PARENTAL COPING

AND

THE ADOLESCENT WITH CANCER

By

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Chair

[Signatures]
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Abstract

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The incidence of cancer among children in the United States has been estimated at approximately 8,400 new cases yearly (American Cancer Society, 1999). The diagnosis of cancer is difficult; adolescence in particular is a vulnerable time in life characterized by struggles over identity, independence and intimacy. Parents cope with the diagnosis of their child differently. The ways in which parents cope can affect the development of the adolescent. The practitioner working with these families must have a broad knowledge base of understanding families, their responses and coping for interventions to be successful.
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Introduction

The incidence of cancer among children in the United States has been estimated at approximately 8,400 new cases yearly (American Cancer Society, 1999). The diagnosis comes as a profound shock both to the affected child and the parents, often affecting the whole family and community. There is both a psychological and physical strain associated with cancer diagnosis and treatment related to the rigorous treatment regimes such as chemotherapy, radiation, and surgery. Many aspects of both the child and family’s life are changed in order to accommodate the demands of this illness. Parent’s priorities and perspectives may be altered: they may be overcome by feelings of fear, anger, and guilt, and may find it difficult to adjust to the changes in their lives.

Cancer can be a life-threatening event. This diagnosis creates a great deal of uncertainty and insecurity among those most intimately affected (Mott, 1990). The diagnosis of cancer is difficult, both socially, emotionally, as well as physiologically. Adolescence, in particular, is a vulnerable time in life characterized by struggles over independence and intimacy. Adolescents have varying responses to their particular cancer and treatment. For some, the disease process becomes overwhelming and disruptive; yet for others, the experience is one of personal growth and development (Dunlop, 1982).

The purpose of this paper is to investigate ways in which parents of adolescents with cancer cope, as well as the development of adolescents and how development is affected. The developmental tasks of identity, independence and intimacy will be looked at specifically.
A conceptual model of the adolescent with cancer is displayed in Figure 1. This model is derived from the ABC-X Family Stress Model (Hill, 1958). The major concepts within this conceptual model are (A) which is the provoking event or stressor, (B) the family's resources or strengths at the time of the event, and (C) the meaning attached to the event by the adolescent and family. (A) interacting with (B) interacting with (C) produces (X), the crisis. Hill defines crisis as any sharp or decisive change for which old patterns are inadequate (Hill, 1958).

Such information may assist the practitioner working with these adolescents and families to construct strategies in addition to managing the illness to assist in the treatment of the adolescent with cancer. A broad knowledge base of understanding families, their responses and coping is needed for interventions to be successful.

Review of the Literature

Parenting During Illness

Parents of adolescents with cancer encounter many stresses related to coping with their child's illness (see Figure 1). Lazarus and Folkman (1984) defined coping as, "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.141). Lazarus and Folkman state that coping occurs along two planes. First, "problem-focused coping" attempts to manage or alter the stressful transaction between the person and the environment. Secondly, "emotion-focused coping" attempts to mediate the person's feeling response to the stressful event.

Each family is unique and comes with many experiences that influence their coping skills, regardless of their financial, educational, or social background. Some have
drug, alcohol, marital, financial, or legal problems. Some have a tremendous amount of support from friends and family, while others have none. The family's adjustment involves moving through psychosocial transitions in ways that facilitate the meaning of the experience, maintain normalization, and respond to illness related demands (Lewis, 1993). Each parent is different and does not deal with the diagnosis, treatment, or death of their child in the same manner as another.

