



Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma

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ABSTRACT

Objective: Parents of individuals with developmental disorders or mental health problems often provide life-long care and support to their children, which negatively affects their health in part due to chronic stress. This study aimed to examine the experience of stigma as a source of chronic stress among parents of individuals with developmental disorders or mental health problems and the effect of stigma on parental health outcomes.

Method: Using data from the Survey of Midlife in the United States (MIDUS 2 and 3), we constructed a sample for a longitudinal analysis including 128 parents of individuals with developmental disorders (e.g., autism, cerebral palsy, epilepsy, Down syndrome, intellectual disabilities, brain injury, ADD/ADHD) or mental health problems (e.g., bipolar disorder, schizophrenia, major depression) and 2256 parents whose children were nondisabled.

Results: Parents who had children with developmental disorders or mental health problems prior to the beginning of the study (i.e., at MIDUS 1) reported higher levels of stigma related to embarrassment/shame and daily discrimination than parents of nondisabled individuals ten years later at MIDUS 2, which in turn were associated with poorer parental health outcomes (poorer self-rated health and a greater number of chronic conditions) nearly a decade after that at MIDUS 3.

Conclusions: The findings suggest that the stigma associated with parenting a child with disabilities may be one mechanism that places such parents at risk for poor health. Efforts to alleviate the stigma associated with developmental disorders or mental health problems may have beneficial effects on health of parents of individuals with such conditions.

1. Introduction

In the U.S., approximately 1 in 6 children have developmental disabilities, and 4.6% of adults have serious mental health problems (Boyle et al., 2011; SAMHSA, 2012). Parents whose sons or daughters have developmental disorders or serious mental health problems face life-long challenges as they care for and support their children. Because a majority of individuals with disabilities are unmarried, parents often provide support to their children with disabilities even after the children reach adulthood (Kessler et al., 1998; Wolfe et al., 2014). An analysis of U.S. national data indicated that 53% of adults with developmental disorders and 29% of adults with mental health problems live with their parents (Ha et al., 2008). The challenges of providing long-term support to children with disabilities take a toll on the health and well-being of parents. Compared to parents of nondisabled individuals, these parents face a greater risk of mental and physical health problems

and cognitive decline (Barker et al., 2012; Olsson and Hwang, 2008; Seltzer et al., 2009, 2011; Song et al., 2016). The chronic stress related to the child's behavior problems is a major determinant of poor parental health. According to Pearlin's (1989) caregiver stress model, these behavior problems often give rise to secondary stressors including stigmatizing interactions for family members. Although stigma is a source of chronic stress experienced by families of persons with disabilities, its effect on the health of these parents has rarely been studied. The current study examines whether stigma contributes to the health disadvantage experienced by parents of individuals with developmental disorders or mental health problems. Using three waves of longitudinal data drawn from a nationally representative sample [the Survey of Midlife in the United States; MIDUS 1 (1995-96), MIDUS 2 (2004-06) and MIDUS 3 (2013-14)], associations between stigma and health are examined among parents with and without children with developmental disorders or mental health problems.

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1.1. Stigma

Link and Phelan (2001) defined stigma in terms of the co-occurrence of its components consisting of labeling, stereotyping, separation, emotional responses, status loss, and discrimination. A large number of first-person qualitative accounts from individuals with disabilities recount their experiences with stigma; they report being made to feel not as smart as others (LeCroy and Holschuh, 2012), receiving poor treatment or service at restaurants (Hyland, 1991; Power, 2008), being treated in a disrespectful and degrading manner, and not being taken seriously (Unzicker, 1989). Individuals who have disabilities are vulnerable to daily acts of discriminatory treatment that continue throughout their lives (Moore et al., 2011; Werner, 2015). A study utilizing a nationally representative Canadian sample showed that individuals who had an emotional, psychological, or psychiatric condition were three times more likely to perceive having been discriminated against than individuals without such conditions (Kassam et al., 2012). A study that analyzed data from more than 1800 patients with a mental illness from multiple states in the U.S. found that more than half of the participants (52.4%) had experienced stigma in the form of discrimination and nearly three-fourths (73%) attributed the discrimination to their psychiatric disabilities (Corrigan et al., 2003). One study of perceived discrimination among individuals with mild to moderate intellectual disabilities showed that about half of these individuals reported that people talked down to them, made them feel embarrassed, or spoke in ways that made them angry (Ali et al., 2016).

