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Unrecognised cognitive impairment in hospice patients: a pilot study

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Abstract

The presence of cognitive impairment in patients who are receiving hospice care can affect numerous practical, ethical and legal aspects of their healthcare. A number of factors can contribute to cognitive impairment in these patients. Prevalence rates of cognitive impairment vary widely, but it remains under-recognised and under-treated. The aims of this pilot study were to evaluate the presence and nature of cognitive deficits in patients receiving inpatient hospice care who did not have a known current or past diagnosis of a cognitive disorder or any obvious cognitive impairments. A convenience sample of 30 patients receiving inpatient hospice care underwent bedside cognitive testing. A comprehensive battery of tests was used, including the Mini-Mental State Examination (MMSE) and standardised neuropsychological tests of pre-morbid intellectual functioning, immediate and delayed recall, digit span forward and backward, verbal reasoning and letter and category fluency. On average, subjects were impaired on the MMSE and on tests of learning, verbal reasoning and letter and category fluency. Furthermore, 12 of the 30 subjects met DSM-IV cognitive impairment criteria for dementia based on impaired performance

in memory and at least one other cognitive domain on testing. The results of this pilot study suggest that a sizable proportion of patients receiving inpatient hospice care have undetected but clinically significant cognitive impairments. Assessing for and helping patients, families and caregivers deal with cognitive impairment might benefit patients' quality of life, relationships and overall care at the end of life. Future research in this population is needed to evaluate the causes and time course of cognitive impairment over time, as well as any relationship between cognitive impairment and decision-making capacity.

Keywords

cognitive impairment; delirium; dementia; hospice; neuropsychology; palliative care

Introduction

Cognitive impairment is likely prevalent in patients with advanced, life threatening illnesses. Yet, published prevalence rates vary widely, with some studies reporting that nearly 80–90% of patients with terminal cancer develop some form of severe cognitive impairment before death.^{1,2} The presence of cognitive impairment can have important implications, potentially affecting numerous practical, legal and ethical aspects of the patient's and family's experience at the end of life, including decision making regarding medical treatment, legal issues (e.g., withdrawing or withholding treatment, estate planning and power of attorney assignment) and the ability to decide upon, reach and appreciate final life goals. Cognitive impairment may also negatively impact important relationships, such as those with family members and caregivers, particularly if the cognitive impairment is misconstrued as wilful behaviour. Assuring comprehensive, ethical, high quality, compassionate and informed end-of-life care, therefore, necessitates consideration of the possibility of cognitive impairment in the dying patient.

Several factors may contribute to cognitive impairment in hospice populations. Serious illness and advanced age are predictors of impaired decision-making.^{3,4} Opiates are frequently used in palliative care for symptom management and have proven to be an invaluable resource for patients with intractable pain and for those suffering from dyspnoea. Yet, opiates may adversely affect various domains of cognition, and patients receiving them may have unrecognised cognitive impairments.⁵ Other commonly used treatments in palliative care, including chemotherapy, benzodiazepines and radiation therapy, can also have deleterious effects on cognitive functions.^{1,6}

Despite the likelihood of being a frequently encountered complication in patients with advanced, life-threatening illness, cognitive impairment is under-recognised and therefore under-treated in the hospice patient population.¹ Hospice staff may have difficulty in recognising cognitive deficits as patient reports often do not correlate with objective measures of their cognitive status.⁷ Furthermore, lack of consistency in terminology and diagnostic classification may also complicate the accurate assessment and labelling of cognitive impairment.⁸ Lastly, other psychiatric symptoms such as depression often co-occur with cognitive impairment.⁸ Such an interaction creates difficulty in assessing

cognitive status even for skilled mental health clinicians⁸ who are often not available in hospice care.

Little research has been published on the neuropsychological status of patients approaching the end of life.⁸ We designed this pilot study to 1) evaluate the presence of cognitive impairment in alert and awake hospice patients who did not, at the time of assessment, carry a current or past diagnosis of cognitive disorder (including, but not limited to, dementia and delirium) or have any obvious or overt cognitive impairments and 2) characterise the nature of these impairments. We expected that impaired cognition would be under-recognised in hospice patients and that at least a portion of the assessed patients would meet DSM-IV criteria for a cognitive disorder.⁹

Methods

Ethical safeguards

This study was approved by the San Diego Hospice & Palliative Care (SDHPC) Institutional Review Board and the University of California, San Diego (UCSD) Human Research Protection Program. Fourteen participants provided written informed consent for this study, following an explanation of the purpose and procedures of the study, and a test of their understanding that included asking if they were aware that they would be answering questions relating to their ability to think and that they were free to refuse to participate or to withdraw at any time. Sixteen patients who met the inclusion criteria, described below, and gave oral consent were tested before the initiation of this study as part of routine clinical care and both Institutional Review Boards (IRBs) granted a waiver of documented consent to use data from those subjects.

