Transitioning into the caregiver role following a diagnosis of Alzheimer’s disease or related dementia: A scoping review

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Introduction

Background
- The diagnosis of Alzheimer’s disease or related dementia (ADRD) marks transition of family members into the caregiver role.
- This transition period is a critical time as family members adjust to the diagnosis and are faced with challenges of becoming a caregiver.
- A sufficient understanding of family caregiver experience and responses around this time of transition can help ensure appropriate support for caregivers.

Purpose
- This scoping review describes the current literature about caregiver’s experiences and needs during the period following diagnosis, and promising interventions.

Methods

Design
- Scoping review of published literature.

Data sources
- A search for published articles was conducted in PsycINFO, Scopus, Ovid and Web of Science databases.

Review methods
- Studies were screened independently for inclusion by two persons. A total of 955 studies, after duplicates removed, were found by the database search.
- From these, 127 full-text articles were retained through the screening of titles and abstracts by two reviewers. The two reviewers assessed 46 full-text articles for eligibility.
- The final 29 studies identified caregiver experiences, needs, and interventions during the period following a diagnosis of ADRD in the scoping review.

Results

The 29 studies were organized around three major categories:
- Family caregiver experiences on receiving the diagnosis (n = 23)
- Needs during this time of transition (n = 18)
- Interventions and outcomes to support their transition into the caregiver role (n = 5).

Experiences
- At time of diagnosis, caregivers experience psychological distress, changes in relationships with family members and increase in responsibilities in the caregiver role.
- Female caregivers have more family conflict, depressive symptoms and distress compared with male caregivers.

Needs
- Transitioning into the role gives rise to needs that include knowledge and information, emotional support including peer support, and assistance with planning care.

Interventions
- Caregivers experience significant strain and depression even early in their care trajectory, though these outcomes can be effectively targeted with interventions.

Discussion

- During role transition following ADRD diagnosis, caregivers experience changes, including changes in their relationship with the recipient of care and new roles and responsibilities.
- Findings suggest the discrepancies in mental health outcomes experienced by female caregivers compared to male begin early in the caregiving trajectory.
- Targeted and timely interventions are significant to this transition in order to support better outcomes for caregivers and care recipients.
  - Promising interventions components include: information, education, psycho-social support, and enhancing problem-solving skills.

Implications

- Caregivers undergo a range of unique experiences and have new needs when transitioning into a diagnosis that can be incorporated into the plan of care.
- Service providers need to be aware that receiving information at the right time is invaluable to caregivers as it helps them anticipate future events.
- Research with longer follow up periods is needed to better understand the impact of early intervention on later caregiving outcomes.
- Despite the plethora of current models of support and interventions for caregivers, more programs tailored to the unique needs of ADRD are needed.

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