Not only do individuals with disabilities experience high levels of stigma, but also their family members are also affected (e.g., Birenbaum, 1992; Goffman, 1963; Mak and Cheung, 2008). This process is known as ‘courtesy stigma.’ Goffman, in his seminal book, described how family members faced devaluation and discrimination because they were “obliged to share some of the discredit of the stigmatized person to whom they are related” (Goffman, 1963, p. 30). Family members (especially parents) of individuals with a disability are exposed to much higher levels of stigma than their counterparts without family members having such conditions (Baxter and Cummins, 1992; Chou et al., 2009; Corrigan et al., 2006; Green, 2004; Kassam et al., 2012; Koro-Ljungberg and Bussing, 2009; Krupchanka et al., 2018; Mak and Cheung, 2008; Yang et al., 2007), although the experience and effects of this stigma vary across individuals (Birenbaum, 1992; Hinshaw, 2007; Larson and Corrigan, 2008).

Courtesy stigma may result from the child’s behavior problems and symptoms that parents find embarrassing and shaming or cause parents to avoid social encounters that may give rise to such feelings (Kinner et al., 2016). One study found that family shame was 40 times more prevalent in families of persons with mental illness compared to families of individuals with cancer (Ohaeri and Fido, 2001). First-person accounts of families of individuals with disabilities often recount experiences in which their child’s behavior caused them embarrassment in public settings (e.g., Gray, 2002; Van der Sanden et al., 2015). Research on stigma finds that families often feel labeled by the public as “bad parents” for their child’s symptoms and problematic behaviors (Karnieli-Miller et al., 2013; Van der Sanden et al., 2015). Parents of individuals with disabilities suffer from other societal stereotypes when a family member has a disability. As a result, parents of children with disabilities may be targets themselves of discrimination, including being treated with less respect than others, receiving poorer service in stores and restaurants, or feeling criticized or insulted.

1.2. Effects of stigma on mental and physical health

The research on the impact of stigma underscores consistent negative associations between stigma and mental and physical health (Link and Phelan, 2006). Greater exposure to discrimination is associated with higher levels of overall mental health problems, burn-out, daily mood problems, anxiety, depressive symptoms, psychological distress,

and lower life satisfaction and psychological well-being (Clark et al., 1999; Paradies, 2006; Pascoe and Richman, 2009; Sutin et al., 2015; Williams et al., 1997, 2003). In addition, stigma has been conceptualized as a chronic stressor that takes a long-term toll on physical health (Hsaio et al., 2018; Pascoe and Richman, 2009, for a review). Research regarding the association between discrimination and physical health indicates that greater exposure to discrimination has generally been linked to poorer self-rated health, more chronic health conditions and cardiovascular health problems, dysregulated hypothalamic–pituitary–adrenal (HPA) axis function, and immune dysfunction (Clark et al., 1999; Friedman et al., 2009; Pascoe and Richman, 2009; Sutin et al., 2015; Williams et al., 1997; Williams et al., 2003).

In sum, research has found: (1) poorer health profiles among parents of individuals with disabilities relative to parents of individuals without disabilities, partly due to chronic stress (e.g., Seltzer et al., 2009, 2011); (2) increased vulnerability to courtesy stigma among parents of individuals with disabilities (e.g., Ali et al., 2012); and (3) the adverse effects of stigma on health in general (e.g., Hsaio et al., 2018; Link and Phelan, 2006). However, a search of the literature found no prior research on the impact of stigma on the physical health of parents of individuals with disabilities. Indeed, only a few studies have examined the effects of courtesy stigma on parents who have a child with a disability, and these studies have focused primarily on psychological well-being outcomes, namely distress and burden (Chou et al., 2009; Green, 2004; Mak and Kwok, 2010). Given the prevalence of disabilities in the U.S. population and the increasing lifespans of both individuals with disabilities and their parents, understanding the health effects of stigma may have significant implications for public health.

