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Readability of Hospice Materials to Prepare Families for Caregiving at the Time of Death

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Abstract

Many health care materials are not written at levels that can be understood by most lay people. In this descriptive study, we examined the readability of documents used by hospices to prepare families for caregiving at the time of death. We used two common formulae to examine the documents. The mean Flesch-Kincaid grade level was 8.95 (*SD* 1.80). The mean Simple Measure of Gobbledygook grade level was 11.06 (*SD* 1.36). When we used the Colors Label Ease for Adult Readers instrument, it became evident that medical terminology was the primary reason for the high grade levels. Most documents (78%) included medical terms that were directly (46.2%) or indirectly (25.6%) explained in the text. Modification of hospice materials could improve families' comprehension of information important for optimal end-of-life care.

Keywords

Death and dying; Caregivers; Health education; Health care delivery

Family caregivers of individuals in hospice care generally receive a large amount of information to assist them in caring for the dying person. Most hospices use written instructional materials to: supplement and reinforce the teaching provided by staff, provide information to family caregivers who were not present during the visit, and provide support to the family during times when hospice staff is not present (Kehl, Kirchhoff, Finster, & Cleary, 2008). If the family cannot read or understand the materials, however, they are of little use.

The ability to read, understand, and use health care information is commonly referred to as health literacy; low health literacy seriously affects the health of individuals across many settings, including at the end of life (Ache & Wallace, 2009; Kutner, Greenberg, Jin, & Paulsen, 2006). The relationships among health literacy, the use of health care services, health outcomes, and costs of care have been well-established over the past 15 years (Berkman et al., 2011). Individuals who cannot understand the written health information they receive may miss appointments, take medications incorrectly, or misunderstand how to perform self-assessments like blood glucose monitoring (Wallace, Keenum, Roskos, Koopman, & Young, 2008). Yet, health care information is often written at a grade level that

many people cannot understand (Cotugna, Vickery, & Carpenter-Haeefe, 2005; Shieh & Hosei, 2008; Wolf, Davis, Shrank, Neuberger, & Parker, 2006). The purpose of this study was to describe the readability of documents given to families in the home hospice setting to prepare them for caregiving in the final days of the patient's life and for the patient's death.

Background

Although there is no direct measure of the level of health literacy needed to comprehend a specific document, readability scores, measures of the grade level needed for most people to understand a passage of text, are commonly used as a surrogate. The first research addressing patient comprehension of written health care information was published in the late 1970s; it focused on informed consent documents (Woodward, 1979). During the 1980s, a number of investigators described patient understanding of written drug information (Eaton & Holloway, 1980; Morris, Myers, & Thilman, 1980; Spadaro, Robinson, & Smith, 1980). L G. Doak and Doak (1980) were the first to recommend applying a specific reading grade level to health care information, suggesting that such information be written at or below an eighth grade level. In 1993, as part of their survey process, the Joint Commission included items concerning how well patients understood health care instruction (C. C. Doak, Doak, & Root, 1996). By the mid-1990s, readability was generally accepted as a measure of health literacy (Miller & Bodie, 1994).

A National Assessment of Adult Literacy (NAAL) was conducted in the US in 2003 to describe the literacy of over 19,000 Americans age 16 or older who were representative of the US population (Kutner et al., 2007). The findings indicated that health literacy was at or below a basic level for 36% of adults (Kutner et al., 2006). A basic level was described as the ability to find, read, and understand simple information in short health-related texts. Shortly after the NAAL study was completed, the readability recommendation for health information was adjusted to suggest that materials should be written at or below a sixth grade level (Center for Health Care Strategies Inc., 2005). Since then, a number of investigators have demonstrated that most health care information is written above an eighth grade level (Cronin, O'Hanlon, & O'Connor, 2011; Sabharwal, Badarunde, & Unes Kunju, 2008; Wilson, 2009). This indicates that much written health care information is likely to be incomprehensible to most Americans.

In one study the investigators assessed the effect of medical terminology on the readability of health care materials. Sand-Jecklin (2007) examined five patient education brochures and found medical terms comprised between 12 and 42 words in each document. Less than half of the terms were explained adequately. Removing medical terminology significantly improved the readability scores (Sand-Jecklin).

