

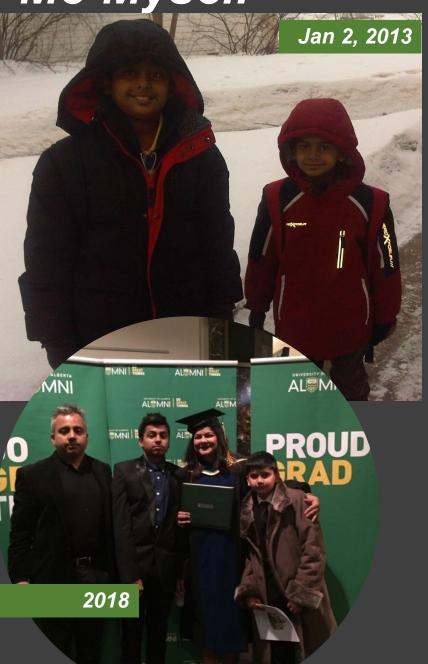
Beyond Meaning and Connectedness: Family Caregivers' Spiritual Experiences in a Hospital Setting

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- July 25, 2019

Presentation Outline

- Background
- Research Purpose
- Methodology
- Findings
- What my research informs
- Future Recommendations

"It is when we include caring and love in our work and in our life that we discover nursing, like teaching, is more than just a job; it is also a lifegiving and life-receiving career for a lifetime of growth and learning." — Jean Watson Me-Myself





- Mother
- Wife
- Immigrant
- Person of a Color
- Nerd

- Nurse
- Educator
- Researcher
- Mentor
- Volunteer







My unwavering gratitude to....

- Friends and Family
- Supervisors
- Mentors
- Colleagues





Funding received....

Research Chair of Aging \$5000

Mu Sigma Chapter Education and Research Award \$2000

Alberta Association of Gerontology \$1000

Background

- Family Caregivers (FCGs) experience various existential and spiritual issues while caring for their family member in the palliative care.
- Families often turn to spirituality in difficult times of caregiving
- Determining spiritual and existential concerns of patients and families are primary goals of palliative care.
- No such studies are available in Pakistan.

Research Questions

- How do family caregivers in Pakistan describe their experiences of spirituality while looking after their family member receiving palliative care in a hospice care setting?
- How do experiences of spirituality shape family caregiving practices in Pakistan?
- How do spiritual practices impact family caregiver's caregiving experiences?



Study Setting

- Baitul-Sukoon Cancer Hospital and Hospice in Karachi, Pakistan
- 45 bed hospital
- Nurse-Patient ratio 1:20
- 38% of the patients require hospice support
- Average length of stay 2 4 weeks
- Most of the physical care is provided by families

Methodology

Design: Interpretive Description Sample: Purposive Sampling

Family caregivers (FCG) (n=18)

Data Collection:
Semi structured
in-depth
interviews (26
interviews)

Data Analysis: Thematic analysis

Collection Data **Process**

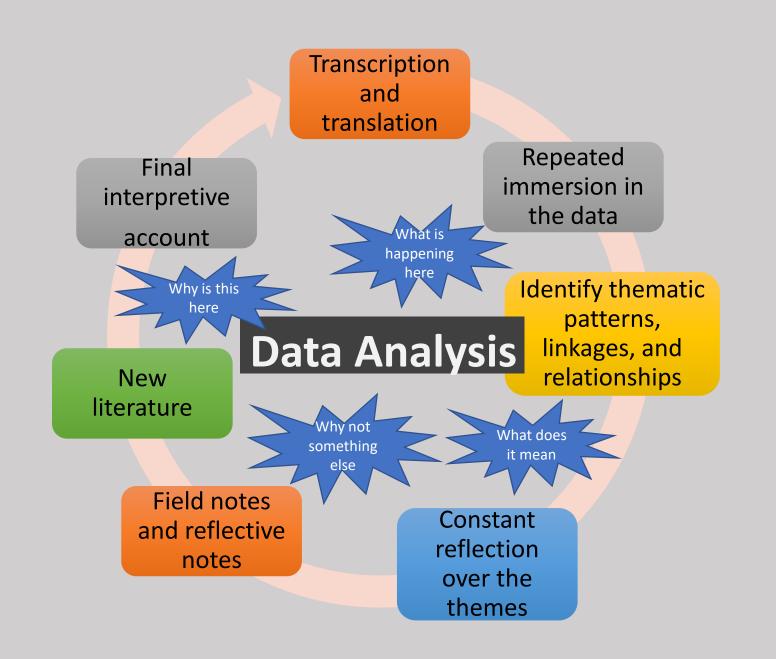
Verbal/Ongoing Consent from Participants

