the developmental literature (Williams & Binnie, 2002; Bank, 1990; Kalish, 1996). Conversely, those that subscribe to the experience paradigm focus solely on children with illnesses such as asthma, diabetes or cancer (McQuaid, et.al., 2002.; Bearison & Pacifici, 1989; Harkavy, 1985). Little has been done which focuses on children's knowledge of illnesses which are contextual, but not necessarily personal, such as a parental diagnosis of cancer. Similarly rare are those studies which consider this variable's impact on the experience children have with and the meanings they make of a parental diagnosis of cancer.

Many children are treated as tangential to or even excluded from their parent's treatment plans. This experience can be exacerbated by a lack of communication regarding illness information between children and their parents after a parental diagnosis of cancer has been made and treatment is ongoing. In the absence of this type of communication, the parental diagnosis of cancer is subject to the elephant in the room phenomenon. It permeates the family in profound ways but is rarely acknowledged and, often, forcibly ignored. However, this phenomenon cannot be understood as solely contingent upon communication within the family system. Both children's existing and desired knowledge of parental illness, either in conjunction with or apart from that directly imparted by their parents must also be addressed. Within this frame lies a story mostly disregarded in reductionistic studies that present causal or correlational explanations for a child's experience of their parent's illness. Only through a more complete narrative approach it is possible to understand both how children actualize the elephant and, more importantly, the impact of this meaning making on their psychological adjustment and mental health as they continually cope with reality of change the illness necessitates.

To date, there are no established guidelines for the support of children whose parents are seriously ill despite evidence to suggest that greater empathy and support from friends, as reported by mothers with breast cancer, was associated with fewer endorsed depressive symptoms in children (Brown, et.al., 2007). That is, there are limited places within which children can tell their story and exercise their unique voice in the experience of their parent's illness.

This study corrected these oversights and filled several gaps in the existing literature by exploring what children understand about their parent's cancer and the role it plays in their ability to derive meaning from the experience. It was innovative in six ways.

1. *The study used direct information about an illness that afflicted a parent and made a connection between meaning making as it relates to coping with the illness and knowledge about the illness.*

Studies of young children's understanding of illness have either focused on arbitrary diseases such as colds or AIDS (Kalish, 1996; Bank, 1990) or have been targeted to children personally dealing with the illness (that is, children with cancer or children with diabetes) (McQuaid, et.al., 2002; Bearison, 1998; Sayer, et.al., 1993; Bearison & Pacifici, 1989; Sanger, Sandler & Perrin, 1988; Harkavy, 1985). There are, as yet, no studies which ask children for direct information about an illness which afflicts their parent. Those which include information as a variable, such as the study by Mukherjee, et. al. (2002) focus on children's desired information regarding their parent's illness and make no connection between meaning making as it relates to coping with the illness and actual knowledge about the illness.

In studies of children coping with nonmetastic breast cancer (Issel, Ersek, & Lewis, 1990; Lewis, 1990; Lewis, et.al., 1993; Northouse, 1995), children were shown to use a wide variety of coping techniques including attempting to adhere to their normal routine, avoiding thoughts about cancer and being considerate or helping out at home. Further, the type of coping strategy employed by children was shown to be related to children's social-peer adjustment (Lewis, et.al., 1993). Research by Compas, et.al.(1996) revealed that the use of avoidant coping strategies in response to a parental diagnosis of cancer was ineffective in managing the child's emotional distress. Similarly, it was related to more avoidant thoughts and more symptoms of anxiety and depression. Thus, the use of avoidant coping strategies initially employed as an attempt to disengage from the stress, in reality, exacerbated it.

Overall, however, there is limited research on children's coping at the time of diagnosis, as many studies are conducted several months or years after the initial diagnosis. Further, the motivations for the strategies the children chose to employ remain unexplored as most studies focus only on self-reports of strategies used. When considering evidence that, in any given situation, children will employ multiple strategies in response to stress (Forsyth & Compas, 1987; Frydenberg & Lewis, 1994), there is growing interest in the variables, underlying specific coping strategies, which distinguish poorly and well-adjusted children of ill parents (Issel, et.al., 1990; Northouse, 1984; Pederson & Valanis, 1988). Such an unexplored variable is the child's level of knowledge about their parent's illness and the means through which the information was acquired. Accordingly, this necessitates movement beyond coping strategy as a factorial variable and toward a conceptualization of coping as a narrative category that dynamically interacts with level of knowledge as it frames the story being told.

2. *The study used semi-structured interviews that not only targeted what the children knew and wanted to know but, also where children were getting their information.*

Most studies on the impact of parental illness on children adopt a quantitative approach by measuring children's psychosocial adjustment as an outcome. This study allowed the entire spectrum of experiences which contribute to this adjustment to be considered and analyzed in a more narrative manner in order to illuminate the child's comprehensive story as they present it. As Daiute and Nelson (1997) suggest, stories not only individuate the general script of having a parent with cancer in terms of the changes in family life, they also allow children to evaluate the events within the narrative form from the point of view of the narrator. This was a child's story in their own voice.

3. *The study applied a narrative method of analysis to non-narrative data generated by the children.*

Narrative inquiry was incorporated into the study in a variety of ways. The individual and group-written charts present an opportunity to explore a specific type of situated knowledge. A parental illness is pervasive in children's lives, but this population (ages seven to twelve) is rarely presented with the opportunity to voice its impact. This research attempted to elevate their forgotten experience (Troutt, 2004) by using a narrative lens to interpret information about their existing and desired knowledge of their parent's illness. It contextualized a childhood lived within these particular, albeit extraordinary, circumstances and empowered the children by establishing them as the storyteller (Bearison, 1991a) and, by extension, an object of importance. Narrative method transcended the conceptualization of knowledge as correlated bits of information and, rather, presented as a story of the experience of parental cancer and the meanings children make. Moreover, through the use of individually written and group constructed charts, it was possible to study the differences between the public and private meanings children made of their experience. It revealed the tension between fitting in and expressing personal identity (Daiute, 2003). Individual charts allowed for a personal exploration of the experience, which when asked to be shared, created a conversation where information could be privileged or hidden. Using a narrative approach allowed for a more complete understanding of the individual interpretation of parental cancer and the image children chose to present to others.

4. *This study focused on school-aged children (aged seven [7] to twelve [12]), a mostly unexplored population in parental illness studies.*

In this way it balances the available literature, which tends to focus on adolescent populations (Compas, et. al., 1996; Compas, et.al., 1994). Although cognitively susceptible to developmental changes, these children are also influenced by indirect experience with and exposure to an illness they have no control over. It is believed that many of the difficulties experienced by these children, due to the, at times, more chronic nature of the disease, are averted through the understanding of what the child knows about the cancer, the misconceptions that they hold and the lingering gaps in the quality of the information.

5. *There were no restrictions about the type of parental cancer or treatment protocols.*

This allowed for a preliminary assessment of knowledge across the range of illness manifestations, treatment and progressive depths of understanding. Further, by utilizing a more narrative approach, it was possible to determine both individual and more universal experiences with parental cancer in general.

6. *The study was conducted within a group setting, focusing on both existing and desired knowledge.*

This normalized the experience for the participants, such that there was a recognition that other children were dealing with similar issues in their lives. Moreover, the group allowed for a more comfortable setting, in which children were also able to help each other and work in collaboration. Daiute (2004) suggests that, while all storytelling may involve soul-searching, it is also a performance such that the audience influences the narratives. By incorporating both individual and group-constructed activities, the format allowed for an exploration, not only of the experience and meaning made of parental cancer but also of those elements not included when the story is made public.

Further, traditional intervention programs, despite containing psychoeducational and therapeutic components are largely focused on the cancer patient (Berger, 1994; Christ, Siegel, Messagno, & Langosch, 1991; Greening, 1992; Taylor-Brown, Acheson,

& Farber, 1993). The concerns of children and other family members are, often, addressed in an ad hoc manner by social workers, physicians and other medical staff (Greening, 1992; Taylor-Brown, et.al., 1993; Walsh-Burke, 1992). They are designed to help the ill parent manage changes in roles and routines, reconnect within the marital relationship and address parenting responsibilities (Christ, et.al., 1991; Greening, 1992; Johnston & Martin, 1992; Walsh-Burke, 1992; Wright & Leahey, 1994). However, in the absence of child-reported information about how they are currently experiencing the illness and what they feel they need to understand to improve coping, such interventions, ultimately, prove ineffective.

Moreover, many existing groups that target the specific needs of children are designed solely for children with terminally ill or deceased parents (Call, 1990; Christ, et.al., 1991) and focus on factors pertaining to anticipatory grief or coping with the changes loss brings (Adams-Greenly & Moynihan, 1983; Black & Urbanowicz, 1987; Siegel, Mesagno, & Christ, 1990). However, in hindsight, limiting these needs to children whose parents have succumbed to their disease ignores the parallel needs exhibited by those children experiencing the daily, living loss a cancer diagnosis incurs.

Thus, an invaluable mechanism to correct these oversights is a group specifically designed for children whose parents have cancer, in which they can share their stories and experiences with similar others and bring these issues to the forefront. To date, however, research on the efficacy of support groups for children conceptualizes the group as a variable and focuses on outcome measures. There are few studies that use the group as a tool to facilitate an understanding of the broader experience of parental cancer. Moreover, information about the parent’s cancer is viewed as a singular thematic element, within the group curriculum and is rarely considered on its own. It is, typically, discussed in terms of what the child currently knows and with an eye toward the clarifications of misconceptions by group facilitators. There is little or no understanding of a child's self-reported desired knowledge or the mechanisms, outside the supposed family unit, where knowledge is ascertained and how this impacts the story told.

In providing a specialized venue for children to present and share their stories, this study was able to actualize the hidden transcripts of this, often, overlooked population and bridges the literature on knowledge of illness, adjustment to parental cancer and support for children in these circumstances.

A New Approach

The design of this study served as a bridge to connect literatures on knowledge of illness, adjustment to parental cancer, family adaptation to traumatic life situations, the role of communication in the parent-child relationship, and the potential support avenues children utilize in their quest for understanding and meaning making. Children only have a voice when they are confident in the language they speak with. Thus, although confronted with the elephant on a daily basis, they have no vocabulary with which to communicate with it and no voice to prompt delivery, making them especially vulnerable. There is an assumption of the child as subordinate; one whose will cannot be equal to the adults who act in their "best interests". As a result, their needs are assumed, often, with historical reference to what worked in past generations and with little consideration for the relevant context of a changing world. Herein lies the central challenge for children's research: to actualize this actively hidden transcript (Scott,

1990) and replace the passé public persona associated with children living with traumatic life circumstances.

With respect to the present study, both individual writing activities and group constructed charts were used to better understand this hidden transcript. Although the activities did not ask the children to construct a narrative in the classic sense, with prompting questions such as *“What is it like to have a parent with cancer?”*, the elements constructed in the written charts did provide evidence of the story of the experience. Specific aspects of their knowledge, as reported by participants, framed the story being told and, by combining an analysis of individual and group-constructed charts, allowed personal meanings to be compared with that chosen to be shared with the group. Further, by utilizing a narrative approach to interpret the data, it was possible to understand the realm of experience as presented by the participants. The hidden transcript reflected not only the children’s level of knowledge about their parent’s illness, but concerned the entire family environment. Cancer is not an event which happens to families it is a dynamic activity which forever changes and is changed by the family it affects. It is a dance of uncertain steps with an unknown partner. This presents a significant challenge for any child, especially since they are often silenced by the circumstances that surround them and the preconceptions about what they can handle “at their age”. There exists a need to listen more actively to their experiences within their specific context as well as recognize the significance of their silences; and to draw from the raw narrative the truest voice possible to preserve not only the experiences of these children but to capture their intentions and meanings, and, most importantly, their spirits. It is an exercise in truly entering the child’s world and seeing it through their eyes (Bruner, 2002).

Research Questions

The specific aims of this study are:

1. To examine what children know about their parent’s cancer and explore the information they desire to know
2. To identify how children come to knowledge, if not directly communicated to them by their parent(s).
3. To understand the role of type of information known and where the information was garnered in a child’s process of making sense of a parent’s illness.

Method

Pilot Study

A pilot study conducted in 2006 utilized one-to-one semi-structured interviews with seven preadolescent children ranging in age from seven years, three months to eleven years, six months. Three mothers had breast cancer, Stage 1 and four fathers had colon cancer, Stage 3. All participants completed written Know and Want-To-Know charts focusing on both existing and desired knowledge of parental illness, with specific reference to parental cancer. Further, information regarding where they did or could obtain this information was generated.

Overall, existing and desired knowledge of the medical consequences of a parent's cancer was found to be paramount. That is, both existing knowledge and desired knowledge skewed significantly toward medical themes. However, there were subtle differences in the quality of medical statements. Existing knowledge of a parent's cancer tended to focus on tangible aspects of the disease such as hair loss and physical illness or exhaustion, whereas desired knowledge focused on a need to understand medical procedures and the logistics behind the treatment names (chemotherapy and radiation) the participants were familiar with. Statements included: *"What happens at the hospital?"*, *"Why are shots necessary?"* and *"What kind of medicine do they (parents) receive?"*

Of equal importance was the desire to understand the emotional impact of cancer on their parent. Statements focused on the possibility of death from the disease and the concerns their parent may have regarding the effectiveness of doctors and treatment protocols. Knowledge of the emotional impact of their parent's cancer was discussed in conjunction with how this emotional state affected changes in routine, which were never more than delineated.

A significant interaction between existing medical knowledge of their parent's cancer and both stage and prognosis was determined. Parents at a more advanced disease stage and those who reported a poorer prognosis had children who reported more existing medical knowledge.

Beyond exploring levels of existing and desired knowledge, the study also considered the means by which children obtain information about their parent's cancer. All of the participants in the study reported discussing the disease with their parents and named family as their primary source of information. However, participants also reported accessing Internet sites to gain additional, more medically laden, information. There were also reports of the use of observation as a means of gathering information. The impact of this technique was evident in the desire to understand the emotional reactions they were witnessing. Although no significant effect was found, participants also reported having spoken to medical staff about their parent's cancer.

However, as this study was a needs assessment and the results were merely exploratory, no connection was made to the impact of these results on coping with the disease within the child's individual experience and the story to be told. Nor were any generalizations about the role of information in adjusting to a parental diagnosis of cancer made.

Overview of Present Study

This study elicited information about children's existing and desired knowledge of family illness, with specific regard to the story of that experience and the meaning making associated with a parental diagnosis of cancer. Information was ascertained through participation in a structured group program. Globally, Au, Romo, and DeWitt (1999) argued that peer group discussions offer a promising approach to improving children's illness knowledge. Conceptual change is, often, induced by participation in goal-directed activities and enhanced by discursive processes in a group (Hatano & Inagaki, 1997). Williams and Binnie (2002) suggest that such improvements are most evident when groups provide children with a mixture of practical experience, factual information and peer group discussion. Children and adolescents whose parents are ill benefit from seeking such support from similar others and sharing experiences, yet few studies have been published regarding interventions specifically designed for children of cancer patients according to these recommendations.

Kids Can Cope (Taylor-Brown, et.al., 1993), one of the first group interventions designed for children and teenagers (ages five to eighteen) whose parents have cancer, stressed the need to learn about the disease and its treatments as well as to provide opportunities to share feelings in a safe environment with similar others and to increase a child's repertoire of coping strategies. Thematically, it focused on the similarities between members, revelations of misconceptions about the cancer and specific developmental concerns. These were accomplished through developmentally appropriate activities and structured discussions. The six, weekly, after-school sessions were divided into ones that built trust and cohesion within the group and allowed for an assessment of the child’s understanding of their parent’s cancer and those that provided information about the physical aspects of the disease and its treatment, including individual fears about death and the unpredictable and unstable nature of the disease. Children were provided with hands on experiences in cancer clinics to better understand the treatment procedures their parents were undergoing. Yet, the structure of the programs continued to be dependent upon assumptions of what children dealing with parental cancer need. There was no attempt to ascertain what was important to the children or whether the activities corresponded to genuine gaps in their understanding. Moreover, the focus was on logistical and medical elements, an area the pilot study determined to be in ample supply and of minimal concern.

The present study addressed those concerns by modifying both the format and content of the groups. Groups consisted of school-aged children aged seven to twelve with varying parental cancer diagnoses. Groups met over two, consecutive, one-hour sessions and included structured individual and group activities and open group discussion of topics. Beyond knowledge of illness factors, modes of information transmission and issues of general coping strategies, as well as those pertaining to the parent’s illness, were explored. Children were provided with ample opportunity to explore their experiences and share their stories and to relate to the stories of others in a collaborative joining of ideas and opinions.

Information obtained through the group activities was coded and analyzed qualitatively to ascertain each child’s individual experience and to understand general themes in children’s experiences of their parent’s cancer. This allowed for a more complete understanding of the role of existing and desired knowledge in how children cope with the illness as well as potential avenues for intervention where desired knowledge can be obtained. As this was also a collaborative exercise, the interactions between children in the group discussions were of invaluable assistance in providing a more applicable picture of their experience.

Participants

The K.I.P. Program (Knowledge Is Power) is a two session structured group offered to children aged seven to twelve years who are currently dealing with a parental diagnosis of cancer. Participants were recruited through the Archdiocese of New York, using fliers posted in church bulletins, and from referrals from social workers and those who work within an oncological population. Twenty-five participants were invited to participate and groups varied in size from three to five participants, depending on participant availability.

Families who met the following criteria were included in the study:

Family Demographic Criteria

1. Families, with at least one child, living in the New York City metropolitan area, in which one parent has been diagnosed as having cancer. (*Note: For families with more than one child in the targeted age group living in the home, and who each desired to participate, siblings were placed in separate groups.)*
2. Participants must be English-speaking
3. Child participants must be between the ages of seven and twelve years old.

4. Families in which there is an additional family member with cancer, such as a sibling or grandparent, or where a family member has recently died from the disease, were not included in the study.

   These exclusionary criteria were meant to minimize possible confounding variables and assure that all participants began with the same general knowledge base

Parent Medical Criteria

1. A formal diagnosis of cancer (not an initial biopsy) in Stages 1-3, where treatment for the disease is currently being received. Participation was not dependent upon sex of the parent or type of cancer.

   By omitting Stage 0 (non-invasive) cancer, it was possible to assume active treatment for the disease as well as familial coping with the illness on a daily basis. This also allowed for an exploration of degrees of severity of illness as perceived by children. By excluding participants in Stage 4, immanent death was removed from impeding on perceptions, as the focus of the study was on families living and actively coping with the disease, not on children actively preparing for the death of a parent. Further, the range of cancers and gender correspondence between ill parents and children allowed, not only for an exploration of similarities across children, but, also, introduced gender congruency as a possible moderating variable.

2. Must be initial malignant diagnosis. That is, this should not be a relapse for the parent or reoccurrence of a second cancer.

