

# Young Caregivers: They're Just Muddling Through



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# 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 Disease

- Chronic diseases account for 70% of all deaths in the U.S. (CDC, 2007)
- “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” (Friedman, Bowden, Jones, 2003).
- 1.4 million children and adolescents in the U.S., 8-18 years old, provide unpaid direct or indirect care for a chronically ill or disabled family member (NAC & UHF).



# Review of Literature

- “Beginning in the 1970s and 1980s, family caregiving, an age-old practice, became a major programmatic and policy topic in the United States” (Levine et al., 2005).
- “Researchers conducting studies in private home, nursing home and clinic settings identified emotional and physical adult caregiver responses to caregiving and the stress placed on the family by caregiving” (Admi & Shaham, 2007, Schumacher, Beck, & Marren 2006, Farran, Loukissa, Lindeman, McCann, Bienias 2004).



# Review of Literature summary

- Types of family caregiver research included:
  - identification of caregiver and care recipient issues
  - descriptive studies of caregivers and care recipients
  - verification research to evaluate the effectiveness of healthcare provider interventions with both caregivers and care recipients.



# Limited research on role of children and adolescents in caregiving.

- Disease focused research: Children caring for family members who had cancer (Gates & Lackey, 1998).
- Retrospective research asking adults about their experiences as caregivers during childhood and adolescence (Shifren, 2001).
- The effects of Family Caregiving on the education of middle school students with family health issues (Siskowski, 2004).
- **As a result: Young Caregivers are largely invisible!**



Problem:

## Young Caregivers' work not easily seen

- **2005:** First U.S. national study to assess prevalence of young caregivers, the role they take in caregiving, and the impact of the role on the life of the child. Study process: 18 minute telephone interview.
  - Results:
    - 1.4 million young caregivers between the ages of 8 and 18 years old.
      - 30% are ages 8 to 11.
      - 38% are ages 12 to 18.



# Results

## A young caregiver helps with:

- *Activities of daily living (ADLs)*
  - Getting in/out of bed
  - Dressing
  - Bathing or Showering
  - Toileting
  - Dealing with incontinence or diapers
  - Feeding
- *Indirect activities of daily living (IADLS)*
  - Moving around the house or community
  - Household chores
  - Keeping company
  - Grocery shopping
  - Preparing meals
  - Helping with medications



# How do Young Caregivers manage their changing complexities?


- The complexity of:
  - **Being/Becoming a Caregiver**
    - Learning new skills, ? Role reversal, Being invisible an invisible caregiver to friends, family, teachers
  - **Being an Adolescent**
    - What is right and wrong? What is my future? What will I do with my life?
  - **School**
    - Learning, social interactions, relationships with teachers and peers

# Managing Changing Complexities



# Muddling Through: How Young Adolescent Caregivers Manage Changing Complexities

C. Kain, 2009.

- 
- Identify the basic social psychological problem shared by young adolescent female caregivers.
  - Explore the basic social process used by young adolescent female caregivers to resolve this problem.



# A Grounded Theory Study

## Data Collection

- Approved by Florida Atlantic University IRB prior to data collection.
- Interviews took place over 1 year
- Audio taped in depth semi-structured interviews with young adolescent caregivers
  - Interviews continued until theoretical saturation occurred
- Participant observation / Field notes



# Participants

- All participants (N=9) were young caregivers recruited through The Caregiving Youth Project by staff and the researcher.
- Age/Gender
  - 11 to 14 years old (young adolescents)
  - All female
- 89% (N=8) Eligible for/Receiving Free and Reduced Lunch
- Ethnic background
  - Haitian 33 % N=3
  - White/European 22% N=2
  - American Black 11% N=1
  - Latino/Hispanic 11% N=1
  - Caribbean Black 11% N=1
  - Mixed/Other 11% N=1



# Care Recipient Demographic Data

- *Chronic illness or disability of care recipients.*

- Diabetes            Disabled
- Cancer             Dementia
- Lupus                Cerebral Palsy
- Post stroke        TIA
- Arthritis            Hypertension

- *Relationship to young caregiver*

- 33% (N=3) Parent
- 44% (N=4) Grandparent
- 22% (N=2) Another category of relative.

- *55% (N=5) of care recipients required more than 2 hours of care per day.*



# Caregiving Activities of Study Participants

- **Tasks involved in personal care. (ADL's)**
- **88%** of participants provided direct care
  - Waking them up and getting ready for the day.
  - Feeding, getting snacks, meals
  - Washing face, showering, bathing
  - Walking with/supporting to walk
  - Toileting, changing adult diaper
  - Getting them ready for bed.
- **Tasks to manage everyday living (IADL's)**
- **100%** of participants provided instrumental care
  - Running errands
  - Cooking
  - Eating together
  - Cleaning, straightening up, mopping
  - Giving medicines and treatments
  - Talking with Doctors and Nurses
  - Keeping track of things (medicines, appointments, daily schedule)
  - Sitting with person to watch T.V. or do crossword puzzles (keeping company)



