Summary of project aims

Preparation of family caregivers (FCG) for the last hours of a loved one's life influences the caregivers' mental health, their response to the experience of the death and indirectly may influence the management of the dying person's symptoms. We know that in the hospice setting, nurses are usually responsible for preparing the family for death (Kehl, Kirchhoff, Finster, & Cleary, 2008). Yet there are several unknown, but important, variables relating to caregiver preparation: what information is given to FCGs to prepare them for caregiving in the hours to days before death?; when does preparation takes place?; is the information given the same for all families or is it tailored to the individual?: if it is tailored, what issues are assessed to tailor the message. During the final hours, the condition of the dying individuals may change rapidly (Emanuel, Ferris, von Gunten, & Von Roenn, 2006). The purpose of this study is to identify how FCGs are prepared for and supported through the last hours to days of a loved one's life and to determine if there are differences in the preparatory messages of certified hospice and palliative nurses as compared to other nurses providing hospice care.

Therefore, the specific aims of this project are:

#1: Identify the content and timing of nurses preparatory and supportive messages delivered to FCGs for care in the final hours of life.

#2: Describe whether most nurses tailor preparatory and supportive messages for FCGs in the final hours of life.

#3: Describe differences in preparatory messages developed by certified hospice and palliative nurses as compared to other nurses providing hospice care.

Theoretical/conceptual framework

A theoretical framework, developed by Hebert, Prigerson, Schulz and Arnold (Hebert, Prigerson, Schulz, & Arnold, 2006) concerning preparing caregivers for the death of a loved one, is being used as a sensitizing framework for this research. This framework links health care provider-caregiver communication, caregiver preparedness and clinical outcomes for the caregiver. The hypothesis is that better communication about death between FCGs and healthcare professionals will improve caregiver preparedness, their mental health and ability to cope. This model emphasizes the multidimensional nature of preparedness and proposes delivering information for preparing families for death directly, such as in booklets, teaching on time of death, etc., or indirectly as part of other communication about end-of-life topics such as prognosis or advance care planning. This theoretical framework provides background on the different aspects of preparedness; medical, psychosocial, spiritual and practical, as well as background on clinical outcomes for caregivers such as caregiver mental health and adjustment, and caregiver satisfaction with clinical care.

Methods, procedures and sampling

This descriptive and comparative study used a self-administered, mailed questionnaire to gather data from registered nurses.

Procedures and Sampling

The Survey Research Shared Service (SRSS) of the University of Wisconsin-Madison Carbone Cancer Center was used as a neutral third party for administration of the surveys. A request was placed to HPNA to supply contact information for all HPNA members who were RNs and listed “hospice” as their primary practice. Information on all who met the criteria and had given HPNA permission to be contacted by other agencies was sent to SRSS. SRSS mailed

packets to all 1553 HPNA members who met the eligibility criteria. Details of the timing, content and number for each mailing are in Figure 1.

Instruments

The "Survey of hospice nurses content and timing of preparatory messages" was developed for this study by the investigator based on the results of a qualitative study on the perceptions of hospice staff concerning preparing hospice families for death. The final version contains 25 questions concerning the content, timing and tailoring of preparatory messages. There are an additional 20 demographic questions.

This instrument was reviewed by an expert panel for content validity. The ten-page questionnaire takes approximately 15-20 minutes to complete and requires responses to multiple choice and short answer questions. The content and questions were initially developed by the investigator and were modified and edited by a research team which included undergraduate honors students, Masters students in nursing and a post-doctoral nursing research scholar. Two of the research team members have hospice nursing experience. The instrument was piloted with hospice nurses who are currently providing bedside care. These nurses provided feedback on clarity, readability, content validity and page design. Experts in survey research from the Survey Research Shared Service (SRSS) at the University of Wisconsin reviewed the instrument and offered recommendations on layout, clarity and readability and additional revisions were made. The final version of the questionnaire was built using Cardiff TeleForms v. 10.2, a software program which designs, captures and processes data sheets.

Data collection and verification

TeleForms was used to scan and extract data from completed, returned surveys. With the first 20 returned surveys, scanning and data extracting tests were performed to assure that there

was 100% reliability between the original document and the extracted data. For those questions where a participant wrote in information or chose an answer in a manner different from what was requested, a research assistant reviewed the original survey and verified that the correct information was entered into the database.

