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Title:

Where is the happiness in dementia?

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Our current research aims to explore how the emotional experiences of individuals with dementia are understood, and to improve the design and delivery of care interventions. A preliminary, incidental, finding from our initial systematic literature search is reported here. Increasingly, the experience of dementia is understood from the viewpoint of the individual. However, this is not reflected in the body of research literature, which is predominantly orientated towards detailing the neuropsychiatric symptoms of mood, cognition, behaviour or physiology and 'managing' the condition (Cerejeira, Lagarto and Mukaetova-Ladinska, 2012). In this way, the whole and varied experiences of dementia are not recognized. There is a distance between these differing perspectives of dementia in the available literature.

Twelve electronic databases were searched between January and April 2016. The systematic review was a means of answering the question: how is emotional distress characterized for individuals with dementia? The databases searched were Applied Social Sciences Index and Abstracts (ASSIA), British Nursing Index (BNI), Cochrane Library, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Health Management Information Consortium (HMIC), International Bibliography of the Social Sciences (IBSS), Medline, ProQuest Dissertation & Theses Global (PQDT), Psychological Information Database (PsycINFO), Scopus, The Campbell Library and Web of Science, offering an international scope of published and grey literature. Our search was limited to papers in English which may cause some bias; in addition the selected databases include some further bias. A search strategy was devised in attempt to capture all relevant literature (Petticrew and Roberts, 2006). Terms were informed by Medical Subject headings (MeSH), subject headings/thesaurus terms for each database and keywords, using truncation and wildcards to accommodate different word endings and spellings. Search terms were 'dementia' or 'Alzheimer' and as many emotion synonyms as we could identify from subject headings/thesaurus terms and preliminary reading of relevant literature: emotion, distress, affect, feeling, depression, anxiety, anger, shame, fear, wellbeing, sadness, agitation, apathy, grief, jealousy, hopelessness, loneliness, jealousy, happiness and desire. 'Happiness' and 'desire' were the only thesaurus terms that were available to maximize the retrieval of 'positive emotion' relevant titles.

In the process of completing this comprehensive literature search, it became apparent that a surprisingly small proportion of literature concerned with the emotional experience of individuals with dementia was concerned with positive emotional experiences. Of the approximately 40,000 titles retrieved, the largest number of titles retrieved from any single database solely using positive emotion terms was 156. Dependent on the database, this was equivalent to between .06 and 1.7% of all titles being comprised from searches of only

'happiness' or 'desire' teemed with search terms for 'dementia'. This showed a marked asymmetry in the research literature towards negative emotions. In one sense, this is merely an incidental and minor finding. However, it may also reflect an undoubtedly more complex issue. It may be a manifestation of the negative and distress-laden lens through which dementia is largely viewed in society, which is self-perpetuating. In this way of thinking, people think of distress in relation to dementia and hence it is researched – individuals, families, healthcare professionals and policy makers turn to research to guide the healthcare environment – and thus distress is the only available lexicon for experience, the only available lens through which dementia is viewed.

These findings might suggest something about what is going on inside the heads of individuals with dementia – that there is a stark absence of happiness – or else something about what is going on inside the heads of those researching dementia – a stark disinterest in happiness. Prevailing intervention models, such as Living Well with Dementia or Person-Centred Care (Alzheimer's Society, 2015; Kitwood, 1997) would suggest that the experience of dementia does not comprise an emotional experience that is 99% distressing.

In conclusion, this suggests that perhaps dementia research, by emphasizing distress, itself reflects the stigma of the condition. There could be a stark and important omission of positive experience that could helpfully contribute towards other drivers of care such as burden, risk and mortality.

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