3. At least two months post-diagnosis. Parents should be receiving treatment on a, primarily, out-patient basis.

    A time lag of two months following diagnosis allowed for reasonable certainty that the first cycle of treatment was either fully completed or near completion. This also allowed for a period of adjustment within the family and the potential for information acquisition that would not have been afforded immediately following the diagnosis. Further, primarily out-patient treatment assured that the ill parent was still living at home with the child on a daily basis. This removed the possible confounding effects of disruption in life routine, as the child was not dealing as consistently with the prolonged physical loss of the parent.

4. The other parent should be healthy and also reside full-time with the child. That is, this parent should not have a chronic illness for which they are also receiving treatment or for which extensive hospitalization is necessary.

    This allowed for a more focused exploration of children's knowledge of illness as only a single parental illness could be isolated and analyzed. Further, it removed the possible confounding effects of dealing with issues of divorce or separation.

Procedure

Recruitment of Participants

Interested families were asked to contact the principal investigator to determine whether they met the eligibility criteria. Those who did not meet the criteria were thanked for their interest and provided with references to resources for families adjusting to a parental diagnosis of cancer.

Once eligibility was determined, an invitation to attend the group was provided to the family including the location of the group meeting and dates and times of sessions. At this time, consent letters were provided to both parents and participants. Written parental consent for each child's participation was obtained. Prior to entrance into the group, parents were also asked to fill out and return basic background information forms. These forms contained basic and emergency contact information, the names of those individuals with permission to pick up the child from the group and any allergies or conditions the child may have which the principal investigator should be aware of. Further, information regarding the nature of the diagnosis, stage, treatment protocol and length of time since diagnosis were obtained using these same forms. An assent form was, similarly, sent to child participants requesting their agreement to participate in the group. In instances where a child refused the invitation to participate, even if parental consent was obtained, the family was thanked for their interest in the study and provided with the aforementioned list of additional resources. Consent, assent and demographic information forms were returned by parents at the initial session of the group.

The **K**nowledge **I**s **P**ower (K.I.P) Program

The K.I.P. program is designed to use existing and desired knowledge of parental cancer as a way to understand children's experience of a parent's illness. To accomplish this, groups were structured to include activities designed, specifically, to address the aims of the study and children were required to attend both sessions. Each session lasted approximately one hour and included both individual and group activities and collaborative discussions reflecting children's individual experience as well as opportunities to explore collective experiences generated by the presence of the illness in the family. Delineation of and elaboration on coping strategies with reference to existing or desired information was also considered.

Groups were conducted in a well-lit space with participants gathered around a circular table. This allowed each participant to view and be viewed by every other and established an equalizing environment. The principal investigator, who also acted as facilitator for the groups, was seated among the participants within the circle. This was meant to address the power issues inherent in an adult facilitating a group for children and to negate the assumption that the facilitator was the central figure in the room. Everyone was given equal respect with reference to status and power. Moreover, beyond the table and activity materials, there was minimal distraction within the room. This ensured that participants would be able to focus on the tasks before them and be fully present in the experience.

Upon entrance into the program, each participant was presented with a comprehensive workbook and provided with writing implements and all additional materials required to complete the activities, such as chart paper and markers. Sessions began with a review of the *Group Rules* (Appendix A) which included turn-taking and openness to all opinions and ideas and which were phrased in developmentally appropriate ways. Most, importantly, emphasis was placed on confidentiality within the group. A *Confidentiality Contract* (Appendix B) was signed by each participant at the initial session and held by the principal investigator. All subsequent sessions stressed the importance of not sharing information that was not your own outside the group as well as confirmation that the principal investigator would not share group information without the express permission of the child or unless there was a danger that the child was being harmed, was in danger of harming themselves or others.

The group sessions were structured as follows:

Session I: The Changes in My Family.

Upon arriving to the group, members introduced themselves and shared their reason for participating in the group. Prompting questions such as *"Tell me about your family"* were used to establish rapport, elicit information from children who may be reluctant to share and facilitate participant comfort with the group format. Similarly, this showcased their parent's illness and the discussions to follow as parameters of their personal experience rather than aberrations or pathological precursors. Further, it allowed for a notation of whether the child spontaneously addressed their parent's illness in conversation. As Bruner (2002) suggests, this allowed for a better understanding of the subjective experience of the child, by noting what they chose to discuss in reference to their current family situation as well as the subjunctive experience of how comfortable they were discussing the illness, in terms of the spontaneous importance they gave it in the informal conversation. By establishing them as narrator and giving each child a voice and an audience, perhaps for the first time, the information presented was not limited to that which was constructed in the workbooks. Encouraging a narrative throughout also allowed for a clarification of details and the ability to probe for maximum information about the individual meaning the child attributed to being a member of a family in which a parent is ill. This also allowed participants to recognize their similarities and explore their differences.

Each child was presented with a workbook which they used for the duration of the sessions. In an effort to avoid preliminary assumptions about the depth of family communication about the cancer, all workbook activities were labeled as "*My Mom/Dad's Illness*". Spontaneous use of the word "cancer" was at the discretion of the individual participants and was not suggested by the principal investigator. All workbooks were collected at the end of each session and held by the principal investigator in a secure location. The information contained in the workbooks was coded and used as a portion of the data for the study. The workbooks contained all the materials the participants needed to complete the individual and group activities as well as a copy of the *Group Rules* (Appendix A) and *Confidentiality Contract* (Appendix B). Participants were asked to choose a colored sticker to place on the outside corner of their workbook to distinguish it as their own and avoid any overt identifiers. They were also encouraged to decorate the book as they wished.

At this point, the group rules were discussed and any questions regarding group purposes and procedures were answered. The importance of confidentiality among group members and the principal investigator was discussed and each participant was asked to sign the *Confidentiality Contract* (Appendix B). Further, participants were assured that the information in their workbooks would not be read by anyone except the principal investigator.

The purpose of Session I was to stimulate discussion about the changes that have occurred as a result of their parent's illness. Participants were asked to, individually, complete the *What Has Changed Chart* (Appendix C) and *When Things Change I…Chart* (Appendix D) in order to be able to voice the noticeable changes in their family and explore their reactions to these changes, including the positive and negative emotions associated with their parent's illness.. This activity also allowed for an understanding of each participants coping style with reference to their actions in the context of family change, without the possible confound of having participated in the group and been exposed to alternative styles. This was then considered with the information obtained in subsequent sessions.

Following the individual activity participants were asked to voluntarily share the information they wrote on their charts with the group. This open discussion allowed for an exploration of the different changes children in their situation face and a discussion of the different coping mechanisms people use to confront these challenges. In order to assist children in the organization of this information and to encourage group participation, collective information was written on a group chart, using chart paper and markers, as a collaborative account of their information. Further, in accord with attempts to empower the participants as storytellers, the principal investigator/facilitator acted, solely, as transcriber for the information volunteered by the participants. No prompting or follow-up questions were provided with reference to the information given. In the same way, no participant was asked to participate who did not wish to do so.

Session II: What I Know and What I Want To Know.

The purpose of Session II was to begin to understand the depth of each participant's level of knowledge about their parent's illness and to encourage participants to explore the areas of their knowledge about their parent's illness that were incomplete. Further, it was designed to allow them the opportunity to share their knowledge with each other.

Upon arrival, participants were given their workbooks. Following a review of the rules and the importance of confidentiality, there was an initial discussion about the topics discussed in the last session as well as an invitation to communicate any pertinent information the participants wanted to share with the group. This was meant to reestablish rapport and provide a comfortable environment for discussion. Further, it allowed participants to purge variables which might have proven distracting during the remainder of the session and, thus confounding. Once each participant who wished to do so had shared with the group, participants were asked to, independently, complete the *What I Know Chart* (Appendix E) and the *Where I Got My Information Chart* (Appendix F) in their workbooks. This information was, then, used during the group activity as participants were encouraged to discuss what they knew about their parent's illness and the strategies they employed to gain this knowledge. Prompting questions included *"Where did you go to learn these things?"* and *"Who are some other people you can talk to about Mommy/Daddy's illness?"* Further, participants were encouraged to report alternative means of getting information such as Internet sources or media presentations (i.e. books, television/radio programs) as a way to include all participants in the discussion. As with the initial session, a group generated, collaborative chart of information was created.

Once each participant who wished to contribute to the first group activity had done so, participants were asked to complete the *What I Want To Know Chart* (Appendix G) and the *Where I Might Be Able To Get This Information Chart* (Appendix H) in their workbooks. Information from this activity was compiled into a final group chart of information which was used as the basis for discussing gaps in what they knew and areas within which they desired to know more and/or deeper information as well as to brainstorm the means through which these elements could be ascertained or better understood. Prompting questions included *"Who could you talk to in order to get this information?"* or *"What would you ask them?"* This provided information about potentially beneficial areas of intervention where information could be made available to children. As in Session I, all collaboratively generated charts were constructed outside the workbooks using chart paper and markers and were transcribed by the principal investigator/facilitator.

Upon completion of these activities, each participant was thanked for their participation and reassured of the contribution they made. They were each presented with a colored stone and a journal at the end of this, final, session. The journals were able to be decorated according to each child's personal design and participants were encouraged to continue to write about their experiences and to use the journals to organize any questions or thoughts they might have as their parent's illness progresses. The journal was a concrete way for each participant to continue and expand upon their story. The stones were designed to be tangible reminders to the group participants that there are other people (both adults and children) who understand what they are going through as they navigate their parent’s illness. Having the stone meant they were never alone.

Finally, time was allotted for group members to say good-bye to each other and allowed the participants to transition from the group. Resources were provided to each family specifying available services for families in which a parental diagnosis of cancer has been made, should additional support be desired following this experience.

Analytic Strategy

Data Analysis

Demographic Criteria

Data was, initially, organized according to family background information. This was coded according to gender of parent and participant, type of cancer presented, stage of cancer (1 to 3), length of time since diagnosis, type of treatment(s) incurred, and parent-reported prognosis (Good vs. Poor). Good prognoses were defined as those in which the cancer was reported to have been caught early and there were, currently, no signs of disease progression. Poor prognoses were defined as those with a higher risk for entrance into Stage 4 despite treatment. This information was provided by the parent on the initial background information questionnaire.

All collected workbooks were assigned a number code to maintain confidentiality. Both individual and group generated charts were coded as separate sets of data according to several thematic categories provided in the coding scheme outlined in Appendix I. This dual form of analysis allowed for the exploration of the silences within the public story being told. That is, by comparing the individual story of personal experience with the generalized collective story, it was possible to ascertain those issues participants possessed but were unwilling to share with the group as well as those which were generated in collaboration with the group, but not considered in the individual charts.

Coping Styles

Responses to the *When Things Change I…* charts (Appendix C) were coded for information pertaining to coping styles. Coping styles were categorized as either active or avoidant according to definitions outlined by Billings and Moos(1981). Active coping styles were defined as those which sought to actively change some aspect of the stressor (parental cancer) either behaviorally or cognitively. This included strategies such as problem solving or monitoring (Forsythe & Compas, 1987). Avoidant coping strategies were defined as those which drew attention away from the stressor with the intention of managing the distressing emotion, such as frequent and prolonged denial. As research suggests that children maintain their coping strategies across situations (Donaldson, Prinstein, Danovsky, & Spirito, 2000), responses to generalized changes would be applicable to the current situation.

Written Charts

What I Know and *What I Want To Know Charts* (Appendices E and G) were coded according to the types of knowledge represented. These were categorized with reference to the system outlined below.

Three general thematic categories were used to structure both the individual and group chart data:

Medical Statements – information about causation, side effects and treatment

Emotional Statements – impact of disease on the individual and/or family members, fears or concerns

Practical/Social Statements - changes in scheduling or missed activities

In addition to these thematic categories, the subject of each statement was considered. Statements which were child-directed ("*Will I still be able to play soccer?*") received a code of one (1). Statements which were parent-directed ("*Will Mommy/Daddy lose their hair?*") were coded as two (2). In this way, it was possible to analyze not only the thematic content of the statements, but also to understand the direction of the child's focus.

Information about the reported avenues for knowledge acquisition [*Where I Got My Information* (Appendix F) and *Where I Might Be Able to Get This Information* (Appendix H)] was summarized according to frequency of responses across participants. This summarization technique was also applied to responses to the *What Has Changed* charts (Appendix C).

Narrative Analysis

In order to better understand the unique experience of a parental diagnosis of cancer and the meanings children make, both individual written and group-generated charts were conceptualized as stories rather than as collections of correlated bits of information. As such, individual charts presented a child's unique experience and group-generated charts became extensions of this situated experience. The coding scheme outlined in Appendix I was elaborated to determine more specific categories of experience and to create a narrative of the experience of a parental illness. Rather than conceptualizing illness knowledge according to thematic categories, participant statements were considered in terms of the specific information they contained within the thematic category and were used to qualitatively analyze the data. This allowed for an understanding of the specific experiences of children within this, specific, illness situation. Reported statements of existing and desired knowledge were used to construct a narrative of the experience of a parental diagnosis of cancer beyond frequencies of thematic categories. Statements became elements of both the lived experience and those required to make sense of the experience. This allowed for a more complete understanding of the role of information in overall attempts to make sense of the condition without delineating a necessarily causal relationship. Each workbook told a very definite story about the experience of parental cancer and as such, was subject to any and all narrative analytic considerations as were the group-generated charts created through conversation.

Prior to utilizing this approach to the non-narrative charts, it was important to acknowledge the asymmetrical relationship between participant and facilitator. Stanley and Billig (2004) argue that it is necessary to acknowledge the context of an interview format and to address the power structure that it possesses. In this project, the relationship was complicated by the principal investigator's perceived role, not only as interviewer, but also as adult. Within this setting, children were asked to assume a more active role, where an adult would be listening to them. This conflicted with their identity as a child who must defer to adults and answer questions when addressed. To be asked to lead discussions, in a less formal environment, violated their established social norms of inequality in question asking (West, 1984) with adults and needed to be addressed. The use of a more narrative approach within a group format allowed for further probing, rephrasing or reassurance that there was no wrong or detrimental answer. As the children were also working in collaboration with each other, the structure allowed for the impetus of a more child-empowering dynamic. Further, as Daiute (2003) suggests, the use of the group provided a means of exposing the dialogue within and around the narrative data. Providing an audience, even of similar others, changed the nature of the information presented and the story told.

In order to frame the narrative of the experience from the written elements in the charts, aspects of narrative cohesion, as argued by Baerger & McAdams (1999), were used to extrapolate the story from the data. In considering the created charts as narratives, cohesion was documented according to attempts to convey both episodic and high-point analysis. This necessitated a separate analysis of existing and desired knowledge as reported by the participants.

The specific statements provided by participants in “What I Know….” charts, which reflected levels of existing knowledge, were more amenable to an episodic analysis. Statements were considered with reference to information on the nature of the experience for children. They provided details concerning the changes that had occurred in the family and a basic understanding of each child’s interpretation of those changes. Viewed through this lens, existing knowledge of their parent’s illness provided a preliminary setting for the lived experience of a parental cancer diagnosis. The specific type of information presented within each statement, and the frequency of such statements within the broader thematic categories, established the place of the child within the family and contained their unique responses to the cancer diagnosis and progression in the form of knowledge acquisition. That is, what is known about a parental illness was conceptualized as corresponding to the lived experience of that illness. A narrative was constructed with reference to these chart elements to answer the narrative question *“What is it like to have a parent with cancer?”* Further, the gaps or misappropriations in the knowledge of their parent’s illness reflected the child’s current state of knowledge and, by extension, their current situation, including their willingness or ability to seek external sources of information.

In the same way, the “What I Want to Know…” charts of desired knowledge were more amenable to a high-point narrative analysis. The specific types of information desired (according to thematic categories) were interpreted as a reflection of the emotional component ascribed by the child to the current family situation. That is, each specific statement was viewed for evidence of what the child deemed important and necessary with respect to understanding their parent’s illness. They presented the fears and concerns associated with a parental diagnosis of cancer as well attempts to make meaning of the experience. This represented the dramatic component to the story told by delineating where the child’s values were to be found. Moreover, understanding to what lengths, if any, the child had gone or was willing to go to in order to secure the information they lacked informed the nature of the experience of having an ill parent and how they wanted their story to be presented.

Thus, the use of a narrative lens to interpret the itemized knowledge contained in the written charts expanded upon traditional definitions of narrative. Interpreting the statements as story elements rather than as correlated bits of information imposed a narrative structure on the raw data and uncovered a generalized individual story woven through the elements presented by the participants. To that end, information provided by participants with reference to the changes cancer brings was used to clarify and corroborate elements of existing and desired knowledge and present a more complete narrative account of the experience.

This same method of analysis was used on the group generated charts. By comparing the individual stories of the children to the collaborative experiences presented in the group charts, it was possible to explore the public and private persona adopted by children within this familial experience according to the aforementioned lens of episodic and high-point narrative cohesion, the discrepancies between the personal information on the individually constructed charts and the collaborative information generated in the group charts provided information on both the privileged and silenced aspects of the experience as well as a more complete understanding of the role of specific meaning making strategies in the direction of the narrative.

Results

Frequency Data

Demographic Criteria

Twenty-five children participated in the study with an average age of nine years, seven months. All participants (N = 25) were Caucasian, lived in New York City and were from middle class families. All families seeking treatment were doing so at local hospitals and were, currently, covered by medical insurance. Frequency data concerning additional aspects of demographic criteria is presented in Table 1.

There were eleven male participants and fourteen female participants. Sixteen of the participants had fathers with cancer and nine had mothers with cancer. The average length of time since diagnosis was eight months. Types of cancer represented included: 40% fathers with colon cancer (n = 10), one at Stage 2, eight at Stage 3, and one at an unspecified stage; 12% mothers with breast cancer at Stage 1 (n = 3); 12% parents with leukemia (n = 3), one mother at Stage 3 and two fathers at Stage 3; 8% mothers with pancreatic cancer Stage 3 (n = 2); 8% parents with lung cancer (n = 2), one mother at Stage 2, one father at Stage 3; 8% fathers with kidney cancer (n = 2), one at Stage 2 and one at Stage 3; 4% (n = 1) mother with Hodgkin's disease with no reported stage; 4% (n = 1) mother with thyroid cancer Stage 1 and 4% (n = 1) father with melanoma (skin cancer) Stage 3. Eleven ill parents reported their prognosis as good and fourteen reported a poorer prognosis. Twenty of the ill parents were undergoing a single type of treatment such as either chemotherapy or radiation. Five were being treated in multiple ways, including the addition of surgical or experimental procedures.

