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The Experiences of Children with Neurological Conditions and Families

Charmaine Alexis Pasion

University of St. Augustine for Health Sciences, c.pasion@usa.edu

Jazminne Orozco Arteaga

University of St. Augustine for Health Sciences

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The Experiences of Children with Neurological Conditions and Families

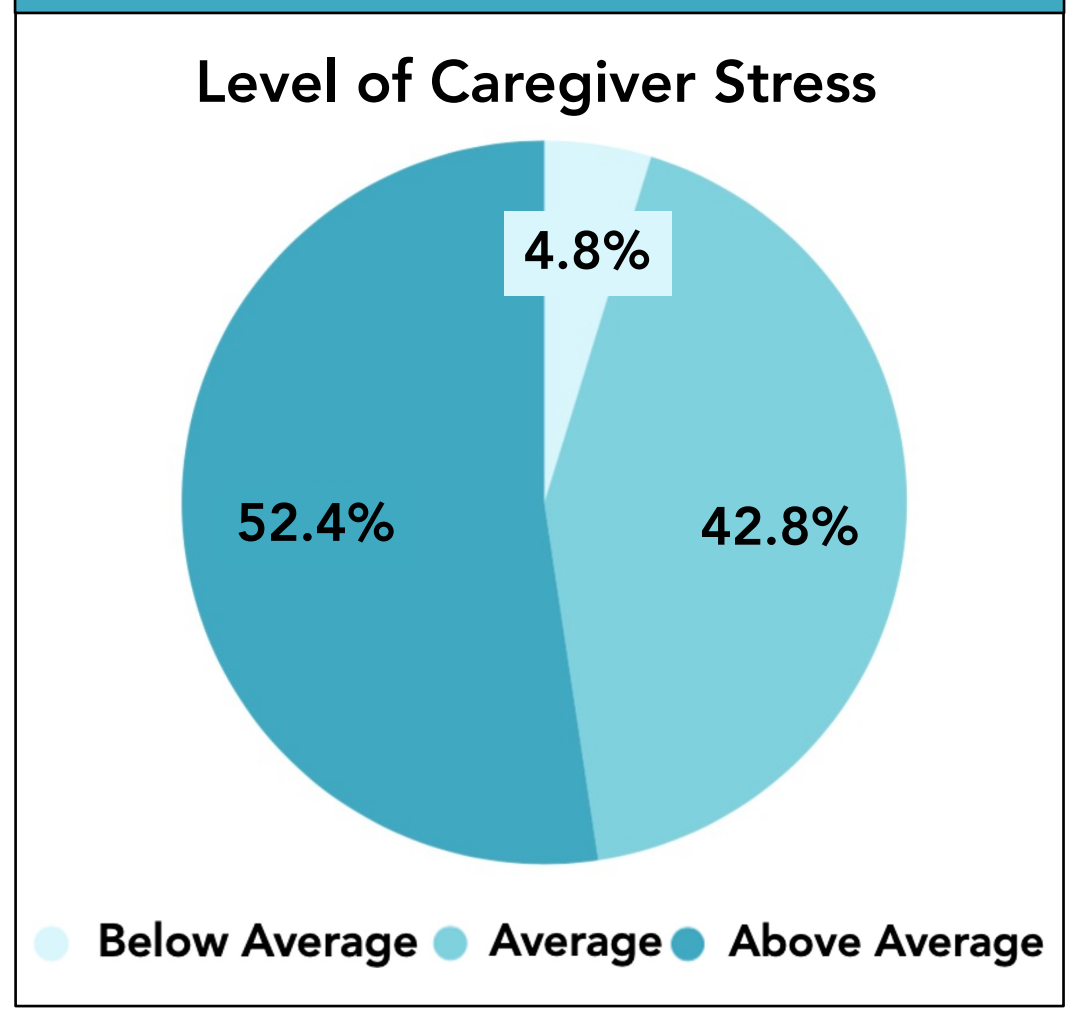
Charmaine Alexis Pasion, OTS; Jazminne Orozco Arteaga, OTD, OTR/L

