Associations of Caretaking with Internalizing Symptoms in Offspring of Huntington's Disease Patients

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Abstract

This study examines Huntington's Disease in the context of patients and their children. Huntington's Disease is a progressive, autosomal dominant, neurodegenerative disorder, meaning that children of parents with the disease have a 50% chance of having the disease themselves. The children have a unique role in taking care of their parents physically and emotionally throughout their parent's disease progression. The purpose of this study is to examine the associations among caregiving, offspring and patient characteristics, and internalizing behavior problems in offspring of Huntington's Disease patients. Caregiving behaviors were negatively associated with internalizing behaviors in offspring of Huntington's Disease patients. Patient emotional well-being was found to be negatively correlated with offspring internalizing symptoms. Patient CAP scores and offspring age were positively correlated with caretaking behaviors. Implications of the findings and future directions for research are explored.

Associations of Caretaking with Anxiety/Depression Symptoms in Offspring of Huntington's Disease Patients

Huntington's Disease (HD) is an autosomal dominant neurodegenerative genetic disease that has physical, cognitive, and psychiatric consequences. The effects go beyond the symptoms that impact the patient and affect their family's quality of life and life satisfaction. The burden of having the disease and caring for someone with the disease is multifaceted and may require nuanced interventions to properly address their situation. There is no consensus on how to best support patients and families with Huntington's Disease, though there are many hypotheses and ongoing investigations on the topic.

Huntington's disease is a progressive, autosomal dominant neurodegenerative disorder that impacts 2.71 out of every 100,000 individuals worldwide and 5.70 out of every 100,000 individuals in Europe, North America, and Australia (Pringsheim, 2012). Huntington's Disease is autosomal dominant, meaning that any child of a patient with HD has a 50% chance of having the disease themselves. The disease is caused by 40 or more repetitions of CAG trinucleotide on the Huntington gene on chromosome 4. If an individual has 27 to 39 repeats of cytosine-adenine-guanine (CAG) they have a higher chance of having the disease (Kowalski et al., 2015). This elongated CAG repeat codes for a longer huntingtin protein in the body. The abnormal huntingtin protein is broken up into smaller pieces that disturb neural functioning throughout the body. The damaged neurons are the basis of the progressive physical and cognitive symptoms of Huntington's Disease (Bates et al., 2015).

The symptoms of Huntington's Disease interfere with daily life, especially as the disease progresses. The physical symptoms of Huntington's Disease include involuntary muscle movement, known as chorea, and difficulty with voluntary movement (Paulsen, 2001). The

cognitive symptoms of Huntington's Disease include the loss of procedural memory and decreased cognitive processing (Bates et al., 2015). This is distinct from Alzheimer's Disease which affects episodic memory and causes a loss of memory acquisition, but it leaves procedural memory functioning. Procedural memory is the ability to recall well-rehearsed movements like riding a bike or playing the piano (Kowalski et al., 2015). In addition to physical and cognitive symptoms, individuals with Huntington's Disease are more likely to have more psychiatric symptoms than the general population, and these symptoms tend to get worse as the disease progresses (Epping et al., 2016). There is a high comorbidity rate of Huntington's Disease with depression and other mental illnesses and an increase in the risk of suicidality (Kowalski et al., 2015). The combination of these symptoms makes it extremely difficult to live with Huntington's Disease and care for someone with the disease.

The onset of Huntington's Disease is typically around 40 years old. However, Juvenile and late-onset Huntington's Disease begin in childhood or adolescence and late 50s respectively (Bates et al., 2015). The average life expectancy for Huntington's Disease patients is 10 to 15 years after diagnosis with increased physical, cognitive, and psychiatric symptoms as the disease progresses. At the moment, there is only experimental treatment or medicine for symptom management, such as dopamine blockers for chorea (Roos, 2010). Without a known cure, the diagnosis and prognosis of Huntington's Disease weigh heavily on patients, spouses, children, and the entire extended family.

