

MUDDLING THROUGH:
HOW YOUNG CAREGIVERS MANAGE CHANGING COMPLEXITIES

by
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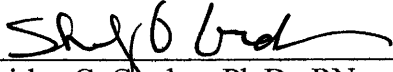
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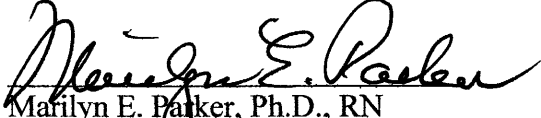
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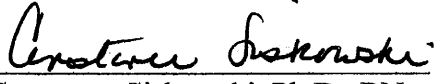
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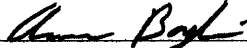
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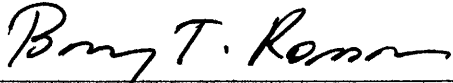
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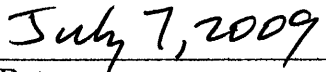

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ABSTRACT

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In the United States, an estimated 1.4 million children and adolescents, age 18 and under, provide daily unpaid physical, emotional and supportive care to a chronically ill or disabled family member (NAC & UHF). While the phenomenon of caregiving performed by adult children and spouses has been extensively explored by nursing, little is known about how Young Adolescent Caregivers manage being a caregiver while they attend school and mature socially as an adolescent. The purpose of this Grounded Theory study was to identify and describe the basic social psychological problem shared by young adolescent caregivers girls, (N=9), aged 11-14, and the basic social processes used to manage the shared problem. Using the constant comparative method of data analysis, from audio taped and transcribed, semi-structured interviews were reviewed. The Basic Social Psychological Process (BSPP) identified was Managing Complexities. Muddling

Through (BSP) was the process identified through constant comparison of the data to create categories. The phases of Muddling Through are: Becoming a Caregiver, Choosing Family, Creating Structure and Maintaining Balance. Young adolescents experienced becoming a caregiver through three paths: Embracing the Challenge, Sharing the Load and Being Assigned. Awareness of the consequences of being a Young Adolescent Caregiver and strategies used by Young Adolescent Caregivers to manage their changing complexities has implications for nursing interventions. Nurses in a variety of settings that treat persons with chronic illnesses can modify their practice to make significant supportive interventions with these largely invisible caregivers. Implications for policy change, nursing education and practice and future research are explored.

MUDDLING THROUGH:
HOW YOUNG CAREGIVERS MANAGE COMPLEXITIES

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CHAPTER 1

INTRODUCTION

Despite the rise of a vast system of health care in the United States since the 1880s, care for the sick and disabled people still is predominantly a private responsibility (Abel, 1994).

Chronic diseases-such as heart disease, cancer, and diabetes are leading causes of death and disability in the United States. Chronic diseases account for 7 in 10 deaths in the U.S. each year (Centers for Disease Control and Preventions, 2009). “Approximately one-fourth of persons living with a chronic illness experience significant limitations in daily activities” (CDC, p. 1). Schumacher, Beck, and Marren (2006), reported that care routine complexity, age, and physical or mental ability, influenced an individual’s success in implementing a disease management plan. “As the U. S. population ages and health care costs soar, family and friends are called upon increasingly to provide care” (p. 40). They predict patients without family assistance and support will require a higher rate of institutionalization.

Friedman, Bowden, and Jones (2003) explored the role of family caregiving. “Family members, and women in particular, play a vital role as primary caregivers not only for the frail elderly, but for family members of all ages who are dependent, often due to chronic physical or mental disabilities” (p. 336). The title “Family Caregiver” has been defined as “family members or spouses who provide emotional support, surrogate decision making, financial contributions, care management or hands-on care for family

members, friends or spouses with chronic or acute long term illness or disability” (Levine, 2007, p. 6).

Adult caregivers’ duties may include instrumental activities of daily living (IADLs) or activities of daily living (ADLs). IADLs are described as providing transportation, grocery shopping, housework, managing finances, preparing meals, helping with medication, and managing outside services. ADLs are considered activities that help to the care recipient with getting in and out of bed and chairs, getting dressed, bathing, toileting, feeding, continence and diapering (National Alliance for Caregiving [NAC] & AARP, 2004).

There is a wealth of information about adult caregiving: who performs it, where it is carried out, by whom and with what consequences. Nursing approaches to assisting the adult caregiver are wide and varied (Farran, 2001). Research has studied the positive and negative effects of caregiving on adult caregivers and care recipients, creating and using effective support programs for caregivers and proposed methods to improve outcomes for all (Nuboer et al., 1998; Santacroce, 2003; Schumacher et al., 2006, Sit, Wong, & Clinton, 2004; Solowiejczyk, 2004). The wide variation in research approaches reflects community or site specific goals to intervene and support local or community specific populations of frail or chronically ill individuals. An attempt to address the needs of adult caregivers as a group began with an assessment of just how many people needed help and who was providing care for them.

“Recent studies estimate that 5.8 million to 7 million Americans provide care to persons aged 65 or older who need help with everyday activities” (Blumberg & Luke, 2007; DeFrances, Hall, Podgornik, 2003; Feinberg, 2004; Popovic & Hall, 1999;

Tennstedt, 1999). National statistics from the landmark study by the National Alliance for Caregiving in collaboration with AARP reported that 22.9 million of households in America provide care for persons 18 to 50+ years of age (NAC & AARP, 2004). It should be noted that of the 28.4 million households in the U.S. that include a child who is age 8 to 18, 3.2% of those households reported including a young caregiver (NAC & United Hospital Fund [UHF]). Even if not identified by family as a caregiver, children living in homes where caregiving is performed by adults are likely to be affected by and be part of the caregiving system of the family.

The disparity in the statistics reflects differences in research methodologies, caregiver and care recipient population definitions as to age or type of disease experienced, different data collection methods and do not specifically address the issue of caregivers under the age of 18. The first U.S. national telephone study with a focus on young caregivers reported approximately 1.4 million children and adolescents in the United States were caregivers (NAC & UHF, 2005). In spite of consideration of differences between studies in data collection methods and resulting statistics, it is clear that the role of children and adolescents in caregiving was omitted in early studies. Lack of comprehensive data about children who are caregivers from research may also be a result of multiple terms and definitions used in identifying children and adolescents who are caregivers. The average age of a young person, a young carer, who has family caregiving responsibilities in England is 12 years old (Carers National Association [CNA], 1997) and 13 years old in Australia (Carers Australia, 2001). The NAC and the UHF (2005) defines a young caregiver as a person between the ages of 8 and 18 who provides unpaid physical, emotional, or supportive help or care, often on a regular basis

to a disabled or chronically ill family member or relative of any age. This definition will be used to study the basic social processes of the young caregivers in this study.

The active involvement of children in caregiving has been largely unrecognized or ignored by the public, healthcare providers, researchers, academics and policy makers (Earley, Cushway, Cassidy, 2007; Siskwoski, 2006). Studies have focused primarily on identifying the tasks and consequences of being a young caregiver.

Modeling on research with adults, definitions of direct and instrumental tasks performed by young caregivers were conceptualized by the researchers the same as those caregiving tasks provided by adult caregivers (NAC & UHF, 2005). Interestingly, these same tasks were identified as “caregiving tasks” provided by adult caregivers in the Caregiving in the U.S. study conducted in 2004 by the NAC in collaboration with AARP. Direct tasks were identified as assisting the care recipient with activities of daily living (ADLs): bathing, transferring, toileting, and feeding. Instrumental tasks were defined as assisting with indirect activities of daily living (IADLs) such as the management of household chores, grocery shopping, preparing meals, and preparing and administering medications.

Parents in the NAC & UHF study were questioned about the effect of performing these tasks on their children. The parents reported that children acting as caregivers were more likely to show anxious or depressed behavior after caregiving began than before undertaking caregiving activities. Young caregivers between 12 and 18 years of age in the study were more likely to exhibit antisocial behavior. The antisocial behavior was demonstrated in four ways: “Showing bullying/meanness to others; having trouble getting along with teachers; disobedience at school and hanging out with kids who get in trouble”

(NAC & UHF, p. 22, 2005). “Antisocial and or depressed behavior increased when the young caregiver and care recipient lived in the same household” (NAC & UHF, p. 8). The researchers asserted the origin of these antisocial and depressed behaviors may be related to the young caregivers stated feelings that “no one loves them or that they are worthless” (NAC & UHF, p. 6). In this study the children’s and adolescents’ behavior, regardless of the children’s or adolescents’ level of involvement in direct and/or indirect caregiving, was affected by the behavior, attitudes and emotional health of the adults providing care to family members with chronic conditions.

Research again supported that a child, regardless of the level of involvement in actual caregiving, is affected by the caregiving requirements of the ill, frail or disabled family member, and by the behavior, attitudes and emotional health of the adults providing care to that family member (Rehm & Catanzaro, 1998; Townsend, Noelker, Deimling & Bass, 1989; Worsham & Crawford, 2005). The crisis of a sick or frail family member calls to all family members who are able to help. Changes in the healthcare delivery system and in our society offer few options to families and children in these situations. Shorter hospital stays, advances in technology, an increase in the number of uninsured individuals, high cost home health care, complex chronic illnesses, the mobility of the extended family and an increasing number of single parent families have affected how and where patients are treated and cared for.

While some information may be generalized from the adult caregiving literature, the significant emotional, cognitive and physical differences between adult caregivers and the young caregiver would suggest that caution is needed in such comparisons. Further research examining the effect of the caregiving role on young caregivers is

warranted in order to assist the nursing community in addressing the unique needs of these youthful providers and their families.

The Problem

Young caregivers and their contributions to caring for family members are largely unrecognized and invisible to health care providers and the healthcare system. School and community based nurses and discharge planning staff are likely to come into contact with unidentified young caregivers in the course of their daily work. In nursing chronically ill and disabled patients, “Nurses play a major role in identifying family caregivers, assessing their needs, intervening with both the impaired family member and the caregiver and evaluating the outcome of this care...and how caregiving affects the caregiver both mentally and physically” (Farran, p. 12, 2001).

Community nurses are in a unique position to identify and support young caregivers. However, there is limited information about the experience of being a young caregiver. Mid range nursing theories are needed to guide the development and evaluation of nursing interventions that are meaningful to young caregivers. The qualitative study described below is a beginning.

Research Question and Purpose

The purpose of this Grounded Theory study is to explore and describe the basic social psychological problem and process used by adolescent girls aged 11 to 14 in caring for adult family members. Research questions include:

1. What is the basic social psychological problem experienced by young girls aged 11 to 14 providing care?

2. What are the basic social psychological processes used by young girls aged 11 to 14 to solve problems they encounter as a result of caregiving?
 - a. How do interactions with parents, teachers, health professionals and care recipients support or hinder the completion of the tasks of caregiving?
 - b. How are interactions with peers and friends affected by the demands of being a young caregiver?
 - c. What strategies do young girls aged 11 to 14 providing care use to manage the multiple roles of caregiver, student, and individual caring for self?
 - d. What consequences are experienced by young girls aged 11 to 14 providing care as they perform the role of caregiver?
3. Which social structural processes affect the experience of being a young female caregiver?
 - a. How do academic, medical care delivery systems and health insurance system structures affect the role of being a young female caregiver?

Significance to Nursing

Nursing is the protection, promotion and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response to health and illness, and advocacy in the care of individuals, families, communities and populations. (American Nurses Association [ANA], 2004)

This definition has guided nursing care of chronically ill individuals and their families. Nursing practice has also been guided by extensive nursing research about individuals with chronic illnesses. This research has created a foundation for nursing interventions

with adult family caregivers of chronically ill persons (Algera, Francke, & van der Zee, 2004; Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; May, Ellis-Hill, & Payne, 2001; Rehm & Catanzaro, 1998). While young caregivers, as a newly identified group of family caregivers in this country, provide a significant contribution to the care adult family members with chronic conditions little is known about this group of adolescents (Gibson & Houser, 2007; Sorrell, 2007). A better understanding of young caregivers may provide a foundation on which to base future care planning and family support. Listening to the voices of young caregivers may lead to a fuller understanding of shared problems and processes from which meaningful nursing interventions can be developed.

CHAPTER 2

LITERATURE REVIEW

“The place of a literature review in a grounded theory study has long been both disputed and misunderstood” (Charmaz, 2006, p. 165). The classic grounded theorist (Glaser, 1978) suggests that a literature review be delayed until the analysis of data is completed. This is to prevent forcing data into previously known or learned categories. It is suggested that the researcher’s previous knowledge and information from practice and the literature be bracketed to prevent this from occurring. Adherence to this position in grounded theory tradition, limits the review of the existing research usually used to identify gaps in knowledge or to expand understanding of the phenomenon under study. Therefore, a limited literature review is presented which will support the need for further research exploring how young caregivers care for adult family members.