In the current study, we hypothesized that relative to parents of nondisabled individuals, parents of individuals with disabilities would experience higher levels of stigma in the form of feeling embarrassed or shame by their child or being targets of acts of discrimination. In turn, the experience of these forms of stigma would lead to poorer physical health profiles (poorer self-rated health and more chronic conditions) over time. We focus on physical health but not mental health mainly to minimize the potential confounding of mental health measures and the stigma experience.

2. Method

2.1. Data and sample

We use data from the MIDUS study, a longitudinal survey of a national probability sample of non-institutionalized, English-speaking adults who were age 25 to 74 in 1995–1996 (MIDUS 1, $n = 7108$). They were studied again at age 35–84 in 2004–2006 (MIDUS 2, $n = 4963$), and at age 43–94 in 2013–2014 (MIDUS 3, $n = 3294$). The retention rates were 75% between MIDUS 1 and MIDUS 2 and 77% between MIDUS 2 and MIDUS 3 (adjusted for mortality) (Radler and Ryff, 2010). Data on the disability status of the respondents’ children was first collected at MIDUS 2.

We analyzed longitudinal data from MIDUS 2 and MIDUS 3 to examine the associations between parenting status, stigma, and physical health outcomes over time. Specifically, the analytic sample included MIDUS 2 and MIDUS 3 respondents whose son or daughter had developmental disorders or mental health problems. The sample was further restricted to respondents whose child had an onset of the conditions prior to MIDUS 1 to capture parents who had been exposed to courtesy stigma for a substantial period of time and thus likely to experience health effects.

The analytic sample consisted of two groups. The first included parents who had children with developmental disorders (e.g., autism, cerebral palsy, epilepsy, Down syndrome, intellectual disabilities, brain injury, ADD/ADHD) or a long-term serious mental health problem (e.g., depression, bipolar disorder, or schizophrenia) with onset prior to the MIDUS 1 survey. The comparison group consisted of parents whose

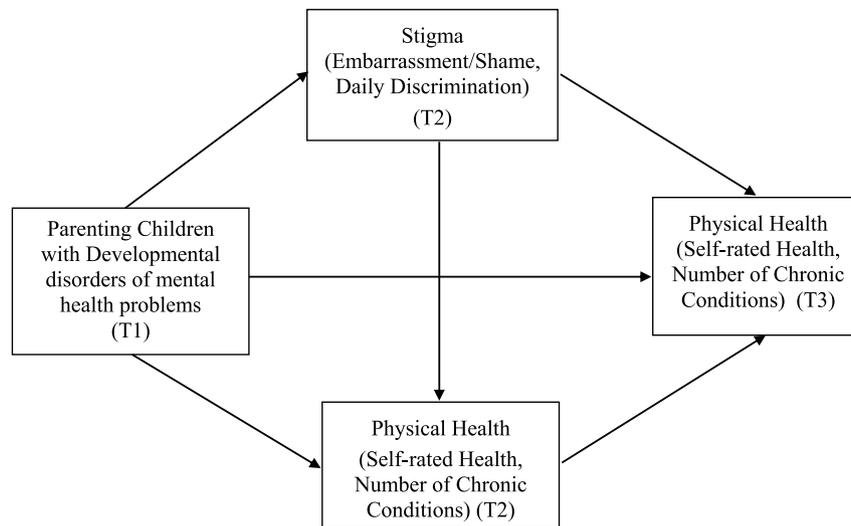


Fig. 1. Conceptual model (T1 = MIDUS 1, T2 = MIDUS 2, T3 = MIDUS3).

children did not have developmental disorders or mental health problems. The analytic sample consisted of 128 parents of individuals with disabilities (76 parents of individuals with developmental disorders and 52 parents of individuals with mental health problems) and 2256 comparison group parents (age of parents at MIDUS 2: Mean = 55.8, $SD = 11.2$; age of the individuals with disabilities at MIDUS 2: Mean = 32.8, $SD = 11.1$). “Disability/disabilities” indicates both *developmental disorders* and *mental health problems* throughout this article.