End-of-Life Literacy Issues

In addition to health literacy issues, hospice family caregivers may be living with other conditions that can adversely affect their ability to understand written materials. Many caregivers are over 65 years old and may have health, vision, or cognitive deficits that might lower their literacy levels. For example, older adults with mild cognitive changes that do not

affect their ability to live independently have demonstrated impaired recall for written information (Federman, Sano, Wolf, Siu, & Halm, 2009). In addition, a correlation has been demonstrated between older age and lower health literacy that is independent of education, race, ethnicity, and gender (Cordasco, Asch, Franco, & Mangione, 2009). Hospice family caregivers face physical and emotional stressors from the responsibilities of 24-hour caregiving and the impending death of their family member. Emotional stress and the corresponding rise in cortisol levels may decrease both reading comprehension and memory (Millar, 2005). Although hospice personnel are available 24 hours a day by telephone to answer any questions that families may have, Finset and Lie (2010) suggested that people with poor reading comprehension may be hesitant to ask for help because they feel embarrassed about not being able to understand the written material. In such cases, the concerns of family members may never be addressed because their questions are not asked.

Findings from the few studies in which investigators evaluated the written materials given to patients and families concerning end-of-life care showed that many materials are written at high grade levels. Payne, Large, Jarrett, and Turner (2000) analyzed written materials provided to patients and families by palliative care units in the United Kingdom and Ireland. Only 14 of the 920 materials they analyzed had a grade level of 10 or below based on the Simple Measure of Gobbledygook (SMOG) formula. Based on known literacy levels of the British population, only an estimated 40% of the British population would be able to understand 64% of the materials. The findings from an examination of materials developed for bereaved individuals in the US (Smeets, Dziobek, & Wolf, 2009) indicated that, on average, the materials were written above a 10th grade level. End-of-life patient education materials from the websites of five US palliative care organizations ranged from 7th to 12th grade reading level according to findings from a study conducted by Ache and Wallace (2009). There has not been an evaluation of the readability of materials designed to provide information to family members about caregiving at the end of life in the home hospice setting in the US.

Methods

This descriptive study is a secondary analysis of written educational documents used by US hospices to prepare family members for the last hours to 5 days of life, when patients are commonly called “actively” or “imminently” dying (Kehl et al., 2008, pg.969). The initial study was classified “exempt from review” by the Health Sciences Institutional Review Board of the University of Wisconsin-Madison. Data were collected in 2006. A stratified random sample of 400 hospices in the US was chosen from members of the National Hospice and Palliative Care Organization (NHPCO) or state hospice organizations. The sample was stratified by the 10 Centers for Medicare & Medicaid Services (CMS) regions, which correspond with hospice regulatory regions. A random number generator was used to select 40 hospices from each CMS region. The 400 selected hospices received a survey and a request to submit the written documents they provide to families to prepare them for the very last days of life. The survey consisted of demographic questions about the hospice population and four questions about the materials including (a) whether the hospice provided written materials to families to prepare them for death, (b) the languages of the materials, (c) what materials were offered and the source of the materials, and (d) how

materials were distributed and reviewed. The analysis reported here is based on documents from the 170 responding hospices.

Documents used in the analysis were written in English and were specific to the end of life. Documents that were part of large manuals were divided based on chapters. Documents from different hospices that had more than 95% identical content (as determined in a side-by-side comparison) were considered one document.

Instruments

The written documents were analyzed using the Flesch-Kincaid Readability Formula (F-K), the SMOG, and the Colors Label Ease for Adult Readers Instrument (CLEAR). Three instruments were used to enhance reliability, which increases by approximately .20 when more than one formula is used rather than a single formula (Ley & Florio, 1996). Either the F-K or the SMOG alone has an intra-class correlation of approximately .76 (Ley & Florio, 1996). The combined reliability of the F-K and SMOG is approximately .93 calculated using intra-class correlation coefficients (Ley & Florio, 1996).

The F-K provides a score that indicates the US grade level or the years of education needed to understand the text. The F-K is one of the most widely used readability formulae in the US; it is available in Microsoft Word. Word length and sentence length are used to calculate the F-K. The F-K is best suited to documents designed to be read by individuals with between a fifth grade and college education (Friedman & Hoffman-Goetz, 2006). For this study, a sixth grade level on the F-K was considered appropriate for hospice documents preparing families for caregiving prior to death.

SMOG includes the number of polysyllabic words in a regression analysis-based calculation of readability (McLaughlin, 1969); it is recommended by numerous authors and agencies for assessment of health care information (Friedman & Hoffman-Goetz, 2006). The SMOG formula samples sentences in each section of the text and looks for the frequency of words with three or more syllables. The calculation gives a SMOG grade, which is the reading grade required for full comprehension. Scores from the SMOG are highly correlated (.99) with the grade level of readers who understand the text (standard error of 1.52 grades; Ley & Florio, 1996). The SMOG tends to result in a grade level approximately two grade levels higher than the F-K because it has more strict criteria for readability (Wilson, 2009). For this study, an eighth grade level on the SMOG was considered appropriate for hospice documents to prepare families for death.

