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ARTICLE

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

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Abstract

Background: 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.

Aims: This study explored prevalence of pain in PwD in a large UK 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: Cross-sectional study of 488 caregiving dyads living in the community. Self and carer-rated pain was assessed as part of the EuroQoL (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% confidence interval (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 presence of pain is associated with high levels of anxiety. Caregiver pain affects carers' perceptions of pain in PwD.

Keywords: people with dementia; pain; EQ-5D; self-rated pain; carer-rated pain; prevalence;

1. Introduction

Pain results in considerable discomfort for older people and constitutes an important physical, emotional and social burden regardless of cognitive status¹. 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^{4,5}. Despite evidence-based guidelines available for the assessment and treatment of pain⁶, PwD are vulnerable to under-assessment and under-management of pain. Untreated pain is a major contributor of reduced quality of life^{7,8}, and a frequently unmet need, related to the occurrence of behavioral and psychological symptoms in dementia (BPSD)^{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 impairment¹², 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 in order to gather more knowledge about the intensity and impact of pain on the PwD¹⁵. 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 depression¹⁶, similar to ratings of quality of life which are often affected by carers' mood or levels of carer burden¹⁷.

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 important²⁰. 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 correctly²¹, which may influence how supportive they are perceived to be by their partner²². Several studies show that older carers of people with various chronic illnesses overestimate pain in the care recipient²³. It is possible therefore that caregiver pain similar to depression may affect proxy ratings of pain in PwD²⁴.

Although caregiver mood and strain have been previously examined as factors affecting self and carer-rated pain²⁵, 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.

2. Methods

2.1 Design

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

2.2 Sample

A convenience sample of a total of 488 people with a diagnosis of dementia according to DSM-IV criteria took part, along with their carers, who had regular contact with the PwD (for approximately 4 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 that 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 NHS 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 REMCARE study, investigating the effects of reminiscence therapy on QoL for people with dementia and their family carers²⁶. This HTA funded trial was approved by the Multi-Centre Ethics Committee in Wales.

2.3 Measures

Pain

We used items from the EQ-5D to measure pain and self-rated health in PwD and their carers. The EQ-5D is a brief generic instrument consisting of a self-administered health index and a visual analogue scale²⁷, representing five dimensions of health-related quality of life, 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 choose one of the following statements: a) I have no pain or discomfort, b) I have moderate pain or discomfort, c) 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 scale, with 100 representing the 'best imaginable health state' and 0 representing the 'worst imaginable health state' today. People with dementia completed the instrument in an interview format. In the proxy version, carers were asked to answer the questions giving their own view of the person's experienced pain and health, as opposed to attempting to provide the person's own view.

Mood

Anxiety was measured by the *Rating of Anxiety in Dementia Scale* (RAID)²⁸, comprised of 18 items assessing anxiety, based on a structured interview with the carer and the PwD, in which a higher score indicates more anxiety symptoms (range from 0-54). Depression was measured through the *Cornell Scale for Depression in Dementia* (CSDD)²⁹, with higher scores indicative of more depressive symptoms (range from 0-38). The CSDD is a 19-item interviewer administered measure, using information from interviewing the PwD and their carer. Anxiety and depressive symptoms experienced by the carer were measured with the Hospital and Anxiety Depression Scale³⁰, in which higher scores indicate greater distress (range from 0–21).

Function of the PwD and dementia severity

The *Bristol Activities of Daily Living Scale* (BADLS)³¹ is a carer rated instrument consisting of 20 daily-living abilities, developed specifically for use with PwD. Higher scores on this scale indicate less functional independence (range from 0 to 60). We measured global severity of dementia using the *Clinical Dementia Rating scale*³², which was administered as a structured interview with the family carer (informant) and the PwD. The CDR measures the following six domains: memory, orientation, problem solving, community affairs, home and hobbies, and personal care. Ratings are 0 for healthy people, 0.5 for questionable dementia and 1, 2 and 3 for mild, moderate and severe dementia.

Caregiver stress

We used the *Relative's Stress Scale* (RSS)³³, administered as a self-report measure, to assess stress specific to caregiving, with higher scores indicating greater stress specific to caregiving (range from range 0–60).

Statistical Analysis

All statistical analyses were carried out using SPSS (Version 20.0). For correlations of continuous variables, Pearson's *r* was used whereas for discontinuous variables Spearman's *rho* was used instead. To determine the effect of clinical variables on ratings of pain, logistic regression analyses were performed. Ratings of pain for the PwD (self and proxy ratings separately) and carer were entered as the dependent variables, whereas the predictors were those factors found to be significant in the bivariate analyses.