Family Caregivers

“Beginning in the 1970s and 1980s, family caregiving, an age-old practice, became a major research, programmatic, and policy topic in the United States” (Levine et al., 2005, p. 2071). Research to date has focused primarily on spousal caregiving and adult children caring for elderly parents (Levine et al.). An additional area of research interest has been caregiving to disabled or chronically ill children provided by parents (Gayer & Ganong, 2006; Madden, 2004).

A picture of the everyday life of an adult caregiver can be drawn from the 2004 study conducted by the National Alliance for Caregiving and AARP. While this telephone based survey was limited by insufficient representation of minorities and those who do not speak English, basic information about whom, to whom and how family caregiving is provided was described in the results. Survey respondents were asked if they performed one of 13 tasks that caregivers usually perform. These included helping manage finances, shopping for groceries, or doing housework (indirect activities of daily living [IADLs]) and the personal or more intimate care (activities of daily living [ADLs]) such as helping someone get in or out of bed or a chair, get dressed, bathe, use the toilet, or eat. The researchers described the typical U.S. caregiver as female, about 46 years of age, with some college education, working and spending more than 20 hours a week providing care to her mother. A later study supported the finding that caregiving is largely a woman's work (NAC & UHCF, 2005). More women than men are caregivers, provide more hours of care than men and are more likely to report emotional stress as a result of their caregiving than men (NAC & AARP, 2004). While a description of the average adult caregiver is enlightening, broad generalizations about gender, age, education and tasks performed that create a picture of the "typical" young caregiver cannot be drawn from the data available.

Researchers conducting studies in private home, nursing home and clinic settings have identified emotional and physical adult caregiver responses to caregiving and the stress placed on the family by caregiving (Admi & Shaham, 2007; Aminzadeh et al., 2005; Farran, Loukissa, Lindeman, McCann, Bienias, 2004). However, it cannot be assumed that young caregivers will respond to caregiving in similar ways.

Gender and Caregiving

In studies exploring the effects of chronic stress on the health of adults caring for family members experiencing dementia, Zhang, Vitaliano, and Hsin-Hua (2006) discovered gender played a role in how caregivers respond. These behavioral researchers explored the differences between men and women on 25 different health indicators. The results suggest that women as caregivers report more psychosocial problems than men (p. 178). The researchers postulated that a willingness to report health or psychosocial problems if they are under stress stems from women's greater awareness of their problems and greater likelihood of reporting those concerns to others (Zhang et al.). Exact effects of caring for others are not clear, because past studies have been based on definitions of health that are multifaceted and inconsistent between studies. Measures of caregiver health indicators have included physiologic measures such as blood pressure, lipid or body mass index, and health habit measures, such as medications used, global self-assessment of health or exercise levels and food diaries. Future researchers are encouraged to "choose health indicators relevant to the specific purpose of the study" (Zhang et al., p. 180).

Kim, Loscalzo, Wellisch, and Spillers (2006) studied husband caregivers of wives with cancer. They reported husbands experienced more stress if their wives had poor emotional and social adjustment to the diagnosis of cancer and their expectations of husbands as caregivers. However, the researchers' intervention suggestions were patient centered, focusing on the wives.

Gender and parental coping while caring for a child with multiple chronic illnesses has also been studied. Katz (2002), focused on the differences in adaptation to

caregiving and the child's chronic illness between mothers and fathers and the buffering effect of resistance factors, self-esteem, social support and perception of the impact of the child's illness on coping behaviors and adaptation. Overall, a father's use of coping behaviors to adjust to having a child with a chronic illness appeared to be influenced the number of stressful general life events that occurred and his use of a social support system. Mothers' adaptations appeared not to be affected by the number of stressful life events or the severity of the child's chronic illness. Further parental gender differences were noted in (a) the parental use of social support, (b) the effect of the parents' internal resources such as self esteem on their adaptation to the illness, (c) the method or role assumed by each parent to facilitate personal coping, (d) the effect of a good marital relationship on parental perceptions, and (e) the degree of involvement with direct physical care of the child assumed by each parent. The effect of gender on the behavior and feelings of a young caregiver, when the care recipient is a parent or grandparent, is not known. There has been limited investigation of the interplay or effect of gender and role in the young caregiver-care recipient dyad.

The 2005 U.S. NAC and UHF study offered some information about young caregiver strength and style of coping but omitted the interrelation of gender and caregiving by gender of the participants. The number of caregiving vs. non-caregiving male and female participants in the study was equal, 49% were male in both samples and 51% were female (NAC & UHF, 2005). The 2004 Caregiving in the U.S. study of adult caregivers reported that 65% of caregivers were female and were providing more hours of care at a higher level of care than men. Women reported a higher level of emotional stress than men (NAC & AARP, 2004). The effect of gender on the behavior and feelings

of a young caregiver, when the care recipient is a parent or grandparent, is not known. There has been limited investigation of the interplay or effect of gender and role in the young caregiver-care recipient dyad.

Nursing Support of Caregivers

The positive and negative components of caregiver stress and burden, how to relieve it, reduce it and support caregivers' experiencing this stress has been investigated (Chelsa, 2005; Farran, 2001; Robinson, 1990; Wilson, 2004). For example, Farran's retrospective review of adult and spousal caregiver intervention nursing research studies identified the gains made through research in a twenty year period. The types of research identified in the review were: descriptive studies of both care givers and care recipients; identification of caregiver and care-receiver issues, such as depression, the effect of caregiving on the caregivers' health and the interaction and effectiveness of a variety of healthcare provider caregiver interactions. Farran encouraged researchers to refine future research through the "use of improved study methods and designs" (p. 42) and investigate the usefulness of technology in caregiver support.

Wilson framed her approach to supporting home based caregivers in Family Theory. She stated that the "key to successful (nursing) management is thorough and accurate assessment of patient and family needs" (Wilson, 2004, p.51) While identifying that more than 114,000 children between 5 and 15 years in the United Kingdom are in the role of caregiver, Wilson did not elaborate on nursing interventions that might be meaningful to this age group. However, she asserted nursing interventions should be focused on the whole family versus an individual patient or any one caregiver. Therefore,

her theoretical approach to nursing intervention includes nursing support for the young caregiver as a family member and not as a unique caregiver.

The breadth of research about adult caregivers in family settings is great. Limitations include lack of a singular research approach, shared and varying definitions of caregiver and care recipient, un-unified models or the lack of the use of consistent theoretical foundations. These limitations make it difficult to compare studies. While much appears to have been learned about adult caregivers, young caregivers may be faced with unique challenges and form responses that significantly differ from adult caregivers.

Young Caregivers

Interest and awareness of caregiving youth as a social issue began fourteen years ago in the United Kingdom (Aldridge & Becker, 1993a). A desire to make changes in legislation and social policy surrounding the delivery of health care in an aging society in the UK stimulated this initial research. Early sociologic studies using both case study and phenomenologic perspectives established the occurrence of the phenomena and described the societal and family circumstances that created the need for a caregiving policy in the United Kingdom. The groundbreaking research by Aldridge and Becker (1993b, 1999) identified the prevalence of young caregivers, provided a description of the tasks carried out by young caregivers, and raised questions about the potentially negative effects of caregiving roles. The term “young carers” was initially coined by Aldridge and Becker (1993b) to identify those people under the age of 18 who were providing primary care for a sick or disabled relative in the home. In a later article, the definition of “young carers” was changed to identify those “who take on caring tasks or responsibilities that

have a negative impact on their own development or opportunity to engage fully in the experiences of childhood” (Aldridge & Becker, 1999, p. 313). While the researchers gave names to themes of feelings identified by young caregivers, they did not create a unifying theory that could be the foundation of future research or direct the development of useful interventions.

Cree (2003), in a study of young carers at the Edinburgh Young Carers’ Project (EYCP), explored worries and problems related to young carer’s emotional health in a mixed methods research approach by using a self-completion survey and follow-up interviews. The purpose of the study was to verify the emotional health of the young carers attending a support program in Edinburgh and to justify programmatic changes to improve care. A convenience sample of young carers was “invited” to participate in the survey. A questionnaire was used to solicit demographic and descriptive caregiving information about the worries and problems in their lives. “Worries” were defined as things that were anticipated to cause difficulties and “problems” referred to difficult things already experienced as concrete events. After completion of the survey, a small number of self-selected volunteers provided “in-depth” personal caregiving stories. The sample was gender unequal, (34 girls and 25 boys) and 75% of the participants were 10-15 years old but the age range of the carers in the study was from 5 to 16 years. The findings of the study identified a range of “worries” that were attributed to being an adolescent, for instance, their appearance, and “worries” that are unique to these young carers. The “worries” of adolescents included concerns about body image, friendships, and relationships with parents, school, money and problems associated with impaired mental health. The worries unique to young carers were identified as the health of the

person they cared for, their own health, and the behavior of their care recipient and wonder about who would take care of them in the future. Outcomes generated by the study were probably affected by the unequal percentage of female to male young carers. More female participation in caregiving reflects data from the adult caregiving literature but in this case may be a result of the method used to recruit participants. A significant finding of the study was that 60% of young caregivers reported sleep disorders and having significant worry about the person for whom they cared. Most alarming however, was the report of a history of self-harm (drug and alcohol use) and thoughts of suicide by one-third of participants (Cree, 2003).

In the U.S., the first attempts to evaluate the effect of caregiving on children began with the “look back” or retrospective method by Shifren (2001) who asked adults who had been young caregivers to recall their emotional feelings about caregiving and report on their current mental health. These adults, who had been caregivers at a younger age, demonstrated vast individual differences in both their caregiving experiences and their current mental health status. “Some former young caregivers appear to have good mental health (in adulthood) however the percentage of individuals who appear at risk of depression in adulthood is large enough to warrant the need for effective support programs “(Shifren & Kachorek, 2003, p. 344).

One of the first studies to work directly with the young caregivers focused on the caregiving tasks performed for family members with cancer (Gates & Lackey, 1998). Young caregivers in this study felt their work with relatives was difficult but worthwhile. These young caregivers expressed the opinion that being a caregiver was an expectation of family membership (Gates & Lackey).

In the United States, the first national study to provide new and specific information about the 1.4 million young caregivers and the activities they perform each day was the Young Caregivers in the U.S. (NAC & UHF, 2005). Additionally, it explored role responsibilities that caregiving children and adolescents assumed and the effect assumption of these responsibilities had on their emotional, behavioral, mental health and educational lives (NAC & UHF, 2005). The stated aims of the study were to examine four areas: (a) how time is used each day; (b) actual behaviors of caregiving youth; (c) caregiving youth self-perceptions; and (d) caregiving youth emotional feelings as described by the child's parents. Over half (58%) of the young caregivers in the study assisted an adult family member with at least one activity of daily living (ADLs). Almost all young caregivers reported participating in the instrumental activities of daily living (IADLs). The researchers concluded that between caregiving and school, there was little time for other usual childhood activities or pastimes. What is not known is how young caregivers manage their time and how being young caregivers impacts their development.

In the study by NAC & UHF (2005), young caregivers reported positive effects of being a caregiver while parents reported observed negative effects. In this study, young caregivers stated they felt more appreciated for the help they provided and did not think that the expectations of others on or about them were too high. In contrast, parents described antisocial and depressive effects of caregiving on their children (NAC & UHF). The contrasting views held by parents and young caregivers conveyed the complex nature of being a young caregiver, but offered limited insight into the origins of positive and negative feelings associated with caring for adult family members

In a first of its kind study by Siskowski (2006), investigated the effect of caregiving on school performance and school attendance in young caregivers in Southeast Florida. Young caregivers in this study self reported experiencing academic problems and school difficulties as a result of the increased time spent in performing routine or supportive care activities for their care recipient. This was the first documentation that one in three young caregivers experienced at least one negative effect of caregiving, such as missing school, not completing homework or not having time to think. Many of the participants in the study experienced more than one negative effect. These findings were supported by a similar study in the U.K. Dearden & Becker, (1994) in which young caregivers reported academic problems and difficulties in choosing a career path as a result of the amount of time spent in performing similar activities.

Chapter Summary

Young caregivers are a unique group with unique challenges and may respond differently from adults caring for family members. Researchers have (a) established the phenomena of young caregivers as an important presence in family caregiving; (b) identified tasks performed by young caregivers; (c) discovered tasks performed by young caregivers mimic those provided by adult caregivers; (d) reported that young caregivers usually live with the care recipient; and (e) reported that young caregivers experience both positive and negative feelings and behaviors that occur as a result of the caregiving experience. The literature is not clear about processes used by young adolescent caregivers to manage caring for adult family members day to day. The meaning young adolescent caregivers assign to the experience of caring for an adult family member and how caring for an adult family member influences social relationships is also not known.

CHAPTER 3

METHODOLOGY

The preceding review of the literature demonstrated that while there are a large number of young caregivers in the United States, they remain virtually invisible in the health care system and therefore have received very little research attention. While there is literature describing the experience of caring for an adult family member differs from the perspective of adult caregivers, the voice of the young adolescent caregiver has not been heard. Qualitative research methods are used to explore a selected phenomenon when an explanation is sought for questions of “how” or “why” and “what” (Nelson & Quintana, 2005). With a description and fuller understanding of a phenomenon, nurse researchers can predict and explain behaviors leading to meaningful nursing interventions.

