Material Hardship in Families with Children with Health Conditions: Implications for Practice

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Material hardship in families with children with health conditions: Implications for practice

Patricia Stoddard-Dare, LeaAnne DeRigne, Linda M. Quinn, Christopher Mallett

1. Introduction

Launched in 1964 by President Lyndon B. Johnson, the war on poverty is 50 years old this year (Lowery, 2014). While great strides have been made in creating and expanding the social safety net system, poverty is still a pervasive problem, especially for children. Over 20% of children live in households with incomes below the poverty line, exposing these families to material hardships such as an inability to pay household bills, food insecurity, and utility and phone disconnection (United States Census Bureau, 2013). Children with limiting health conditions are even more likely to live in poverty (28%) compared to children without limiting health conditions (Fujiura & Yamaki, 2000; Porterfield, 2002), and poverty status alone underestimates material deprivation experienced by families who have a child with a disabling health condition (Ghosh & Parish, 2013).

A bidirectional relationship exists between children with limiting health conditions and family hardship (Elwan, 1999; Emerson, 2007; Fujiura & Yamaki, 2000), in which poverty, through exposure to hazards (physical, psychosocial, nutritional), leads to disability, which in turn leads to financial hardship (Alexander & Korenrot, 1995; Ghosh & Parish, 2013; Pagnini & Reichman, 2000). This article explores the difference in material hardships (specifically struggling to pay household bills, experiencing utility and/or phone disconnection, food stamp participation) between families with children with limiting health conditions (defined as physical, learning, mental, or chronic health conditions that limits participation in the usual kinds of activities done by most children his/her age) and those with children without limiting health conditions.

2. Review of the literature

2.1. Direct and indirect costs

Over 20% of families who have a child with a health care condition report financial problems due to their child’s condition (Kuhlthau, Hill, Yucel, & Perrin, 2005). One reason for this is that health care conditions among children generate both direct and indirect costs for families (Chen & Newacheck, 2006; Contact a Family, 2012; Parish, Seltzer, Greenberg, & Floyd, 2004; Perrin, 2002). The direct costs include treatment, prescriptions, specialized therapies, and day care as well as adapting homes to accommodate disabilities (Emerson, 2007; Newacheck & Kim, 2005; Parish & Cloud, 2006). The direct costs include treatment, prescriptions, specialized therapies, and day care as well as adapting homes to accommodate disabilities (Emerson, 2007; Newacheck & Kim, 2005; Parish & Cloud, 2006). Research has found that the out of pocket expenses of parenting children with disabilities are two to three times higher than expenses associated with parenting children without disabilities (Parish & Cloud, 2006, U.S. Dept. of HHS, 2014). The indirect costs of parenting a child with a disability can be even more profound on family finances.
2.2. Parental employment

One important reason for increased poverty among families who have a child with a limiting health condition is the impact the disability has on parental employment. One fifth of working parents report that their caregiving responsibilities have led to loss of wages and income (Earle & Heyman, 2012). Research has found that parents of children with disabilities have lower levels of employment and are more likely to be employed in unskilled or semiskilled jobs compared to parents of typically developing children (Corman, Noonan, & Reichman, 2005; Kuhlthau & Perrin, 2001; Lawton, 1998a, 1998b; Porterfield, 2002; Tozer, 1999). Indeed, daily life can be very complicated for parents of children with limiting health conditions as they attempt to juggle employment and the responsibilities of caring for children, which often requires time away from work. Maintaining a job while simultaneously needing to be absent from work for doctor’s appointments is practically an impossible scenario for many caregivers. Consequently, parents often reduce work hours or give up employment entirely in order to provide needed care (DeRigne & Porterfield, 2010). One United Kingdom study found that only two percent of mothers with one severely disabled child work full time outside the home, this drops to one percent of mothers with two severely disabled children (Lawton, 1998a).

The decision to reduce work hours or quit working all together is likely a multi-faceted one that takes into account both child-level factors such as age and severity of condition as well as family-level factors such as educational level of the parent, the need for health insurance coverage, and marital status. Married mothers of children with disabilities are particularly likely to remain out of the paid labor force or to work only part time even as their children reach high school age; whereas, single mothers are more likely to work out of economic necessity (Porterfield, 2002). Unfortunately, the odds of work loss are higher among families with younger children and children with more limiting conditions (Lawton, 1998a, 1998b; Okumura, Van Cleave, Gnanasekaran, & Houtrow, 2009). This unfortunate contradiction, loss of work for families who have higher expenses, is of particular relevance since employment can be vital not just as a source of income but also of health insurance.