Table 1

Frequency Data for Demographic Criteria

Criteria Category	Frequency	Percent
Participant Gender		
Male	11	44.0
Female	14	56.0
Parent Gender		
Male	16	64.0
Female	9	36.0
Type of Parental Cancer		
Colon	10	40.0
Breast	3	12.0
Leukemia	3	12.0
Pancreatic	2	8.0
Lung	2	8.0
Kidney	2	8.0
Hodgkin’s Disease	1	4.0
Skin (Melanoma)	1	4.0
Thyroid	1	4.0

Table 1 (continued)

Frequency Data for Demographic Criteria

Criteria Category	Frequency	Percent
Stage of Cancer		
1	4	16.0
2	3	12.0
3	16	64.0
Unknown	2	8.0
Parent-reported Prognosis		
Good	11	44.0
Poor	14	56.0
Length of Time Since Diagnosis (in months)		
3	2	8.0
4	1	4.0
5	2	8.0
6	1	4.0
7	1	4.0
8	4	16.0
9	3	12.0
11	1	4.0
12	5	20.0

Table 1 (continued)

Frequency Data for Demographic Criteria

Criteria Category	Frequency	Percent
Length of Time Since Diagnosis (in months)		
13	2	8.0
15	1	4.0
20	2	8.0
Type of Treatment Received		
Singular[a]	20	80.0
Multiple[b]	5	20.0
Participant Coping Style		
Active	15	60.0
Avoidant	10	40.0

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[a] Chemotherapy or radiation only

[b] Chemotherapy or radiation as well as surgical or experimental procedure

Coping Style

Frequency data on coping style was also compiled based on independent responses to “When Things Change I…” charts and is presented in Table 2. Fifteen participants were categorized as active copers, according to the established criteria and ten participants demonstrated an avoidant coping style.

When compared with those categorized as using avoidant coping strategies, those with active coping styles reported a greater number of responses and a wider variety of techniques to deal with change. Comments made by those with active coping styles reflected a desire to look beyond the information that was presented to them. Thirty percent of responses corresponded to seeking additional information in order to understand the causes of the change and anticipate what would happen next. Though active coping strategies led to reports of emotional responses to change, such as crying and anger (26.7%), emotional responses were always coupled with activities engaged in as a response to those emotions. For example, these participants were more likely to draw, watch a movie or spend time thinking about the good times (13.3%). They were also more likely than those who utilized avoidant coping strategies to use prayer (10%) or talk to others (6.7%) to respond to life changes and were more concerned with finding ways to make the situation better (13.3%).

Participants who reported using avoidant coping strategies, by contrast, did not present as wide a variety of responses. The greatest number of responses corresponded to their emotional reactions to change (50%). These included fear and nervousness. However, unlike active coping strategies, which combined emotional responses with

Table 2

<u>Frequency Data for Responses to "When Things Change I…" Charts by Coping Category</u>

Coping Category	Frequency	Percent
Active Coping (n = 15)		
Seek additional information	9	30.0
Emotional responses[c]	8	26.7
Try to make it better	4	13.3
Engage in activities[d]	4	13.3
Pray	3	10.0
Talk to others	2	6.7
Avoidant Coping (n = 10)		
Emotional response[e]	6	50.0
I hide	3	25.0
I do nothing	3	25.0

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[c] Emotional responses included *"I cry sometimes.", "I get mad."* and *"I worry."* For those using active coping strategies, emotional responses were combined with additional statements concerning actions taken in response to these emotional states

[d] These included drawing, watching a movie or thinking about the good times

[e] Emotional responses included *"I am scared."* and *"I get nervous."* Participants with avoidant coping strategies rarely qualified these statements with additional explanations or actions.

actions to understand them, those with an avoidant coping styles merely reported their emotions without further explanation. Any actions taken by these participants were passive in nature. They reported activities such as hiding (25%) and doing nothing (25%) in an effort to avoid the change.

Individually Constructed Charts

Frequency data was compiled separately for each of the charts constructed by the participants and combined in order to analyze the frequency of themes and statement direction across participants.

Existing Knowledge Charts: "What I Know About Mom/Dad's Illness."

Responses to "What I Know…" charts were summarized and categorized thematically. These results are presented in Table 3.

Only two of the participants (8%) reported any medical information about themselves, including *"I know what it feels like to be sick."* Ninety-two percent of the participants, however, listed at least two individual responses referring to their parent's medical condition such as *"Mommy has cancer" or "I know Daddy's chemo makes him sick."* The average number of responses relating to a parent's medical condition was 4.2.

Six of the participants (24%) reported a personal emotional impact when discussing their parent's cancer *("I get sad when Mommy is sick")*. Only 14% (n = 3) reported knowledge of how the cancer was emotionally impacting their parent *("Mommy gets sad a lot")*.

Another dichotomy was found in knowledge of the social impact of the disease. Only 16% (n = 4) reported knowledge of any direct changes in their daily schedule, such missed activities *("We go lots of places with Grandma")*. Four participants (16%) noted

Table 3

Statement Frequency for Individual (N = 25) “What I Know” Charts (existing knowledge of parental illness)

Number of Statements[f]	Frequency	Percent
Child-Directed Medical Statements		
0	23	92.0
1	2	8.0
Parent-Directed Medical Statements		
1	1	4.0
2	4	16.0
3	4	16.0
4	5	20.0
5	6	24.0
6	1	4.0
7	4	16.0
Child-Directed Emotional Statements		
0	19	76.0
1	4	16.0
2	2	8.0

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[f] Reflects the total number of participant responses corresponding to the specified category of knowledge

Table 3 (continued)

Statement Frequency for Individual (N = 25) “What I Know” Charts (existing knowledge of parental illness)

Number of Statements	Frequency	Percent
Parent-Directed Emotional Statements		
0	21	84.0
1	3	12.0
2	1	4.0
Child-Directed Practical/Social Statements		
0	21	84.0
1	3	12.0
2	1	4.0
Parent-Directed Practical/Social Statements		
0	21	84.0
1	4	16.0

knowledge of how the disease was affecting the social routines of their parent *(“Daddy doesn’t go to work anymore”).*

Desired Knowledge Charts: “What I Want To Know About Mom/Dad’s Illness.”

The desire for medical knowledge about their parent was equally as prevalent as existing knowledge of the same category. Seventeen participants (68%) reported wanting to know more about their parent’s illness. Statements included: *“How did he (Daddy) get cancer?” and “What happens at the hospital.”* However, only 20% (n = 5) considered their own medical condition in reference to their parent’s cancer, such as whether or not they were going to contract the disease.

Most prominent in the charts was the desire to understand the emotional impact of cancer on their parent. While only 28% (n = 7) of participants wanted to know more about their own emotional responses to the cancer (*”Why did this happen to me?”),* 80% (n = 20) reported a desire to know more about how the cancer was emotionally affecting their parent (*”Is Daddy sad because he wonders if he picked the right doctors?,” “Does Mommy ever think about the good times before she got cancer”).*

Information concerning desired knowledge of practical and social issues was similar to participant reports of existing knowledge in this same category. Twenty-eight percent (n = 7) of participants wanted to know how the cancer would change their daily schedules *(“Will I have to be man of the house now?,” “When will life return to normal?”).* Only 8% (n = 2) wondered about the social impact of cancer on their parent (*”Why does Mommy have to leave all the time?”).*

Table 4 lists the summarization and categorization of responses to participant “What I Want to Know…” charts.

Table 4

Statement Frequency for Individual (N = 25) “What I Want to Know” Charts (desired knowledge of parental illness)

Number of Statements[g]	Frequency	Percent
Child-Directed Medical Statements		
0	20	80.0
1	3	12.0
2	2	8.0
Parent-Directed Medical Statements		
0	8	32.0
1	6	24.0
2	6	24.0
3	2	8.0
4	3	12.0
Child-Directed Emotional Statements		
0	18	72.0
1	7	28.0

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[g] Reflects the total number of participant responses corresponding to the specified category of knowledge

Table 4 (continued)

Statement Frequency for Individual (N = 25) “What I Want to Know” Charts (desired knowledge of parental illness)

Number of Statements	Frequency	Percent
Parent-Directed Emotional Statements		
0	5	20.0
1	9	36.0
2	5	20.0
3	6	24.0
Child-Directed Practical/Social Statements		
0	18	72.0
1	5	20.0
2	2	8.0
Parent-Directed Practical/Social Statements		
0	23	92.0
1	2	8.0

Information Acquisition

Individual charts were also coded for information regarding where the child was or could obtain the information presented in the charts. Frequency data for these responses is presented in Table 5.

Eighty-eight percent of the participants (n = 22) reported getting most of their information from their parents and 32% (n = 8) reported seeking out additional family members such as siblings or grandparents for information. Nine participants (36%) reported seeking information from the Internet. Five participants (20%) reported gaining much of their information by observing their parent and other family members within the home environment. Twenty-eight percent (n = 7) reported contact with doctors or members of the medical community as a way they received additional information and 20% (n = 5) looked to other sources such as books, periodicals, teachers and friends for information.

Group Constructed Charts

The group data reflects six formulated groups with no fewer than three and no more than five members in each. Fifty percent (n = 3) of the groups had five participants, 33.3% (n = 2) had four participants and 16.7% (n = 1) had three participants. Information concerning the different frequencies in the categories of responses for the group charts was also compiled and is presented in Tables 6 and 7.

Existing Knowledge Charts.

Unlike the individual charts, no information on child-directed medical knowledge was presented by the groups. However, 100% of the groups (N=6) included information

Table 5

Frequency Data for Individual (N = 25) Sources of Information

Category	Frequency	Percent
Parent	22	88.0
Internet	9	36.0
Family Members	8	32.0
Medical Community	7	28.0
Observation	5	20.0
Other[h]	5	20.0

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[h] Includes information from books, periodicals, teachers and friends

Table 6

Statement Frequency for Group (N = 6) "What I Know" Charts (existing knowledge of parental illness)

Number of Statements[i]	Frequency	Percent
Parent-Directed Medical Statements		
3	1	16.7
5	1	16.7
6	2	33.3
7	2	33.3
Parent-Directed Emotional Statements		
0	5	83.3
1	1	16.7
Parent-Directed Practical/Social Statements		
0	5	83.3
1	1	16.7

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[i] Reflects the total number of responses corresponding to the specified category of knowledge within each group chart

Table 7

Statement Frequency for Group (N = 6) "What I Want to Know" Charts (desired knowledge of parental illness)

Number of Statements[j]	Frequency	Percent
Parent-Directed Medical Statements		
0	2	33.3
1	1	16.7
2	1	16.7
3	2	33.3
Child-Directed Emotional Statements		
0	3	50.0
1	2	33.3
2	1	16.7
Parent-Directed Emotional Statements		
0	2	33.3
1	2	33.3
2	1	16.7
3	1	16.7

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[j] Reflects the total number of responses corresponding to the specified category of knowledge within each group chart

Table 7 (continued)

Statement Frequency for Group (N = 6) “What I Want to Know” Charts (desired knowledge of parental illness)

Number of Statements	Frequency	Percent
Child-Directed Practical/Social Statements		
0	4	66.7
1	1	16.7
2	1	16.7

regarding their parent's medical situation in the charts *("They [parents] have cancer," "Chemo makes them [parents] sick.")* The average number of responses was 5.67.

Information regarding emotional responses to parental cancer was limited. No groups chose to present information regarding their personal emotional responses and only one group (16.7%) privileged information regarding their parent's emotional response *("They [parents] get sad a lot.")*

The reported social and practical implications of the cancer mirrored the emotional ones. No record was made of personal changes in routine and only 16.7% of the groups (n = 1) mentioned knowledge of changes in their parent's routine *("They [parents] can't go places anymore.")*

<u>Desired Knowledge Charts.</u>

The choice of medical information to share with the group was similarly skewed. No groups presented a desire to know about their own medical condition with respect to their parents' cancer. However, 66.7% (n = 4) of the groups expressed a desire for additional medical information *("When will they[parents] get better?," "Are there other/better treatments?")*

The desire for information on the emotional impact was more evenly distributed. Fifty percent of the groups (n = 3) included information regarding a desire to know about the depth of the personal emotional impact *("Why did this happen to me?")* and 66.7% (n = 4) presented information about a desire for more information about the emotional impact of cancer on their ill parent *("Are they [parents] scared?," "Does it[the cancer] hurt?")*

The practical implications regarding the social changes that may accompany a parental diagnosis of cancer reflected the impact these changes had on the participants more than on their parents. That is, while no groups presented information about the social implications of the disease on their ill parent, 33.4% (n = 2) mentioned a personal practical impact *(”Why can’t we ever talk about the good times?”)*

Narrative Analysis

Traditional quantitative analyses failed to provide an accurate picture of the complete experience of having a parental diagnosis of cancer in the family and the role information plays in the construction of each child’s story of their experience. Therefore, a narrative approach to the data was necessary to allow the children’s voices to be more clearly heard and the steps to the dance more intricately delineated.

The specific changes incurred in families with a parental diagnosis of cancer were analyzed according to the exact nature of the statements provided by the participants. No additional thematic categories beyond those presented as stimuli for the participants *(In My Family, In My Ill Parent, In Myself,* and *In Others)* were used. Statements were, spontaneously, provided by the participants and were considered in their entirety as part of the independently and group-constructed stories.

The thematic categories applied to the individually constructed and group-generated charts used previously (*Medical, Emotional, and Practical/Social)* were expanded to reflect the specific nuances of the individual statements. This was an important layer above merely reporting the frequency of themes or directional categories (*child- or parent-directed*).

The Changes Cancer Brings: Individual Charts

The diagnosis of and treatment for parental cancer necessitates a myriad of life changes for the children involved. In each of the aspects the participants were asked to consider (*family, ill parent, self, and others*), some definite patterns emerged in the changes they noticed and commented on. Noted familial changes reflected the negative connotations associated with the situation and concerned several themes. The candor evident in the individual charts was drastically altered when the participants were asked to share their story with the group and collaboratively discuss the changes parental cancer necessitates. While the proportion of statements with the four given categories was similar, the content of the stories that were told individually and those that were presented in the group showed marked differences. Participants were willing to share only specific changes within a group setting. The group stories demonstrated fewer expressions of negativity and, when compared with the individual charts, allowed for an exploration of both the individual story of a child in this situation and the story they choose to present to society. Information from group charts, when compared with that of individual charts, is presented in Table 8.

Changes in the Family.

The majority of participants created a story set within a family where communication was limited and, for the most part, centered on the illness. They also expressed communication within the family that was permeated with anger and fighting. The heightened stress associated with family adjustment to the parent's cancer was evident in their descriptions. Statements included: *"My family no longer talks to each other or eats together," "There is a lot more yelling and fighting,"* and "*Cancer is all we*

Table 8

Summation of Statements of Incurred Changes from “What Has Changed” Charts

Nature of Statement	Number of Responses Individual Charts (N = 25)	Group Charts (N = 6)
Changes in Family		
Family members no longer talk to each other/eat together	8	6
More yelling/fighting	7	0
Illness is the only topic of conversation	5	1
More sadness	5	2
Well parent is depressed	4	0
Less laughter	3	3
Fewer celebrations	3	1
Financial strain	3	0
Loss of religious activities	1	0
More time spent with babysitters	1	1
Well parent must go to work	1	0
More stress	0	3
Changes in Ill Parent		
Can no longer do activities with child	10	5
Is sad/cries frequently	9	5

Table 8 (continued)

Summation of Statements of Incurred Changes from “What Has Changed” Charts

	Number of Responses	
Nature of Statement	Individual Charts (N = 25)	Group Charts (N = 6)
Changes in Ill Parent		
Sleeps a lot	8	5
Is angry	7	5
Is a different person	6	4
Is sick all the time	6	2
Is depressed	5	5
Is away from home more frequently	3	1
No longer attends school functions	1	0
No longer asks child to do chores	1	0
Changes in Self (Child)		
Emotional response	15	8
Nothing feels the same	7	0
Miss time spent with ill parent/old life	6	0
Feel guilty for having fun	4	4
More responsibility	2	0
No one to talk to	1	0
More freedom	1	0

Table 8 (continued)

Summation of Statements of Incurred Changes from "What Has Changed" Charts

	Number of Responses	
Nature of Statement	Individual Charts (N = 25)	Group Charts (N = 6)
Changes in Others		
No one asks how child is feeling	7	3
No one talks about parent's illness	5	2
They provide child with preferential treatment	5	0
They have changed	5	3
Illness is the only thing people talk about	3	1
Visit more frequently	2	1
Always ask how child is feeling	0	3

ever talk about." This negativity, associated with a lack of communication and time spent together was present in every description of family change. Participants described sadness or greater emotionality in the family. Statements included: "*There is less laughter in my house,*" and "*We don't celebrate anything anymore or have parties*." Noted depression in the well parent was an additional aspect, prompting a feeling of the loss of both parents through the duration of the illness. Financial strain (necessitating the well parent returning to work), limited experiences of joy and more time spent with extended or non-family members was also cited.

There was little mention of positive changes associated with the disease or garnered strength as a result of having dealt with their parent's cancer. Only one participant claimed that the illness allowed for additional time spent with the well parent. Overwhelmingly, for these participants, cancer was an unwelcome interloper that wreaked havoc upon their family.

Changes in Ill Parent.

Negative characteristics were also ascribed to the changes participants noted in their ill parent. This category comprised the greatest number of individual recorded responses (n = 63). Most statements reflected on the emotional experience of their parent in the form of increased sadness, anger, physical illness, and exhaustion. These emotional responses were understood by the majority of the participants as the impetus for a decrease in opportunities to engage in activities as a family. Statements reflected activities lost, such as: "*My parent no longer attends school functions*." Moreover, much of the responsibility for these social changes was placed with the ill parent's emotionality. The negative emotions reportedly exhibited by the ill parent were considered the reason for the lack of family activities and the ill parent's inability to engage in activities. Statements such as: *"My parent is sad and cries a lot," "My parent is depressed," "My parent is angry,"* and *"My parent is sick all the time"* reflected this new reality. Further, there was the recognized dichotomy of the greater amount of free time available to a parent too ill to work but still frequently away from home.

Changes in Self.

For the participants in this study, reflection upon personal changes necessitated an exploration of the emotional impact of a parental diagnosis of cancer. The majority of responses reflected the greater sadness, anger, and confusion they felt as a result of the illness. These emotions also permeated their social activities such that, not only was there reportedly less laughter and celebration at home but, there were, also, marked experiences of personal guilt when the opportunity for fun arose. Coupled with the overwhelming nature of parental cancer in the family, enjoyment seemed a taboo. This sense of social detachment and emotional weight was evident in statements such as: "*I always think about cancer,"* and "*I have no one to talk to*." Moreover, even in descriptions of increased freedom brought about by parental preoccupation with the illness, there were no positive feelings ascribed to the experience.

Changes in Others.

