

Statistical Modeling of Outcomes for Children of Parents with Disabilities

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Abstract

Few studies have explored the impact of parental disability on children. Utilizing a sample of 982 young adults (17 to 21 years old), we used statistical modeling to examine the relationships between parental disability characteristics (type of disability, onset, course, and severity); presence of disability in the adult child; gender of parent and child; income; family interaction with others; perception of family within the community; access to resources and support; and adult children's self-esteem, perceived stigma, and positivity of growing up with a parent with a disability. The challenges faced included the handling of "missing" data and the realization of non-normal outcomes for appropriate modeling. The results revealed reasonably viable correlates despite the challenges of interpretation of parameter estimates using various outcome types.

Key Words: parental disability, statistical modeling, young adult

1. Introduction

Relatively little analysis has been performed to examine children's perceptions of growing up with a parent with a disability. Research on children of parents with disabilities has largely been based on the medical model of disability and assumes negative consequences for parents and their children (Kirshbaum & Olkin, 2002; Preston, 2010). In examining outcomes for children of parents with disabilities, there is a plethora of examples where some children experience negative outcomes whilst others prosper, even when the parent has the same type of disability. Because of this non-uniformity of experience, it then becomes important to determine important factors that help to facilitate different outcomes (Van Loon et al., 2014). This information, in turn, could then be useful for focus of intervention and support for those most in need.

Pedersen and Revenson (2005) developed a family ecology model to assist in the analysis of factors that may be associated with outcomes for children of parents with disabilities or illness. These types of models can be used as a basis for developing sound hypotheses for conducting analysis on data collected on families with disabilities.

Two commonly studied indicators influencing current and prospective positive or negative outcomes for young adults include (1) self-esteem (Boden, Fergusson, & Horwood, 2008; Bulanda & Majumdar, 2009; Orth, Robins & Widaman, 2012) and (2) stigma (Lehmann, Hilimire, Yang, Link, & Berger, 2014; Mason, Sultzman & Berger, 2014; Oliver (2016); Quinn & Chaudoir, 2015;). The current study examined a third outcome specific to the

population being studied, viz., the adult child's overall experience growing up with a parent with a disability.

The current study examines the relationship between parental disability characteristics (type of disability, onset, course, and severity); presence of disability in the adult child; gender of parent and child; income; family interaction with others; perception of family within the community; access to resources and support; and adult children's self-esteem, perceived stigma, and positivity of growing up with a parent with a disability.

2. Methods

1.1 Participants

Study participants were young adult high school seniors or current college students ($n=982$; 17 to 21 years of age) who had a parent with a disability. Participants were recruited from a pool of students who had applied for a USD1000 college scholarship during the period of 2009 to 2011 to be awarded to children of parents with a disability. Applicants were invited and volunteered to complete an optional online survey about their experiences growing up with their parent. Scholarship awards were independent of participation in the survey.

1.2 Measures

The young-adult participants completed a 55-item online survey designed specifically for this study. The survey included questions about their parent's disability (type of disability, onset, course, severity, functional impact, activity limitation, and participation restriction); demographic information including household income and whether the adult child has a disability; a perceived societal stigma toward children of parents with disabilities scale (adapted from Gershon, Tschann & Jemerin (1999) and Green (2007) based on Link et al. (1987)); the Rosenberg Self-Esteem Scale (1965); information about the perceived advantages and challenges of having a parent with a disability; questions on the families' amount of socializing with others with and without disabilities; a question on the amount of resources and support available to the family; a question on how positively the neighborhood and community viewed the family; the amount and type of assistance the young adult provides to the parent; and a rating of the positivity of the adult child's overall experience.

1.3 Statistical Analysis

We calculated descriptive statistics for each variable and examined bivariate relationships with the outcome variables of adult child self-esteem, adult child's perceived societal stigma of having a parent with a disability, and positivity of overall experience growing up with a parent with a disability. We ran regression models for each of these outcome variables to assess whether outcomes varied with parental disability characteristics (viz., type of disability, onset, course, and severity); presence of disability in the adult child; gender of parent and child; household income; family interaction with others; perception of family within the community; family income; and access to resources and support.

The data were cleaned and statistical analyses were performed using SAS v9.3 (SAS Institute, 2011, 2015). Over half (55%) of responses to a household income question from

2009 were missing. In that year's survey, students were asked to provide exact amounts for household income. Because of the significant amount of missing data on this item, we revised this question in subsequent years to provide participants with six broad income categories from which to select their household income. We imputed income level data for the 2009 cohort using the full-data augmentation method (MCMC in the SAS MI procedure).