2.3. Insurance status

Health insurance status is an important variable which influences and is influenced by poverty and hardship in these families. Families with a child with a limiting health condition not only have lower house hold incomes, but also lower rates of employer based insurance (Heck & Makuc, 2000). This is important because researchers have found that insurance status and type of insurance, as well as type and severity of the condition, all impact the extent of financial out of pocket expenses (Newacheck, Inkelas, & Kim, 2004). For example, children with more severe conditions had higher out of pocket expenses (Bumbalo, Ustich, Ramcharran, & Schwalber, 2005), and children with mental health needs had greater expenses than children with other specialty service needs (Busch & Barry, 2009). Children with autism had the highest out of pocket expenses compared to those with mental health conditions (Busch & Barry, 2009). Bumbalo et al. (2005) found that children covered by public health insurance (Medicaid and the Children’s Health Insurance Program) had lower out of pocket expenses than children covered by private health insurance. Although public health insurance recipients incur lower out of pocket costs, this is not a preferable option since families’ incomes must fall below certain low to poverty income levels in order to qualify for Medicaid or SCHIP and then only certain family members are eligible for coverage (Center for Medicaid Services, 2013).

2.4. Food insecurity

Food insecurity (defined as limited or uncertain availability of nutritionally adequate and safe foods) is one of the key variables in analyzing family hardship. One out of every six households in the U.S. is food insecure with nearly a quarter (24.5%) of all children under the age of 6 living in food insecure households in 2011 (United States Department of Agriculture, 2012). Food insecurity can lead to more health problems, both under and overnutrition (obesity), hospitalizations, and develop mental delays in children (Hampton, 2007). Preliminary research suggests that households with children with limiting conditions are at a higher risk of food insecurity compared to households with children without limiting health conditions (Parish, Rose, Grinstein Weiss, Richman, & Andrews, 2008). A survey of UK families found that in families with a disabled child do not have the food they require (Contact a Family, 2012).

2.5. Family composition

Many variables have been discussed as influencing the relationship between having a child with a disabling health condition and material hardship. Households led by a single mother are at a much greater risk for poverty (Brady & Burroway, 2012) and those households are also more likely to have a child with a disability (Fujiiura & Yamaki, 2000) making gender, marital status, and number of adults and children in the household all important variables to control. Traditional factors which influence poverty such as parent’s educational attainment and race are also important to consider.

Another important consideration is the cumulative effect of having more than one child with a limiting health condition. Three percent of U.S. households have more than one child with a disabling health condition and although the research on these individuals is limited, it suggests that material hardship is more pronounced in these house holds (Ghosh & Parish, 2013). One study of United Kingdom households (Lawton, 1998a, 1998b; Tozer, 1999) found that compared to families with only one disabled child, families with more than one disabled child are less likely to use respite care, less likely to have family nearby or receive help from family, and are less likely to have a single worker that coordinates their care. Furthermore, these parents are more likely to be sick or disabled themselves.

2.6. Material hardship

The literature regarding material hardship among families with children with limiting health conditions is limited. One of the first studies analyzed data from the 1994 National Health Interview Study (Hogan, Msall, Rogers, & Avery, 1997) and examined functional limitations as a function of socioeconomic factors (living in households with below poverty income, residing in a mobile home, and not having a telephone). The researchers found that children living in households with below poverty level incomes were 40% more likely to be functionally limited than those not in poverty. Children who reside in a mobile home were 35% more likely to be functionally limited than those living in apartments or houses and children living without a telephone are 24% more likely to be functionally limited. Our research is interested in explaining material hardship as a function of limiting conditions instead, and obviously using more current data.

Parish et al. (2008), using data collected in 2002 from the National Survey of America’s Families, found that households with a child with a disabling health condition are more likely to be food insecure in the previous year, unable to pay rent in the prior year, and more likely to have their phone disconnected than were households with children without disabling conditions. Our study examines many of the relationships evaluated by Parish et al. (2008) but does so using more current data on families collected during and after the severe economic
downtown and also includes a never previously analyzed dependent variable, utility disconnection.

One UK study which examined material hardship experienced by United Kingdom families with a disabled child found that one in six of those households is going without food, one in five is going without heat, nearly a quarter do not have necessary specialized equipment their disabled child needs, nearly one third have taken out a loan to pay for typical household expenses such as food, and one in five is at risk for court action for falling behind on their utility bills (Contact a Family, 2012).