Purpose of the Study

The purpose of this research is to explore and describe the basic social psychological problem and processes used by young adolescent caregivers. Grounded theorists’ believe that individuals make sense and put order into the activities of their everyday lives even if that order is not apparent to observers (Hutchinson & Wilson, 2001). Therefore, people who share a common circumstance, like young adolescents caring for adult family members, are also thought to experience shared meanings and behaviors. A better understanding of these social processes should enable nurses to

recognize, intervene and support the health and well-being of young adolescent caregivers.

Grounded Theory

The grounded theory method is a qualitative approach used by nurses seeking “theory-guided knowledge to better understand and promote human health when the research question seeks to better understand and promote human health experiences and the underlying human-environment processes of health and well-being” (Reed & Runquist, 2007, p. 119). Grounded theory is a method of “theory discovery” through the identification of basic social processes (Glaser & Strauss, 1967; Reed & Runquist, 2007).

Grounded Theory, developed by sociologists Glaser and Strauss in 1967, has its philosophical foundations in symbolic interactionism (Mead, 1934). Mead stated that human beings are involved in a continual process of adaptation as they consider the situations they are engaged in during social interaction with others (Jeon, 2004). Blumner, a student of Mead’s, expanded the original theory of social interactionism by adding interpretation of an individual’s interactions (Blumner, 1969).

From this perspective, a young adolescent caregiver interacts in his/her world through relationships. These relationships are with family members or others at school, church or with peers. Evaluation of both the process and outcomes of these interactions seen through the lens of symbolic interactionism, include the following basic precepts:

1. The meaning that things have for an individual is based on a social interaction that a person has with another being.
2. Human beings act toward people and objects on the basis of the meaning that those things have for them.

3. Humans arrive at meanings about those people and objects through an interpretative process based in their interactions (Blumner, 1969).

Grounded theory, based on a symbolic interaction framework, offers an ideal method to discover how young adolescents solve everyday problems associated with caring for an adult family member. The goal of grounded theory is the development of an inductively derived theory, grounded in the experience of young adolescent caregivers. The theory is generated around a core variable or process that explains a pattern of behavior which is “relevant and problematic for those involved” (Glaser, 1978, p. 93). “The researcher aims to capture all of the variation in the phenomenon under study and examining conditions under which the phenomena occurs, as well as conditions under which it varies” (Chenitz & Swanson, 1986, p. 41). To ensure that the developing theory is grounded in the data and not in existing theory, the researcher combines theory building techniques that involve continual redesigning of data analysis with careful coding and a constant data comparison method (Schreiber, 2001).

Sample

Initial recruitment of participants for a grounded theory study is based on purposive or selective sampling. Using this approach the researcher can focus data collection on individuals who have experienced the phenomenon of interest and who are likely to provide data about the research question (Glaser & Strauss, 1967).

Nursing research with caregiving children and adolescents is limited, possibly reflective of past concerns about conducting clinical research on underage participants and the invisible nature of the work. Previous researchers gathered information by proxy about a child’s experiences to the phenomenon of interest. Interviews with a child’s

parents asked the parents to identify the child's feeling and behavior (NAC & UHF, 2005). A retrospective approach also has been used by asking adults, who experienced the phenomenon as children, to reflect on and describe an experience as they remembered it (Lackey & Gates, 2001, Shifren, 2003). Both approaches created limitations in the data or theory discovered. In contrast, Robinson (2001) simply accepted as believable all data gathered from adolescents aged 12 to 14 years. He used that data to create a conceptual model of health behavior selection (Robinson, 2001). This believability approach was also used and supported by Chenitz and Swanson (1984). Presently, it is increasingly acknowledged that research with children can be safely performed and provides "a rich resource of data that has been largely unexplored" (Coyne, 1998, p.410).

For this study, sampling was directed by the research questions and guided through a process of theoretical sampling (Chenitz & Swanson, 1986). Participants were solicited from the Caregiving Youth Project (CYP), a support program in South East Florida. The program offers middle school caregivers, identified through general survey and self-identification, the opportunity to participate in educational, support and social services. The program is designed to provide support to the child or adolescent and family during the time of caregiving duties.

In this study, the term "young adolescent caregiver" was defined as those 11 to 14 years old who provide direct or indirect care to a chronically ill or disabled family member who experience both negative and positive outcomes in all areas of their lives as a result of providing care. Because the literature suggests the majority of caregivers are women, and gender is thought to play a significant role in caregiver response, this study was limited to adolescent females. Criteria for participation in this study included: (a)

verified designation by the CYP survey or by self-report of caregiver status; (b) no previous or current participation in CYP direct support activities; (c) identification of the care recipient as a parent, grandparent or family member; (d) co-residence with the care recipient at least 50% of the time; (e) being female between the ages of 11 and 14; and (f) being a proficient English speaker.

CYP nurse and social work staff received general information about the student and instruction regarding the inclusion criteria. Prior to receiving services from CYP, evaluation of potential research participation interest was determined through a brief explanation of the study by CYP staff. If a potential participant demonstrated interest, the staff sought parental permission to have the researcher contact the parent. Following parental permission, contact information was provided to the researcher by the CYP staff. The researcher then contacted the parent for verification of caregiving status, participation interest and to establish interview appointments and locations. Nine adolescent girls, who were active caregivers, accompanied by a parent were involved in the study. Although encouraged by the researcher to allow their daughters to take part in the interview privately, two mothers chose to remain with their daughters during the interview process. This had a brief limiting effect the participants' interaction with the researcher but was easily overcome through the use of friendly and active engagement of the participant.

Sample Description

As described in the study criteria, all participants (n=9) were female adolescents between the ages of 11 and 14 years old. Participants reported providing care to grandparents, (N=4, 44%), parents, (N=3, 33%) and others (N=2, 22%). The ethnicity of

the participants and their families reflected the multi-cultural environment of Southeast Florida. Participants described their ethnicity as Haitian (33%, n=3), White/European (22%, n=2), American Black (11%, n=1), Latin/Hispanic (11%, n=1), Caribbean Black (11%, n=1) and mixed/other (11%, n=1).

The demographic form completed by parents before the interviews began demonstrated that eight (88%) of participants provided direct care (feeding, bathing, dressing, getting in and out of beds and chairs and assisting to the bathroom), and 100% of the participants provided instrumental care (household chores, grocery shopping, preparing meals or preparing and administering medications). Young adolescent caregivers in the study spent from 30 minutes to more than 2 hours each day in completing these activities. Several participants (44%, n=4) reported spending more than 2 hours each day providing care. 55% (n=5) of the care recipients required more than 2 hours a day of care provided by combination of adult and young adolescent caregivers. This suggests that these young caregivers are making a significant contribution to the total care of the chronically ill or disabled family member in their home.

Eight (89%) of the participants reported being eligible for free or reduced price lunch offered by the Palm Beach County School System. Federal standards guide the acceptance of student in the national free and reduced lunch program. Income eligibility guidelines are related to household size and income levels. Eligibility guidelines for free lunch are at or below 130% of the Federal poverty guidelines and at or below 185% of the Federal poverty guidelines (U.S. Department of Agriculture, 2008). Therefore 89% of the young caregivers in this study were living below the poverty levels.

The effect of caregiving on school attendance, tardiness and absence was reported as limited or none. All students were said to attend school everyday. The one exception was a participant who stayed out of school to care for her father on one regularly scheduled day each week for six months. She stayed with him in place of her grandmother and provided this care in both the acute care hospital setting and rehab facility. Participants in this study reported caregiving had a minimal effect on school attendance. This finding is in contrast to the 13.2% of participants identified by Siskowski (2003) who “miss school or school activities” as a result of their caregiving duties (p. 7). The reason for the variance is not clear and bears further study.

Informed Parental Consent and Participant Assent

Until 1998, clinical research about treatments and interventions for children was based on clinical trials conducted on adults (National Institute of Health [NIH], 1998). The treatments available to children were accordingly limited. Direction from Congress to NIH mandated the creation of developmentally appropriate guidelines for research with this vulnerable population (Broome & Richards, 2003; Committee on Bioethics, 1995). Primary among these guidelines was the process of how “informed consent to participate” in was obtained. This study obtained both a “parental consent to participate” and a “child/adolescent assent to participate” before data collection began (see Appendix C and D). Discussion of the caregiving role was expected to cause minimal risk or harm to the participants. Recognition of the sensitive nature of the topic was discussed during the consent/assent process and participants were told they were free to stop the interview and/or withdraw from the study at any time. No participants asked to withdraw from the study or required counseling after participation. However, one interview was terminated

early by the researcher when a participant became upset during an interview and began crying. The situation was discussed with the participant's parent and the participant. While the participant stated she was happy to stop talking about caregiving, she did not want to withdraw her interview from the study.

Data Collection

The study was approved by the Institutional Review Board and the Christine E. Lynn College of Nursing at Florida Atlantic University. Participant information was de-identified through the use of codes known only to the researcher and the dissertation committee chair.

Following completion of the informed consent/assent process, a demographic questionnaire was completed by the parent (See Appendix D). Information was gathered about the participant's age, gender, ethnicity, relationship to the care recipient, medical diagnosis of the care recipient, duration of the requirement for caregiving activities (years or months) and types of caregiving activities performed (IADLs or ADLs). Open ended questions in a semi-structured interview format were used to explore how the young adolescent caregiver managed multiple social interactions. An interview guide was used to facilitate the face-to-face interviews (See Appendix E). Interview times and places were determined based on participant preference and the interviews lasted approximately 60 to 120 minutes. The audio taped interviews and coded interview transcriptions were kept in a locked file box in the office of the researcher.

Interviewing in this study was a process between an adolescent girl and an adult, the researcher. This was an interactive process and the data generated could have been influenced by age, role, ethnicity and class differences of the participant and researcher.

Strategies to overcome or diminish these effects were: (a) coming to know the participant and her family as individuals before guiding the interview toward questions about caregiving; (b) allowing the participant to feel valued by the attitude and positive verbal and non-verbal responses from the researcher such as positive comments, laughter and affirmations about how successfully the young caregiver was managing her life; and (c) by concluding the interview by asking for advice on what would be helpful to other young caregivers. This last question validated the worth of the participant and always stimulated thoughtful responses (Edwards, 1993).

Data Analysis

Grounded theorists assume persons who share an experience, like being a young adolescent caregiver, also share a specific basic social-psychological problem (BSPP) which is solved using a shared basic social-psychological process (BSP) (Hutchinson & Wilson, 2001). Data analysis therefore was directed toward discovering the shared BSPP and BSP of young adolescents caring for an adult family member. In keeping with a grounded theory tradition, data analysis began following the first interview. A constant comparative method was used to conduct ongoing line by line, phrase by phrase analysis of the data, as recommended by Glaser and Strauss (1967). The first stage of analysis included the coding of data into as many categories as possible while considering the theoretical properties of each category of similar events and incidents. Second, the incident or data was compared to the properties of many categories. Constant or continual comparison of each line of the transcript with that which preceded it was done to insure verification of the categories in the data. Through considering which data was the best fit for the category, integration began to occur. As diverse properties become integrated, the

third stage or theory emergence began. The categories are grouped into hypotheses, which were again compared to categories in an ongoing process (Backman & Kyngas, 1999; Chiovitti & Piran, 2003; Glaser & Strauss; Strauss & Corbin, 1990). With the use of inductive thinking and discussion with mentors and experts in the field, the core social processes of the phenomenon were discovered.

Observations were recorded through the use of field notes, personal notes and theoretical memos. Field notes are defined as observational data produced by fieldwork. A field note was written by the researcher immediately after each interview. In it, the researcher sought to capture the observations and interactions that added depth and provided context for the transcribed interview (Montgomery & Bailey, 2007). Theoretical memos, in contrast, are the informal records of the developing ideas about the codes and the way they might fit together to create themes and concepts. Such memos were an important step between data collection and recognition of the emerging theory by moving from the participant's words to a more abstract view of the data (Charmaz, 2006; Montgomery & Bailey). Personal notes were used to capture feelings, reactions and thoughts of the researcher. Many of the stories shared by the participants described difficult situations. The use of personal notes helped the researcher control the urge to offer help and advise to assist or support the participant. After interviewing the initial participant, subsequent participants were chosen via theoretical sampling process. During the first two interviews, it was necessary to make changes in the language of the questions used to guide the interviews. The first two participants were more familiar with the title "helper" than "young caregiver." Use of the term "young caregiver" caused confusion and misunderstanding between the participant and researcher which was

reflected in the transcripts of the first interviews. To help the participants understand the subject being investigated, both terms, “helper” and “young adolescent caregiver,” were used interchangeably in subsequent study discussions and interviews. Generally the participants were reluctant to identify themselves as young adolescent caregivers but happily described how they helped their care recipient and family. In keeping with the grounded theory method, this investigator collected, coded and analyzed the initial data to decide how to modify the open ended questions used to collect future data with good results (Glaser & Strauss, 1967) (See Appendix E).