**Uncertainty**

Increased survival rates for the adolescent with cancer have created hope, and along with hope, there is uncertainty. Cohen and Martinsen's study (1988) reported that the "chronicity of uncertainty" is responsible for much of the perceived stress and particular coping strategies. Uncertainty is a difficult stressor with which the parents of children with cancer are confronted and must learn to cope. Mishel (1981) found that uncertainty about events occurring during hospitalization rather than the events themselves accounted for patients' perceptions of their experience as stressful. Koocher & O'Mally (1981) state that uncertainty, "is experienced as a heightened sense of vulnerability accompanied by a compelling need to know the unknowable future." The uncertainty that arises from the adolescent's life-threatening illness includes etiologic uncertainty, existential uncertainty about ultimate survival, uncertainty about the effect of the illness on the adolescent's development and the quality of life that can be expected (Cohen & Martinson, 1988). The relative newness of therapies and the fact that late effects are only just beginning to appear among long-term survivors increases uncertainty. Social uncertainties about the child's future, including schooling, employment, marriage or the ability to bear children, are also experienced. There is the
uncertainty that arises in the day-to-day life of the family as they attempt to achieve a sense of normalcy in their daily activities (Koocher & O'Malley, 1981). There is also uncertainty of parents as they doubt their ability to adequately interpret their child’s physiologic and behavioral cues (Cohen & Martinson, 1988). How parents cope with the stress of uncertainty has long range effects on the family (Koocher & O'Malley, 1981). Interventions must be directed towards helping parents cope with their uncertainty rather than removing it.

Adolescent Development

Adolescence is a period of life, characterized by struggles over independence and intimacy (Heiney, Wells, & Ruffin, 1990). There is conflict in the adolescent’s life related to physical, mental, and social changes (see Figure 1). Developmentally, these years are in a constant cycle of change. Loss, an element of change, is constant, as the adolescent separates from childhood with all its familiar rules and roles and enters into adulthood (Dunlop, 1982).

Erikson’s developmental theory stresses the importance of adolescents completing developmental tasks and separating from the family unit (Erikson, 1963). Developmental tasks to be completed prior to adulthood include establishing identity and self-image, developing a positive sexual role, becoming autonomous from parents, and making career plans (Heiney et al, 1990). When stressors associated with the diagnosis and treatment of cancer override the mastering of these tasks, the adolescent is at risk for developing psychosocial problems. “For the young adult, caught between the past and the anticipated future, choosing to grow seems hopeless, and going backwards into childhood feels uncomfortable and conflicting” (Dunlop, 1982, p.33).
Research findings indicate that returning to school, maintaining peer relation, and becoming independent are difficult for the adolescent with cancer who may be overwhelmed with trying to cope with stressors, including isolation from peers, hair loss, or possible sterility (Heiney et al, 1990). The adolescent may withdraw or find it difficult to relate in social situations related to long periods of social isolation. This may include many school absences related to neutropenia and hospitalizations.

Body image is a crucial concern of the adolescent. Physical changes related to cancer result in an altered body image, which can cause further anxiety. Anxiety may be centered around starting new relationships and sexual intimacy. Cancer alters physical appearance through hair loss, surgical scars, weight change, both weight loss related to gastrointestinal effects and weight gain related to steroids, and low energy levels. The impact of being different can be devastating to the adolescent at a time when the norm is to conform (Adams & Guido, 1984). The effect of illness plays a role in development. Adolescents with cancer may experience delayed mastering of developmental tasks, identity, independence, and intimacy, and may have long term psychological sequelae (Heiney et al, 1990).

Adolescence is a time when struggle for independence escalates. Independent-dependent conflicts between parents and young adults are intensified and are complicated by cancer (Fiore, 1979). At a time when rebellion from parental authority is the norm, the adolescent with cancer is confronted with a choice between desired independence and required dependence for physical and emotional survival (Adams & Guido, 1984). Normally, adolescents see their parents as hurdles or roadblocks in the road to full independence. Illness presents a new hurdle and many times the adolescent gives up and
becomes dependent (Fiore, 1979). The more independent the child is, the harder it is to accept this new role, to accept care. Dunsmore and Quine's (1995) study found that adolescents preferred parental involvement but not parental control. They reported that there was a fine line between support and overprotection.

A degree of insecurity about the self and life direction are an expected part of young adulthood (Dunlop, 1982). Research shows that cancer can bring to an adolescent's life both meaning and a definite role to play. Some adolescents are rewarded for this role through praise for being positive and brave. Others are rewarded through attention and the power gained from being “on stage” within the family and community. This occurs when the adolescent begins to see themselves as fused with cancer (Dunlop, 1982). Identification with an illness occurs because the by-products of the illness are valued, such as dependency, attention, or power (Fiore, 1979). As a result, some young people are reluctant to let go of their identification as ‘a person with cancer’. This, in part, may happen when the adolescent sees this as their only true identity (Adams & Guido, 1984). New roles and challenges can become very frightening for the adolescent who has become secure in their sick role. When they start to get well and expectations shift accordingly, the young adult may react by fearfully clinging to dependency (Adams & Guido, 1984).

