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The Resilience Factor: What Extension Can Learn from Adolescents Coping with Parental Cancer

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Abstract: Using a developmental systems framework and grounded theory methods, the study reported here describes the psychosocial experiences of late adolescents coping with parental cancer. Results suggest three primary psychosocial developmental influences, including multilevel influences, coping strategies to maintain control, and responses to uncertainty and anticipatory grief. Identity and intimacy were the two most salient psychosocial tasks. The central unifying concept of resilience was the primary psychosocial developmental outcome that resulted from coping with parental cancer during late adolescence. This finding illuminates the need for Extension to expand its focus on positive outcomes that can result from coping with life crises during adolescence.

Introduction

Adults with life-threatening illnesses are living longer than ever before thanks to modern medical interventions. Prolonged life is generally viewed as a positive change, often accompanied by improved quality of end-of-life care for patients and their families. However, extending the terminal phase of a disease can place a heavier burden on family members with caretaking and financial responsibilities. This extended terminal phase has important implications for the development of adolescents whose parents have been diagnosed with terminal cancer.

In our work with at-risk audiences through Extension, we need to consider the home lives of adolescents and young adults we serve. This reflects a paradigm shift in our organization toward a systemic or ecological framework where multiple contexts must be considered in our work with youth. The programs and skills we teach young people may have minimal impact among those coping with the acute stress associated with life-threatening illness in their families if we do not address the issues they are facing.

We need to be comfortable talking about illness and death in families and be prepared to understand and support adolescents who are coping with these experiences. We also need to listen to the needs and experiences of these young people to develop more effective prevention efforts through Extension that are geared toward adolescents facing all kinds of family crises. We will then be better prepared to reach out to those who can benefit the most from the services we offer.

The purpose of the study reported here was to develop grounded theory on the psychosocial experiences of late adolescents coping with parental cancer. This research was guided by a developmental systems perspective, which views adolescents as developing within an interdependent family system and larger ecological context. The research questions were (a) What are the particular psychosocial developmental impacts or experiences that result from coping with parental cancer during late adolescence? and (b) What are the most salient psychosocial developmental influences identified by late adolescents who are coping with parental cancer? The psychosocial tasks of adolescence explored in the study were achievement, autonomy, identity, intimacy, and sexuality (Hill, 1980). The findings are instructive for Extension professionals who work with adolescents and families coping with illness, death, or other major life crises.

Background

The literature pertaining to adolescent psychosocial experiences of coping with parental cancer can be divided into three major areas of study:

1. Adolescent grief and bereavement (Adams et al., 1999; Balk, 1996, 1997, 1998, 2001; Christ, 2000; Dowdney, 2000; Marwit & Carusa, 1998; Morin & Welsh, 1996; Siegel et al., 1992; Thompson et al., 1998; Tyson-Rawson, 1996; Van Epps, Opie, & Goodwin, 1997);

2. Anticipatory grief and terminal illness (Berezin, 1977; Kowalski, 1986; Lund, 1989; Moss, Moss, & Hansson, 2001; Parkes, 1975; Peterson & Rafuls, 1998; Rando, 1997); and

3. Psychosocial development and death (Adams, 1997; Balk, 1996, 1998, 2000; Carter & McGoldrick, 1999; Corr, 2000; DeBaryshe, Patterson, & Capaldi, 1993; Douvan & Adelson, 1966; Fleming & Balmer, 1996; Goosens & Phinney, 1996; Grotevant, 1998; Hill, 1980; Horton, 1998; Ingersoll, 1998; Kandt, 1994; Klass, 1993; Lerner, 2002; Parkes, 1993; Schultz, 1999; Shapiro, 1994; Silverman & Worden, 1993; Steinberg, 1996; Tyson-Rawson, 1996; Worden, 1996; Yoder, 2000).

This literature base has not yet filled in many of the gaps for answering the research questions in the study reported here. Outcomes have been mixed, developmental stages have not been explored separately, and the influence of the larger environment remains largely unexplored. In fact, this literature suggests a need to examine the larger environmental context to more fully understand the impact that parental illness and death has on adolescents' development and attitudes toward the future. Studies also indicate a need to examine risk factors, protective factors, and systemic influences identified by adolescents who are coping with parental cancer.

