Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies

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CRD summary
This review concluded that there were several ways to improve healthcare experiences of people with dementia and their caregivers; strategies for improving service delivery for these groups were in line with an emphasis on person-centred care. There were some areas in which the synthesis was not transparent this review is probably reliable.

Authors’ objectives
To explore the healthcare experience of people with dementia and their caregivers in primary care settings.

Searching
MEDLINE, EMBASE, CINAHL and PsycINFO were searched from inception to August 2011. Search terms were reported in an online appendix. Two qualitative journals were also searched. Only studies published in English were eligible for inclusion.

Study selection
Qualitative studies that used interviews or focus groups to assess the healthcare experiences of people with dementia in primary care were included. Mixed methods studies were also included but only qualitative data were extracted from these. People with dementia were defined using standard criteria (not reported) and caregivers were defined as informal caregivers such as friends and family.

Most studies focused on caregivers, while many included both people with dementia and caregivers; only a minority exclusively looked at the experiences of people with dementia. Most studies used interviews but there were also a number of focus groups. The principal experiences explored ranged across all aspects of service provision, and included some experiences of minority groups. Where reported, several methodologies were employed including grounded theory, content analysis and thematic analysis. Most of the included studies were conducted in the UK, USA, Canada or Australia.

Two reviewers independently assessed the studies for inclusion in the review.

Assessment of study quality
The studies were assessed for validity using the Consolidated Criteria for Reporting Qualitative Research (COREQ) which assesses 32 items. Two reviewers independently assessed around two-thirds of the studies; the remainder were assessed by a single reviewer.

Data extraction
Two reviewers extracted relevant quotations (first order constructs) and the investigators’ interpretations of these (second order constructs) from the studies. The process was carried out in chronological order of study publication and extraction continued until saturation was achieved.

Methods of synthesis
Meta-ethnography was used to synthesize the second-order constructs from the included studies into third order constructs which represented the reviewers’ interpretation of the common themes from the primary studies, derived from first and second order constructs. The reviewers met to discuss the process and interpretations throughout the review process. A conceptual framework for overall healthcare experience was developed.

Results of the review
Forty-six studies were included in the review. These included 1,866 participants with a mean number of 41 participants per study. Seven studies involved people with dementia, 25 involved carers and 14 involved both. The mean score on the Consolidated Criteria for Reporting Qualitative Research (COREQ) assessment was 15 (range 3 to 25) out of 32
items. Strengths reported by most studies were consistent data and findings, clarity of major themes, participant quotations, sampling methods, methods of approach and sample size. Common weaknesses were reporting of interviewer characteristics and participant knowledge of, or prior relationship with, the interviewer.

Five major themes were identified: seeking a diagnosis; accessing supports and services; addressing information needs; disease management; communication and attitudes.

Seeking a diagnosis: The importance of timeliness in receiving a diagnosis was emphasised; earlier diagnoses led to easier subsequent transitions. Reactions to diagnosis ranged from shock to relief and were related to whether dementia had been suspected.

Accessing support and services: The importance of support or services being in line with current needs was emphasised. People often felt that it took too long to find assistance. Participants perceived a lack of knowledge about available services by primary care providers which led to difficulty obtaining help. There were delays in accessing specialist services such as memory clinics but the services were regarded positively.

Addressing information needs: The experience of having to "push" to obtain information was reported. Clarity of information and written communication were valued but it was important that the quantity of information should not be overwhelming.

Disease management: The level of knowledge about dementia by healthcare providers significantly impacted on the perceived effectiveness of disease management. Many caregivers reported needing to initiate the process of aspects of disease management.

Communication and attitudes: Both people with dementia and their caregivers felt it was important that their perspectives were valued. Sensitivity and validation of feelings, together with being treated with respect and dignity, were appreciated. Poor communication and/or attitudes could be barriers to treatment, whereas when these were good it put patients at ease and facilitated interactions.

Authors' conclusions
Several opportunities were identified to improve the healthcare experiences of people with dementia and their caregivers. Strategies for improving service delivery for these groups were in line with an emphasis on person-centred care.

CRD commentary
The review explored a clear question supported by clear and appropriate inclusion criteria. The search was reasonable but may not have identified unpublished studies. The authors also described extracting data until saturation (no new concepts identified) was reached. Included studies were relevant to the review question but mostly reflected the perspectives of carers. There was also little information on the characteristics of the participants. The authors used methods designed to reduce the potential for error or bias throughout their review process.

The review process was clearly described and concepts at each level could be linked to each other, although it was not clear whether all the evidence informing each theme was presented. Study quality was assessed using an appropriate tool and results of the assessment were reported in enough detail. However, it was difficult to link study quality to the concepts and themes informed by each study. Although the role of investigators in included studies was assessed, the perspective of the reviewers was not clearly documented.

Although there were some issues around the precise contributions to each higher order concept, the review was reasonably well-conducted and the findings are probably reliable.

Implications of the review for practice and research
Practice: The authors noted both general and specific changes to dementia care which might improve people with dementia and their caregivers' experience. General measures were the improvement of communication and attitudes around dementia and primary care providers' awareness of person-centred care approaches. These may be improved by additional education around dementia and its management. Specific measures included outreach and public education strategies for raising dementia awareness; the introduction of screening programmes for at-risk populations; education
and interventions to improve self-management capability; specific services such as dementia care managers in primary

care teams; psychoeducation for caregivers, including links to community agencies and information.

Research: The authors did not state any implications for research.

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