

Using Medical Words with Family Caregivers

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Abstract

Background: Although there is poor communication about pain management between informal caregivers and hospice providers, little research has examined these interactions.

Objective: This study explored communication between informal caregivers and hospice team members by investigating the use of medical words in care planning discussions.

Design: Transcripts of clinical communication between caregivers and hospice team members were reviewed for use of medical words, word placement (statement or question), whether or not the word was explained, and the caregiver's response to the word.

Setting/subjects: As part of an ongoing randomized clinical trial in the midwestern United States, informal hospice caregivers participated in recorded hospice care planning discussions.

Measures: A selection of videorecorded interactions from an ongoing study was analyzed.

Results: Hospice team members used six times as many medical words compared to caregivers. The majority of medical words used by caregivers and team members were drug names. Medical words were predominantly used as statements rather than questions that sought clarification. Three-fourths of medical words used by team members were not explained to caregivers. Caregivers provided little response to medical word use, indicating a lack of understanding.

Conclusions: The propensity to use medical words during clinical communication with family caregivers is cautioned. In order to recognize the caregiver as a contributing team member, clinicians should limit the use of medical words, provide lay explanation alongside medical terminology, and use questions to check for understanding. More research is needed to determine assessment tools to capture the caregiver's level of understanding of medication and pain management protocol.

Introduction

DURING SERIOUS ILLNESS, approximately 70% of a patient's prior medical history is shared orally between health care providers, informal caregivers, and patients.¹ Commonly, complex medical words and abbreviations are used to describe medications, medical treatments, procedures, and disease processes during consultations with patients and families.² Medical words are also used when making recommendations, providing health education,³ and when giving discharge instructions,⁴ affecting patient/family understanding and their ability to follow directions.³ This is an especially salient issue in hospice, which relies on informal caregivers (family or friends) to oversee the patient's medication man-

agement.⁵ Prior research has documented that the ability to orally receive instructions can be impeded by the complexity and difficulty of spoken messages.⁶ Given that poor communication with hospice staff impedes caregiver pain management,⁷ an exploration of discussions about pain management between hospice team members and caregivers and the use of medical words is warranted. Specifically, we sought to examine how medical words were used and what types of words were common in care planning discussions with family caregivers.

Methods

Data come from an ongoing randomized controlled trial of caregiver participation in hospice care planning discussions to

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improve caregivers' perceptions of pain management. Caregivers utilized video technology to virtually join team meetings from their home. Details of the larger trial are published elsewhere.⁸ For this study, videorecorded interactions between caregivers and team members that had been transcribed to date were analyzed. The institutional review board at the supporting university approved the study.

Medical words

The Medical Subject Headings (MeSH) list on the National Library of Medicine website was used to identify medical words within the transcripts. Additionally, a medical abbreviations and pharmaceutical abbreviations dictionary website and the U.S. National Library of Medicine consumer medication information website were used to discern medical acronyms and drug names.^{9,10} Medical words on the MeSH index list with high frequency in the hospice context (e.g., hospice, transfer, decline) were identified as common words; the use of common words indicates prior understanding of the word in this context. To ensure that all medical words were captured, two members of the research team independently identified medical words within the transcripts. This resulted in a reliability of $r=0.90$, and through discussion, a final medical word list was derived for each transcript.

To account for the use of medical words within the transcripts, we duplicated the approach of Koch-Weser and colleagues¹¹ by coding the following: (1) the type of the medical word (e.g., drug name, disease, symptoms); (2) placement of the medical term as a question or statement; (3) if introduced by the team, whether or not it was explained; and (4) the caregiver's response to use of the word. The caregiver's response to the medical word was coded into one of the following categories: continuation—caregiver continues discussion and demonstrates understanding of the word; clarification—caregiver asks for clarification or definition of word or idea of word; confusion—caregiver comments indicate lack of understanding; short response—caregiver responds with a short response (yes, no, uh-huh) but does not convey understanding; or no response—caregiver's next line is a new topic in the transcript and videorecording shows no evidence of nonverbal understanding (e.g., nodding), or team members continue talking without allowing caregiver an opportunity to ask a question. Intercooder reliability between coders was calculated using Pearson's r reliability statistic, revealing an average reliability of $r=0.86$ for all coding categories.

Data analysis

Frequency counts for coding categories were calculated using SPSS Version 20 (SPSS Inc., Chicago, IL). Means and ranges were also calculated. Frequencies and corresponding proportions are reported below.

Results

A total of 47 transcripts of meetings between hospice team members and caregivers were analyzed for this study. Caregivers ($n=18$) participated in two or more team meetings (range 2–7) and demographics are summarized in Table 1. Overall, 410 medical words were introduced, with 341 by the

team and 69 by caregivers. Table 2 shows the frequency of medical term use by caregivers and team members. Team members averaged 7.26 medical words per interaction. The most common type of medical words was drug names (29%), followed by treatments or medical procedures (23%). Caregivers averaged 1.47 medical words per interaction that were similarly predominantly drug names (42%), followed by treatment or medical procedures (13%). When the caregiver used medical terms, the majority were in statement form (88%; $n=61$) rather than questions (12%; $n=8$). Similarly, team members incorporated medical words into statements (83%; $n=284$) rather than in asking caregivers questions. The majority of medical words were not explained by team members (72%; $n=245$); and caregivers predominantly had no response (40%) or provided a short response (24%), suggesting that there was uncertainty about understanding. Table 3 displays response categories and examples.