Integrity

Grounded Theory research validity depends on data saturation in which similar descriptions from multiple participants who share a common social process increase the potential for validity. Data was considered saturated after interview number 7 when no new information was being collected. Two additional interviews were conducted to ensure saturation. The method of participant selection together with data saturation enhanced the believability of the information discovered. Adolescent participants, who were unknown to each other, described their experiences and feelings caregiving experiences from which the grounded theory emerged.

Integrity in the research was also supported by demonstrating the connection of the data to the theory. Reliability, a positivistic term from quantitative research, is described in grounded theory as fit and relevance. Additionally, the theory must “work” or be able to explain the phenomena and predict and describe actions that are related to the phenomena (Glaser & Strauss, 1967). Suspension or bracketing this researcher’s previous knowledge of theories and concepts that could be related to the phenomenon of

caregiving was necessary. As a pediatric nurse practitioner and family caregiver, this researcher insured that the data gathered reflected the social processes of the participants through self-evaluation and discussions with grounded theory experts. Additionally, data was not “forced” into pre-existing categories or theories. The theory arose from of the data gathered (Eaves, 2001).

Chapter Summary

Exploring the experience of young adolescent caregivers through the use of Grounded Theory and Symbolic Interactionism acknowledges the complex nature of their lives. Daily interactions with parents, care recipients, teachers and other adults, as well as same age peers and friends, affect all other interactions and choices that young adolescent caregivers make. While studies in the U.S. to date have identified the role of young adolescent caregivers and views of their parents about the effect of caregiving on their child, young caregivers have yet to tell us their stories. This study provides a beginning in the process of understanding how a particular group of young adolescent female caregivers manages the caregiving role.

CHAPTER 4

RESULTS

Grounded theorists explore the way individuals define their worlds and the way they respond to it. Grounded theory is based, in part, on the principle that people sharing common circumstances and experiences share common meanings and behaviors and a common, although often non-articulated, social psychological problem (Hutchinson & Wilson, 2001). The basic social psychological problem identified in the lives of young caregivers was Managing Changing Complexities. This chapter will define these complexities and discuss the processes used to manage the changing complexities.

Critical Event: Becoming a Young Caregiver

In this study, the critical event of becoming a young caregiver had its origin in situations in which adult family members began to provide nursing care to a chronically ill adult family member in the home setting. In this context, decisions and accommodations were made by the adults in the family about what care was needed and how care tasks would be divided among those available within the family to help. However, the onset of illness or accident that resulted in an adult family member becoming a care recipient did not automatically bestow the status of caregiver upon the adolescent participants in the study. The process adult family members used to make decisions about who is able to provide direct or indirect personal care or emotional support influenced how the participants became young caregivers but was beyond the scope of this study.

This study focused on adolescent girls, age 11 to 14 years who became young caregivers and began by asking participants to “tell me about how you became a young caregiver”. In describing the critical event of becoming a young caregiver, three distinct paths were discovered:

1. embracing the challenge.
2. sharing the load.
3. being assigned.

Embracing Challenge

The work of caregiving, such as personal care for the body, ambulation, feeding and administering both oral and injectable medications are some of the tasks used by caregivers in the daily provision of direct and indirect care activities for the care recipient. Some of the adolescents were intrigued to learn these processes and skills. Some of the participants saw the manipulation of the devices, procedures and medications that offer information, comfort or pain relief as interesting, fun and a useful thing to know about and do. They learned to be a caregiver by taking an interest in what was going on around them and embraced the opportunity or challenge to learn new things.

I became a caregiver by going to her (grandmother's) doctor's appointments. Basically I'm very nosy, so I hear when the doctor comes and I started understanding. Later, I was watching my Mom everyday before I went to school and I decided OK that looks interesting. I would like to help. I kept watching and then I started to follow what she was doing. I started to like it and enjoy it and it made me feel good and made me know I was helping her. When I saw my Mom giving insulin, she like got her the little bag and she opened everything and got out the booklet and I started feeling that this was fun.

To me it's sort of fun and it's an adventure every day. You learn something new, something new happens always. ...

I had to learn. I was there so I might as well learn since I would have to take care of him at home... when she told my Dad how to do it, she told me how to do it. Okay, I was translating for him and I was learning how to give the shot.

Participants in this group anticipated using the skills learned in the future or adult life.

Several mentioned careers as a doctor. These participants demonstrated a self-driven desire and pride in learning and using these supportive indirect and direct skills.

I think a person who's a young caregiver takes care of anybody... basically understands and knows everything they're going through and what medications they take, what kind of food they eat, and if somebody new comes to take care of them and they don't understand or they're doing the wrong thing, you're there to like tell them, verify the right things...

After I go to Boca High... then get in a good college. I have to do some volunteering too. I'm going to be a Pediatrician

The important thing is like they (young caregivers) have responsibilities that most people would not have and I think that its sorta kinda good because they are learning things that other people wouldn't be learning at their age and I think that is taking a good toll out on their life because they are learning how to deal with different things and different issues so when they get older they will know what to do and how to do things and like when they get married it will be easier...they'll know how to clean, watch their children and things of that nature.

Participants on this path described being eager to volunteer to become a caregiver and learn new things. When "embracing a challenge" was accepted, young caregivers spoke with pride about the tasks they perform. Participants, who became a young caregiver following this path, spoke freely to the researcher and were happy about their caregiving position.

Sharing the Load

Other participants chose to become a young adolescent caregiver by following observing the work done by adult family members in support of the chronically a path of volunteering to share the load. Participants who were sharing the load described the ill family member, and the negative emotional and physical impact this work was having on the adult family caregiver. Their path to becoming a young adolescent caregiver began by first simply watching the adult caregivers. After observing, for varying periods of time, they began to make personal judgments about the effect the caregiving tasks were having on the adults of their family who had begun caregiving duties. They expressed concern about the tiring nature of caregiving tasks.

Well it all started when I when I started going to school and I realized that I had a handicapped Uncle and you know my Grandma it was like stressing her because she had to wake him up in the morning and get him dressed and feed him and I said...hmm, why don't I try to help my Grandmother out. So I helped her get his food ready, I help her with the diabetes testing when she got a diagnosis of diabetes hmm, um sometimes I would get his breakfast ready, get his lunch ready dinner , hmm get his clothes out and things of that nature.

This process often began as the number of home visits by home health nurses decreased and more of the overall responsibility of caregiving was transferred to the family. The observations of the adolescent created concern for the adult family caregiver and motivated them to voluntarily choose to offer to help out by participating in the work that was required. In contrast to participants who were embracing a challenge, the decision to become a young adolescent caregiver by sharing the load was influenced by what participants in this group perceived to be needs of and concern for the adult caregivers in the family.

...so we all stayed home with her and I used to be there with my Mom. And at that time I thought that –well since my Mom has school and she has work and everything, maybe I'd like to help her ...you know take a lot of stuff off her back.

Well my Mom used to work and my brother...he used to work too ...to help pay the bills since my Dad couldn't work anymore...so I stayed home. I cleaned, I cooked. I gave him his medicine, get his insulin.

The young adolescent caregivers who were “sharing the load” described an emotional closeness with the family member they were helping i.e. their mother's and grandmothers. In field notes, praise from those adult caregivers was lavish. They reported that their young adolescent caregivers were “exceptional--did a fabulous job-as caregivers.” Much praise was given for helping the family. One family is of note. Both Mother and Dad greeted me at the door of the garage with their daughter pushing her Dad's wheelchair. Before I could get out of my car, they began introductions. The parents introduced themselves by name and then focused on their daughter. They told me she was a young adolescent caregiver and that she was fantastic and had been SO much help. Dad suggested that he couldn't have gotten along without her. The parents hugged her as they praised her and shared beaming smiles. Their gaze was focused on their daughter the most of the time. The praise continued from the door of the garage where they greeted me, through the house and was completed as we sat down at the dining room table. The young adolescent didn't speak much throughout the introductions and effusive descriptions. She kept her eyes downcast, as if embarrassed, but smiled broadly at both parents as they stated “she should be a nurse!”

Being Assigned

In contrast to embracing a challenge or sharing the load, some participants perceived that they did not have a choice in becoming a young adolescent caregiver and experienced becoming a young adolescent caregiver as “being assigned.” For this group, the path of “being assigned” occurred when the participant was judged by another, usually a parent, to be capable of assuming the responsibilities of caregiving. Participants on this path expressed that they were not consulted about their readiness or interest in becoming young adolescent caregivers. They described caregiving as expected family work that they were told or assigned to do.

I've been taking care of my Grandma since I was 8 or 9 and I'm 12 now. Dad told me to.

Well, um, the tragedy that happened to my grandma, like my Dad sometimes would ask me to come and stay with him, cause I used to stay with my Dad on the weekends, and everything so now I stay here [Grandma's house] with him.

Participants in this group described caregiving as a job. Their responsibilities' didn't shift with their input.

Um, because my Dad works morning and night. In the afternoons and my Mom wasn't here when I was 8 years old. She came when I was in 5th grade from Haiti. When I started [taking care of Grandma] in middle school, it [responsibilities] changed. I don't know how it changed, it just did...

In contrast to the young adolescent caregivers who were “accepting a challenge” and “sharing the load”, participants who experienced becoming a young adolescent caregiver as “being assigned” did not take an active interest in caregiving.

Um, I help her, um I help her get her medication, brought food out for her and do things like that....I don't know what kind of medicines.

Some participants quietly did as they were assigned, offering no dissent in spite of negative feelings about being a young adolescent caregiver.

I don't like taking care of my Grandma when I have a lot of homework to do and she asks me for help. I don't tell. I just do it and find another time to do my homework. No! I never get angry!

I take care of my Grandma on weekends. I sit with her and spend time with her and I walk her to bed and like at night when she's asleep, I'll put her head down.

Other participants on this path were more vocal about being assigned to care and asserted caregiving boundaries about activities or tasks they would not do.

I don't do much with feeding her. Like every once and a while I'll help my Dad prepare some food or whatever, for her.

No, I don't help her take a bath. Not my category!
No, I don't help her go to the bathroom!! I have nothing to do with already digested matter. NOTHING!

Conceptualizing the critical event of becoming a young adolescent caregiver as following the three distinct paths of embracing a challenge, sharing the load and being assigned offers new ways of thinking about the experience from the perspective of the young adolescent caregiver. It describes the social interaction of becoming a young adolescent caregiver within the family setting from the perspective of the young adolescent caregiver and offers insight into the meaning being a young adolescent caregiver has for the individual.

This conceptualization offers a contrast to the process of becoming young adolescent caregiver currently described in the literature. In a dissertation using the grounded theory method, Clapp (2005) used story line to research the process used by older adolescents to become a caregiver when a parent became chronically ill. Clapp's study included 13 male and female caregivers from 12 to 18 years old and their care

recipients who were parents and grandparents. She acknowledges that choosing this age group of young caregivers might have been a limitation but states “since young childhood is marked by concrete thinking, it was necessary to limit this initial investigation to those adolescents who were able to think abstractly (p. 65). The participants’ abstract thinking ability was not tested. She suggests that an adolescent “learns her or his own place” (p. 92) and “to manage the chaos” (p. 92) of daily life as an “automatic thing“(p. 92) that required no conscious effort or thought. In learning his or her own place, the adolescent is said to intuit the needs of the parent (care recipient). They also interpreted the behavior of other family members, if the family is larger than a parent-child dyad. The adolescent “steps up” (p. 92) if the parent’s needs are not seen by others and “there’s no one else to do it, so I have to do it” (p. 92).

While Clapp’s research is focused on the process of becoming a young caregiver, she suggested that young caregivers share the same critical event and path in becoming young caregivers. Clapp’s described path is similar to “sharing the load” which emerged from this study as one path described by the participants. The current study offers a fuller description of how adolescent females become young adolescent caregivers and suggests there are multiple paths and that young adolescent caregivers perceive the experience differently. This study suggests that understanding the critical event of becoming young adolescent caregivers is essential in coming to know this group of caregivers. Nursing interventions reflecting those three paths will be discussed in chapter five.

The Basic Social Psychological Problem (BSPP)

Grounded theorists seek to discover a core category that explains a pattern of behavior demonstrated by the study participants. This central core variable is the basic

social psychological problem (BSPP) that illustrates social processes as they continue over time across conditions. The basic social problem (BSPP) answers the question, “What is going on here?” Defined by Glaser (1978) as ‘pervasive, fully fundamental, patterned processes in the organization of social behaviors which occur over time and go on irrespective of the conditional variation of place’ (p. 100). The participants in this study were purposively chosen because they were all identified as assisting with the care of an adult family member with a chronic illness or disability, and attending middle school. For the participants in this study, the basic social psychological problem identified in the lives of the participants was Managing Changing Complexities.

Managing Changing Complexities

As described above, the critical event of becoming a young adolescent caregiver may or may not be in the control of the young adolescent. However, once the young adolescent had become a young caregiver, through embracing the challenge, sharing the load, or being assigned, they shared the BSPP of managing changing complexities that occurred in a variety of situations and settings. They struggled each day to manage complexities related to adolescence and social life, school, and caregiving that were constantly changing.