One final study of note analyzed material hardship in families with children with disabilities (Ghosh & Parish, 2013). This study analyzed the financial well being of families with multiple children with disabilities but again the data is pre economic downturn and it did not find any significant differences in the households with less than 200% of federal poverty level incomes. The only significant findings were in the households with higher incomes. In those families having multiple children with disabilities increased the likelihood of material hardship, which may document the importance of expanding safety net systems currently available to low income households to include households with higher incomes if there is a child member with a limiting health condition (Ghosh & Parish). Given the limited research on this topic, this line of inquiry merits additional analysis utilizing more recent data.

3. Summary of the literature and justification for the study

Given their vulnerability, it is important to understand the odds of experiencing material hardship in families that have a child member with a limiting health condition. As such, this study measures the odds of being unable to pay household bills, the odds of experiencing utility disconnection within the last 12 months, the odds of experiencing phone disconnection within the last 12 months, and the odds of food stamp participation between families that do and do not have a child with a limiting health condition. We hypothesize that families with children with limiting conditions will be more likely to experience material hardship than families with children who do not have limiting conditions. We will also compare families with only one child with a limiting condition to families with multiple children with limiting conditions hypothesizing that these families are even more likely to experience material hardship.

The research is valuable in that it analyzes specific hardship variables rather than simply analyzing income, poverty level, or out of pocket medical costs. It is also valuable because it adds to the very limited body of existing research which investigates these hardships in families that have a child with a limiting health condition and also in families with more than one child with a disabling health condition. It also adds currency, in that all previous studies analyzed data before the severe economic downturn and our research utilizes data collected between 2008 and 2011, which provides a more contemporary understanding of the relationship between these variables. A final uniqueness is its inclusion of the dependent variable “utility disconnection” which was not included in similar studies.

4. Methods

4.1. Data collection and sampling

Cross-sectional data from the third wave of a ten year data collection initiative designed to study how individual, family, and community level factors impact the well being of children and their families were used. The full Making Connections data set contains 6221 variables collected during 28,262 interviews. Seven high poverty US communities were selected for inclusion in this study. These represented communities, which do not follow specific geographic boundaries, are located in the metropolitan areas of Des Moines, IA; Indianapolis, IN; Denver, CO; San Antonio, TX; Seattle, WA; Providence, RI; and Louisville, KY.

Area probability sampling via a master list of USPS postal addresses was used to generate a list of potential respondents within those seven neighborhoods. In all, N = 4315 households chose to participate, which provides a response rate of 75 87% among the seven sites. Of those, N = 2375 households did not have children, and were removed from the analysis, leaving a total of N = 1940 household for the present analysis.

Between 2008 and 2011, trained interviewers from the National Opinion Research Center used a paper and pencil survey to record answers during an in person or telephone interviews with study participants. Surveys were available in English, Spanish, and other prevalent languages in the selected areas. One adult respondent from each household was selected to report about themselves, any spouse or partner living in the house, and all children between the ages of 0 and 17 living in the household. Ethics approval was granted for the original collection of data as well as the analysis of secondary data.

4.2. Measurement

Four dependent variables which assess material hardship were measured dichotomously (yes/no). The first, inability to pay bills, was measured by asking the adult respondent, “During the last 12 months was there a time when you/you and your family were not able to pay your mortgage, rent or utility bills?” To measure the dependent variable, utility disconnection, adult respondents were asked, “Have your utilities been cutoff in the last 12 months due to non payment of bills?” To measure phone disconnection, adult respondents were asked, “Has your phone been cutoff in the last 12 months due to non payment of bills?” To measure food stamp participation, adult respondents were asked, “In the past 12 months, have you (or anyone in your household) received food stamps?”

Ten explanatory variables were measured including adult respondent’s age in years, adult respondent’s sex, adult respondent’s race (Non White/White), and adult respondent’s employment status (yes/no). The presence of a spouse or partner living in the home was measured by asking, “Do you have a spouse or partner that lives in this house hold?” (yes/no). Number of adults who reside in the household, and number of children ages 0 17 who reside in the household were both coded as quantitative variables. Adult respondent’s highest level of education was used as a proxy for income and was measured using a 9 category variable measured ordinaly from “eighth grade or less” to “graduate degree.” Given the large number of missing cases for the income variable (N = 527, 27%) a decision was made not to impute the missing data and instead use the education variable which only had 26 missing values. Substantiating its fit as a proxy, for observations where both variables were available, the mean and median total household income increased as education category increased, confirming a positive relationship between education and total household income (p < .0001, r = .38). The strength of this relationship is high considering education is an ordinal variable and income is a quantitative variable.

