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The symptom experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptom assessment measures

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Abstract

OBJECTIVES—The symptom experience of community-dwelling persons with dementia adopting an open ended approach has not been well documented. We sought to identify the most bothersome symptoms experienced using self and caregiver report, and to evaluate whether these

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Consultant		x		x		x		x
Stocks		x		x		x		x
Royalties		x		x		x		x
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symptoms are captured by commonly used symptom assessment measures including the ESAS-Edmonton Symptom Assessment System (standard in palliative care), Neuropsychiatric Inventory (NPI), and End of Life Dementia Scale- Symptom Management (ELDS-SM).

DESIGN—The authors use data from the Palliative Excellence in Alzheimer Care Efforts (PEACE) study to characterize the symptom experience.

SETTING—PEACE included outpatient primary care geriatric patients in an urban setting affiliated with the University of Chicago.

PARTICIPANTS—Data were examined from the 150 patient-caregiver dyads.

MEASUREMENTS—The most bothersome symptoms of persons with dementia during the past week were reported separately by self and family caregiver. Symptoms were asked in an open ended format and qualitative analysis using constant comparative technique was applied for each response. Reports were categorized and frequencies tabulated.

RESULTS—115 persons (35 could not respond to the interview questions) with dementia reported 135 symptoms (median 1, range 0 to 3). The most frequently reported symptoms were pain (n=48; 42%), depression (n=13; 11%), cognitive deficit (n=12; 10%), anxiety (n=7; 6%) and ophthalmologic complaint (n=5; 4%). 150 caregivers reported 259 symptoms (median 2, range 0–5) with cognitive deficit (n=71; 47%), pain (n=46; 30%), depression (n=26; 17%), activity disturbance (n=23; 15%) and thought and perceptual disturbances (n=12; 8%) being reported most frequently. The ESAS, NPI, and ELDS-SM missed 2 or more of the most commonly reported symptoms by dyads of persons with dementia and their family caregivers.

CONCLUSION—Symptoms were frequently reported by persons with dementia and their caregiver; however, commonly used symptom assessment measures overlooked important symptoms. All physicians should be vigilant about screening for both psychological and physical symptoms in this population.

Keywords

dementia; symptoms; patient and caregiver report; Edmonton Symptom Assessment System

INTRODUCTION

Most dementias are incurable and shorten life expectancy by about half.¹ As a dementia progresses, cognitive, functional, and behavioral changes can diminish the physical, psychological, social, and spiritual well-being of patients and families.^{2–4} Moreover, multiple morbidities often co-exist with dementia, such as arthritis, heart disease, and diabetes, each of which are associated with a noteworthy symptom burden, further diminishing quality of life.⁵ For example, 50% of persons with arthritis report discomfort on a regular basis. Compared to cognitively intact persons, those with impairment are significantly more likely to have their pain inadequately treated.⁶ Palliative care's focus on alleviating multidimensional suffering, in part through improvements in symptom assessment and management makes such care well suited to complement the role of the geriatric psychiatrist in caring for patients with dementia.

The majority of research on dementia has focused on epidemiologic studies and pharmacologic interventions targeted at behavioral symptoms and cognitive decline.^{7–9} Less attention has been given to pain and other physical symptoms even though they may be associated with neuropsychiatric symptoms.¹⁰ Also, a better understanding of the non-psychiatric symptom burden experienced by persons with dementia is important as these contributors to neuropsychiatric symptoms may be more amenable to treatment, thereby

decreasing the need for therapies with a narrower therapeutic index, namely antipsychotics, anticonvulsants, and anxiolytics.^{7,11}

The purpose of the current study is to describe the range of symptoms experienced by community-dwelling older adults with dementia. We captured the patients experience by asking the patient and family caregiver to report the most bothersome symptom(s) in the past week, using an open ended approach. We compared these reports with the Edmonton Symptom Assessment System (ESAS), a brief and easy to use assessment tool that has been suggested as a standard measure of symptom burden in palliative care, cancer, and other life-limiting diseases including dementia. We also compared the most bothersome symptoms reported with dementia specific measures, namely, the Neuropsychiatric Inventory (NPI), and End of Life Dementia Scale- Symptom Management (ELDS-SM).¹²⁻¹⁴ It is hoped a greater appreciation of the full range of symptoms experienced by persons with dementia will facilitate improvements in symptom assessment, leading to more appropriate and effective management for physical, psychosocial, and psychiatric issues, and will promote symptom-based research in this vulnerable population.