Family Stress

Due to the multifaceted nature of this disease, it has a potentially complex impact on patients and their loved ones. Because there is no cure, patients can only be provided with palliative care. Moreover, the 50% heritability of the disease causes increased stress on the children as they look at their potential future. Due to these factors, families with a parent with

Huntington's Disease on average have a decrease in family functioning. Huntington's Disease impacts not only the affected patient's parenting but also the parent without Huntington's Disease because of the strain of caring for and living with their affected partner (Aubeeluck, 2005; Vamos et al., 2007). Despite the high levels of chronic stress that Huntington's Disease puts on families, one study found that 27.5% of patients with Huntington's Disease said that the disease brought their family closer together. Because Huntington's Disease heavily influences family functioning, there need to be family-level interventions to properly address their situation (Vamos et al., 2007).

The stress of having a spouse with Huntington's Disease can be overwhelming, but familial caregivers who find purpose in their role as a caregiver have higher life satisfaction. In a study by Roscoe et al. (2009), cognitive appraisal of their situation and protective factors such as social support mediated the relationship between caregivers' stressors and their well-being. The way that the caregivers thought about their situation had a larger impact on them than the amount of stress they were actually under. Huntington's Disease's impact extends beyond the patient; it influences their friends and family as they attempt to comfort the individual and each other as the disease progresses.

Although there is little consensus in the scientific community about effective interventions for families impacted by Huntington's Disease, there are a number of different ideas and preliminary research. Identifying with the caretaking role can lead to higher life satisfaction. Additionally, maintaining familial connections, friendships, and outside activities helps familial caregivers cope with the stress of their role. This gives them support and perspective outside of their relationship with their loved one with Huntington's Disease. As the disease progresses, this balance between their lives within and outside of the caretaking role

becomes more challenging, but even more important in maintaining their quality of life (Rothing, Malterud, & Frich, 2015).

More research is needed in each of these areas to have a more comprehensive and multidimensional way to support these families and increase their quality of life. In interviewing familial caregivers about their quality of life, four themes emerged including, "levels of support, dissatisfaction with caregiving role, practical aspects of caring, and feelings and emotional well-being" (Aubeeluck, Buchanan, & Stupple, 2012). These are four distinct aspects of well-being that need to be addressed and investigated more thoroughly to better address the question of what the families need and how to intervene effectively. Even with all of the biological knowledge surrounding Huntington's Disease, there is little research regarding the psychological implications of HD on the family and interventions to try to cope with the situation. The current study is going to focus on caregiving.

Caregiving

Because of the progressive nature of the disease and the lack of treatment, familial caregivers have a unique burden in caring for patients with HD. There seems to be a lack of consensus about the types of burdens that the caregivers face, and, even though there are numerous ideas about ways to assist families, there is no clear line of research on interventions (Yu et al., 2019). There is an understanding that there are several stressors that these families face, but there is not a concrete next step in developing scientifically based methods to support them. A quantitative analysis is needed of the burden of caregiving on the child as the parent becomes more and more dependent. Children of parents with HD, ranging from elementary school to young adulthood, may assume the caregiver role in the family as their parent has more advanced stages of the disease. Once more research is done on the specific roles and their impact, these responsibilities can then be acknowledged and supplemented by many different

professions within the medical field. The impact of Huntington's Disease is unique to every child, so their individual needs should be at the forefront of every intervention.

The burden of caregiving has been well documented in other populations. In many situations, caregiving can be draining and challenging, especially for adolescents who are less equipped to handle the responsibilities. For example, divorced families that require children to have a role-reversal with their parents predicted emotional problems regardless of gender (Johnston, 1990). For children with a parent diagnosed with cancer, family responsibility stress was highly correlated with anxious/depressed symptoms, which was much more prevalent in girls than boys (Grant & Compas, 1995). Many children of parents with AIDS take on an adult and parental role which has been associated with internal emotional distress and externalizing problems respectively (Stein, Riedel, & Rotheram-Borus, 1999). For children of mothers with depression, emotional caretaking is correlated with anxiety and depressive symptoms, but instrumental caretaking is not (Champion et al., 2009). In terms of the at-risk offspring of HD patients, they receive very little training or guidance on caregiving, which can increase the stress and impact of caring for their parent on their lives (Kavanaugh, Cho, & Howard, 2019). Additionally, caregiver subjective burden is associated with caregiver depression (Pickett, Altmaier & Paulson, 2007). For children of HD patients with a substantial caregiving role, there is a correlation with school problems (Kavanaugh, 2014).

