

Burnout Syndrome in Caregivers of Children with Cerebral Palsy

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Abstract

Caregivers of children with cerebral palsy (CP) are faced with constant stress, which may lead to poor mental health conditions and burnout syndrome. However, burnout syndrome for caregivers of pediatric conditions like CP is under-researched, especially in the United States. The primary objective of this study is to show that caregivers of children with CP experience significant levels of burnout. Moreover, this research aims to identify caregivers that are at higher risk for burnout by comparing burnout levels between caregivers in the privatized American health care system and caregivers in the socialized Canadian health care system. The experimental population of 280 caregivers – consisting of 140 caregivers in Houston and 140 caregivers in Vancouver – were evaluated for burnout syndrome using the Maslach Burnout Inventory Human Services Survey (MBI-HSS), which measures three distinct aspects of burnout: emotional exhaustion (MBI-EE), depersonalization (MBI-DP), and personal accomplishment (MBI-PA). After statistical comparison of the survey results, this study will reveal significantly elevated levels of burnout for caregivers of children with CP, especially in Houston. The expected results of this study will demonstrate an immediate need for caregivers to have access to resources and training in order to reduce burnout levels. In addition, this study highlights the need for research that improves caregiving strategies in order to help caregivers combat the significant psychological stresses associated with caring for children with CP.

Introduction

Cerebral palsy (CP) is the most common childhood motor disability in the U.S.: approximately 764,000 people exhibit symptoms of CP (Cerebral Palsy Facts and Statistics, 2018). CP encompasses a broad set of conditions caused by disturbances in the fetal or infant brain that result in speech, motor, and neurodevelopmental disabilities (Armstrong, 2007). While CP can be a debilitating condition, arguably those who suffer most are the caregivers of children with CP. To handle the massive stresses associated with caring for children with CP, some caregivers resort to extreme, expensive solutions for providing adequate care while others have even reported fantasizing about murdering their children (Solomon, 2012).

The particularly infamous case of Ashley X, who was diagnosed with a severe form of CP, exemplifies the incredibly difficult decisions parents of children with CP are forced to make:

“At their appointment several weeks later, [an endocrinologist] acknowledged that Ashley’s growth could be attenuated by administering estrogen, which would close her growth plates. Since Ashley will cry for an hour when she sneezes because she is so upset by slight discomfort, [Ashley’s dad] thought she would have a hard time with menstruation and the cramping it can cause. He proposed a hysterectomy, He thought breasts would get in her way when she was turned on her pillow or strapped in a wheelchair and asked that his daughter’s breast buds, the small, almond-shaped glands that enlarge into breasts at puberty, be removed. All this would result in a person who was easier to move – which, in turn, he argued would mean better circulation, digestion, and muscle condition for her and fewer sores and infections. Giving Ashley a permanent child’s figure would leave her with what her father called ‘a body that more closely matched her stage of mental development’” (Solomon, 2012, p. 386).

Ashley X's medical case was full of controversial decisions that many believe walk the line between caring for and abusing a child. However, for Ashley X's parents, these situations were commonplace; caregivers of children with CP and other severe disabilities are constantly required to make difficult decisions (Solomon, 2012). In these situations, parents of children with CP struggle with constant stress, leaving them at higher risk for negative health consequences. In fact, a study in Bangladesh found that 41.8% of mothers of children with cerebral palsy were at risk for psychiatric morbidity (Mobarak, Khan, Munir, Zaman, & McConachie, 2000). Previous studies have also shown that caregivers of children with CP are faced with perpetual stress, and the compounding effects of the stress faced by caregivers of children with CP leaves them more prone to conditions like burnout syndrome, anxiety, and depression (Basaran, Karaduvut, Uneri, Balbaloglu, & Atasoy, 2013; Byrne, Hurley, Daly, & Cunningham, 2010).

Burnout syndrome refers to the collective feelings of emotional exhaustion, depersonalization, and low personal accomplishment that caregivers and physicians often feel while they struggle with overwhelming stress (Penson, Dignan, Canellos, Picard, & Lynch, 2000). Potential consequences of excessive burnout levels include deteriorating mental health status, declining personal satisfaction with life, and worsening quality of care provided to patients (Penson, Dignan, Canellos, Picard, & Lynch, 2000). Schmid, Spiegl, Vukovich, and Cording (2003) report that burnout in caregivers and physicians often corresponds to personal attachment to the patient. Since they have a high degree of personal investment, it is unsurprising that parents acting as caregivers for their children with CP would experience unusually high levels of burnout. However, while the psychiatric effects of caregiving for geriatric and adult patients is well documented in existing research, burnout syndrome for caregivers of pediatric conditions like CP is still under-researched. Vicentic et al. (2016) notes that caregiving for

children with developmental disabilities like CP presents significant challenges over caregiving for normally developing children.