# Data Analysis

- Grounded Theory Method
  - Symbolic Interaction
  - Constant comparison method
    - Each line, phrase, sentence or paragraph compared to identify similarities, differences and general patterns
  - Coding levels
    - I Substantive codes using informant's words
    - II Data moved to a higher level of abstraction called categories
    - III Theoretical constructs developed which added meaning & scope to the substantive theory

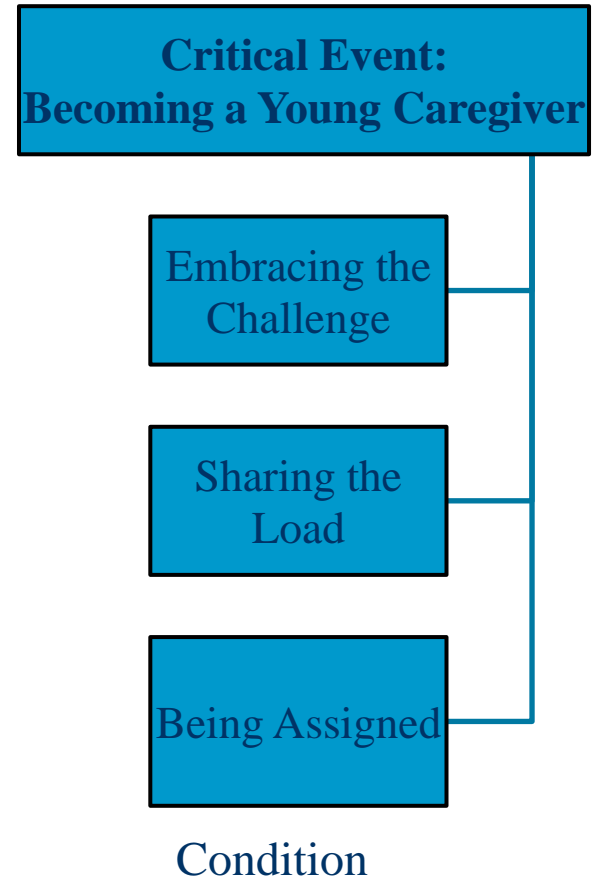


# Results

- Basic Social Psychological Problem (BSPP)
  - **Managing Changing Complexities**
- Basic Social Process (BSP)
  - **Muddling Through**

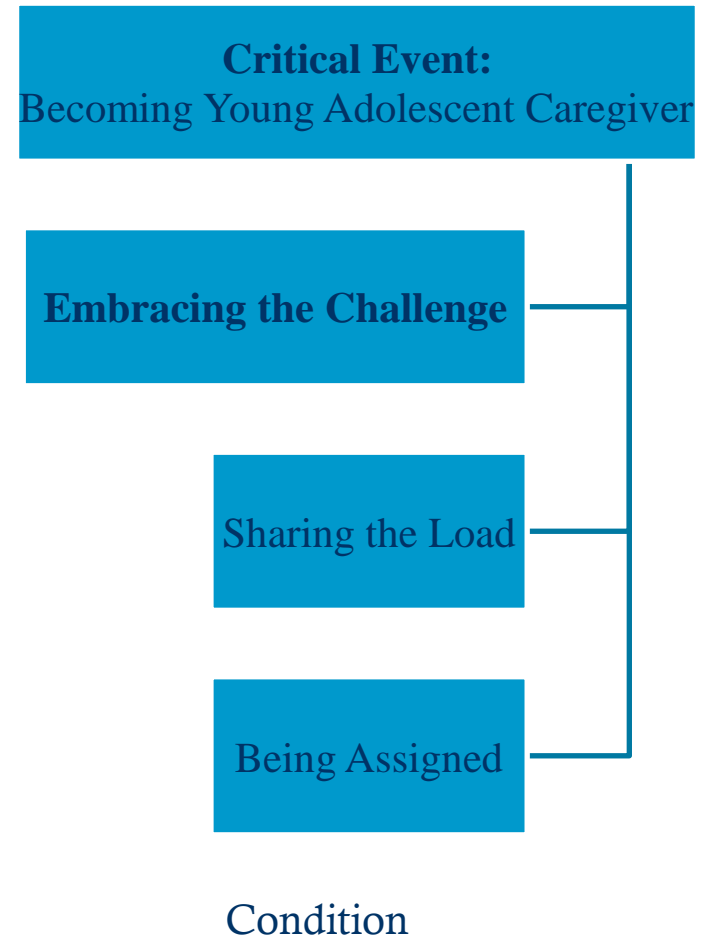
# Becoming a Young Adolescent Caregiver

- Describes the conditions under which a young adolescent becomes a young caregiver.
  - Embracing the Challenge
  - Sharing the Load
  - Being Assigned