Complexities related to adolescence. Families, schools, peers, and after-school activities are the main social contexts in which adolescents spend their time. These contexts provide the general framework for the study participants who were young adolescents, 11 to 14 years old, developing their own outlooks on life.

Adolescence means growing up. This developmental period includes significant changes in brain and physical development, emotions and emotional regulation,

cognition, behavior and interpersonal behavior (Evans & Seligman, 2005). The age range in which adolescent changes are seen extends from 10 to 22 years of age. This age range reflects individual differences in personal developmental trajectory, the age of the onset of puberty and the influence of culture and diet on the individual (Evans & Seligman). Adolescents can be considered a “work in progress”. Throughout early and middle adolescence individuals try on new roles, and experiment with new views of self while ...”managing major biological, educational and social role transitions concurrently” (Bandura, 2006, p. 6). These substantial developmental changes and challenges include:

(1) coping with peer pressure; (2) undergoing transitions from the relatively intimate, personal confines of elementary school to ever larger and often more impersonal secondary school; (3) successfully renegotiating balances between autonomy and relatedness in the family; (4) coping with cumulative, stressful life events; and (5) the development of friendships and romantic relationships.

(Cummings, Davies, & Campbell, 2000, p. 230)

I wouldn't really get mad, cause I feel it's my responsibility. I just do it and tell them I can't go. It's my responsibility cause that's my family and I need to help them.

Yea, I want to do things for myself but since I don't hang out with my friends—it doesn't really bother me...my friends come later.

Through middle and late adolescence, the adolescent continues to develop with the creation of a personal identity, preparing for a choice of occupation and choosing a life partner. Negotiating a healthy adolescence depends on the individual, their family and the situations they find themselves in. Achieving expected developmental goals is the objective (Erickson, 1950). The participants in this study were faced with the

expected complex situations of adolescence in their young lives but had one significant addition. They started caring for a chronically ill family member during this period.

Participants in the study described managing changing complexities related to adolescence and social life, school and caregiving.

Complexities related to school. As a young adolescent makes the educational transition from elementary to middle school, life changes significantly. The middle school is usually larger and not located in their neighborhood. Students no longer have a single teacher who knows them well but are faced with a new teacher every hour throughout the day for every subject. Attending class involves moving from classroom to classroom within time limits through crowded hallways. Each class is filled with different groups of students, known and unknown to the student. Peer approval becomes important and the key to fitting in with the right crowd must be discovered. There is a greater emphasis placed on academic achievement and the student is expected to develop an understanding of how to create their own academic success under the specter of parental and peer pressure (Steiner, 1996). The rewards can be great for the high achiever but may be overwhelming to those who need support to cope with these complex situations.

Some participants in this study were confronted with complexities of defining and achieving success at school by themselves. The admonition to achieve was implied while little parental support the path to success was offered. This created uncertainty about how to replicate behaviors that would lead to greater school success.

My grades, I don't check myself. I have A's and barely B's but I used to have Fs. I don't know how I brought up my grades...doing my work and being focused. I decided myself to do better cause they are always saying they want me to fall father from the tree-don't do like my Mama or my

Auntie-be different and be successful but they're not helping me, they're saying I'm just like them, especially my Mama.

I had nobody to help me, encourage me you know tell me to sit down and do your work. I was just...if I didn't feel like doing it, I didn't.

Other young adolescent caregivers used the school setting to learn life skills or health information in the school setting that expanded their understanding of the health problem of their care recipient.

My angry feelings? I just write it and then I feel better and then I throw the paper away. My 5th grade counselor taught me that.

I learned about diabetes from like books...text books in health class, but I don't know much about high blood pressure.

Some participants were most concerned with the social aspects of school. If they could not stay connected with friends they feared not belonging.

When I moved to Pennsylvania I had to meet new friends there and then I ended up leaving them and going back (to Florida). Well I wanted to go back to my old school cause well, I didn't want to have no friends and I didn't know if I was going to meet somebody new and they wasn't a good friend.

For the participants there were multiple levels of complexities involved in attending school. They were academic, social and sometimes supportive of the caregiving role.

Complexities related to caregiving. Becoming a caregiver as a young adolescent presents special challenges. When a family assumes responsibility for the care of a family member or a family member unexpected becomes ill, sudden and unexpected role and responsibility changes occur. Parents who had previously been freely available to the young adolescent may be preoccupied with multiple tasks associated with caring for a family member. Changes in family living arrangements, finances, meal times, social interactions and the use of leisure time can occur. The young adolescent may be asked to

assume more responsibility with household chores, care of younger siblings or care of the chronically ill or disabled person. Learning new skills of household management, new skills of babysitting and the multiple tasks of caregiving force the young adolescent to reallocate how they spend their time at home and at school. The young adolescent must reorganize or alter school priorities, social activities and having access to family for support and advice. With the additions of caregiving tasks the uncertain adolescent world becomes more complex. See Table 1.

Being a caregiver has helped me grow up. Before I was more like a kid and I was goofy, like I was getting bad grades. Before I was nothing really, I was here, I went to school, I had friends, I had family, but now it's more like I have responsibilities and it has brought us closer...It's made me different.

The basic social psychological problem identified for young caregivers in this study was changing complexities. For the participants, managing changing complexities influenced every aspect of their day-to-day lives. They described managing changing complexities related to adolescence and social life, school, and caregiving. The meaning placed on the complexities was influenced by the critical event of becoming a young caregiver. Regardless of whether they become a young caregiver by embracing a challenge, sharing the load, or being assigned, participants in the study learned to manage changing complexities by a process of muddling through.

Muddling Through: The Basic Social Psychological Process

Grounded theorists seek to discover a core category which identified and explains a pattern of behavior (Glaser, 1978). A Basic Social Psychological Process (BSP) is one type of core category. A BSP is defined by Glaser as “a pervasive, fundamental patterned process in the organization of social behaviors which occurs over time and goes on

irrespective of the conditional variation of place (p. 100). In order to be considered a BSP the core category identified must be central to the phenomenon, account for the variation within the phenomenon and have two or more clear emergent stages (Glaser). BSPs explain the variation of the day-to-day world of the persons who share a common experience and do not claim theoretical completeness (Glaser). The only claim advanced is that the BSP accounts for much of the variation found in the actions, interactions and perceptions found in the data. Variation in behavior and differences between participants can be explained by identification of the categories of the BSP they are using and the theoretical properties of those categories. In this study, the BSP identified in the lives of adolescent girls who were caring for an adult family member was learning to manage changing complexities through the process of “muddling through”.

The American Heritage College Dictionary (2004) describes those who muddle through as “to push on to favorable outcomes in a disorganized way” (p. 912). A second source, the Oxford College Dictionary (2007), states that muddling through is to “cope more or less satisfactorily despite lack of expertise, planning or equipment” (p. 893). The construct “Muddling Through” used in this research will describe the methods used by participants to manage changing complexities on their own without prior knowledge, organization, or direct planning without perceived adult supervision and no certainty of success. The “Muddling Through” process contains consequences, and strategies of Choosing Family, Creating Structure and Maintaining Balance. Participants in this study managed changing complexities on their own without prior knowledge, organization, or direct planning often without perceived adult supervision with no certainty of success.

“Muddling Through” is described through delineation of the stages of choosing family, creating structure and maintaining balance.

Choosing Family

For the participants in this study, a consequence of becoming a young caregiver was choosing to put family first. Caring for an adult family member required a significant amount of time and took precedence over other activities. Participants who become a young caregiver by embracing a challenge or sharing the load, made the choice to put family first.

I look at what's mainly important and my family to me is more important than going out and have fun...Cause you can go out and have fun anytime but family comes first.

You can go to a party or movies or anytime, anytime!
So, but you can't put off a **sick** person with a really severe illness just to go do that !!

Participants who were experienced becoming a young caregiver as being assigned, had the choice made for them.

I wanted to sign up for soccer but I was getting ready to start swimming and then my Dad had his care accident and that was it!

Isolating self. As a result of choosing family, young caregivers in the study experienced a separation from friends and social situations with peers outside the family. Opportunities to socialize with same age peers, and to learn and practice social skills were missed.

Like sometimes I may not be able to go to parties or hang out with my friends. Like maybe if they're having a, or if they are going...like if its their birthday or something and they're going to Boomers or the Skating Rink, sometimes I may be able to go and sometimes I might not be able to go.

The resulting isolation reflected the values the adolescent had learned and adopted as part being a family member in their family.

Because it's your family member you should, you should, mm, time to put off your friends

If my Grandma says I have to stay home and I can't go to my girlfriends...well, I wouldn't really get mad, cause I feel it's my responsibility.

Their primary focus was on being ready to perform direct and indirect caregiving tasks In this study, the young caregivers "choosing family" defined their duty and set limits on their own personal behavior. Personal social interactions were relegated to positions of lesser importance.

Yeah like since I don't hang out with my friends. But it doesn't really bother me. I like doing stuff with people. Some of my friends they come like later.

I don't really like to go out ...I just stay home sometimes. If I do go out, it's really once a month. I don't really like to go out. No, I don't really miss it. I am kinda used to it.

The caregivers in the study who lived with the care recipient rarely stayed after school to participate in after school clubs or activities. The activities with peers were limited to seeing family cousins on weekends and seeing their friends in school. When the young caregiver discussed making changes in their caregiving situation, the response varied. Sometimes changes were able to be made and sometimes they weren't.

I kinda got mad at myself and my mom. I just told my mom that it was about like not having like more fun time outside, playing with my friends. She kinda figured that I didn't want to help out more but I wanted to play with my friends and so she gave me that chance to play with my friends. Yeah, it depends, like my cousin plays soccer, so I might go to a

game. Or, my Mom's side of the family, I might go to their house because their kids are like more my age, so I'll hang out with them.

I just do it [stay home to care for Grandmother] and tell them [friends] that I can't go. Cause that's my family and I need to help them.

I wouldn't really get mad, cause I feel it's my responsibility. I just do it and tell them I can't go. It' my responsibility cause that's my family and I need to help them" Yea, I want to do things for myself but since I don't hang out with my friends—it doesn't really bother me....my friends come later.

Struggling to fit. Struggling to fit addresses the difficult and often unspoken choices that young caregivers face as they take on caregiving and continue to meet the challenges in their daily complex adolescent lives. There is uncertainty about what level of importance to place on the multiple and varied activities in their daily lives. While they might fit in at school today, that might change tomorrow. Perhaps they understood what was expected of them as caregivers and couldn't figure out to perform the tasks involved. The evidence of their struggle to fit or uncertainty was seen in long and hesitant verbal passages about how they make choices.

I just know it's like in some part of my brain. I just know its always there for me to not let people down, like if I say I'm going to, if I say I'm going to be at my grandmas, and I can't be there because I have something I always have to remind my Mom that I have to be there, or I, I find a way to be there or cancel something else. [not caregiving].

I was really scared but I didn't want her [Grandma, the care recipient] to see me crying. She would get emotional and really worry... cause it would um bring more pain and stress and everything on her...with the situation [frequent hospitalizations for sickle cell crisis] that's going on.

The movement from concrete thinking to more abstract thought allows the young adolescent caregiver to begin to think about the consequences of their actions that might

not have been considered before. Choosing to forgo or being unable to be with friends or peers as often as non-caregiving adolescents may create the loss of a safe non-parental environment to discuss how choices are made and how to handle consequences of choices. Being an adolescent is about trying on new identities and experimenting with what might be a future interest or path to adulthood. Young adolescent caregivers struggle to fit with additional challenges.

Meeting family expectations. Struggling to fit was closely linked to the concept of meeting family expectations. Meeting family expectations required the adolescent to know the explicit and implicit family expectations and configure a plan to meet those requirements. The operating rules of the family learned through time and shared experiences were reconciled with the job of caregiving. When the young caregiver did not seek the task of caregiving, it was difficult for them to question the authority of their parents who made them take the job.

No, I don't want to be a nurse or go into medicine-no,
I can't I don't like that kind of stuff. Nothing I would do. I was
thinking of being a marine biologist but now a news reporter.

Participants in the study often perceived family expectation about caregiving as unspoken and their contributions to care unrecognized. The unspoken expectation is that the adolescent be there to do her job in the family and that caring for the adult family member is family work. Field notes indicated that under these conditions, young caregivers struggled to meet family expectations because they did not receive instruction on what to do, how to do it or feedback on how they are doing. As a result they continued to muddle through, making it up as they went.

I can see Grandma doing something and she needs

something else done then I go and do it for her. I see something and I go and handle it. No, we don't ever talk about it.

They don't ever say anything about it. I don't know what they think about it. I want to get mad but yet I can't get mad cause it's my responsibility.

Creating Structure

The work of creating structure was based in the participants desire to manage changing complexities. All participants attempted to manage changing complexities through the strategies of ordering tasks, staying vigilant and deciding to tell. However there was considerable variation in their approaches and level of success.