Risk taking in adolescence is part of the developmental process. Adolescents challenge adult authority as they develop a sense of self. This commonly involves experimentation with drugs and alcohol. Studies done with adolescents with cancer and risk taking behavior include Dunlop's (1982) experience which found the most common expressions of negative risk taking behaviors of adolescents with cancer were use of
drugs and avoidance of treatment. Nichols (1995) found that adolescents with cancer did not use substances such as alcohol and drugs for means of coping at the same rate as adolescents without cancer. Speculation about this finding included the notion that adolescents with cancer had a greater awareness of health risks involved with substance abuse, particularly smoking and lung cancer. Another reason included the frequency of blood tests and perceived increased risk of detection. Social isolation, which may decrease pressure from peers for experimentation, may be another factor (Nichols, 1995).

**Meeting developmental needs**

Adolescents are at an age when belief in and reliance on outer resources, such as friends and appearances, are at a peak. It is hard to be different and the adolescent with cancer at times feels very lonely. Friends do not always know how to be supportive with issues related to cancer treatment. Adolescents may not share concerns with friends in an attempt to maintain sameness, therefore not giving them an opportunity to be supportive. Friends begin to stay away as the illness progresses. The adolescent may come to resent friends that are not ill. In time, friendships may collapse, except for one or two friends who have less fear and more loyalty than most. At this time there is an increased dependency on the family as a result of the illness. Parents may limit the adolescent’s activities needlessly in their effort to protect the adolescent. This becomes a vicious circle in which the already different and isolated adolescent experiences negative social interactions.

In meeting the adolescent’s developmental needs, parents were found to continually struggle (Knafl & Deatrick, 1986). The parent must continually weigh the potential risk to the adolescent’s physical health against the potential benefits to his or her emotional health of engaging in certain activities. The case studies presented by Knafl
and Deatrick (1986), in their analysis of the concept of normalization, illustrate the importance of parents focusing on the child. The inability to meet the child’s developmental needs is directly related to, and dependent upon, the ability to accept the child’s condition. If a parent perceives his or her child, particularly an adolescent, as unable to function normally and with limitations, then they will treat the child in that way, focusing on the child’s limitations instead of the child’s strengths. This can lead to overprotectiveness and lowered expectations of the adolescent (Knafl & Deatrick, 1986).

Meeting the adolescent’s developmental needs is dependent upon parents having a good understanding of the major developmental tasks facing the adolescent and how illness can interfere with these tasks (Canam, 1993).

**Coping Mechanisms**

**Denial**

Parents go through the sequence of emotions which follow any bereavement as they mourn the loss of the healthy child they had hoped for and thus they experience shock, distress, denial, anger, guilt, worry, sadness and depression before they can make a realistic adjustment (Whyte, 1990a). One of the most common coping strategies is denial. This can occur with reference to actual facts, to the meaning of those facts, or to one’s own emotional state (Shapiro, 1983). Eiser (1990) suggests that parental denial is probably the least understood and most poorly dealt with reaction. It may represent a positive process of coping and adapting. Eiser (1990) suggests that denial is functional as it allows the family time to distance themselves from the tremendous emotional impact and to collect and mobilize their energies towards coping with the loss of a ‘perfect’ child. Denial helps parents to master the situation and, “sets the stage for later
acknowledgement of the illness and mobilization of more effective coping strategies” (Eiser, 1990).

**Meaning**

Giving the illness meaning is another coping strategy of parents found in the literature (see Figure 1). Meaning evolves over a period of time. The task for parents is to assign personally significant meaning to their child’s illness, which allows them to accept it and carry on with their normal family patterns. Assigning meaning is done by defining the situation within a previously existing philosophy, as found in Venters’ study in 1981. This provides the family with a predictable explanation of the illness event. Venters found that a preexisting religious and/or medical scientific philosophy of life enabled families to ascribe an acceptable meaning to their situation. They saw the illness as a planned part of their lives, a belief that the illness was part of God’s plan. Other parents found meaning from a scientific or medical approach studying the child’s disease and current treatments, providing an explanation. It was found that adopting an optimistic interpretation of the situation permitted hope in the future, or perceiving the situation as a challenge, which helped families gain a sense of control over influencing the outcome. Other approaches for assigning a personal significant meaning included identifying with families who appeared to be dealing with worse situations, and the philosophy of “live for today” (Venters, 1981).

