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Research Paper

The associations between resilience and socio-demographic factors in parents who care for their children with congenital heart disease☆

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ABSTRACT

Objective: To examine the resilience of parents of children with congenital heart disease and to investigate socio-demographic factors that may influence parents' resilience.
Methods: This is a web-based survey study using a cross-sectional design. A purposive sampling method was utilized to recruit 515 parents who care for children with congenital heart disease. Resilience was assessed using the Dispositional Resilience Scale-II. Based on expert-interviews, a questionnaire was designed to collect socio-demographic data. Descriptive statistics, factor analysis, and linear regressions were used to analyze data.
Results: A total of 413 parents completed the survey study. The mean resilience score was 3.75 (SD = 0.61; range = 1.89–4.89) with higher scores indicating higher resilience. The linear regression models demonstrated that parents who had lower education levels and lower gross household income had lower resilience ($P < 0.05$).
Conclusions: Parents reported resilience that reflected their ability to cope with stressful events and mitigate stressors associated with having and caring for children with congenital heart disease. Lower education levels and lower gross household income are associated with lower resilience. To increase parents' resilience, nursing practice and nurse-led interventions should target screening and providing support for parents at-risk for lower resilience. As lower education level and financial hardship are factors that are difficult to modify through personal efforts, charitable foundations, federal and state governments should consider programs that would provide financial and health literacy support for parents at-risk for lower resilience.

What is known?

- Advances in medical treatments and health care have transformed congenital heart disease into a lifelong chronic condition.
- Resilience reflects one's ability to cope with stressful events and mitigate stressors.
- Providing day-to-day care for children with congenital heart disease may force parents to face many stressors.

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What is new?

- Lower level of education is associated with lower resilience of parents who care for children with congenital heart disease.
- Financial hardship in terms of annual gross household income is associated with parents' lower resilience.
- Clinical practice and nurse-led interventions should target screening and support for parents at-risk for lower resilience.
- Lower education level and financial hardship are factors that are difficult to modify through personal efforts.
- Charitable foundations, and federal and state governments should provide financial and health literacy support for parents at-risk for lower resilience.

1. Introduction

Congenital heart disease (CHD) is the most prevalent birth defect in the United States, affecting 40,000 births annually [1]. Advances in medical treatments and health care have transformed many formerly lethal congenital defects into lifelong chronic conditions requiring ongoing medical and nursing care as well as day-to-day care from parents [2–4]. Studies have shown that having children with chronic illnesses, such as CHD, can negatively impact the well-being of the whole family [5]. Parents who care for children with chronic conditions may have increased vulnerability to psychosocial distress [6,7]. Caring for children with CHD may impose multi-faceted stressors, for example, day-to-day care to meet the special needs of the children with CHD, repeated clinic or hospital appointments, uncertainty of CHD prognosis, and dealing with health care systems [8–13]. These stressors can impact the daily lives of parents and children with CHD, the quality of care for the children, as well as parents' and children's own well-being [14].

Researchers have conceptualized resilience as a cognitive personality trait that reflects one's ability to cope with stressful events and mitigate stressors or ways that people manage potentially harmful stressors [15,16]. In the face of stressful events, individuals may have feelings of powerlessness, alienation, and vulnerability, but they may also develop resilience by cultivating their ability to accept the challenges of coping with stressful events and mitigating stressors [16,17]. Providing day-to-day care for children with CHD may force parents to face many stressors, yet, this experience may also help parents develop their resilience to enhance their coping ability and adapt to these stressors. Little is known about resilience and factors that may influence the resilience of parents who care for children with CHD. In addition, empirical evaluation of resilience is needed to elucidate dimensions of the construct of resilience in this population. Therefore, the objectives of this study were to 1) examine the resilience of parents who care for children with CHD; and 2) to investigate socio-demographic factors that may influence parents' resilience. We present the following article in accordance with the STROBE and CHERRIES Guideline.

2. Methods

2.1. Ethical considerations

This web-based survey study was approved by the Institutional Review Board (IRB) at The University of Baltimore (IRB Protocol# UB19-43), approved as archival data at Boston College (BC IRB Protocol# 21.137.01e) and Rutgers University (IRB Study # Pro2022000252). Completion of the survey served as the respondents' consent. No identifiable information was collected.

2.2. Design

This voluntary web-based survey study used a cross-sectional design.