Ordering tasks. Ordering Tasks described the strategies used by young caregivers to organize and identify the large and small areas adolescence and social life, school and providing care to a family member in their daily lives. Participants created structure by compartmentalization the various areas. Ordering tasks were centered on having a social life outside the family, attending school and providing care to a family member. These daily tasks competed for the young caregivers' attention and time.

Participants ordered many tasks related to adolescence and social life. Time spent with family was seen as a social task or chore to be done. Many of them saw extended family members on weekends and a few of the caregivers would be visited by cousins who came to their homes to help with the caregiving. In all families, being with family or visiting relatives substituted for a social life with peers to some degree.

' You know what its okay though, because I have fun with my family when I'm helping them out. We laugh and stuff, make jokes so it's the same as hanging with my friends, you laugh, you make jokes.

Despite being a major developmental task, making friends and maintaining friendships often took a low priority for the young caregivers in this study. Friendships were limited to those that could be developed and maintained in school or those that were formed before becoming a young caregiver. Sometimes newly formed friendships took on more significance than would be expected. For example, one participant spoke of befriending a new student in the school setting and they becoming “best friends” in a brief period of three months. They did not visit each other’s homes and did not get together outside school and rarely spoke on the phone.

I found my best friend when I started 7th grade. She came in the second month. OK I see her expressions , her facial expressions so then went over to her and I started talking to her and then day in and day out we started talking and then that’s how we became best friends. No she hasn’t come over to my house yet. Mainly our friendship is at school. And over the phone.

Young caregivers in the study spoke about ordering school in two ways. Some caregivers loved school and spoke happily about being in that social and academic environment. Participants in this group enjoyed school, were doing well were excited to share their accomplishments.

I get to school about 8:40 a.m.; talk with my friends and most of my days there are very, very great, I always learn something new from my teachers, from my friends. I make really good grades and I love every one of my teachers and I get along with them very nicely. I really don’t have that many problems in school, not really any people that don’t like me or I don’t like them . I try to get along with everyone and interact with everybody. So it’s mainly good.

“What happens during the day....Go to first period, second period, third period, lunch, fourth, fifth, and sixth...I have my magnet program, graphic design and video...I love it. It is so much fun”.

The best grade, um an A. or the lowest, the lowest I want is a B. Cause I usually want to like um, um like back: to helping people. I want like the grades and I always hear that they don't only look at your grades so I have to start joining groups and everything so I can get into college.

Others were reluctant to talk about school. Their comments were very brief and moved quickly to other topics.

The best thing about school? ...Lunch!

Poor performance and grades were common in this group and the participants did not dwell on them or made excuses for why they were not doing well.

Well, I'm on the border, I have two A's, F, C, B. I'm happy with that cause I got my F in math up to a B. I just have one F now.

I had nobody to help me, encourage me you know to tell me to sit down and do your work. I was just...if I didn't feel like doing it, I didn't do it. And the school, I had a whole bunch of Fs and then I was ashamed of it, but to make me feel not ashamed of it, I would tell everybody--I was like yes, I like making Fs. My mom loves it when I make Fs. I just make excuses.

Participants ordered school related tasks as less important than caregiving tasks. For example, homework was considered something to be done between other activities that the young caregivers were involved in.

I don't like helping my Grandma, when I have a lot of homework to do and she asks me for help. I have to help and do it later.

Some of the participants ordered school related tasks by doing homework in school or denying that they had homework assignments.

I don't have homework.

I usually don't have homework cause I do it in school.

I don't like helping my Grandma, when I have a lot of homework to do and she asks me for help. I have to help and do it later.

In contrast with other studies on young caregivers (Aldridge & Becker 1993; NAC & UHF, 2005; Siskowski, 2004) most of the participants in this study found missing school was not a problem. Only a few of the participants reported missing a significant amount of school as a consequence of being a young caregiver.

No missing school hasn't been a problem for me. I keep my grades up. I like make sure of that...

Students who are absent from school are generally expected to notify their teachers when they are absent. Surprisingly, only one participant went directly to a teacher by herself, without ongoing parent support. This participant obtained homework assignments and formulated a method of obtaining future assignments on her own.

Most students got the assignments from other students or "friends" and merely turned their work in when they returned to school. Homework was often completed on the bus or during school. Very few told their teachers that they were caregivers and perceived their teachers were only concerned about their academic performance.

I would mostly talk to the teachers to see if they could help me or my friends. I would always ask them if I'm not there a day can you please for me to do the homework later? I don't recall telling them I was taking care of my Dad...maybe once...I don't remember

Ordering school tasks was easier when participants knew in advance that they would miss school in order to provide care. For example, knowing in advance meant they or their parents could get their work early and turn it in on time.

By contacting the school, having Mom contact the school, get all my work, and then like I'll turn it in. They'll give me the points for it.

But at other times the changing complexity of the care requirements could not be anticipated in time to order school tasks in a meaningful way.

Sometimes I don't get to tell them before hand. It comes right out of the blue, um he's having a surgery tomorrow and we'll be like oh –ok so we all go. It's happened so many times

we just , all right so we go pack all the stuff up, get him ready to take him to the hospital.

During the interviews, participants discussed spending more of their energy and time on ordering the tasks of caregiving. They quickly and thoroughly described how they performed the tasks of caregiving, what was needed and were quick to share their own area of caregiving expertise. This might mean recounting the names and dosages of all medications and how the care recipient received the medication or their Granma or Grandpa's favorite recipe and how they prepared it. These detailed descriptions of their performance of both instrumental caregiving activities of housekeeping, preparing meals, giving medicines and direct care caregiving activities of moving in and out of bed or around the house, bathing, toileting and feeding or helping to eat reflects their pride in the work they do. These skills were not taught in a formal way. The young adolescent caregivers learned most caring skills by watching the adult caregivers.

if you're seeing somebody in your family taking care of one of your family members, Um, you can watch them or ask them how do you do this or how can I help and that's basically how you're on your way to being a caregiver.

They used previously learned skills to complete housekeeping or were guided by discussions with their care recipients about other activities that had to be done. No study

participant described that anyone checked on them while they were providing care. While it seems prudent and expected that an adult would oversee the caregiving activities of the young adolescent caregivers, it was the perception of the young adolescents that they were acting alone.

The care tasks performed by young adolescent caregivers in this study were consistent with the activities identified in the Young Caregivers in the U.S. (NAC &UHF, 2005) study and those performed by the adult caregivers in Caregiving in the U.S. (NAC & AARP, 2004). See Table 1. These activities varied in intensity over time as the care recipient became frailer or more able to care for themselves.

I hold her milkshake now, cause if she holds it
it will fall out of her hand.

... he tries to pick out his own clothes because they think I don't pick out
clothes that match.

Which of the tasks to be ordered was considered the most important by the young adolescent? Was being an adolescent with a active social, school life or caregiving life important? It appears that from the amount of time spent and the detail used to describe the caregiving tasks that ordering caregiving tasks was most important to study participants. There was variation in the intensity of feeling used to describe the ordering of caregiving tasks. However, all participants placed caregiving as more the important task associated with school life or adolescent social life.

Staying vigilant. The strategy of staying vigilant was described by participants as constantly being aware of the status of the care recipient and paying extra caution as they performed their duties.

She stays in bed all day and but we turn her in different spots.

Like now she has a rash. Because my aunt wasn't paying attention to her. So I was telling her, I was telling my Mom and now my Mom, they know how to turn her now. They know that, so the rash is healing.

Caregivers worried about their care recipients when they weren't with them. They stayed vigilant about what is happening when they are away at school or social activities.

Participants described feeling uncomfortable being away from the care recipient and uncomfortable that others would be as vigilant as they were.

Sometimes when people are helping him it's hard to let others help, there are certain things I do for him. He uses this thing for the bathroom and I don't like to let them do that, I'd rather me do it. I just feel uncomfortable.

They observed the condition of the care recipient when they returned from a period away from them and stepped to help as they judged necessary.

I say hi to everyone and go straight to my grandma and ask if she's OK and if anything has changed from when I was gone and then I check the medicines or stuff like that.

Staying vigilant also meant protecting the care recipient by taking caution and paying extra attention when performing care tasks. For example participants described safeguarding slippery surfaces when bathing and mashing or blending food to prevent choking.

He would take a shower so you walk him up two stairs, like I would walk him, he would hold on to the rail on one side and the other was me. He would take a shower like make sure it's not slippery in there and put some towels or something for him and then he comes down and my Mom comes home.

She gets mashed potatoes with boneless fish or if she gets chicken we take it off the bone-we blend the rice real soft like baby food.. so she digests it.

Deciding to tell. Participants struggled to decide if they should tell and who they should tell that they were caring for an adult family member at home or how they were feeling about being a young adolescent caregiver. Deciding to tell for participants in the study was influenced by time, the establishment of trust through the perceptions that the person being told has experienced a similar situation.

The concept of time appeared relative as it related to friendship for young adolescent caregivers. Some spoke of friendships made in pre-kindergarten, 6-7 years before, which they continued to regard as close and supportive. Being unable to see their friends or talk with them regularly did not appear to affect the friendship bond felt by the young adolescent caregiver and their friend. Others described close friendships developed one to two years ago with girls whom they now had intermittent physical contact and irregular telephone contact. These were the friends they would tell problems to. The perception of sharing a family hardship also encouraged young adolescent caregivers to share stories with one another. It was the perception of the young adolescent caregiver that the friend would understand because they had also experienced hardships.

Like if I've known them awhile and I know they'll keep a secret
for me and they won't tell and or tell all
of their other friends. I'll usually talk to them.

And, she's had some tragedies. I've had some tragedies.
We have happy times.

In general, perhaps as part of a "family expectations", participants did not see a need to tell everyone about the health of their family member or their part in caregiving.

Um. No, not really, I just don't tell my friends. Like, I don't really
share all of this with them. I don't know, I just...I don't know I don't
know why, I just keep it on the down low. Something between me and

my family. Yes, my best friend knows. But she is the ONLY one that knows about it. Anybody else, they don't really know.

No, I don't really explain what I do on weekends (i.e. caregiving) because my friends, they're the kind of people that like don't care about much stuff like they mind their own businesses and because they don't ask.

My friend is in the caregiving youth project, so I think she knows something. She didn't guess about my Dad. We were at the table at the caregiving thing and we sat down and talked about it. I told her my Dad has diabetes. Cause sometimes it will get me sad and depressed so I'll tell how I feel sometimes and that will help me with that.

I feel more comfortable talking with my family and then I go to friends. My Mom first, my cousin or one of my aunts.

Talking to teachers and school nurses was not identified as a helpful and the participants. In general, participants did not report speaking to members of the school team about their caregiving responsibilities.

No I never talk about to my teachers about caregiving, I'm not that close to them. Nope, I never talk to the school nurse about it, cause...once I talk about one thing then I'm going to have to talk about another thing and then I'm going to have to talk about another things then I'll just say everything and I don't like doing that.

I was in the nurse's office with my friend who has diabetes cause she had to go toke her insulin and the nurse asked me if I had anybody in my family with um diabetes and I said my grandmother has it. And she asked if I heard about the Caregiving Program? She started telling me where to get the papers but I haven't got them yet.

Creating structure involved constantly managing changing complexities in multiple areas of their lives by focusing on one area of their lives at a time. Participants described little overlap between being an adolescent, attending school and being a caregiver. By ordering tasks, staying vigilant and deciding to tell the changing complexities in each area were managed. Aldridge and Becker (1993) suggested that the time consuming nature of caregiving "may severely restrict children's lives having

implications for their physical and psychosocial development (p. 460)". Study participants might agree.

Maintaining Balance

Maintaining balance was a consequence of Creating Structure. Participants who were able to maintain balance expressed being understood, seeing self as a caregiver and looking to the future.

Being understood. The consequence of being understood is related to the strategy of deciding to tell. When a young adolescent caregiver allowed another to know what they were experiencing as a caregiver or sought out that trusted person to talk with about their feelings, that listening individual often demonstrated concern and kindness toward the adolescent. The young adolescent caregiver felt good and understood that someone wanted to help them. They accepted the offered suggestions from the other person as helpful. They also felt accepted because they did not have to share their entire caregiving story to be understood.

Like my Mom when she was a girl she used to watch her cousin Inflowia and you know she used to care for her cousins and stuff and sometimes she couldn't go to parties with her friend and she had the same feeling that I have and now she tells me about them and it sorta kinda helps me to deal with my problems and things of that nature.

I'm thankful that my brother is there for me, like when I'm really sad, he tries to cheer me up. I only like to talk to someone my own age. And so I deal with it.

Yeah, I talk to my friends...they give me advice. That's it they just give me advise and they are there for me .

Seeing self as caregiver. Adult caregivers experience a degree of self-satisfaction as they perform their helping role (Aminzadeh et al., 2005; Dellmann-Jenkins,

Blankemeyer, & Pinkard, 2000,). For young caregivers personal satisfaction as a result of caregiving is not quite as clear and may reflect their levels of psychosocial development or the levels of emotional support or positive feedback they have received for participating in the care of a family member. The participants in this study were in varying stages of seeing self as being a caregiver. Some participants expressed that being a caregiver was not their choice and if given a choice they would prefer not to continue as a caregiver.