Most specific to the study, the literature on anticipatory grief and terminal illness points to the utility of studying the time period prior to parental death and to examining the impacts and meanings parental illness has for adolescents. The study reported here attempted to fill these gaps by developing grounded theory on the psychosocial experiences of late adolescents at the interface of coping with parental cancer.

Methods

The sample for the qualitative study consisted of five males and three females. (See Table 1 for participant characteristics>) The procedures for data collection and analysis were modeled after grounded theory, a general method of comparative analysis that uses a systematically applied set of methods to generate inductive theory about a substantive area (Glaser, 1992). Data were collected through one in-depth, qualitative interview with each of the eight participants.

Table 1.
Participant Characteristics

Nickname	Gender	Age at Interview	Age at Diagnosis	Diagnosis of Parent	Gender of Parent	Status of Parent
Tai	M	20	19	Pancreatic	M	Living
Dave	M	20	20	Breast	F	Living
Shawn	M	18	16	AML (Leukemia)	F	Deceased
Pierre	M	19	19	Esophageal	M	Living
Victoria	F	21	16	Stomach	F	Deceased
Elayne	F	51	18	Bone Marrow	M	Deceased
Nat	F	28	16	Blood	M	Deceased
Narsky	M	21	11	Mantle Cell Lymphoma	M	Deceased

The interviews consisted of 13 open-ended questions about coping with parental cancer during late adolescence designed to gain a better understanding of psychosocial developmental experiences and impacts. Information gathered in the interviews included positive and negative experiences encountered during the illness, most and least helpful things about self and others, fears and concerns resulting from the diagnosis and illness, psychosocial tasks encountered as a result of having a parent with cancer, negative and positive impacts of going through this experience, and familial and systems information.

These interviews ranged from 1 to 3 hours in length with each participant. Interviews were all audiotape. Analysis of the data began after the first interview was transcribed and continued throughout the data collection process. This type of analysis is called the "constant comparative method" (Glaser & Strauss, 1967), an inductive form of analysis where each new interview was compared to categories that had emerged from previous interviews. Nvivo™ qualitative data management software was used to facilitate data analysis. Ultimately, nine overall categories containing 30 codes were generated. Selective coding was then used to validate the relationships between the codes and categories as well as the interrelationships between categories and to develop the final grounded theory and developmental systems model (Figure 1).

Results

Research Question 1: What Are the Most Important Psychosocial Developmental Influences Identified by Late Adolescents Who Are Coping with Parental Cancer?

Study participants identified three primary psychosocial developmental influences. The first was *multilevel influences*, which included individual level influences of perceived role in the family system and personal theories on the experience of parental cancer that were related back to autonomy and identity; familial level influences of attachments, communication, family dynamics, prior losses, and family roles, which were related back to intimacy, autonomy, and identity; and extrafamilial level influences of others' ignorance, support, and understanding, which were related back to intimacy. There were 10 codes containing 41 themes on three levels of influence (Table 2) that participants perceived as influencing their psychosocial experience from the time of a parent's cancer diagnosis up to and beyond a parent's death.

Table 2.
Multilevel Influences on Conceptualization of Psychosocial Experience

Subcategories	Codes	Prominent Themes
Individual	Perceived role in family	Birth order, life-long identity, evolved identity, identifying with ill parent, what identity did not or could have evolved into, level of autonomy
	Theories on the experience of parental cancer	Self as normal, self as different, dichotomies, culture and society
Participant Quote: "He was diagnosed with cancer as soon as I leave for school....Something like this is happening at the time where we need to be moving into the house to help out. It kind of seems like the exact opposite of what needs to be going on." - Tai		
Familial	Attachments and bonds	Bond with ill parent, bond with non-ill parent, increase in closeness, impact of illness on attachment
	Family communication	Communication channels, increase in communication, future orientation, avoidance
	Family dynamics	Addiction, cutoffs, secrets, suppression of emotion, triangles
	Family roles	Informant, filling in, primary role of ill parent, non-ill parent as helpful or not helpful, sibling