2.3. Recruitment

A purposive sampling method was utilized to target parents who care for children with CHD. In collaboration with *The Ethan M. Lindberg Foundation* (EMLF), a non-profit advocacy organization for parents of children with CHD, multiple approaches were used to recruit study participants for this voluntary survey study. First, EMLF advertised the study on Facebook to reach parents who may be interested in this study in the United States. Second, EMLF posted the study information on its website and emailed study information to members. Interested parents accessed the study online and completed the survey. The survey opened on March 26, 2019, and closed on April 7, 2019. A total of 515 respondents accessed and responded to the survey. Participants were allowed to review and change their answers prior to submitting their answers to the survey questions.

2.4. Participants

Participants were parents who identified themselves as the primary caregivers of children with CHD. Inclusion criteria were: 1) parents who self-identified as the parent of at least one living child with CHD; 2) and parents who self-identified as the primary caregivers of the children with CHD. Respondents who did not complete the instrument assessing resilience and social-demographic information were excluded. Among the 515 respondents, 413 met the study inclusion criteria. No incentives were provided to participants.

2.5. Variables and measures

2.5.1. Resilience

The 18-item Dispositional Resilience Scale-II (DRS-II), a reliable and valid self-report instrument, was used to assess resilience [16]. Nine items of the 18 items are indicative of one's belief that the stressors can be overcome (e.g., "*I feel confident I can handle just about any challenge*") and the remaining nine items represent one's negative beliefs with regard to stressful events or stressors (e.g., "*Sometimes life feels meaningless to me.*" Each item was rated on a 5-point Likert scale (i.e., 1 = strongly disagree to 5 = strongly agree). The nine negatively-worded items were reverse-scored before analysis and reporting. The DRS-II has been used to assess resilience among other populations [17].

Since this study was the first to investigate resilience using the DRS-II in this population, it is important to empirically elucidate the dimensions of the DRS-II as a measure of resilience for parents who cared for children with CHD. Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were used. First, EFA using principal-factor extraction without rotation was performed. A factor was retained if it had a minimum of 5% explained sample variance, an eigenvalue $\geq$1, and the principal of discontinuity (i.e., a sharp drop in the percentage of explained variance that indicates the appropriate termination point) [18]. Of the 18 items in the DRS-II, 15 items were retained. The first retained factor had an eigenvalue of 5.46 and explained 74% of the item variance, whereas the next largest eigenvalue was 1.53 and explained 21% of the item variance. Fifteen items loaded onto the first factor with factor loading $\geq$0.40; only three items loaded onto the second factor. These three items are related to daily routines and schedules (e.g. "*It bothers me when my daily routine gets interrupted*") which seem

to measure something other than resilience. Findings of the EFA supported a one-factor (15-item) or single-dimension of resilience construct. Following EFA, CFA with maximum likelihood estimation was used to confirm the final factor structure and evaluate its fit based on the following fit measures: CFI, RMSEA, and SRMR. Specifically, a congeneric factor model was fit in which all 15 retained items were allowed to load freely onto a single resilience factor. A parallel factor model was also fit, in which factor loadings and residual variances were constrained to be equal across all items. The constraints of the parallel model reflect the set of strict assumptions for the use of sum or mean scores for a measure in analyses, such as regression [19]. Cronbach's α and McDonald's ω were calculated to evaluate the internal consistency of the retained 15-item DRS-II. Cronbach's α of the 15-item measure demonstrated a good internal consistency (α = 0.89) compared to the 18-item measure (α = 0.86). McDonald's ω also supports the internal consistency of the 15-item resilience measure (ω = 0.89). McDonald's ω for the measure including all 18 original items is 0.85. These findings also supported a single-factor structure of resilience construct.

2.5.2. Socio-demographic information

To capture a comprehensive assessment of socio-demographic factors, semi-structured interviews were conducted with eight experts (four clinicians and four caregivers and/or advocates) to identify socio-demographic factors of interest in this population. Based on the interviews, self-reported socio-demographic variables were collected to include: parent age, child age, parent gender, the highest level of education, employment status, gross household income (GHI), out of pocket monthly expenses for the child with CHD, primary financial responsibility for the household, primary responsibility for taking the child with CHD to most clinical appointments, taking most days off for most clinical appointments of the child with CHD, and travel distance for care at cardiac/cardiac surgical center.

2.6. Data downloading and verification

The study team downloaded the raw data from the Qualtrics platform into a Microsoft Excel file. The human-in-the-loop (HITL) method refers to the need to have human interaction when managing electronic data [20,21]. HITL was used to verify data accuracy and ensure minimal data errors. There are two basic steps in HITL: 1) The IP address was used to identify duplicated responses. No responses had the same IP address and there were no duplicates identified in this study. 2) To determine the most constant items reflecting the real number of respondents. In this study, there were three constant items identified. These included the parent age, parent gender, and travel >30 miles for cardiology care. For each of these questions, only one true answer could exist, that is, respondents can only provide one answer to each question. Therefore, the sum of the responses for each question should come to 100%, indicting the number of respondents.