2. Results

2.1 Bivariate Analyses

Bivariate analysis was performed with for each outcome variable by individual substantive variables. Independent variables were assessed for significance with each outcome: *self-esteem*, *stigma* and *overall experience*. Descriptive statistics for outcome variables are shown below.

2.1.1 Self-Esteem

Respondents' average self-esteem on the Rosenberg Self-Esteem Scale was 34.2 (SD = 5.0), with a range of 17 to 40. Possible scores on this scale range from 10 to 40 with higher values indicating higher self-esteem.

2.1.2 Stigma

Adult children's mean perceived societal stigma toward children of parents with disabilities was 26.9 (SD = 7.7), with a range of 10 to 57. Possible scores on the stigma scale range from 10 to 60 with higher values indicating more stigma.

2.1.2 Overall Experience

A majority of respondents, 59%, characterized their experience growing up with a parent with a disability as generally positive or very positive; 34% characterized it as mixed; and 7% as negative or very negative.

2.2 Model-building Analyses

We performed three separate regression analyses to test the three separate hypotheses that the outcome variables self-esteem, stigma, and overall positivity of growing up with a parent with a disability will vary with type of parental disability, onset, course, and severity of disability; presence of disability in the adult child; gender congruence of parent and adult child; household income; family socialization with others with and without disabilities; perception of family within the community; and access to resources and support.

The general model-building and selection methodologies included (Hocking, 1976):

- (1) Backward deletion via the manual method (MBD);
- (2) Automatic
 - a. Backward deletion (ABD)
 - b. Stepwise (AS);
 - c. Forward addition (AFA).

2.2.1 Self-Esteem

Self-esteem was not normally distributed and attempted transformations to normality did not yield an acceptable normal distribution for standard multiple regression analysis. Therefore, we partitioned self-esteem into quintiles and utilized ordinal regression analysis using the four methods (i.e., MBD, ABD, AS, AFA) until a parsimonious model predicting self-esteem remained. For the manual method, the SAS LOGISTIC procedure was used and for the automatic method, the SAS HPGENSELECT procedure was used.

The final model showed five of the 11 hypothesized variables retained in the model as significant predictors of self-esteem: course of disability ($X^2(5) = 24.6, p < 0.001$); whether the adult child had a disability ($X^2(2) = 12.7, p = .002$); socializing with others with disabilities ($X^2(4) = 12.0, p = .02$); socializing with others without disabilities ($X^2(4) = 15.8, p = .003$); and how positively others in the neighborhood and community viewed the family ($X^2(5) = 91.7, p < .001$). Table 1 shows the resulting predictors for the initial self-esteem model using the various manual and automatic variable selection methods. All model selection methodologies agreed on the final model.

Manual	Automatic		
Method: SAS/Manual	Method: SAS/HPGENSELECT	Method: SAS/HPGENSELECT	Method: SAS/HPGENSELECT
Backward	Backward	Stepwise	Forward
Course of disability	Course of disability	Course of disability	Course of disability
Adult Child has Disability	Adult Child has Disability	Adult Child has Disability	Adult Child has Disability
Socializing with others WITH disabilities	Socializing with others WITH disabilities	Socializing with others WITH disabilities	Socializing with others WITH disabilities
Socializing with others WITHOUT disabilities	Socializing with others WITHOUT disabilities	Socializing with others WITHOUT disabilities	Socializing with others WITHOUT disabilities
Community perception of family	Community perception of family	Community perception of family	Community perception of family

2.2.2 Stigma

We performed a multiple regression analysis to determine whether type, onset, course, severity of parental disability; presence of disability in adult child; gender congruence of parent and adult child; household income; socialization with others with and without disabilities; perception of family within the community; and access to resources and support were related to adult children's perception of societal stigma toward children of parents with disabilities. To find the set of variables that best predicted stigma, a full multiple regression model with all substantive variables was initially fit using the four methods (i.e., MBD, ABD, AS, AFA) until a parsimonious model predicting stigma remained. For the manual method, the SAS MIXED procedure was used and for the automatic method, the SAS GLMSELECT procedure was used.

The final model using the manual backward deletion method (Table 2) showed that five of the 11 hypothesized variables remained in the model as significant predictors of stigma: Type of parental disability ($F(5, 938) = 6.1, p < .001$); adult child disability ($F(2, 938) = 6.8, p = .001$); amount of time the young adult’s family spent socializing with people with disabilities when the young adult was growing up ($F(4, 938) = 4.9, p < .001$); how the young adult’s family was viewed by the neighborhood and community when growing up ($F(5,938) = 31.1, p < .001$); and access to resources and support ($F(4,938) = 3.1, p = .01$). Surprisingly, the automatic model-building methods using the defaults showed only parental disability type and community perception of family as the resulting predictors. However, when the PRESS statistic was specified as the model selection criteria, the resulting predictors agreed with the manual backward selection method (Table 3).