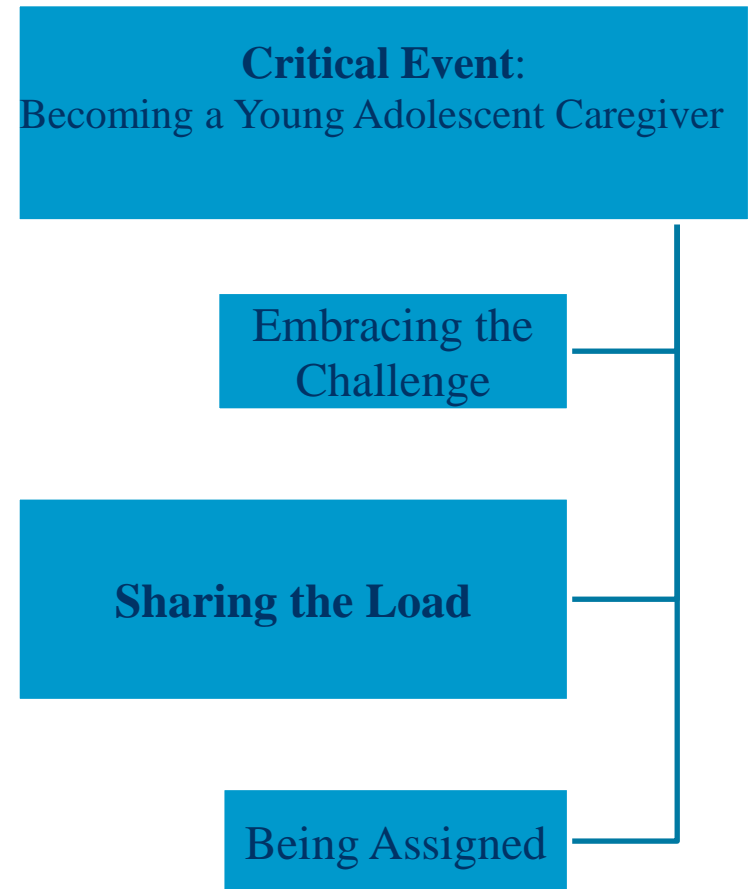
# Becoming a Young Adolescent Caregiver: Embracing the Challenge

- Participants were intrigued and interested in learning the steps and methods of providing care. They saw the manipulation of devices and use of medicines as interesting and **fun**.
  - “I decided that, OK, that looks interesting. I would like to help. ...I started to like it and enjoy it and it made me feel good and made me know I was helping her (Grandma). 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...”



# Becoming a Young Adolescent Caregiver: Sharing the Load

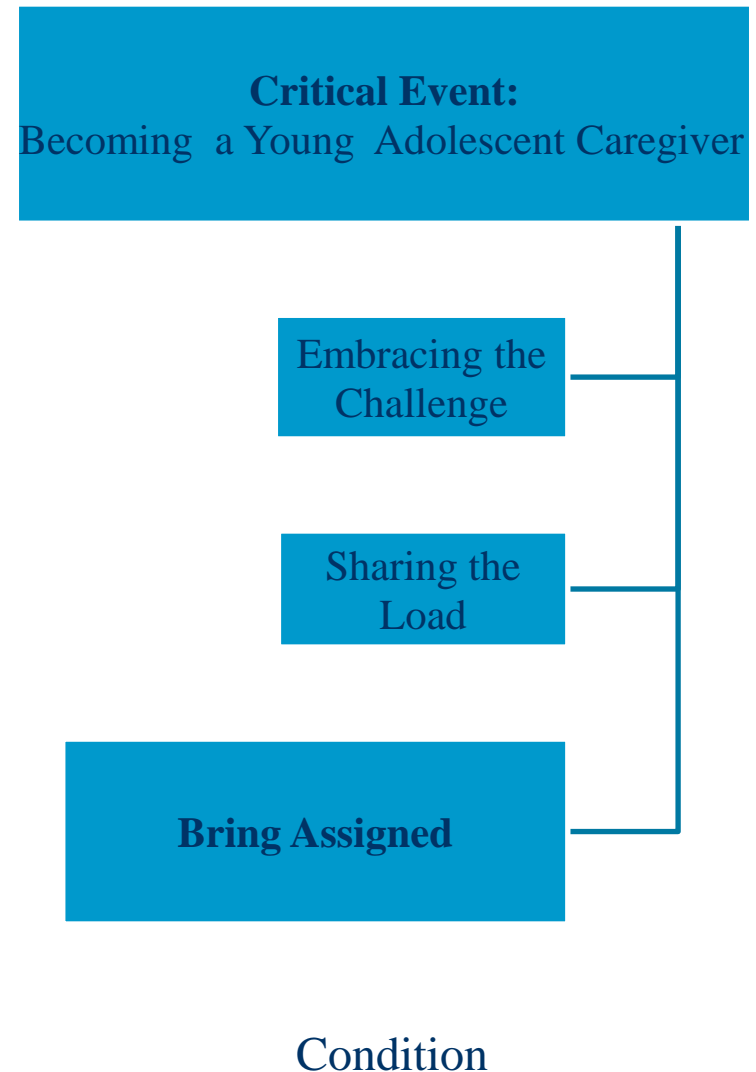
- Young adolescent caregivers described watching a family caregiver struggle with the strain and tasks of being a caregiver and making a personal judgment to relieve the strain of the family caregiver by participating in caregiving activities.
- “...so we all stayed home with Grandma and I used to be there with my Mom. And at that time I thought that-well since my Mom has school and she has to work and everything, maybe I’d like to help her...you know take a lot of stuff off her back”.