BACKGROUND

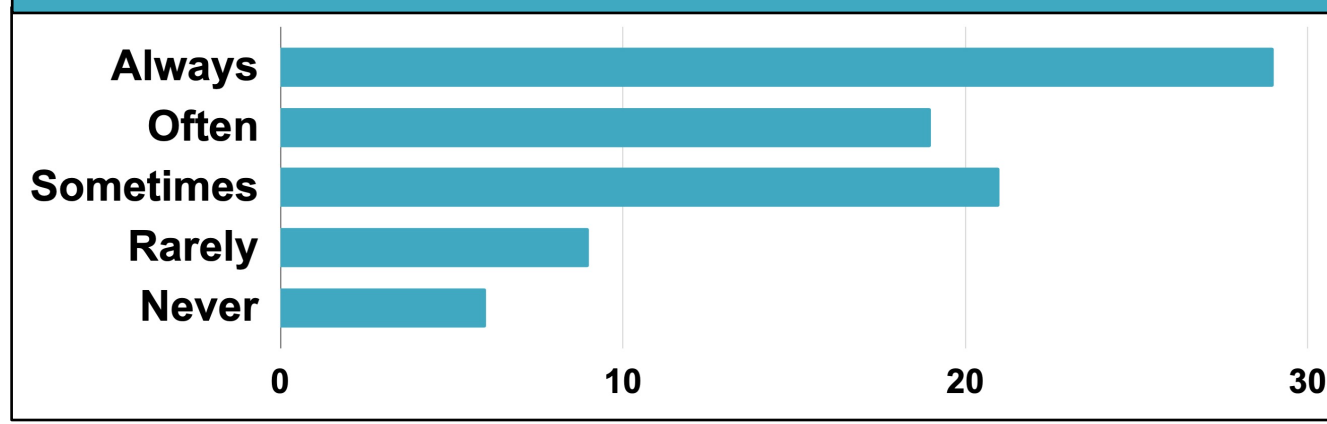
- Children with chronic neurological conditions experience cognitive, global, and physical challenges, which impacts their occupational participation in areas, such as self-care, education, social participation, and leisure (Dumas & Grajo, 2021).
- Due to the unpredictable nature of caring for children with neurological conditions, their families also experience challenges that impact their occupational participation in areas, such as self-care, work, education, social participation, and leisure (Taib et al., 2021).
- Rehabilitation for children with chronic neurological conditions focuses on addressing functional impairments and self-care activities rather than transitioning home (Diener et al., 2021).
- Children and their families receive limited resources and services to address their occupational impact as they return to their occupations and reintegrate back into their communities (Diener et al., 2021; Dumas & Grajo, 2021).