		roles
	Prior losses	Grandparents, divorce
Participant Quote: "It forced me to create my identity, first in coming out with my sexuality, second with just, forcing, my stepdad and my brother wanted me to automatically take my mother's position, take her role...I rejected that because I'm a sister, I'm a daughter. I'm not a mother and I realized that I needed to detach myself away from that a little bit...become my own person." - Victoria		
Extrafamilial	Ignorance	Insensitivity, avoidance and forgetting, don't know what it's like, apologies, sympathy
	Support	Openness, offering help, being there
	Understanding	Comfort, relating
Participant Quote: "You just need to be there...it's okay to be worrying about something other than their parent, that they do have their own concerns and their own life doesn't stop because of what's going on....Just be there to do whatever needs to be done." - Elayne		

The second area of influence on psychosocial development was *coping strategies to maintain control*. Coping strategies were a route for accomplishing or hindering the psychosocial tasks of late adolescence in the midst of their family crises. Analyses resulted in 11 codes containing 27 themes. These codes were organized into three domains of coping, including appraisal-focused strategies, which were tied to identity; problem-focused strategies, which were connected to all five psychosocial developmental tasks; and emotion-focused strategies, which were tied to achievement, identity, intimacy, and sexuality (Table 3). These domains came from existing research on coping with life crises (Moos & Schaefer, 1986) due to a close fit with participants' terms. A common thread that ran between these codes and themes was maintaining balance and control. This was viewed as a crucial aspect of facing a crisis like parental cancer. The overwhelming nature of the crisis led some respondents to lose a sense of control over their lives.

Table 3.
Coping Strategies Employed to Maintain Control

Subcategories	**Codes**	**Prominent Themes**
Appraisal Focused	Denial	Dodging, false optimism, naivety
	Journaling	NA
	Negative thinking	Fatalism, giving up, hopelessness, self-pity
	Theorizing	Causes, culture, gender, getting over it
Participant Quote: "The main thing that got me through it was myself...remembering the little things that happen over a week or that happened over the past year, and just		

talking them out to yourself and rationalizing them...what happened as far as your parent dying or going to the hospital....it's the hardest thing for somebody to do, make a positive out of a negative."-Narsky		
Problem Focused	Multiple stresses	Juggling act
	Knowledge seeking	NA
	Priority Changes	Priority reversal, quality time, re-assessing romantic relationships
Participant Quote: "[School work] was hopeless and seemed a chore because it was my very first semester, my very first year....I'm sitting there studying for finals, I have all this crap going on with the family, and I'm sitting around looking at my physics notes thinking, 'What the crap is this?' I have no idea what I'm looking at." - Pierre		
Emotion Focused	Escape	Drugs, exercise/sports, sex, staying busy, studying
	Fantasizing	Release, substitutions, support, turning back time
	Guilt	Not being there, self-absorption
	Humor	Breaking the ice
Participant Quote: "When she was first diagnosed, I played basketball. I was really into it, so I guess that helped me a lot. I kept busy like that, and I do it to this day. I just think that if I keep being busy that I can't dwell on things." - Victoria		

The third area of influence on psychosocial development was *responding to uncertainty and anticipatory grief*. Uncertainty was an important factor in understanding participants' responses to illness and dying because the chronic stress from uncertainty left them feeling like they had no control. One participant noted that uncertainty was the most negative part of the whole experience due to the "constant fact of not knowing what's going to happen." Analyses resulted in 10 codes containing 25 themes. These codes were organized into three subcategories (Table 4), including triggers, which were connected to identity; concerns for the future, which were connected to autonomy, identity, intimacy, and sexuality; and meaning making, which was connected to achievement, autonomy, and identity.