3. Results

3. 1 Sample characteristics

A total of 488 people with dementia were interviewed, of whom 49.6% were females. The mean age was 75.55 (range 54-95 years) and the mean years of age leaving school was 15.5 years. Of the 488 PwD, 72.1% were married and the remaining 27.9% were single, separated, widowed or divorced. A total of 399 PwD (82.3%) lived in the community with their family carer, whereas the rest of the sample lived on their own or with other family members. A total of 67.1% of the sample of carers were female, where 71% of carers were the PwD' spouse, 20.7% were the son or daughter of the PwD, whereas the remaining carers (8.3%) were another relative/friend or partner. The mean age was 69.83 (range 23-91 years) and the mean years of age leaving school was 16.7 years.

A total of 74.6% of PwD had a score of 1 (mild dementia) in the CDR scale. Mean scores of overall health as measured by the EQ-VAS were 71.33 (SD = 20.05) for self ratings, and 61.20 (SD = 18.94) for carer (proxy) ratings. The mean BADL score was 15.93 (SD = 9.59). For the person with dementia, mean Cornell score was $M = 6.96$ (SD = 5.02), and mean RAID score was 8.51 (SD = 7.07). Caregiver stress specific to the caregiving situation (RSS) was 21.63 (SD = 10.75), and the mean EQ-VAS for carers was 73.63 (SD = 18.65). Mean anxiety for carers using the HADS was 6.24 (SD = 4.25) and mean depressive symptoms were 4.22 (SD = 3.44).

Prevalence of pain in PwD

Table 1 shows prevalence of pain in PwD (self and carer-rated pain) and family carers. A total of 45.3% of people with dementia reported pain, including 4.1% reporting extreme pain. Carers more frequently rated pain in PwD with a total of 59.2% reporting that the person they cared for experienced some or extreme pain, $\chi^2(4) = 64.79, p < .001$. Carers rated pain in 44.2% of PwD who did not themselves report any pain. However, carers reported no pain in the PwD for 25.2% of the sample who had self-reported pain. Overall exact agreement was 58.2%, with slightly higher levels across both levels of pain (65%), with kappa coefficient 0.25.

Factors associated with ratings of pain in PwD

Table 2 shows the characteristics of people with dementia experiencing pain for both self and carer ratings. Results from bivariate analyses showed that amongst the characteristics of the PwD, both self and carer-rated pain were associated with lower levels of education, and lower self and carer-rated health as measured by EQ-VAS. Higher presence of depressive and anxiety symptoms in the PwD were associated with higher levels of self and carer-rated pain. Carers reported higher ratings of proxy pain when the PwD was older. Amongst carer characteristics, lower levels of self-rated health and higher ratings of anxiety and depression predicted higher levels of carer-rated pain in the PwD. As hypothesised, carers reporting pain were more likely to report that the PwD was in pain.

Logistic regression analyses for self and carer-rated pain in PwD

A multivariate logistic regression analysis predicting self and carer rated pain in PwD was conducted (see Table 3). This analysis showed that self-rated pain was predicted by self-rated health (EQ-VAS) and presence of anxiety symptoms in the PwD. In carer ratings, both self and carer-rated health in the PwD also contributed to the prediction of pain. As can be seen in Table 3, higher levels of anxiety and whether the carer experienced pain remained significant predictors in the logistic regression analyses after controlling for all other factors.

Discussion

Prevalence and factors associated with self and carer-rated pain in PwD

The aim of our study was to investigate prevalence of self and carer-rated pain in a cohort of people with mild to moderate dementia living in the community and to identify which factors are associated with presence of pain. Our results show that pain is a frequent and highly prevalent symptom in people with dementia. Given the proportion of PwD experiencing pain, this study offers important information about the contribution of pain in the psychological health of PwD and whether carers themselves experiencing pain can influence proxy ratings. We found a higher percentage of pain in PwD in comparison to previous studies², with 45% of our community sample reporting self-rated pain, and 59% reporting carer-rated pain.

Although we found that carers reported more pain than patients as in previous studies, we also observed that for 25% of our sample carers did not report pain in their relative despite the PwD self-reporting pain. In fact in 42% of cases carers' judgements regarding the presence of pain in the PwD differed from their relative's self-report which is in line with previous evidence of low agreement between self and carer ratings of quality of life for PwD³⁴. Results are consistent with prior literature that dimensions that are observable are more likely to be associated with higher agreement and that proxy raters tend to report more disability³⁵. Our findings suggest that assessment of pain and behavior measurement would require both self and proxy (carer) reports in order to identify those at risk of experiencing persistent pain, as well as assessment of other behaviors, consistent with a multidimensional approach³⁶.