Condition

# Becoming a Young Adolescent Caregiver: Being Assigned

- The participants described being judged ready or able to begin providing care to the care recipient by another---usually a parent. The young adolescent caregiver was not asked about their readiness or willingness to participate in care giving activities.
- “I’ve been taking care of my Grandma since I was 8 or 9 and now I’m 12 now. Dad told me to”.
- “Well the tragedy happened and like my Dad would ask me to come and stay with him and everything—so now I stay here”.





# **Basic Social Psychological Problem (BSPP): Managing Changing Complexities**

- **Adolescence and social life**
  - **Creating an identity separate from that of the family.**
  - **Choosing and maintaining friendships and relationships.**
- **School**
  - **Achieve academic success.**
  - **Investigating and “trying on” future careers.**
- **Caregiving**
  - **Identifying and accepting their own individual role in caregiving.**
  - **Learning and implementing care skills.**



## Basic Social Process (BSP)

### Muddling Through

- Describes the methods used by study participants, i.e., young adolescent caregivers, to manage the changing complexities in their lives, on their own, without prior knowledge, organization or direct planning or perceived adult supervision and with no certainty of success.

# Process of Managing Changing Complexities: Muddling Through

## Muddling Through

*Critical Event:*

**Becoming a  
Young  
Caregiver**

**Conditions**

**Choosing  
Family**

**Consequences**

**Creating  
Structure**

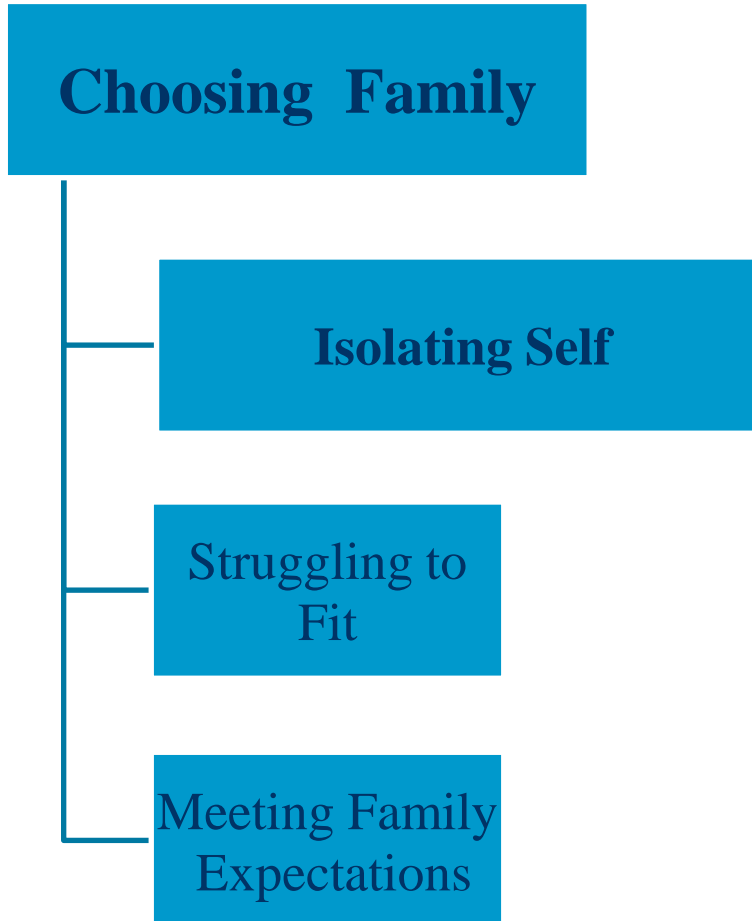
**Strategies**

**Maintaining  
Balance**

**Consequences**

# Choosing Family

## *Isolating Self*

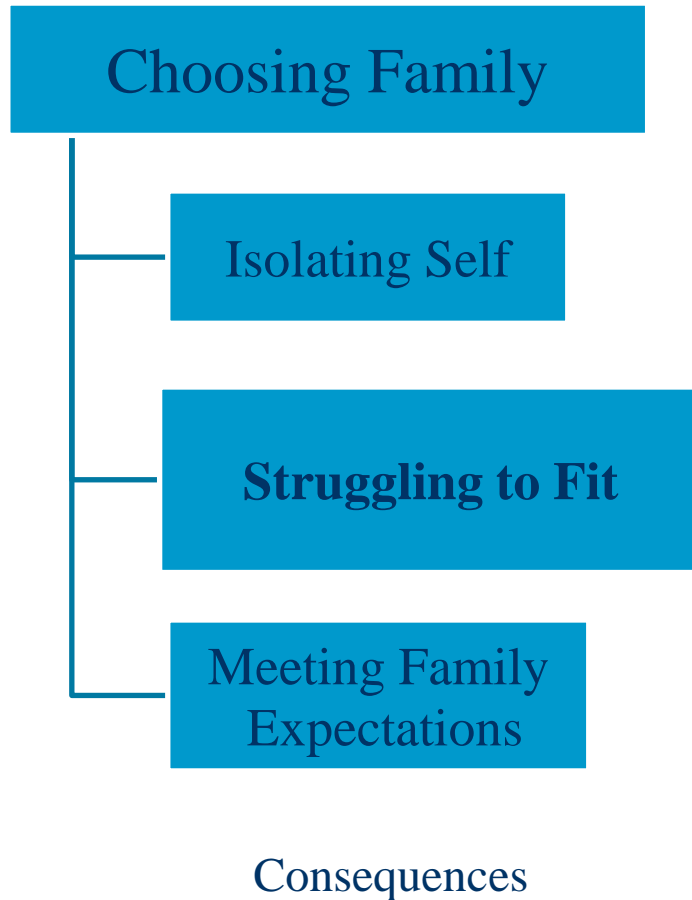


Consequences

- Young Adolescent caregivers made family their first priority and as a result turned away from friends.
- “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”.