Participants

A convenience sample of 30 inpatients at SDHPC was studied (see Table 1 for demographic characteristics). SDHPC provides hospice and/or palliative care for patients of all ages, anywhere in San Diego County, who have any qualifying advanced life-threatening (terminal) illness (i.e., 'with a prognosis of less than 6 months if the disease runs its expected course').¹⁰ A majority of patients receive care in their own homes or in long-term care facilities. Most patients who need an increased level of care receive inpatient care in a 24-bed Inpatient Care Center (ICC). To illustrate the scope of this hospice's care, 45.7% of the 18,649 people with non-violent/non-traumatic deaths in San Diego County during 2005 had received hospice care. Of those, over 2850 (or 33.5% of those receiving hospice care) received this care from SDHPC. Interdisciplinary care is provided by a team consisting of a chaplain, nurse, social worker and volunteers, with medical input from the patient's primary care physician and/or a palliative medicine specialist associated with each team. When necessary, patients were seen by other medical consultants.

Procedure

Inpatients at SDHPC were requested to undergo bedside cognitive testing if they met the following criteria:

(A) over 18 years of age; (B) English speaking; (C) could sustain wakefulness and attention for at least an hour and (D) did not have 1) a chart or clinical diagnosis of dementia or delirium; 2) any clinically obvious or overt cognitive impairments, 3) a history of neurological disease or injury (e.g., stroke, traumatic brain injury) or 4) other known cognitive impairment (e.g., mental retardation). The administered tests took approximately 1 h in total, and rest breaks were provided as requested by the patient. Measures were scored according to published norms and were corrected for age and education whenever possible.

Measures

The neuropsychological battery consisted of a number of published, validated measures with normative data. The battery was designed to be brief, yet to adequately assess cognitive domains relevant to aging and decision-making capacity. None of the tests required motor responses other than speaking. The test battery assessed the following domains:

1. General orientation and cognitive functioning (Mini-Mental State Examination [MMSE]).¹¹
2. Pre-morbid intellectual functioning (reading subtest of the Wide Range Achievement Test [WRAT-3]).¹² This test of oral word reading ability yields an estimate of Verbal IQ.
3. Verbal Learning (Trials one to three total immediate recall from the Hopkins Verbal Learning Test-Revised [HVLTR]).¹³ This oral list-learning task involves learning a list of 12 words over three trials.
4. Verbal Memory (HVLTR percent retained).¹³ The delayed recall condition of the HVLTR measures percent of words retained following a 25-min delay.
5. Attention (Digit Span Forward from the Wechsler Adult Intelligence Scale-Third Edition [WAIS-III]).¹⁴ This test measures the ability to repeat digits read aloud at a rate of one per second. The digit span lengths range from easy (two digits) to difficult (up to nine digits).
6. Working Memory (Digit Span Backward from the WAIS-III).¹⁴ This test measures the ability to repeat digits read aloud (as above) in backward order, with digit span lengths ranging from 2 to 9 digits.
7. Verbal Reasoning (Word Context total consecutively correct score from the Delis Kaplan Executive Functioning System [DKEFS]).¹⁵ This test measures the ability to reason with novel verbal information. For each of 10 items, the examinee read a series of five clue sentences that give progressively more information about the meaning of a nonsense word. After each clue sentence is read, the examinee attempts to guess the meaning of the nonsense word. The total consecutively correct score measures overall achievement on this test, that is, the number of items guessed correct in a row across the 10 items.
8. Freedom from Perseveration (total repeated incorrect score from the Word Context subtest from the DKEFS).¹⁵ This score on the Word Context subtest measures the extent to which examinees avoid repeating incorrect guesses on the test.

9. Letter fluency (Controlled Oral Word Association Test [COWAT]).¹⁶ Letter fluency measures speeded generation of words beginning with the letters F, A and S (1 min/letter).
10. Category fluency (animals from the COWAT).¹⁶ This test, another task of speeded word generation, measures the number of animals the examinee can name in 1 min.