Hayout and Krulik (1999) found that families who observed other families in the same situation, comparing how they were coping with how the other family was coping, emphasized for these families the effectiveness of their coping strategies. The parents found strength, resources, and abilities when they compared their coping to that of
another family (Hayout & Krulik, 1999). This study also found it was helpful to compare themselves to families in worse situations as was found in Venters’ study.

**Normalization**

Normalization is acknowledging the existence of the impairment, defining family life as normal, defining the social consequences as minimal, and engaging in behaviors that are consistent with a view of the family as normal (Knafl & Deatrick, 1986). This is another coping mechanism used by families and adolescents experiencing cancer (see Figure 1). By continuing to participate in usual activities, the stresses of being different are reduced. One of the behavioral strategies that parents use in normalizing their situation is to engage in usual parenting activities (Knafl & Deatrick, 1986) which involves relating to and interacting with the adolescent with cancer in the same way as they do the other children in the family, not giving them ‘special treatment’. The parent focuses on what the child can do and not on his or her limitations. The adolescent is disciplined, helping them develop a sense of security by having limits placed on their behavior.

Knafl, Breitmayer, Gallo, & Zoeller (1996) in their study identified five management styles of families in response to childhood chronic illness. These management styles include thriving, accommodating, enduring, struggling, and floundering. In the style of thriving, which appeared to be the most effective style, normalcy was the overriding theme. The characteristics of this style were consistent with the concept of normalization.
Social Support

Social support and social networks are essential for success in the family faced with cancer (see Figure 1). Pelletier, Godin, Lepage and Dussault, studied social support received by mothers of chronically ill children and adolescents, and found that mothers wanted more support than they received. The types of support the mother's identified included emotional, appraisal, and informational support. The 'professional' was an important source of support and that more support was needed in this area. The spouse was found to be the most important source of support. The results of this study also found that there is an increased probability of receiving less support if the chronically ill child is an adolescent. One reason stated for this finding was that others thought the adolescent would be more autonomous in his or her care, when in effect these parents needed additional support (1994).

Mercer and Ritchie (1997) identified needs parents experienced during their child's treatment for cancer. These needs included informational, emotional, and instrumental. Informational support included information regarding the child's care, illness, and treatment. It was found that health professionals did a good job in this area. The second need, emotional, included spiritual support, reassurance or affirmation of the parent's ability to care for the child, relief from anxiety, and the ability to discuss concerns. Thirdly, instrumental needs were identified as being able to take time off from work, respite care, and financial assistance. Families did not feel they were given enough support in these last two areas.
Health Care Provider Role

In the 1950’s and 1960’s, the health care provider’s task for the adolescent with cancer was to primarily provide pain control and supportive care for the patient and his or her family. Now with increased survival rates, the health provider’s role with the adolescent with cancer is expanded and multifaceted (see Figure 1). The role is much greater than managing the illness and treating the adolescent. Medical treatment of the adolescent takes priority, but supportive needs, including social, emotional, as well as physiological needs of both the adolescent and the parents, require attention.

Dunsmore and Quine (1995) reported that adolescents with cancer wanted to know that the health professionals who treated them were concerned about them as individuals, not just another patient with cancer. The provider must establish rapport with the family, identify parentai concerns, be certain informational needs are met, and provide support both directly and through connecting with other services of the medical team. The role of the provider is to help them be empowered but not to foster dependency (Mercer & Ritchie, 1997). By intervening in these areas clinicians improve the ability for adolescents to adapt to their illness and meet developmental needs.