The CLEAR was used to identify difficult words by assessing the reading grade level of individual words. A grade level between 1 and 20 corresponds to the years of education an adult needs for understanding a word; aggregated mean grade scores are calculated for the sentence and the document (McLaughlin, 2009). Words are color coded by level of difficulty. In this study, the CLEAR was used to assess which words were responsible for the high grade levels in the other readability formulae. Assessing the difficulty of individual words so they can be replaced or explained is an important step in improving the readability of written information (Ley & Florio, 1996).

Scores for each of these formulae were calculated using the WordsCount 4.0 web site (<http://www.wordscount.info/index.html>) developed by Trottier and Trottier (2009) and McLaughlin (2009) for accurate calculation of each of these formulae. After difficult words (beyond eighth grade level) were identified using the CLEAR, one author (KM) reviewed difficult words and coded those that were medical terminology, such as apnea or catheter. The full text of all documents was further reviewed for additional medical terminology and for explanations of the medical terms. The first author reviewed the coded medical terms and explanations for accuracy. For this study, direct explanations were defined as those that either provided a definition of the term or a clear statement of what the term meant. Indirect explanations included inferences in the text or the surrounding text that might allow the reader to deduce the meaning of the term.

A cluster analysis was conducted using the contents of the documents from the parent study and five clusters were revealed: (a) preparation for approaching death (100 documents), (b) signs and symptoms of approaching death (33 documents), (c) what to do at the time of death (9 documents), (d) emotional and spiritual responses to dying (5 documents), and (e) nearing death awareness (3 documents). Mean readability grade levels were calculated for each cluster and compared across clusters. Descriptive statistics, nonparametric comparison of means, and graphs were generated using SPSS 18.0 (Chicago, IL).

Results

The response rate for the survey was 45.3%. The 170 participating hospices were approximately equally distributed among the 10 CMS regions. The demographic information of the participating hospices was similar to the overall demographics of hospices in the US. Most participating hospices were mid-sized (100-489 patients per year). The hospices were primarily located in rural (45.7%) or mixed rural/suburban/urban (40.3%) settings, although 14% represented urban hospices.

Hospices provided one to seven documents in response to the survey request resulting in a total of 150 documents. Seventeen documents were available from professional organizations or bookstores; these were used by multiple hospices. The other 133 documents were only available from the hospices; some of these were used by chains of hospices. Most of the documents were separate pages in a folder, binder, or booklet; two were published books. Nearly half (63 or 42%) of the documents included a bulleted or numbered list. Of those with lists, 58 were lists of symptoms likely to occur within a specific time-frame. The other five documents used lists or bullet points for instructions about what to do when a patient is dying. The remaining 87 documents were in narrative form.

Readability of the Documents

Few documents met the recommended grade levels for adequate comprehension. The F-K grade scores ranged from 4.80 to 17.42 with a mean of 8.95 (*SD* 1.80; Figure 1). Three documents (2.0%) were below F-K grade 6, and an additional nine (6.0%) documents were between F-K grades 6 and 7, resulting in 12 documents at or below the recommended grade level for health care information. The results of the SMOG showed that the easiest to read documents had a grade level of 7.96, with the most difficult documents reaching grade 15,

the equivalent of a junior in college. The mean SMOG was 11.06 (*SD* 1.37; Figure 2). There was one document at or below grade 8 on the SMOG.

There was no significant difference in mean grade levels based on the content of the documents. An independent sample test (Kruskal-Wallis) revealed no significant difference in grade level between clusters for the F-K (asymptotic significance .10) or the SMOG (.24).

Inclusion of Medical Terminology

The majority of documents (78%) included medical terms such as catheter, apnea, or hydration. The number of medical terms per document ranged from 0-20 with a mean of 3.0 (*SD* 3.39) and a median of 2. Almost half (46.2%) of the medical terms were directly explained in the text, and an additional 25.6% of the medical terms were indirectly explained. Table 1 gives examples of direct and indirect explanations. No significant differences in the number of medical terms per document between clusters were revealed using the Kruskal-Wallis test (asymptotic significance .56).