METHODS

Study Design

The current study comprises an analysis of a subset of data derived from the Palliative Excellence In Alzheimer Care Efforts (PEACE) program, an innovative model of care that sought to integrate the provision of palliative care for persons with dementia throughout the course of the illness.⁴ Community-dwelling persons with dementia who had a regular caregiver were recruited as a convenience sample from an outpatient geriatrics clinic associated with the University of Chicago. Consent to participate was obtained from the person with dementia and his or her caregiver; if the person with dementia lacked decision-making capacity, caregiver consent and patient assent was sufficient for participation. The University of Chicago, Biological Sciences Division, Institutional Review Board reviewed and approved the study.

Separate face to face interviews with persons with dementia and their caregiver each took from 15 to 30 minutes to complete, and occurred at baseline and every 6 months thereafter for 2 years. A total of 150 dyads were enrolled between July 1999 and June 2000. The data included in the current analyses were extracted from the earliest interview cycle in which the person with dementia reported a most bothersome symptom, along with the corresponding caregiver interview. If the person with dementia reported no symptoms or was non-verbal, data were extracted from the earliest interview in which the caregiver reported a bothersome symptom for the person with dementia.

Measures

The most bothersome symptoms were elicited by asking persons with dementia (or in parallel questions, caregivers), "In the last week, what symptoms or problem has been the most bothersome for you (person with dementia)?" A follow-up question was asked to elicit any additional problematic symptoms, "Is there a second symptom or problem that has been bothersome for you (person with dementia)?" Verbatim responses for the most bothersome symptom(s) were extracted for analysis by the research team. All symptoms mentioned by persons with dementia and the caregiver from that interview cycle were included, even if more than 2 were volunteered.

To better describe the population, additional information for persons with dementia and caregivers were collected. Characteristics of person with dementia included demographics (age, gender, ethnicity, education, current marital status) cognition (Folstein mini-mental

status exam-MMSE), and comorbidity as determined by a chart review (Charlson Weighted Index of Comorbidity-CCI). The MMSE is an 11-question screening measure for cognitive impairment, in which scores range from 0 to 30 and higher scores indicating a higher level of cognitive functioning.¹⁵ The CCI evaluates whether any of 19 health conditions are present (weights of 1 to 6 assigned depending upon condition) or absent (0), with summary scores ranging from 0–37 and higher scores indicating greater comorbidity.¹⁶

Family caregiver interviews collected demographics (caregiver age, gender, ethnicity, and education as well as relationship to the patient), caregiver strain (Caregiver Strain Index-CSI), caregiver depression (Beck Depression Inventory-BDI) and patient functional status (Instrumental Activities of Daily Living-IADL and Activities of daily living-ADL). The CSI assesses strain of informal caregivers by inquiring about the presence (1) or absence (0) of 13 common stressors, where scores range from 0 to 13 and higher scores indicate greater caregiver strain.¹⁷ The BDI consists of 13 questions about how one has been feeling over the past week with each response score ranging from 0 to 3. Summary scores range from 0–39 and higher scores indicate greater severity of depressive symptoms.¹⁸ The IADL evaluates those skills required for independent living and includes questions about independence with the telephone, traveling, shopping, preparing meals, housework, medication, and money. Functionality is rated as independent (1), assistance required (2), and dependent (3), so that summary score ranges from 7 to 21.¹⁹ The ADL evaluates basic care activities including bathing, dressing, toileting, transferring, continence, and feeding. Functionality is rated similarly to IADL, but with summary scores ranging from 6 to 18.²⁰

Data Analysis

Demographic variables were summarized using descriptive statistics. Qualitative analysis using constant comparative technique was applied for each bothersome symptom response for persons with dementia and the caregiver, separately. Symptom categorization occurred through an iterative process among three authors (TM, CS, JWS), in which each symptom was reviewed by each author and subsequently discussed among the group to reach consensus for each response. Based upon the initial review of all symptoms reported, responses were categorized in a stepwise process using the following approach: 1. ESAS related or not, 2. dementia-specific or not, and 3. new symptom categories. The ESAS was initially validated and developed in cancer patients,¹¹ and later adopted for use in chronically ill populations including those with end stage renal disease, chronic obstructive pulmonary disease, and congestive heart failure.^{13–14} All symptoms reported were reviewed and if appropriate placed into one of nine ESAS symptom categories, namely pain, activity, nausea, depression, anxiety, drowsiness, appetite, sensation of wellbeing, and shortness of breath, and those that did not fit were separated for further classification. Dementia-specific categories included cognitive changes, activity disturbance, swallowing difficulty, apathy, and thought and perceptual disturbance.^{8, 21} Non-ESAS symptoms were subsequently reviewed and further classified as dementia-specific or not. For example, “sees children” and “hears voices” were categorized as a ‘thought and perceptual disturbance’, whereas “hiding things” and “wandering” represented an ‘activity disturbance.’ Finally, for those symptoms that could neither be coded into ESAS nor dementia-specific, additional symptom classifications were generated until all responses were categorized. The frequency of each symptom reported by both the patient and caregiver were calculated as well as the median number of symptoms reported by each. Percentage agreement and kappa statistic between dyads was calculated for the most frequently reported symptoms.

