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Title: People with dementia report that relationships, purposefulness, wellness and an attachment to their living environment are the most important factors associated with quality of life


Objective: To synthesise the findings of qualitative research studies regarding factors that affect quality of life (QoL) from the perspective of people with dementia.

Design: Systematic review and meta-synthesis (AMSTAR=6/11, determined by CAPs author).

Search strategies: Searches were conducted in nine electronic databases including gray literature databases from date of database inception until April 2012. Search filters for qualitative and mixed methods studies were applied.

Selection criteria: Eligible studies were qualitative research papers in which one of the primary purposes was to identify factors that affect QoL from the perspective of the person with dementia. Studies were excluded if they did not differentiate the views of people with dementia from their carers or were published in languages other than English.

Methods of the review: Two authors independently screened 5% of the titles and abstracts and finalised inclusion and exclusion criteria. Following this, one of the authors proceeded to review the remaining titles and abstracts. The reviewer discussed seven studies
which did not clearly fit the criteria with a second reviewer to reach consensus. One reviewer extracted study data and two reviewers independently appraised the study using the Critical Appraisal Skills Program (CASP) tool.

Main findings: Eleven studies with a total of 345 participants met the inclusion criteria; the participants included people with mild, moderate and severe dementia. The majority of participants were women aged over 65 years. Study quality varied and CASP scores ranged from 3 to 9 out of 10. Nine of the studies reported explicit findings supported by the data and thus the findings were deemed credible. Relationships and contact with family, friends, care staff and care home residents was important and a lack of opportunity to interact led to reduced QoL. People with dementia reported that autonomy and independence enhanced their QoL. A degree of control over one’s daily activities was valued whereas factors that limited participation in meaningful activities (e.g., rules in care home settings) detracted from QoL. Helping others or contributing to society and feeling at home within their living environment and having a ‘sense of place’ whether that was in their own home or residential care were also of importance. QoL was poorer when the person was bored or disengaged from their surroundings.

Author’s conclusions: Factors associated with improved QoL according to people with dementia can inform clinical intervention studies and target areas for intervention.

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The importance of the perspectives of people with dementia is central to person-centred care (Ballard & Aarsland, 2009). Quality of life (QOL) can be difficult to describe and express, and is influenced by a range of life experiences, abilities, needs and values (Liddle & McKenna, 2000). Qualitative methodologies are highly appropriate for flexibly eliciting this information from participants with dementia in meaningful way. These methods however are not designed to explore whether there are shared aspects of QOL, common to people with differing severities of dementia, living in different countries and in different care settings. This metasynthesis draws together findings from 345 people for this broader exploration.

A rigorous process following an established interpretative metasynthesis methodology (Sandelowski & Barroso, 2007) is described, which aims to integrate findings of studies of sufficient quality and importance to the topic. The six critical concepts relating to QOL may be of considerable interest to occupational therapists working with people with dementia. *Togetherness* (feeling attached, connected and involved with other people), *Agency in Life today* (feeling purposeful and expressing independence, meeting goals and living an enjoyable life) and *Sense of Place* (feeling settled and attached in the environment) seem particularly pertinent.

People with dementia focussed particularly on what they could do, and how this could be supported by people and the environment, rather than difficulties with cognitive function. This suggests that in taking a client-centred approach, occupational therapists should also focus on what is possible and meaningful rather than purely on deficits. Occupational therapists with their understanding of person, environment and occupations are well placed to
assess, intervene and monitor outcomes that are personally meaningful to clients within these areas.

It should be noted that the original studies tended to use focus groups and interviews with questions that related to topics of interest for the researchers broadly related to QoL (e.g. “What is it like living here?” “What do you like to do day to day?”) and these would have influenced the responses of participants. It is possible that other life aspects not raised by the researchers could have contributed to QOL. Given the abstract nature of QOL and the potential for difficulties in defining and describing aspects, future investigations may also incorporate observational methods along with eliciting direct perspectives. Other cultural contexts also need exploration. The individual and shared things affecting QOL for people with dementia should be considered by occupational therapists.

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References
