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How Emerging Adults are Affected by Parental Chronic Illness: A Study of Psychosocial Functioning and Academic Achievement

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An honors thesis presented to the Department of Psychology, University at Albany, State University of New York in partial fulfillment of the requirements for graduation with Honors in Psychology and graduation from The Honors College.

Ashley May

Research Advisor: Julia M. Hormes, Ph.D
My Mom was diagnosed with Lupus in 2010. Lupus SLE is an incurable, degenerative autoimmune disease. It causes me to have daily anxieties that seem to be unique to me and other people who are in my position. I oftentimes find myself overwhelmed by feelings of worry and helplessness, suffering from lowered self-esteem, having trouble falling asleep, etc. I’d like to be able to help other people in my position and let them know that they’re not alone.
Abstract

Chronic illness is widespread and often affects parents, yet the impact of parental chronic illness on emerging adults has been largely ignored by research. The existing literature on the impact of chronic illness on family members suggests spousal and parental caregivers can suffer significant adverse psychological, social, cognitive, and physical consequences. This study was designed to examine the effects of parental chronic illness on children transitioning to adulthood. Participants were asked to complete several questionnaires, which quantified psychosocial and academic functioning of college students. Upon comparing those with parents with chronic illness to those without, we found that emerging adults with a parent with chronic illness have significantly higher levels of anxiety, stress, depression, and significantly lower levels of optimism, yet showed no statistically significant differences in academic performance. This suggests the need for interventions to prevent these adverse effects, and raises questions about causations.

Keywords: Chronic Illness, Emerging Adult, Psychosocial Functioning, Academic Achievement, Parental Illness
How Emerging Adults are Affected by Parental Chronic Illness: A Study of Psychosocial Functioning and Academic Achievement

Chronic illness reaps destruction for everyone within its radius. There have been several studies that have looked at the effect of a child’s chronic illness on other family members, but, only recently have researchers started to look at the effects of parental chronic illness on the child. Emerging adults have been studied even less; there is little to no literature about how parental chronic illness affects adolescents in the transition to adulthood. Parental chronic illness creates a unique situation for a family, because it often causes a role reversal in care-taking. The aim of this research was to characterize the effects of parental chronic illness on psychosocial and academic functioning in emerging adults. The ultimate goal of this line of work is to raise awareness of the impact of chronic illness on a traditionally understudied group, and to lay the groundwork for more effective prevention and intervention efforts targeting children and adolescents growing up with one or more parents affected by chronic physical and/or mental illness.

Introduction

Chronic diseases affect more than 40% of the total population in the United States (National Health Council, 2014). A review of the existing literature on the psychosocial impact of chronic illness on relatives and caregivers reveals a striking absence of research specifically focused on the study of children of chronically ill parents, and in particular on any long-term effects as these children transition into adulthood.

A growing body of research points to extensive psychosocial impairment in individuals caring for a partner. Spousal caregivers display elevated levels psychosocial distress, greater risk of illness, sleep problems, and risky behavior (Vitaliano et al., 2003). They also tend to worry
and ruminate more than typical spouses (Stenberg et al., 2009). Previous research has shown that wives caring for chronically ill husbands also exhibited increased hostility created by social isolation (DeRosier et al., 1992). Those caring for a family member showed higher levels of stress, depression, and decreased levels of well-being (Schulz et al., 2008). This population also showed lower levels of self-efficacy; these effects were moderated by the relationship to the person with chronic illness, as well as gender and age of the caregiver. Those whose self-efficacy was impacted the most were spouses, females, and older relatives (Pinquart and Sorensen, 2003). Other risk factors for adverse outcomes include low level of education and financial status, living with the spouse with the illness, a greater portion of day devoted to care-taking, isolation, and not having a choice in the caretaker role (Adelman et al., 2015). Once caregiving responsibilities were stopped, spouses seemed to regain their psychological health (Lavela and Ather, 2010).

Chronic illness affects not only adults and their partners, but also commonly impacts entire families. Parents of children with chronic illness are put in a unique situation where they, especially, must find a balance between being a disciplinarian and caretaker. They show much higher rates of parenting stress than the rest of the population (Cousino and Hazen, 2013). Parents of children with cancer show lower rates of psychological resilience, increased amounts of stress, and higher rates of binge drinking (Rosenberg et al., 2013). After diagnosis, these parents experience higher rates of marital distress, but they did not show higher divorce rates than other parents (Grootenhuis, 1997). Mothers of chronically ill children showed less confidence in their parenting capability (Hauenstein, 1990).