# Choosing Family

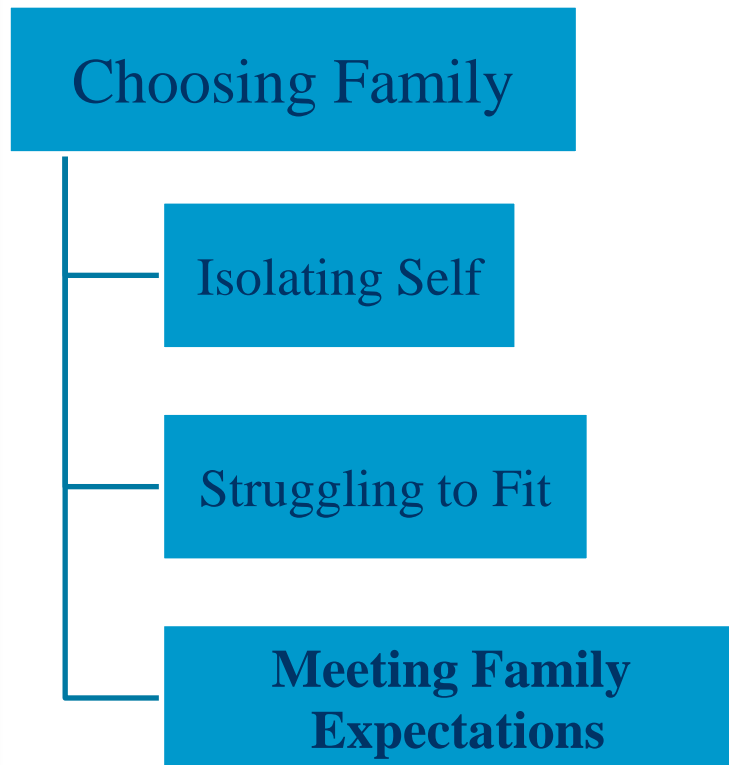
## *Struggling to Fit*



- Young adolescent caregivers did not have clear guidelines about how to manage the multiple changing complexities in their lives. They were uncertain of the right thing to do in each situation.
- Making choices was often difficult for them
  - “ 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 else, I always have to remind my Mom that I have to be there, or I ...I find a way to be there or cancel the other thing (not caregiving).

# Choosing Family:

## *Meeting Family Expectations*



Consequences

- In order to meet family expectations in all the areas of changing complexities, the young adolescent caregiver had to:
  - discern or learn both the obvious and the more subtle family rules
  - And create a plan to meet those expectations.
- “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. Maybe a marine biologist.”
- “I can see Grandma doing something and she needs something else done then I go and do it for her. No, we don’t ever talk about it.”

# Process of Managing Changing Complexities: Muddling Through

**Muddling Through**

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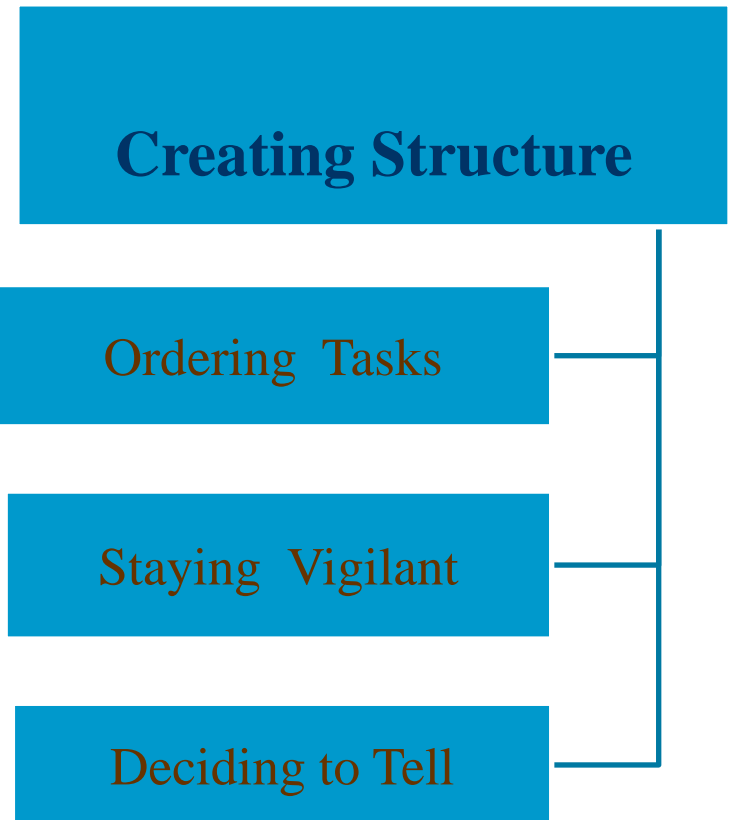
**Strategies**

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# Creating Structure

- In attempts to manage the changing complexities in their lives, participants used the strategies of ordering tasks, staying vigilant, and deciding to tell.