One potential limitation of using education as a proxy for income is that income’s relationship to education varies by race and gender (Braveman, Cubbin, Egerter, et al., 2005). This potential limitation was controlled for in this study by adding both race and gender as control variables as noted above. Finally, two independent variables were measured which assess the presence of a child with a limiting health condition in the family. The first question, measured dichotomously, asks adult respondents, “Has a health professional ever told you that your child has a physical, learning, mental, or chronic health condition that limits his or her participation in the usual kinds of activities done by most children his or her age or limits his or her ability to do regular school work?” (yes/no). For use in a second model, this question was also coded ordinaly to assesses if there are multiple children between the ages of 0 and 17 living in the home who have a limiting health conditions.
condition (0 = no children with a disabling health condition; 1 = only one child with a disabling health condition; 2 = two or more children with a disabling health condition).

4.3. Data analysis

With the exception of changing the dependent variable, identical analyses were conducted to assess the odds of A) being un able to pay household bills, B) experiencing utility disconnection, C) experiencing phone disconnection, and D) receiving food stamps between families that do and do not have a child with a limiting health condition.

For all four research hypotheses (A–D), the same control demographics variables were examined including respondent characteristics of age, gender, race, and employment status. Additionally, household level control characteristics included whether or not a spouse or partner is present in the household, the number of adults and children in the household, and highest level of education attained (as a proxy for income). Finally there are two potential definitions for the independent variable. In what are labeled models 1A–D, an indicator variable of whether or not there is at least one child with a limiting condition in the family is used. And in models 2A–D, an ordinal variable with three levels which assesses how many children with a disabling health condition live in the family is used (0 = no children, 1 = one child, 2 = more than one child with a limiting condition). These were analyzed separately because models 1A–D help us determine if any children in the household have a limiting health condition whereas, models 2A–D assess the cumulative effect of having multiple children with a limiting condition in the household.

The first stage of data analysis involved examining descriptive statistics and bivariate relationships between each control or independent variable and the dependent variables. For categorical variables, a chi square analysis was performed and overall percentages, percentages for each level of the dependent variable, and the p value for the relationship were calculated. For quantitative control variables, a Kruskal Wallis two sample median test was performed. The overall medians and the median per level of the dependent variables, as well as the p value were calculated (see Tables 1 and 2; findings are labeled “A,” “B,” “C,” or “D” to correspond to each dependent variable).

The next stage of data analysis was to construct a multivariable logistic regression using the binary variable of any child with a limiting condition in the model. These are labeled “models 1A–D” with “A–D” corresponding to the four research questions, and are presented in Table 3.

<table>
<thead>
<tr>
<th>Demographics</th>
<th>(A) Pay bills</th>
<th>(B) Utilities cutoff in the last year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unable</td>
<td>Able</td>
</tr>
<tr>
<td>n</td>
<td>Column %</td>
<td>n</td>
</tr>
<tr>
<td>Dependent variable*</td>
<td>1940</td>
<td>742</td>
</tr>
<tr>
<td>Respondent sex</td>
<td>0.0060</td>
<td>0.9306</td>
</tr>
<tr>
<td>Male</td>
<td>303</td>
<td>15.6%</td>
</tr>
<tr>
<td>Female</td>
<td>1635</td>
<td>84.4%</td>
</tr>
<tr>
<td>Missing information</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Respondent race</td>
<td>0.5541</td>
<td>0.4881</td>
</tr>
<tr>
<td>Non-White</td>
<td>1345</td>
<td>70.5%</td>
</tr>
<tr>
<td>White</td>
<td>562</td>
<td>29.5%</td>
</tr>
<tr>
<td>Missing information</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Is respondent employed?</td>
<td>0.0007</td>
<td>0.0404</td>
</tr>
<tr>
<td>No</td>
<td>876</td>
<td>46.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>1061</td>
<td>55.8%</td>
</tr>
<tr>
<td>Missing information</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Is respondent’s spouse or partner present</td>
<td>0.4315</td>
<td>0.3361</td>
</tr>
<tr>
<td>No</td>
<td>1680</td>
<td>88.3%</td>
</tr>
<tr>
<td>Yes</td>
<td>222</td>
<td>11.7%</td>
</tr>
<tr>
<td>Missing information</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Respondent education</td>
<td>0.0001</td>
<td>0.0055</td>
</tr>
<tr>
<td>Eighth grade or less</td>
<td>207</td>
<td>10.8%</td>
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<tr>
<td>Beyond eighth but not HS graduate</td>
<td>417</td>
<td>21.8%</td>
</tr>
<tr>
<td>GED</td>
<td>150</td>
<td>7.8%</td>
</tr>
<tr>
<td>High school graduation</td>
<td>460</td>
<td>24.0%</td>
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<tr>
<td>Trade or vocational school</td>
<td>99</td>
<td>5.2%</td>
</tr>
<tr>
<td>One to three years of college</td>
<td>424</td>
<td>22.2%</td>
</tr>
<tr>
<td>Graduated four year college</td>
<td>94</td>
<td>4.9%</td>
</tr>
<tr>
<td>Some graduate education</td>
<td>17</td>
<td>0.9%</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>46</td>
<td>2.4%</td>
</tr>
<tr>
<td>Missing information</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Any child with limiting condition</td>
<td>0.0001</td>
<td>0.0298</td>
</tr>
<tr>
<td>No</td>
<td>1473</td>
<td>75.9%</td>
</tr>
<tr>
<td>Yes</td>
<td>467</td>
<td>24.1%</td>
</tr>
<tr>
<td>Number of children with limiting condition</td>
<td>0.0001</td>
<td>0.0928</td>
</tr>
<tr>
<td>0</td>
<td>1473</td>
<td>75.9%</td>
</tr>
<tr>
<td>1</td>
<td>371</td>
<td>19.1%</td>
</tr>
<tr>
<td>2+</td>
<td>96</td>
<td>5.0%</td>
</tr>
</tbody>
</table>

