Exploring the Concept of "Young Carer" in Families Living with Parental Mental Illness

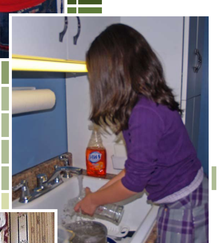
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Background Information

The concept of "young carers" has been framed in the literature as children providing care and assuming household responsibilities when parents have physical and/or mental disabilities (Aldridge & Becker, 2003). In the United Kingdom, young carers have been studied extensively, leading to increased access to services and supports (Dearden & Becker, 2004). Our goal is to explore the concept of young carers in the U.S.







Children's Background & Experiences as Reported by Parents

Variables	Percent of Interviewed Children*
Males	51
Hispanic ethnicity	11
Race:	
White	93
African American	11
Asian	4
American Indian	4
Age:	
6-12 yrs	66
13-18 yrs	34
Education:	
Currently enrolled in school	100
Ever had an IEP	53
Personal Histories:	
Ever had any emotional/behavioral problems	68
Ever had a psychiatric hospitalization	15
Ever beaten, severely hit, or slapped/hit to the point of leaving a mark	15
Ever inappropriately touched/made to touch someone in a sexual way	9
Ever involved with DSS and/or a child protection service	77
Ever run away without caregiver knowing	11
Ever been involved with police and/or probation	13
Ever smoked cigarettes	4
Ever used alcohol or other drugs	0

*n=36 parents; *children's n ranged from 44-47*

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Aims

1) To describe the care giving and household responsibilities of children and youth living with parents with mental illnesses, how often they are performed, and the feelings of children and youth about these responsibilities. In addition, we are exploring the daily activities and interactions of children and youth; and
2) To assess the feasibility and usefulness of certain measures for use with younger children.

Household Chores (n=47 children & youth)

In a normal week, do you do any of the following household chores?	Percent 'Yes'*	Percent Responding "a lot"**
Doing laundry?	69	33
Shopping for groceries?	76	50
Making dinner?	67	40
Washing dishes?	60	42
Sweeping, vacuuming, or dusting?	84	57
Doing homework?	96	84

** n varied from 32-47; ** % of youth responding "yes"*

15 year old girl:

A: "…and do homework, then around six, I help her get them … ready to go home, and then… sometimes I cook and then when she comes in, I'll [help with] dinner. And then after dinner is over, I clean up the kitchen, take a shower, talk on the phone, and then, use the computer and I fall asleep basically."

Feelings About Responsibilities (*n*=47 children & youth)

	Percent 'Yes'	Percent "a lot"
Do you think you have a lot of responsibility?	66	59
Have you ever had to skip a fun activity because you had a more important responsibility?	80	15
Do you have time for yourself?	91	50
Do you feel like people expect too much from you?	50	41
Does the amount of work you have to do around the house seem fair to you?	95	64
Do you feel like you have to be more grown up than you really are?	52	50
Are you too worried about something to concentrate on your schoolwork?	36	13
Has helping your parent kept you from doing schoolwork?	20	33
Has helping your parent made you miss a school or after-school activity?	23	30

10 year old girl:

Q: "What were the hardest times of the day or the hardest things you had to do yesterday?

A: Watch the baby…When he kept walking, walking into the water.

Q: So it was hard to watch the baby at the pool?

A: Um-hum.

Q: Was it hard cause like your friends were there and stuff? Did you get to hang out with them much?

A: Yeah. But okay, it was hard to find him with all those people in the water…and then give him back to my Mom.

Q: Okay. Do you just kind of help her a bit?

A: Yeah."

Methods

Data were obtained in baseline interviews conducted with children and youth participating in the Family Options study. Interview data were obtained from 47 children and youth between the ages of 8 and 16 years at the time of entry into the study. The sample is balanced in terms of gender. The majority of the children are white. About half had ever had an IEP. Over two thirds had ever had any emotional/behavioral problems. The majority had been involved with child protection services. Interviews included questions from a structured measure used in previous research on young carers (Aldridge & Becker, 1993) and open-ended interview items from the Behavioral and Emotional Rating Scale-2nd Ed. (BERS-2; Mooney, Epstein, Ryser, & Pierce, 2005).