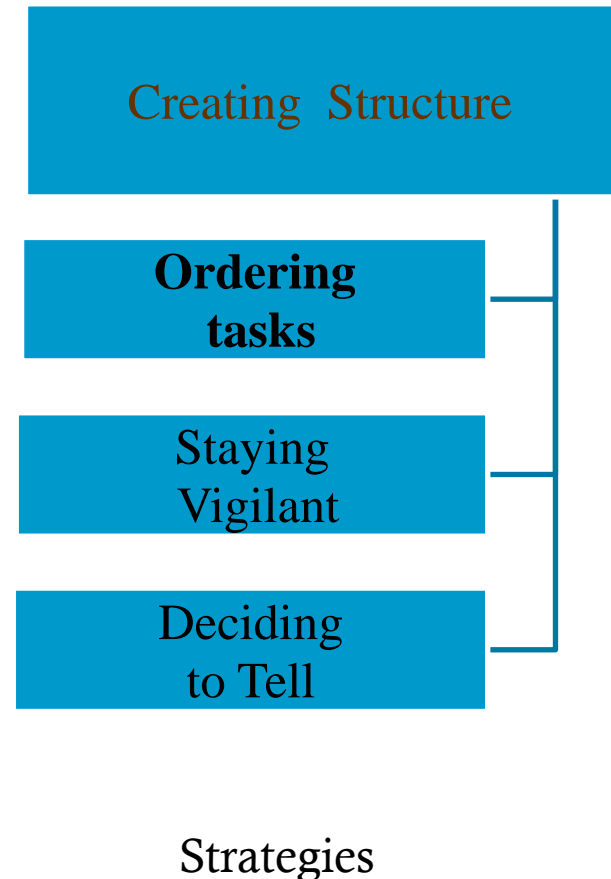


Strategies

# Creating Structure:

## *Ordering Tasks*

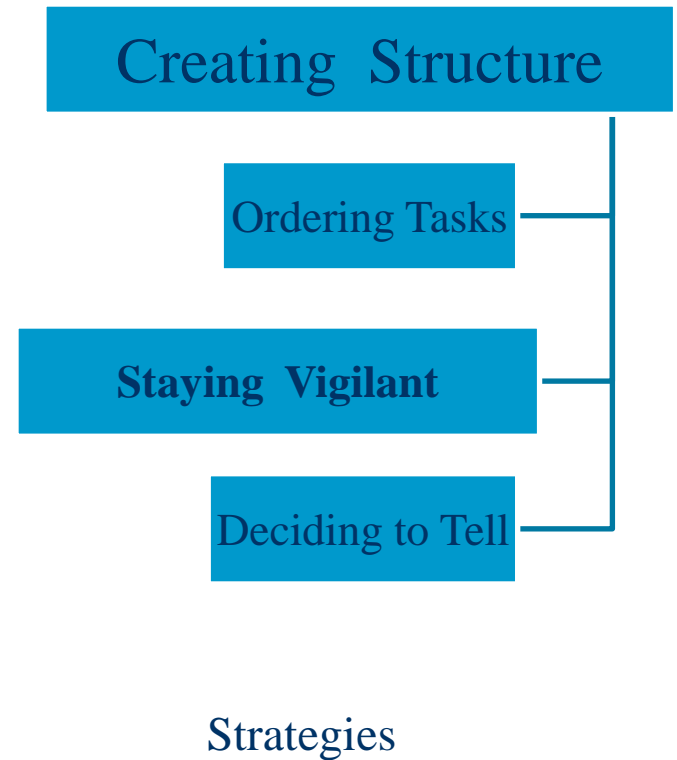
- The strategies used by young adolescent caregivers to organize, identify and anticipate/plan their own behavior for each situation they were confronted with.
  - Participants appeared to partially compartmentalize setting priorities and actions. When at school, the young adolescent caregivers focused on attending class, socializing with friends and doing homework. When at home, they thought first of their caregiving duties or the care recipients.



