

Brief Report

Exploring Oral Literacy in Communication With Hospice Caregivers

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Abstract

Context. Low oral literacy has been identified as a barrier to pain management for informal caregivers who receive verbal instructions on pain medication and pain protocols.

Objectives. To examine recorded communication between hospice staff and informal caregivers and explore caregiver experiences.

Methods. Using transcripts of interactions ($n = 47$), oral literacy features were analyzed by examining the generalized language complexity using the Flesch-Kincaid grading scale and the dialogue interactivity defined by talking turns and interaction time. Means for longitudinal follow-up measures on caregiver anxiety, quality of life, perception of pain management, knowledge and comfort providing pain medication, and satisfaction were examined to explore their relationship to oral literacy.

Results. Communication between team members and caregivers averaged a fourth-grade level on the Flesch-Kincaid scale, indicating that communication was easy to understand. Reading ease was associated ($r = 0.67$, $P < 0.05$) with caregiver understanding of and comfort with pain management. Perceived barriers to caregiver pain management were lower when sessions had increased use of passive sentences ($r = 0.61$, $P < 0.01$), suggesting that passive voice was not an accurate indicator of language complexity. Caregiver understanding and comfort with administering pain medications ($r = -0.82$, $P < 0.01$) and caregiver quality of life ($r = -0.49$, $P < 0.05$) were negatively correlated with dialogue pace.

Conclusion. As the grade level of talk with caregivers and hospice teams increased, associated caregiver anxiety increased. Caregivers with higher anxiety also experienced greater difficulty in understanding pain medication and its

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Key Words

Caregivers, pain management, hospice team, health literacy

Introduction

Health literacy involves the “capacity to obtain, process, and understand” health information and services to inform and improve decision making.¹ Many studies demonstrate extreme limitations for people with lower incomes, lower levels of education, and older age—most specifically, adults older than 65 years, nonwhites, those with less than a high school degree, those at or below the poverty level, and non-English speakers.² Nationally, approximately 88% of adults older than 16 years do not have proficient health literacy and adults older than 65 years have lower average health literacy than younger adults.³ Limited health literacy is associated with worse health outcomes and higher costs.²

Although most of the health literacy research has focused on written materials to determine if a patient/family can demonstrate comprehension, health literacy includes more than reading comprehension and numeracy skills.⁴ Health literacy also includes language, context, culture, communication skill levels, and technology.⁵ Previous research has established that health literacy barriers include providers’ frequent use of medical jargon, language discordance, purposeful ambiguity, and cultural insensitivity;⁶ however, assessments of health literacy have been limited to educational level and written comprehension, with few studies investigating oral literacy.⁷

Oral literacy, both speaking and listening, is a component of health literacy that is central to hospice pain management because medication management entails complicated instructions that are often delivered verbally by hospice staff.⁸ The ability to orally communicate about health and receive instructions can be impeded by an individual’s conceptual knowledge of pain management and the complexity and difficulty of spoken messages.⁹ Lower aural (listening) skills complicate the ability to understand and recall

complex information delivered orally and impede the ability to manage medication.^{10–12} For example, poor communication between the providers and caregivers impedes the understanding of prescription instructions.⁸ Few studies have examined the oral literacy demand and its relationship with health care experiences.⁷ In an exploratory study, we investigated the features of oral literacy in recorded care planning sessions between informal caregivers and hospice team members as they related to the caregiving experience.

Methods

Data for this study come from a larger, randomized, controlled trial aimed at assessing outcomes related to family caregiver participation in hospice interdisciplinary care planning meetings.¹³ Both intervention and control caregivers received standard hospice care; control caregivers did not participate in the interdisciplinary meetings. The study enrolled hospice family caregivers and interdisciplinary team members at two hospice agencies in the midwestern United States. Family caregiver participation was facilitated via Virtually Interactive Families (www.vifamilies.com), a web-based video-conferencing platform. As part of the larger study design, a random sample of care planning discussions was video-recorded on an ongoing basis. Several caregiver measures were collected for the larger parent study: on study enrollment, two and four weeks postrandomization, every month up to six months, and every 45 days thereafter. The review board at the supporting university approved the study.

Participants

Caregivers had to be at least 18 years of age and the designated primary caregiver(s) for a hospice patient (as determined by hospice

staff). The telemedicine component required a high-speed Internet connection with a computer to participate in the video-conference session. However, audio participation was available with any telephone device. After hospice staff gained permission to contact from eligible family caregivers, a member of the research team met with the caregiver to obtain informed consent and provide instruction with video-conferencing. Hospice staff who participated in weekly meetings also provided informed consent.