2.7. Data analysis

Data were analyzed using Stata 16 SE (StataCorp LLC, College Station, Texas, US). Descriptive statistics were used to summarize study variables. Continuous variables were summarized in terms of means, *SD*, and ranges. Categorical variables were summarized using frequencies and proportions. We conducted statistical analysis according to SAMPL Guideline [22].

Linear regression predicting resilience scores. A multiple linear regression model (i.e., Ordinary Least Squares [OLS] regression) was used to examine the relationship between socio-demographic factors and resilience with 95% confidence interval. These socio-demographic variables included: parent age, child age, parent gender, the highest level of education, employment status, GHI, out of pocket monthly expenses for child with CHD, primary financial responsibility for the household, primary responsibility for taking child with CHD to most clinical appointments, taking most days off for most clinical appointments of the child with CHD, and travel distance for care at cardiac/cardiac surgical center. Based on prior research on children with CHD, we also included mean-centered parent age and mean-centered child age in the OLS regression [13,23–26]. The outcome variable for the regression analysis was the parent's resilience score. The parent's resilience score was calculated as the mean of the 15 retained items (i.e., the sum of the item responses divided by 15), ranging from 1 to 5, with higher scores representing higher levels of resilience.

Robustness check. Since the congeneric model fit measures were marginally acceptable (CFI = 0.86, RMSEA = 0.09 [90% CI: 0.08–0.10], SRMR = 0.06, $R^2 = 0.90$) and the parallel factor model fit was suboptimal (CFI = 0.66, RMSEA = 0.12 [90% CI: 0.12–0.13], SRMR = 0.17, $R^2 = 0.89$), a robustness check was conducted for the linear regression analysis with estimated factor scores from the 15-item congeneric factor model and estimated factor scores from the 15-item parallel factor model as outcomes. The regression results with the parallel factor estimated factor scores were identical to the regression results using the mean resilience score as the outcome, as expected. Results from the regression analysis using the estimated factor scores from the congeneric model were very similar and the inferences were identical. These results support the use of mean resilience scores as regression outcomes. In addition, simple mean scores may be favorable in clinical practice due to ease of use.

3. Results

3.1. Socio-demographic characteristics of the participants

Table 1 presents the characteristics of the participants. A sample of 413 parents who self-identified as primary caregivers for children with CHD completed the study. Briefly, the majority of parents were female (91.0%) with a mean age 37.6 years (*SD* = 7.66; range = 19–69). The mean age of the children with CHD was 5.8 years (*SD* = 5.46, ranged = <1–31). Among the 413 parents, 29.3% had a GHI below the United States annual average household income of $68,703.

3.2. Resilience

The mean resilience score for this sample based on the 15 DRS-II items retained by the factor analysis (Table 1) is 3.75 (*SD* = 0.61) ranging from 1.89 to 4.89, with 1 indicating the lowest level of resilience, and 5 the highest level of resilience.

3.3. Resilience and socio-demographic factors

As shown in Table 2, the linear regression model demonstrated several significant relationships between socio-demographic factors and resilience. Parents with a high school diploma had lower resilience scores than those with a master's or higher degree ($P = 0.009$). Specifically, the difference in the resilience scores between the two groups was 0.25 (95% CI = [0.06–0.44]), suggesting parents with a high school diploma had 0.25 points lower resilience scores than those with higher education levels. Parents with a bachelor's degree also had lower resilience scores than parents with a master's degrees or higher degree ($B = -0.16$, $P = 0.031$).

A lower GHI predicted lower resilience. The difference between the group with more than $100,000 household income and the group with less than $20,000 income was 0.45 ($P = 0.009$, 95%

Table 1
Participant characteristics ($n = 413$).

Variable	***n*** (%)
Parent Gender	
Male	37 (9.0)
Female	376 (91.0)
Highest level of education	
High school diploma	79 (19.1)
Bachelor's degree	177 (42.9)
≥Master's degree	157 (38.0)
Gross household income, $	
<20,000	18 (4.4)
20,000–39,999	40 (9.7)
40,000–59,999	63 (15.3)
60,000–99,999	126 (30.5)
≥100,000	166 (40.2)
Employment status	
Employed	248 (60.0)
Unemployed/Do not work	165 (40.0)
Taking primary responsibility for financial needs of the household	
Participant	83 (20.1)
Spouse/Partner/Other family members	169 (40.9)
Shared responsibility	161 (39.0)
Out of pocket monthly expenses for care of child with CHD, $	
<500	263 (63.7)
500–999	86 (20.8)
1,000–3,999	56 (13.6)
≥4,000	8 (1.9)
Taking most days off for clinical appointments of the child with CHD	
Participant	298 (72.1)
Spouse/other family member/shared responsibility	115 (27.9)
Taking child with CHD to most clinical appointments	
Participant	316 (76.5)
Spouse/other family member/shared responsibility/adult child	97 (23.5)
Traveling >30 miles for cardiology care of the child with CHD	
Yes	244 (59.1)
No	169 (40.9)
Traveling >30 miles for care at primary surgical center of the child with CHD	
Yes	289 (70.0)
No	124 (30.0)

Note: CHD = congenital heart disease.