Siblings of chronic illness patients also show a number of impairments. In siblings, the type of illness as well as the gender of the sick child were shown to have the greatest correlation with the psychological impact that it has on the sibling; same-sex siblings seemed to face the
greatest risk (Ferarri, 1984). These impacts include higher rates of depression and anxiety, conflict with peers, and lower cognitive development (Sharpe, 2002). Siblings of chronically ill children are also at higher risk for exhibiting post-traumatic stress (Alderfer et al., 2003). Research has shown that no significant difference exists between the dysfunction of families with children with illness, and those with healthy children, but did find other slight differences in areas such as higher rates of parental treatment for anxiety and increased negative affect in mothers (Cadman et al., 1991).

These findings point to the importance of research in this field. Children of chronically physically or mentally ill parents remain a particularly understudied population, and are likely to be exposed to the above risk factors, as well as to a reversal of care-taking. Just recently, there has been some research that examined the effects of parental chronic illness on children, but it seems to be just the tip of the iceberg.

Recent studied found that adolescents with chronically ill parents, especially females, with high amounts of stress experience less parent-child interaction, and thus endorse weaker attachment to their parent (Seih et al., 2012). Adolescents of parents with chronic, severe illness show elevated signs of post-traumatic stress (Houck et al., 2006). Daughters that had mothers experiencing post-traumatic stress disorder (PTSD), were more likely to develop PTSD themselves (Boyer et al., 2002). They also have a significantly elevated incidence of internalizing problems, more caretaking-related responsibilities, and lower grade point averages (GPA, Sieh et al., 2013). Both children and adolescents show heightened symptoms of psychosocial maladjustment when the parent of the same gender was ill (Barkmann et al., 2007).

When it came to parents with cancer, more advanced stage and worse prognosis were predictors of elevated stress levels in children (Compas et al., 1996). In these children, problem
behaviors were also more intense in children of lower socioeconomic status and who were exposed to longer-lasting illness (Sieh, 2010). In cases of parental multiple sclerosis, social support was deemed to be a protective factor (Pakenham & Bursnall, 2006). Children of mothers who have HIV showed greater rates of depression and varying rates of anxiety (Forsyth et al., 1996). Overall, families who struggle with parental chronic illness show less cohesion and less passion about culture and religion (Peters & Esses, 1985).

**Aims and Hypotheses**

The aim of the present research was to examine the impact of parental chronic illness on emerging adults’ mental health, life orientation, social support, quality of life, self-esteem, and life satisfaction. As a secondary aim, we sought to examine potential differences in academic achievement between emerging adolescents with and without a chronically ill parent.

We hypothesized that emerging adults growing up with a chronically ill parent endorse greater psychosocial impairment, including lowered self-esteem, higher anxiety, and less overall happiness. Academic performance was hypothesized to be negatively impacted by these psychosocial challenges specifically in respondents with a chronically ill parent.

**Materials and Methods**

All methods were approved by the local Institutional Review Board. All respondents were informed of the nature and purpose of the study, and consented prior to participation. Participants took the survey either in groups of up to 15 participants at a time while seated at individual computer stations in a departmental computer lab, or individually using their personal computer at home.

**Participants**
A total of 231 individuals completed the study questionnaire. Respondents included 204 students at a State University at Albany who received research participation credit, and 27 individuals recruited from the community, using websites such as Facebook support groups and Reddit pages for chronic illness, who completed the survey without compensation.

Measures

Participants completed an online survey hosted on the secure web server SurveyMonkey. Respondents provided information about their demographics. These questions consisted of the following: age, gender, race, year in college, GPA, number of course credits currently being taken, number of major(s) and minor(s), expected amount of time to graduate, plans following graduation, and current living arrangements. Participants were asked questions about their parents, including marital status of parents, presence of one or more physical or mental chronic illnesses, age when parent was diagnosed, any caretaking activities respondents are engaged in, number of siblings, and household income.

