

Background

Chronic diseases-such as heart disease, cancer, and diabetes-are the leading cause of death and disability in the United States. Chronic diseases account for 70% of all deaths in the U.S. each year" (CDC, 2007). Individuals of all ages with a chronic illness or disability often require support to manage their condition. " 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 illness or disabilities" (Friedman, Bowden, Jones, 2003).

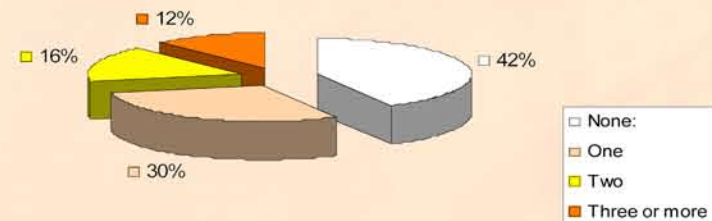
A wealth of information about family caregiving is found in the nursing literature. This includes: studies of the relationship between adult caregivers and care recipients, itemization of the care provided and the description of the consequences of being a caregiver. Positive and negative outcomes are identified for adult caregivers providing care for a spouse, aged parent, grandparent or ill child.

"Necessary reliance" appears central to the concept of family caregiving. The caregiver feels responsible for the overall health and well being of the care recipient, while the care recipient develops dependence on the caregiver (Schofield, 1998). This relationship can create happiness as well as a sense of burden for caregiver and care recipient. Increasing burden is related to the inability to prevent losses due to progression of a disease or disability in the overall health of the care recipient. This contrasts to a sense of well-being and contentment and happiness created by the observation of care recipient milestone achievement (Schofield, 1998).

Yet, there is little similar information available about the role of children or adolescents, who as family members are pressed into service to assist in responding to a family health issue.

- 1.4 Million children and adolescents in the United States, 8-18 years old, provide unpaid direct or indirect care for a chronically ill or disabled family member or adult [National Alliance Caregiving (NAC) & United Hospital Fund (UHF), 2005].

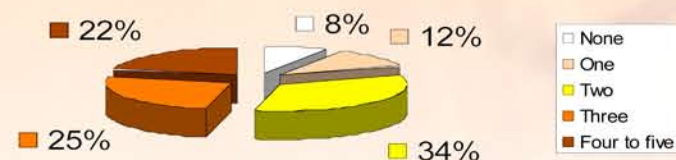
Number of ADLs performed by young caregivers



Activities of daily living (ADLs)

- Getting in/out of bed
- Toileting
- Dressing
- Dealing with incontinence or diapers
- Bathing or Showering
- Feeding

Number of IADLs performed by 8-11 year old young caregivers



Indirect activities of daily living (IADLS)

- Moving around the house or community
- Grocery shopping
- Household chores
- Preparing meals
- Keeping company
- Helping with medications

National Alliance for Caregiving & United Hospital Fund, 2005

Young Caregivers: A Grounded Theory Study

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A Story

Ann Marie was EXCITED! It was the first day of school. Middle school-at last! As she looked around the classroom, she wondered how the year would go. New teachers, new friends, maybe things would be different. Last year her friend, Betty, didn't come to her house much after school. Ann Marie always had lots of things to do to help her Grandma. It took a lot of time! But, she loved Grandma Brown and didn't really mind helping her go to the bathroom or giving her the insulin. Plus, it was sort of fun to talk with her. But today was NEW! She had done all her chores before coming to school. Mom left early for work and depended on her. First, she took the breakfast that Mom made to Grandma and then helped her get cleaned up and settled andCHECKING GRANDMA'S OXYGEN TANK!



She forgot to do that. OH NO!! What if it ran out! The last time that happened, Grandma Brown was in the hospital for a week! How could she check it now? How could she call her Mom? Was Grandma O.K.? The more she thought about it, the more she worried! She felt the tears slipping down her cheeks. The more she wiped them away, the faster they came.

Everyone would see!

When her new teacher asked her what the problem was, Ann Marie couldn't even talk. She just cried harder. The teacher threw her hands up in frustration and suddenly Ann Marie was in the School Nurse's office.

COULD THIS DAY BE ANY WORSE!!



The Problem

- Nursing research in the United States investigating the role of children and adolescents in the provision of care to chronically ill or disabled relatives is limited. Little is known about how young caregivers manage these responsibilities.
- Existing research documents:
 - The negative effect of caregiving on academic achievements (Siskowski, 2006).
 - Young caregivers experience both negative and positive feelings as a result of their caregiving experiences. (National Alliance for Caregiving & The United Hospital Fund, 2005).
 - The tasks performed by young caregivers are similar to those performed by adult family caregivers. (NAC & UHF, 2005)
 - Young caregivers usually live with those they care for. (NAC & UHF, 2005).

The Research Purpose/Question

- The purpose of this grounded theory study is to explore and describe the processes used by female young caregivers, aged 11 to 14 years old, to manage the multiple demands of caregiving, school attendance and achieving social and physical maturity.
- What is the basic social psychological problem experienced by female young caregivers?
- What are the basic social psychological processes used by female young caregivers to solve the problems they encounter as a result of caregiving?

Methods and Results

- Qualitative research methods are used when explanations are needed for the questions of "how", or "why" and "what" of a selected phenomenon (Nelson & Quintana, 2005).
- This study uses the grounded theory method of research. Participants will take part in an audio taped interview which will be transcribed and analyzed in to categories (e.g. themes, concepts). These themes will be further analyzed for relationships between them. Theory creation will result. (Corbin & Strauss, 1998).
- This study was approved in May 2008 by the Christine E. Lynn College of Nursing and the IRB of Florida Atlantic University. It is currently in progress. Results are expected later this year.

Implications for School Nurses

School nurses are in a unique position to identify and support the needs of young caregivers in the student populations they serve. Through nursing support and collaborative interventions, a student's academic success and health can be improved. This support begins by expanding initial and ongoing student health and home assessment information to include an assessment for family health situations. This will identify students who may be young caregivers. Nursing interventions to support these students will be improved through the use of a mid-range nursing theory. Understanding how a young caregiver approaches and creates solutions to the issues they face daily will produce better interventions (Weber, 2005). Student support may be needed to enable emotional coping, academic achievement or family assistance through referral to outside service agencies.

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