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Feature Article

The picture of happiness in Alzheimer's disease: Living a life congruent with personal values

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A B S T R A C T

It is generally understood that happiness is an important goal of dementia care, though evaluation has been challenging. Concerns about cognitive and communicative limitations have led to the use of proxy reports to assess positive affect. However, proxy reports have been shown to differ from appraisals obtained by the person with Alzheimer's disease (AD). This article reports on a qualitative study of happiness in a sample of 12 persons with mild to moderate AD using photo-elicitation and individual interviews for data collection. Results demonstrate people with mild to moderate AD can provide meaningful evaluations of happiness, and that lifelong values continue to be important in the presence of AD. This study suggests photographs may offer a novel approach to obtain a contextualized understanding of happiness and other values in this population which may lead to the development of person centered interventions aimed to improve the individual's quality of life.

Introduction

Happiness, a vital component of quality of life, can be experienced in the context of Alzheimer's disease (AD).[1] This is good news for the approximate 5.2 million Americans currently living with Alzheimer's disease (AD), a number expected to rise dramatically due to the aging of the baby boomers and increased longevity.[2,3] However, gains in life expectancy do not necessarily correspond to improvement in well-being. Well-being, a term which commonly refers to the presence of positive emotions and overall life satisfaction, has been associated with multiple health benefits. Happiness was identified as a meaningful outcome of well-being in Healthy People 2020 and 2010.[4,5]

Though the capacity for happiness may continue in AD, studies suggest the experience of happiness eludes many. Prevalence rates of major depression range from 5% to 40%, adding to the suffering, disability and functional impairment of people with dementia.[6] Little is known about the significance of happiness for people living with AD. This is due, in part, to the lack of reliable and valid measure of happiness and/or well-being. When happiness is measured it is often as a single item within a measure of effect or mood in dementia quality of life tools.

To improve the measurement of happiness among individuals with Alzheimer's disease the inclusion of subjective information is needed.[7,8] However, there are inherent challenges to obtaining data from persons with AD due to impairments in language, memory, and cognition which may limit verbal communication and the ability to understand and respond appropriately to questionnaires.[9,10] To overcome these challenges, many quality of life (QoL) and well-being measures allow for proxy reports. Research suggests a weak to moderate association between ratings supplied by the caregiver and patient with AD, with the respondents living with AD frequently rating their QoL and psychological well-being higher than the proxy[10] Proxies tended to report more functional impairment, more depressive symptoms, and lower levels of psychological well-being than the person with AD.[11–13] Caregivers may be influenced more by dementia-related loss than by a positive sense of remaining capacity.[14–16]

Given the discrepancy between self and proxy reports, alternative approaches are needed to understand the lived experience of happiness in this population. The use of photographs to encourage dialog is known as photo-elicitation, a term first coined by researcher photographer John Collier in 1957.[17] More recently, photographs have been used to look at social issues[18] the experiences of children and adolescents[19] and the lived experience of mental illness.[20] Photographs can be created by the researcher or participant, the latter approach known as autodriving[21] to indicate that the interview is guided or "driven" by the photographs taken by the participant.[22] Autodriving has also been called reflexive

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photography,[23] photo novella[24] and photovoice.[22] Given the deficits associated with AD, multiple forms of data collection including photography may improve the individual's ability to reflect and dialog.

The purpose of this study was to explore the subjective experience of happiness in individuals with mild to moderate Alzheimer's disease in an attempt to gain a more nuanced understanding of their experience of happiness. The specific aims of this study was to: (1) to establish if individuals with mild to moderate AD would participate in photo-elicitation; (2) to use photos to describe the subjective understanding and perception of happiness in individuals with mild to moderate AD; and (3) to compare and contrast what people with AD considered important to their happiness with what the caregiver believed was important for happiness for their care recipient.