The impact of parental cancer extends far beyond the nuclear family. Yet, overall, recognition by others of the direct impact on the participants was infrequent. The majority of responses to the changes in others centered on a sense of personal invisibility associated with having a parent with cancer. Statements such as: "*No one asks me how I am feeling," "No one wants to talk about it (the parent's illness),"* and "*Everyone has* *changed"* reflected the perception of their tangential role when a parent has cancer. Despite consideration that "*Cancer is the only thing anyone talks about*," there was little suggestion that anyone was speaking directly to the child. This seemed equally true for reported offers of aid. According to the participants, attempts at interaction with them, by others in their lives, were limited to preferential treatment and more frequent visitations. Theirs was a story without an audience.

The Changes Cancer Brings: Group Charts

Changes in the Family.

As in the individual charts, the absence of conversation and time spent together was stressed in the group charts as the primary change in the family. However, the emotional atmosphere of the house was presented more benignly in the groups. Individual charts prominently reflected the anger, fighting and dual parental depression perceived. Within the groups, however, anger, depression, financial strain and additional time spent with non-nuclear family members were reduced to the singular statement "*There is more stress in my family."*

Changes in Ill Parent.

Statements regarding changes in the ill parent dominated the group charts, as they did in the individual charts. However, within the group charts, there was more balance between the amount and nature of the information conveyed. There was recognition of more missed activities and the greater negative emotions presented by the ill parent. Yet, as with the changes in the family, the language used to describe changes in the ill parent within the group charts altered the way the story was told. A parent individually described as being bored and having additional free time because they were no longer able to work, simply became a parent who was indecisive about what to do with their time. No further explanation for the situation was given.

Changes in Self.

This same pattern was seen in reports of self-change. Statements reflected overt changes in emotionality without elaboration about the causes of these changes. That is, anger, sadness and confusion were delineated by participants, as were statements regarding the guilt associated with having fun, and the omnipresent thoughts of cancer. However, there was no credence, as was present in the individual charts, to those statements which may have explained these emotional responses, such as additional responsibility; sorrow over limited time spent with parent(s) or loneliness associated with their perceived tangential existence.

Changes in Others.

Interestingly, in describing the changes in others, there was a glaring omission of the preferential treatment reported in the individual charts. It was replaced with "*Everyone always asks how I am*." This was a marked example of the differences in the public and private story of parental cancer and the level of comfort in revealing specific aspects of the experience.

The Role of Coping Style in Perceptions of the Changes Cancer Brings

In order to address some of the contradiction and inconsistencies within the written charts, statements of incurred changes were considered according to specified coping styles. Information on statements for both active and avoidant coping are comparatively presented in Table 9.

Table 9

Summation of Statements of Incurred Changes from Individual (N = 25) "What Has Changed" Charts by Coping Style

	Number of Responses	
Nature of Statement	Active Coping (n = 15)	Avoidant Coping (n = 10)
Changes in Family		
Family members no longer talk to each other/eat together	6	3
Well parent is depressed	5	0
Less laughter	3	0
Illness is the only topic of conversation	3	2
Financial strain	3	0
More yelling/fighting	2	5
Fewer celebrations	2	1
More sadness	1	4
More time spent with babysitters	1	1
Well parent must go to work	1	0
Loss of religious activities	1	0
Changes in Ill Parent		
Is sad/cries frequently	5	4
Can no longer do activities with child	4	6
Is a different person	4	2

Table 9 (continued)

Summation of Statements of Incurred Changes from Individual (N = 25) "What Has Changed" Charts by Coping Style

	Number of Responses	
Nature of Statement	Active Coping (n = 15)	Avoidant Coping (n = 10)
Changes in Ill Parent		
Is sick all the time	3	3
Sleeps a lot	3	5
Is angry	2	5
Is depressed	2	3
Is away from home more frequently	1	2
No longer attends school functions	0	1
No longer asks child to do chores	0	1
Changes in Self (Child)		
Emotional response (sad, angry, upset, confused, etc.)	10	5
Nothing feels the same	5	2
Miss time spent with ill parent/old life	4	2
Feel guilty for having fun	3	1
More responsibility	2	0
No one to talk to	1	0
More freedom	0	1

Table 9 (continued)

Summation of Statements of Incurred Changes from Individual (N = 25) "What Has Changed" Charts by Coping Style

	Number of Responses	
Nature of Statement	Active Coping (n = 15)	Avoidant Coping (n = 10)
Changes in Others		
They have changed	3	2
No one asks how child is feeling	2	5
No one talks about parent's illness	2	3
Visit more frequently	2	1
Illness is the only thing people talk about	1	2
They provide child with preferential treatment	0	5

Active Coping.

When compared with avoidant coping styles, participants who reported the use of active coping strategies, on average, reported more specific statements about the nature of the changes incurred by their parent's cancer.

Statements focused on the lack of communication within the family and the inability to share meals together. Participants were also more forthcoming in their acknowledgement of the increased financial strain and depression, and the decreased laughter and celebration within the family. They reported more changes in the social aspects of life, including changes in living situations, via extended family moving in and increased time spent with babysitters. Those with active coping strategies were more candid than those utilizing avoidant coping strategies about the emotional and physical changes experienced by their ill parent, but were not concerned with the ill parent's absence from school functions. They were also less likely to mention concern over not being asked to engage in as much household responsibility.

The descriptions made by those with active coping strategies of the personal emotional responses associated with their parent's illness reflected an understanding of both their regret over time lost together, their guilt over any enjoyment had, even as their ill parent could no longer do so, and the added responsibility and increased loneliness associated with the experience. They had a story they felt could not be shared because they perceived no one as paying attention. Their perception of others also reflected this sense of loneliness and isolation. Rarely were they asked to describe their experiences to others. Rarer still were inquiries, by others, about their emotional state. Cancer was talked about without recognition of the personal impact it had on the children. Therefore, despite the increased visitation and offered support by others, participants still did not report being recognized as part of the experience.

Avoidant Coping.

Participants identified as utilizing avoidant coping strategies had very different perspectives on the changes inherent in a parental diagnosis of cancer. Unlike their active counterparts, who nuanced their descriptions of familial change, the use of avoidant coping strategies led to greater preoccupation with the negative emotional changes experienced within the family. Participants with avoidant coping styles mentioned the increased yelling, fighting and sadness they perceived. Unlike those with active coping strategies, the statements of those with avoidant coping styles lacked references to the social changes, such as more time spent with babysitters or less time spent together as a family.

References to perceived increases in negative emotions were also evident in the descriptions of those with avoidant coping strategies regarding changes in their ill parent. Participants focused mainly on overt characteristics such as increased anger and exhaustion. They were less likely to consider what they could not see. That is, unlike those who reported active coping strategies, statements by those with avoidant styles focused on the personal impact of their parent’s changes and did not include the experiences of the parent during free time. They reported that “*My parent can no longer attend my school functions”* or “*My parent no longer asks me to do household chores*.”

Like those with active coping styles, reports of the personal changes noted by these participants were, largely, emotional in nature. However, there was little explanation of the nature of these emotional experiences. Subsumed under the blanket of parental cancer, there was limited suggestion of the loneliness or preoccupation with the cancer that was evident in the statements of active copers. Much like the recognition of less chores being required, explanations for the emotional changes in their ill parent were coupled with an element of additional personal freedom. However, freedom did not bring with it the, expected, positive emotional response. Freedom and lack of responsibility did nothing to negate the negative impact of a parental diagnosis of cancer for participants with avoidant coping styles.

One of the most noted discrepancies between the reports of those with active and avoidant coping strategies was in their descriptions of the changes in others. Those with avoidant coping styles did not report experiencing additional help and support from significant others in their lives, as those with active strategies did. Rather, those with avoidant coping style were more likely to report receiving preferential treatment by others. However, similar to the additional freedom reported by these participants, there were no statements reflecting the positive emotionality presumed by the preferential treatment. For participants with avoidant coping styles, the preferential treatment was negated by the sense of isolation reported by the majority of these participant as "*No one asks how I am feeling*."

Illness Knowledge

In considering the knowledge these participants possessed, statistical procedures failed to reveal the subtleties inherent in the quality of the information. For the participants in this study, being a child whose parent has cancer was a consuming reality. Cancer seemed to permeate every aspect of their lives in very definite ways. An overview of the general categories of illness knowledge used in this study (existing and desired), as well as a comparison of individual and groups charts and coping styles (active and avoidant), is presented in Table 10 and will be more specifically discussed in subsequent sections.

Existing Knowledge.

Broadly, across charts, medical statements comprised the greatest percentage of statements. Frequency data suggested that all participants possessed medical knowledge of their parent's illness and made at least one statement in their existing knowledge chart corresponding to medical aspects of their parent's illness. However, when the charts were looked at from a narrative perspective, medical knowledge comprised a range of 61% to 82% of overall existing knowledge depending on the characteristics of the story told. While this still represented the majority of existing knowledge, it was more varied than statistical analyses suggest.

When compared with medical knowledge, knowledge of the emotional aspects of parental cancer was, significantly, less (12% to 28% of overall existing knowledge). The smallest portion of existing knowledge pertained to information about the changes in daily schedules or household routines as a result of a parental diagnosis of cancer, corresponding to only 6% to 11% of existing knowledge.

Desired Knowledge.

Compared to charts of existing knowledge, medical statements comprised only 33% to 40% of desired knowledge. However, in contrast to percentages of existing emotional knowledge, the desire for emotional knowledge took precedence and comprised 51% to 56% of the desired information indicated by the participants. As with existing knowledge, the desire for information about the practical or social changes

Table 10

Summation of Levels of Knowledge by Category

Knowledge Category	Individual Charts (N = 25)	Group Charts (N = 6)	Active Coping (n = 15)	Avoidant Coping (n = 10)
	Percents			
Existing Knowledge				
Medical	80.0	61.0	78.0	82.0
Emotional	12.0	28.0	12.0	12.0
Practical/Social	8.0	11.0	9.0	6.0
Desired Knowledge				
Medical	39.0	33.0	40.0	37.0
Emotional	54.0	51.0	54.0	56.0
Practical/Social	7.0	15.0	6.0	7.0

incurred as a result of the parent’s cancer comprised the smallest percentage of statements, corresponding to only 7% to 15% of total desired knowledge.

Episodic Analysis of Existing Knowledge: Individual Charts

Numerical representations of participant information contained in both individually written and group-generated “What I Know...” charts of existing knowledge limited the scope of the differences between individual existing knowledge and the existing knowledge the children chose to share within the group setting. Each had important implications in delineating the context of their story and revealing their perceived position within this, new, plotline. Therefore, individual and group charts were analyzed according the specific information contained in the statements presented within the larger thematic categories. This, more narrative, approach expanded the understanding of the experience of a parental diagnosis of cancer by revealing not only the nuanced personal story but also the story presented to an audience. Information comparing individual and group statements of existing knowledge across thematic categories is presented in Table 11.

Medical Knowledge.

Medical themes, most typically, reflected the overt changes cancer brings. As a result, knowledge of the cancer leaned heavily on the logistics and effects of treatment. That is, having a parent with cancer meant physically seeing the changes the disease and treatments for it bring. Regardless of the type of cancer, all participants discussed the effects of treatments. They freely described the hair and weight loss, exhaustion and physical changes.

Table 11

Summation of Statements of Existing Knowledge from "What I Know" Charts

	Individual Charts (N = 25)		Group Charts (N = 6)	
Category of Statement	Number of Responses	Percent of Category	Number of Responses	Percent of Category
Medical Statements				
Treatment effects[k]	28	28.0	6	27.0
Treatment logistics[l]	18	18.0	3	14.0
Illness logistics[m]	18	18.0	4	18.0
Parent is sick/ has cancer	16	16.0	5	23.0
Parent goes to doctor/hospital	13	13.0	4	18.0
Evaluative[n] statements	7	7.0	0	0.0
Emotional Statements				
Emotional state of parent	6	36.0	6	60.0
Emotional state of child	2	13.0	0	0.0
Told not to worry	2	13.0	2	20.0

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[k] Lack of coordination, weight/hair loss, paleness, exhaustion, etc.

[l] Chemotherapy, radiation, medication, etc.

[m] Symptoms, location of cancer, cure rate

[n] Includes statements such as "Mommy got cancer because she smoked," "Daddy has cancer just like Grandpa," "Chemo isn't helping very much" and "My Dad is not doing as well as everyone tells me he is."

Table 11 (continued)

Summation of Statements of Existing Knowledge from “What I Know” Charts

	Individual Charts (N = 25)		Group Charts (N = 6)	
Category of Statement	Number of Responses	Percent of Category	Number of Responses	Percent of Category
Emotional Statements				
Cancer is a terrible disease	2	13.0	0	0.0
Illness effects everyone in the family[o]	2	13.0	2	20.0
Parent has no interest in anything	1	7.0	0	0.0
Practical/Social Statements				
Parent no longer goes to work	3	30.0	0	0.0
Parent no longer plays with child	2	20.0	0	0.0
Other relatives stay over/ take them places	2	20.0	0	0.0
No longer go places as a family	1	10.0	4	100.0
No one talks about it	1	10.0	0	0.0
Importance of prevention[p]	1	10.0	0	0.0

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[o] Pertains to information describing the emotional toll on all family members

[p] Reflects statements such as “My parent should not have smoked,” “My parent should have worn sunscreen,” etc.

Treatment logistics, such as spontaneous mentions of chemotherapy, radiation or medications taken, comprised the next largest category of medical knowledge. Participants possessed a definite vocabulary for their parents' illness and freely presented information about treatment protocols such as: "*Chemotherapy is powerful medicine,*" *"Mommy takes a lot of medicine," and "You have to go the hospital and get an IV for it* (chemotherapy or radiation) *to work*."

Participants were equally capable of delineating the nature of the illness. That is, despite the absence of the word anywhere in the workbook, a number of elements of medical knowledge were simple declarative statements like "*Daddy has cancer*." These statements ranged from the aforementioned generalities ("*Daddy has to go to the hospital"*), to more specific illness logistics, including the location of the cancer (specific organ), the symptoms of the disease ("*Mommy's lung cancer makes her cough"*), and the potential cure rate ("*The doctors caught Daddy's cancer early so it's probably going to go away."*)

A smaller percentage of participants ventured into more evaluative aspects of the experience. They considered possible causes for the cancer ("*Mommy got cancer because she smoked*"), possessed knowledge of an additional acquaintance or family member with cancer, questioned the efficacy of the current treatment protocols, or reported a suspicion that the knowledge they possessed was not valid. Specifically, they stated "*I know my parent isn't doing as well as everyone says."*

Emotional Knowledge.

Similar to the overt and visible characteristics noted in the medical knowledge, the majority of existing emotional knowledge pertained to the emotional state of the ill parent. Statements included: “*Mommy is sad a lot,*” “*Daddy gets mad all the time,*” and “*Sometimes he [Daddy] is depressed*.” Participants also suggested that this emotional state may be contingent upon a parent who “*has no interest in anything.*” Once again, cancer permeated their existence and preoccupied all other thoughts and activities.

Few statements dealt with the emotional state of the participants in response to the illness. These statements included: “*I cry a lot*” and “*I feel sad because Mommy is so sick*.” Similar to the emotional state of the parent, further exploration into the nature of subsequent emotional statements revealed potential rationales for these emotional responses. Statements included: “*Everybody tells me not to worry*” and “*I hate that cancer is such a terrible disease.*”

Beyond the effects on both the participant and ill parent, statements regarding the emotional effects the illness had on all members of the family were also considered. These statements reflected sentiments such as: “*Cancer makes everyone sad*” and “*Everyone in my family is so sad and scared but no one wants to talk about it*.”

Practical/Social Knowledge.

The majority of statements of existing practical and social knowledge pertained to the physical absence of the parent from everyday activities and the, overall, lack of communication within the household. Statements included: “*My grandma/aunt/uncle/neighbor stays over and takes me places,*” “*We don’t go anywhere as a family anymore,*” and “*No one ever wants to talk about how nothing is the same.*” Of equal consideration were the social ramifications for the ill parent, reflected in statements like “*My Daddy doesn’t go to his job anymore.*”

Interestingly, in describing the practical/social changes, there was an evaluative element to the stories told. *"Mommy should not have smoked"* or "*Daddy should have remembered to wear sunscreen"* were common statements which, either existed on their own or were attached to statements about other lifestyle changes such as: "*We have to go places with Grandma now because Mommy smoked too much and now she has cancer*."

Episodic Analysis of Existing Knowledge: Group Charts

Medical Knowledge.

Similar to individual charts, information on treatments effects such as: "*They [parent] look different," "Chemo makes them even sicker,"* and "*They get tired really easy now"* comprised the majority of information constructed by the participants in the group charts. Declarative statements identifying the parent as being ill or having cancer comprised the next largest percentage of statements. This differed from individual charts, in which treatment logistics were of higher importance. Within the group charts statements regarding treatment logistics ("*They [parent] go to the hospital for chemo/radiation"*) comprised a smaller percentage of statements. Statements reflecting visits to the hospital and those concerning the logistics of the illness such as: "*The cancer is in the lungs/colon/kidney"* comprised the remainder of the category. Therefore, as was evident in the individual charts, the use of illness vocabulary and the, at times, profoundly overt physical and emotional changes parental cancer entailed, were paramount in the public story.

Notably, however, unlike the individual charts, the group constructed charts went no further. There were no statements entertaining possible causes for the cancer, no reported knowledge of additional people with the disease or evaluative statements pertaining to the quality of the treatment or of the information participants reported being told.

Emotional Knowledge.

Similar to the individual charts, the majority of the emotional knowledge expressed in the group charts were statements pertaining to the emotional state of the parent. These included: "*They [parent] get sad a lot*" and "*Sometimes they are angry*." Additional credence was only provided to the affirmation that they (participants) were continually told not to worry and to an understanding of the emotional consequences of parental illness on subsequent family members.

No mention was made in the group charts of the emotional effects of parental cancer on the participants. That is, there was no expression of their own sadness, anger or confusion, despite it being present in the individual charts. Further, group charts lacked an evaluative element regarding the illness, itself. Statements regarding cancer as a "*terrible disease,*" which were present in the individual charts, were not shared with the group.

Practical/Social Knowledge.

All of the statements, expressed in the group charts, concerning knowledge of practical or social elements referred to an inability to go places as a family since the advent of the parental cancer. That is, activities were not as frequently engaged in with the ill parent. Unlike the individual charts, however, little specification was made regarding the exact nature of these activities. There was no attempt to share their parent's changed employment status, the presence of others in their lives, the lack of communication within the family about the cancer or the cessation of individual playtime with the ill parent. These same elements were evenly distributed among the individual charts, however.

The Role of Coping for Statements of Existing Knowledge

Additional nuances in existing knowledge were revealed when individual charts were considered with reference to coping style. Information comparing statements reported by active and avoidant copers is presented in Table 12.

Active Coping.