CI = [0.11–0.79]), suggesting that parents with < $20,000 GHI had a resilience score 0.45 points lower than that of parents with more than $100,000 GHI. Resilience scores increased with increasing GHI, but all income groups have significantly lower resilience scores than the parents with > $100,000 GHI. There was no pattern to the residuals plotted.

4. Discussion

4.1. Resilience and socio-demographic factors

This study is the first to report resilience measured with DRS-II in a larger sample of parents who care for children with CHD. In this study, the empirical data using the DRS-II supported resilience as a one-dimensional construct. This study is also the first to investigate the associations between resilience and socio-demographic factors that are important for caring for children with CHD. The findings of our study demonstrate that a lower level of education is associated with lower resilience. Parents with a high school diploma had lower resilience than those with higher education levels. This finding underscores the need for targeted interventions for parents with a lower education level. Future research is warranted to explore the specific needs and concerns of parents with a lower education level to increase their resilience in caring for children with CHD. Caring for children with CHD necessitates parents to have knowledge related to CHD treatment, medications, and self-management [27]. Perhaps, educational interventions directed toward health literacy specific to CHD might help parents with lower education levels.

It is important to note that 29.4% of the 413 parents had a GHI <$60,000, which is below the US annual average household income of $68,703. A lower GHI predicted lower resilience. Medical expenses for children with CHD are a common cause of financial hardship among families of children with CHD and are associated with high rates of food insecurity and delays in care for these children [28]. It is important to note that lower GHI is a factor that is difficult to modify through individual effort. Financial hardship may elicit more stress for the parents of children with CHD [28]. Efforts to help offset medical expense-related financial burdens for low GHI parents may decrease their coping vulnerability and assure that parents are able to provide quality care for their children with CHD. It should be noted that even families with high GHI may hold debt or incur other expenses related to a child with CHD, and therefore also struggle with resilience [29]. Future studies should explore financial hardship defined not only by GHI, but also by household debt, or parents' perceptions of financial hardship in relation to resilience. As an initial step, nurse-led screening programs may facilitate the identification of at-risk parents for lower resilience [30–33]. Screening tools focusing on constructs that are meaningful to parents and families are important in building a parents' resilience (e.g., education level, GHI, debt) [30–33]. Nursing is in an ideal position to lead the efforts to build family

Table 2
Relationships of socio - demographic factors with mean resilience score by OLS multiple regression ($n = 413$).

Variable	Resilience Scores			
	Coef.	*SE*	95% CI	*P*
Parent Gender				
Female	−0.10	0.11	−0.33, 0.12	0.368
Male	Ref.			
Level of Education				
High school Diploma	−0.25	0.10	−0.44, −0.06	0.009
Bachelor's degree	−0.16	0.07	−0.30, 0.01	0.031
>Master's Degree	Ref.			
Gross Household Income, $				
<20,000	−0.45	0.17	−0.79, −0.11	0.009
20,000–39,999	−0.33	0.13	−0.58, −0.08	0.009
40,000–59,999	−0.23	0.10	−0.43, −0.02	0.009
60,000–99,999	−0.21	0.08	−0.36, −0.05	0.009
≥100,000	Ref.			
Employed				
Employed	0.04	0.08	−0.12, 0.21	0.610
Unemployed/Do not work	–	–	–	–
Taking primary responsibility for financial needs of the household				
Participant	−0.04	0.09	−0.21, 0.14	0.694
Spouse/Partner/Other family members	−0.15	0.09	−0.32, 0.02	0.081
Shared responsibility	Ref.			
Out of pocket monthly expenses for care of child with CHD, $				
<500	−0.07	0.23	−0.53, 0.39	0.753
500–999	−0.09	0.24	−0.57, 0.38	0.697
1,000–3,999	−0.12	0.25	−0.61, 0.36	0.622
≥4,000	Ref.			
Taking most days off for clinical appointments of the child with CHD				
Participant	0.04	0.08	−0.11, 0.19	0.630
Spouse/other family member/shared responsibility	Ref.			
Taking child with CHD to most clinical appointments				
Participant	−0.14	0.09	−0.31, 0.03	0.520
Spouse/other	Ref.			
Traveling >30 miles for cardiology care of the child with CHD				
Yes	0.06	0.09	−0.12, 0.23	0.520
No	Ref.			
Traveling >30 miles for care at primary surgical center of the child with CHD				
Yes	0.03	0.09	−0.15, 0.21	0.751
No	Ref.			
Child Age[a]	−0.00	0.01	−0.01, 0.01	0.979
Parent Age[a]	−0.01	0.01	−0.02, 0.01	0.350
Intercept[a]	4.11	0.26	3.59, 4.62	<0.001