Participants then completed the following widely used and well-validated self-report measures:

**Depression Anxiety Stress Scales (DASS-21).** The 21-item DASS-21 are a reliable measure to assess depression, anxiety, and stress. Respondents indicate how well items applied to them over the past week on a four-point Likert-type scale ranging from 0 = “Did not apply to me at all” to 3 = “Applied to me very much or most of the time.” The DASS-21 was included here due to prior research linking familial illness to elevated levels of depression, anxiety, and stress in caregivers (Lovibond & Lovibond, 1995).

**Life Orientation Test.** The Life Orientation Test is a ten-item measure of optimism versus pessimism. Items are scored on a four-point Likert scale from 0 = “strongly disagree” to 4
= “strongly agree” (Scheier et al., 1994). The Life Orientation Test was included here as a measure of level of positivity versus negativity in this population.

**Quality of Life.** Quality of Life was assessed via a visual analog scale ranging from 0 = “worst possible quality of life” to 100 = “best possible quality of life.” It was included in this study to determine if participants’ quality of life was impacted by the presence or absence of parental chronic illness (Boer at al., 2004).

**Rosenberg Self-Esteem Scale.** The Rosenberg Self-Esteem Scale is a ten-item measure of feelings toward oneself, rated using a four-point Likert scale ranging from “strongly agree” to “strongly disagree.” It was relevant to this study, because decreased self-esteem is a symptom of depression (Rosenberg, 1965).

**Satisfaction with Life Scale (SWLS).** The SWLS is a five-item questionnaire that measures overall life satisfaction on a 7-point Likert scale ranging from 1 = “strongly disagree” to 7 = “strongly agree.” We were interested in measuring this construct in the present study due to research that suggests that depression may interfere with satisfaction with life (Diener et al., 1985).

**Statistical Analyses**

Respondents with and without parents with a chronic illness were compared using chi square and independent samples t-tests, as well as multivariate analyses of variance for those measures containing multiple subscales.

**Results**

The sample of 231 respondents was made up of 57.3% females (n= 130), 42.3% males (n= 96), and 0.4% “other” (n= 1). The average age was 19.48 years old (SD = 2.11, range: 18–40). The respondents were 55.1% White (n= 125), 22.0% African-American or Black (n= 50),
15.0% Hispanic or Latino (n= 34), 12.3% Asian (n= 28), 0.4% American Indian or Alaskan
Native (n= 1), and 0.4% Native Hawaiian/Other Pacific Islander (n= 1), and 5.1% of participants
identified with multiple racial/ethnic categories (n= 12). Of the respondents, 50.2% were
Freshmen (n= 114), 21.1% were Sophomores (n= 48), 16.3% were Juniors (n=37), 10.6% were
Seniors (n= 24), and 1.8% were “other” (n= 4).

A majority (75.2%, n= 170) lived on campus when completing the survey. More than half
of respondents (60.8%, n= 138) reported that their parents were currently married and living
together. There were no significant differences between those with and without a parent with a
chronic illness in the likelihood that parents were married and living together at the time of
survey completion (p=.66), in the number of siblings (p=.84), or in household income (p=.07).

About one third of respondents (34.1%, n= 75) reported having one or more parents with
a chronic illness; 78.7% (n= 59) of these respondents were recruited through research pool, and
21.3% (n= 16) were recruited from the community. Among those with a parent with a chronic
illness, 60.0% of participants had a mother that was ill (n = 45), 29.3% had a father that was ill (n
= 22), and 10.7% had two ill parents (n = 8). Respondents were on average nine years old when
the parent was diagnosed (M = 9.28, SD = 8.23, range: 0-49). A significantly greater proportion
of respondents with a parent with a chronic illness were female (66.7.0%, n = 50) than male
[32.0%, n = 24, χ² = 6.13, p = .05, φ = .17). Respondents with a parent with a chronic illness
were on average significantly older than controls [M = 19.85 years, SD = 1.99 vs. M = 19.14
years, SD = 1.34; t (218) = 2.80, p = .002, d = .42].

Participants without parents with a chronic illness scored significantly higher on
measures of quality of life, satisfaction with life, and self-esteem (see Table 1 for descriptives
and statistics). Parental chronic illness had a significant multivariate main effect on combined
subscale scores of depression, anxiety, and stress \( F (3, 207) = 8.47, \) Wilk’s \( \lambda = .89, p < .001, \eta_p^2 = .11 \), with respondents with chronically ill parents reporting greater impairment on all three subscales (see Table 1). Parental chronic illness also has a significant effect on life orientation \( F (2, 216) = 5.90, \) Wilk’s \( \lambda = .95, p = .003, \eta_p^2 = .05 \), with those with sick parents reporting a less optimistic and more pessimistic outlook on their future, compared to controls (see Table 1).