However, caregiving is not universally detrimental to the caregiver. There can be many benefits to taking care of someone, including a dependent parent. In the short term, parent role reversal can bring closeness to the parent (Herer & Mayseless, 2000). Additionally, caretaking is correlated with maturity, social ability, and increased responsibility (Champion et al., 2009). Multiple studies have also shown that family caregivers have lower mortality rates than non-caregivers, highlighting a potential stress-buffering system that reduces mortality in this

population (Roth et al., 2018). The impact of caregiving may depend on the population and the amount of caregiving that the child has to do. The characteristics of the patient, such as physical and emotional well-being and disease severity, may also have an impact on the caregiver. While a child may be able to provide for their parents to some extent and give some of their time and energy, at some point it may be taking away from their other responsibilities and aspects of their lives. That is why it is essential to consider factors of the patient and the offspring, as both can have significant impacts on the offspring's response.

The Current Study

Further research is needed on how to measure caregiving, especially in how it impacts this specific population. The current study used observational measures of caregiving based on the Iowa Family Interaction Rating Scale (IFIRS; Melby et al., 1988) These measures were used examine caretaking behaviors and attention given and knowledge of parent in children with parents with Huntington's Disease. This observational method has been established previously in a study on children of mothers with depression (Champion et al., 2009). Instrumental caretaking, emotional caretaking, parent centeredness, and parent monitoring measures some of the unique burdens that children of parents with Huntington's Disease have, and it may account for some of their stress and depressive symptoms as a result.

This leads to my specific research questions and hypotheses: What are levels and correlates of caretaking in at-risk offspring Huntington's Disease patients? My primary hypotheses are:

1. Higher levels of caretaking will be associated with greater levels of offspring internalizing problems.

2. Characteristics of the patient and the offspring will be associated with greater levels of offspring internalizing symptoms.
3. Characteristics of the patient, including disease severity, will be associated with higher levels of offspring caretaking behaviors.

Method

Participants and Procedure

Participants in this study were 86 parent-child dyads with an offspring mean age of 19.14 and a parent age of 45.45. Patients in the Neurology Department being treated for Huntington's Disease and their at-risk child were asked by a staff member about the study. If they were interested, a member of the lab discussed the research with them and described the process. Inclusion criteria for the study include using English as a primary language, being part of the Huntington's Disease Multidisciplinary Clinic at Vanderbilt University Medical Center, range in severity from HD- to Prodromal stage to Motor Manifest HD, and the offspring must be at least 7 years of age. Vanderbilt Medical Center is a Center of Excellence for HD, so there are patients from all over the country who come there for treatment. They are introduced to the concept of the research and described its potential implications and goals. From there, the parents sign the consent form and the child sign the assent form after learning more about the study. The families include one parent with Huntington's Disease and their biological child between the ages of 7 and 39 who are at-risk for having Huntington's Disease. Parents with Huntington's Disease can be a part of the study with multiple biological children.

Design

This study done includes surveys and a video recorded interaction between parents and their offspring. The independent variables include a combined code of caretaking strategies,

measured by emotional caretaking, instrumental caretaking, parent monitoring, and parent centered codes in the IFIRS coding scheme. Additionally, characteristics of the HD parent are used as independent variables including their CAP score, CAG repeats, and measures of health status on the Short Form 36 Health Survey Questionnaire (SF-36) including physical functioning, role limitations due to physical health, role limitations due to emotional problems, energy/fatigue, emotional well-being, social functioning, pain, and general health. The dependent variables will be Internalizing Symptoms score measured by the Youth Self-Report (YSR) or the Adult Self-Report (ASR), and measured by the parent-report survey Child Behavior Checklist (CBCL) or Adult Behavior Checklist (ABCL), depending on the age of the child.