In addition to evaluating burnout levels of caregivers, this study compares the burnout levels of caregivers of children with CP in the U.S. with those in Canada in an attempt to evaluate how improved access to healthcare resources affects burnout syndrome in caregivers. Under the Canadian system, all patients have equal access to care based solely on medical necessity whereas Americans are not federally guaranteed health insurance and, thus, are not guaranteed access to health care (Krajewski, Hameed, Smink, & Rogers, 2009). Recent research has shown that healthcare resources in the Canadian universal healthcare system are utilized by a larger portion of the population than in the American healthcare system (Pylypchuk & Sarpong, 2013). Lasser, Himmelstein, and Woolhandler (2006) also found that American residents had access to significantly fewer healthcare resources than Canadians because universal health insurance coverage mediates healthcare disparities.

This study aims to not only show that caregivers of children with CP experience significantly higher burnout levels but also to identify potential avenues for developing effective solutions to alleviate burnout syndrome in caregivers of pediatric conditions. To accomplish this, having two study populations, one in the United States and one in Canada, is important because it provides insight into how the different healthcare systems support caregivers of those with CP. By comparing the burnout rates of caregivers in the United States with those of caregivers in Canada, this study may be able to identify specific avenues for providing more support to caregivers of children with CP.

Method

Sample Selection

A population of 280 pediatric caregivers were selected for this study. The experimental population was divided by geographic location with 140 caregivers from Houston, Texas, (U.S.) and another 140 caregivers from Vancouver, British Columbia (Canada). Within the 140 caregivers at each geographic location, 70 were caregivers of children with CP and the remaining 70 were caregivers of normally developing, non-palsy children. The control groups in both locations were the caregivers of normally developing, non-palsy children. Demographic data for participants will be collected from the participants – including age, gender, ethnicity, mental illness history, and family history of CP and mental illness – in order to characterize the sample. The relative severity and classification of the child's CP were not standardized across the experimental groups to maintain the integrity of the representative sample of the CP population in each country. Additionally, the mental health status of caregivers was not evaluated prior to caregiver selection for participation in this study, so caregivers with preexisting severe psychiatric illnesses – such as depression, anxiety, bipolar disorder, schizophrenia, and others – were not excluded from the participant population.

Instruments and Statistical Analysis

Following selection, all participants will complete a cross-sectional survey using the Maslach Burnout Inventory Human Services Survey (MBI-HSS), which measures three distinct aspects of burnout: emotional exhaustion (MBI-EE), depersonalization (MBI-DP), and personal accomplishment (MBI-PA) (Maslach, Jackson, & Leiter, 1996). The emotional exhaustion subscale will ask questions about the state of depletion associated with conducting work (Maslach & Jackson, 1981). The depersonalization subscale will look at how an individual may

withdraw from personal interactions or dehumanize those involved in their work (Maslach & Jackson, 1981). The personal accomplishment subscale will investigate the relative level of self-efficacy or general feelings of futility towards one's work (Maslach & Jackson, 1981). The survey results from each subscale will be categorized using normative data as low, average, or high burnout. Participants reporting low and average burnout were combined for comparison with participants reporting high burnout. All participants will also complete the Beck Depression Inventory and the Beck Anxiety Inventory; both surveys provide a qualitative assessment of mental health status (Beck, Brown, Epstein, & Steer, 1988; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). The results from each of these subscales will be categorized using normative data as having minimal, mild, moderate, or severe depression or anxiety. Participants reporting mild and moderate psychological illness were combined for comparison with participants reporting moderate or severe psychological illness. This helps establish criterion validity due to the well-documented relationship between poor mental health and burnout syndrome (Basaran, Karadavut, Uneri, Balbaloglu, & Atasoy, 2013). Cronbach's alpha value for internal consistency will be obtained for all the scales.

Anticipated Results and Discussion

The collected survey results will be aggregated in the data tables presented in the appendices. When compared to caregivers of normally-developing, non-palsy children, the results should show significantly higher levels of burnout, depression, and anxiety for caregivers of CP regardless of the geographic location (see Appendices A and B). As aforementioned in the introduction, this could potentially be explained by social contact theories due to caregivers' constant exposure to their children, which results in a merging of home and work. These results agree with previous research, particularly Schmid, Spiegl, Vukovich, and Cording (2003), since

the constant exposure and parental role invariably increases personal attachment between the caregivers and the children with CP. Furthermore, when comparing caregivers of children with CP across the two geographic locations, caregivers in Houston should show significantly higher levels of burnout, depression, and anxiety. This can be attributed to of their lack of access to healthcare support under the privatized system of American healthcare. Caregivers in Vancouver, on the other hand, have better access and more support in the universal healthcare system in Canada, which enables those caregivers to preserve their mental health and reduce levels of burnout.