Discussion

Regardless of the instrument used, we found few documents that met the criteria of being at or below sixth grade reading level. Although the F-K levels were appropriate for the average adult in the US (at or below an eighth grade level), the majority of the hospice documents did not meet the recommendations for health care educational materials (at or below a sixth grade level). CLEAR analysis identified medical terms as the words that increased the reading levels of the documents, making them more difficult to understand.

Many medical terms used in materials for hospice families are not commonly used by the public, but are used regularly by hospice staff. Although removing these terms may improve readability (Sand-Jecklin, 2007), caregivers need to understand medical terms that they will hear frequently in verbal communication with hospice staff. In this sample, the medical terms were directly explained less than half of the time (46.2%). If indirect explanations are included, the percent of terms explained increases to 71.8%. Explanation of medical terms will not lower the grade level using most readability formulae, but may make the material easier to understand.

Limitations

All documents were provided by hospices that chose to participate in a research project focused on the content of written materials given to family caregivers in the days before the patient's death. Efforts were made to increase the generalizability of the findings by seeking a national sample. Existing readability formulae were not developed for health-related documents and may not accurately estimate the difficulty of understanding health-related materials.

Another limitation is that we used the readability analysis of a document as a surrogate for caregiver understanding of the information. Because there are a number of variables that affect comprehension other than the readability of a document, future researchers should include direct measures of caregiver understanding such as return explanation of the

information or demonstration. It is not known if removal of medical terms would make the documents more understandable, or if explanations of the terms would aid comprehension. Additional research is needed to determine the best way to improve written documents to increase reader comprehension.

Practice Implications

The foremost needs of family members caring for a dying loved one include communication and information (Cagle & Kovacs, 2011). The distribution of printed education materials is one of the most common ways that hospices provide information to family caregivers. To improve the comprehensibility of written hospice materials for caregivers, we recommend that readability formulae be used to determine the overall grade level. Then, as suggested by Ley and Florio (1996), we recommend identifying difficult words in the text using a formula such as the CLEAR. The document then should be revised by replacing difficult words when possible or providing direct explanations of terms. Medical terms should be highlighted in the documents and clear explanation of the terms provided. Ideally, volunteers similar to the hospice family caregivers should review the revised documents to determine if they are easily understood.

In addition to addressing the readability of the documents, there are other changes that may increase comprehension of materials concerning caregiving at the end of life. Document design factors such as simplicity, use of bullet points instead of blocks of text, appropriate use of illustrations, and appropriately large font size can improve the reader's ability to understand the text (Ache & Wallace, 2009; Bernardini, Ambrogi, Fardella, Perioli, & Grandolini, 2001; Eames, McKenna, Worrall, & Read, 2003). Examination of such features was beyond the scope of this study, but assuring that materials have sufficient illustrations, large enough font size (>12 point), active voice, and highlighted bullet points will assist readers in ways that cannot be measured using common readability scores (Ache & Wallace, 2009).

Conclusion

At present, the materials used by most hospices to provide information to caregivers are written at a level that is unlikely to be understood by the majority of Americans. If caregivers do not understand the materials, it may impair their ability to provide adequate end-of-life care for their loved ones. If hospice instructional materials are revised to a lower grade level than is currently used or if healthcare providers find a different means to convey such critical information, family caregivers may better understand directions for assessing and managing symptoms in the final hours of life. Education materials provided by hospices need to be written in a manner that can be easily understood by families under high levels of stress to improve the experiences of both patients and families at the end of life. Actions such as direct or indirect explanations of medical terminology used in these documents may increase the comprehension and usefulness of such written materials.

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FIGURE 1.
Grade level of hospice materials according to the Flesch–Kincaid readability formula.

FIGURE 2.
Grade level of hospice materials according to the Simple Measure of Gobbledygook formula.

Table 1

Examples of Direct and Indirect Explanations of Medical Terms

Direct	Indirect
At first, during sleep, you will notice breathing patterns in your loved one change to an irregular pace; there may be 10-30 second periods of no breathing. Your physician or Nurse/Case Manager may refer to this as apnea .	The breathing patterns become slower and more irregular. More and longer periods of apnea may be seen.
When your loved one sleeps all the time but you can rouse them while turning, saying their name, to take their pills, this state is referred to as semi-comatose . When they are unarousable, this is comatose .	The person may seem unresponsive, withdrawn, or in a comatose -like state.
A purplish or blotched red/blue coloring on knees and/or feet (mottling) is the clearest sign that death is nearing.	The underside of the body may become darker and the skin become mottled .

Note. Medical terms are in boldface.