In addition to the ESAS, we also compared whether or not symptoms reported by person with dementia and their caregiver was captured by the NPI and ELDS-SM.^{22,23} These two scales represent commonly used measures to assess dementia-specific symptom burden. The NPI assesses 10 behaviors including delusions, hallucinations, agitation, depression, anxiety,

euphoria, apathy, disinhibition, irritability, aberrant motor behaviors, night-time behaviors, and appetite and eating disorders.²² The ELDS-SM measures pain, shortness of breath, depression, fear, anxiety, agitation, calm, skin breakdown, and resistance to care.²³ Statistical analysis was conducted using STATA, version 11.0 (STATA Corp., College Station, TX).

RESULTS

All of the 150 dyads recruited into the PEACE study had at least one interview cycle in which either the person with dementia or the caregiver reported a most bothersome symptom. Symptom data was gathered from the initial interview for 119 of the dyads, from the 6-month for 21, from the 12-month for 7, from the 18-month for 1, and from the 24-month for 2. A total of 35 persons with dementia were unable to respond to the interview questions resulting in 115 for whom interview data were available. Persons with dementia and caregiver characteristics are displayed in Table 1. A majority of persons with dementia in our sample were African American, female, and in their mid-eighties. The 150 caregivers were younger and also mostly African American and female.

A total of 26 categories were used to code all of the most bothersome symptoms reported. Persons with dementia reported a total of 135 symptoms which were coded into 23 symptom categories (Table 2), with a median of 1 symptom reported per person (range 0 to 3). We subsequently report symptoms as the number (or proportion) reported by patients or caregivers. The 5 most frequently reported symptoms were pain (48/115; 42%), depression (13/115; 11%), cognitive deficit (12/115; 10%), anxiety (7/115; 6%), and ophthalmological complaints (5/115; 4%). Caregivers reported 259 symptoms which were coded into 26 categories (Table 3), with a median of 2 symptoms reported per caregiver (range 0 to 5). The 5 most frequently reported symptoms were cognitive deficit (71/150; 47%), pain (46/150; 30%), depression (26/150; 17%), activity disturbance (23/150; 15%), and thought and perceptual disturbance (12/150; 8%). Among the three most common symptoms reported by persons with dementia, the percent agreement with caregiver report was 68% for pain, 83% for depression, and 54% for cognitive deficit. The corresponding kappa for each of these three symptoms are 0.32, 0.25, and 0.07, respectively.

The ESAS captured 3 of the 5 most frequently reported symptoms for persons with dementia (pain, anxiety, and depression), and 2 of the 5 most frequently reported symptoms by caregivers (pain and depression). Drowsiness, one of the original ESAS symptom categories, was not volunteered by any persons with dementia or their caregivers. The NPI did not capture 3 of the 5 most common symptoms reported by persons with dementia (pain, cognitive deficit, and ophthalmologic complaints) and 2 of the 5 (cognitive deficit and pain) reported by family caregivers. The ELDS-SM did not capture 2 of the 5 most bothersome symptoms reported by both persons with dementia (cognitive deficit and ophthalmologic complaints) and their caregivers (cognitive deficit and thought and perceptual disturbances).

DISCUSSION

Persons with dementia and caregivers frequently reported physical, psychological, and dementia-specific symptoms as bothersome during the week prior to the research interview. The caregiver reported more symptoms on average than the person with dementia. Among the five most common symptoms, caregivers reported a number of dementia-specific symptoms (cognitive deficit, activity disturbance, and thought and perceptual disturbances), whereas persons with dementia described cognitive deficits as their only dementia-specific symptom. Pain was the most frequently reported physical symptom and depression the most frequently reported psychological symptom by both persons with dementia and their

caregivers. Importantly, the ESAS, NPI, and ELDS-SM each missed several of the most bothersome symptoms reported by both groups.

