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Occupational Impact of Caregivers in Pediatric Palliative Care

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Occupational Impact of Caregivers in Pediatric Palliative Care

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BACKGROUND

- Palliative care ≠ Hospice care**
 - Hospice:** a comfort care approach for those who have a limited life expectancy at the end stages of a terminal illness and when curative treatments are no longer effective or appropriate (Chow & Pickens, 2020)
 - Palliative care:** a care approach at any stage of a person's illness, aimed at improving the QOL of patients *and family members*, that is provided alongside curative treatments (Eshaghian-Dorcheh et al., 2019; Chow & Pickens, 2020).
 - Holistic family-centered approach
 - Improve patient/family QOL through physical, emotional, social, and spiritual needs
 - Pediatric conditions: prematurity, birth traumas, genetic disorders, cancer, neurological disorders, congenital anomalies (AOTA, 2023)
- Occupational Therapy in Pediatric Palliative Care**
 - ACOTE and OTPF:** not mentioned
 - AOTA Position Statement** (AOTA, 2023)
 - To generate guidance and support for OTs
 - Supporting caregivers= simplify caregiving tasks, problem-solving, identify/prioritize desired occupations, maintain occupational balance
 - Specific to *pediatrics*= bonding, attachment, co-occupations, bereavement support
- Caregiver Impact in Pediatric Palliative Care**
 - Experience higher levels of physical and psychological symptoms taking a toll on overall health and well-being (Boyden et al., 2022; Koch & Jones, 2018)
 - Neglecting own needs and desires. Identity shift from parent to provider = a norm (Hansson et al., 2023; Thomas et al., 2023)
 - Supporting caregiver needs, benefits the entire family unit (Boyden et al., 2022)

PURPOSE

- The purpose of this research study is to explore the occupational impact of caregiving for a child with a life-limiting and life-threatening condition receiving palliative care services.

METHODS

Design / Analysis

- Mixed methods
- Survey and interview
- Unobtrusive methods
- Guided by PEOP theory
- Dedoose coding software
- Braun and Clarke (2006) Thematic Analysis
- Descriptive analysis
- Survey (n=3)**
 - Microsoft Forms
 - Demographic information
 - Quantitative data
- Interview (n=2)**
 - Microsoft Teams
 - Qualitative data

Participants / Recruitment

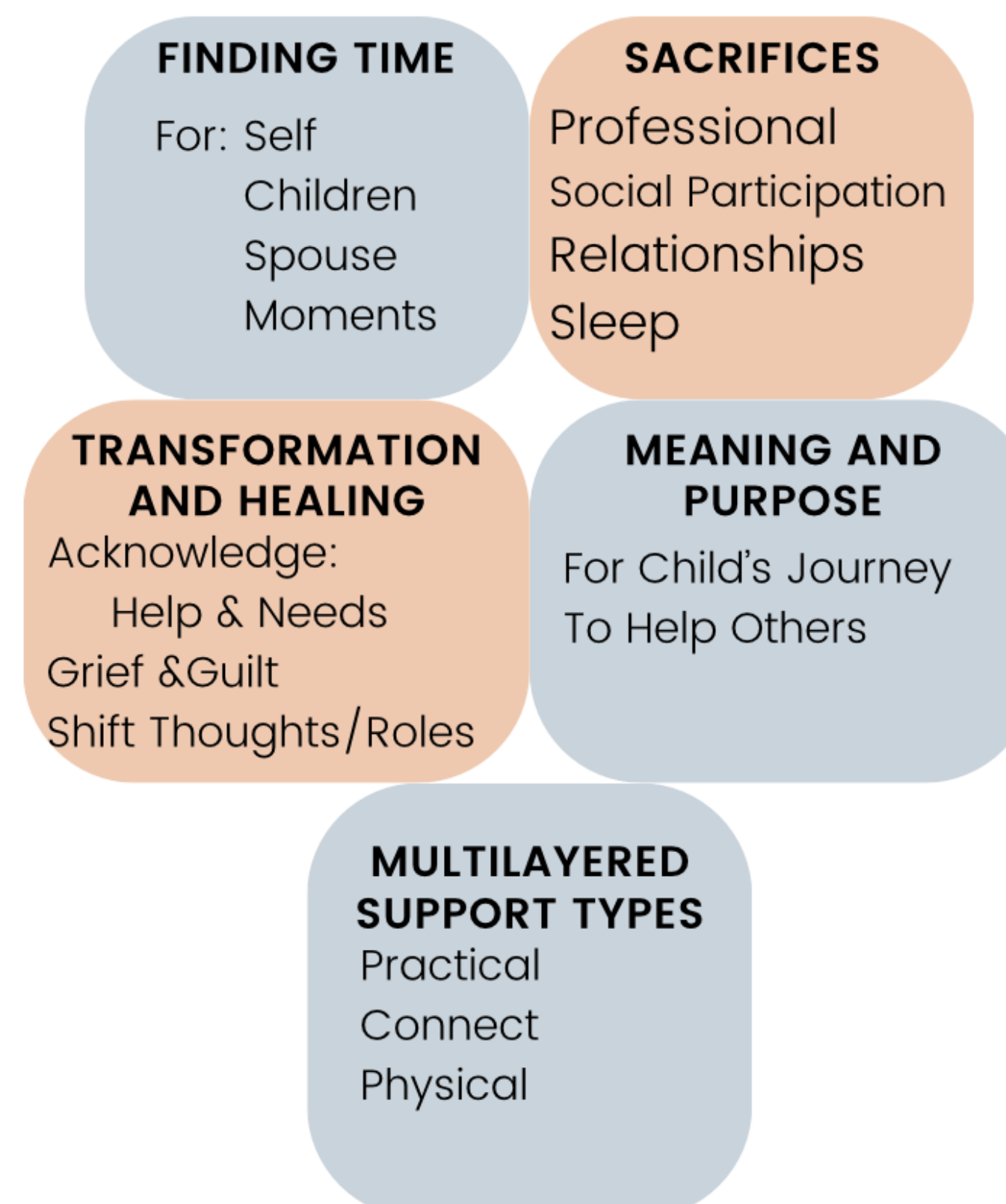
- Recruitment
 - Social media, snowball sample, personal connections
- Participant Inclusion Criteria
 - Caregiver to a child
 - receiving PPC <1 month
 - received PPC in the last 7 years
 - Caregiver aged 18-65
 - Any gender
 - English/Spanish-speaking
- Unobtrusive Methods/Criteria
 - Social media, organizational web pages, academic search engines, streaming services
 - Feb. 2014 – Feb. 2024

