Original Article

Self- and Carer-Rated Pain in People With Dementia: Influences of Pain in Carers

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Abstract

Context. Although pain is frequent in people with dementia (PwD), evidence on the prevalence and factors influencing ratings of pain in dementia is limited. Carer variables are often associated with bias in proxy ratings of pain, but few studies have examined the role of caregiver pain in influencing these ratings.

Objectives. This study explored the prevalence of pain in PwD in a large U.K. sample. A secondary aim was to identify factors influencing ratings of pain in people with mild to moderate dementia and whether carer pain systematically influences proxy ratings.

Methods. This was a cross-sectional study of 488 caregiving dyads living in the community. Self- and carer-rated pain was assessed as part of the EuroQoL-5D (EQ-5D). Depression and anxiety for the PwD were measured by the Cornell Scale for Depression in Dementia and the Rating of Anxiety in Dementia Scale. The Hospital Anxiety and Depression Scale was used to measure anxiety and depressive symptoms in carers. Using logistic regression modeling, we examined the relationship between self- and carer-rated (proxy) pain in PwD and psychological distress, functional ability, and health status. Carer variables included self-rated health, strain, anxiety, depression, and caregiver pain.

Results. A total of 45% of PwD reported pain, whereas carer-rated pain was higher (59%). Self-rated pain was more frequent in those with lower self-rated health (adjusted odds ratio [AOR] 0.97; 95% CI 0.96−0.99, $P \leq 0.001$) and higher anxiety (AOR 1.07; 95% CI 1.01−1.12, $P = 0.013$). Carer-rated (proxy) pain was additionally predicted by poor proxy-rated health in the PwD (AOR 0.98; 95% CI 0.96−0.99, $P = 0.006$) and carers' own experience of pain (AOR 0.36; 95% CI 0.21−0.63, $P \leq 0.001$).

Conclusion. Our results indicate that pain is very frequently reported in PwD and that the presence of pain is associated with high levels of anxiety. Caregiver pain affects carers' perceptions of pain in PwD. J Pain Symptom Manage 2015;49:1042−1049.

Key Words
People with dementia, pain, EQ-5D, self-rated pain, carer-rated pain, prevalence

Introduction

Pain results in considerable discomfort for older people and constitutes an important physical, emotional, and social burden regardless of cognitive status.[1] Depending on setting and method of measurement, prevalence of pain in people with dementia (PwD) ranges from 20% to even higher than 50%,[2,3] especially for those living in nursing care environments.[4,5] Despite evidence-based guidelines available for the assessment and treatment of pain,[6] PwD are vulnerable to underassessment and undermanagement of pain. Untreated pain is a major contributor

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of reduced quality of life (QoL)[7,8] and a frequently unmet need, related to the occurrence of behavioral and psychological symptoms in dementia.[9,10] Despite evidence that, in cognitively intact older adults, pain predicts lower levels of psychological health, very few studies have examined the factors that influence self- and carer-rated pain in community-dwelling PwD.[1,11]

Self-ratings are currently the preferred method for assessing pain in older adults with cognitive impairment,[12] consistent with studies showing that people with moderate to moderately severe dementia are able to use some of the available self-reporting instruments.[13,14] However, as the disorder progresses, health care providers often turn to family carers to gather more knowledge about the intensity and impact of pain on the PwD.[15] It has been consistently observed that although carer-rated pain can provide useful information in the assessment of pain in dementia, proxy assessments often raise issues of bias. For example, carer ratings of pain are influenced by carer's depression,[16] similar to ratings of QoL, which are often affected by carers' mood or level of carer burden.[17]

Theoretical models and empirical evidence examining interpersonal effects of suffering within the context of a dyadic relationship show that physical or psychological distress experienced by a loved one can influence emotional experiences of carers and directly affect their own well-being.[18,19] In line with the sociocommunications model of pain, attending to both patient and carer is considered equally important.[20] Carers, for example, often experience stress as a result of seeing their loved one in distress or may find it difficult to estimate levels of pain correctly,[21] which may influence how supportive they are perceived to be by their partner.[22] Several studies show that older carers of people with various chronic illnesses overestimate pain in the care recipient.[23] It is possible, therefore, that caregiver pain, similar to depression, may affect proxy ratings of pain in PwD.[24]

Although caregiver mood and strain have been previously examined as factors affecting self- and carer-rated pain,[25] no studies have examined whether pain in proxies (i.e., family carers) affects proxy ratings of pain experienced by PwD. There is currently limited evidence on the prevalence, characteristics, and clinical correlates of pain in PwD living in the community. The specific objectives of this study, therefore, were to 1) provide an estimate of prevalence of pain in people with mild to moderate dementia living in the community, 2) investigate the factors associated with self- and carer-rated pain in PwD, and 3) examine whether caregiver pain affects proxy ratings of pain for the PwD. We hypothesized that pain will be frequent and that it will be strongly associated with emotional distress and poor self-rated health in PwD. We also predicted that carers' own ratings of pain will influence proxy ratings of pain in the PwD.

Methods

Design

This was a cross-sectional study of a large sample of people with mild to moderate dementia and their family carers living in the community.

Sample

A convenience sample of 488 people with a diagnosis of dementia according to *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) criteria took part, along with their carers, who had regular contact with the PwD (for approximately four hours per week or more). Inclusion criteria for PwD were living in the community, being in the mild to moderate stage of dementia (DSM-IV criteria for dementia of any type), and having a relative or other caregiver who could act as an informant. Those with high levels of disability or any major physical impairment were excluded. All participants gave their consent to participate in the study. Most participants were recruited through National Health Service Memory Clinics and Community Mental Health Teams for older people. All assessment instruments were administered by a team of research assistants. The present data were collected at baseline as part of the Reminiscence Groups for People with Dementia and Their Family Caregivers (REMCARE) study, investigating the effects of reminiscence therapy on QoL for PwD and their family carers.[26] This health technology assessment (HTA)-funded trial was approved by the Multicentre Ethics Committee in Wales.

Measures

Pain. We used items from the EuroQoL-5D (EQ-5D) to measure pain and self-rated health in PwD and their carers. The EQ-5D is a brief generic instrument comprising a self-administered health index and a visual analogue scale (VAS),[27] representing five dimensions of health-related QoL, including a separate dimension of pain/discomfort. Participants were asked to indicate which statement best described their health state at the present time. There are three levels per dimension: no problems, some problems, or extreme problems. For the pain/discomfort dimension, participants chose one of the following statements: 1) I have no pain or discomfort, 2) I have moderate pain or discomfort, and 3) I have extreme pain or discomfort, with the three ratings relating to the severity of symptoms. Respondents are asked to mark their current health state on a 100-point VAS, with 100 representing the "best imaginable health