A better appreciation of symptom epidemiology is an important aspect of improving the quality of care of persons with dementia and this study takes a first step toward describing the range of physical and psychiatric symptoms experienced in this population across the continuum of disease severity. This importance can be illustrated with pain, an extremely common symptom that has been associated with psychological and dementia-related outcomes. That is, self report of pain in persons with dementia is associated with an increased likelihood of depression.²⁴ Moreover, depression is more likely to be refractory to standard therapies in the presence of pain.¹¹ At the same time, caregiver report of pain has been correlated with agitation, in which pain reports account for 20–30% of the variance of this activity disturbance.²⁵ In our study, pain, depression, and activity disturbance, were cited in the top five most bothersome symptoms by persons with dementia and by caregivers, highlighting the importance of incorporating a broad symptom assessment as part of routine care.

The ESAS is a standard symptom-assessment measure used in palliative care for persons with life-limiting illness and has been suggested for use in persons with dementia.^{12–14} We found the ESAS by itself lacked content validity to capture many of the most bothersome symptoms reported by persons with dementia and their caregivers. The NPI similarly missed some frequently reported physical symptoms by persons with dementia and their caregivers. The ELDS-SM, a more recently developed symptom measure for advanced dementia, also overlooked several common symptoms. Importantly, cognitive deficit was commonly reported but was not captured by any of the standard measures examined. Educational interventions surrounding this symptom that target caregivers can reduce their strain and optimize well-being.²⁶

The current study has several limitations to consider. The study was conducted at a single location in an urban setting which may limit the generalizability of the findings. Also, a convenience sampling methodology was used to establish the study population potentially impacting the representativeness of the sample. However, the demographics of the study participants reflect those of the overall dementia population at the clinic. Persons with dementia were asked to report their symptom experience over the past week and the accompanying memory loss may impede the recollection of some symptoms. Also, the ascertainment of symptoms was open ended and likely underestimates the actual prevalence of symptoms that would be obtained using a systematic inquiry.²⁷ In addition, we used group consensus to categorize symptoms. Others may have chosen different classifications, especially for some of the more vague responses reported by persons with dementia.

In conclusion, physical, psychological, and dementia-specific symptoms are frequently reported over a one week period by persons with dementia and their caregivers. Several symptom measures commonly used in this population do not capture many symptoms. The development of reliable and valid self and proxy report symptom measures across multiple domains of suffering are sorely needed to advance the science of symptom-based research and clinical care in this vulnerable population. Palliative care clinicians may be able to provide support for physical symptom assessment and management to geriatric psychiatrists managing the neuropsychological and behavioral symptoms of dementia, resulting in transdisciplinary care.

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Table 1

Characteristics of 115 Persons with Dementia and 150 Caregivers

Persons with dementia characteristics	Value	Caregiver characteristics	Value
Age, y	81 ± 7	Age, y	62 ± 14
Female	84 (73)	Female	117 (78)
Ethnicity		Ethnicity	
African American	96 (83)	African American	119 (79)
Caucasian	17 (15)	Caucasian	27 (18)
Other	2 (2)	Other	4 (3)
Education, y*		Education, y	
≤ 8	26 (23)	≤ 8	6 (4)
9–12	49 (43)	9–12	48 (32)
> 12	32 (28)	> 12	92 (62)
Unknown	8 (7)	Unknown	3 (2)
Marital status		Relationship to patient	
Widowed	68 (59)	Spouse	33 (22)
Married	34 (30)	Child	90 (60)
Other	13 (11)	Other	27 (18)
MMSE†	17 ± 7	Lives with patient	93 (62)
Functional status		CSI‡	6 ± 4
ADL‡	8 ± 3	BDI**	3 ± 4
IADL§	15 ± 4		
CCI	3 ± 2		

Notes: Data are presented as mean ± SD or number (%). Numbers did not always add up to N due to some missing demographic data.

* Total percentage > 100 due to rounding.

† Folstein Mini-Mental State Examination (MMSE) scores range from 0–30; higher scores indicate higher cognitive functioning.

‡ Activities of Daily Living (ADL) scores range from 6–18; higher scores indicate greater functional dependence.

§ Instrumental ADL (IADL) scores range from 7–21; higher scores indicate greater functional dependence.

|| Charlson Comorbidity Index (CCI) scores range from 0–37; higher scores indicate increased level of comorbidity.

‡ Caregiver Strain Index (CSI) scores range from 0–13; higher scores indicate greater strain.