Materials

The surveys used are a part of the Achenbach System of Empirically Based Assessment (ASEBA), a broad approach to assessing adaptive and maladaptive functioning. The Youth Self Report (YSR) is a child-report survey used to measure a child's overall functioning, mood, anxiety, and social problems in the form of a Likert-type scale for children ages 7 to 17 with options being 0, 1, or 2. 0 is not true, 1 is somewhat or sometimes true, and 2 is very true or often true (Achenbach & Rescorla, 2001). The Adult Self-Report (ASR) is an adult report measure of one's behavior, emotions, and social abilities for children ages 18 to 39 using the same scale (Ivanova et al., 2014). The Child Behavior Checklist (CBCL) for children ages 7 to 17 and Adult Behavior Checklist (ABCL) for children ages 18 to 39 are completed by the parents to measure their child's behavioral and emotional problems with the Likert scale (Achenbach & Rescorla, 2001). These are broken up into several subcategories including internalizing, externalizing, and mixed internalizing and externalizing problems. Internalizing problems includes anxious/depressed, withdrawn, and somatic complaints. This study will focus on the internalizing problems scale using a combination of the two measurements.

The Short Form 36 Health Survey Questionnaire (SF-36) is a survey used to determine various aspects and overall level of health. The Huntington's Disease patients fill out the survey before their visit to document their level of their level of physical functioning, physical role limitations, emotional role limitations, energy/fatigue, emotional well-being, social functioning, bodily pain, and general health. Participants answer 36 questions about these 8 aspects of their health, with an emphasis on the last 4 weeks (Ware & Sherbourne, 1992).

The number of CAG repeats is used to determine the severity of an individual's Huntington's Disease. The higher the number of repeats, the more severe the disease. To account for the development of the disease over time, the number of repeats is multiplied by the patient's age to create a CAP score, or the CAG Age Product (Ross, 2014).

The Iowa Family Interaction Rating Scale werer used to measure the emotional and instrumental caretaking through a coding scale rating 1 to 9 with 1 being not at all characteristic and 9 being mainly characteristic (Melby et al., 1998). This is an observation scale from two 10-minute video-recorded interaction tasks, one about a positive topic and one about the stresses about HD, that is completed by two research assistants who meet for consensus to settle more than one point discrepancies between their codes. There are 27 codes used for the parent and 29 for the offspring. The four codes used for this analysis are Instrumental Caretaking (IC), Emotional Caretaking (EC), Parent Centered (PC), and Parent Monitoring (MO). These are combined to create a composite code to represent the aspects of caretaking. The complete definitions can be found in the Appendix.

Procedure

After recruitment, participants are followed up with and asked to schedule an appointment and sent online questionnaires to complete before their appointment. The questionnaires ask about emotions, behaviors, and social support of both the parents and the

child in the form of the ASR and YSR and the patient about their overall health in the Short Form-36 (SF-36). After the questionnaires are completed, the family comes into the lab in the Neurological Department at Vanderbilt University Medical Center. The families can leave the study at any point if they do not want to finish. Once in the lab, the parent and the child are filmed in a closed room talking in two 10-minute segments and instructed that they are being recorded for these two conversations. For the first conversation, they were instructed to talk about a positive experience that they had recently, using a cue card with prompting questions as a guide. For the second conversation, the dyad was instructed to discuss some of the stressful things that they have experienced because of Huntington's Disease, using a different cue card with questions to outline the topic. The queue card questions for both tasks found in the Appendix. The conversation ended with a research assistant coming into the room, stopping and starting the recording, and sharing the next prompt. After the recordings, they are thanked for their time and compensated $25 for the visit and $25 for completing the online survey before the visit.

