A META-SYNTHESIS: THE CAREGIVER'S EXPERIENCE WITH INSTITUTIONALIZING A LOVED ONE WITH DEMENTIA

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LEARNING OBJECTIVES:

1. Identify two overarching phenomenological themes confronting caregivers when experiencing institutionalization of a loved with dementia.

2. Illustrate an example of successful interventions by a health care provider in response to an overarching theme during the timeline to institutionalization.

RESEARCH PURPOSE:

To execute a meta-synthesis of qualitative literature on the course caregivers navigate when faced with the institutionalization of a loved one with dementia. Constructing a larger narrative by identifying overarching themes will advance the knowledge and understanding of the caregiver’s journey and the decisions they make.

BACKGROUND:

Dementia affects more than 5 million Americans and is predicted to rise to 12 million cases by the year 2050. Profoundly disabling in nature, dementia gradually reduces all of the patient’s personal and interpersonal functional abilities. The average caregiver delivers 8 years of support to the dementia patient and by end stages, there is a severe calculable burden recognized. Caregivers are conflicted, confused and confounded with the concept of institutionalization.

RESEARCH METHODS:

The process and product of scientific inquiry aimed at systematically reviewing and formally integrating the findings of completed qualitative research studies. Ten studies were synthesized according to Noblit and Hare’s methodology. Key themes were reciprocally translated into a set of overarching metaphors for a greater understanding of patterns, milestones and goals of the placement process.
RESEARCH RESULTS:

Analytic data revealed a comprehensive schema to understand the experience and process of caregivers navigating the intrinsic and extrinsic issues surrounding institutionalization.

Five overarching metaphors were identified:

1. **The Defining Moment.**

   The flash of recognition when a caregiver realized the impossibility of continuing primary home care of their loved one with dementia is a genuinely despairing moment. A crisis or precipitating event was recognized in 9 of the 10 studies.

2. **The Emotional Roller Coaster**

   Caregivers are tasked with superhuman roles and assignments. The weight of the world seems to lie on their shoulders with frequent thoughts of not wanting to burden others. This theme was the singular overarching concept shared by all ten of the studies reviewed. The participants reported problems with their mental health. Family caregivers reported guilt, helplessness, loss, loneliness and regret.

3. **Seeking Absolution**

   Attending to responsibility, vows and commitments are at odds with the process of institutionalizing a loved one. The framework of a marriage was notably strong in studies with vows and commitments being very powerful. There is an important role that professionals play in the decision making process, and allows attribution of blame to authorities as well as legitimation.

4. **Improvising a Plan**

   The impracticality of caregiving or the safety of a loved one is at risk. The next step is to navigate the journey, literally and figuratively, to find suitable alternative plans that will in effect share the caregiver’s burden. The possibilities include structure, support of kin-care relationships, day care, assisted living, respite or nursing home accommodations.

5. **Renewing Self**

   The caregiver’s renewal of their own sense of self that is their personal identity. The arduous task of caregiver roles and provider of care and nurturance does not end when a loved one is institutionalized. Caregivers struck with the sense of freedom, yet determined responsibility for spousal-parental care, are conflicted. This engenders an ambiguous role while they desperately search for identity.
CONCLUSIONS/IMPLICATIONS:

The perspectives derived from the overarching themes allow a vision which characterizes that arduous experience. It identifies the unique challenges and potential responses which determine the healthiness and degree of success a family will find in healing, grief and bereavement when a loved one is institutionalized. It can allow healthcare providers to monitor, plan, guide, treat and educate clients at appropriate times along the continuum of the decision process.

OVERARCHING THEMES ALONG A TIMELINE:
REFERENCES