Measure of Oral Literacy

Consistent with previous work on oral literacy, readability statistics of the transcripts were produced using Microsoft Word grammar summary statistics.¹² General language complexity was assessed through the summary statistics, which included a Flesch-Kincaid grade level score, reading ease score (0–100, where higher scores indicate material that is easier to read), and average number of words per sentence for each transcript. The average number of syllables per word was calculated using a formula based on the work of Roter et al.¹² Dialogue pace, defined as the rate of speech speed in syllables per second of session time, also was calculated. Finally, general language complexity included the percentage of transcript sentences in the passive voice. To account for the structural measures of the dialogue (dialogue interactivity), the number of teams and caregiver talking turns (continuous, uninterrupted dialogue by a single speaker) were summed for each interaction. The total minutes of the interaction also were recorded. Averages for each of the aforementioned variables were used for caregivers who participated in multiple interactions.

Caregiver Measures

Caregiver measures were collected throughout participation in the larger study and have been averaged for this analysis. These measures include the Caregiver Pain Medicine Questionnaire (CPMQ), the Caregiver Quality of Life-Revised (CQOL-R) Index, and the Caregiver State Anxiety Inventory (CSAI). Average scores for these measures over time were computed for each caregiver. The CPMQ was used to assess the caregiver's overall perception regarding pain management.¹⁶ The CPMQ

measures the caregivers' agreement with statements regarding pain management using a five-point Likert scale of agreement. Lower scores indicate more problematic perceptions regarding pain management.

The CQOL-R Index¹⁷ measures self-reported quality of life in four domains (emotional, social, financial, and physical). The instrument uses an 11-point scale anchored with 0 to indicate the lowest quality and 10 to indicate the highest quality. The maximum score for each dimension is 10, with a total maximum score of 40 that is derived by summing the four items. Finally, the CSAI consists of 20 items and measures current ("state") anxiety, with higher scores indicating greater anxiety.¹⁸ The scale identifies high (score 60–80), moderate (score 40–59), and low (score 20–39) anxiety.

Additionally, caregivers completed a bereavement interview in which they were asked to rate their personal knowledge and skills related to pain management, their understanding and comfort with their loved one's pain medications, and overall satisfaction with the hospice team's pain management.

Data Analysis

SPSS for Windows v. 19 (SPSS, Inc., Chicago, IL, USA) was used to run descriptive statistics (e.g., mean, SD, range) for oral literacy variables.¹⁴ Pearson correlations were calculated between the general language complexity and dialogue interactivity variables and the caregiver measures (e.g., caregiver anxiety rating, quality of life). We defined correlations of 0.8 or higher as indicating a very strong association and correlations from 0.6 to 0.79 as indicating a strong association.

Results

Overall, 47 care planning discussions occurring between 18 caregivers and their hospice interdisciplinary team were analyzed. Care planning discussions that had been transcribed in the larger ongoing clinical trial were randomly selected for analysis. An average of two care planning discussions were included for each caregiver (range 1–7).

Most caregivers were white (94%), female (78%), or married (66%). The mean age of caregivers was 64.5 years (range 49–86 years); most

(77%) were adult children of the patient. Approximately one-third of caregivers held an undergraduate degree or were retired (Table 1). Caregivers had an average CSAI score of 47.81, an average CQOL-R Index score of 30.75, and an average CPMQ score of 3.87, indicating that the average caregiver had moderate anxiety, quality of life, and perceptions of barriers to pain management.

Table 2 shows the means, SDs, and ranges of general language complexity and dialogue interactivity variables across interactions. The average reading level was just above the fourth grade (4.21), with wide variation from first grade to postsecondary education levels (range 1.50–18.6). The average number of syllables per word was 1.28 (range 1.18–1.42), virtually no dialogue sentences were in the past tense, and long sentences—averaging 12 words per sentence (range 6.40–49.90)—were regularly used. The average Flesch reading ease score was 86.4, indicating that dialogue from the sessions was easy to understand. Dialogue interactivity scores revealed that the hospice team

Table 2
Means (SDs) and Ranges of General Language Complexity and Dialogue Interactivity

Oral Literacy Measure	Mean (SD)	Range
General language complexity		
Average syllables per word	1.28 (.64)	1.18 – 1.42
Average words per sentence	12.28 (6.38)	6.40 – 49.90
Flesch-Kincaid reading grade level	4.21 (2.58)	1.50 – 18.60
Flesch reading ease score	86.38 (8.32)	50.30 – 97.90
% of passive sentences	0.01 (.02)	0.00 – 0.08
Dialogue interactivity		
Dialogue pace (syllables per minute)	33.54 (4.48)	20.67 – 43.06
Team talking turns	34.09 (19.34)	10 – 129
Caregiver talking turns	25.68 (13.10)	6 – 83
Length of interaction (minutes)	5:57 (3:13)	1:18 – 17:00

averaged 34 talking turns per session, with caregivers averaging 25 talking turns. This pattern reflects that hospice team members did most of the talking, yet caregivers engaged in a substantial proportion of talking turns as well. The average session length was almost six minutes, but varied greatly with a range from a little over one minute to 17 minutes.