Results

There were 80 offspring who completed the discussion task and 67 offspring and their parents who completed the ASR or YSR, or ABCL or CBCL, respectively. Additionally, the SF-36 was filled out by 72 HD patients and their CAG-repeats and CAP scores were processed.

Instrumental caretaking (IC), emotional caretaking (EC), parent centered (PC), and parent monitoring (MO) in the offspring for both task 1 and task 2 were combined to create a composite caregiving code that encompasses many aspects of caregiving. The intercorrelations and Cronbach's alpha between the 8 codes are reported in Table 1. The average intercorrelation between the codes in task 1 and 2 is 0.41. Cronbach's alpha is 0.85.

Offspring characteristics were related to both their caregiving and their internalizing problems. Bivariate correlations were calculated to determine the relationships. The complete descriptive statistics and correlation matrix are reported in Table 2. Age is significantly positively correlated with the caregiving composite ($r = .40$, $p < .001$), supporting part of the third hypothesis. Age is also correlated with negatively correlated with internalizing problems in the offspring ($r = -.30$, $p < .05$), supporting part of the second hypothesis. Gender was also correlated caregiving composite, as shown in Table 3 with a p-value of .07. Lastly, we found that the caregiving composite is negatively correlated with internalizing problems ($r = -.28$, $p < .10$). This is the opposite of the first hypothesis that predicted that caretaking would be associated with an increase in internalizing problems.

Patient characteristics were also associated with caregiving. The descriptive statistics of the HD patient can be found in Table 2. Bivariate correlations were done comparing caregiving and child internalizing symptoms to patient CAP score, physical functioning, and emotional wellbeing. The complete correlation table is presented in Table 5. As predicted by hypotheses 2 and 3, patient health had an association with caregiving and internalizing problems. The complete correlation table can be found in Table 5. Caregiving was positively correlated with patient CAP score ($r = .32$, $p < .05$) and negatively correlated with physical functioning ($r = .39$, $p < .01$). This demonstrates that the condition of the patient is associated with the caregiving of their offspring. Child internalizing problems is negatively correlated with patient emotional well-being ($r = -.45$, $p < .01$).

To predict internalizing problems in offspring, patient and offspring characteristics were included in the regression model, presented in Table 6. In step one, SF-36 Emotional Well-Being was the only significant patient characteristic predictor ($\beta = -.41$, $p = .03$). The lower the patient's emotional well-being, the greater the child's internalizing problems. In step 2, child

demographics, age and gender, were included in the model. Child age approached significance (β=-.26, p=.16), with an increase in age predicting less internalizing problems. SF-36 Emotional Well-Being approached significance with the addition of the child demographic characteristics (r=-.39, p=.06). Within this model, the patient's emotional well-being is a stronger predictor of offspring internalizing symptom. This supports hypothesis 2; patient and offspring characteristics have an association with offspring internalizing symptoms.

The final regression analysis is presented in Table 7, predicting offspring caretaking from offspring and patient demographics. As in the first regression, patient characteristics were added in Step 1 as predictors. The patient CAP score was the only significant predictor in the group, with an increase in CAP score predicting an increase in child caretaking behaviors (β = .30, p = .05). In Step 2, offspring demographics were added to the model. Child age was found to be a significant predictor of caregiving (β = .31, p = .03), with an increase in age predicting an increase in caregiving. CAP score increased its significance as a predictor in Step 2 (β = .33, p = .03). Though they are very close, CAP score is a slightly better predictor than child age with p-values of p = .027 and p = .034, respectively. These findings of patient and offspring characteristics associated with caretaking behaviors support hypothesis 3.

