INTRODUCTION

The caregiving career is a phase-oriented framework acknowledging the myriad of complex tasks and adjustments family members are subject to when assuming the caregiver role. A phase approach allows for deeper insight into how the role of caregiver becomes embedded in an individual's identity; however, there exists a space to understand how the assumption of the caregiver identity and the loss of interational/shared identity between caregiving daughters and their mothers with dementia (MWD) influence daughters’ postcaregiving experiences.

STATEMENT OF THE PROBLEM

The specific problem addressed in this study was the lack of understanding about how the loss of interational/shared identity between caregiving daughters and their MWD and assumption of the caregiver identity influence daughters’ postcaregiving experiences. The information gleaned in this study will inform therapists, health care providers, and care professionals who interact with and treat former caregivers of persons with dementia.

RESEARCH QUESTIONS

RQ1: How do caregiving daughters describe the loss of interational/shared identity that occurred during the disease process with their MWD?

RQ2: How do caregiving daughters describe the influence of the loss of interational/shared identity that occurred during the disease process on their postcaregiving experience?

RQ3: How do the experiences of postcaregiving daughters of MWD inform current dementia caregivers and professionals?

MATERIALS & METHODS

Qualitative methodology, narrative approach
  • Two semistructured, open-ended interviews
  • Field Notes
  • Participant Artifacts

Careographies
  Careographies create a visual timeline that links salient moments in caregiving with the caregiver’s internal reactions and processes to provide a more holistic view of the context of care (Orzech. 2016, 2017).

RESULTS

RQ1:
  • Change the Dance Steps
    - Follow Mom’s Example
    - Protect Mom’s Identity
    - Preserve Our Relationship
    - Innocence of Dementia
    - Loss of Shared Identity
  Each daughter’s candid and thoughtful dialogue about her caregiving journey revealed conscious and unconscious efforts to change the dance steps in order to move with the innocence of dementia as daughters worked to protect their mothers’ identity, preserve their relationships with their mothers, and insulate themselves from the loss of shared identity by following their mother’s example and drawing on their lifetime of intimate exchange with their mothers.

RQ2: Walk Her Home
  - Mom’s Messages About Identity
  - Legacy of Loss
  - Reframe Shared Identity
  - Things to Do Differently
  - Healing Journey
  Daughters faithfully walked their mothers home by preserving or examining the messages their mothers gave them about identity and choosing to experience the legacy of loss inherent with caregiving. Daughters reframed their shared identity, selected things to do differently in the future, and learned to see their caregiving experience as a healing journey for themselves but also for their shared relationship with their mothers.

RQ3: Messages to Caregivers and Professionals
  - Caring for More Than One
  - Family Dynamics
  - Supports
  - Self-Care
  - Lessons Learned From the Pandemic
  - Filling the Postcaregiving Void
  - Messages to Caregivers and Professionals
  Daughters felt compelled to speak to other caregivers with words of encouragement and advice, and to advise professionals in the dementia care community about the needs of caregivers during and after the caregiving experience.

CONCLUSIONS

• Caregivers of persons with dementia need more psychosocial support to help them manage the conflicting feelings they have about the care recipient, their role as caregiver, and the loss of intimate exchange they are experiencing with the care recipient.
• Caregivers of persons with dementia need greater access to resources and services.
• Caregivers of persons with dementia need an inclusive approach to caregiving where existing interventions are embedded into family dementia care (Ormel, 2017; Suitor, 2019).
• Former caregivers need immediate and ongoing assistance in transitioning to the postcaregiving phase and making sense of the other phases of caregiving (caring onset, active caring, ending caring; Aneshensel et al., 1995; Cavaye & Watts, 2016; Lindgren, 1993; Ume & Evans, 2011).
• Professionals should be looking for and promoting ways to extend care to former caregivers by offering support groups, granting access to health care professionals who the caregivers already know and trust from their dementia caregiving experience, and pairing newly former caregivers with peer supporters who understand the loss of intimate exchange during the dementia journey and are able to walk alongside the newly bereaved caregiver during the first critical months of the postcaregiving phase.

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