

Systematic review

Feeling fearful and lonely are indicative experiences of emotional distress for people with dementia

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Implications for practice and research

- ▶ Using the advanced nursing process could provide individual as well as evidence-based care for people with dementia who suffer from emotional distress.
- ▶ Further research is necessary to demonstrate all emotional aspects of individuals with dementia.

Context

People who suffer from dementia have a decline in thinking, memory, orientation and behaviour.¹ Furthermore, this syndrome is accompanied by a lack of ability to act appropriately in everyday activities. Currently, about 50 million people have dementia worldwide.¹ This disease does not only affect the person concerned but also their caregivers, their families and society. The signs and symptoms linked to dementia are forgetfulness, getting lost in familiar places, and at home, or having increased difficulty communicating.¹ These are all associated with emotional distress, the focus of the present study.²

Methods

A systematic mixed-method review was used to answer the following questions of the present study²: 'How can emotional distress be characterised for individuals with dementia? What descriptions of emotional distress exist? What explanations for emotional distress exist?'. The researchers searched 12 electronic databases, using Medical Subject Headings as well as grey literature. In addition, manual searching was applied. Two researchers independently screened the initial hits whereby a previous power calculation indicated that 456 titles have to be jointly reviewed to demonstrate substantial agreement (using Cohen's kappa coefficient (Cohen K)). Overall, 121 studies met the inclusion criteria and underwent quality appraisal. For data synthesis, the descriptions of distress were analysed quantitatively and qualitatively using corpus-based methods, a well-recognised approach for analysing large samples of written text.²

A computer package, WordSmith Tools, was used whereby keywords (words which occurred more frequently than in general language), collocation ('strength of the relationship between the keywords and words that occurred as their neighbours'² and concordance analyses ('excerpts of original text that displayed the wider textual contexts of keywords and their collocates')² were employed. For the explanations of distress, meta-ethnography was employed, which is a common method for synthesising qualitative literature. Thereby ideas that exist within different literature can be systematically found and mapped out.

Findings

Approximately 900 of over 1000 statements, identified in the literature, were self-reported from individuals with dementia. Additional reports from family members, professional caregivers and academic writers/researchers were synthesised in this study. Comparing the self-reported and other-reported statements, the researchers found that family members, care givers and academic writers used summarising words for emotional distress (eg, anxiety or depression) compared with individuals with dementia whose language was more emotional. Overall, they both described the intensity of distress equally. People with dementia described distress most frequently as feeling fearful. Loneliness was the second highest attribution to emotional distress. Possible explanations for emotional distress included a negative social position and changing the sense of self.

Commentary

This well-conducted review found that, besides forgetfulness, feeling fearful, lonely, worried, angry or sad are additional psychological conditions in caring for people with dementia, which should not be overlooked.

The most significant distressing experience for people with dementia was feeling fearful. Setting a high-quality standard in nursing practice, it is recommended working with the advanced nursing process, consisting of valid nursing assessments as well as nursing classifications based on evidence.³ There are nursing diagnoses which focus on fear or anxiety but currently there is no nursing diagnosis available which precisely targets these specific feelings in people with dementia. In this case, the NANDA-International nursing diagnosis Impaired comfort (00214) could be applied.⁴ This nursing diagnosis is defined as 'perceived lack of ease, relief, and transcendence in physical, psychospiritual, environmental, cultural, and/or social dimensions'. Its defining characteristics/symptoms include anxiety, distressing symptoms and fear.⁴ Adequate nursing interventions suggested from the Nursing Interventions Classification Anxiety Reduction (5820), Calming Technique (5880) or Dementia Management (6460) could be applied.⁵ According to the Nursing Outcome Classification, the recommended nursing outcome Comfort Level (2100) should be considered.⁶

Loneliness is another crucial aspect of emotional distress with dementia. Therefore, an appropriate nursing diagnosis could be risk for loneliness (00054), defined as 'susceptible to experiencing discomfort associated with a desire or need for more contact with others, which may compromise health'.⁴ In combination with adequate nursing interventions (eg, Anxiety Reduction (5820), Presence (5340) or Family involvement Promotion⁵ (7110)) and nursing outcomes (eg, Loneliness Severity⁶ (1203)), individual and evidence-based care can be provided.^{3–6}

Correction notice This article has been corrected since it was published Online First. It is now Open Access under CC-BY-NC license.

Competing interests None declared.

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