Our findings are in line with work suggesting that pain in community-dwelling older people is associated with higher rates of psychological distress¹⁵, poorer health and that pain is not influenced by severity of dementia^{5, 16}. Contrary to previous studies however we did not find any differences in ratings on the basis of gender. Education of the PwD on the other hand influenced both self and carer ratings, with those of lower education reporting higher levels of pain, consistent with evidence that lower education is often implicated in poor prognosis in the management of pain in the general population^{37, 38}. Anxiety symptoms were a significant predictor of both self and carer-rated pain, in line with evidence that anxiety explains more variance in experiencing pain in comparison to depression in older adults³⁹. Our findings therefore may guide treatment recommendations in assessing the role of anxiety in the experience of pain in dementia.

An important contribution of the present study is that pain in carers influenced the ability to perceive pain in the PwD indicating that proxy agreement varies as a function of carer characteristics³⁵. Our findings provide support for current theoretical conceptualisations of dyadic patterns of pain⁴⁰ and indicate that further research is required to understand how dementia caregiving dyads experience and communicate pain. Carers in pain were more likely to report pain in the PwD, compared with self-reports, indicating that they are sensitive to indicators of pain in daily life. This is consistent with the finding that carers did not miss presence of pain in those reporting experiencing extreme levels of pain. Although our findings can not generalise to people with severe dementia they do stress the importance of a multifaceted approach to pain assessment and to behavioural indicators which may be particularly important for people with dementia who are at greater risk of experiencing pain.

Our findings of presence of pain in carers influencing perceptions of pain in PwD are consistent with similar reports in other populations such as stroke patients demonstrating that carers experiencing pain may report more pain than the patients themselves²⁴. These findings indicate that further research that examines the impact of pain in carers of patients with other conditions is warranted²³.

The present study has some limitations. Self and carer-ratings of pain were based on assessing pain at a specific point in time, using a single-item rating, which did not allow to examine factors such as the specific intensity or level of pain. Presence of symptoms were based on self-report rather than clinical diagnosis, so it remains unclear whether these results are applicable to those experiencing clinical pain. In addition, as the current analyses are cross-sectional we cannot comment on direction of causality. Although this study adds new knowledge additional studies are needed to understand possible mediators of pain and factors such as access to medical care or use of analgesics, which were not measured in this study. We did not have access to data on pain medications however we can expect that pharmacological treatment of pain is likely to be limited in this population^{41,42}. A further limitation of the present study is the lack of comorbidity data and the inability to adjust for these in the analyses, as PwD may have experienced pain related to other diagnosed comorbid conditions⁴³. We did not measure agitation or aggression which are common correlates of pain, therefore inclusion of these variables may have yielded better predictive models. We were also not able to control for the independence of observations in pain perceptions, so it will be important for future studies to apply specialised analyses for dyadic data such as actor-partner independence model techniques⁴⁴.

Conclusion

It is widely recognized that people with dementia are at high risk of experiencing pain⁴⁵. Our study adds to the limited data available on the prevalence, and factors influencing self and carer rated pain in PwD, indicating that it is a highly frequent symptom for PwD⁴⁶. We conclude that many people with mild to moderate dementia are able to report pain via self report instruments such as the EQ-5D, and that although carer ratings are

important in identifying pain in this population, they are influenced by carer variables such as carers' own experience of pain. Future work should investigate experience of pain in longitudinal studies and dyadic approaches in the experience of pain in dementia caregiving dyads. This information will be useful in designing interventions that aim to modify and minimize pain-related disability in PwD.

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Table 1

Prevalence of self and carer rated pain in people with dementia and carers

Pain ratings in People with Dementia				
<i>Carer ratings (proxy)</i>				
<i>Self ratings</i>	No pain	Moderate pain	Extreme pain	Total
No pain	145 (30.5)	110 (23.1)	5 (1.1)	260 (54.7)
Moderate pain	47 (9.9)	128 (26.9)	21 (4.4)	196 (41.2)
Extreme pain	2 (0.4)	14 (2.9)	4 (0.8)	20 (4.1)
	194 (40.8)	252 (52.9)	30 (6.3)	476 (100.0)
Pain ratings in Family Carers				
	No pain	Moderate pain	Extreme pain	
	246 (50.8)	211 (43.6)	27 (5.6)	
Pain in Caregiving dyads				
	Carer			
	No pain	Moderate pain	Extreme pain	
PwD	No pain	Moderate pain	Extreme pain	
No pain	141 (29.7)	101 (21.3)	18 (3.8)	
Moderate pain	91 (19.2)	95 (20.0)	9 (1.9)	
Extreme pain	9 (1.9)	11 (2.3)	0	

Data were missing for n = 12 dyads (self and carer ratings of the PwD's pain), and for n = 4 (carers' own ratings).