Discussion

This study analyzed how the Huntington's Disease, an autosomal-dominant, neurodegenerative disorder, affects offspring of patients who are often faced with the task of caregiving their parent and processing their own risk of inheriting the disease. These children must assist with taking care of their parent significantly earlier than they would have otherwise, which may lead to an increase in internalizing symptoms. Offspring demographics and patient health were tested to determine their association with offspring internalizing symptoms and

caregiving behavior. A combination of observational, self-report, and objective measures was used within this study. The caregiving composite was composed of multiple observational codes, internalizing symptoms and patient health used self-report measures, and the CAP score was determined through silva testing. The combination of types of measures bolsters potential validity of the results of this study.

The first hypothesis stated that an increase in caretaking will be associated with an increase in reports of offspring internalizing symptoms. This was proved to be incorrect by the study. In fact, higher levels of caretaking behaviors were associated with reports of *lower* offspring internalizing symptoms. Those that displayed more caretaking behaviors during the task tended to report fewer internalizing symptoms before the study. This may be because taking care of one's parent decreases their internalizing symptoms, or those that have fewer internalizing symptoms tend to take on more of a caregiving role.

The second hypothesis stated that characteristics of the patient and the offspring will be associated with higher levels of offspring internalizing symptoms. This was found to be supported by bivariate correlations and the regression analysis. Offspring age was negatively correlated with internalizing symptoms, with older offspring reporting fewer internalizing symptoms than younger offspring. Patient emotional well-being, as self-reported by the SF-36, was positively correlated with offspring internalizing symptoms. Lower levels in patient emotional well-being was associated with higher levels of offspring internalizing symptoms. In the regression analysis, patient emotional well-being was the best predictor of offspring internalizing behavior and approached significance. This may be because the emotions of the patient impact the emotions of their offspring, or patients that generally have lower emotional well-being model internalizing symptoms that their children experience growing up. On the other

hand, the offspring's internalizing symptoms may impact their ability to emotionally support their parent and that leads to a decrease in the patient emotional well-being.

The third and final hypothesis stated that characteristics of the patient, including disease severity, would be associated with an increase in caretaking behaviors. Both bivariate correlations and the regression analysis supported this hypothesis. Age was significantly positively correlated with caretaking behaviors, with older offspring associated with more caregiving behaviors. Gender of offspring approached significance in its association with caregiving, with females displaying more caregiving behaviors than males. As for patient health, CAP score was positively correlated, and physical functioning was negatively correlated with offspring caregiving. The more severe the Huntington's Disease and the less the patient was able to function physically, the more caregiving behaviors the child displayed during the task. In the regression analysis, offspring age and CAP score were significantly positively correlated with caretaking. Older offspring take on more of a caregiving role potentially because they are more mature, independent, and capable of doing so to a greater extent than younger children. It may also be because the disease gets more severe over time, and many of the older offspring have older parents with more advanced Huntington's Disease, so there needs to be more caregiving on the part of the child. Children with parents with more severe Huntington's Disease may have to do more caregiving out of necessity because of the parent's condition.

There are several strengths of this study, including the variety of measures that were used. The caretaking composite was created by watching how the offspring interacted with their parents in two 10-minute conversations. This method allows for two coders to observe the interaction and determine their level of caregiving, as opposed to children reporting the types of caregiving that they do. This was compared to self-report measures, allowing the correlations to have a mixed-method design. The sample size of the study is another significant strength.

Huntington's Disease is not a common illness or clustered in a specific area, so recruitment can be challenging. Recruiting 86 dyads for the study made the results more meaningful and better able to get a scope of the differences within the population. In the future, even greater sample sizes should be used in order to detect differences and determine associations with greater power. There are follow-up studies that are ongoing aiming to have more participants within this population.

This study is cross-sectional, therefore there is no definitive causality or directionality that can be interpreted. In the future, even larger sample sizes and longitudinal measures should be used to determine which of the variables influence the others. Within this study, there was a limit to the implications of the findings that can be made, as there are only associations between the variables. There is no way to know if an increase in caregiving caused a decrease in internalizing problems; all that can be determined is that they are significantly associated with one another. However, this does not negate the importance of the results and the conclusions and implications that can be drawn from them.