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* = Not provided due to the disclosive nature of the information as required by Annie E. Casey Foundation.

* The number of missing values for each of the dependent variable is as follows: pay the bills n = 6 and utility cutoff n = 9.
The final part of the analysis was to construct a multivariable logistic regression using the ordinal variable of whether there was zero, one, or more than one child within the household with a limiting condition in the model. These are labeled “models 2A-D” in the results and are also presented in Table 3. Again, “A D” corresponds to the four research questions.

5. Results

5.1. Inability to pay household bills (A)

5.1.1. Inability to pay bills bivariate

In the bivariate analyses, sex, employment, education, number of adults and number of children in the household were all significantly related to not being able to pay the bills (Table 1). Having a child with a disabling health condition in the family was significantly related to not being able to pay bills, this was also true when considering the number of children in the household with a disabling health condition.

5.1.2. Inability to pay bills, model 1

Model 1 uses 1834 households after listwise deletion of missing data. In multivariable model 1, if the household had any child with a limiting condition, the odds were 1.41 times more likely that they would be unable to pay the bills than if the household had no children with a limiting condition after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults and number of children in the household (Table 3). And, for households where the respondent is unemployed, the odds are higher that they will be unable to pay the bills than if employed. If there are fewer adults in the household or more children, the odds are less likely the household can pay the bills.

5.1.3. Inability to pay bills, model 2

Model 2 uses 1834 households after listwise deletion of missing data. In multivariable model 2, the number of children in the household with a limiting condition is an ordinal variable (0, 1, or more than 1 child with a limiting health condition). For households with more than one child with a limiting condition the odds are 1.25 times higher than 1 child with a limiting health condition. For households with more than one child with a limiting condition the odds are 1.25 times higher than if the household had no children with a limiting condition after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults and number of children in the household (Table 3). And, for households where the respondent is unemployed, the odds are higher that they will be unable to pay the bills than if employed. If there are fewer adults in the household or more children, the odds are less likely the household can pay the bills.
unable to pay their mortgage, rent, or utility bills than if the household had no children with a limiting condition (CI 1.09 2.20). Each of these odds is after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults in the household, and number of children in the household. Similar to the first model (1A), for households where the respondent is unemployed, the odds are higher that they will be unable to pay the bills than if employed. If there are fewer adults in the household or more children, the odds are less likely they can pay the bills.

5.2. Utility disconnection (B)

5.2.1. Utility disconnection bivariate

In the bivariate analyses, employment, education, and number of children in the household were all significantly related to having utilities cutoff in the last 12 months. Having a child with a disabling health condition in the family was significantly related to utilities being cutoff in the last 12 months, this was not true when assessing the number of children with a disabling health condition in the household (Table 1).

5.2.2. Utility disconnection, model 1

Multivariable model 1 uses 1835 households after listwise deletion of missing data. In this model, only one variable was significant. With every additional child in the household there was an increased odds of utility disconnection (Table 3). The independent variable, any child with a limiting condition after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults in the household, and number of children in the household (Table 3). Adult respondents who were younger, non White, unemployed, and less educated were more likely to have their phone disconnected. And, households with fewer adults or more children had increased odds of experiencing phone disconnection.