Analyses

Neuropsychological performance was examined to determine if any patients met the DSM-IV cross-sectional cognitive impairment symptom criteria for dementia,⁹ defined as impaired performance (T score <40 or age-corrected standard score <7) in memory and in at least one other cognitive domain.⁹ Independent samples *t*-tests were also used to evaluate differences between patients who met these cognitive criteria for dementia and those who did not.

Results

Patients' performance on neuropsychological tasks ranged from average to moderately impaired (see Table 2). Mean pre-morbid intellectual functioning, attention and working memory, delayed recall and freedom from perseveration scores were all within the range traditionally labelled 'average', whereas mean scores on measures of learning, verbal reasoning and letter and category fluency were all mildly to moderately impaired. Mean performance on the MMSE was also in the impaired range according to the commonly used cut-off score of 24.¹¹

Although none of the subjects had previously been diagnosed with any cognitive disorder, 12 of the 30 individuals in this sample met DSM-IV cognitive criteria for dementia. All these 12 patients were impaired on both immediate and delayed recall; other domains of impairment included attention/working memory ($n = 3$), verbal reasoning ($n = 7$), freedom from perseveration ($n = 2$), letter fluency ($n = 9$) and category fluency ($n = 9$). Differences between those who met cognitive criteria for dementia and those who did not are summarised in Table 3. These two groups did not differ in age, education, gender, ethnicity, presence of cancer versus noncancer diagnosis or on specific domains of cognitive function except for delayed recall (lower score in those who met criteria for dementia).

Discussion

Hospice care is increasingly recognised as an important option for patients at the end of life.¹⁷ For optimal management, it is critical for healthcare providers and family members to have a complete picture of the patient's functioning and needs in all domains. Yet, much remains to be learned about neuropsychiatric impairments in hospice patients.⁸ Among these gaps is an appreciation of the prevalence, nature and impact of cognitive deficits in this population.

To our knowledge, this study is the first to examine the neuropsychological status of hospice patients using a comprehensive battery of cognitive tests. On average, the sample was of average pre-morbid intelligence and retained intact functioning in several cognitive

domains, including working memory and delayed recall. Mean performance on measures of learning, verbal reasoning and verbal fluency, however, was mildly to moderately impaired; the sample also showed impaired performance on the widely used MMSE.

Although none of the 30 participants had been previously diagnosed with a cognitive disorder, 12 met the cognitive criteria for dementia. We did not find any differences between those who did or did not meet these criteria in terms of basic demographic data including age, ethnicity, gender, education level or medical diagnosis. This finding suggests that cognitive impairments are common among hospice patients who require inpatient care; furthermore, it highlights the under-recognition of cognitive impairments in this population. Finally, the MMSE did not differentiate these groups and therefore may not be sensitive enough to properly screen for cognitive impairment in this population. The two groups differed only on delayed recall; the MMSE does not include a measure of long delay recall and often misses mild memory impairments.

This pilot study had several limitations. First, the sample size was small, although it was large enough to answer our main question regarding the presence of unrecognised cognitive impairment in this population. Second, we did not gather information about the time course of cognitive decline and current psychosocial functioning, which precluded us making more definitive diagnoses of dementia in those who met the cognitive criteria for dementia. Third, as this was a pilot study to determine if cognitive impairment was present, we did not attempt to determine the aetiology of this impairment, which is likely to be complex and multifactorial in a primarily elderly and medically ill sample. There were probably multiple potential causes of cognitive impairment in this sample, including medications such as opiates, terminal illness its sequelae (e.g., brain metastases), interventions targeted at the illness (e.g., chemotherapy), mood disturbances, substance abuse and different types of dementias. We did not conduct a comprehensive work up such as neuroimaging to determine the precise aetiology of the cognitive deficits in individual patients. Larger studies are needed to further discern the characteristics and causes of cognitive impairments in this population, as well as investigate appropriate interventions.

The benefits of detecting cognitive impairment in this population may extend to the psychological and social aspects of the patient's life, including 1) psychoeducation for family members and caregivers, 2) psychopharmacological treatment for the patient and 3) more timely final preparations for all such that maximum functions of daily living can be maintained, adequate understanding and coping mechanisms can be in place and important business such as wills, advanced-directives, legacy work and saying 'good-byes' can all be completed optimally.

Not only does the evaluation of cognitive status in hospice patients warrant additional investigation, further study is also needed to examine relationships between cognitive impairment and the nature and quality of decision making in various domains among hospice patients, given previous research documenting the infrequent detection of impaired treatment-related decision-making capacity among medically ill patients.¹⁸ It would also be important to understand whether and to what degree cognitive impairment fluctuates over

time and what the effects of such fluctuations are on psychosocial functioning, decision making and general well being.