Participants who reported using active coping strategies reported a larger number of statements representing an understanding of illness logistics, treatment logistics and treatment effects. They were more likely than those with avoidant coping styles to note the overt changes experienced by their parent as a result of the disease and to comment on the type of cancer presented, type of treatment necessary and the potential for cure. Those utilizing active coping strategies were also more likely than their avoidant counterparts to consider possible causes for the disease, to possess knowledge of additional family members with cancer, to report an evaluative account of the perceived quality of the treatment incurred, or to consider the possibility that the information being told to them was inadequate. However, they were less likely to provide declarative statements pertaining to the presence of illness or to comment on doctor visits and hospital stays.

As in all individual charts, existing emotional knowledge was not as prevalent as existing medical knowledge. The majority of the knowledge in this area corresponded to an awareness of the emotional state of the parent. This was balanced by an understanding

Table 12

Summation of Statements of Existing Knowledge from Individual (N = 25) "What I Know" Charts by Coping Style

	Active Coping (n = 15)		Avoidant Coping (n = 10)	
Category of Statement	Number of Responses	Percent of Category	Number Responses	Percent of Category
Medical Statements				
Illness logistics[q]	15	26.0	5	12.0
Treatment logistics[r]	13	23.0	7	17.0
Treatment effects[s]	11	19.0	13	32.0
Parent is sick/ has cancer	8	14.0	8	20.0
Parent goes to doctor/hospital	6	10.0	7	17.0
Evaluative[t] statements	5	9.0	0	0.0
Emotional Statements				
Emotional state of parent	5	56.0	1	17.0
Emotional state of child	2	22.0	0	0.0
Illness effects everyone in the family[u]	1	11.0	1	17.0

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[q] Symptoms, location of cancer, cure rate

[r] Chemotherapy, radiation, medication, etc.

[s] Lack of coordination, weight/hair loss, paleness, exhaustion, etc.

[t] Includes statements such as "Mommy got cancer because she smoked," "Daddy has cancer just like Grandpa," "Chemo isn't helping very much" and "My Dad is not doing as well as everyone tells me he is."

[u] Pertains to information describing the emotional toll on all family members

Table 12 (continued)

Summation of Statements of Existing Knowledge from Individual (N = 25) "What I Know" Charts by Coping Style

	Active Coping (n = 15)		Avoidant Coping (n = 10)	
Category of Statement	Number of Responses	Percent of Category	Number Responses	Percent of Category
Emotional Statements				
Parent has no interest in anything	1	11.0	0	0.0
Told not to worry	0	0.0	2	33.0
Cancer is a terrible disease	0	0.0	2	33.0
Practical/Social Statements				
Parent no longer goes to work	2	29.0	1	33.0
Other relatives stay over/ take them places	2	29.0	0	0.0
No longer go places as a family	1	14.0	0	0.0
No one talks about it	1	14.0	0	0.0
Importance of prevention[v]	1	14.0	0	0.0
Parent no longer plays with child	0	0.0	2	67.0

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[v] Reflects statements such as "My parent should not have smoked," "My parent should have worn sunscreen," etc.

of the participant's own emotional state, as well as an awareness of the consequences of parental cancer for additional family members and a notation of their ill parent's lack of general interest in activities. Unlike participants with avoidant coping strategies, those with more active coping styles did not express having been told, by others, not to worry, nor did they comment on their perception of the cancer (*"Cancer is a terrible disease."*)

As was evident in both individual and group charts, the smallest amount of existing knowledge for participants utilizing active coping strategies corresponded to their practical/social knowledge. They were evenly concerned with knowing that their ill parent was no longer able to work and noting the presence of other relatives either in their home or accompanying them on activities. Similarly, there was consistency in information concerning the inability to go places as a family, the lack of communication within the family and the importance of prevention in avoiding cancer.

Avoidant Coping.

Unlike participants utilizing active coping strategies, whose knowledge reflected an understanding of the range of treatment logistics and effects, those utilizing more avoidant strategies focused on the overt treatment effects such as hair loss, exhaustion and weight loss. By comparison, they were also less likely to consider that these effects pertained to the illness itself or to the nature of the treatment. Moreover, when compared with participants using active coping strategies, the statements of those with avoidant strategies were more often declarative. They, spontaneously, recognized the existence of the illness/cancer and realized the necessity of doctor visits and hospital stays. However, unlike those using active coping strategies, who provided more varied information regarding the logistics of the illness and treatment, participants utilizing avoidant coping strategies equated the effects they noted simply with having cancer. Information appeared to be taken at face value without additional probing for accuracy or explanations. That is, they were less likely to report the location of the cancer, its specific symptoms or cure rate. They also provided less information about the type of treatment their parent was receiving. Further, unlike those using active coping strategies, participants who reported avoidant coping strategies did not report knowledge of others with cancer or concern over the quality of the information they possessed.

Similar to their medical knowledge, the emotional knowledge of participants utilizing avoidant coping strategies was, also, more declarative. They were more likely to consider cancer a *"terrible disease"* and to report having been told not to worry. Unlike those reporting active coping strategies, however, those with more avoidant styles provided fewer recognitions of the emotional state of their ill parent and presented no information on their own emotional state or suggestions that their ill parent possessed a general lack of interest in things as a result of the illness.

Practical/social knowledge for participants using avoidant coping strategies also differed from that of those with active strategies. These participants provided no information about the lack of family communication or activities, the presence of others in their lives or the importance of prevention. Rather, the most significant noted change in social routine was an ill parent who no longer went to work but who did not use that free time to play with them.

High-point Analysis of Desired Knowledge: Individual Charts

Existing knowledge charts tended to be factual in nature. Participants presented lists of occurrences and attempted understanding. These were the logistics of the experience of parental cancer. Yet, the story lacked a specific dramatic component, corresponding to the more nuanced experiences of the participants. In order to understand the meanings made of a parental diagnosis of cancer, it was necessary to explore the gaps in their knowledge beyond a linear description of their experience. The information contained in the "What I Want to Know" charts outlined this desired knowledge and represented the ways in which participants wanted their story to be told; the values they held and the deeper experience of coping with their parent's illness. By considering these charts narratively through the exploration of the specific statement information within each thematic category, it was possible to expand upon the frequency data and more fully understand the unique and shared experience, as well as the meanings associated with that experience, as presented by the participants. Similar to the patterns noted in the episodic analysis of the existing knowledge charts, there were definite differences between the private components of the story, contained in the individually written charts, and those the participants chose to make public when asked to generate charts within the group. A comparative account of the specific desired information contained in the individual and group charts is presented in Table 13.

Medical Knowledge.

Regardless of the content of their existing medical knowledge, the central question among participants pertained to a desire to understand the specifics of the treatment vocabulary they possessed. They wanted to know: *"Why is Mommy getting this type of treatment?," "What happens during chemo?," "Why does chemo make Daddy sicker?,"* and *"Why can't the doctors cure it?"* Because of this limited

Table 13

Summation of Statements of Desired Knowledge from "What I Want To Know" Charts

	Individual Charts (N = 25)		Group Charts (N = 6)	
Category of Statement	Number of Responses	Percent of Category	Number of Responses	Percent of Category
Medical Statements				
What is treatment like?[w]	9	25.0	7	54.0
When will they get better?	8	22.0	3	23.0
Are there other/better treatments/doctors available?	6	17.0	1	8.0
How did they get cancer? / Could it have been prevented?	6	17.0	1	8.0
Could the cancer get worse or come back?	4	11.0	0	0.0
Where is the cancer and how serious is it (illness)?	2	6.0	0	0.0

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[w] Includes statements such as "Why is Mommy getting this kind of treatment?," "Why can't the doctors cure it?," "What happens during treatment?," and "Why does treatment just make Daddy sicker?"

Table 13 (continued)

Summation of Statements of Desired Knowledge from "What I Want To Know" Charts

Category of Statement	Individual Charts (N = 25) Number of Responses	Individual Charts (N = 25) Percent of Category	Group Charts (N = 6) Number of Responses	Group Charts (N = 6) Percent of Category
Emotional Statements				
What is it like to have cancer?[x]	10	20.0	8	40.0
Will parent die?	8	16.0	0	0.0
Why did this happen?	8	16.0	5	25.0
Will this happen to me/ other family members?	7	14.0	0	0.0
Will parent ever get better? / What will happen to them?	6	12.0	0	0.0
Why didn't parent take better care of themselves?	5	10.0	1	5.0
What is it like when parent does not feel sick?[y]	5	10.0	5	25.0
Why am I not old enough to understand?	1	2.0	1	5.0

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[x] Includes statements such as "Is Daddy scared?," "What does cancer feel like?," "Is treatment scary/painful?," "Does Mommy miss us when she goes to the hospital?," "How does Mommy really feel about having cancer?" and "Does everyone with cancer feel like my Dad?"

[y] Includes statements such as "Does my Mom ever think about the "good times"?" and "Why doesn't Daddy laugh anymore?"

Table 13 (continued)

Summation of Statements of Desired Knowledge from "What I Want To Know" Charts

	Individual Charts (N = 25)		Group Charts (N = 6)	
Category of Statement	Number of Responses	Percent of Category	Number of Responses	Percent of Category
Practical/Social Statements				
When will life return to normal?	2	33.0	4	67.0
Why does parent have to leave so much?	1	17.0	0	0.0
Will I have to assume more responsibility?	1	17.0	0	0.0
What will happen to the family?	1	17.0	0	0.0
Why can't we talk about it (illness)?	1	17.0	1	17.0
Why can't we do more things as a family?	0	0.0	1	17.0

understanding, participants also frequently wondered, *“When will Mommy/Daddy get better?”* The noted treatment effects seemed not to inspire confidence of progress in a positive direction. This was evident in questions such as: *“Are there other/better treatments/doctors available?”* Even in situations where prognosis was good, the fear of relapse was present.

While a large portion of desired knowledge corresponded to the potential outcomes of the illness, there was interest in the corresponding causes for the illness as well. Statements such as: “*How did Daddy get cancer?”* and “*Could it [cancer] have been prevented?*” reflected these gaps in existing knowledge. That is, while much of existing knowledge pertained to the immediate experience of the illness, desired knowledge focused on either the cause or prognosis of the illness.

Overall, statements of desired knowledge reflected a lack of understanding of the reasons for the overt changes noted in existing knowledge charts and what these changes might mean as the disease progressed. This suggested that having a parent with cancer allowed for a realization of what was happening without an understanding of why.

Emotional Knowledge.

Questions about a rationale for the presence of cancer in their lives were paramount. Statements included: *“Why did this happen?,” “Why didn’t Daddy take better care of himself?,”* and *“Why are there so many bad people in the world who never get cancer?”* In focusing on the immediate experience of the illness, statements reflected a desire to understand the more subtle impact of the disease on their parent, beyond the emotional delineations. Participants were aware of the emotional changes in their parent, but questioned the connection between those changes and having cancer. Thus, they wondered, *"What is it like to have cancer?"* Questions such as: *"Is Mommy scared?," "What does cancer feel like?," "Is treatment painful?," "Does Daddy miss everyone when he goes to the hospital?," "How does Daddy really feel about his cancer?,"* and *"Does everyone with cancer feel like my Dad?"* suggested a limited understanding of the overt effects that the participants were confronted with everyday. There was a desire to contextualize the experience and generalize what they were witnessing.

Questions also considered the experience of not having a parental diagnosis of cancer. That is, there was a desire to transcend the omnipresent nature of the disease and explore a more optimistic perspective. Statements reflecting this desire included: *"How does Mommy feel when she does not feel sick?," "Does Daddy ever think about the 'good times' before cancer?,"* and *"Why doesn't Daddy laugh anymore?"*

Finally, gaps in emotional knowledge corresponded to the fears associated with the limited scope of existing information. The anxieties and frustrations stemming from a perceived lack of adequate information were reflected in statements such as: *"Will Mommy die?"* and *"Will this happen to me/other family members?"* These statements, along with the question *"Why am I not old enough to understand?"* suggested the tangential experience of the participants in their parent's cancer; facing an uncertain future and being considered incapable of fully understanding the experience.

Practical/Social Knowledge.

Overall, desired practical and social knowledge was in the pursuit of the question *"When will life return to normal?"* Subsequent statements reflected voids in the understanding of their immediate experience, as well. These included: *"Why does my parent have to leave so much?," "Why does everyone fight all the time?," "Why can't* *we talk about it [illness]?'* and *"Will I have to assume more responsibility now?"* Such questions reflected a reliance on the logistics of the experience over an explanation of the reasons for the changes. That is, as with other desired knowledge categories, participants reported knowing what was happening without understanding why. For this reason, desired practical and social knowledge also prompted future projections. Participants wondered, *"What will happen to my family?"*

High-point Analysis of Desired Knowledge: Group Charts

Medical Knowledge.

As was evident in the individual charts, desired knowledge of medical statements, as shared with the group, was not as prominent as existing medical knowledge in this same category. When compared with individual charts, group charts reflected a greater desire to understand the experience of being treated for cancer. There was a desire to understand why a specific treatment was being used, what occurred during treatment and why this led to their parent becoming sicker. Similar to the individual charts, there were also a large number of questions about the efficacy of the treatment protocol and whether their parent would ever get better. Fewer statements, than were present in the individual charts, corresponded to a desire to explore where the cancer originated or to consider alternative treatments.

A noted difference between the individual story and that chosen to be presented in the group was that the group story lacked an exploration of the more negative aspects of the experience. That is, no questions were raised about the reasons for the, as yet, lack of cure or the possibility that the situation could deteriorate. Further, there were no questions regarding how the cancer could have been prevented or the desire to explore the severity of the disease.

Emotional Knowledge.

As was evident in the individual charts, emotional statements made up the majority of the desired knowledge presented in the group charts. The majority of these questions reflected a desire to fully understand their parent's experience of having cancer. These included questions such as: *"What does cancer feel like?"* and *"Is treatment scary/painful?"* Further, participants were concerned with whether their parent was afraid of what was happening to them and questioned when they (participants) would be considered old enough to fully understand what was happening. Equally, the question *"Why did this happen?"* was widely explored. Fewer statements, when compared with individual charts, reflected a desire to understand their parent's habits prior to the diagnosis in order to have a sense of how those actions may have contributed to the illness.

In direct proportion with questions regarding the reasons for the cancer were questions about the relevance of life before the disease. This was one of the few categories of statements for which all the participants who included questions of this nature in their individual charts also chose to share them in the group chart. This was an element all the participants felt comfortable including in their public story. Many of these questions suggested a desire to understand why the laughter had stopped and to explore those moments when their parent did not feel sick. Thus, there was a great desire to focus on the '*good times"*, occasionally.

However, there were also some glaring omissions between the desired knowledge present in the individual charts and those questions chosen to be included in the group charts. Most notably, none of the participants chose to consider what would happen to their parent within the group or share their fears regarding their parent's mortality. Despite questioning *"Will Mommy/Daddy die?"* in their individual charts, it was never opened for group discussion. Similarly, none of the participants shared their fear that this might happen to them or another family member or their concerns over whether their parent would ever get better. Further, there was no attempt to explore how their parent felt about the illness or the frequent hospitalizations, or to consider the experience of cancer across the parents of other group members (i.e. *"Does everyone with cancer feel like my Daddy?"*)

Practical/Social Knowledge.

The desire for information about the practical/social changes parental cancer necessitates, while still the lowest proportion of desired knowledge, was greater among the group charts than it was in the individual charts. The most prevalent question reflected a desire to know when their life would return to normal. This was shared only by a desire to understand why no one communicated about the cancer within the family.

Absent in the group charts were questions about the necessity of their ill parent spending so much time away from home or the possibility that they (participant) would have to assume more responsibility. Equally, the more negative aspects associated with their experience were omitted when asked to share their story. For example, there was no mention of the increased family arguments or any consideration of what was going to happen to their family. Rather, participants replaced these concerns by introducing a question in the group charts which was not present in the individual charts. Participants reported a desire to understand why activities with the entire family were limited or nonexistent.

The Role of Coping for Statements of Desired Knowledge

As with individual existing knowledge charts, questions presented in individual desired knowledge charts were considered as a function of coping style. Patterns in the types of questions asked and the silences evident across styles allowed for a better understanding of the gaps in existing knowledge. Information regarding the nature of these questions by coping style is presented in Table 14.

Active Coping.

Medical knowledge questions among participants who reported using active coping strategies were, largely, focused on *“What is treatment like?,” “When will Mommy/Daddy get better?,” “Are there other/better treatments/doctors available?”* and *“How did Mommy/Daddy get cancer?”* Participants questioned the need for the specific types of treatment being received, expressed their frustration over the medical community’s inability to cure the cancer and worried about the possibility that, despite treatment, the cancer could get worse or return if their parent became better. Further, those utilizing active coping strategies were more likely to wonder whether the cancer could have been prevented. Medically, participants who reported more active coping strategies were less likely than those using avoidant strategies to wonder where the cancer was located or to question the severity of the illness.

Table 14

Summation of Statements of Desired Knowledge from Individual (N = 25) "What I Want To Know" Charts by Coping Style

	Active Coping (n = 15)		Avoidant Coping (n = 10)	
Category of Statement	Number of Responses	Percent of Category	Number Responses	Percent of Category
Medical Statements				
What is treatment like?[z]	4	21.0	6	31.0
When will they get better?	4	21.0	4	25.0
Are there other/better treatments/doctors available?	4	21.0	1	6.0
How did they get cancer? / Could it have been prevented?	4	21.0	2	12.0
Could the cancer get worse or come back?	3	16.0	1	6.0
Where is the cancer and how serious is it?	0	0.0	3	19.0
Emotional Statements				
What is it like to have cancer?[aa]	5	19.0	5	20.0

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[z] Includes statements such as "Why is Mommy getting this kind of treatment?," "Why can't the doctors cure it?," "What happens during treatment?," and "Why does treatment just make Daddy sicker?"

[aa] Includes statements such as "Is Daddy scared?," "What does cancer feel like?," "Is treatment scary/painful?," "Does Mommy miss us when she goes to the hospital?," "How does Mommy really feel about having cancer?" and "Does everyone with cancer feel like my Dad?"

Table 14 (continued)

Summation of Statements of Desired Knowledge from Individual (N = 25) "What I Want To Know" Charts by Coping Style

	Active Coping (n = 15)		Avoidant Coping (n = 10)	
Category of Statement	Number of Responses	Percent of Category	Number Responses	Percent of Category
Emotional Statements				
Will parent ever get better? / What will happen to them?	5	19.0	1	4.0
Why did this happen?	4	15.0	4	17.0
Will this happen to me/ other family members?	4	15.0	3	13.0
Why didn't parent take better care of themselves?	3	12.0	2	8.0
What is it like when parent does not feel sick?[bb]	3	12.0	2	8.0
Will parent die?	2	8.0	6	25.0
Why am I not old enough to understand?	0	0.0	1	4.0
Practical/Social Statements				
When will life return to normal?	2	67.0	0	0.0
What will happen to the family?	1	33.0	0	0.0

[bb] Includes statements such as "Does my Mom ever think about the "good times"?" and "Why doesn't Daddy laugh anymore?"