2.2. Measures

Stigma. We used two measures of stigma: embarrassment and shame and the experience of daily discrimination.

Embarrassment/shame. Embarrassment/shame was measured by the parents’ response to the following: “Problems with my children have caused me shame and embarrassment at times” (1 = not true at all, 2 = a little bit true, 3 = moderately true, 4 = extremely true).

Daily discrimination. Daily discrimination was assessed by respondents’ answers to questions developed by Williams et al. (1997), which asked how often on a day-to-day basis the respondent experienced each of the following nine types of discrimination: “You are treated with less courtesy than other people,” “You are treated with less respect than other people,” “You receive poorer service than other people at restaurants or stores,” “People act as if they think you are not smart,” “People act as if they are afraid of you,” “People act as if they think you are dishonest,” “People act as if they think you are not as good as they are,” “You are called names or insulted,” and “You are threatened or harassed” (1 = Often, 2 = Sometimes, 3 = Rarely, 4 = Never). Items were reverse-coded so that higher scores indicate a higher level of perceived daily discrimination. The scale is constructed by calculating the sum of the values of the items ($\alpha = .92$ at MIDUS 2 and 0.91 at MIDUS 3). The correlation between the two measures of stigma (embarrassment/shame and daily discrimination) was only 0.10, indicating that the two measures were tapping distinctly different components of stigma.

Health. We used two measures of health: self-rated health and number of chronic conditions.

Self-rated health. Self-rated health was assessed by a single question asking, “In general, would you say your physical health is excellent, very good, good, fair, or poor?” The response was coded so that a higher score indicated better physical health (1 = poor to 5 = excellent).

Number of chronic conditions. Number of chronic conditions was assessed by counting how many physical health conditions the

respondent had experienced or been treated for in the past 12 months among 17 listed items: asthma/bronchitis/emphysema, other lung problems, sciatica, persistent skin trouble, hay fever, recurring stomach trouble, urinary or bladder problems, being constipated most of the time, gall bladder trouble, persistent foot trouble, lupus or other autoimmune disorders, persistent trouble with gums or mouth, persistent trouble with teeth, chronic sleep problems, stroke, hernia or rupture, piles, or hemorrhoids (yes or no for each) (0–17).

Covariates. Several variables shown to be associated with physical health outcomes were included in the analyses as controls: age, gender, race, and education. Because older age and lower education are associated with poorer health profiles (e.g., Adler et al., 2008), they were controlled in all analyses. Research has found that gender is also a significant predictor of health, with patterns that are described by the “gender and health paradox,” which states that, relative to men, women are generally in poorer health and experience greater declines in physical health and increases in morbidity as they age, although they tend to live longer than men (Luy and Minagawa, 2014). Thus, the gender of the respondents was controlled in all analyses. Disparities in health between various racial groups also have been consistently reported in the literature (e.g., Williams and Mohamed, 2009); thus we controlled the race of the respondents in the analyses. We identified the race of the respondents based on their self-reported racial origins (white, black and/or African American, Native American or Alaska Native/Eskimo, Asian, Native Hawaiian or Pacific Islanders, other) and whether they reported being of Hispanic descent. The respondents who self-identified as white and not being of Hispanic descent were coded 1 and 0 otherwise.

2.3. Analysis plan

Fig. 1 portrays the hypothesized model fitted to the data. For the examination of the hypothesis, which posits longitudinal associations between parenting children with disabilities, the experience of stigma (embarrassment/shame and daily discrimination), and parents’ physical health (self-rated health and number of chronic conditions), the SPSS macro of conditional process analysis (Hayes, 2013) was implemented to examine mediation effects, with controls for age, gender, race, and education. The proportion of respondents with missing data on analytic variables ranged from none to 4% across waves and variables. Multiple imputation using Stata 15 was performed to estimate missing values. The analytic results with listwise approach for the missing values and those with imputed values did not differ substantially; the latter are presented in this article.