There were no significant differences between groups on any measures of academic performance (see Table 2). Participants with and without chronically ill parents did not differ in self-reported GPA, number of credits (current semester), double/single major, minor(s), and years to graduate. There were no statistically significant differences in reported plans following graduation between the two groups \( \chi^2 = 5.24, p = .07, \varphi = .17 \), with 50.0% \( (n = 61) \) of respondents with healthy and 46.0% \( (n = 29) \) of respondents with sick parents reporting plans to seek employment, 43.4% \( (n = 53) \) and 54.0% \( (n = 34) \), respectively, wanting to continue on to graduate school, and 6.6% \( (n = 8) \) of emerging adolescents with healthy parents and none with one or more chronically ill parents indicated plans to travel or volunteer after graduation.

**Discussion**

In summary, the respondents in this research showed significant impairment in multiple domains of psychosocial functioning, including elevated depression, anxiety, stress, and a lack of optimism. At the same time, we found no evidence for significant group differences in any measures of academic performance. Our finding of substantially more psychosocial impairment in children of chronically ill parents was consistent with previous literature on spousal and parental caregivers. All three groups shared similarities, showing more depression and anxiety.

The fact that both groups studied here performed equally well academically, on the other hand, was unexpected. One would assume that respondents with chronically ill parents would do
less well in school as a result of the reported impairments in psychological well-being. It may be the case that those whose parents have chronic illness are working harder to keep up academically in the face of conflicting demands placed on their time and attention by the parental illness, and thus feel more stress, depression, and anxiety. Alternatively, they may be more inclined to put in extra effort to impress their ill parent and/or put themselves in a position to help provide for their family. The fact that they are more likely to live at home may play a role in it as well. It would make for interesting future research to examine these hypotheses and clarify the exact nature of the direction of associations between the variables examined here.

This study had certain limitations such as using self-report measures, which are always subject to reporter bias. It is possible that when reminded of their parents’ chronic illnesses, participants felt prodded to respond in a certain way, potentially over-endorsing impairment. Also, participants were recruited from research pool, which could add sampling biases to the mix. Research pool is most often used in Psychology 101 classes, and therefore may create a slant in the population in the direction of lower classmen.

It should also be noted that the chronic illness group contained several potentially meaningful subgroups. We recruited participants whose parents suffered from chronic mental and physical illness, as well as terminal or non-terminal illness. There may be interesting differences between these groups worth evaluating in greater depth in subsequent studies.

With the new knowledge added by the present study, it may be beneficial for students with chronically ill parents to be encouraged to take advantage of services offered at colleges to prevent these psychosocial impairments. With counseling resources available, these students may gain better psychological wellbeing. Some future directions for this line of work include looking into the possibility that maladaptive coping strategies such as substance abuse may contribute to
the impairments observed here. It is important that this research doesn’t stop here; with more knowledge come better strategies to help people caught in this position. Emerging adulthood is a critical point in development and a time in which individuals gain increasing independence, form romantic relationships, and enter professional careers. It is vital that emerging adults with chronically ill parents experience these milestones without interference from psychosocial deficits. Awareness and action are much needed.
References


Table 1

Psychosocial Functioning in Emerging Adolescents With and Without Chronically Ill Parent(s)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Parent(s) with chronic illness</th>
<th>No parent with chronic illness</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
</tr>
<tr>
<td>Quality of Life</td>
<td>72.33 (21.39)</td>
<td>81.22 (13.44)</td>
<td>$F (1, 214) = 13.96, p &lt; .001, \eta^2_p = .06$</td>
</tr>
<tr>
<td>Satisfaction with Life Scale</td>
<td>19.82 (7.60)</td>
<td>23.00 (6.16)</td>
<td>$F (1, 217) = 11.07, p = .001, \eta^2_p = .05$</td>
</tr>
<tr>
<td>Rosenberg Self-Esteem Scale</td>
<td>27.16 (6.24)</td>
<td>29.78 (4.94)</td>
<td>$F (1, 215) = 11.37, p = .001, \eta^2_p = .05$</td>
</tr>
<tr>
<td>Depression Anxiety Stress Scales (DASS-21)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>7.21 (6.34)</td>
<td>4.08 (4.24)</td>
<td>$F (1, 209) = 18.22, p &lt; .001, \eta^2_p = .08$</td>
</tr>
<tr>
<td>Variable</td>
<td>Mean 1 (SD 1)</td>
<td>Mean 2 (SD 2)</td>
<td>F (df, n)</td>
</tr>
<tr>
<td>----------------</td>
<td>---------------</td>
<td>---------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6.31 (4.63)</td>
<td>4.06 (3.93)</td>
<td>$F (1, 209) = 13.60$, $p &lt; .001$,</td>
</tr>
<tr>
<td>Stress</td>
<td>8.96 (4.93)</td>
<td>5.82 (4.16)</td>
<td>$F (1, 209) = 23.58$, $p &lt; .001$,</td>
</tr>
</tbody>
</table>