Table 4.
Uncertainty and Anticipatory Grief

Subcategories	**Codes**	**Prominent Themes**
Triggers	Changes in ill parent	Decline, remission, what is wrong?
	Helplessness	Feeling incapacitated, no control, inevitability of death

	Suddenness	Emotional reactions, no time to prepare
Participant Quote: "[My father] had always been such a big man. I can remember looking at his hands, because they'd always been huge, but I kept thinking how small they looked, and I just couldn't go back [to the hospital]." - Elayne		
Concerns for Future	Fears for self	Filling the void, getting cancer, transference of fear
	Future losses	Developmental milestones, drifting apart, other deaths
	Post-death changes	Reestablishing routines or normalcy, role renegotiation
Participant Quote: "I don't know that I'm ever gonna be able to share the same type of relationship with anyone I had with my mom...it was just totally unique, kind of awesome, connection that we had, and I don't know that it's replaceable." - Shawn		
Meaning Making	Advice to others	Perseverance, seizing the moment, self-reliance
	Closure	Barriers, peace of mind
	Faith	Afterlife, putting things in God's hands
	Legacy	Carrying on the torch, desire to help others
Participant Quote: "As time goes on, the positives begin to outweigh any of the negatives. That's what you have to focus on." - Dave		

Research Question 2: What Are the Particular Psychosocial Developmental Experiences or Impacts That Result from Coping with Parental Cancer During Late Adolescence?

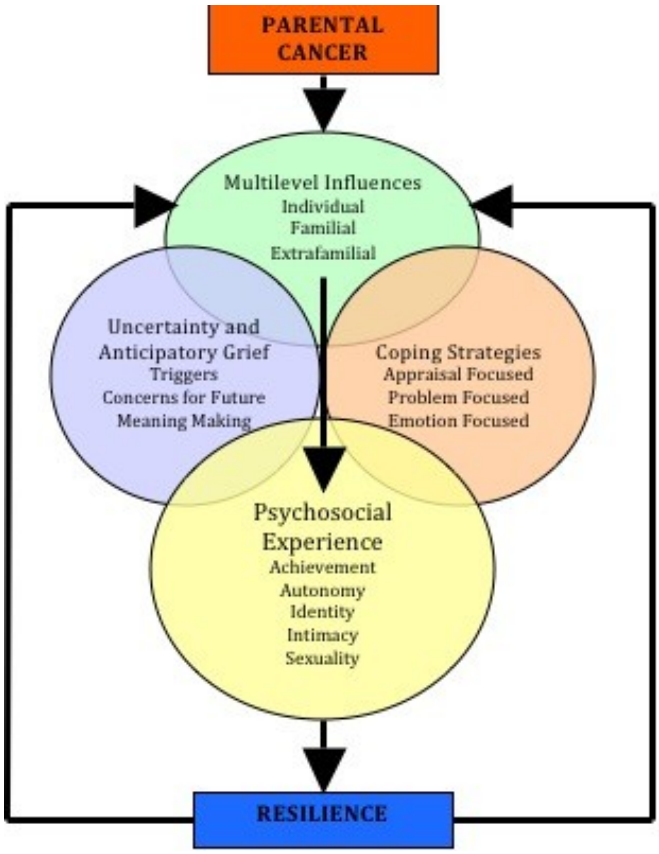
The central unifying concept of resilience was the primary psychosocial developmental experience and impact that resulted from coping with parental cancer during late adolescence. Resilience is conceptually defined as the ability to stretch or flex in response to pressures and strains, including normative stress from everyday hassles, expected transitions, and stress and trauma from the unexpected (Boss, 2006). Participants believed they had experienced a "fork in the road" where they consciously decided which way they would go.

Nat describe this phenomenon by stating that each person had to decide whether to be "bitter or better." Dave described a pivotal moment where one direction would be "dark, cold, and depressing," and the other was "appreciation and optimism." Victoria saw it as "going one of two ways" when faced with "adversity."

Adolescents can either get "really depressed and fail" or "put all that energy and emotion into succeeding." All participants chose the positive route, which revealed a form of resilience in action as the final grounded theory derived from the study (Figure 1). This conscious choice to take a resilient path seemed to affect all aspects of their psychosocial experience. The resulting maturity they gained then fed back into their individual, familial, and extrafamilial experiences, which enhanced their coping strategies and responses to uncertainty and anticipatory grief, and facilitated further psychosocial development.