Table 1
Descriptive statistics of analytic sample.

| | Parents of Children with Disabilities | Comparison Parents |
|------------------------------------|---------------------------------------|--------------------------|
| | Mean (SD) | Mean (SD) |
| Embarrassment/Shame (T2) | 1.7 (0.9) | 1.3 (0.6)*** |
| Daily discrimination (T2) | 13.3 (4.6) | 12.6 (4.3) ⁺ |
| Self-rated health (T2) | 3.5 (1.0) | 3.7 (0.9)** |
| Self-rated health (T3) | 3.1 (1.2) | 3.5 (1.0)*** |
| Number of conditions (T2) | 3.3 (3.2) | 2.2 (2.2)*** |
| Number of conditions (T3) | 4.4 (4.5) | 3.1 (3.0)*** |
| Age (T2) | 59.7 (10.5) | 56.5 (11.1)** |
| Education (T2) | 14.2 (2.8) | 14.5 (2.6) ^{ns} |
| Women, % | 68.8 | 55.8** |
| Non-Hispanic white, % ^a | 88.3 | 91.4 ^{ns} |
| n | 128 | 2256 |

Note. T2 = MIDUS 2, T3 = MIDUS 3. Disabilities = Developmental disorders or mental health problems. *** $p \leq .001$; ** $p \leq .01$; * $p \leq .05$; + $p \leq .10$. ns = not significant.

^a Non-Hispanic white vs. other races (e.g., African American, Native American or Alaska native, Asian, Native Hawaiian or Pacific Islander).

3. Results

3.1. Descriptive data

Table 1 presents the descriptive statistics for the analytic sample. Parents whose children had developmental disorders or mental health problems were older than parents in the comparison group. There were no significant differences between parents who had children with disabilities and parents of unaffected children with respect to education and race, but women were more likely to disclose that their child has a disability than men, consistent with other surveys (e.g., Seltzer et al., 2004).

The level of perceived daily discrimination at MIDUS 2 was higher in parents of individuals with disabilities than the comparison parents whose children were nondisabled, at a trend level. The level of embarrassment and shame at MIDUS 2 was significantly higher in parents of individuals with disabilities than the comparison parents whose children were nondisabled. Health outcomes were significantly different between the parents of individuals with disabilities and their peers without children with disabilities, indicating that parents of individuals with disabilities had poorer health profiles than their counterparts (lower levels of self-rated health and more chronic health conditions at both MIDUS 2 and MIDUS 3). The two health outcomes were significantly correlated ($r = -0.394$, $p < .001$ at MIDUS 2, $r = -0.432$, $p < .001$ at MIDUS 3).

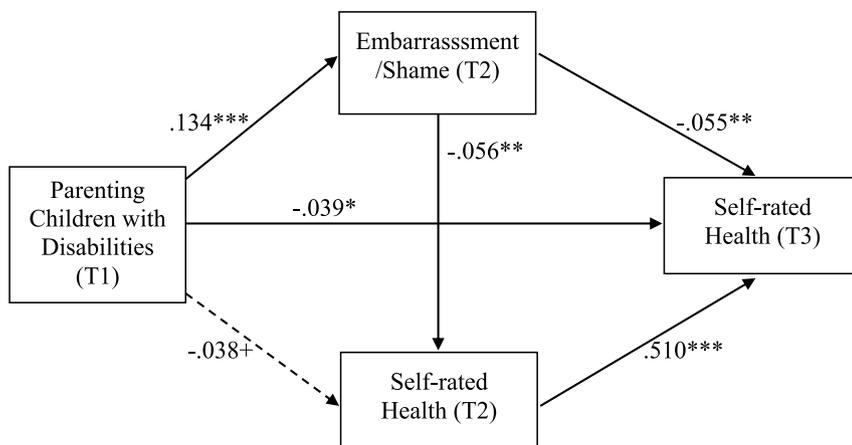


Fig. 2. Embarrassment/Shame Mediating Longitudinal Association between Parenting Children with Disabilities and Self-rated Health (** $p \leq .001$; * $p \leq .01$; * $p \leq .05$; + $p \leq .10$. Values are based on z-scores. Models adjust for age, gender, race, and education. T1 = MIDUS 1, T2 = MIDUS 2, T3 = MIDUS 3. Disabilities = Developmental disorders or mental health problems).