Life Orientation Test

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean 1 (SD 1)</th>
<th>Mean 2 (SD 2)</th>
<th>F (df, n)</th>
<th>p</th>
<th>$\eta_p^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism</td>
<td>6.51 (2.60)</td>
<td>7.64 (2.23)</td>
<td>$F (1, 217) = 11.36$, $p = .001$,</td>
<td></td>
<td>.05</td>
</tr>
<tr>
<td>Pessimism</td>
<td>6.47 (2.56)</td>
<td>5.72 (2.64)</td>
<td>$F (1, 217) = 4.00$, $p = .05$, $\eta_p^2 = .02$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2

Academic Performance in Emerging Adolescents With and Without Chronically Ill Parent(s)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Parent(s) with chronic illness</th>
<th>No parent with chronic illness</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPA</td>
<td>Ÿ² = 4.47, ( p = .48 ), ( \varphi = .14 )</td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \geq 4.1 )</td>
<td>-</td>
<td>0.7% (( n = 1 ))</td>
<td></td>
</tr>
<tr>
<td>3.6 – 4.0</td>
<td>18.7% (( n = 14 ))</td>
<td>19.3% (( n = 28 ))</td>
<td></td>
</tr>
<tr>
<td>3.1 – 3.5</td>
<td>33.3% (( n = 25 ))</td>
<td>33.8% (( n = 49 ))</td>
<td>( t (215) = .45, p = .65, d = .07 )</td>
</tr>
<tr>
<td>2.6 – 3.0</td>
<td>26.7% (( n = 20 ))</td>
<td>33.8% (( n = 49 ))</td>
<td></td>
</tr>
<tr>
<td>2.1 – 2.5</td>
<td>13.3% (( n = 10 ))</td>
<td>6.2% (( n = 9 ))</td>
<td></td>
</tr>
<tr>
<td>( \leq 2.0 )</td>
<td>8.0% (( n = 6 ))</td>
<td>6.2% (( n = 9 ))</td>
<td></td>
</tr>
</tbody>
</table>

Number of Credits (current semester) 
\( M = 14.59 \ (SD = 3.53) \) \( M = 14.38 \ (SD = 2.36) \)
### Double Major

<table>
<thead>
<tr>
<th></th>
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<th>No</th>
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<tbody>
<tr>
<td>Yes</td>
<td>15.1% (n = 11)</td>
<td>7.0% (n = 10)</td>
</tr>
<tr>
<td>No</td>
<td>84.9% (n = 62)</td>
<td>93.0% (n = 133)</td>
</tr>
</tbody>
</table>

$X^2 = 3.59, p = .09, \phi = .13$

### Minor

<table>
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<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Yes</td>
<td>50.0% (n = 36)</td>
<td>47.1% (n = 65)</td>
</tr>
<tr>
<td>No</td>
<td>50.0% (n = 36)</td>
<td>52.9% (n = 73)</td>
</tr>
</tbody>
</table>

$X^2 = .16, p = .77, \phi = .03$

### Years to Graduate

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;4 years</td>
<td>18.9% (n = 14)</td>
<td>18.3% (n = 26)</td>
</tr>
<tr>
<td>4 years</td>
<td>71.6% (n = 53)</td>
<td>75.4% (n = 107)</td>
</tr>
<tr>
<td>&gt;4 years</td>
<td>9.5% (n = 7)</td>
<td>6.3% (n = 9)</td>
</tr>
</tbody>
</table>

$X^2 = .74, p = .69, \phi = .06$