This finding supports the notion that more attention needs to be paid to restoration, a positive aspect of development that can occur after parental loss (Balk, 1998; Stroebe & Schut, 1999). The primary difference was that the study reported here targeted the time period prior to a loss. Thus, the concept used to describe this positive development prior to a parent's death was resilience rather than restoration.

Figure 1.
Developmental Systems Model



Conclusions & Implications for Extension Professionals

There are five primary implications from this study that Extension professionals can apply to practice (Table 5). These results can serve to enhance understanding of the interplay of multiple risk and protective variables in the presence of traumatic life events and paths toward resilience.

Table 5.
Implications for Extension Practice

Recommendation	Translating to Extension Practice
Attending to Context	1) Adolescents do not develop in a vacuum. Practitioners must remember the context of development and help adolescents find ways to navigate through all levels of

	influence. 2) It is important to work directly with adolescents, but supporting/educating parents provides care for the parents, which indirectly provides care for adolescents, facilitating the development of protective factors.
Need for Support	1) Listening was an important aspect of support for this age group. They want people to communicate honestly with them and keep them in the loop, but mostly need someone to be there to listen. 2) Relating was a second important aspect of support. This age group believed it was crucial to feel like there was someone else that could identify with them. Practitioners can bring people together in a group atmosphere and find ways to connect people who have shared similar experiences in order to allow adolescents to feel understood and less alone while they are coping with a major life crisis.
Creative Coping Solutions	1) Practitioners can help adolescents in finding creative and satisfactory ways to cope, but also be non-judgmental about strategies that have been employed in their attempts to cope. 2) Adolescents need assistance in realizing what they can and cannot control and with letting go of guilt about things they cannot control. 3) Practitioners can help adolescents derive meaning out of their experiences and put it to positive use for themselves and others.
Holistic/Developmentally Grounded Practice	1) Identity and intimacy were the most heavily influenced psychosocial tasks in this study. This can serve as a starting point for programs/ support groups that assist this audience. The other tasks can then be woven into discussions on identity and intimacy. 2) This study revealed the importance of developmental grounding. Practitioners can use developmental grounding in their efforts to help adolescents who are coping with major life crises because it offers a lens for creating some order out of a complex crisis.
Risk and Protective Factors	1) Practitioners can uncover the protective factors present in adolescents' lives to help them bolster existing factors and to develop new protective factors they do not yet have. 2) Practitioners can help adolescents become aware of risk factors in their lives and assist them to reduce these risks. Practitioners can also reframe risk factors as opportunities for

	growth/skill development that can become protective factors by gaining strength out of adversity.

Terminal illness can require renegotiation of individual and family development and processes as family members cope with constant uncertainty, multiple stresses, and shifts in communication, roles, and priorities. Understanding the unique experiences adolescents face when confronted with parental illness and death can lead to developmentally and contextually appropriate interventions and resources. The resiliency factors used by these adolescents to negotiate developmental tasks in the midst of coping with a major family crisis may also be informative for Extension professionals when working more generally with issues of death and dying or with family crises.

In conclusion, the study was exploratory, and the conclusions that can be drawn from it are limited, but it does suggest some key issues for Extension professionals to consider when working with this population. These findings help to build a knowledge base for preventing negative short- and long-term outcomes from traumatic life events. Extension professionals cannot prevent an adolescent from experiencing a crisis, but can help to bolster protective factors and make adolescents aware of risk factors in their lives. This awareness can go a long way in learning how to cope with a major crisis.

Extension professionals who are working with at-risk adolescents should not make assumptions that only negative outcomes are possible or that youth in all developmental stages of adolescence experience parental illness uniformly. Instead, future research, theoretical development, and practice should focus on positive outcomes that can result from the experience (Balk, 1998; Stroebe & Schut, 1999; Tyson-Rawson, 1996). Examples of positive outcomes include increased maturity, life skills and competencies gained for coping with future problems, improved confidence, and improved physical and mental health, which can lead to productive contributions as adult members of society. Extension professionals play an important role in developing skills that foster strength through adversity and, accordingly, we can set the stage for improving developmental outcomes for adolescents coping with a major crisis such as parental cancer.

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