Discussion

Little research has addressed communication and patient education with hospice caregivers, despite the caregiver's influential role in pain medication administration and their reported need for less medical jargon and more plain language in pain management education.¹² Although common medical words for hospice staff are typically incorporated into written materials for patient/family,^{13,14} this study found that

TABLE 1. SUMMARY DEMOGRAPHIC VARIABLES FOR CAREGIVERS

Variable	Caregiver ($n=18$)
Mean age	64.5 years (range 49–86)
Sex	
Female	78% (14)
Male	22% (4)
Race	
White/Caucasian	94% (17)
Black/African-American	6% (1)
Education	
Less than high school	6% (1)
High school	22% (4)
Some college	22% (4)
Undergraduate college degree	33% (6)
Graduate/professional degree	17% (3)
Marital status	
Never married	6% (1)
Married	66% (12)
Separated	6% (1)
Divorced	6% (1)
Widowed	16% (3)
Caregiver employment	
Not employed	6% (1)
Part-time	17% (3)
Full-time	27% (5)
Other	17% (3)
Retired	33% (6)
Relationship to patient	
Spouse	11% (2)
Adult child	77% (14)
Sibling	6% (1)
Other relative	6% (1)

TABLE 2. MEDICAL WORDS USED BY CAREGIVERS AND TEAM MEMBERS

<i>Type of medical word</i> ¹¹	<i>Caregivers' use of medical words (n = 69)</i>	<i>n (%)</i>	<i>Team members' use of medical words (n = 341)</i>	<i>n (%)</i>
Drug names	Torsemide, acetaminophen, Seroquel, oxycodone	29 (42%)	Seroquel, Klonopin, morphine, Roxanol, Ativan, Loritab, Doxycycline, Zofran, Cipro, Nystatin, Prednisone	98 (29%)
Diseases and disease processes	Virus, fracture, anxiety, UTI, sugars	8 (12%)	Fluid, edema, wound, COPD, cardiac, drainage	35 (10%)
Parts of the body	Urine, upper extremities	5 (7%)	hip fracture, urine, bowel, urinary, vaginal, discharge	24 (7%)
Symptoms	Frail, confusion, dehydration, pressure sore, appetite	13 (19%)	Aspiration, forced lung sounds, secretions, lethargy, spasms, chronic pain, vomiting, nausea	52 (15%)
Treatments or medical procedures	EEG test, PRN, defibrillator, DNR	9 (13%)	Sedation, PRN, PPS, MMSE, BMI, dosage, catheter, PR, code blue, cannula	80 (23%)
Names of medical specialties	EMT, long-term care	2 (3%)	Geriatric principle, primary care, ADLs, pharmacist, podiatrist	19 (5%)
Other	Prognosis, formulary, quality of life	3 (4%)	Exertion, cognition, executive function, quality of life, comorbidities, generalized	33 (10%)
	Total	69 (100%)	Total	341 (100%)

hospice team members used six times as many medical words as family caregivers during care planning discussions. Caregivers' infrequent use of medical words as well as their response to them compared to team members suggests either minimal understanding of the words or understanding that needed no elaboration.

Despite a difference in frequency of medical word usage, the most prevalent medical words used by both caregivers and team members were drug names. Caregivers often report confusion about pain medications, their desired effect, side-effects, and how to administer medications;¹² so it was not surprising that drug names were most prominent among caregiver medical word usage. Although drugs are commonly referred to by their brand names,¹⁵ caregivers often receive generic equivalents from pharmacies. Drug naming practices change over time,¹⁵ contributing to caregiver confusion; the most problematic look-alike and sound-alike drug names include Roxanol, MSIR and morphine oral liquid, dilaudid and morphine, and clonazepam and klonopin,¹⁶ all of which are common in hospice care. However, drug names and the majority of other medical words identified in this study were used in statements and not as questions aimed at seeking clarification or checking for understanding. This suggests that caregivers knew medication names, but what remains unknown is their level of understanding of the medication. Future research should examine caregiver understanding of written and oral instruction on drug labels and administration of medications.

Almost three-quarters of the medical words used by team members were not explained to caregivers during the observed encounters. When clinicians use medical words they distance themselves from patients and family members, decreasing trust, satisfaction, and patient intention to adhere.¹⁷ Especially when medical words are used to explain disease processes or facilitate pain management instruction, clinicians

need to be aware of verbal and nonverbal cues (e.g., not answering questions directly or looking away) that indicate misunderstanding and need for information and support.¹⁹ Caregivers provided little to no response to team members' use of medical words, demonstrating withdrawal, subdued interactivity, and little understanding of verbal information. A lack of knowledge and understanding impedes the ability to recall information¹⁴ and can influence the caregiver's ability to follow instructions and problem solve on behalf of the patient.