Table 14 (continued)

Summation of Statements of Desired Knowledge from Individual (N = 25) "What I Want To Know" Charts by Coping Style

	Active Coping (n = 15)		Avoidant Coping (n = 10)	
Category of Statement	Number of Responses	Percent of Category	Number Responses	Percent of Category
Practical/Social Statements				
Why does parent have to leave so much?	0	0.0	1	33.0
Will I have to assume more responsibility?	0	0.0	1	33.0
Why can't we talk about it (illness)?	0	0.0	1	33.0

As was present across individual charts, emotional understanding continued to account for the greatest percentage of desired knowledge for those utilizing active coping strategies. The majority of statements concerned the illness experience for their parent. Statements included: *"Is Mommy/Daddy scared?," "What does cancer feel like?,"* and *"Does everyone with cancer feel like my Mommy/Daddy?"* Equally, these participants were more likely to wonder *"What will happen to Mommy/Daddy?"* and whether their parent would get better. Further, they questioned *"Why did this happen?"* and were more likely than those reporting avoidant styles to consider the possibility that this could *"happen to me/other family members"* or to wonder why their parent *"didn't take better care of themselves?"* Finally, participants who reported the use of active coping strategies were less likely to wonder *"Will my parent die?"* and more likely to want to discuss life before cancer, which they, often, referred to as the *"good times"*. Absent in the desired emotional knowledge of these participants, however, were statements corresponding to a feeling that they were being excluded from the experience due to their status as younger.

The concerns of those utilizing active coping strategies, with respect to practical/social understanding, were heavily skewed toward their evaluations of the essence of their experience. Their most immediate concern appeared to be *"When will life return to normal?"* While no specifications for normal were articulated, participants expressed concern over the increased anger and more negative emotions expressed by family members. There was also concern with the future in terms of *"What will happen to our family?"* as well as an evaluative aspect with respect to the diagnosis in order to make sense of their experiences. Statements such as *“Why are there so many bad people in the world who do not get cancer?”* spoke to this concern.

Avoidant Coping.

Despite similarities in the percentage of overall desired medical information and that which was devoted to the experience of treatment and whether their parent would get better, there were marked differences between those using active and avoidant coping strategies in the content of additional questions regarding medical knowledge.

Statements concerning the efficacies of treatments and doctors, as well as consideration of alternatives to both, exploration of how the illness was contracted, the possibility that the cancer could have been prevented or could get worse and frustration over the inability for a cure were less frequently reported by participants reporting avoidant coping strategies. Further, unlike those using active strategies, there was no consideration that the cancer could return if their parent went into remission.

What was evident, however, were statements not present in the charts of participants reporting active coping strategies. These statements reflected the necessity of a deeper logistical understanding of the illness. That is, participants using avoidant coping strategies presented questions such as *“How serious is it [cancer]?”* and *“Where is the cancer?”* These statements were absent in the charts of those with active styles and reflected a noted difference in their perceptions of the experience.

As in the charts of participants demonstrating active coping strategies, most of the desired knowledge expressed by those with an avoidant style focused on emotional knowledge. However, as with medical statements, the nature of these statements revealed the subtle differences in the stories being told across coping styles. Whereas only a small percentage of those with active styles focused on the question of their parent's mortality, the question *"Will Mommy/Daddy die?"* accounted for the largest percentage of desired emotional knowledge for those utilizing avoidant styles. It was balanced by questions concerning the experience of having cancer, the reason this happened to their family and the worry that it could also happen to them or another family member. However, the participants reporting more avoidant coping strategies in this study focused less on whether their parent would get better or on the deeper issue of what would happen to their parent. They were less likely to wonder why their parent did not take care of themselves or to consider past experiences before the cancer diagnosis. As a result, the desired emotional knowledge of those with avoidant coping styles addressed the immediate experience of parental cancer and was more likely to focus on explanations for the overt characteristics they noted in their existing knowledge charts. They were less concerned than participants reporting active coping strategies on the cause or prognosis of the illness. Finally, participants using avoidant coping strategies were the only group to overtly articulate their experience as tangential to the illness. Their description of their lack of knowledge seemed to correlate with their perception of their developmental stage. *"When will I be old enough to understand?"* addressed a belief that information was being withheld because of an adult perception that, as yet, they would not be able to comprehend or digest the information.

Desired practical/social knowledge, as in all individual charts, accounted for the smallest percentage of desired knowledge for participants demonstrating avoidant coping styles. However, there were marked differences in the nature of the statements when compared with those of active coping strategies. This represented the only category within the study which presented no overlap between groups and presented two distinct categories of knowledge. Participants reporting the use of avoidant coping strategies demonstrated no concern for those categories presented by those using more active strategies, such as the desire for life to return to *“normal,”* or concern over what would happen to their family as a result of their parent’s cancer. Rather, as was evident in their desired emotional knowledge, participants with avoidant coping styles focused on the immediate experience of parental cancer. Statements were evenly split between *“Why does my parent have to leave so much?,” “Will I have to assume more responsibility?,”* and *“Why can’t we talk about it [the cancer]?”*

Discussion

Summation of Results

The Story Told in Private

To be a child whose parent has cancer is to live in a world consumed by the illness; where your story is driven by all that you are witnessing and the questions that lie beneath those overt changes. The majority of participants in this study were living with parents in Stage 3 cancer, many with poor self-reported prognoses. Yet, regardless of the type of cancer presented, gender of the parent and child or length of time since diagnosis, the stories they told were, essentially, the same. The information they gathered came, mostly, from their parents, but also included extended family members, doctors, the Internet, books and other sources. There was also a reliance on observation. However, this was only used by participants to describe their existing knowledge. It proved fruitless for satisfying the gaps in their understanding as described by their desired knowledge.

Thus, a parental diagnosis of cancer provided a unique setting for the narratives of these children. Every cancer had a name and a place and a definite trajectory. It required hospital stays and doctor visits and led to family alterations which were impossible to ignore. Cancer created an environment where illness information was limited to overt medical characteristics. Knowledge of a parent’s illness was based on the noted changes in appearance and behavior initiated by the presence of the disease. Cancer was defined by the changes they could see and the illness vocabulary that was, now, a part of their vernacular. That is, the participants in this study freely invoked the word “cancer” as the illness their parent had, even though it was not present in any of the study materials.

They knew its specific symptoms and possessed a rudimentary understanding of the treatment protocols (e.g., chemotherapy and radiation). Cancer was a tangible entity and their knowledge became a standardized list of all that cancer brings.

Participants wrote of parents who were debilitated physically and *"different than they used to be."* Hair and weight loss, exhaustion and constant illness were the reported hallmarks of treatment. Yet, these medical changes were taken as natural consequences of the illness. Few participants speculated on the causes of the cancer or the efficacies of current treatment protocols. When compared with desired knowledge of medical information, it was possible to view how unsatisfying this logistical understanding of the disease was for the participants. Most wondered why a specific treatment was being used and why it seemed to make the situation worse. There was a lingering presumption that there might be other doctors or protocols that were more effective. Information regarding treatment and the ensuing effects did nothing to inspire confidence of a cure. Participants lacked concrete information on causation and worried about the possibility of "relapse"; another term they possessed in their illness vocabulary.

The emotional impact of the disease was as obvious to children as the physical changes. They reported parents who were increasingly irritable and sad, or frequently depressed and uninterested in the things they used to enjoy with their child. The laughter had stopped and been replaced by anger and argumentation. This had dramatic consequences for participants, who came to mirror their parent's emotionality and begin to experience guilt when tempted to enjoy activities away from the cancer. Yet, because cancer was ascribed to the ill parent alone, there were fewer statements which demonstrated an awareness of the personal emotional impact of the disease on the child or the effects on additional family members.

However, despite this awareness of the emotional changes experienced within the family, emotional understanding represented the greatest gap in participant knowledge about the disease as was evident in statements of desired knowledge. What they were experiencing could not explain to them why it was happening or whether they or additional family members were at risk. They were concerned about their ill parent's mortality and whether their parent was also afraid. Noting the lack of joy in the house, they longed to determine if they were the only ones who noticed. Did cancer cause their parent to forget about the "good times" or fail to remember what life was like before the cancer? They wondered if there were ever moments when the sickness was not as consuming and whether these were the experiences for everyone with cancer. Yet, much like existing emotional knowledge, participants removed themselves from the questions they asked.

The personal ramifications of the illness were most noticeably evident in knowledge of the practical and social changes. Although representing the least amount of existing knowledge, this category possessed a clearer picture of the child' place in the experience. Most notably, the family no longer engaged in activities together. Celebrations were infrequent and time spent in extra curricular activities was, typically, done in the company of another relative or family friend. Even simple family dinners and frivolous conversations were rare. Life revolved around the cancer and it was an all-consuming and highly demanding houseguest. Cancer was even the topic of conversation among those who came to visit. Still, no one had told them why this was so, or, for that matter, directed these conversations to them and their experiences. They wondered why they, specifically, could not talk about the illness or why their life had to change so dramatically.

Being acknowledged as a part of the experience of parental cancer was rare for the participants. Adults who told them not to worry or provided chronic assurances of the positive results of treatment did little to stem their anxiety. On the contrary, these fostered suspicion, especially when the words were dissonant with their observed changes in behavior and emotionality within the family. Their tangential existence, as perceived by others, was most noted in their reports that, despite an increase in outside visitors offering support, few spoke directly to the participants. They expressed feeling isolated and unnoticed and longing for life to return to *"normal."*
In conjunction with their reports of adult reluctance to discuss the cancer in the presence of the children, there was also a perceived reluctance to ask the child how they were doing or express an interest in their experience of their parent's illness. The child remained invisible and was compelled to deal with the experience singularly – to dance with the "elephant" without guidance. Thus, it became important to note how they chose to cope with the illness. Viewing the stories through this alternate lens presented an additional layer to the narrative.

Those who coped actively, either by seeking outside information for topics they did not understand through books or the Internet, talking to trusted others about their experiences or finding ways to transform negative experiences into personal positive outcomes, told stories more clearly representative of an attempt to transcend the gaps in their understanding. Existing knowledge demonstrated a greater awareness of the logistics of the illness and was more balanced in the understanding of treatment protocols and the effects that ensue as a result. Participants demonstrating the use of active coping strategies were also more evaluative, commenting on the dissonance between what they were being told and what they were witnessing. Accordingly, their questions centered on a desire for more complete information. Their desired knowledge focused on justifications for the specific treatments being used, an understanding of specific illness causation, an exploration of the existence of more effective treatments, and consideration of the possibility of relapse. Beyond the medical ramifications, those who were coping actively were more likely to comment on the negative emotional reactions of both their ill and well parent, their own emotional state and the effects of the disease on additional family members, such as siblings. For example, they noted the pronounced decrease in family activities and the presence of additional others in their lives. Most significantly, they recognized the perception that they were tangential to the experience, either through the absence of direct conversation with them or recognition of the impact of the illness on them. They were aware of the conspiracy of silence. Yet, such medical, emotional, and social awareness did not provide them with an understanding of why this happened or whether it could happen directly to the participant or to someone else they knew. They were talking about the cancer, but the information was not satisfying. Their evaluative stance was evident in their presumption of the possibility that their parent could have prevented the illness and their focus on the moments when their parent was not consumed by the illness and the memories that might invoke. That is, the use of active coping strategies led participants to question the lack of focus on the “good times”. Although they wondered if their parent was scared and what cancer must feel like, they possessed significantly fewer statements questioning their parent’s mortality. Death was not the inevitable answer to *“What will happen to my Mommy/Daddy?”* Still, they wondered what the outcome would be and why their family was chosen to bear this reality. They returned to an evaluative perspective and sought concrete reasons for a disease that seemed impossible to understand. They wondered how there were so many evil people in the world without cancer when their family had to deal with it. Like most participants, however, those designated as possessing active coping strategies desired that their life return to normal. They wanted a family in which cancer was not the sole focus and there were fewer arguments and negative emotionality.

Avoidant coping styles were evident in those participants characterized as either defining themselves by their emotional reactions or denying the ramifications of the illness altogether. Their individual charts concentrated, almost exclusively, on the overt effects of the illness. Though aware of the nature of the illness and the vocabulary inherent in the experience, their stories lacked an emotional or evaluative component. They were more concerned with the severity and logistics of treatment. Participants using avoidant coping strategies desired a greater understanding of the location and severity of the cancer, as well as what occurred during treatment. This adherence to the concrete was also evident in their inability to articulate the emotional consequences of the cancer for their ill parent. Unlike those utilizing active coping strategies, those with avoidant strategies provided no existing knowledge of their own emotional reaction to the experience. As a result, their desired knowledge reflected a greater desire to know if their parent experienced treatment as scary or painful or whether they were missed when their parent was in the hospital. They expressed trust in those who told them not to worry and assumed that at some point they would be deemed old enough to understand. Thus, they sought fewer additional avenues of information acquisition. Participants demonstrating an avoidant coping style were also more significantly plagued by questions of their parent’s mortality. Denying their ability to understand, and relying on others for information had not been able to satisfy their belief that the inevitable end to what they were seeing their parent go through was death. Still, for these participants, the reality of an ill parent who did not play with them was compensated for by others who provided them with preferential treatment either through gifts or increased attention. Though they wondered why their parent had to leave so frequently, whether they would have to assume more responsibility and why no one ever wanted to talk about the cancer, it was easier for them to ignore the impact and forgive the lack of direct consideration. As a result, those reporting avoidant coping strategies were less likely to present themselves as tangential. They were less concerned with being included in the illness experience and more concerned with whether they were still receiving attention, whatever the motivation.

In summary, regardless the type of cancer or stage, participants told similar stories of the experience of a parental illness. Cancer was a consuming entity that permeated every aspect of their life. Yet, they portrayed themselves as tangential to the experience of parental cancer – talked at or about but rarely to. Having the opportunity to express their levels of knowledge allowed them a voice few had ever exercised. Across individual charts, existing knowledge was, predominantly, medical in nature. All participants articulated the illness as cancer and freely used the vocabulary associated with symptoms and treatment. Overall, existing knowledge centered on overt changes – the medical consequences of treatments, the negative emotions demonstrated by their ill parent and the simple fact that there were fewer family activities since diagnosis. Yet, this knowledge proved insufficient and many questions remained. Having a parent with cancer proved an exercise in knowing what without why. Thus, desired knowledge focused on those missing explanations and was, predominantly, emotional in nature. There was a need to understand the changes being witnessed; both the reasons for them and what may happen as a result of them. Questions of parent mortality, the potential for relapse, personal vulnerability and the efficacy of treatment were evident. Yet, the nature of participant statements and questions also depended upon how they were coping with the illness. Those who coped actively, either by seeking additional information to that which they were witnessing or being told or finding positive rationales for negative circumstances, possessed greater information on illness logistics and presented a more comprehensive picture of the effects of treatment upon the family. They were also more evaluative in their statements; qualifying what they knew with their opinion of the situation. As a result, they desired a more complete understanding of what they were experiencing beyond what they were being told or could discover on their own. These participants shifted their focus from the immediate situation and, rather, explored both the past and future trajectory of the illness. They desired information on causation and prognosis. Participants designated as using more avoidant coping strategies, by contrast, sought escape from the illness, were, largely, present-oriented. Their existing knowledge focused on overt changes in health, emotions and family life. Theirs was a list of experiences. However, despite their ability to delineate the experiences and use the vocabulary, participants utilizing avoidant coping strategies lacked a true understanding of what they were noting. As a result, their desired knowledge was also related to their immediate experience. They rarely considered the causes or prognoses of the illness. Rather, they desired additional information about the logistics of treatment and the emotional reactions they were witnessing. However, their present-orientation also caused them to be more concerned than those with active strategies about their parent's mortality. For participants reporting avoidant coping styles, cancer was equated with death. Yet, rather than considering the impact of the question, they were readily able to shift their focus to the preferential treatment they enjoyed as a result of having a parent with cancer. The increased attention from others, in the form of time or gifts, compensated for their lingering fears and concerns.

The Story Shared

Although they shared a large proportion of similarities, the noted discrepancies between the private story, illustrated in the individually written charts and the public story, when aspects of that information were asked to be made public, was glaring.

Medical understanding within the group was limited to known illness vocabulary and overt illness ramifications. That is, statements focused on declarations that the illness (always, spontaneously, referred to as *"cancer"*) existed within the family, the logistics of the illness such as where the cancer was located, and the symptoms it presented. There was recognition of hospital stays to receive different types of treatment, which were delineated, as well as the physical effects of the protocols. However, unlike the individual charts, there was no desire to understand causation or any admission of prior knowledge of someone else with cancer. Further, none of the participants volunteered a belief that the situation was not as optimistic as they were being told and that, at times, procedures were not successful. Emotionally, they also removed themselves from the story. Cancer was all about the changes evident in their parent and other family members. Their emotional state was either deemed unnecessary to share with the group or was done without deeper explanation. Participants labeled how they felt but not, specifically, why.

The family situation chosen to be presented in the group charts was also altered when compared with individual charts. No longer was the family plagued with arguments or anger. Expressed parental depression (in both ill and well parents), financial strain, the addition of new members to the household and greater general emotionality was replaced by a single statement denoting "*more stress*" in the home. Equally, an ill parent privately described as bored was, publicly, unable to decide what to do with their additional free time.

Practical and social changes in the group charts were, solely, ascribed to the lack of family activities. There was no mention of the lack of communication within the family or the presence of other relatives in their lives. Once again, cancer became a more global disease and the personal impact was downplayed. No participant chose to share evidence of the preferential treatment by others, either through the receipt of gifts or increased attention, they reported enjoying in their individual charts. Rather, this was portrayed as increased regard with respect to others in their life (*"Everyone always asks me how I am"*).

The dichotomies between the private stories, written in the individual charts, and the public story, portrayed in the group charts, were also evident in the statements of desired knowledge participants chose to share. There was discomfort presenting any information that spoke to the negativity of the situation. Participants wondered it their parent would get better, but not if they would get worse or relapse. They wondered about the choice of treatment but not if there were more effective ones available. Emotionally, they wondered why the illness happened and whether their parent was scared, but refused to entertain the possibility that it could happen to them or someone else they knew. Most striking, however, despite its prevalence in the individual charts, was the lack of acknowledgement, in the public story, that their parent might die. Issues of mortality or those which projected the, potential, negative aspects of the future outcome were silenced. There was a unanimous preference to neither voice nor speculate with others where this illness might lead. Their focus remained on their immediate experience and that which they all, overtly, shared. Primarily, they were concerned with their life returning to normal, which seemed to be defined by increased communication on topics other than cancer and the renewed ability to do activities as a family. They wanted to be just like every other family they knew.