5.3. Phone disconnection

5.3.1. Phone disconnection bivariate findings

In the bivariate analyses, sex, race, employment, education, age, number of adults in the household, and number of children in the household were all significantly related to having phone service cutoff in the last 12 months (Table 2). Having a child with a disabling health condition in the family is significantly related to having phone service cutoff in the last 12 months, this was also true when considering the number of children in the household in a disabling health condition.

5.3.2. Phone disconnection, model 1

Multivariable model 1 uses 1835 households after listwise deletion of missing data. In this model, if the household had any child with a limiting condition, the odds were 1.33 times more likely that they have a phone disconnected than if the household had no children with limiting condition after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults in the household, and number of children in the household (Table 3). Adult respondents who were younger, non White, unemployed, and less educated were more likely to have their phone disconnected. And, households with fewer adults or more children had increased odds of experiencing phone disconnection.

5.3.3. Phone disconnection, model 2

Model 2 uses 1835 households after listwise deletion of missing data. In multivariable model 2, the number of children in the household with a limiting condition is an ordinal variable (0, 1, or more than 1 child with a limiting health condition). For households with only one child with a limiting condition the odds are 1.27 times higher that they will have their phone disconnected than a household without a child with a limiting condition (Table 3). For households with more than one child with a limiting condition the odds are 1.27 times higher.
that they will have their phone disconnected than a household with only one child with a limiting condition. When there is more than one child with a limiting condition, the odds are 1.60 times higher that they will have their phone disconnected than if the household had no children with a limiting condition (CI 1.09 2.34). Each of these odds is after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults and number of children in the household. Those that are younger, non White, and unemployed were more likely to have their phone disconnected. Also, households with fewer adults are more likely to experience phone disconnection.

5.4. Food stamp participation

5.4.1. Food stamp participation bivariate findings

In the bivariate analyses, sex, race, employment, spouse, education, age, number of adults in the household, and number of children in the household were all significantly related to receiving food stamps in the last 12 months (Table 2). Having a child with a disabling health condition in the family is significantly related to receiving food stamps in the last 12 months, this was also true when considering the number of children in a household with a disabling health condition.

5.4.2. Food stamp participation, model 1

Multivariable model 1D uses 1826 households after listwise deletion of missing data. In this model, after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults in the household and number of children in the household (Table 3), whether or not the household has a child with a limiting health condition is not significant in predicting receipt of food stamps. Respondents that are younger, female, non White, unemployed, less educated, and live in the households with fewer adults, and more children all have larger odds of receiving food stamps.

5.4.3. Food stamp participation, model 2

Model 2D uses 1826 households after listwise deletion of missing data. In multivariable model 2D, the number of children in the household with a limiting condition is an ordinal variable (0, 1, or more than 1 child with a limiting health condition). For households with only one child with a limiting condition the odds are 1.23 times higher that they will receive food stamps compared to a household without a child with a limiting condition (Table 3). For households with more than one child with a limiting condition the odds are 1.23 times higher that they will receive food stamps than a household with only one child with a limiting condition. When there is more than one child with a limiting condition, the odds are 1.51 times higher that they will receive food stamps than if the household had no children with a limiting condition (CI 1.01 2.23). Each of these odds is calculated after removing the effects of respondents’ age, sex, race, employment, spouse, education, number of adults in the household and number of children in the household. Just as in model 1D, respondents who were younger, female, non White, unemployed, less educated, and lived in a household with fewer adults and more children all have larger odds of receiving food stamps.

6. Discussion

This study found in the multivariable models that having a child in the household with a limiting health condition increased the odds the household would be unable to pay bills, and have their phone service disconnected. It did not increase the odds of having utilities cutoff, or receiving food stamps in the last 12 months. This study also found that the number of children in a household with a limiting health condition increased the odds of being unable to pay bills, the odds of having a phone disconnected, and the odds of receiving food stamps. Again, it did not increase the odds of utility disconnection.

6.1. Implications for social work practice

Broadly speaking, these findings add to the body of evidence which indicates that families with children with limiting health conditions are more likely to experience material hardship. As discussed previously, the relationship between these variables is bidirectional – material hardships can impair healthy development, caring for a sick family member can compromise adult’s ability to work and earn money, which makes them vulnerable to continued material hardship.

An implication of this research is the need to interrupt this negative feedback loop. One specific goal is to reduce material hardship in families with a child with a limiting health condition. Policy and clinical interventions proposed below to interrupt this negative feedback loop include direct assessment of material hardship and referral to the appropriate safety net program, care coordination via a “medical home,” expansion of Individual Development Account (IDA) Accounts to include savings for medical bills, expanded health care programs for children, and expansion of employer based short term sick leave programs.