Table 2. Final Statistical Models for Total Stigma using Manual & Automatic Variable Selection Methods (n=982)

Manual	Automatic		
Method: SAS/Manual	Method: SAS/GLMSELECT	Method: SAS/GLMSELECT	Method: SAS/GLMSELECT
Backward	Backward (BICC or AICC)	Stepwise (SBC)	Forward
Parental Disability Type	Parental Disability Type	Parental Disability Type	Parental Disability Type
Adult Child has Disability			
Socializing with others WITH disabilities			
Community perception of family	Community perception of family	Community perception of family	Community perception of family
Amount of resources & support			

Table 3. Final Statistical Models for Total Stigma using Manual Backward Elimination and the Stepwise Automatic Variable Selection Method using PRESS statistic (n=982)

Manual	Automatic
Method: SAS/Manual	Method: SAS/GLMSELECT
Backward	Stepwise (PRESS)
Parental Disability Type	Parental Disability Type
Adult Child has Disability	Adult Child has Disability
Socializing with others WITH disabilities	Socializing with others WITH disabilities
Community perception of family	Community perception of family
Amount of resources & support	Amount of resources & support

2.2.3 Overall Experience

We conducted an ordinal logistic regression analysis to determine whether type, onset, course, and severity of parental disability; presence of disability in the adult child; gender

congruence of parent and adult child; household income; amount of time families spent socializing with people with and without disabilities; how families were viewed by the neighborhood and community; and access to resources and support were related to the positivity of the overall experience of growing up with a parent with a disability (categories: negative, mixed, and positive overall experience). To find the set of variables that best predicted overall experience, the full model with all hypothesized predictors was initially run using the four methods (i.e., MBD, ABD, AS, AFA) until a parsimonious model predicting overall experience remained. For the manual method, the SAS LOGISTIC procedure was used and for the automatic method, the SAS HPGENSELECT procedure was used.

The final model using both the manual and automatic selection methods showed that six of the 11 hypothesized variables remained in the model as significant predictors of overall experience of growing up with a parent with a disability. These variables were type of parental disability ($X^2(5) = 43.9$, $p < .001$); course ($X^2(5) = 15.5$, $p = .008$); severity ($X^2(4) = 13.4$, $p = .01$); gender congruence of parent and adult child gender ($X^2(3) = 11.5$, $p = .009$); amount of time families spent socializing with others with disabilities ($X^2(4) = 18.5$, $p = .001$); and how positively the family was viewed by the neighborhood and community ($X^2(5) = 43.2$, $p < .001$). Table 4 shows the results of the final predictors for the initial stigma model using the various manual and automatic variable selection methods.

Table 4. Final Statistical Models for Overall Experience using Manual & Automatic Variable Selection Methods (n=982)			
Manual	Automatic		
Method: SAS/Manual	Method: SAS/HPGENSELECT	Method: SAS/HPGENSELECT	Method: SAS/HPGENSELECT
Backward	Backward	Stepwise	Forward
Parental Disability Type	Parental Disability Type	Parental Disability Type	Parental Disability Type
Course of disability	Course of disability	Course of disability	Course of disability
Severity of disability	Severity of disability	Severity of disability	Severity of disability
Parent/Child Gender Congruence	Parent/Child Gender Congruence	Parent/Child Gender Congruence	Parent/Child Gender Congruence
Socializing with others WITH disabilities	Socializing with others WITH disabilities	Socializing with others WITH disabilities	Socializing with others WITH disabilities
Community perception of family	Community perception of family	Community perception of family	Community perception of family

3. Discussion

The dangers of automatic variable selection methods are well documented (Derksen and Keselman, 1992; Flom, 2007; Hurvich and Tsai, 1990). George Box famously quipped in 1978, “All models are wrong, but some are useful”, meaning one cannot find the perfect model having all the predictors that explains a phenomenon completely. However, using theory and evidence-based model-building can be useful in avoiding superfluous models.

Both the manual automatic modeling methodologies for the *Self-Esteem* and *Overall Experience* outcomes converged to the same, respective, parsimonious models using the procedure defaults. However, the initial manual backward deletion method for the *Total Stigma* outcome yielded a model with five of eleven predictors whilst the automatic

methods with the defaults yielded only two final predictors. This illustrates the need to choose the model-selection stopping criteria wisely or at least try different stopping criteria as a check on model stability or robustness.

As shown above, utilizing different methods for model-building can help avoid missing important variables. One can be confident that what is left is a substantive model buttressed by theory and the literature.

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