3.2. Longitudinal effects of stigma on physical health

We examined the longitudinal effect of parenting status and the experience of embarrassment/shame (Fig. 2) and daily discrimination (Fig. 3) on parents' self-rated health. Parenting children with disabilities had a significant impact on self-rated health at both MIDUS 2 and MIDUS 3 via the indirect effect of embarrassment/shame and daily discrimination (significant at both MIDUS 2 and MIDUS 3), as well as the direct effect of parental status on self-rated health (marginally significant at MIDUS 2 and significant at MIDUS 3). Specifically, parents whose children had developmental disorders or mental health problems reported a higher level of embarrassment/shame and daily discrimination at MIDUS 2; this factor, in turn, was significantly associated with poorer self-rated health nearly 10 years later at MIDUS 3. Also, a higher level of embarrassment/shame and daily discrimination at MIDUS 2 was significantly associated with poorer self-rated health at MIDUS 2, which was related to poorer self-rated health at MIDUS 3. In addition, parenting children with disabilities at MIDUS 1 was a significant predictor of self-rated health at MIDUS 3 directly. Tables 2 and 3 provide summary statistics of indirect effects that are presented in Figs. 2 and 3.

The models presented in Figs. 2 and 3 adjust for age, gender, race, and education of parents. Of these control variables, parents' education and gender were significant predictors of embarrassment/shame; mothers and parents who had less education reported higher levels of embarrassment/shame than their counterparts (see Online Supplemental Tables for the full results). Even after controlling for these covariates and intervening variables, parenting a child with a disability had a direct effect on self-rated health with parents of individuals with disabilities reporting poorer self-rated health than parents in the comparison group.

Next, we examined the longitudinal effect of parenting status and experience of embarrassment/shame and daily discrimination on parents' number of chronic conditions. The overall findings were similar to those reported above for self-rated health, although there were two differences. First, the direct effect of parenting children with disabilities at MIDUS 1 was not a significant predictor of the number of conditions at MIDUS 3. Second, the mediation effect of embarrassment/shame at MIDUS 2 on the association between parenting children with disabilities at MIDUS 1 and the number of conditions at MIDUS 3 was not significant, possibly due to limited statistical power. Otherwise, the two sets of results were convergent.

4. Discussion

The current study examined whether the experience of stigma contributes to our understanding of the health disadvantage experienced by parents of individuals with developmental disorders or mental health problems. The results from the longitudinal analysis showed that

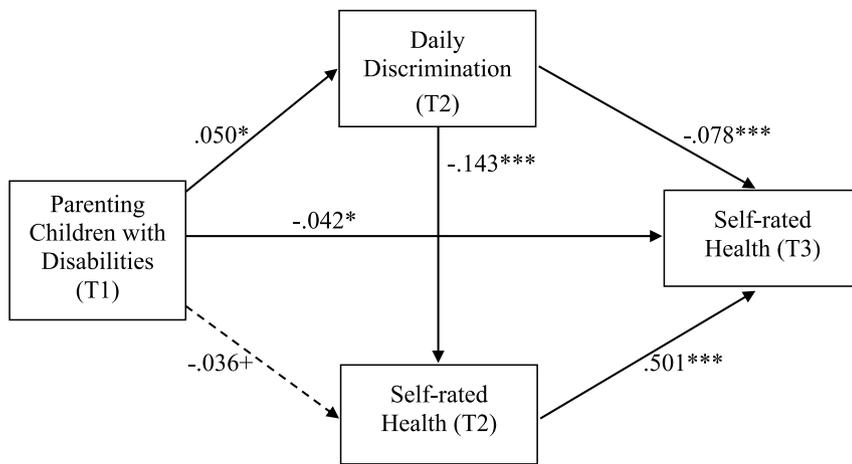


Fig. 3. Perceived Daily Discrimination Mediating Longitudinal Association between Parenting Children with Disabilities and Self-rated Health (** $p \leq .01$; * $p \leq .05$; + $p \leq .10$). Values are based on z-scores. Models adjust for age, gender, race, and education. T1 = MIDUS 1, T2 = MIDUS 2, T3 = MIDUS 3. Disabilities = Developmental disorders or mental health problems).