Being a caregiver is a big responsibility and you have to live up to that responsibility which could be hard for people. So like, I am a caregiver. I still love giving help to my Grandma and my Dad but if I could choose... I'd choose not to be a caregiver.

I guess I'll be a caregiver till I'm 18. Then I hope around then I'm gonna go to college. I want to be a doctor, singer or musician.

Some of the participants expressed ambivalence about seeing themselves as a caregiver.

This may also be related to fear that an end to caregiving activities could signal the worsening condition of their care recipient. A few participants spoke reluctantly about the possibility of the death of their beloved family member

I don't know how long I'll keep taking care of my Gram. I don't really know. I don't know if it will be forever or no more.

Um, well my parents already told me well...my Mom already told me that my grandmother, she's going away already. So I know that. That's what I think is happening...I think that's the stage she is at.

Other participants were comfortable seeing themselves as helping others and recognized that helping others made them special. They described advantages gained by being a young caregiver. Examples included being responsible, learning to deal with people, being more mature, learning respect and being comfortable with yourself.

Yeah, I would say that I'm different than somebody who doesn't take care of somebody. I have more responsibilities and I learn more from what I'm doing than they do. I learn to deal with different people and how to help them get through things but they don't.

I would always be a caregiver. It made me more mature. It made me more responsible. I don't know, I just don't want to be a bad kid. I don't want to grow up and be bad or like grow up and be a criminal or like I'd rather be smart. Caregiving has shown me more, shown me to respect everything and be thankful for everything. I think caregiving makes me a better person, a lot better.

It can probably help the person you are helping to know you are comfortable being yourself around them...just be yourself.

Looking to the Future

The ability of study participants to imagine a future for themselves varied between the young adolescent caregivers. Those who were experiencing understanding support from family, friends or in the school setting were able to see beyond their day to day tasks. As might be expected from young adolescents, they enjoy trying on different possible futures. Some saw a career in a helping profession others wanted to be fashion designers or singers. Those who did not experience similar support by deciding to tell or being understood could not maintain balance and couldn't imagine what their lives might be like when they were no longer caregivers. Those who equated not being a caregiver with the death of their loved one the future was to upsetting and not something they didn't want to think about or discuss. These adolescents, who had not learned to manage changing complexities, lived in the moment and were unable to think or plan for the future. Others who were managing the complexities in their lives and did not fear or anticipate the death of the care recipient were able to identify future goals for themselves.

Regardless of where they might be in maintaining balance, every participant in the study had some advice to offer to future young caregivers. Their advice and recommendations reflected areas they were struggling with or advice they offered from lessons they had learned. The recommendations can be loosely grouped together as (a) managing emotions; (b) believing in yourself as a caregiver; and (c) reach out to others to help maintain focus.

Managing emotions.

Do your best. Don't be stressed. Don't be sad about what's happening to your family or your relative. Make your relative happy.

I would say, um, don't always get mad cause you'll know that you're helping somebody that really needs it.

Be positive. Be thankful, be positive, at least they're [care recipient] still alive. Grow up!

Believe in yourself as a caregiver.

I would tell them that if you think you're not normal to be taking care of somebody or it's not a good thing a child would do, um then they're thinking wrong because it's actually a good thing. And not many people do that. Not many people think that. So, they're doing a good thing and I know the person who's taking care of them, they feel that it is a good and they feel that, they feel grateful.

I would tell them, like, be strong, don't let any body get to your head. And just, I mean, the more you care about them and do things for them, the more you'll get time to get close to that person.

Reaching out to others to stay focused.

I'd say to them to just stick it out, you know how like we have one life time and you should —be there and help out where ever you have to help out because if you were in that position you would want to be helped too.

I would tell them to stay focused and not get distracted. And to ...if you have problems go to talk to someone and don't take matters into your own hands. I also suggest they pray.

Chapter Summary

The process of muddling through began with the critical event of becoming a young caregiver and then depicted how young adolescent girls managed changing complexities while caring for adult family members in the home. The phases of muddling through included Choosing Family, Creating Structure and Maintaining Balance. In response to choosing family, young caregivers in the study faced isolating self, struggling to fit and meeting family expectations. They managed changing complexities by ordering tasks, staying vigilant, and deciding to tell. Participants who described being understood, had the ability to see self as a caregiver and look to the future were able to maintain balance as they struggled day-to-day to manage the changing complexities of being a young caregiver.

CHAPTER 5

SUMMARY AND RECOMMENDATIONS

This chapter presents a summary of the study. Implications of the findings for policy development, nursing practice, education and research are offered.

Recommendations for additional studies in this topic area are suggested as a way to broaden the awareness of the existence of young caregivers and to expand our understanding of the process of caregiving as carried out by young caregivers.

Summary of Theory

The purpose of this research was to develop a substantive, middle range theory about the response of young adolescent girls age 11-14 to the critical event of becoming a young caregiver. Middle range theory, as described by Liehr and Smith (2003) is a basic, usable structure of ideas, less abstract than grand theory and more abstract than empirical generalizations of micro-range theory.

Through the use of semi-structured interviews, the researcher invited young caregivers to tell their stories in their own words. The constant comparative method, consistent with Grounded Theory developed by Glaser (1967), was used to analyze the data. Managing changing complexities emerged as the basic social psychological problem faced by the participants in the study. Following the critical event of becoming a young caregiver, managing changing complexities became part of everyday life. Participants responded to managing changing complexities through the process of

Muddling Through. The phases of muddling through included choosing family, creating structure and maintaining balance. In response to choosing family, young adolescent caregivers in the study faced isolating self, struggling to fit and meeting family expectations. They managed changing complexities by ordering tasks, staying vigilant, and deciding to tell. Participants who maintained balance described being understood and had the ability to see self as a caregiver and looked to the future as they struggled day-to-day to manage changing complexities of their lives.

Policy Implications

A broad understanding and awareness of the multiple challenges young caregivers face is necessary to create supportive policy changes at the national, state and local levels. It is estimated that there are approximately 1.4 million children and adolescents in the United States who are functioning as young caregivers (NAC & UHF, 2005). Increased awareness of the number of young caregivers and the scope of potential problems associated with being a young caregiver may lead to increased funding for support programs.

With the support of state Departments of Education, an educational environment that encourages innovative, local and site specific responses to the needs of young caregivers could be formed. Recognition of young caregivers at the highest level of administration in state governments could lead to funded mandates for the identification and tracking of young caregivers. This would encourage individual school districts to put cost effective policies in place to encourage partnerships with local support networks. The identification of young caregivers could be accomplished by adding questions about the presence of a family member with a chronic health problem to an annually updated

mandated existing student health form. Children and adolescents identified as potential caregivers could then be further assessed by the school nurses or counselors.

The focus of this data gathering should be to understand the environment the school child contends with every day and not to invade family privacy. Moreover, policies to track absences from school could be created to identify children in high risk situations early. Early identification and monitoring of students at risk educationally could lead to the development of School Study Teams that could create individualized interventions to improve school progress and dropout rates.

A public education program created through a consortium of existing disease specific agencies such as the American Heart Association, the Alzheimer's Association, the American Cancer Association, the National Caregivers Association and the American Association of Retired Persons could raise public awareness of the existence of young caregivers and lead to fund-raising activities for support programs. This group of agencies would be able to use existing networks to formulate a common message concerning the needs of young caregivers as unique and different from those of adult caregivers. Public awareness campaigns could begin in school settings with presentations to entire school populations through the Parent Teacher Associations or by inclusion of caregiving as a topic objective in health or civics curricula. An educational campaign could be coordinated with the celebration of National Caregivers month each November. As a result of awareness campaigns in school settings, teachers and staff might become more sensitized to issues facing young caregivers, and could potentially participate in identifying young caregivers and making appropriate referrals to school nurses, psychologists or guidance counselors.

The Caregiving Youth Project in south Florida serves as an example of a model program in supporting the needs of young caregivers and families. This program is designed to identify the needs of young caregivers and link the family with existing community resources. The program representatives survey incoming 6th grade students to identify and assess the needs of young caregivers. Program representatives collaborate with individual school counselors and Principals to develop plans of care.

Recommendations for Practice

Access to care. The active involvement of children in caregiving has been largely unrecognized or ignored by the public, healthcare providers, researchers, academics and policy makers (Earley, Cushway, Cassidy, 2007; Siskwoski, 2006). Consequently the needs of young caregivers often go unnoticed by nurses and other health care providers. “Nurses play a major role in identifying family caregivers” (Farran, 2001, p.12) and may, therefore, be the first to recognize the contribution young adolescent girls provide in caring for family members within a home setting. This study suggests that young caregivers are very selective regarding who they decide to tell about their experiences or whom to ask for help. The nurse who enters the world of the young caregiver with value and respect for each person’s beauty, worth and uniqueness, while seeking to understand their values, choices and priorities could create an environment in which they could safely communicate their experience, concerns and needs (Boykin & Schoenhofer, 2001).

Awareness of multiple paths. This study suggests that understanding the critical event of becoming a young caregiver from the perspective of the individual caregiver is essential to creating an atmosphere of support and developing interventions that are meaningful. Becoming a young caregiver through a path of embracing challenge, sharing

the load or being assigned may significantly affect how a nurse enters into a relationship with a young caregiver, the calls for nursing that are heard and the creation of responses to those calls for nursing. For example, the nurse may hear a call for support in setting care boundaries from a young adolescent girl who became a young caregiver through the path of being assigned. School nurses who are aware of the multiple paths might anticipate that young caregivers who embrace a challenge may be interested in medical magnet school programs.

Awareness of muddling through. The discovery of the process of muddling through used by young caregivers to manage changing complexities adds to our understanding of the complex nature of their lives and suggests potential nursing assessment and intervention areas. For example, the study suggests young caregivers often isolate themselves as a consequence of choosing family first. School nurses, aware of students who decrease their involvement with school activities and friends, could talk with them about how they are spending their time away from school and what kinds of things they do to help out at home.

Nurses in all specialties, regardless of practice setting, that care for clients with chronic illnesses or long term disabilities have potential contact with caregivers in general and with young caregivers specifically. In developing plans of care for the care recipients and adult caregivers, nurses could also plan for the unique needs of young caregivers. The study suggests that in muddling through, young caregivers do not have the prior knowledge, organization or planning skills required to successfully care for adult family members. Nurses can not assume young caregivers have received instruction

on how to care, that the care they provide is supervised or that it is provided in a way that is safe for the young caregiver and or the care recipient.

As reported in this research, young caregivers learned caregiving skills by watching adults perform the activities. There is no evidence of validation of these caregiving skills for young caregivers. Both hospital and school nurses could implement skill checking in order to protect the health of both the care recipient and the caregiver. Further investigation of the method young adolescent caregivers use to learn caregiving skills is needed.

Nursing Education

In order to understand the issues facing young caregivers, basic chronic illness nursing education could be extended beyond medical and nursing information about treatments. Supporting a whole person view of nursing practice, it is appropriate to include the psychosocial, physical and spiritual responses of clients and caregivers. In this study, young adolescent caregivers did not perceive nurses in both the hospital and school settings as supportive. The hospital based treatments and education focused on the client and family adults who were presumed by the nurses to be the only caregivers in the home.

School nurses were seen as providers of care for “illnesses” experienced at school by the young caregiver. Emotional support or education was not routinely offered because the young caregivers did not tell and the school nurses did not ask about caregiving. Expanded basic and continuing nursing education about the needs of young caregivers to nurses could improve this situation.

Nursing Research Implications

Additional research focusing on the feelings, needs and opinions of young caregivers is needed. For example, national studies should explore regional differences between young caregivers and caregiving support programs; how specific disease or the disability level of care recipients influences the tasks young caregivers perform; and how young caregivers and non-caregivers compare in their psychosocial response to adolescent development.

More studies are needed that give voice to young adolescents who are performing the tasks of caregiving as these may be significantly different from parental accounts. Young caregivers are best able to identify the challenges they face as they proceed through adolescence, school and caregiving.

Young caregivers remain a hidden population. Research is needed to help identify students who may need our support. For example, it is not known if students who became young caregivers by the path embracing a challenge are more interested in medical magnet school programs than the general population. Programs like the Caring Youth Project in south Florida might be useful in facilitating this work.

This study also suggests that home care assessment tools that reflect the contribution and needs of young caregivers are needed. In caring for persons 65 and older, it is common for home health assessments to be initiated by a registered nurse who is charged with completing a Medicare client assessment. This form could be modified to include young caregivers.

Summary

This chapter summarized the theory of Muddling Through, discussed policy implications, and presented practice recommendations such as access to care, awareness of multiple paths and nursing education. Grounded theories are also useful in raising potential areas of research and research questions. Research questions related to identifying young adolescent caregivers, the tasks they perform and their needs for support were described. In addition, suggestions for tool development were identified. Like all studies, this study raises more questions than it answers.

