Beyond Meaning and Connectedness: Family Caregivers Spiritual Experiences in a Hospice Setting

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Purpose:

The study aimed to describe the experiences of spirituality among family caregivers and how these experiences shape their family caregiving practices while caring for a terminally ill family member in a hospice setting in Karachi, Pakistan.

Methods:

Interpretive descriptive design guided the study. Individual in-depth interviews were used as a method of data collection. Study setting was Baitul-Sukoon Cancer Hospital and Hospice in Karachi, Pakistan. A sample of family caregivers (n=18) and healthcare professionals (n=5) was selected from a cancer hospice facility in Karachi. A total of 28 interviews were taken from the family caregiver participants. For collateral data collection, 5 interviews were taken from the healthcare providers. The qualitative data analysis software, Quirkos, was used to manage the data. Permission for the study was obtained from the Bait-ul-Sukoon Hospice. Ethical approval was obtained from Human Research Ethics Board of the University of Alberta.

Results:

Demographic characteristics of family caregivers showed that mean age of family caregivers was 34.06 years. 83% were Muslims, 78% were female, 72% were married, 28% did not have any formal education, and 72% were living in extended families. 61% reported their income between Canadian $160-200/month. The average caregiving period was 1.72 years. Analysis of the rich descriptions revealed four themes under study which were: family love, attachment, and belongingness; honoring family values and dignity; acts of compassion and selfless service; and seeking God’s kindness and grace. All these themes led to a central theme ‘rise above or self-transcendence’. The four themes reflect the unique experiences of spirituality among family caregivers. Family caregivers identified their uncertainties, losses, and sufferings as part of life and perceived them as invitations to open themselves to the depths of their spirits and to the support, service, and love of others as they experienced ‘rise above’ or self-transcendence. Family caregivers uncovered meaningful engagement, a sense of belonging, and a sense of attachment while serving family and others. They highly valued the love, respect, and honor of the family, showed compassion, believed in God’s blessings and grace and experienced constant spiritual growth and self-transcendence.

Conclusion:

My findings present a novel perspective of spirituality and family caregiving from an eastern context. Findings signify that spirituality is a major resource of coping among family caregivers. Healthcare professionals need to acknowledge and develop spiritual care interventions to support family caregivers' spirituality and spiritual wellbeing at the end of life in the hospice setting.
Title:
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Keywords:
family caregivers, self transcendence and spiritual growth

References:


Abstract Summary:
Participants will be able to embrace the experiences of spirituality among family caregivers caring for their dying family member in a hospice setting from an Eastern context. Findings will guide healthcare professional in developing spiritual care interventions in palliative care

Content Outline:
Discuss the experiences of spirituality among family caregivers in a hospice setting
Meaning of spirituality among family caregivers
Culture, Values, Beliefs
Relational Engagement, Compassion, Love, belongingness, Altruism, Faith

Self Transcendence, Spiritual growth/Transformation

Spiritual Distress

Listening, Presence, Empathy

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**Author Summary:** A qualitative nurse researcher with more than 20 years of experience in nursing in academia, management, and clinical practice setting, from Pakistan and Canada. Her research interests are in the areas of palliative care, spirituality, nurse/women empowerment, and clinical practice. Most of her research work is among underserved and diverse population.