Table 2
Indirect effects of parenting children with disabilities on self-rated health with mediation of embarrassment/shame.

| | Effect | SE (Boot) | 95% CI | |
|--|--------|-----------|--------|-------|
| | | | Lower | Upper |
| NN parenting (T1) → Embarrassment/shame (T2) → Self-rated health (T3) | -.007 | .003 | -.015 | -.003 |
| NN parenting (T1) → Embarrassment/shame (T2) → Self-rated health (T2) → Self-rated health (T3) | -.004 | .002 | -.008 | -.001 |
| NN parenting (T1) → Self-rated health (T2) → Self-rated health (T3) | -.019 | .012 | -.045 | .004 |
| Total Indirect Effect | -.031 | .013 | -.056 | -.007 |

Note. Values are based on z-scores. Models adjust for age, gender, race, and education. Bias-corrected bootstrap 95% confidence intervals are presented (5000 Bootstrap Samples).

NN parenting = parenting children with disabilities. T1 = MIDUS 1, T2 = MIDUS 2, T3 = MIDUS 3. SE = Standard error, CI = Confidence interval. Disabilities = Developmental disorders or mental health problems.

parents of individuals with disabilities experienced higher levels of stigma (embarrassment/shame and discrimination) than parents of nondisabled children, and that higher levels of stigma were linked to poorer health outcomes at MIDUS 2 and MIDUS 3 (self-rated health and number of chronic conditions). In total, this process unfolded over a 20-year period in the lives of parents of individuals with disabilities.

Table 3
Indirect effects of parenting children with disabilities on self-rated health with mediation of daily discrimination.

| | Effect | SE (Boot) | 95% CI | |
|---|--------|-----------|--------|-------|
| | | | Lower | Upper |
| NN parenting (T1) → Daily Discrimination (T2) → Self-rated Health (T3) | -.004 | .002 | -.009 | -.001 |
| NN parenting (T1) → Daily Discrimination (T2) → Self-rated Health (T2) → Self-rated Health (T3) | -.004 | .002 | -.008 | -.001 |
| NN parenting (T1) → Self-rated Health (T2) → Self-rated Health (T3) | -.018 | .012 | -.042 | .004 |
| Total Indirect Effect | -.026 | .013 | -.051 | -.002 |

Note. Values are based on z-scores. Models adjust for age, gender, race, and education. Bias-Corrected Bootstrap 95% Confidence Intervals are presented (5000 Bootstrap Samples).

NN parenting = parenting children with disabilities. T1 = MIDUS 1, T2 = MIDUS 2, T3 = MIDUS 3. SE = Standard error, CI = Confidence interval. Disabilities = Developmental disorders or mental health problems.

Past research has shown that parents whose children have disabilities are at increased risk of mental and physical health problems, including higher levels of depressive symptoms, higher body mass index, musculoskeletal and cardiovascular conditions, and activity limitations, as well as accelerated cognitive decline (especially with age) (Barker et al., 2012; Olsson and Hwang, 2008; Seltzer et al., 2009, 2011; Song et al., 2016; Yamaki et al., 2009). The chronic stress associated with parenting individuals with disabilities has been shown to contribute to the health disadvantage experienced by these parents (Seltzer et al., 2011; Yamaki et al., 2009). The results of the current longitudinal study deepen our understanding of how having a child with disabilities may lead to elevated health problems in their parents. Our findings suggest that the adverse health effects of parenting individuals who have developmental disorders or mental health problems are at least partially attributable to the experience of higher levels of stigma among these parents. It is possible that stigma increases the risk of health decline not only at the time of the child's diagnosis but also after a prolonged period of parenting via changes in life style, health behaviors, and physiological responses to stresses (Pascoe and Richman, 2009). Efforts to reduce the stigma of disabilities may have positive effects not only for individuals with disabilities, but also have rippling effects throughout the family. Stigma might be best viewed as a major public health problem, and stigma-reducing efforts may narrow health disparities and decrease public health care costs over time.