6.1.1. Safety net programs and policies

In our sample, 46.7% of households with at least one child member with a limiting health condition were unable to pay their mortgage, rent, or utility bills. There are a number of programs available to families that struggle financially and have difficulties keeping up with their monthly expenses and bills. First, children with disabilities may qualify for health insurance and cash assistance from either Social Security Disability (pay roll tax funded federal insurance program for retirees and disabled adults and children) or Supplemental Security Income (cash stipend program for low income disabled or retired individuals funded by general revenue) programs. Referring families to the Social Security office to apply for cash benefits and Medicaid (health insurance for low income individuals) coverage may result in increased monthly income and decrease health care costs for these families. These funds can help families stretch precious dollars so that they can pay their household bills.

In our sample, 31.9% of families who have at least one child with a limiting health condition, and 38.5% of families who have two or more children with a limiting health condition had their phone cutoff in the last year. To support families who have had their phone disconnected, the Lifeline Program for Low Income Consumers, supported by the Federal Communications Commission and available in all states, provides discounts on pre paid wireless service plans and landline services. This is an important resource for families who have a child with a limiting health condition as they may need to both reach, and be reached by doctors and service providers, and contact their employers when a child’s illness prevents them from attending work. Families eligible must have an income below 135% of the poverty guidelines (Federal Communications Commission, 2014).

Although only significant in the bivariate model, in our sample, 15.2% of families who had a child with a limiting health condition had their utilities cutoff in the past year which has practical significance. To protect against utility disconnection, families that struggle with paying their monthly energy bills may be eligible for the Low Income Home Energy Assistance Program (LI HEP). Families eligible for assistance have incomes below 150% of the poverty guidelines, though some state eligibility criteria varies. This program provides federally funded assistance in managing costs associated with home energy bills, energy crises, and energy related minor home repair (U.S. Department of Health and Human Services, 2014). It is also of importance to note that although specific policies vary by state, unlike for phone service, a utility company is mandated to undergo a certain process before disconnecting utilities which includes notifying the household of payment delinquency, attempting to work out a payment plan, and determining if there is a household member with a medical condition that requires utility service in order to remain medically stable (such
as a ventilator} (Zuckerman, Sandel, Smith, & Lawton, 2004). These protections may be one reason why the odds of utility disconnections are not higher in families who have a child or children with a limiting health condition in our sample.

In our sample, 58.9% of families who have at least one child member with a limiting health condition, and 70.8% of families who have two or more child members with a limiting health condition received food stamps in the previous year. Given this high percentage of families in need, families who have a child member with a limiting health condition should routinely be assessed for food insecurity, and when appropriate, referrals should be made to federal and local programs to assist families who need food. The federal government’s largest food and nutrition assistance programs include the Supplemental Nutrition Assistance Program (SNAP; Food Stamps); the National School Lunch Program (free or reduced price meals at schools); the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC; nutritional assistance for pregnant women and their young children); the School Breakfast Program (served at public schools); and the Child and Adult Care Food Program (meals served at day care centers) (Oliveira, 2014). For all of these programs, only a percentage of those eligible choose to participate which highlights the importance of education and referral (Dion & Pavetti, 2000).

The largest program is the SNAP, formerly the Food Stamp Program, which provides monthly stipends for food to families who qualify. The states are responsible for the funds distribution, in the form of an electronic benefit transfer (ATM or debit card), but the eligibility requirements are set by the United States Agriculture Department. Eligibility normally requires households to have less than $2000 in countable resources, gross monthly income below 130% of the federal poverty guidelines (with net income less than 100%), and the provision of household members’ Social Security numbers (United States Department of Agriculture, 2012). SNAP benefits are received by over 46 million people (15% of the population), over a 60% increase from 2008 (Hoefer & Curry, 2012). Unfortunately, over 4 million of these recipients will have their benefits decreased (or eliminated) by approximately $90/month in 2014. This is one of the largest cuts in this food security program in history (CLASP, 2014). Also, many households in need are not eligible to receive benefits, such as noncitizens (Coleman Jensen, Nord, & Singh, 2013). Other local private programs such as food pantries (which provide free grocery items for recipients to prepare at home), soup kitchens (which serve prepared meals), and Backpack Programs for kids (which provide food for school age children to consume at home on the weekends) are not only important for families that are not eligible for federally funded assistance programs, but also help fill the gap in the need for families who do receive federal benefits such as SNAP, but remain unable to feed their families a sufficient amount of nutritious food for an entire month (Cotugna & Forbes, 2007).

