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Review

Best practices interventions to improve quality of care of people with dementia living at home

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ABSTRACT

Objective: To identify effective interventions which improve quality of care for people with dementia (PwD) living at home.
Methods: MEDLINE-(via PubMed), CINAHL, PsycINFO and ISI Web of Science databases were searched. Inclusion criteria: (1) randomized controlled trials; (2) published in English-language, peer-reviewed journals between 1990 and 2012; (3) evaluated strategies to improve quality of care for PwD cared at home; and (4) participants older than 65.
Results: 23 studies met inclusion criteria. All the studies aimed to improve PwD quality of care and most of them focused on PwD caregivers. Psychoeducational programs are the most frequently assessed interventions and multicomponent interventions produced the most promising results.
Conclusion: Due to the great variety of interventions describing specific samples and contexts, comparison of practice effectiveness is difficult. However, cognitive rehabilitation in PwD is effective when applied at an early stage of the disease. Case managers have demonstrated to reduce PwD institutionalization and the use of other community services. The studies were limited by sample heterogeneity, short follow-up or insufficiently detailed description.
Practice implications: To improve PwD homecare, health professionals should educate and support caregivers. Before specific interventional recommendations can be made, further research addressing the limitations of current studies is needed.

Contents

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1. Introduction

Health care systems face challenges with regard to chronic-disease management, including how providers should assist patients in their choices and improve the bio-psycho-social aspects of their health and well-being [1]. Policies should focus on improving the adequacy of the services covering new care needs and increasing social participation in health care matters [2,3]. Chronicity care, which involves health promotion, prevention, self management, disease control, treatment and disease palliation [4] as applied to patients with dementia, requires interdisciplinary teams formed by professionals who provide distinct health and social services and ensure continuity of care with patient and family commitment [5]. Although, not much is known about what constitutes best clinical practice for this population, most European countries' policy is to try to keep people at home as long as possible, considering admission to a nursing home as a clinical endpoint when the family is overwhelmed by the patient's cognitive and functional impairment [6,7].

Dementia affects about 24 million people worldwide and this number is expected to increase to 42 million by 2020 and to 81 million by 2040 [8]. The prevalence doubles with every five-year increment after the age of 65 [9]. Alzheimer's disease (AD) and other related dementias are public health priorities in European Union Member States due to their prevalence, cost and profound impact on society [10].

The complexity of this disease, the heterogeneity of the family support and the differing healthcare, social and welfare services across countries and communities make it very difficult to establish best practices to improve the quality care for this population in a home care setting [11]. A considerable body of the published literature exists indicating that caring for PwD in their homes, as compared with caring for other types of patient, is extremely demanding and places a huge burden on the family and other caregivers [12–16] as 90% of their care is provided by relatives [5,17]. Consequently, there is a substantial need for caregiver support from professionals, depending on the nature of the most serious problems they face and their experience in dealing with the disease [17–19]. Since there is no single *guideline* on how best to care for PwD at home and a lack of strong evidence supporting any particular intervention in previous reviews [20,21], we have defined the term 'best practice' as "a program, activity or strategy that has the highest degree of proven effectiveness supported by objective, comprehensive research and evaluation" [22].

Traditionally, in order to provide better care and support, home care professionals have prioritized associated-symptom management using antipsychotic, antidepressant or anxiolytic medication [23–25]. However, available pharmacological treatments are only modestly effective, have a notable risk, and do not effectively treat some of the behaviors that family members and caregivers find most distressing [11]. Therefore, it is necessary to identify effective non-pharmacological interventions that improve quality of care in home-setting dementia care. Psychosocial interventions [22,26] should include a diverse set of approaches including emotional support, extending social networks, stress management, problem-solving, behavioral management and cognitive restructuring, or focus on particular outcomes, such as caregiver burden [22,27]. It is also important to bear in mind that there are other best practices depending on the symptom or complication being treated. PwD symptoms are usually distressing both for the person with dementia and for the *caregiver* and this has been considered in this review.

The goal of this review is to identify effective interventions to improve quality of care of people with dementia living at home addressed to the PwD themselves and their caregivers, guided by health care professionals. This review would help in the development of preliminary, evidence-based interventions for PwD home care.

This review is part of RightTimePlaceCare (RTPC) – (HEALTH-F3-2010-242153), a European Commission 7th program project that includes eight European countries: Germany (Coordinator), England, Estonia, Finland, France, Spain, Sweden and The Netherlands.

2. Methods

2.1. Study selection

A literature search was conducted using the MeSH terms "dementia", "Alzheimer's disease", "patient care" and "home-care" as key search words in the following electronic databases: MEDLINE (PubMed), CINAHL, PsycINFO and ISI Web of Science. To focus on best practice and to obtain a general overview of the quality of care, the Donabedian model [28], as a classic and comprehensive paradigm for assessing quality of care, was used in the literature search. The MeSH terms were combined with 52 key words from this model in its three components: structure, process, and outcomes (see Table 1). Structure identifies the care setting (type of facilities, equipment required, economic aspects, human-resource coordination, integration of services and organizational structure). Process relates to the nature of caregiving (frequency, intensity, coordination, evaluation, family involvement, education, and consideration of the person with dementia and their caregivers' preferences, needs, safety and beliefs). Outcome represents the effect of the practice on the patients' quality of care. The focus was solely on randomized controlled trials (RCT) dealing with interventions to improve quality of care for people