Dunsmore & Quine (1995) also found that less than half of the adolescents in the study felt they were kept fully informed. Two-thirds felt that they would like to learn more about their illness and would like their friends, teachers and families to know more about their illness. The majority of the respondents believed that treatment decisions should be made collectively by the provider, parents, and themselves, but only a few said that had actually occurred. Almost all respondents said they should be told if they were going to die, their prognosis was poor, or their treatment was not effective.
It is essential that informational needs are met. Two large studies (Whyte, 1990; Pelletier et al, 1994) have reported a general lack of awareness among health professionals of families’ emotional and informational needs. Both parents and adolescents should be provided the opportunity to share their feelings and worries and to be encouraged to ask for information. In the study by Dunsmore and Quine (1995), it was shown that adolescents cope more effectively as a consequence of being adequately informed. Receiving ongoing information reduces anxiety of both adolescents and parents.

It is important that the provider possesses good communication skills. The qualities of health professionals that facilitated communication included the ability to listen and answer questions, professional friendship, knowledge and professional expertise, honesty and a straightforward approach. The qualities of health professionals that hindered communication were tied in with power and status. Impersonal, high-powered authoritarian behavior, including the use of technical jargon, is likely to alienate adolescents further at a time in their development when alienation from authority figures is already at its height. The findings from this study also suggest that adolescents with cancer wish to be involved in the decision-making aspects of their care to a greater extent than generally occurs (Dunsmore & Quine, 1995).

The practitioner can play a large role in normalization. In a study by Robinson (1993) it was found that, according to parents, health care professionals often ‘sabotage’ doing normal things. Families reported the negative judgements of health care professionals who see the normalizing practices as evidence of denial (Robinson, 1993). Parents stated that they felt judged as being mean and uncaring when they pushed their
children to do normal things or set limits (Robinson, 1993). Knafl and Deatrick (1986) determined that for parents to maintain normalization, they needed to receive validation that they are handling things appropriately from people outside the immediate family and that it was very important that the health care professional do so.

Support is recognized as a major influence in the ability of parents to cope positively. The provider must identify family supports early in the treatment period (Mercer & Ritchie, 1997). Since the spouse was found to be the most important source of support and often the adolescent is accompanied by only one parent for logistical reasons, professionals could encourage spouses to share more of the responsibilities in the daily care. Two occasions where it is important that both parents be present include when they are initially informed of the diagnosis and when teaching, regarding care, is done (Pelletier et al, 1994). Clinicians could also be supportive of both adolescent peer groups and parent groups, making this information readily available to the family.

Families need to be equal participants involved with a group of professionals in whom they develop confidence. An effective communication network needs to be set up between all the disciplines concerned in the care of the family (Mott, 1990). The professionals’ appreciation of the uniqueness of each parent’s coping is essential. What is effective coping for some parents may be ineffective for others with different values or experiences (Chesler & Barbarin, 1987).

Conclusion

Parents of adolescents with cancer encounter many stresses related to coping with their child’s illness. Coping strategies utilized are dependent on the individual parents, their values, and experiences. The ability to develop healthy coping is essential.
Interventions are necessary in helping parents cope as they work through denial, uncertainty, and meaning of the illness. Normalization is used by parents to help minimize the impact of the child’s condition and meet his or her developmental needs. Meeting the adolescent’s developmental needs is dependent upon parents having a good understanding of the major developmental tasks facing the adolescent and how illness can interfere with these tasks. It is necessary that parents assist the adolescent with interaction and building socialization skills, enhancing positive relationships with peers and family, providing and encouraging normalizing experiences, encouraging independence and a sense of responsibility, and by giving them decision-making power.

Health provider awareness of supportive needs of both the adolescent and parents is essential. It is necessary that the provider understands the importance of involving adolescents in the decision-making aspects of their care and establishes rapport with the family. They need to be certain informational needs are met and provide support both directly and through connecting with other services of the medical team.

Studies conducted on childhood illness and cancer, how parents cope, and studies on the development of adolescents and how cancer affects this are well documented in the literature. Recent years have seen changes in both the adolescent and treatment. Further research is needed to validate the effect parental coping styles and strategies have on the developmental milestones of the adolescent with cancer and how health professionals can intervene.
Parental Coping and the Adolescent with Cancer

Using the ABC-X Family Stress Model

Figure 1.

A-The provoking event or stressor

B-the family’s resources or strengths at the time of the event

C-the meaning attached to the event by the adolescent and family

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