** Beck Depression Inventory (BDI) scores range from 0–39; higher scores indicate increased depressive symptoms.

Table 2

Symptoms reported by community dwelling persons with dementia, n = 115

Symptom category	Example(s) of verbatim responses*	No. [†] (%) N=115
Pain [‡]	Hurt in my side; aches and pains	48 (42)
Depression [‡]	I do have some sadness	13 (11)
Cognitive deficit [§]	Remembering; sometimes I run into snags in my memory	12 (10)
Anxiety [‡]	My nerves—I'm nervous	7 (6)
Ophthalmological	Blurred vision at night; cataract in my left eye	5 (4)
Upper respiratory symptoms	My nose has been putting out snot	5 (4)
Relationship strain	Me and my daughter not understanding one another	4 (4)
Limited activity [‡]	Trouble moving about	3 (3)
Weakness	Weakness in my legs	3 (3)
Neurological symptoms	Facial paralysis; hands feel like a tingling	3 (3)
Dermatological	Skin growth on forehead; itching	3 (3)
Nausea [‡]	Upset stomach	2 (2)
Decreased sensation of wellbeing [‡]	It's hard to get used to having health problems	2 (2)
Shortness of breath [‡]	Makes my wind short	2 (2)
Constipation	Constipated	2 (2)
Decreased appetite [‡]	Not a good appetite	1 (1)
Dizziness	I was dizzy last week, passed out	1 (1)
Hearing loss	Sometimes I have a hard time hearing strangers	1 (1)
Swallowing difficulties [§]	My throat when the food goes down it—stops in my throat	1 (1)
Apathy [§]	Lately, I really hate cooking. I used to like it, but lately I haven't wanted to.	1 (1)
Description of medical condition	Had a blood clot in the left arm	8 (7)
Not able to be classified	Trouble in the left toes	6 (5)
Other physical symptoms	Frequent urination	2 (2)

* Patient responses to the following questions: "In the last week, what symptoms or problem has been the most bothersome for you?" and "Is there a second symptom or problem that has been bothersome for you?"

[†] Number of patients reporting each symptom, with some patients reporting more than one symptom

[‡] Indicates symptom included in the ESAS

[§] Indicates symptom considered "probably dementia specific"

Table 3

Caregiver report of symptoms bothersome to community dwelling persons with dementia, n = 150.

Symptom category	Example(s) of verbatim responses*	No. (%) [†] N=150
cognitive deficit [‡]	Forgetting how to get to the bedroom	71 (47)
Pain [‡]	Arthritis all over her body	46 (30)
Depression [‡]	Sadness and loneliness	26 (17)
activity disturbance [§]	Packing bags, trying to leave; Hiding things; Wandering	23 (15)
Thought and perceptual disturbance [§]	Extremely paranoid; Hears voices; Sees children; Thinks I'm stealing her money	12 (8)
Limited activity [‡]	Getting around is difficult; can't walk	9 (6)
Anxiety [‡]	Heightening anxiety	9 (6)
Incontinence	Couldn't control urine	8 (5)
Decreased appetite [‡]	Not eating properly	6 (4)
Dermatological	Skin irritation; Itching	6 (4)
Weakness	Leg is weak from a stroke	5 (3)
Shortness of breath [‡]	Having trouble breathing	4 (3)
Constipation	No bowel movements in four days	3 (2)
Upper respiratory symptoms	Coughing	3 (2)
Relationship strain	Clashing with caregiver	3 (2)
Nausea [‡]	Nausea	2 (1)
Ophthalmological	Cataracts	2 (1)
Swallowing difficulties [§]	Having problems swallowing food	2 (1)
Apathy [§]	Basically sits around in a chair	2 (1)
Decreased sensation of wellbeing [‡]	Used to being independent	1 (1)
Dizziness	Became light headed while walking	1 (1)
Hearing loss	Hearing has decreased	1 (1)
Neurological symptoms	Tremor	1 (1)
Description of medical condition	Blood pressure out of control; had a seizure	9 (6)
Not able to be classified	Complains feeling funny around the head	2 (1)
Other physical symptoms	Hot flashes	2 (1)

* Caregiver responses to the following questions: "In the last week, what symptoms or problem has been the most bothersome for the person with dementia?" and, "Is there a second symptom or problem that has been bothersome for the person with dementia?"

[†] Number of caregivers reporting each symptom, with some caregivers reporting more than one symptom

[‡] Indicates symptom included in the ESAS

[§] Indicates symptom considered dementia specific