Note: Adjusted $R^2 = 0.079$, $F = 2.85$, $P < 0.001$. [a] Child and Parent Age were both mean-centered for the analysis. The intercept therefore reflects the expected mean resilience score (on a 5-point Likert scale) for an individual who is in the reference category for each categorical predictor, and who has the mean parent age and mean child age. OLS = Ordinary Least Squares. CHD = congenital heart disease.

resilience through ongoing identification of at-risk parents as early as the pre-natal stage at the time of a prenatal diagnosis of CHD and re-assessment throughout the life spectrum.

4.2. Strengths and limitations of the study

Strengths of the study included the use of a valid and reliable instrument to assess resilience, a comprehensive tool to evaluate socio-demographic factors, and a comparatively large sample size. All of these strengths enhanced the examination of the relationships of socio-demographic factors with resilience. Limitations of the study included its cross-sectional design which prevented an evaluation of changes in resilience over time. Although linear regression using large and detailed datasets with a thorough set of control variables is one of the most commonly used predictive modeling techniques to identify statistically significant predictors as in our study, cautions should be exercised as accurate predictions may not be guaranteed by a cross-sectional study. Stressors that parents of children with CHD face (e.g., day-to-day care for the children with CHD, clinical or hospital visits, uncertainty of CHD prognosis, and issues related to complex health care system) may also impact parents' resilience that may, in turn, influence parents' psychological and physical health, parenting behaviors, well-being, health care utilization, and quality of life [10]. Future research should include the aforementioned stressors. Future investigations should focus on the relationships of resilience with these additional factors and assess their associations. Given that the congeneric factor model fit was superior to the parallel factor model fit in this study, the use of simple scale scores (e.g., mean and sum scores) should be cautioned in future research on resilience using the DRS-II.

5. Conclusion

This is the first study that reported the resilience of parents who care for children with CHD, which reflected parents' ability to cope with stressful events and mitigate stressors associated with caring for their own children with CHD. This is also the first study that evaluated the relationships between resilience and socio-demographic factors. Lower education levels (i.e., high school diploma and bachelor's degree) and lower GHI (i.e., < $60,000) are difficult to be modified through personal efforts. To increase parents' resilience, nursing and clinical practice should target on screening and supporting parents at risk for lower resilience.

Information for obtaining financial and health literacy support for parents should be available to support parents at risk for lower resilience. Charitable foundations and federal and state governments should consider programs that provide support for parents with lower education levels and those with lower GHI.

Compliance with ethical standards

This web-based survey study was approved by the Institutional Review Board (IRB) at The University of Baltimore (IRB Protocol# UB19-43) and approved as archival data at Boston College (BC IRB Protocol# 21.137.01e) and Rutgers University (IRB Study # Pro2022000252). Completion of the survey served as the respondents' consent. No identifiable information was collected.

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Data availability statement

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

CRediT authorship contribution statement

Amy E. Delaney: Conceptualization, Methodology, Data curation, Data analysis and interpretation, Writing – original draft, Writing – review & editing. **Mei Rosemary Fu:** Conceptualization, Methodology, Data curation, Data analysis and interpretation, Writing – original draft, Writing – review & editing, Validation, Supervision. **Melissa L. McTernan:** Software, Data analysis and interpretation, Validation, Writing – original draft, Writing – review & editing. **Audrey C. Marshall:** Data curation, Writing – review & editing. **Jessica Lindberg:** Conceptualization, Investigation, Writing – review & editing. **Ravi R. Thiagarajan:** Conceptualization, Investigation, Writing – review & editing. **Zhuzhu Zhou:** Data analysis and interpretation, Writing – review & editing. **Jeibei Luo:** Data analysis and interpretation, Writing – review & editing. **Sharon Glazer:** Conceptualization, Methodology, Data curation, Writing – review & editing.

Declaration of competing interest

Authors declare that they have no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijnss.2022.06.003.

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