RESULTS

Participant Demographics (n=3)

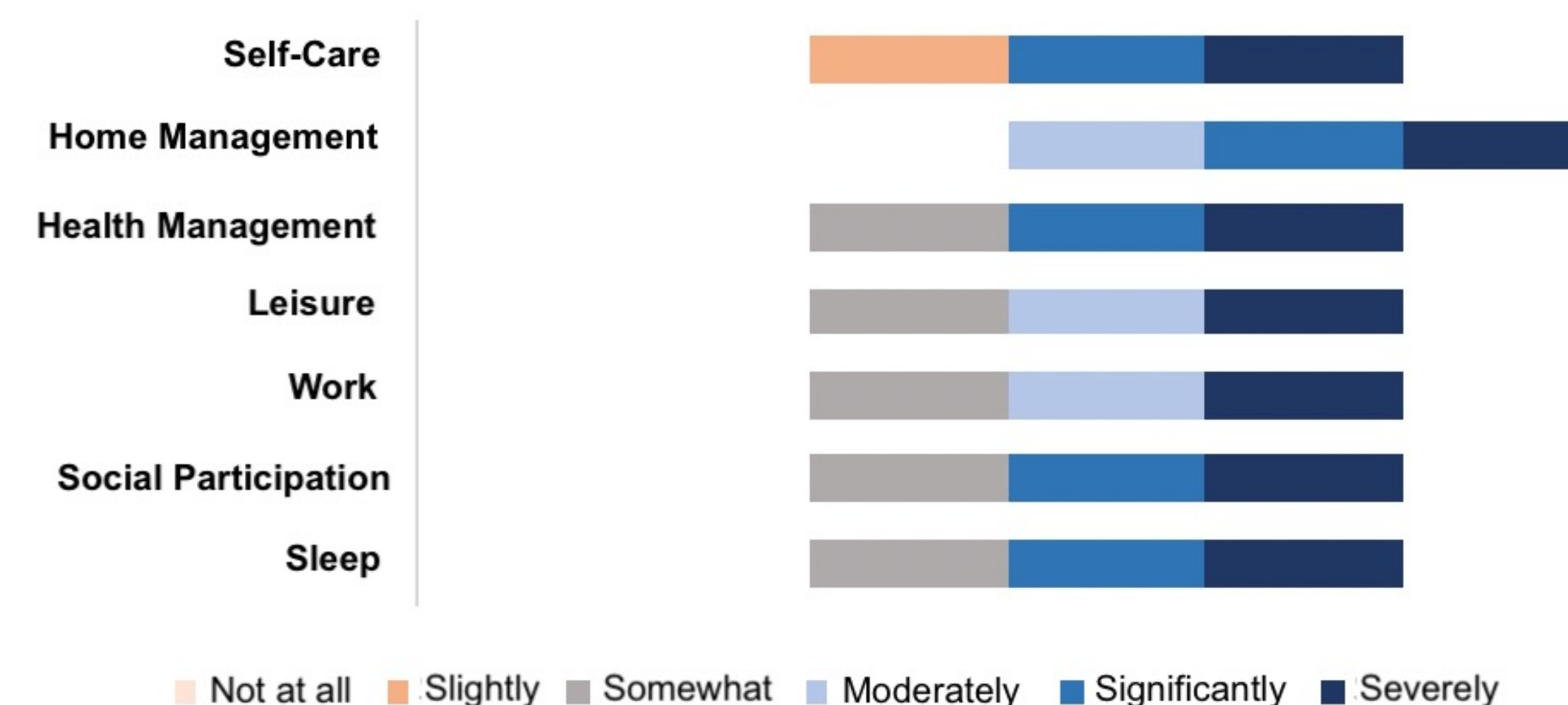
Relationship to the child (n)	Parent (3)	
Age (n)	25-34 (1)	35-44 (2)
Gender (n)	Woman (3)	
Ethnicity (n)	White/Caucasian (3)	
Child's age (n)	0-5 (2)	11-15 (1)
Child time receiving PPC (n)	2 years (2)	4+ (1)