All of these programs may be vital for families with children with limiting health conditions. Indeed, a recent study has found that safety net programs cut poverty nearly in half (Center on Budget and Policy Priorities, 2014a, 2014b). Beyond awareness of the programs, service providers must assess and refer needy families. When children are seen in doctor’s offices, school settings, and mental health counseling centers, clinicians need to be screening and referring families with needs to federal and local community service programs that may be able to assist them. Becoming knowledgeable about federal policies, and getting connected to local programs that may provide assistance are keys to stabilizing families with health conditions.

6.1.2. Care coordination in a medical home

Another intervention that may be helpful in interrupting the negative feedback loop is for a child to receive coordinated medical care in a “medical home.” Indeed, several studies have found that the way a child receives medical treatment influences parental employment (DeRigne & Porterfield, 2010; Okumura et al., 2009; Turchi et al., 2009). When children are treated in a medical home (having a usual source of care, family centered care, receiving care coordination, and receipt of needed referrals) a parent’s risk of cutting work hours is reduced by 51% and the risk of stopping work altogether is cut by 64% (DeRigne & Porterfield, 2010). Coordinated care in a medical home often provides needed assistance to parents in managing complex treatment plans and referrals which, in turn affords them a better opportunity to maintain employment and thus support their fragile families. Access to a social worker in health care settings can be especially helpful to parents in making sure they are connected to all needed services. Indeed, social workers have a demonstrated expertise in managing complex health and social service situations and are thus an important partner in health care settings (Bachman & Comeau, 2010).

6.1.3. Expansion of IDA account programs

Another way to potentially interrupt the negative feedback loop between having a child with a limiting health condition and material hardships is to expand Individual Development Asset (IDA) Account programs to allow families to save for health care costs. IDAs assist families in saving money by matching savings and by disregarding the balances in calculations of eligibility for federal social programs. Traditionally, the money saved in these accounts can only be applied to very specific expenditures which support employment, such as paying for education or training, buying a house or vehicle, or starting a small business. Participants typically receive financial literacy training while in the program as well. Research has found that IDAs promote household stability, decrease intergenerational poverty transfer and increase health and satisfaction among adults in the household (Center on Social Development, 2014). Having an IDA account could be beneficial in stabilizing families with children with limiting health conditions. Utilizing IDAs for health care costs could allow families to better plan and pay for the added direct costs associated with having a child with a special health care need.

6.1.4. Expanded health care coverage for children

Families with children with limiting or chronic health conditions require health care coverage to meet important medical needs but to also keep family health care costs lower. Families without health insurance carry the financial burden for all care necessary for their children, often a debilitating fiscal situation. Families with sufficient health care coverage are often able to meet their child’s basic medical needs and not face fiscal peril (Park & Solomon, 2014). The expansion of health care coverage to the low income and working poor population (as well as others) in the United States through The Patient Protection and Affordable Care Act is designed in part to contain or lower family health care expenses (Morene, 2013). Less money spent on health care expenses can result in lower material hardship.

7. Limitations

One limitation to this study is the generalizability of the findings. Although households were selected randomly from within the study neighborhoods, the seven metropolitan areas themselves were selected in a nonrandom fashion and focused on high poverty areas. Another limitation is our inability to use income as an explanatory variable. Direct measurement of that variable could have strengthened the analysis. Since secondary data was used for this project, several variables that would have been desirable to include were not available for use. Future research would benefit from including variables such as severity and type of health condition, health insurance status, type of health insurance, and participation in specific safety net programs. Worth noting, caution should be used if trying to make generalizations about food insecurity in this sample since food stamp participation underestimates the material hardship of food insecurity. Indeed, only 58% of U.S. households who are food insecure participate in the three largest federal food and nutrition programs (Coleman Jensen et al., 2013). Finally, the 12 month time frame covered by the dependent variables presents
two limitations. First, over-dimensioning recall may be a factor which limits internal validity of the results. A second limitation is that the 12 month time frame will likely underestimate the long term prevalence of these hardships.

8. Conclusions

This research demonstrates that the odds of experiencing specific material hardships do not favor families with a child with a limiting health condition, or families with more than one child with a limiting health condition. Specifically, families with a child with a limiting health condition are more likely to be unable to pay their bills and have their phone disconnected. Similarly, households with more than one child with a limiting health condition are even more likely to be unable to pay their bills and have their phone disconnected. They are also more likely to receive food stamps. Interventions that may assist these families include referral to social safety net programs, receiving care in medical home setting, use of an IDA account for medical expenses, and expanded health insurance coverage. Future research should evaluate the outcomes of expanded use of these types of interventions in families who have a child or children with a limiting health condition.

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