Findings from this study demonstrate the need to limit medical word use in discussions with informal hospice caregivers, but also accommodate potential caregiver responses to the medical words that are utilized. Still, several limitations should be noted. Unlike clinical visits that consist of physician and patient, these team meetings involved multiple professionals who addressed the caregiver as well as each other, potentially minimizing opportunities for the caregiver to talk or ask questions. In many instances, medical words were used in team conversation that occurred with the caregiver present, but team members did not acknowledge or clarify caregiver presence. Care planning discussions analyzed in this study included longitudinal data for caregivers, and the lack of explanation for some medical words may be the result of repeated prior word use and topic orientation with the caregiver. Further research on caregiver understanding of prognosis, drug names, and pain management protocols is needed. Finally, we caution the generalizability of these findings, as this study did not include individual cognitive assessments including memory and comprehension for participating caregivers.⁶

Limiting the use of medical words with patients and families enacts an interactional approach to care allowing shared knowledge and deliberation to emerge from patient- and family-centered communication.¹⁸ For example, when

TABLE 3. CAREGIVER RESPONSES TO THE TEAM'S USE OF MEDICAL WORDS

Caregiver response type ¹¹	Example from data	n (%)
Continuation Caregiver continues discussion and demonstrates understanding of the word	Medical director: Is she still taking her <u>Doxycycline</u> ? Nurse: Yes, she is still taking <u>Doxycycline</u> . She's been on that quite a while, hasn't she (caregiver)? Caregiver: Yeah, yeah, it helps keep down <u>infection</u> , I mean it's supposed to. Medical director: And the <u>nausea</u> is something that she's had for a long time? Or just... Caregiver: Yeah Medical director: <u>Doxycycline</u> can sometimes cause <u>nausea</u> . Caregiver: Yeah, but that was before she was put on the <u>Zofran</u> . Dr. (name) and Dr. (name) and Dr. (name) went through periods of trying her on different meds before they settled on the <u>Zofran</u> .	115 (34%)
Clarification Caregiver asks for clarification or definition of word or idea of word	Medical director: So why don't we say increase the Tylenol to scheduled four times a day. And maybe find a <u>PRN</u> medication that doesn't have Tylenol in it. Tylenol free we could use an <u>oxycodone</u> product, if we needed a PRN you know like a 2.5, whatever her doctor is comfortable with; that way she doesn't have too much Tylenol. Caregiver: Ok, <u>oxycodone</u> product four times a day, right? Doctor: No, the Tylenol would be four times a day scheduled, but then if she needed something extra we'll let her doctors decide what he thinks is best but it looks like she's getting too much Tylenol; we won't let her get too much. Caregiver: Okay, I don't mind her getting too much to keep the pain down.	6 (2%)
Confusion Caregiver comments indicate lack of understanding	Caregiver: Who's responsible for making sure she gets that medication? Medical director: We'll check in with that. They'll have something there called a <u>director of nursing</u> , so we'll have our nurse talk to their <u>director of nursing</u> a little bit so we can communicate about our plan on the team. Caregiver: Because I wasn't happy with it at all. Nurse: That's right, that's frustrating to have her be in pain and feel like you're not getting anything. I think this will help and then, [nurse's name], can you talk to you know, their nursing department out there and make sure we're all on the same page, okay? Caregiver: Okay.	1
Short response^a Caregiver responds with a short response (yes, no, uh-huh)	Doctor: Looking at her medicines, there are no major flags for fall risk. Is her heart failure worse to where <u>lower extremity fluid burden</u> is impacting her transfers? Nurse: It's about the same. The <u>edema's</u> really not changed. Medical director: <u>Edema</u> has not changed, so her going up on <u>Lasix</u> is not going to make her suddenly walk. I heard you say that she fell while there was a person with her assisting her back to the chair. Caregiver: Right.	81 (24%)
No response^a Caregiver's next line is a new topic in the transcript, and videorecording shows no evidence of nonverbal understanding (e.g., nodding); or team members continue talking without allowing caregiver opportunity to ask question	Nurse: He's had an increase in <u>weakness</u> and <u>lethargy</u> , no longer able to safely ambulate; he had 2 <u>UTIs</u> , increased pain; we've increased his long-acting <u>morphine</u> . He was put on <u>Roxanol</u> because there was difficulty swallowing his medication, his pills, and increased problems breathing when he <u>exerts</u> himself; and he's also been more <u>incontinent of urine</u> . Volunteer coordinator: I just wanted to let you know that the volunteer who's been out is having some problems with her knees, so a new volunteer is going to come out.	138 (40%)

^aOriginally defined by Koch et al. and modified to account for team meeting context.

providing pain medication instruction, both the brand and generic name for medication should be included in verbal and written instruction to caregivers, and their relationship clarified.¹⁶ When patients consider clinicians to be informative and supportive, they are more satisfied with care, express greater

trust, and are more likely to follow recommendations.¹⁷ This analysis indicates that medical word usage in high density with no attention to caregiver orientation diminishes the caregiver as a contributing member of care planning communication.

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Author Disclosure Statement

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