QUANTITATIVE RESULTS

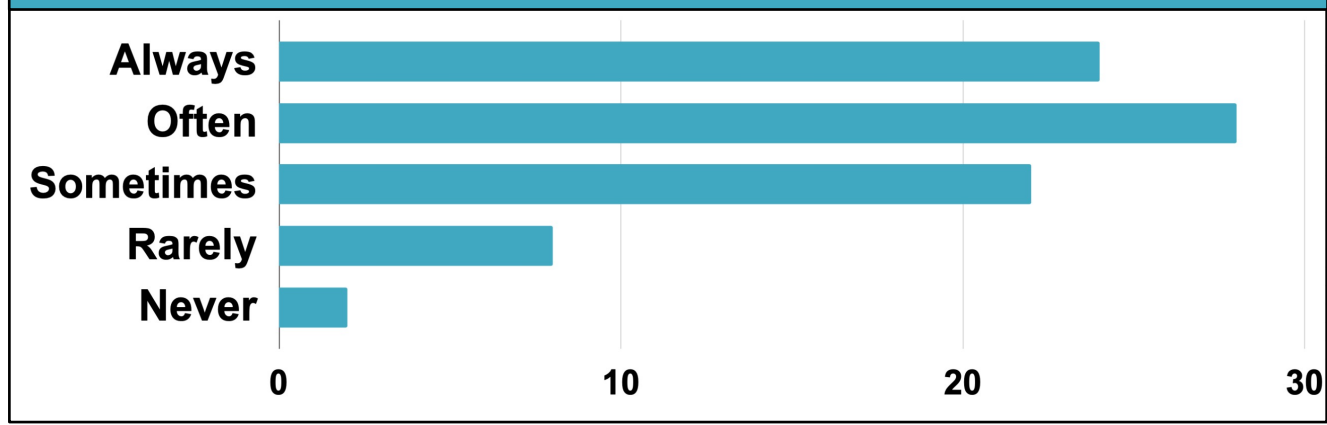
UW Caregiver Stress Scale



How often were children's occupations impacted?



How often were caregivers' occupations impacted?



COPM: Children's	PERF	SAT
Self-Care	4.59	5.71
Productivity	5.70	5.10
Leisure	4.60	5.53

COPM: Caregivers'	PERF	SAT
Self-Care	6.15	4.33
Productivity	5.56	5.00
Leisure	3.76	3.50

PURPOSE

- To explore the experiences of children with neurological conditions and their families and further understand their change in quality of life and occupational impact
- To support the role of occupational therapy in addressing children and families' occupational participation, quality of life, and community reintegration.

QUALITATIVE RESULTS

Themes	Subthemes	Quotes
Navigating the Unexpected	<ul style="list-style-type: none"> • Shift in Life Trajectory • Lack of Anticipatory Guidance • Managing Stress and Emotions • Impact of COVID-19 	<ul style="list-style-type: none"> • "I just feel like this is something I wasn't prepared to deal with, like I thought we were gonna grow out of the constant hand holding." • "With the information that was given, you had to do your own research. Like you were so on your own."
Experiencing Social Isolation	<ul style="list-style-type: none"> • Change in Relationship Dynamics • Societal Stigma • Limited Opportunities for Social Participation 	<ul style="list-style-type: none"> • "... Lots of people in your life just disappear..." • "It was a very, very dark time, and I think the reason that it was so dark is because of the lack of resources and the lack of connectivity to other people who are going through the same thing."
Children's Loss of Occupational Normalcy	<ul style="list-style-type: none"> • Disruption in Occupations • Square Peg in Round Hole 	<ul style="list-style-type: none"> • "We used to go camping, but we had to cut that out. So those kinds of things become disrupted." • "I wish that our schools were more open to different ways of learning, instead of the round peg in the round hole."
Sacrificing Self to Meet Children's Needs	<ul style="list-style-type: none"> • Mom Comes Last • Mom Guilt 	<ul style="list-style-type: none"> • "Mom comes last, so like what gets given up is my free time or my rest or my self-care maintenance and sleep."

DISCUSSION

- Aligned with the literature, children and their families experience negative impacts while participating in their occupations due to unexpected changes, limited guidance, shifts in relationship dynamics, lack of social and educational support, and increased caregiver burden (Dumas & Graco, 2021; Taib et al., 2021).

METHODS

- A mixed methods research design was utilized to gather information on caregivers' perspectives on their children's and their own occupational impact following the diagnosis of chronic neurological conditions. Participants were recruited from online community support groups, national organizations, pediatric clinics, and snowball sampling methods. Instruments included the University of Washington Caregiver Stress Scale and the Canadian Occupational Performance Measure (Amtmann et al., 2020; Law et al., 2014).
 - 21 survey participants (20 mothers, 1 father)
 - 9 interview participants (8 mothers, 1 father)
- In addition to research, observations were conducted to gain insight on the needs of children with chronic conditions and their families at Ronald McDonald House Charities, San Diego.

CONCLUSION

- This research study contributes to the profession of occupational therapy by providing an increased understanding of the experiences of children with chronic neurological conditions and their families as they reintegrate back into their communities.
- Occupational therapists can address their needs by identifying barriers, providing caregiver education, facilitating social support opportunities, and creating wellness programs.
- Future research is needed to support occupational therapy's role in community reintegration for children with chronic neurological conditions and their families, as well as validate the efficacy of occupational therapy programs in community settings.

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REFERENCES

