

Negative Affect, Caregiver Burden, and Resilience Levels in Parent Caregivers of Children with Chronic Conditions: A Longitudinal Cohort Study

Abstract

Providing care for another person impacts the caregivers’ personal well-being in many aspects of their lives. (Schulz & Sherwood, 2008) With the growing population and rise in chronic illness across the globe, it is imperative to understand how caregiving affects those providing caring on an individual level. Therefore, the primary purpose of this study was to examine the relationship between negative affect (stress, depression, anxiety), caregiver burden, and resilience levels in parents of children with chronic illnesses, both before and after the onset of the COVID-19 pandemic. The COVID-19 pandemic introduced new stressors, including fears of illness, reduced healthcare access, and social isolation, which may exacerbate the challenges faced by caregivers. A longitudinal design was used, involving 120 parents of children with chronic illnesses and a control group of parents of typically developing children. Participants were assessed for resilience, negative affect, and caregiver burden, with 60 parents reassessed after the onset of COVID-19. The results are expected to show a positive correlation between negative affect and caregiver burden, and an inverse relationship between resilience and caregiver burden and negative affect. This study aims to provide valuable insights into the compounded psychological and physiological impact of chronic caregiving, particularly in the context of external stressors like the COVID-19 pandemic. The findings may inform targeted interventions to help caregivers manage their mental health and improve their well-being, benefiting both caregivers and the children they care for.

Introduction

- Caregiver stress on overall health
- Examine the degree of change that negative affect and caregiver burden have on resilience levels.
- Examine between group differences in negative affect and caregiver burden with resilience levels with parents of those with chronic illnesses before COVID-19 and another group of those same parents after COVID-19.
- Explore the relationships between caregiver groups, resilience, caregiver burden, and negative affect.
- Identify therapeutic approaches and strategies

Methods

- Longitudinal design
- Data collected in two phases (May 2019–Feb 2020; Sept 2022–Sept 2023).
- Convenience sampling
- 175 expressed interest: 55 excluded or withdrew, final sample = 120 participants. n=60 in follow up.
- Negative affect measured using the DASS-21 (Lovibond & Lovibond, 1995)
- Resilience measured with RS-14 (Wagnild, 1993)
- Caregiver burden Inventory (Novak & Guest, 1989)

Results

- Descriptives:
- Middle aged (42.9 & 44.3) , white (95.2% & 92.3%), higher income (147,190.48 & 111,555.38) women (90.5% & 92.9%)
 - Children age: Control=9.99 (5.38) and CHSCN=10.6 (4.44)

Employment Status	Control (n=21)	NC-CD (n=14)	C-CD (n=25)
Full Time Caregiver	4.80	7.10	40.0
Employed Parttime	19.0	7.20	36.0
Employed Fulltime	76.2	85.7	24.0

- Aim 1:
- Parents of children with chronic health conditions experienced greater negative affect (F = 7.72, p = 0.007) and caregiver burden (F = 8.24, p = 0.006) than parents of healthy children.
 - No differences were observed in resilience (F = 0.10, p = 0.75)
 - Significant differences existed on caregiver burden subscales time (p = 0.03), development (p = 0.008), physical health (p = 0.04), all subscales of the DASS-21, anxiety (p = 0.005), stress (p = 0.03), and depression (p = 0.012) and social relationships (p=0.03), but not emotional health (p = 0.14)
 - C-CD group experienced greater caregiver burden (p = 0.002), negative affect (0.036), greater caregiver burden subscales time (p=0.004), development (p=0.016), physical health (p=0.003) and social relationships (p=0.005) and subscales anxiety (p=0.012) and stress (p=0.033) of the DASS-21 than the NC-CD group.
- Aim 2:
- There was a significant main effect for time (F=16.54, p<0.001), but no significant interaction between groups based on child severity and time (F=1.59, p=0.70)
 - Significant main effects for time existed in all subscales and total scores of the DASS-21 and resilience with p<0.001, total caregiver burden (p=0.014) and caregiver burden subscales time (p=0.004) and development (p=0.027).
 - Only the anxiety subscale was significant for the interaction between group and time (p=0.042).

Aim 3:

	Caregiver Group	Resilience	Time Dependency	Development	Physical Health	Emotional Health	Social Relationship	Caregiver Burden	Depression	Anxiety	Stress	DASS-21 Total
Caregiver Group	1.00											
Resilience	0.07	--										
Time Dependency	.428**	-0.082	--									
Development	.399**	0.010	.498**	--								
Physical Health	.331**	0.185	.550**	.701**	--							
Emotional Health	0.137	-0.104	0.190	.593**	0.233	--						
Social Relationships	.418**	0.111	.408**	.733**	.626**	.405**	--					
Caregiver Burden	.464**	0.028	.730**	.909**	.807**	.572**	.825**	--				
Depression	.328*	0.141	.335**	.622**	.604**	.263*	.626**	.636**	--			
Anxiety	.438**	0.081	.416**	.651**	.659**	0.220	.626**	.675**	.694**	--		
Stress	.361**	0.069	.322*	.706**	.611**	.365**	.628**	.678**	.678**	.719**	--	
DASS-21 Total	.424**	0.103	.400**	.742**	.699**	.322*	.700**	.744**	.857**	.904**	.914**	--

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

Discussion

- Homogenous control group and small sample size
- The significant interaction in the anxiety subscale suggests caregivers’ anxiety fluctuates over time, influenced by the child’s health and developmental changes.
- Group C-CD with more full time caregivers have more detrimental overall health statistics possibly due to the higher burden and time dependancy
- Social relationship strain highlights lack of social support which can be related to negative affect, time dependancy, and caregiver burden strains
- Emotional health not significant possibly due to subjectivity of self reporting and confounding factors
- Effects of COVID-19 can exacerbate all groups of people immensely causing no significant group difference

Conclusion

- Higher severity and time dependency in children significantly strained multiple aspects of daily life
- Addressing emotional distress and enhancing resilience may mitigate the negative impacts of caregiving demands.
- Lack of variation in resilience between groups may indicate the need for targeted interventions to enhance in parents under chronic caregiving stress.
- Interventions should focus on reducing caregiver burden through strategies that address time management, developmental guidance, and physical health maintenance.

References

Albayrak, I., Biber, A., Çalışkan, A., & Levendoglu, F. (2019). Assessment of pain, care burden, depression level, sleep quality, fatigue and quality of life in the mothers of children with cerebral palsy. *Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community*, 23(3), 483–494. <https://doi.org/10.1177/1367493519864751>

Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy*, 33(3), 335–343. [https://doi.org/10.1016/0005-7967\(94\)00075-U](https://doi.org/10.1016/0005-7967(94)00075-U)

Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, 29(6), 798–803. <https://doi.org/10.1093/geront/29.6.798>

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American Journal of Nursing*, 108(9 Suppl), 23–27. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>

Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement*, 1(2), 165–178. <https://doi.org/10.1891/1061-3749.1.2.165>