This observational paradigm may not allow for all aspects of caregiving to be effectively displayed and therefore measured and accounted for. The daily caretaking that the offspring does outside of the task may not have been represented, or it may not have fit within the four codes that made up the composite. Because there was not a report measure, there was no way for the coder to know if it was not explicitly stated during the task. More instrumental or emotional caretaking may have been happening outside of the task and study. However, this composite does take into account multiple aspects of caregiving including centeredness and monitoring of the parent, so the definition and method are fairly robust.

These results have important implications for this population and those that work with Huntington's Disease. Offspring of Huntington's patients have a unique burden and

responsibility to their parent. For providers, there should be a greater understanding of the association of patient emotional well-being and offspring internalizing symptoms. Emotional caretaking of the patient is an essential factor to monitor, not just the physical symptoms of Huntington's Disease. Additionally, younger offspring may have a more difficult time processing the disease and its impact on their lives, so their needs and perspective should be attuned to. There also should be attention paid to the relationship between Huntington's Disease severity and the caregiving done by the offspring, as decreased physical functioning and increase in severity are associated with more caregiving. Older offspring also play a greater role in caregiving, and providers should acknowledge and support their place in managing the patient. Overall, this study gives a greater insight into the offspring of Huntington's Disease patients and their situation. Further studies should look into these results, especially focusing on internalizing symptoms and caregiving, to have a more detailed understanding of this population and allow for causal claims to create better support systems and interventions.

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Table 1
Patient and Offspring Demographic Descriptive Statistics

Variable	*n*	*M*	*SD*
Offspring Age	86	19.14	7.63
Offspring Gender.	86	.53	.50
Combined Caregiving	76	26.74	8.24
Internalizing Problems	61	54.80	11.77
Patient Age	79	45.45	9.03
Patient Gender	79	.58	.50
CAG Repeats	76	43.66	2.90
CAP Score	68	448.01	101.91
SF-36 Physical Functioning	68	61.03	28.98
SF-36 Emotional Well-Being	72	64.17	21.40

Note. For gender, 0= male, 1= female

Table 2
Descriptive Statistics and Correlations for IFIRS Codes for Task 1 and 2

Variable	*M*	*SD*	1	2	3	4	5	6	7
1. Child PC, Task 1	4.46	1.60	—						
2. Child MO, Task 1	4.28	1.70	.80**	—					
3. Child IC, Task 1	2.38	1.14	.35**	.42**	—				
4. Child EC, Task 1	1.31	0.81	.31*	.43**	.36**	—			
5. Child PC, Task 2	4.73	1.53	.61**	.62**	.17	.39**	—		
6. Child MO, Task 2	4.53	1.73	.54**	.61**	.15	.35**	.81**	—	
7. Child IC, Task 2	2.81	1.65	.29*	.32*	.37**	.15	.47**	.53*	—
8. Child EC, Task 2	2.44	1.48	.24	.33**	.09	.11	.63**	.57*	.36**

**=Correlation is significant at the 0.01 level (2-tailed)
*=Correlation is significant at the 0.05 level (2-tailed)

Table 3
Descriptive Statistics and Correlations of Offspring

Variable	*n*	*M*	*SD*	1	2	3
1. Child Age	86	19.14	7.63	—		
2. Combined Caregiving	76	26.74	8.24	.40**	—	
3. Internalizing Problems	61	54.80	11.77	-.30*	−.28^{+}	–

**=Correlation is significant at the 0.01 level (2-tailed)
*=Correlation is significant at the 0.05 level (2-tailed)
$^{+}$=Correlation is significant at the 0.1 level (2-tailed)

Table 4
Independent Samples T-Test of Caregiving and Gender

	Gender	*n*	*M*	*SD*	*SE*
Caregiving Composite	Male	27	24.96	7.72	1.49
	Female	34	28.15	8.48	1.45

	F	*Sig*	*t*	*df*	*One-sided p*	*Mean difference*	*SE*
Equal variance assumed	0.49	0.49	-1.51	59	0.07	-3.18	2.10
Equal variances not assumed			-1.53	57.83	0.07	-3.18	2.08