In summary, the group charts presented a carefully constructed public story. Information was presented in generalities without explanation or depth. Existing knowledge remained concentrated on the overt changes, but the use of vocabulary to describe those changes differed. Medical knowledge was a declarative listing of symptoms and effects. There was no speculation about causation or prognosis. Public stories lacked the specifics of the, often, negative emotional changes that were prevalent in the private stories. A home with greater anger and sadness became one with additional stress. Moreover, unlike private charts, there was no recognition of their own emotional reaction, other than to label their feelings. Similarly, the only privileged changes in family life were the cessation of family activities and increased concern from others. This sense of optimism was also evident in their statements of desired knowledge. There was little consideration of the severity of the situation or the potential outcome. Unlike the individual charts, the groups never expressed concern for their parents' mortality or whether they or anyone they knew was also at risk. Across groups there was an almost tacit agreement to speak in generalities and remain focused on the most positive aspects of their immediate experience. They seemed unwilling to share their fears or discuss their concerns.

Explanation of Results

A parental diagnosis of cancer is not an event that happens to a family, it is an activity engaged in, at times, independently, by each family member. As the disease progresses, this process continually changes and is changed by individual responses to it. It is a dance; the steps of which cannot solely be understood through a quantitative exploration of the logistics of the choreography. Coupled with the reality that most children are dancing with an unknown and unarticulated partnered, it must be understood within the context of the dance as told by the dancer; each step explained and every nuance explored. For this reason, this study transcended a needs assessment of the levels of knowledge children possess regarding their parent's cancer and the gaps in that knowledge. It took a narrative approach to these variables in order to understand the themes surrounding the experience of a child whose parent has cancer and how this might affect their choice of steps to cope with the illness and dance with the "elephant".

Compas et. al. (1994, 1996) argued that neither stage of parent cancer nor prognosis was related to symptoms of anxiety or depression in preadolescent children of cancer patients. This study expanded those results by suggesting that the impact of stage and prognosis were more strongly evident in what children understood about the cancer rather than how it impacted them psychologically. Indeed, a significant interaction between existing medical knowledge of their parent's cancer and both stage and prognosis was determined. Parents at a more advanced disease stage and those who reported a poorer prognosis had children who reported more existing medical knowledge. Due to the advanced nature of the condition, it was possible that the effects of disease and treatment were more evident and, as a result, more readily perceived by the children. This was most evident in the individually written charts. Portrayals of the immediate experience of their parents' illness skewed significantly toward medical themes and focused on overt aspects of the disease as it related to their ill parent. Cancer was portrayed as a tangible entity and most existing medical knowledge was logistical, with little detail or explanatory intent. Desired medical knowledge, in contrast to existing medical knowledge, focused on the need to understand the effectiveness of these medical procedures, as well as the finite logistics behind the familiar treatment names (chemotherapy and radiation) and the precursors and severity of their parent's illness. While still parent-directed, this desire to go beyond factual knowledge mirrored results reported by Kalish (1998) which suggested that children would specifically seek out causal information about illness. This activity was found to be a central element, not only for individual illness understanding but also for children's ability to cope with the illness (Kailsh, 1996). Moreover, the prominence of these parent-directed statements in both existing and desired medical knowledge was in direct contrast with results of previous studies which indicated that preadolescent children of cancer patients reported significantly more ego-centric positions such as concern with personal activities (Armsden & Lewis, 1994).

The differences between existing and desired medical knowledge found in this study were consistent with a quantitative study conducted by Mukherjee et. al.(2002) on children of parents with irritable bowel syndrome. However, the use of a more qualitative approach in the present study allowed for deeper exploration of the dichotomy and a more detailed account of each child's unique perspective. Factual knowledge about illness did not always lead to conceptual understanding (Bibace & Walsh, 1991; Osborne, et. al., 1993). This was evident in results which suggested that increased amounts of medical knowledge led to an increased desire to understand the personal social ramifications of the illness. Thus, although participants knew the vocabulary and could articulate the observed physical changes, they were unable to determine how such effects impacted them. Once again, cancer was linked exclusively to the ill parent.

Existing emotional understanding also focused on overt characteristics. That is, most statements referred to the negative emotional changes experienced by the ill parent, such as increased sadness, anger and a lack of interest in activities. Participants were less likely to express an understanding of their own emotional reaction or to reflect upon the emotional effects on other members of the family. As with their medical knowledge, the reported emotional effects of cancer were ascribed, solely, to the ill parent.

Desired knowledge, corresponding to the need to understand the emotional impact of cancer on their parent, mirrored the prominence of medical statements in existing knowledge. There was a strong desire to explain what their parent was experiencing, even as some of the questions lacked simple answers. Unlike existing knowledge which focused on overt changes and immediate experience, desired emotional knowledge reflected a gap in the understanding of that which they could not immediately see. For example, central to their emotional understanding was the answer to "*What is it like to have cancer?*" Additional statements focused on future perspectives, including the possibility of death from the disease and the possibility that cancer could happen to them (participant) or other family members. Similarly, consideration of past events and a desire to regress to a time when cancer was not the consuming theme of their family life was evident in statements desiring conversation about "*the good times*" and those which pondered whether their parent always felt sick. Such understanding was significantly lacking in the knowledge of the participants and was closely tied to knowledge of their social situations. Knowledge of the emotional impact of their parent's cancer was discussed in conjunction with how this emotional state affected changes in routine.

Despite this correlation, and contrary to studies with adolescent children(Compas, et. al., 1994, 1996; Pederson, 1988) and those of children whose parents have irritable bowel syndrome(Mukherjee et. al., 2002), the preadolescent participants in this study rarely mentioned the social ramifications of their parent's cancer. Existing knowledge of social changes was presented as factual accounts of the daily routine and focused on an inability to engage in familiar activities as a family. It suggested a familial lack of communication regarding the disease. As expected, therefore, in terms of desired knowledge of further changes in routine, the focus was, predominantly on when and whether life would return to "*normal*". This was articulated as those routines established before cancer, in which activities were engaged in as a family and communication covered a variety of topics.

Beyond exploring levels of existing and desired knowledge, this study also considered the means by which children obtain information about their parent's cancer as an important element in the story told. The majority of participants reported discussing the disease with their parents and named family as their primary source of information. Studies (Williams & Binnie, 2002; Korneluk & Lee, 1998) and suggestions made by the American Cancer Society (1999) suggest that providing children with factual information concerning their parent's illness, and allowing them the opportunity to discuss their ideas and understandings is highly beneficial for the child's ability to cope with the disease in the long-term. Yet, despite this admission, lack of direct communication about the disease was a recurring theme in the changes the participants articulated as a result of a parental diagnosis of cancer. This would suggest a comment upon the quality of the information being presented, and the efficacy of what they were being told, in their ability to cope with the changes cancer brings. As was evident by the nature of their existing information, discussions were limited to what was immediately evident, with parents or family members providing information specific to the nature of the cancer without deeper explanation of why it occurred or the impact it had for everyone involved. As McQuaid, et.al. (2002) suggest, this set up a hierarchy whereby responsibility for expert knowledge of the illness was ascribed to a single family member and there seemed to be no need to educate the rest of the family. In this case, the ill parent was the expert on their illness and they only shared specific aspects of it with the children. Thus, children's knowledge was limited to what could be seen and the vocabulary associated with the illness. Often, this necessitated an outward search for additional information.

McQuaid et.al. (2002) suggest that repeated experience with and exposure to domain-specific information may lead to more advanced understanding. Participants reported accessing Internet sites, using books and periodicals, speaking with others and relying on personal observation as methods they employed to gain additional information beyond what was told to them by their parents. Some participants even reported having spoken to members of the medical staff about their parent's cancer. The opportunity to talk to health care professionals in order to be given information about their parent's health and treatment has been shown to be an important concern for children (Muhkerjee, et.al., 2002) and requires further study. While it was evident that participants who sought external information about the cancer were denser in the amount of existing information they reported, they were equally likely to desire more causal information. Despite knowledge of the changes, there was no explanation provided regarding why those changes were unfolding as they were or when they would end. The end of these anomalies would signify the end of the cancer. This suggests that the quality of information made available to children from outside sources may also be lacking in depth. However, despite this lack of significance in terms of the perceived quality of existing and desired knowledge, what was evident was that the use of one external means was related to the use of another. That is, a participant who sought information from a source beyond what was being told to them by their parents was likely to have used multiple sources in the pursuit of additional information.

The desire to seek out information not being directly provided by parents had important implications for coping with the illness and shaped the nature of the stories told by active and avoidant copers. Active coping strategies such as problem-solving and monitoring have been found to be related to better functioning when compared with less active or avoidant strategies such as distraction (Compas, Malcarne, & Fondacoro, 1988; Endler & Parker, 1990; Pedersen, 1989).

Children described as utilizing active coping strategies told stories that reflected their increased knowledge of the nuances of the illness, prompted by a greater willingness to seek additional information from sources beyond their parents. They coped with the illness to create a sense of order in understanding reality by developing relatively absolute mental structures (Johnston & Martin, 1992). Their observations tended to be more refined and based on a factual understanding, which they continually sought to corroborate. Consistent with research on adjustment to parental illness (Johnson, et.al., 1992), the stories presented by these participants were devoid of magical thinking and were more grounded in an understanding of and identification with the problems associated with the illness. Cancer was happening to everyone. Further, they were less likely to report being angered by the limitations the illness imposed on their lives. Their ability to seek additional sources of information or find the positive aspects of their situation allowed them a better understanding of their own emotional reaction and more objective observations on the nature of the changes in their family.

The quality of information guiding the stories of those reporting avoidant coping strategies was subtly different. In a parental cancer population, Steele, Forehand and Armistead(1997) found increased use of avoidant strategies predicted more internalizing problems in children. Glass (1985) cited an increased desire in children dealing with parental disability to keep their feelings hidden from parents and siblings. Beavers (1982) expanded upon this idea and suggested that their, more avoidant, coping style manifests itself as acting-out behavior, poor school performance, social withdrawal, sexual promiscuity or substance abuse. As a result, a sustained reliance on such a strategy has been found to impede individual confrontation with and overcoming of the stressor of parental illness, resulting in psychological dysfunction (Holahan & Moos, 1987). While the stories of participants reporting more avoidant strategies in this study lacked such pessimistic extremes, they did express a reliance on reassurances by others that they should not worry. They sought no deeper understanding of what they were experiencing and remained focused on the overt, predominantly negative, changes they were experiencing across thematic categories. However, unlike those demonstrating active strategies, who used others as additional sources of information, those reporting avoidant strategies relied on others for the distraction, provided through increased time spent or gifts given, as compensation for their parent’s illness.

Beyond these private narratives regarding the experience of and meanings made from a parental diagnosis of cancer, in terms of existing and desired knowledge, both generally and by coping style, this study added an additional element by asking participants to share their experiences and collaboratively construct a public story. This shared narrative differed from the one independently written in the charts in important ways. While individually written charts reflected numerous elements of situated evaluation (Daiute & Nelson, 1997) as participants made sense of the experience by exploring what was happening and considering what might happen next, group constructed charts were more script-like, adhering to the referential core of the narrative (Labov & Waletzky, 1967). Existing knowledge was still medically-based. However, it pertained almost exclusively to a tacit understanding of the location of the cancer and its discernable effects, without further mention of the potential causes or evaluation of the severity of the condition. Emotional understanding was equally overt and exclusively parent-directed. No mention was made of the participant's own emotional reaction and there seemed to be a conscious desire across participants to present the most optimistic portrait of the illness. This carried over into their presentation of the incurred changes and the information they desired to know. Unlike the individual charts, there were no statements shared which considered the severity of the cancer or the possible role the parent could have played in prevention. Similarly, the possibility of relapse after successful treatment was never considered. The most glaring omission, however, was the complete absence of questions surrounding their ill parent's mortality. Though "*Is Mommy/Daddy going to die?*" was a prominent part of their individual narratives, it was never voiced within the group.

The language of the group narrative was, similarly, altered in articulating the changes that had occurred. The individual portraits of a home wrought with anger, sadness and argumentation became a family where cancer created an environment of stress. There seemed no need to reveal the subtleties or explain the choice of words. This suggests the possibility that group charts reflected an active desire to position oneself within the narrative (Davies & Harre, 1999). There was a specific relational context between the language represented in the individual and group generated charts. Each was written for a specific audience and, as such, subject to linguistic and thematic issues of addressivity (Bakhtin, 1986). Individual charts were, arguably, written for the families and those in the intimate network sharing the experience. They provided a more open forum to explore less optimistic aspects of the experience, as these were being shared by those witnessing them as well. Thus, there was more candor. Within the group, however, familiarity was more generally assumed. While finite explanation was not necessary, due to tacit understanding of the experience by all the participants sharing it, the audience was significantly different. As a result, the story was more script-like; reflecting globally shared experiences without finite exploration of the darker aspects of the story.

Equally, as this was only a two session group, familiarity with other group participants was limited and, therefore, certain aspects of the personal experience remained guarded. Glass (1985) cites an increased desire for children dealing with a parental illness to keep their feelings hidden from parents and siblings. Though postulated as an effort to protect those in their most intimate network, this social phenomenon was also evident in the presentation of the experience to similar peers. Though not expressly required to, each participant contributed at least one statement to each of the group charts. However, there was a marked reluctance to argue with the trajectory of the statement being presented or to deter from the tacit, and emotionally optimistic, script. Developmentally, this may reflect the Eriksonian (1982) crisis of Industry and Inferiority experienced by this age group. The absence of negativity or contradictory statements in the group charts speaks to the possibility that participants were attempting to present a sense of self within the group as one who was competent to cope with the experience. This increased concern with the opinions of others, and the possibility of judgment from the group with regard to the statements presented, skewed the nature of the information shared. In accord with the need to tailor a specific personal persona for the group, suggestions of personal vulnerability or situations without an element of optimism were not permissible. Given the brevity of the sessions and the limited ability to form relationships, the discrepancies between individual and group charts may be more a function of the social phenomenon of a specific audience rather than of the desire to extend the conspiracy of silence and protect one's parents.

Overall, the candor of the participants, especially with regard to their individual charts, presented a comprehensive story of the experience of parental cancer. Though statistics created globally significant thematic categories, it was the more narrative approach that allowed for a nuanced exploration of those categories and recognition of the, often, unheard voices of these children. Through their private articulations and the silences revealed when those articulations were made public, it was possible to create a portrait of the actual experience of the illness. Through the structural frame of their existing and desired knowledge, analyzed both globally and through the lens of their coping styles, as well as determining the lengths they were willing to go to obtain information, it was possible to actualize the "elephant" and provide him a proper place within the family. In doing so, the children in this study were able to present their experience of their parent's illness and, simultaneously, find their unique and shared voice in the meanings they made from the experience. Combining individual written activities with public sharing within the group provided a context for the development of self. Participants were afforded the opportunity to engage in individual evaluation and interpret which aspects of that evaluation to present to an audience. This created an exploration of different kinds of me (Daiute & Nelson, 1997). Privately, their written charts displayed a breadth of information, existing and desired, occurring in spite of a lack of familial communication and in the full presence of the "elephant" in the room.

Publicly, a social persona of positivity and resilience was assumed by these children. Ultimately, this activity empowered their ability to cope effectively with their parent's cancer. For in presenting their stories, both individual and shared, not only was the "elephant" actualized, the child was now able to dance with it according to a fluid, recognizable pattern borne of familiarity and mutual respect.

Implications

Theoretical and Methodological

Participants reflected an underrepresented age group in the literature on coping with parental cancer, which tends to focus on adolescents, especially female adolescent children of breast cancer patients (Compas, et.al., 1994, 1996) and represented a cross-section of cancer types and stages. However, the implications of the results of this study transcended the need to support or refute existing research on parental cancer in families and children's knowledge of illness. What became evident was that such delineations were inadequate to explain the results. The merits of this study lie not in the ability to agree or disagree with existing research. Rather, they serve as a bridge between conflicting theories by illuminating the potential gaps in each.

The nature of the study greatly supports the definition of narrative inquiry proposed by Polkinghorne's (1997). The written charts, constructed both individually and cooperatively, presented parental illness, less as objective truth or a reflection of reality, but, rather, as knowledge as human construction. Despite the overt characteristics delineated in the "*What I Know*" charts of existing knowledge, the choice of story elements and the emotional impact revealed in the *"What I Want To Know"* charts of desired knowledge, were in the control of the child as storyteller. Through these selective patterns of attention (Bronfenbrenner & Ceci, 1994) each child was actively engaged in making meaning of their experience, often in the absence of familial communication. Thus, their stories represented an understanding of their evident perspectives on a lived experience and their attempts to make sense of that experience (Padgett, 1998; Ricoeur, 1985). It was a specific type of situated meaning (Patterson & Garwick, 1994). By applying a narrative perspective and avoiding the clinical lens so often used in studies of coping with a parental diagnosis of cancer (Compas, et.al., 1994, 1996), it was possible for the children to tell their stories without pathologizing their experiences.

A reliance on more than a statistical approach to the data allowed for a richness of findings that were not, otherwise, evident. Statistical analyses yielded limited significance and failed to reflect the nuances revealed in the narrative data. This suggests a fundamental need to consider layers beyond quantitative approaches to data collection. The application of a narrative analysis to the non-narrative data contained in the workbooks broadened the merits of the approach and enabled greater access to levels of meaning which may have been unknown to the children as they lived through the experience (Mattingly, 1991). The individual written charts allowed them the opportunity to reflect upon their experiences as a meaningful story to be told. In, then, verbalizing elements of their story to the group, they gained empowerment through controlling the way they chose to present their story and controlling the elements revealed to the audience. Group constructed charts allowed participants to select those facts they deemed permissible to share. Facts which represented negative aspects of the experience or which associated the storyteller with negative stereotypes (Apfel & Simon, 1996; Daiute, Buteau, & Rawlins, 2001) were not included in group charts but were evident in individual written charts. Thus, a design which included private activities and public sharing allowed as much to be learned from the silences, present in the individual charts but excluded from the group charts, as from their shared voice and represents a unique area of exploration. Research must be extended beyond the individual, and pathologized, experiences of a parental illness to explore the story children choose to present publicly in the presence of similar others. How a child chose to position themselves within the story told to the audience reflected a desire to present an identity and position themselves within the experience (Bamberg, 1997; Daiute, et.al., 2001; Nystrand & Wiemelt, 1991).