Theoretical framework

The theoretical framework used to understand happiness in AD from the perspective of care recipient and caregiver includes concepts from symbolic interactionism, positive psychology, and Kitwood's theory of personhood. Symbolic interaction serves as the grand theory and presumes humans exist in a world of objects, the nature of which is determined by the meaning the object has for the individual.[25] Positive psychology, first introduced by Maslow in 1954 and reintroduced by Martin Seligman in 1999, notes the imbalance of psychology's focus on illness as compared to an individual's strengths, and adds positive processes such as resilience, strength, growth and happiness to the existing knowledge of pathology and dysfunction.[26,27] Finally, Kitwood[28] defined *personhood* as "a standing or status that is bestowed upon one human being by others" (p. 8).[28] Kitwood's concept of personhood suggests that personhood is socially constructed, the result of the interaction and communication between the person with AD and the social environment. Further, Kitwood believed the personhood of the individual with AD may be undermined or supported through exchanges with others.[28]

Methods

Study design and sample

This qualitative interpretive study utilized semi-structured interviews and the photo-elicitation with autodriving method of data collection. Participants were referred to the study by community-based geriatricians in accordance with Institutional Review Board guidelines. Participants were eligible if they were: English-speaking adults age 70 or older; living in the community with a caregiver; diagnosed with mild to moderate AD by a geriatrician or psychiatrist at least 4 months prior to referral; capable and willing to express themselves verbally and score between 3 and 7 on the Short Portable Mental Status Questionnaire (SPMSQ)[29] at the initial meeting. Seventeen persons were referred and contacted; 12 met inclusion criteria and agreed to participate. Five individuals were not accepted in the study: 1 was excluded because he lived outside the state, 1 was unable to communicate, and 3 scored too low on the SPMSQ.

The consented individuals were then contacted via telephone by the principal investigator (PI). At that time, the study was explained and all individuals willing to participate were offered appointment times for an initial in-person meeting at a place of their choosing. At the first meeting, face-to-face consent was completed and participants were given a disposable camera and written instructions for use. Caregivers accompanied the participant during picture taking for logistical assistance. Cameras were picked up by the PI for film development one week later and a date of the interview was identified.

Participants were individually interviewed by the PI within ten days of picture taking. Interviews lasted between one and 2 h and occurred in the home of the participant. Photographs were placed on a table one at a time, and the participant was asked to explain how the picture represented happiness. Interviews were digitally recorded after obtaining consent by the participant. Data saturation was reached with twelve participants.

Measures

For descriptive purposes we obtained some limited demographic information (gender, age, education, ethnicity, marital status and living arrangement), and evaluated general health status and cognitive function:

Health status

Medical information was obtained from the participant and the caregiver, including medical and psychiatric diagnoses, and physical limitations that might impact participation in the study.

Level of cognitive function

The 10-item SPMSQ developed by Pfeiffer (1975)[29] was used to describe and evaluate orientation, memory, and concentration. The scores on the observer-rated test range from 0 (normal) to 10 (severe intellectual impairment), with test-retest reliability reported to be 0.8 and a sensitivity of 0.84 and specificity of 0.89 at a cut point of 3 or more errors.[29,30] A score of 0–2 indicates intact intellectual function, scores of 3–4 suggest mild cognitive impairment and 5–7 indicates mild dementia. Scores above 8 suggest severe intellectual impairment.[29]

Measurement of happiness using photo elicitation intervention

Participants were asked to use the cameras given to them to take pictures representing situations and events that hinder or support their experience of happiness. Photographs were not coded or analyzed in this study. They were solely used as a catalyst for discussion at the final meeting. A semi-structured, open-ended interview guide was used during the review of the photographs. The initial question asked of each person with AD was, *In what way does this picture represent happiness to you*? From that point on, the discussion of the picture was led by the participant's narrative. Additional questions included: How do you feel when you look at this picture? What is it about this picture that you wanted to share with me? *Was there anything you wanted to take a picture of but couldn't?*

Data analysis

Transcripts of interviews were analyzed using interpretive design to develop shared themes of the key elements of the participants' experience of happiness. Interviews were digitally recorded and transcribed verbatim. Transcripts were coded, and analyzed as completed, staying close to the data. Transcripts were read and re-read to ensure accuracy and to increase familiarity with the data. Coding began with application of "in vivo" coding which preserves the participants wording of their ideas and meanings.[31] For example, participant JC stated "I go to New York, go in and I stand up with a group of men and we sing our hearts out and have a ball". Line-by-line coding was then used to identify concepts and processes, and to see the nuances within the data. Line-by-line and in vivo codes were subjected to a comparative analysis process, grouping codes by similarities and differences, and grouping codes into themes.[31] For example, several codes arose from the data that