The correlations between the general language complexity and dialogue interactivity and the caregiver measures yielded several statistically significant relationships (Table 3). The Flesch reading ease was statistically significantly correlated ($r = 0.67$, $P < 0.05$) with caregiver understanding of and comfort with pain management, revealing that greater reading ease was associated with better understanding of and comfort with pain management. The percentage of sentences in the passive voice was statistically significantly ($r = 0.61$, $P < 0.01$) correlated with the average CPMQ score, revealing that barriers to caregiver pain management were lower when sessions had increased language complexity characterized by the use of passive sentences. Greater caregiver understanding and comfort with administering pain medications ($r = -0.82$, $P < 0.01$) and average caregiver quality of life ($r = -0.49$, $P < 0.05$) were negatively correlated with dialogue pace.

Discussion

In general, discussions between hospice staff and caregivers were easy to understand. Greater

Table 1
Summary Demographic Variables for Caregivers

Variables	Caregivers (N = 18) % (n)
Mean age (yrs) (range)	64.5 (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 the patient	
Spouse	11% (2)
Adult child	77% (14)
Sibling	6% (1)
Other relative	6% (1)

Table 3
Relationship Between Oral Literacy Demand and Caregiver Measures

Oral Literacy Measure	Average Caregiver Anxiety Rating	Average Caregiver Quality of Life	Average CPMQ Rating	Knowledge and Skill	Understanding and Comfort	Overall Satisfaction With Hospice
Average syllables per word	-0.04	-0.23	0.28	-0.22	-0.48	0.08
Average words per sentence	0.15	-0.28	0.39	-0.21	-0.27	-0.04
Flesch-Kincaid reading grade level	0.14	-0.37	0.31	-0.34	-0.57	-0.00
Flesch reading ease score	-0.11	0.46	-0.16	0.36	0.67 ^a	-0.03
% of passive sentences	0.24	-0.10	0.61 ^b	-0.26	-0.26	0.22
Dialogue pace	-0.12	-0.49 ^a	0.04	-0.60	-0.82 ^b	-0.36
Team talking turns	-0.02	-0.06	-0.08	-0.41	-0.56	-0.17
Caregiver talking turns	-0.02	-0.01	-0.03	-0.30	-0.49	-0.09
Length of interaction (minutes)	0.21	-0.06	0.09	-0.23	-0.48	-0.15

CPMQ = Caregiver Pain Medicine Questionnaire.

^a $P < 0.05$.

^b $P < 0.01$.

reading ease was associated with higher understanding of and comfort with pain medication administration. Several associations were identified with slower dialogue pace, including increased comfort with managing patient pain, and higher quality of life. As a result of these findings, this study translates oral health literacy research to the meaning and measure of caregiver health measures.⁹ Still, we caution that future research is needed to investigate oral literacy in education and counseling sessions during at-home visits, on-call telephone assistance, and other contexts for hospice provider-caregiver communication.

Although the study sample is small and all care planning discussions occurred remotely, study findings identify specific adjustments for health care staff to consider when working with caregivers and future refinement of the operationalization of oral literacy. Modifications to team communication should aim to improve the caregivers' confidence in managing patient pain and lower caregiver anxiety. Specifically, team communication about pain management instruction and education should use a slower rate of speech, include more emphasis and detail, and use higher rates of dialogue interactivity with the caregiver. Researchers also should consider the use of passive voice frequency as a measure

of conversational formality, as initially included in oral literacy research.¹² Results from this study suggest that communication with caregivers provides a different context in which passive voice is not an indicator of language complexity but rather indicates the presence of another variable. Future research is needed to further operationalize oral literacy and explore the association between passive voice and caregiver health. We surmise that the care planning context in which most discussions highlight previous events rather than focus on future events (as in clinical visits) may explain why study findings concluded that passive voice is associated with lower levels of barriers to caregiver pain management.

Although it is possible that the number of care planning sessions per caregiver could have impacted caregiver health measures, this was not accounted for in this exploratory study. However, this work indexes oral literacy concepts as having a clear associative relationship with caregiver understanding, anxiety, and satisfaction with hospice, persuasively supporting the argument that myths and misperceptions about pain management are influenced by health literacy needs.¹⁵

For the researchers, language complexity was overall lower than expected and dialogue interactivity higher than anticipated. The

nature of hospice itself includes multiple interactions between the team and the caregiver and high caregiver responsibility, which normalizes some topics and content for the caregiver and perhaps better calibrates the interaction overall to include the caregiver as compared with acute care settings. As such, hospice can serve as an exemplar to other health care practices in attending to caregiver oral literacy.

Although the findings analyze a small number of caregivers, this analysis interprets real interactions and not self-reported, reflective, or simulated communication between health professional(s) and patients that has been used in previous research on oral literacy.⁷ Still, the study sample is reflective of the geographic area in which participants reside and representative of national hospice demographics. Because all participants took part in the hospice team meetings, it is possible that ongoing discussions affected their health literacy, anxiety, or comfort administering pain medications, which may limit generalizability.

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