In addition, the concepts of cumulative advantage/disadvantage (CAD) suggest that the adverse impacts of stigma might contribute to more pronounced health disadvantages in older parents of children with disabilities than in younger parents of children with disabilities. CAD is defined as “the systemic tendency for interindividual divergence in a given characteristic (e.g., money, health, or status)” especially with the passage of time (Dannefer, 2003, p. 327). Thus, health disparities between parents who had children with disabilities and their peers without children with such conditions might widen as parents get older, the duration of parental caregiving is extended, and, consequently, potential exposure to chronic stress due to the child's condition is prolonged, as previous studies have evidenced (e.g., Seltzer et al., 2011). Exposure to stigma and the subsequent detrimental health impacts might exacerbate the health disadvantages in older parents of children with disabilities relative to their younger counterparts. This potential outcome warrants a focus on the vulnerability of older parents of children with disabilities to stigma experiences and their subsequent health outcomes.

4.1. Limitations and strengths

Limitations of this study should be acknowledged. First, because we used secondary data from MIDUS, we did not have detailed information

about certain characteristics of the children with disabilities (e.g., severity or visibility of conditions) that could be related to parents' experience of stigma. Prior research suggest that courtesy stigma may be the direct result of the child's behavior problems and symptoms (Kinner et al., 2016). We were unable to examine this pathway in our analysis because measures of the child's behavior problems and symptoms were not collected as part of the MIDUS study. The current study also did not consider potential genetic influences on the health processes of parents, which would be particularly salient for certain inherited conditions such as Fragile X syndrome.

Second, the measures of stigma used in the current study did not assess parents' stigma specifically related to their child with developmental disorders or mental health problems. The daily discrimination scale did not assess disability-specific discrimination. However, the measure of embarrassment and shame did focus on these feelings specifically emanating from children's problems. Thus, we made the inference that child-related shame and embarrassment was at least partly reflective of their child with the disability. In addition, although significant associations between race and stigma have been reported in literature, the number of the cases in non-white group did not provide sufficient power to test the moderating effects of race. Therefore, race/ethnicity of the respondents were controlled in analyses instead of directly tested in the current study.

Despite these limitations, the present study also had a number of unique strengths, including the longitudinal design used to examine the long-term (i.e., approximately 20 years) associations between parenting a son or daughter with disabilities, experience of stigma, and physical health; the use of nationally representative data, which increases the generalizability of the findings, was also a strength of the study. Additionally, the current sample of parents of individuals with disabilities did not volunteer for a study of caregiving effects, as is the case with most research on such parents, thus rendering the results less vulnerable to self-selection bias. A recent systemic review of courtesy stigma among family caregivers of individuals with intellectual disabilities (Ali et al., 2012) noted that most studies in the field were based on small-scale, non-representative samples with a cross-sectional design. The current study helps address this gap in the literature by utilizing representative longitudinal datasets.

5. Conclusions

In conclusion, this study suggests that long-term parenting of individuals who have developmental disorders or mental health problems may place the parents at increased risk for poorer physical health (poorer self-rated health and a greater number of chronic conditions) in part due to the adverse effects of the experience of stigma in the forms of embarrassment/shame and daily discrimination. Considering the prevalence of developmental disorders and mental health problems in the U.S. population, the increased lifespan of the individuals with such conditions, and subsequent cost of their health care, interventions and policies that mitigate the experience of courtesy stigma for parents of individuals with disabilities would have important implications for public health.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.socscimed.2018.09.044>.

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