Table 1

List of Care Tasks Performed by Study Participants

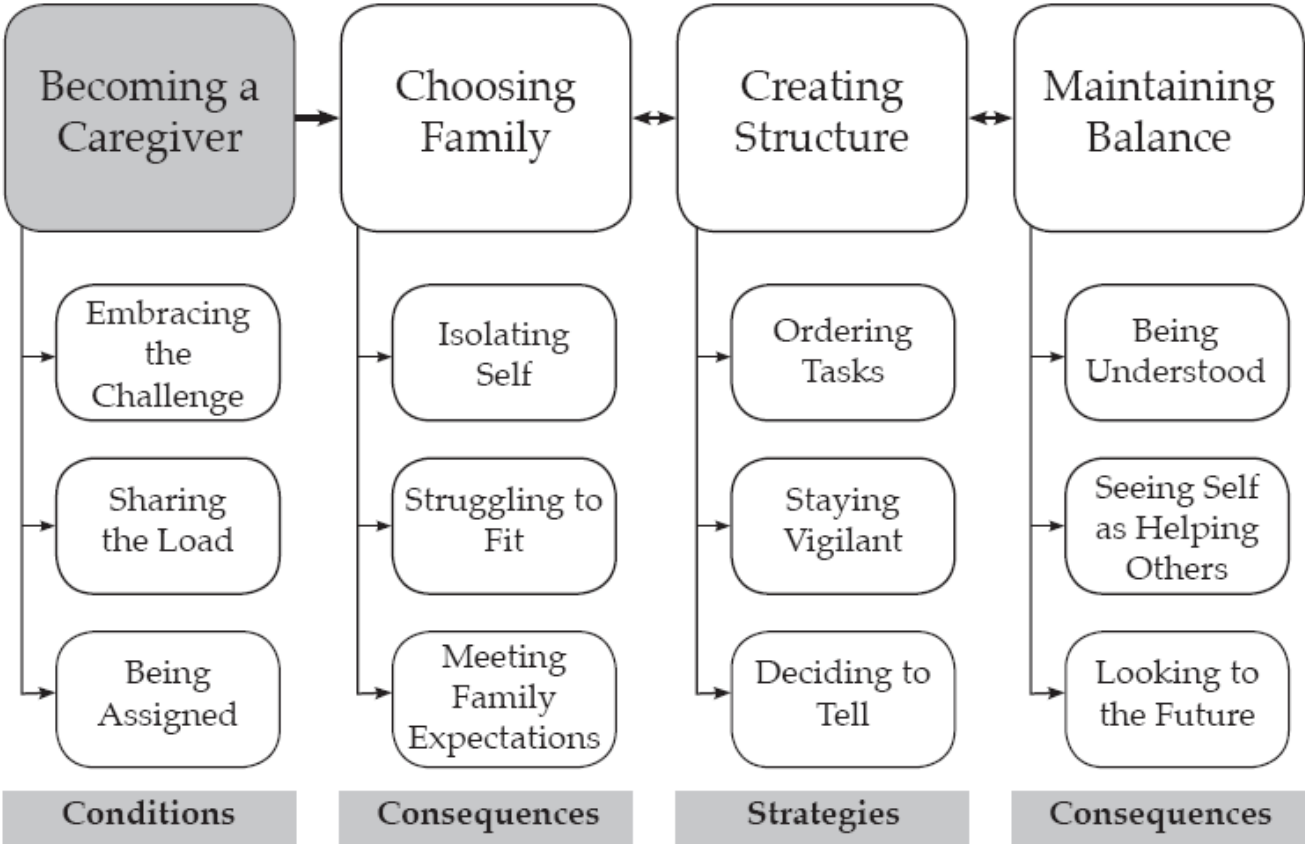
Activities of Daily Living (ADLs)	Instrumental Activities of Daily Living (IADLs)
<ol style="list-style-type: none"> 1. waking them up and getting ready for the day 2. Brushing teeth, washing hair 3. pulling up pants, dressing 4. picking out clothes 5. putting on braces 6. feeding, getting a snack, breakfast, lunch, dinner 7. washing face, showering, bathing 8. exercising arms and legs 9. walking with/supporting care recipient 10. toileting, changing adult diaper 11. getting them ready for bed 	<ol style="list-style-type: none"> 1. putting on the bus for school 2. cooking 3. observing 4. preparing to eat(setting table, getting drinks) 5. eating together 6. cleaning, straightening up, keeping things organized, mopping floor 7. watching/controlling diet 8. giving multiple medicines, pills, drops 9. going to doctor's appointments 10. talking with doctors and nurses 11. keeping track of things(medicines, appointments, daily schedule of care recipient) 12. diabetes testing 13. running errands 14. sitting with them to watch T.V. or do crossword puzzles

APPENDIX A

Model

Muddling Through: How Young Caregivers Manage Changing Complexities

Muddling Through: How Young Caregivers Manage Changing Complexities




APPENDIX B

Institutional Review Board Approval



Division of Research
 Office of Sponsored Research
 Institutional Review Board
 777 Glades Road
 Boca Raton, FL 33431
 Tel: 561.297.0777
 Fax: 561.297.2319
osra.fau.edu/research/irb

MEMORANDUM

DATE: May 14, 2008
TO: Shirley Gordon,
 Carole Kain,
 College of Nursing
FROM: Nancy Aaron Jones, Chair 
RE: H08-59 "Caregiving Youth: A Grounded Theory Study"

The Institutional Review Board (IRB) has reviewed the above protocol. Under the provisions for expedited review, the proposed research has been found acceptable as meeting the applicable ethical and legal standards for the protection of the rights and welfare of the human subjects involved.

This approval is valid for **one year from the above memo date**. This research must be approved on an annual basis. It is now your responsibility to renew your approval annually and to keep the IRB informed of any substantive change in your procedures or of any problems of a human subjects' nature.

It is important that you use the approved, stamped consent documents attached.

Please do not hesitate to contact either myself (6-8632) or Elisa Gaucher (7-2318) with any questions.

NJ:mg
Final Expedited Review Category: BT

APPENDIX C

Parental Consent Form

PARENTAL CONSENT FORM

1) Title of Research Study: Young Caregivers: A Grounded Theory Study.

2) Investigator(s): Shirley C. Gordon, PhD, RN and Carole Kain, DNs (c), ARNP.

3) Purpose: The purpose of this research study is to identify and describe the shared problems young female caregivers face and to explore the processes and strategies they use to solve shared problems.

4) Procedures:

The staff of the Caregiving Youth Partners Project (CYPP) will obtain permission from the parents/guardians of the interested and eligible young caregivers for the researcher to contact them by phone to discuss the study and what it involves. Participation in this study will require parents to sign consent to participate for themselves, prior to answering a brief family demographic survey, and a consent that your child/ child in your charge may take part in an audio taped interview to discuss their role as a young caregiver. Parents/guardians who allow their children to participate in the study will be given a choice of having the study interviews conducted in the offices of Caregiving Youth Partners Project in Boca Raton or in the participant's home. The interview will be conducted during non-school hours and at a time convenient for the family. The private interview will take approximately 1 to 1 1/2 hours.

5) Risks:

The risks involved with participation in this study are no more than you or your child/child in your charge would experience in regular daily activities. It is unlikely you or your child/child in your charge will experience any harm or discomfort, but in the event they experience any emotional upset from discussing their role as a young caregiver, you will be notified and your child/child in your charge will be referred to their primary health care provider and the Caregiving Youth Partners Project for follow-up.

6) Benefits:

Each young caregiver who participates in part or all of the study process will receive a \$10.00 gift card. There are no direct benefits to you, as the parent, for participating in this study. However, you and/or your child/child in your charge may gain greater knowledge and personal insight about being a young caregiver.

7) Data Collection & Storage:

The demographic survey forms and any audio taped and transcribed information shared by your child will be kept confidential and secure. Only the people working with the study will see the data, unless required by law. The data will be kept for five years and then destroyed. Only the aggregate of the data will be published.

8) Contact Information:

*For questions or problems regarding your or your child's/child in your charge rights as a research subject, you can contact the Florida Atlantic University Division of Research at (561) 297-0777. For other questions about the study, you should call the principal investigator, Dr. Shirley Gordon, PhD, RN at 772-873-3382.

9) Consent Statement:

*I have read, or had read to me, the information describing this study. All of my questions have been answered to my satisfaction. I consent to take part in this study and to allow my child/child in my charge to take part in this study. I understand that I or my child/child in my charge can stop participating at any time without giving any reason and without penalty. I can ask to have the study information returned to me, removed from the research records, or destroyed. I have received a copy of this consent form.

Signature of Parent or Guardian: _____ Date: _____

Signature of Investigator: _____ Date: _____

IRB
Approval Date: 5/14/09
Initials: CS
Expiration Date: 5/13/09

APPENDIX D

Child/Adolescent Assent Form

Young Caregivers: A Grounded Theory Study
Child/Adolescent Assent Form

People who do research at Florida Atlantic University, College of Nursing are trying to learn how young caregivers manage their work when they are a caregiver, a student and just growing up. You have been asked to be in the study because you are a young caregiver, a girl, and are 11-14 years old and have lots of things to share.

When you are part of this study, you will be asked to talk with the interviewer and have your words tape recorded. You will be asked questions like:

1. Tell me what led up to you becoming a young caregiver.
2. What was it like? What did you think? Who, if anyone, influenced your actions?
2. Could you describe a typical day for you as a caregiver?
... As a student?
... As a pre-teen?
3. What problems do you run into because you are a young Caregiver?
4. Who has been the most helpful to you as a young caregiver?
5. Has any organization or group been helpful to you as you learned to be a caregiver?
6. After being a young caregiver, what advice would you give to someone else who is just starting to be a young caregiver?
7. Is there anything else you think I should know?

Some people like to talk about the things that they do and what happens to them. However, some things you talk about may make you uncomfortable. All the stuff you share about what you do or about the people you are talking about will be kept private unless you tell the interviewer something that makes you unsafe. This interview will be held in the offices of the Caregiving Youth Partners Project in Boca Raton and should take about 1 hour to 1½ hours of your time.

The people doing the study hope this work will help nurses and other medical people know about young caregivers and how to help them. To say thank you, everyone who has an interview for the study will get a \$10.00 gift card.

You do not have to be in this study if you don't want to and you can stop being in the study anytime. If you don't like a question, you don't have to answer it. You can read the report when it is finished, if you want to.

Initials of the child/adolescent: _____

APPENDIX E
Demographic Data Form

Young Caregivers: A Grounded Theory Study

Minor Participant Code: _____ Adult Participant Code: _____

1. Relationship of child/adolescent to chronically ill or disabled family member:
(please circle)

Parent Grandparent Other family member: _____

2. Chronic illness or disability of affected family member.

Diabetes _____ Cancer _____ Other _____
Hypertension _____ Disabled _____
Heart Disease _____ Drug or alcohol problem _____
Stroke _____ Depression _____
Multiple Sclerosis _____ Dementia _____

3. Family ethnicity:

_____ White/European American
_____ Black/African American
_____ Haitian
_____ Caribbean-Black
_____ Latino/Hispanic Other _____

4. Is your child eligible for the "Free or Reduced Lunch Program?"

Yes No

5. The child/adolescent lives with the chronically ill or disabled family member at least 50% of the time. Yes _____ No _____

6. Does your child/adolescent help in providing direct care (feeding, bathing, dressing, getting in and out of bed and chairs, using the bathroom dealing with incontinence or diapers) to your chronically ill or disabled family member? Yes _____ No _____

7. Does your child/adolescent help in providing instrumental care (household chores, grocery shopping, preparing meals, or preparing and administering medicines) to your chronically ill family member? Yes _____ No _____

8. What is the estimated amount of total time needed by **all caregivers** spends in providing care for the chronically ill or disabled family member each day?

0-30 min. _____ 0-60 min. _____ 0-90 min. _____ More than 2 hours _____

9. What is the estimated amount of time your **child/adolescent** spends in providing care for your chronically ill or disabled family member each day?

0-30min. _____ 0-60 min. _____ 0-90 min. _____ More than 2 hours _____

10. In the past month how often has your child/adolescent been LATE to school? _____

11. How many days has your child/adolescent been ABSENT from school this year?

12. What prevents your child from getting to school? _____

APPENDIX G

Initial Interview Guide

Young Caregivers: A Grounded Theory Study

Interview Guide 1

1. Tell me what led up to you becoming a young caregiver.
2. What was it like? What did you think? Who, if anyone influenced your actions?
3. Could you describe a typical day for you as a caregiver?
...as a child?
...as a pre-teen?
4. What problems do you run into because you are a young caregiver?
5. Who has been the most helpful to you as a young caregiver?
6. Has any organization or group been helpful to you as learned to be a young caregiver?
7. After being a young caregiver, what advise would you give someone else who is just starting to be a young caregiver?
8. Is there anything else you think I should know?

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