# Creating Structure:

## *Staying Vigilant*

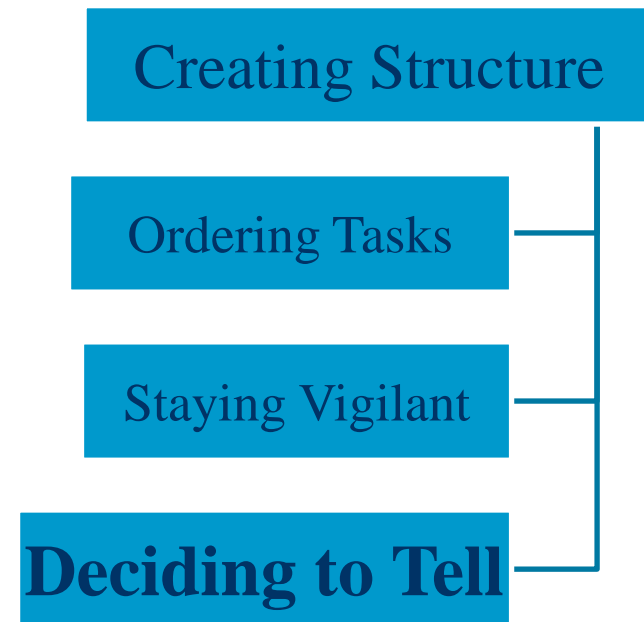
- Being continually aware of the safety and condition of the care recipient was expressed by the young adolescent caregivers. The thoughts were about the care recipients' physical safety while providing care and having thoughts or worry about the care recipient when apart from them.
- "Sometimes when people are helping him it's hard to let others help. I'd rather me help. I just feel uncomfortable."
- When I come home "I say hi to everyone and go straight to my grandma and ask if she's O.K. and if anything has changed from when I was gone?"



# Creating Structure:

## *Deciding to Tell*

- When participants decided to tell they considered how long they had known an individual and looked for a feeling of shared circumstances with the person to be told.
- School nurses and teachers were **not identified as someone they could share their caregiving stories and stresses.**
- “...she’s had some tragedies... I’ve had some tragedies. We have happy times.”  
“Like if I’ve known them awhile and I know they’ll keep a secret for me and won’t tell...I’ll usually talk to them.”
- “No I never talk to my teachers about caregiving, I’m not that close to them.”
- “I was in the nurse’s office and she asked me if I knew about the Caregiving Program...she told me where to get the papers but I haven’t got them yet.”



Strategies

# Process of Managing Changing Complexities: Muddling Through

**Muddling Through**

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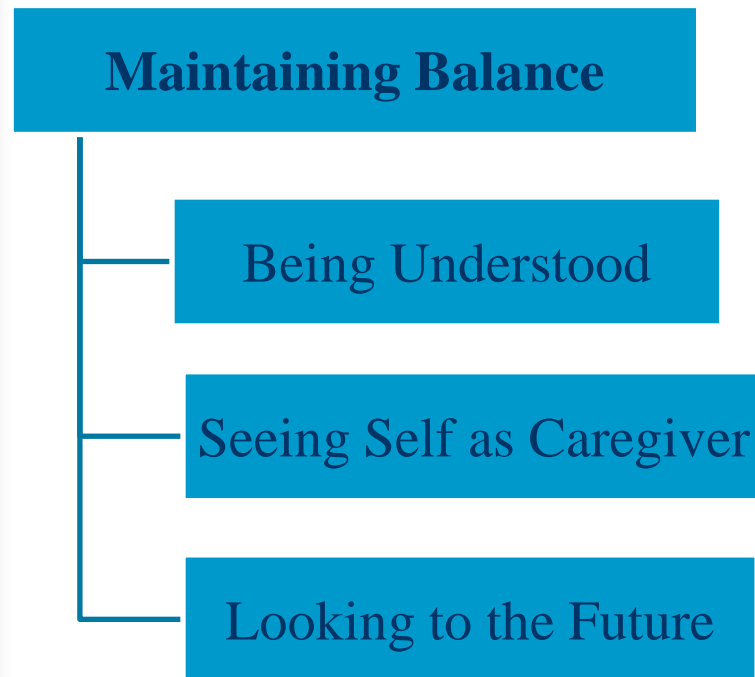
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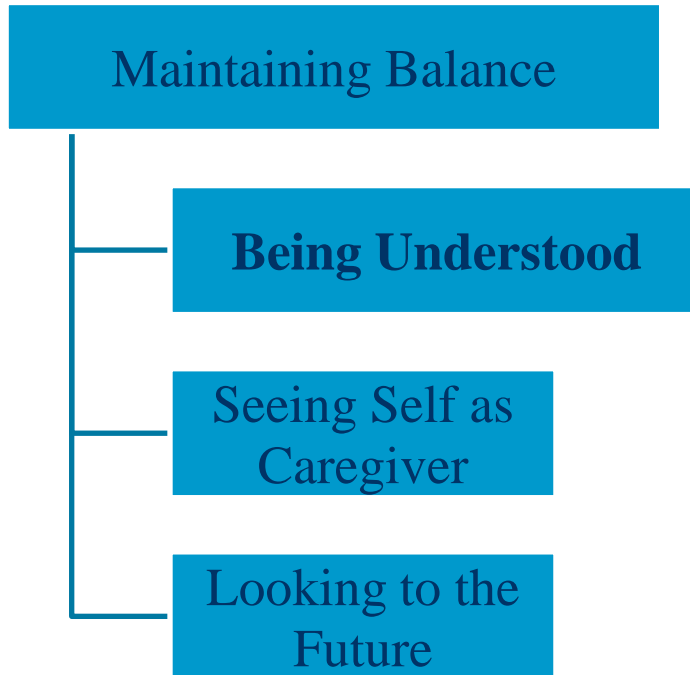
# Maintaining Balance:



Consequences

- When the study participants could Create Structure, they were more likely to be able to express feelings of Balance. The ability to Maintain Balance was not a fixed, unchanging condition but depended on their abilities to manage their Changing Complexities.