Nature of Caregiving (n=47 children & youth)

In a normal week…nature of caregiving	Percent 'Yes'*	Percent Responding "a lot"**
Help taking care of your mom or dad?	82	72
Taking care of brothers or sisters?	67	59
Help your mom get ready to go out?	58	28
Help your mom talk with doctors or nurses?	40	23
Keep your mom company or provide emotional support?	93	59
Help your mom with paperwork or paying bills?	26	54
Call or arrange for someone else to come to your house to help your mom?	26	27
Help your mom get up in the morning?	50	38
Help your mom get around the city?	33	29
Does your mom confide in you?	34	34

** n varied from 32-47; ** % of youth responding "yes"*

15 year old girl:

Q: "What are your hardest times of the day or the hardest things that you have to do?

A: Watching my nephew.

Q: Okay. How come?

A: He's into everything. There's not one minute where you're not after him. He touches everything; he plays with everything; he opens everything; everything."

11 year old boy:

Q: "And you did some stuff on the computer, did you talk to friends online?

A: Yeah

Q: Do you talk to them pretty often?

A: Oh Yeah! We talk all the time

Q: Do you talk to them more do you think more on the computer or like the phone or hang out with them?

A: Well remember all my friends from school so I usually saw them everyday so now we don't see each other as much so we just talk on the phone or online, most of the time we're online though.

Q: Okay that's cool. And you said you watched a little bit of TV too?

A: Yeah

Q: So you had a couple hours to talk to your friends?

A: Yeah"

13 year old girl:

"And me and daddy do stuff together. Mommy doesn't do much. She usually lays down or she goes out with her friend, … Sometimes mommy will do things and she'll bring us… to go swimming,… or she'll do stuff like that with us, and sometimes she'll bring us to go shopping and stuff, for like, stuff for school, and she'll bring me to the libraries, to the library and out to eat."

Results

Most of the children and youth reported having responsibilities such as helping to provide care for their mother (82%), helping mom get ready to go out (58%), and helping mom to get up in the morning (50%). Children also reported doing chores such as washing dishes (60%), helping with laundry (69%), and helping with sweeping, vacuuming or dusting (84%). Most children (95%) said the amount of work they had to do around the house seemed fair to them and that they felt appreciated for this work (91%).

Ninety-four percent of children and youth indicated they spend time "doing things they like." Also, about half (51%) indicated they would like to be doing more of these activities. Almost ninety percent (89%) reported they spend time playing or hanging out with friends.

Interviewers noted that children's ages may have affected their interpretation of some of the questions. Also, parents were often nearby while children were being interviewed, which may have influenced children's responses.

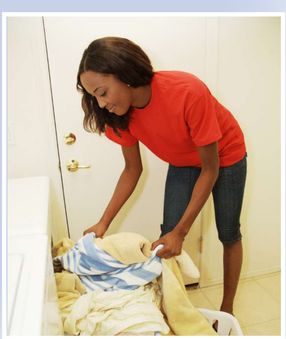
Personal Activities (n=47 children & youth)

In a normal week, do you do any of the following personal activities?	Percent 'Yes'	Percent "a lot"
In organized after-school/weekend activities (e.g., sports teams, clubs, scouts, lessons, etc.)?	50	83
Playing/hanging out with your friends?	89	74
Watching television?	89	61
By yourself doing things you like (not counting TV)?	94	61
Working at a job? *NOTE—only for youth ≥12 yrs*	12	-----

Thinking about the amount of personal activities you have in your life right now…	'Would like to be doing more'	'About enough'	'Too much'	
Do you feel that you are doing…	51	44	4	

Discussion

While children perform care giving and other responsibilities in the home, these responsibilities seem to be balanced with engagement in personal activities and friendships. Further research might explore children's attitudes about their responsibilities in relation to their parents' illnesses and their relationships with their parents, as well as their perceptions of the balance between these responsibilities and their personal activities. Recommendations for the future include interviewing children without their parents present and providing additional clarification for younger children on the meaning of questions regarding care giving and household responsibilities.



Susan Phillips, 2008