Demographic Information

Interview (60-90 min, audiotaped/transcribed and translated)

Appointment for the next Interview

Field Notes and Reflexive Notes





Demographic Information

Context of Caregiving

Experiences of Spirituality among FCGs

FCGs Expectations from Healthcare Providers

Findings (Four Major Sections)

Demographic Information

Total participants=18

Age: Mean: 34.06, SD: 10.95

Gender: Male: 22% Female: 78%

Marital status: Single: 28%, Married: 72%

Religion: Muslims: 83%, Hindus: 11%, Christians: 6%

Length of caregiving: Mean: 1.72 years, SD: 1.10

Type of family: Extended: 72%, Nuclear: 28%

Family members living under one roof: Mean: 8.56, SD: 4.69

Family Love, Attachment, and Belongingness (Apnaiyat): *My family gives me purpose in my life*

Major Findings

Honoring family values and dignity: *I do not want to bring any* shame or dishonor to my family

Acts of Compassion and selfless service: *I find eternal peace* and satisfaction in serving others

Seeking God's kindness and grace: *Everything lies in God's hands*

Rising above or self transcendence: *I see myself a better person*

Family Love,
Attachment, and
Belongingness
(Apnaiyat): My
family gives me
purpose in my
life

- Spirituality is 'apnaiyat', meaning "a feeling of relatedness", or "belongingness towards family and others".
- "Spirituality is natural, not everyone has it...this feeling grows as you live with others, you develop attachment or belongingness."
- Belongingness vs connectedness
- Family relationships, perseverance, and devotion was highly valued- "It is my family that gives me spiritual serenity and spiritual certitude."

Honoring Family Values and Dignity: "I don't want to bring any shame or dishonor to my family"

- Serving parents and elderly was considered as a blessed and meaningful task.
- Deep sense of closeness and engagement among family members.
- Values of Filial piety and Dharma was evident.
- "Yes it is not (ehsaan) favor to my parents. This gives me happiness. I am lucky that I am getting opportunity to serve him in this condition. ...it is a huge sin to ignore parents care. I say if parents are there in anyone's life there is meaning in it. Otherwise there is not life without them."

Acts of Compassion and Selfless Service: "I find peace and eternal satisfaction in serving family and others" Family caregivers relished compassionate and altruistic values, that provided a strong sense of self worth and positive spiritual outlook.

- The selfless care and compassionate service provided a sense of togetherness and prevented the families from experiencing isolation while experience pain and suffering.
- "Serving is life...without it life seems meaningless and incomplete. I feel addicted to serving others. Serving others keep me composed, peaceful, and calm."

Seeking God's Kindness and Grace: Everything lies in God's Hands

- God is absolute. Everything happens with his will.
- Acts of submission follows the path of spiritual attainment.
- My inner strength lies in my faith in God.
 Medicine and treatment are all secondary.
- Some family caregivers experienced spiritual distress but had complete faith in Allah's mercy and forgiveness.
- "Every time I have been in trouble, Allah has guided and supported me."
- Performing prayers and spiritual practices provided strength and courage to cope.

Rise Above or Self Transcendence: "I see myself a better person"

- "Hardships (Majboori) takes a person to a place where one would never imagine going."
- Suffering acted as a spiritual call for FCGs. Spirituality enabled to find meaning in the caregiving practices and eventually led them to a transcendent experience.
- "The though of dying helps and brings you closer to God."
- Spiritual reciprocity was a driving force, a source of motivation and encouragements among FCGs.
- Humanistic and spiritual values such as love and kindness, selfless service, faith and trust in the higher power, all these qualities within FCGs helped them to spiritually grow and transformed them into a strong, resilient and self-effacing individuals.

My doctoral research informs...



- Spirituality can be major resource of coping for FCGs and therefore is an important dimension of care.
- Suffering acted as a spiritual call for FCGs. Spirituality enabled participants
 to find meaning in caregiving practices and eventually led some
 participants to a transcendent experience.
- Presence, listening and compassionate caring serve as a source of hope, spiritual strength, and satisfaction for the family caregivers.
- Spirituality need not to be added as a part of our but should become a foundation of our care

The real challenge is how to incorporate spirituality in our curriculum and practice?