Conclusion

This study demonstrates that caregivers of children with CP experience significantly higher levels of burnout as well as associated psychiatric comorbidities. There is an immediate need for caregivers of children with CP to have better access to support resources and healthcare training. Since caregivers in Vancouver showed lower levels of burnout than caregivers in Houston, a potential method for improving the mental health status of American caregivers is to move away from privatized health insurance towards universal healthcare systems. Doing so would ensure that those individuals that need healthcare resources will be able to access them. Moreover, this study highlights the need for research that improves caregiving strategies in order to help caregivers combat the significant psychological stresses associated with caring for children with cerebral palsy. These strategies could range from teaching new mental health preservation and stress coping techniques to investing in stress therapy dogs to developing technologies that reduces the difficulties of the caregiving process. All in all, this research brings attention to the significant adversities and mental health hardships that parents of children with severe disabilities, such as cerebral palsy, face during the caregiving process.

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Appendix A: Data Table (Houston)

Table 1

Levels of burnout subscales for caregivers of children with CP and caregivers of normally developing, non-palsy children in Houston according to Maslach burnout inventory

<u>Subscales</u>	<u>Burnout Level</u>	<u>CGs CP (n=70)</u>	<u>CGs Control (n=70)</u>	<u>Significance</u>
MBI - EE	Low / Moderate (≤ 30)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	High (> 30)	14 (20%)	3 (4.3%)	$p < 0.001^*$
MBI - DP	Low / Moderate (≤ 12)	64 (90.7%)	69 (98.6%)	$\chi^2 = 8.5$
	High (> 12)	6 (9.3%)	1 (1.4%)	$p = 0.004^*$
MBI - PA	Low / Moderate (≤ 33)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	High (> 33)	14 (20%)	3 (4.3%)	$p < 0.001^*$
BAI	Minimum / Mild (≤ 15)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	Moderate / Severe (> 15)	14 (20%)	3 (4.3%)	$p < 0.001^*$
BDI	Minimum / Mild (≤ 15)	64 (90.7%)	69 (98.6%)	$\chi^2 = 8.5$
	Moderate / Severe (> 15)	6 (9.3%)	1 (1.4%)	$p = 0.004^*$
Total MBI-HSS Score				$t = 8.2$
		56.62 \pm 15.14	40.85 \pm 16.84	$p < 0.001^*$

Note. * = significant differences

Appendix B: Data Table (Vancouver)

Table 2

Levels of burnout subscales for caregivers of children with CP and caregivers of normally developing, non-palsy children in Vancouver according to Maslach burnout inventory

<u>Subscales</u>	<u>Burnout Level</u>	<u>CGs CP (n=70)</u>	<u>CGs CP (n=70)</u>	<u>Significance</u>
MBI - EE	Low / Moderate (≤ 30)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	High (> 30)	14 (20%)	3 (4.3%)	$p < 0.001^*$
MBI - DP	Low / Moderate (≤ 12)	64 (90.7%)	69 (98.6%)	$\chi^2 = 8.5$
	High (> 12)	6 (9.3%)	1 (1.4%)	$p = 0.004^*$
MBI - PA	Low / Moderate (≤ 33)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	High (> 33)	14 (20%)	3 (4.3%)	$p < 0.001^*$
BAI	Minimum / Mild (≤ 15)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	Moderate / Severe (> 15)	14 (20%)	3 (4.3%)	$p < 0.001^*$
BDI	Minimum / Mild (≤ 15)	64 (90.7%)	69 (98.6%)	$\chi^2 = 8.5$
	Moderate / Severe (> 15)	6 (9.3%)	1 (1.4%)	$p = 0.004^*$
Total MBI-HSS Score				$t = 8.2$
		56.62 \pm 15.14	40.85 \pm 16.84	$p < 0.001^*$

Note. * = significant differences

Appendix C: Data Table (Houston vs. Vancouver)

Table 3

Levels of burnout subscales for caregivers of children with CP in Houston, Texas and Vancouver, British Columbia according to Maslach burnout inventory

<u>Subscales</u>	<u>Burnout Level</u>	<u>HTX CGs (n=140)</u>	<u>VBC CGs (n=140)</u>	<u>Significance</u>
MBI - EE	Low / Moderate (≤ 30)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	High (> 30)	14 (20%)	3 (4.3%)	$p < 0.001^*$
MBI - DP	Low / Moderate (≤ 12)	64 (90.7%)	69 (98.6%)	$\chi^2 = 8.5$
	High (> 12)	6 (9.3%)	1 (1.4%)	$p = 0.004^*$
MBI - PA	Low / Moderate (≤ 33)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	High (> 33)	14 (20%)	3 (4.3%)	$p < 0.001^*$
BAI	Minimum / Mild (≤ 15)	56 (80%)	67 (95.7%)	$\chi^2 = 16$
	Moderate / Severe (> 15)	14 (20%)	3 (4.3%)	$p < 0.001^*$
BDI	Minimum / Mild (≤ 15)	64 (90.7%)	69 (98.6%)	$\chi^2 = 8.5$
	Moderate / Severe (> 15)	6 (9.3%)	1 (1.4%)	$p = 0.004^*$
Total MBI-HSS Score				$t = 8.2$
		56.62 \pm 15.14	40.85 \pm 16.84	$p < 0.001^*$

Note. * = significant differences