# Maintaining Balance: Being Understood

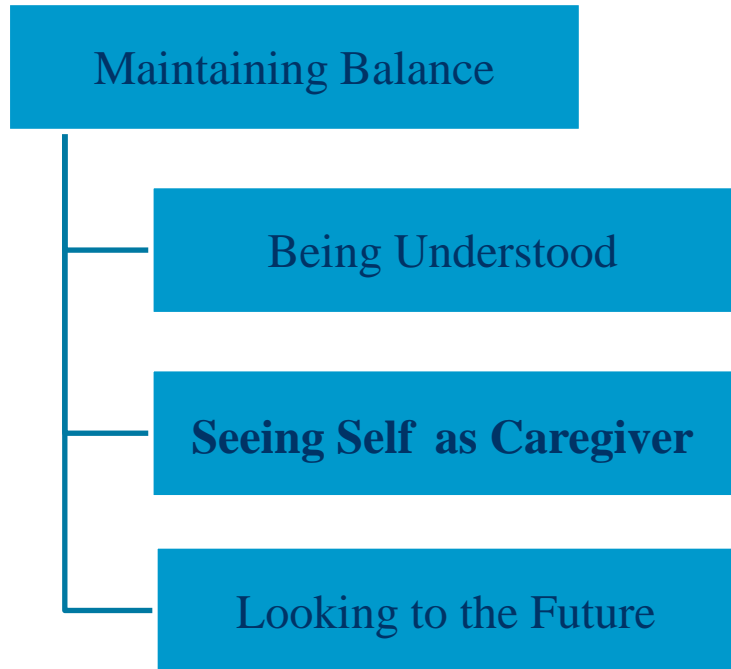


Consequences

- Expressions of kindness and/or concern often resulted when the young adolescent caregivers decided to tell. They liked **being understood** and this may have added to the likelihood that they would decide to tell in the future.
- “Like my Mom when she was a girl she used to watch her cousins...and she had the same feelings I do now... she tells me about it and it kinda sorta helps me deal with my problems...”.
- “Yeah, I talk to my friends...they give me advice. That’s it they just give me advice and are there for me.”

# Maintaining Balance:

## *Seeing Self as Caregiver*

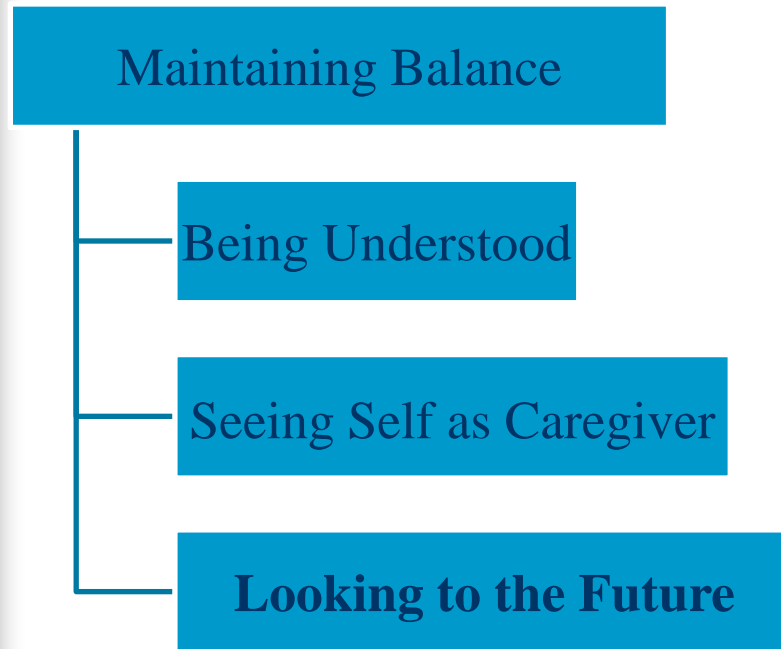


Consequences

- Personal satisfaction derived from caregiving was not always present. This contrasts to responses by family caregivers found in the literature.
- Perhaps influenced by psychosocial development, positive or negative emotional feelings for the care recipient or positive feedback received for being a caregiver.
- “I guess I’ll be a caregiver till I’m 18. Then I hope to go to college...I want to be a singer, doctor or musician.”
- “I don’t know how long I’ll keep taking care of Gram. I don’t know if it will be forever or no more.”
- “I would always be a caregiver. I think caregiving makes me a better person, a lot better.”

# Maintaining Balance:

## *Looking to the Future*



Consequences

- The ability of the study participants to imagine the future varied.
- Those who successfully Created Structure and Decided to Tell or Maintained Balance could describe multiple possible futures.
- Others who had not learned to manage the changing complexities in the multiple areas of their lives could not see the future clearly.
- All participants seemed to draw pride from being asked to advise future young adolescent caregivers. Their advice usually reflected their own struggles and is divided into three categories.
  - Managing your emotions
  - Believe in yourself as a caregiver
  - Reach out to others to stay focused

# Young Adolescent Caregivers

