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Values of Occupational Balance and Harmony among BIPOC Caregivers

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BACKGROUND

- Hospice care as a philosophy of practice
 - Comprehensive, interdisciplinary care that focuses on living (NHPCO, n.d.)
- The values of hospice: respect patients and their families and provide dignified care during the end-of-life (Kennedy, 2016)
- Barriers to hospice care for BIPOC communities: language barriers, low-health literacy, and lack of insurance (Ko et al., 2020; Rising et al., 2021)
- **Family caregivers** may experience burden, guilt and self-doubt related to making health-related decisions (Oliver et al, 2017; McFarlane & Liu, 2020)
- Occupational concerns: research suggests that family caregivers experiencing occupational imbalance negatively impacts their capability to provide care and increase the risk of complications for their loved one (Watford e al, 2019; Teixeria et al, 2020; Ward et al, 2021; Starr et al, 2022)

PURPOSE

To learn about how BIPOC family caregivers value and perceive occupational balance and occupational harmony through a qualitative research study design. The results will support the development of a culturally responsive resource that addresses occupational concerns.

METHODS

Research Question

 What are the values and perspectives of occupational balance and occupational harmony among BIPOC family caregivers in hospice?

Research Design

• **Survey:** Occupational Balance Questionnaire, open-ended questions, and demographics

Inclusion Criteria

family caregivers in hospice or bereavement, ages 18-70 years, identify as BIPOC

Recruitment:

- Contacted eligible family caregivers via phone calls and email
- Community: places of faith, community resource centers, and more.

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PRELIMINARY FINDINGS

Qualitative Findings: Survey Codes

Domains Of Caregiving

 Participant 2 reported that they provide "care and companionship of my family member. Along with working full time."

Spirituality

- Participant 1 reported: "My faith and commitment to my parents.... Others have said I am putting my life on hold and making a sacrifice, but I find myself rather fortunate in that I still have my parents alive and that's something I don't take for granted considering how many people wish they still had their parents. Despite their age and condition, I am truly blessed and thank God every day that I still have them."
- Participant 3 reported: "Prayer and GOD WILL."

Spectrum of Caregiving Strategies

Participant 1 reported: "My time is very limited and find myself exhausted and burned out at times" and that they "work out consistently, eat well (I do cheat sometimes) and try to limit any type of stress or distractions that don't provide anything positive."

Sense of Purpose

 Participant 2 reported: "It is an obligation out of love. It is the most loving act to help and support them as they face end of life."

Quantitative Findings: Occupational Balance Questionnaire

Item	Occupational Balance Item	Mean	Median	Mode
1	In a typical week, I feel there are just enough things to do.	1.33	1	1
2	There is a balance between things I do for myself and things I do for others.	1.33	2	2
3	I make sure I do things I really want to do.	1.33	2	2
4	I balance the different kinds of activities in my life, e.g., work, household chores, leisure, rest, and sleep.	1.67	2	2
5	I have enough time to do the things I must do.	1.33	1	1
6	I have a balance among my physical, social, intellectual, and restful activities.	2	2	2
7	I am satisfied with the amount of time that I spend on my various daily activities.	2	2	2
8	In a typical week, I am satisfied with the number of activities that I take part in.	2	2	2
9	There is enough variation between things that I must do and things that I want to do.	1	1	-
10	There is a balance between activities that give me energy versus those that drain my energy.	1.67	1	-
11	I am satisfied with the amount of time that I spend relaxing, recovering, and sleeping.	1.67	1	-
	Total Score	12.67	11	-

Note. Scale 0-3; 0: Strongly disagree; 1: Disagree; 2: Agree; 3: Strongly agree.

CONCLUSION

- Preliminary codes identified in the study are consistent with current research regarding the experiences of family caregivers in hospice care
 - Values of familism impacting their sense of purpose as they provide care
 - Spirituality is supportive in managing stressors
- Participants identified with cultural values such as familism, mediating the negative effects of caregiver stressors, like caregiver burden (Maximiano-Barreto et al., 2020)
- Though participants didn't discuss social support, research identifies it as supportive and a mediator of caregiver burden (Kayaalp et al., 2021; Hebdon et al., 2022)

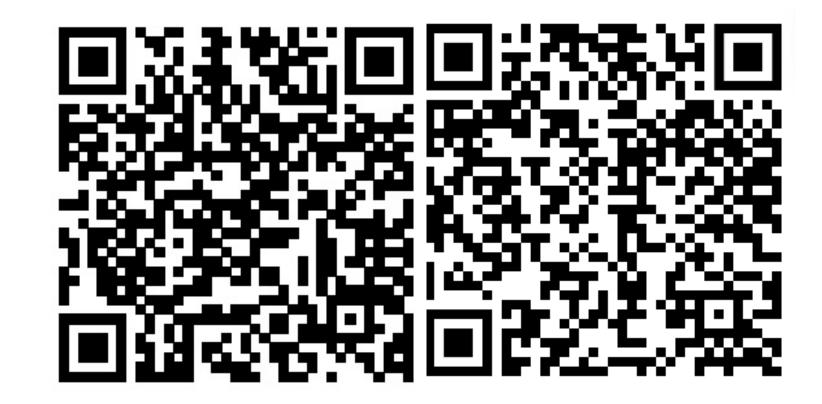
LIMITATIONS

There was a small sample size recruited that completed the survey, and at varying depths in the open-response questions. There were no participants that expressed interest in participating in the virtual interview. The demand on family caregivers in hospice could be too demanding of their time to request time for an interview after completing the survey.

FUTURE RESEARCH

Future research should aim to recruit a larger sample size to learn of the vast diversity within BIPOC communities. In addition, recruiting caregivers of younger ages would further assess the impact of caregivers that provide care for their loved one receiving hospice care and for their children.

REFERENCES & DELIVERABLE



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