Table 2
Characteristics of people with dementia experiencing pain

Characteristics	Self Ratings			Carer Ratings		
	No Pain (n = 260)	Pain (n = 216)	p value	No Pain (n = 194)	Pain (n = 282)	p value
PwD Characteristics						
Age, mean \pm SD	77.37 (7.58)	77.84 (6.86)	.48	76.65 (8.20)	78.21 (6.51)	.03
Education (years), mean \pm SD	15.76 (3.52)	15.16 (2.05)	.03	15.82 (3.72)	15.25 (2.29)	.04
Female, %	50.8	48.4	.61	46.9	51.8	.29
Married, %	74.8	74.3	.97	76.7	72.8	.63
Living with spouse, %	66.1	71.3	.23	67.0	69.1	.57
Cared for by a spouse, %	71.2	70.0	.96	74.6	67.7	.26
EQ-5D VAS Self ratings, mean \pm SD (range 0-100)	76.66 (18.53)	65.79 (18.73)	< .001	75.35 (19.22)	69.14 (19.13)	.001
EQ-5D VAS Carer ratings, mean \pm SD (range 0-100)	64.62 (18.32)	56.93 (18.86)	< .001	67.97 (19.21)	56.53 (17.33)	< .001
CDR score of 1, %	78.2	71.0	.20	73.1	76.9	.51
CSDD, mean \pm SD (range 0-23)	6.14 (4.78)	7.93 (5.20)	.001	5.49 (4.12)	8.01 (5.39)	< .001
RAID, mean \pm SD (range 0-38)	6.93 (5.57)	10.48 (8.19)	< .001	6.00 (4.94)	10.42 (7.87)	< .001
BADLS, mean \pm SD (range 0-47)	15.29 (9.56)	16.47 (9.47)	.18	14.83 (9.60)	16.52 (9.44)	.06
Carer Characteristics						

Age, mean \pm SD	69.95 (11.65)	69.94 (11.74)	.50	69.29 (11.86)	69.79 (11.58)	.65
Education (years), mean \pm SD	16.84 (4.92)	16.58 (4.69)	.55	16.60 (3.61)	16.81 (5.50)	.65
Female, %	67.4	67.1	.51	71.0	64.8	.16
Married, %	87.6	89.3	.97	87.8	88.8	.80
Living with relative %	45.8	36.1	.28	34.2	47.6	.27
EQ-5D VAS ratings, mean \pm SD (range 0-100)	73.91 (19.30)	73.30 (17.85)	.72	76.01 (19.18)	72.39 (17.65)	.034
Carer Experiencing Pain, %	45.8	53.5	.06	35.2	58.9	< .001
RSS, mean \pm SD (range 0-24)	21.32 (10.94)	21.97 (10.60)	.52	20.70 (10.86)	22.18 (10.69)	.15
HADS –Depression, mean \pm SD (range 0-16)	6.10 (4.31)	6.48 (4.21)	.33	3.83 (3.30)	4.52 (3.54)	.031
HADS –Anxiety, mean \pm SD (range 0-19)	4.09 (3.49)	4.44 (3.40)	.28	5.55 (4.14)	6.74 (4.29)	.003

Note. EQ-5D – EuroQoL ⁴⁷; CDR – Clinical Dementia Rating ³²; CSDD - Cornell Scale for Depression in Dementia ²⁹; RAID -Rating of Anxiety in Dementia ²⁸; BADLS - Activities of Daily Living Scale ³¹; RSS – Relative Stress Scale ³³; HADS – Hospital and Anxiety Depression Scale ³⁰.

Table 3
Logistic regression analysis predicting self and carer rated pain for people with dementia

Variable	<i>p</i>	Odds ratio Exp (B)	Lower 95% C	Upper 95% CI	Variable	<i>p</i>	Odds ratio Exp (B)	Lower 95% (Upper 95% CI
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Self and carer-rated pain in dementia 16

Self Ratings					Carer ratings				
Education	0.118	0.927	0.843	1.020	Relative's Age	0.264	1.020	0.985	1.055
EQ VAS Self	0.000	0.973	0.960	0.986	Relative's Educatio	0.227	0.948	0.869	1.034
EQ VAS Proxy	0.180	0.991	0.979	1.004	EQ VAS Self PwD	0.043	0.986	0.973	1.000
CSDD	0.287	0.592	0.919	1.049	EQ VAS Proxy	0.006	0.979	0.965	0.994
RAID	0.013	1.067	1.014	1.123	CSDD	0.470	0.973	0.904	1.048
					RAID	0.001	1.108	1.043	1.178
					EQ VAS Self Carer	0.316	1.009	0.991	1.027
					Experiencing Pain	0.000	0.363	0.207	0.634
					HADS-Anxiety	0.764	0.984	0.887	1.092
					HADS-Depression	0.839	1.008	0.936	1.085

Note. EQ-5D – EuroQoL ⁴⁷; CSDD - Cornell Scale for Depression in Dementia ²⁹; RAID -Rating of Anxiety in Dementia ²⁸.