Cognitive impairment can affect patients' quality of life, relationships and overall care at the end of life, but often, it may be at least partially reversible.¹⁹ Given the already high rates of physical and mental co-morbidity in patients with advanced, life-threatening illnesses, recognition of cognitive impairment, and intervention when possible, should be a standard part of care in this vulnerable population.

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Table 1Demographic and performance features of the sample ($n = 30$)

Demographic variables	Mean (SD)
Age (years)	63.9 (16.9)
Years of education	13.0 (3.4)
% Male	47%
% Ethnic minority	20%
% Married	50%
Terminal diagnoses	
AIDS/HIV	3%
Cardiovascular disease	10%
Neoplasms	63%
Neurological disease	3%
Pulmonary disease	17%
Renal disease	3%
Days of acute care stay	37.4 (44.3)
Days on hospice service	143.4 (148.8)

Table 2Neuropsychological performance of the sample ($n = 30$)

Neuropsychological variables	Mean (SD)	Observed range	Normal range (within 1 SD)
General orientation and cognitive function (MMSE)	23.6 (2.4)	18–28	<24 signifies cognitive impairment
Pre-morbid IQ (WRAT-3)	99.0 (11.3)	70–113	85–115
Verbal Learning (HVL-T-R Total Immediate Recall T-score)	32.8 (11.1)	19–57	40
Verbal Memory (HVL-T-R Percent Retained T-score)	42.2 (15.8)	19–80	40
Attention and Working Memory (WAIS-III Digit Span Total Scaled Score)	7.8 (2.7)	3–13	7
Verbal Reasoning (DKEFS Word Context Total Consecutive Correct Scaled Score)	5.6 (2.8)	1–12	7
Freedom from Perseveration (DKEFS Word Context Repeated Incorrect Scaled Score)	9.1 (3.4)	1–16	7
Letter Fluency (COWAT FAS T-score)	35.3 (7.9)	19–50	40
Category Fluency (COWAT Animals T-score)	34.2 (10.5)	10–55	40

MMSE, Mini-Mental State Examination; WRAT-3, Range Achievement Test; HVL-T-R, Hopkins Verbal Learning Test-Revised; WAIS-III, Wechsler Adult Intelligence Scale-Third Edition; DKEFS, Delis Kaplan Executive Functioning System; COWAT, Controlled Oral Word Association Test.

Table 3

Comparisons between patients meeting versus not meeting cognitive criteria for dementia

Neuropsychological variables	Cognitive criteria for dementia met (<i>n</i> = 12)		Cognitive criteria for dementia not met (<i>n</i> = 18)		<i>t</i>	df	<i>P</i>
	Mean (SD)		Mean (SD)				
General orientation and cognitive function (MMSE)	22.9 (2.6)		24.1 (2.3)		1.31	26	0.20
Pre-morbid IQ (WRAT-3)	99.8 (9.9)		98.5 (12.3)		0.29	28	0.77
Verbal Learning (HVL-T-R Total Immediate Recall T-score)	28.8 (6.2)		35.5 (12.8)		1.89	26	0.07
Verbal Memory (HVL-T-R Percent Retained T-score)	26.5 (7.4)		52.7 (10.1)		7.68	28	<0.001
Attention and Working Memory (WAIS-III Digit Span Total Scaled Score)	7.8 (2.9)		7.7 (2.7)		0.11	28	0.92
Verbal Reasoning (DKEFS Word Context Total Consecutive Correct Scaled Score)	4.7 (2.1)		6.2 (3.2)		1.45	27	0.16
Perseveration (DKEFS Word Context Repeated Incorrect Scaled Score)	9.3 (4.2)		9.0 (2.8)		0.19	27	0.85
Letter Fluency (COWAT FAS T-score)	35.8 (9.6)		35.0 (6.8)		0.27	27	0.79
Category Fluency (COWAT Animals T-score)	33.3 (10.0)		34.9 (11.0)		0.41	27	0.69

MMSE, Mini-Mental State Examination; WRAT-3, Range Achievement Test; HVL-T-R, Hopkins Verbal Learning Test-Revised; WAIS-III, Wechsler Adult Intelligence Scale-Third Edition; DKEFS, Delis Kaplan Executive Functioning System; COWAT, Controlled Oral Word Association Test.