Themes and Sub-Themes



Survey Results

Please rate how much pediatric palliative care has affected your . . .



Themes		Quote
Finding Time	For other children	"we tried to offer our other daughter a normal life and so you know my husband was off doing things with her while I was caring for [child]"
	For self	"and also, just taking time for ourselves, which unfortunately we haven't been able to do a whole lot of lately"
Meaning Purpose	In child's journey	"one of the things I really wanted to emphasize is that I wanted her life to mean something, I didn't want to go, I didn't want it to be quickly forgotten nor did I want it to be wasted, didn't think her life, per say [sic], was wasted, but I didn't want to just have this child forgot about"
	To help others	"like this for instance, me doing a reel about how palliative care is so important and now I can help someone else understand why it's important too"
Sacrifices	Social	"I do not have a social life at home. I cannot go out. I cannot meet any friends. They do not come to me. They say that they do not want to disturb me. I want them to come, but I cannot force anyone to do so. They do meet up with each other, but I stay at home"
	Sleep	"Yes, I don't think I've had much good sleep in the last eight years, probably for various reasons, but uh, you're always on alert at this point"
Transformation and Healing	Thoughts	"I have come to understand that for me, that leaving the home periodically as a form of self-care is a necessity not a luxury"
	Ack. Needs	"the important thing is to develop an awareness of your needs and to strive to fulfill them in whatever way is doable, manageable, and attainable for you."
Multilayered Support Types	Connect	"there's not many other people that you can actually talk to about that it's a very special little tight community and only so many people get it not many people get it unless you go through it"
	Practical	"some of the most helpful ways were people who were very directive with their help, for example can I bring dinner by tonight, can I drive the girls to band tomorrow . . . things like 'how can I help you' felt like a burden to me, I don't know how you can help me"

DISCUSSION

Occupations and themes/sub-themes are interconnected and have an influence on the extent of occupational participation among caregivers

- Self-Care**
 - The ability to *acknowledge areas of help* supports awareness for *self-care* occupations
 - Sacrificing relationships* from those who do not fully understand their needs to focus on prioritizing their *self-care activities*
- Home Management**
 - Willingness to receive or obtain *practical help* supports lightening the *caregiver load around the home*
 - Finding time for their other children and their spouse* may support to maintain familial harmony and a sense of normalcy in the home
- Health Management**
 - Finding meaning and purpose* in their child's illness can help develop a sense of direction and resiliency to *navigate challenges*
 - Finding moments of joy* helps *recharge emotionally and mentally* to enjoy small celebrations and be in the present
- Leisure and Social Participation**
 - The inability to *find time for oneself* may hinder leisure participation levels
 - Connecting with others* in similar situations increases *social participation* opportunities
- Work**
 - To *prioritize their child and family*, professional sacrifices, such as abandoning career aspirations, are a non-negotiable
 - Navigating feelings of grief and guilt* can help develop and understanding of *personal limitations in the workplace*
- Sleep**
 - Developing a hypervigilant mind leads caregivers to sacrifice their own sleep needs to remain attuned to the child's nighttime needs

LIMITATIONS / FUTURE DIRECTIONS

Limitations

Small sample size	All participants were mothers	Delivery of interview questions -unintentional emphasis on the entire family impact
Survey: n=3 Interview: n=2		

Future Directions

Examine effects of occupational therapy led support groups for caregivers	Develop and validate a caregiver-centered outcome measure	Explore the occupational impact of caregivers throughout the lifespan
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QR CODES

Linktree QR Code: →
deliverables, resources, etc.



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This study involves human subjects; it has been reviewed by the IRB and deemed exempt from IRB approval.

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