Research that suggests the beneficial role of information in positively adjusting to a parental diagnosis of cancer (Horowitz & Kazak, 1990; Kazak & Barakat, 1997; Kliewer & Lewis, 1995) is merely the tip of the iceberg. This study supports the need to qualify the type and depth of information received, by directly asking children what they deem necessary. In accord with existing research, the participants in this study reported disruptions in family processes variables (Cunningham, et.al., 1999; Gilbar, 1998; Grant & Compas, 1995; Leedham & Meyerowitz, 1999; Lewis, 1990; Lewis, 1986; Lewis & Hammond, 1996; Siegel et.al., 1992), as well as limited familial communication and increased hostility and irritability (Armsden & Lewis, 1994; Christ, et.al., 1994; Compas, et.al., 1994; Garber & Robinson, 1997; Garber, et.al., 1997) . However, while this comprised a majority of children’s existing knowledge and were the elements recommended as necessary to communicate to children (Compas, et.al., 1991; Fields & Prinz, 1997), such elements of their changed world were realities assumed by the children and did not account for the full experience of parental cancer. Medical issues and life changes could be seen. What became evident in the reports of the participants was the importance, not of the concrete elements of the experience, but of the elements that remained unspoken - the "*Why?*" so often ignored in existing research. To argue that children specifically seek out causal information in the effort to understand the illness (Kalish, 1996) is meaningless without an understanding of what types of causal information are being sought. As was evident in this study, it is not merely why the cancer occurred, but the emotional impact of the changes it brings to everyone involved. In direct opposition to studies which recommend the use of knowledge as a way to remove blame from the child (Cunningham, et.al., 1999; Leedham & Meyerowitz, 1999; Veach, 1999), the results of this study indicate an absence of self-blame and a focus on a desire to understand the emotional needs of the parent through the experience of the illness. That is, while existing research focuses on the emotional needs of the child, this study indicated a definite desire to understand the emotional response of the parent as an important addition to the literature.

Cummings and Davies (1994) caution against the tendency to pathologize children's responses to parental cancer. The mere presence of a parental illness does not, inevitably, lead to adjustment difficulties. This study corroborated evidence that children cling to the surviving elements of their life before their parent became ill in their attempt to cope with the experience. However, unlike Altschuker, et.al. (1999), it was not within the safe haven of school that this was accomplished. Rather, in this study, children reported clinging to the happy memories of life before cancer and the activities previously done as a family. This remains an unexplored protective factor. Though cancer consumes many of the daily activities of life, it does not steal the memories of these children. Unlike research by Beavers (1982), which argued for the importance of an orientation toward the present when coping with a parental illness, an orientation toward the past may have important coping benefits and was employed by those participants utilizing active coping strategies.

Thus, parental cancer can no longer be viewed as a singular event happening to the patient, with only tangential effects on subsequent family members. As Pedersen and Revenson (2005) suggest, merely invoking the label “cancer” provides little information about the potential losses incurred. Rather, it is necessary to explore the stories which can only be told, accurately, by those experiencing them. The children in this study were participating in the process of the illness to the same degree as their ill parent and, as a result, their experiences were no less valid. Though, this more functionalist perspective to children’s concepts of illness, emphasizes the role of experience over more structural, cognitive interpretation (Eiser, 1989), children’s illness knowledge must be expanded beyond traditional or functionalist models to include knowledge of illnesses which are contextual but non-personal. Cancer is a dance dynamically and actively engaged in by all family members and requires research within an ecological frame to explore the uniqueness of these individual experiences.

Applied Application

This more dynamic and ecological approach to children’s adjustment to parental cancer can assist families as they cope with the disease. What became evident in this study was the effective use of the support group as a tool rather than an independent variable or outcome measure. Moreover, it spoke to the need to tailor such groups to the specific needs of the participants. This is only possible if research first explores the stories of these children, so as to understand the meanings they make of their experiences.

This would suggest the benefit of health interventions for families which ascribe to an Information-Motivation-Behavior Skills Model (IMB) (Fisher & Fisher, 2002) which combines presentation of topical information with the motivation to continue effectively coping with the experience and providing the behavior skills necessary to do so. Information is developmentally appropriate and can be generated directly from the children and reflects the needs described in this research. For that reason, it is necessary to explore a child's lived story through their existing and desired knowledge. Support groups can be tailored to the needs presented and effectively intervene in those areas deemed important by the children. Unlike existing information currently available to children and families, nothing would be assumed. Information would not be limited to the changes cancer brings, but would also focus on the experience of cancer and the alleviation of fears. In accord with the avenues of information generated by the children and consistent with their developmental level, this could include discussions with cancer patients, the opportunity for medical play as described in Bolig, Yolton, and Nissen (1991) and McCue (1988) as well as the opportunity to speak with members of the medical community.

Further, attempts to increase family communication with specific reference to the reported gaps in knowledge could be employed to address areas of concern. For example, a family journaling activity, where questions and concerns could be written and addressed may prove a useful tool. It would provide a non-threatening forum for children who may be reluctant to approach parents or family members due to their belief that doing so would contribute to the reported household stress. Such an activity would transcend the silences of the public story by allowing for a private recitation of concerns. Questions could be answered and concerns addressed in general family meetings which would increase the breadth and depth of family communication. That is, the family journal would provide a script for the conversation and a way to ensure the needs of all family members were addressed.

Williams and Binnie (2002) argue for support groups which provide children with factual information concerning the illness, along with an opportunity to discuss their ideas and understandings of the illness, as effective in assisting their process of adjusting to the illness. Yet, it is equally important to address the emotional needs of the children. As was suggested by Kalish (1998), children dealing with a parental illness can work successfully in groups which focus on loss, such as those for death of a parent, divorce or separation. Despite an unwillingness to share the deeper loss concerns with the group, individual stories spoke to the myriad of losses incurred by the changes parental cancer brings. A bereavement slant would allow children to grieve the lack of communication and time spent with their ill parent, as well as to mourn the loss of a world diminished by the illness. In doing so children would have the opportunity to share those important memories of life before cancer.

Limitations of Dissertation Research

Design Issues

Despite the significance of the study, there were many limitations. Participants were referred through the Archdiocese of New York and from referrals from social workers and those who work with oncological populations, there was the possibility of selection bias.

The study was biased toward in-tact families. Future studies should explore the ramifications of cancer in single-parent families. Children in these situations may present a different kind of existing and desired social knowledge, as there may be less of an ability to present a consistent family routine. Similarly, a family in which there is a single income may have greater financial concerns and increased limitations on family activities, including the presence of non-family members in their lives. These can be confounding variables that influence the findings. A more diverse socioeconomic sample also might reveal more limited possibilities for information acquisition.

Further, a more diverse ethnic sample (all participants were Caucasian) may reveal differences in the willingness to discuss cancer with children. For example, studies of Asian populations reveal a view of illness as shame and an unwillingness to burden others by discussing the experience (Landrine & Klonoff, 2001). The degree to which such cultural norms have been internalized by children may impact the nature of the information presented or their comfort with the group environment. While willing to explore their story privately, a more ethnically diverse sample may have altered the public story voluntarily shared with the group.

In contrast to existing studies, there were no gender differences for the types of information presented or desired (Wagner & Compas, 1990; Altschuler, 1993; Dale & Altschuler, 1997; Parker, 1993; Steele, Forehand, & Armistead, 1987; Levinson, 2000) nor were their differences when the degree of symmetry between the gender of ill parent and child were explored (Compas, et.al., 1994, Brown, et.al., 2007; Gilligan, 1982;

Goldner, 1985). This, too, may also have been due to the small sample size and lack of diversity in the ethnic and socioeconomic structure of the groups.

Statistical Problems and Measurement Error

The small sample size did not allow for expansive generalization of findings. As a result, these findings can only be viewed as preliminary results which can be expanded upon with larger, more diverse samples.

Similarly, the two session design may have been too short a time frame to allow for participants to fully acclimate to the format. It was assumed that participants were comfortable with the group setting and the assurances of confidentiality regarding the information they presented. It was possible, however, that participants were cautious, especially with regard to having an adult facilitating a group for children, and tailored their responses. This may have provided an alternate explanation for the differences noted between the individual and group results and provided confounding variables which went unexplored. As such, it could also have affected the statistical significance of the results.

Of equal concern was the lack of inter-rater reliability checks on coding. Codes were developed and used by the researcher and were not reviewed by additional raters. Therefore, measurement error must be considered and could have impacted the nature of the results. There may have been additional confounding variables, inherent in differing interpretations of the construct, which may have gone unexplored. Such variables could also have impacted the nature of the results.

Future Directions

Despite these limitations, the results of this study inform the literature on illness knowledge and adjustment to parental cancer and allow for the application of findings in the pursuit of helping families effectively cope with a parental diagnosis of cancer. Perspective is gained when a child discusses an illness of which, while not an active participant in, still personally impacts them. This necessitates a view of the family as an ecological, dynamic, system where the interrelation between members supersedes the singular experience of any individual member.

Faulkner and Davey (2002) argue that children of cancer patients are good at sensing when something is wrong. Therefore, while it is important to discuss the situation in developmentally appropriate ways (Cunningham, et.al., 1999; Leedham & Meyerowitz, 1999; Veach, 1999), it is equally important to expand theoretical assumptions of what that entails. Future research must rely on a more narrative approach in order to allow children to generate their own meanings. That is, it is inadequate to assume what children know or want to know in the absence of directly asking them. Similarly, strict adherence to developmental theories on illness knowledge may limit the understanding of the level of knowledge actually held. Future studies should consider a theory of knowledge to include contextual experiences and multiple avenues of information acquisition.

In the same way, research allowing children to generate their own concerns and illuminate the true breadth and depth of their knowledge must also explore the beliefs parents hold about their children’s existing and desired knowledge. By comparing the differences in statements generated by the children and the presumptions of what their children know as reported by parents, it will be possible to gain a greater understanding of the nature of family communication. Although the participants in this study reported their parents as important sources of information, the differences in their existing knowledge (more medially based) and desired knowledge (more focused on emotion) suggest that parents are a less than adequate resource. It is necessary to understand both what children are being told and the questions asked in pursuit of additional knowledge.

A child's style of coping with respect to a parent's illness may also be influences by the coping strategies employed by the parents. Children perceive their parents to be the most frequent providers of coping assistance, mainly in the form of reestablishing roles and routines and providing distraction (Prinstein, et.al., 1996). Kotchik, et.al.(1996) and Steele, et.al.(1997) reported that parents' coping styles significantly predicted child adjustment to the disease, such that avoidant coping employed by either parent was associated with increased parental reports of internalizing and externalizing problems in children. Parents are often reluctant to engage in conversations they believe will be distressing for their children. However, the assumption that children's coping strategies are merely mirrors of those employed by their parents ignores a certain developmental trajectory. Compas, et.al.(1991) found that active coping strategies were acquired earlier than avoidant ones. This suggests that active strategies may involve behavior modeled by parents whereas avoidant strategies are less easily observed and require more sophisticated cognitive development.

In such a way, the results obtained by the present study may be useful in providing a foundation for services made available to children coping with parental cancer and their families. Pamphlets and children's books concerning a parent's cancer can be altered to limit the amount of medical information they present. Children are aware of the physical, emotional and practical changes cancer brings. What is needed is developmentally appropriate literature which explores the experience of having cancer for their parent and the emotional impact felt throughout the family.

Similarly, interventions can be designed according to the actual needs of these children and provide a more effective tool in normalizing the experience of parental cancer, rather than pathologizing it. Increasing the number of sessions beyond those presented in this study will allow for greater comfort with the format and the ability to build relationships with each other. This may expand the nature of the public story as trust and confidentiality will become more internalized. Further, interventions can not be limited to the children and their needs. It is also necessary to provide children with concrete coping skills which can be used within the family.

In Conclusion

The present study supports a developmental-ecological-contextual theoretical framework (Bronfenbrenner & Morris, 1998; Lerner, 1989). A parental diagnosis of cancer is not a singular entity or static event. It is a dynamic and complex activity engaged in by the entire family, not merely the afflicted. It is a dance whose steps are dictated by the choices made, both collectively and individually, in the continuous process of making sense of the disease. Yet, the knowledge inherent in that understanding, especially for the children involved, cannot be understood within a single methodology or conceptual framework. It requires a contextualized and situated study of illness knowledge.

When we come to understand what children know and desire to know about their parent’s illness, we are able to actualize the “elephant” of cancer and provide it with a proper place within the family. The stories told by the children in this study represented the meanings made through their negotiations of this process and are only beginning to be told. Individually, the knowledge woven through the narratives provided them with a vocabulary and a voice. It empowered their ability to cope effectively with their parent’s illness, as they were provided with the opportunity to consider their steps in response to the “elephant” and make him a less intimidating partner. Once shared, however, their stories now serve to empower others by normalizing and depathologizing the experience of parental cancer.

Epilogue

Gergen (2004) suggests that, when doing narrative research, it is important to reflect on the self as researcher and to understand that the researcher, at the very least, enters into the way the narrative is organized and framed. While I was privileged to have been able to bear witness to the voices of these children and to share their stories, and while I recognize my role in framing the story told, the experience of working with these children transcended these research results.

When I started this process, I was intimately aware of the subjectiveness of the experience. Having grown up in a home with an ill parent, the desire to see this project to fruition was a deeply personal one. Their story was my story and I knew how important it was that it be told and how much it would mean to these children and to those who would come after them. Though I never shared my story with the participants (I did not want to be considered an "expert" or someone who could answer all their questions), I was also not shocked by their concerns, their anger or their exploration of the negative aspects of the experience. Yet, in being able to relate to them, I was also forced to consider aspects of my own experience. It was, often, a challenge not to internalize their emotional responses and revisit my own past.

As a trained child bereavement facilitator, it was also a challenge to listen without intervening. However, in understanding their experience, I also understood that, in their position, having someone listen is more important than getting advice from an adult who "knows better". That was part of the reason for doing the study in the group. By exposing the children to others who were living under the same circumstances, their own expertise was paramount. They deserved equal time and attention. It was important for me to stress that they were not alone and could gain much from each other. Most especially, that there were many definitions of "normal" – most of which are abnormal. I knew how much they had lost and were continually losing as well as how readily these changes in life are accepted. Never understood fully or appreciated, but always accepted. This forum was something I could provide, but I was unprepared for how much that would mean or how greatly it would help me. I gained a new perspective on my experience and how much that has shaped the direction of my life and the choices I have made.

The feedback I received from both the participants and their parents surprised me. I have met several of them since the group ended and they have such positive stories about the experience and the friends that they made. Despite the brevity of the sessions, each participant made the most of the opportunity. Nowhere was this more eloquently portrayed than in a dream one of the participants shared with me and allowed me to share now:

> *"I dreamed that there was a lot of bad stuff in the world and I was really scared. I was trying to run away and find a safe place to hide. Then, I came to this place where a magic sorcerer lived. I got to meet the sorcerer and she gave me super powers to fight the bad stuff. I even got to meet the other superheroes at the place and became part of a super hero team. But, we had to keep our powers a secret. None of my other friend, outside, knew my secret identity. But I knew I had special powers to fight the bad stuff. And I did and I saved the world !"*

The knowledge that such a sense of empowerment could be garnered in such a short period of time seems unbelievable. Yet, when I was able to reflect on my experiences listening to these children, I realized was that as much as the group may have given them, it gave me infinitely more. In listening to them, I began to hear my own voice and, now, hoping I have done justice to their stories, I look forward to their voices empowering others who have yet to make the journey. In essence, there is no magic formula or specific training necessary to successfully interact with children who are coping with traumatic life situations. You need only remember what it was like to be a child and give to them what you wished had been provided for you. In that genuineness, there are infinite and life altering rewards.

Appendix A

Group Rules

1. **Confidentiality**

   Everything we talk about is private. It is important not to talk about what anyone else has said outside of the group.

2. **Time**

   Every group will start and end on time. If you have to come late or leave early, please let the leader know.

3. **Commitment**

   It is important to come to every meeting so that you can learn as much as possible. If you have to be absent, please let the leader know.

4. **Equality**

   Everyone will have a chance to talk at every meeting. You do not have to talk if you do not want to, but everyone must take turns.

5. **Respect**

   It is important to listen quietly when someone else is talking. It is also important not to say mean things or hurt someone's feelings. Everyone is different.

Appendix B

Confidentiality Contract

Confidentiality Contract

I promise not to tell anyone outside of this group what the other group members say or do.

I understand that I can share the things that I have said and done, if I want to, but NOT what anyone else has said and done.

Signed:________________________________
Date:__________________________________
Witnessed By:___________________________

Appendix C

Changes Chart

What Has Changed

In My Family

In My Parent

In Myself

In Other People

Appendix D

Response to Changes Chart

When Things Change I……..

Appendix E

Existing Knowledge Chart

What I Know About
Mom/Dad's Illness

Appendix F

Avenues for Knowledge Acquisition Chart

Where I Got My Information

Appendix G

Desired Knowledge Chart

What I Want To Know About Mom/Dad's Illness

Appendix H

Avenues for Desired Knowledge Acquisition

Where I Might Be Able To Get This Information

Appendix I

Coding Scheme

Grouping Variables

Direction of Statements – Parent- or Child-centered

Global Category – Coping Styles

1. *Active Coping Style* – strategies such as problem solving or monitoring which seek to behaviorally or cognitively affect the stressor (parental cancer)
2. *Avoidant Coping Style* – strategies such as prolonged denial which seek to draw attention away from the stressor (parental cancer)
3. *Other* – strategies which may not adhere to either above categorization

Global Category – Existing Knowledge

1. *Medical Statements* – information about causation, side effects, treatment
2. *Emotional Statements* – impact of disease on the individual and/or family, fears or concerns
3. *Practical/Social Statements* - changes in scheduling or missed activities

Global Category – Desired Knowledge

1. *Medical Statements* – information about causation, side effects, treatment
2. *Emotional Statements* – impact of disease on the individual and/or family, fears or concerns
3. *Practical/Social Statements* - changes in scheduling or missed activities

Appendix I (continued)

Coding Scheme

Global Category – Acquired Knowledge

1. *Medical Statements* – information about causation, side effects, treatment

2. *Emotional Statements* – impact of disease on the individual and/or family, fears or concerns

3. *Practical/Social Statements* - changes in scheduling or missed activities

Global Category – [Potential] Avenues for Knowledge Acquisition

Categorized by frequency of responses

Global Category – Experienced Illness-related Changes

Categorized by frequency of responses

Appendix J

Child Assent Form

I am a student who is doing a project about what it is like to have someone who is sick in your family. I am hoping you will be interested in helping me with my project. I am having four group sessions with children just like you who have someone in their family who is sick. We will be talking about your Mom/Dad’s illness and all the things you know about it. We can even talk about what you want to know about the illness and who you can and do talk to about it. A lot of the things you tell me will be helpful to other children and families who are just like you.

Even though I will be asking you some questions and there will be times everyone in the group will want to share their ideas, you don’t have to answer anything you don’t want to or participate in any of the discussions. You can ask me to stop whenever you want or ask me questions. I will do my best to explain anything you do not understand. If you do not want to participate, you do not have to. This is your choice and nothing bad will happen if you don’t want to join or if you decide to stop later on.

I promise not to use your name in anything I write or say unless you tell me it is okay.

I would also like to audio-tape our talk, if it would be alright with you. This way, I can remember everything you tell me.

I have been told about the study and I agree to be interviewed and audio-taped.

_____ YES ______NO

____
Child’s Signature and Date

____
Investigator’s Signature and Date

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