Table 5
Correlation of Patient Health and Offspring Behaviors

Variable	1	2	3	4	5
1. Child Internalizing	—				
2. Caregiving Composite	−.28+	—			
3. Patient CAP Score	-.05	.32*	—		
4. Patient Physical Functioning	-.15	-.39**	-.31*	—	
5. Patient Emotional Well-Being	-.45**	−.07	.06	.28*	—

**=Correlation is significant at the 0.01 level (2-tailed)
*=Correlation is significant at the 0.05 level (2-tailed)
+=Correlation is significant at the 0.1 level (2-tailed)

Table 6
Regression Analyses Predicting Offspring Internalizing from Patient Characteristics and Offspring Demographics

	Beta	*t*	*Sig (p)*
Step 1.			
Patient CAP Score	.-.04	-.21	.83
SF-36 Physical Functioning	-.01	.06	.95
SF-36 Emotional Well-Being	-.41	-2.22	.03
Step 2.			
Patient CAP Score	-.10	-.56	.58
SF-36 Physical Functioning	-.02	-.11	.92
SF-36 Emotional Well-Being	-.39	-2.00	.06
Child Age	-.26	-1.44	.16
Child Gender	.14	.73	.47

Dependent Variable = Offspring Internalizing
Characteristics

Table 7
Regression Analyses Predicting Offspring Caretaking from Offspring Demographics and Patient Health

	Beta	*t*	*Sig (p)*
Step 1.			
SF-36 Physical Functioning	-.21	-1.23	.20
SF-36 Emotional Well-Being	-.06	-.38	.71
CAP Score	.30	2.00	.05
Step 2.			
SF-36 Physical Functioning	-.04	-.22	..83
SF-36 Emotional Well-Being	.15	-.97	.33
CAP Score	.33	2.29	.03
Offspring Age	.31	2.20	.03
Offspring Gender	.20	1.39	.17

Dependent Variable = Offspring Caretaking

Appendix

Parent Monitoring (PO): This scale assesses the child's knowledge and information, as well as the extent to which the parent pursues information, concerning the parent's life and daily activities. It measures the degree to which a child knows what the parent is doing, where the parent is, and with whom. It assesses the child's awareness of the parent's daily life and routines, who the parent's friends are, and what his/her interests and activities might be.

Sensitive/Parent Centered (PC): This scale assesses the extent to which the parent's interactions toward the child are child-centered. The child displays an awareness of the parent's needs, moods, interests, and capabilities. He/she anticipates rather than merely complies with the parent's request and needs. Interactions with the parent are well timed and paced to the parent's behavior and mood. The childl's interactions appear to be "in sync" with those of the parent. If the parent initiates interaction, the child responds appropriately based on the parent's behavior and speech. The child paces activity to keep the parent engaged and interested but allows the parent to disengage if interest is lost. Attempts to engage and/or redirect the parent permit the parent as much choice, and autonomy as possible while enforcing necessary rules, regulations, and constraints.

Instrumental Caretaking (IC): This scale measures the extenet to which the child takes care of the parent or takes on tasks or responsibilities that may be age-inappropriate and typically considered parental roles. It includes taking on household responsibilities such as watching siblings or other family members, cleaning, doing dishes, preparing meals, etc or carrying out parental roles during the interaction (e.g., taking charge of the interaction, adjusting the parent's

clothing, or correcting misbehavior). At high levels, the child may seem very mature for his/her age.

Emotional Caretaking (EC): This scale measures the extent to which the child takes care of the emotional needs of the parent or takes on an emotional burden that *may,* especially at high levels, be age-inappropriate. At lower levels, the child may display knowledge of the parents' problems or difficulties (e.g., emotional symptoms, financial difficulties, martial probelsm, or interpersonal difficulties). At higher levels, the child may offer solutions for the parent's emotional problems or take responsibility for the parent's difficulties and may seem overly mature for his/her age.