Data analysis

Data was extracted from the survey using Cardiff TeleForms. Descriptive and comparative statistical analysis was conducted using R (http://www.r-project.org) and presented as a whole and by certified/non-certified groups. Questions answered with Likert scales will have results presented as means with confidence intervals (CIs). P-values comparing the certified/non-certified groups were prepared (Wilcoxon rank-sum test for numerical and Likert-type questions, Pearson chi-squared test for unordered categorical questions). As they are intended as a guide to possible differences only, no explicit adjustment for multiplicity of these comparisons was be made.

Summary of findings

Response rate was 56.7%. Most nurses agreed that families can be prepared for the patient's death (88.4%) and more agree that families can be specifically prepared for physical changes (97.7%) and for care giving tasks (96.7%). There is less agreement that families can be prepared for the emotional changes at the time of death (85.1%) Detailed tables of all findings are attached as Appendix A.

Content and timing of preparatory messages

The content of preparatory messages varies. Nurses usually give almost every family information on the following; decreased food intake (84.8%), breathing pattern changes (82.9%), decreased fluid intake (81.8%) decreased activity (77.6%), audible secretions (72.4%), pain

(67.7%), vital sign changes (65.2%), urine out changes (62%), bedbound state (62.7%), dysphagia (61.2%), cold extremities (60.8%), mottling (59.9%), comatose state (58.6%), dyspnea (55.1%). Items that were discussed with few patients included; surge of energy (5.85%), emotional changes in the patient (3.21%), unusual communications or near death awareness (2.63%), increased temperature (2.63%), sensory changes (2.5%), incontinence (2.39%).

Preparatory information is usually given when the patient's condition changes (81.4%), upon admission (59.1%) or when medications change (43.0%). Preparation is usually done over time (79.6%).

Tailoring

Most preparation is tailored either in content or delivery. Only 24.9% of the respondents give the same message to all families. And 97.8% tailor the delivery. Factors affecting the tailoring of the messages include: patient signs/symptoms (85.7%), how much the family wants to know (84.9%), family cultural background (84.6%), family education (84.4%), the family's spiritual beliefs (80.7), prognosis (74.9%), whether the family member has provided care for a dying person in the past (70.3%), what the family asks about (67.2%) and patient diagnosis (64.8%).

Comparison of hospice certified nurses and those without hospice certification

Certified nurses (c) were more likely to work for a longer time in hospice ($p=0.00$) and work for larger agencies ($p=0.00$) than those without hospice certification (nc). They were also more likely to work for hospice than for a combined hospice and palliative care ($p=0.07$) While there was no significant difference in education between groups, certified nurses were more likely to have roles as supervisors or clinical administrators and uncertified nurses were more likely to have roles with case management responsibilities ($p=0.01$).

Certified nurses were more likely to agree that families can be prepared for care giving tasks (p=0.03), to use written materials (p=0.01) and to discuss symptoms such as dysphagia (p=0.02), cold extremities (p=0.02) and vital sign changes (p=0.07). Certified nurses said that the patient's prognosis and diagnosis affected their preparatory messages more often (prognosis c= 78.7%, nc=68%; diagnosis c=68%, nc=59%). Certified nurses were more likely to ask the family what they want to know (c= 78.5%, nc=67.3%) and less likely to have a standard message (c=33.8%, nc=42.7%). Certified nurses were more likely to personalize written materials by highlighting issues that pertain to the patient (c=60.8%, nc=50.7%) and to read materials with or to families (c=38.5%, nc=28.7%).

Discussion

The results of this study describe current hospice nurse practices in preparing FCGs for death. There is very little information available about current preparatory practices and this information, along with data from other studies on FCG needs in the final days, will be useful in developing a FCG assessment to determine informational and support needs concerning preparation for the final days of life and the death of the ill individual. Through description of current practices in assessment and interventions for preparing FCGs, clinicians may gain insight into their own practice and get ideas for improvement.

The information from this study complements that of previous work which examined the written materials that hospices provide to assist with preparation for death. That study (Kehl, et al., 2008) found that the written materials often lacked information on pain, dyspnea and vital sign changes in the final days. It is apparent, based on the results of the current survey, that hospice nurses are providing this information to FCGs in their verbal teaching.

The findings regarding the differences between hospice certified nurses and those who do not hold hospice certification are among the most interesting. While the difference between the two groups in time working in hospice (c mean=10.6 years, nc mean=6.6 years) may explain some of the differences found, it is important to remember that there were NOT differences in age or years of experience in nursing. There also was not a difference in education between hospice certified nurses and others.

The differences between hospice certified and other nurses in terms of using written materials and how they are used, as well as how the nurse tailored the preparatory messages would indicate a greater sophistication on the part of hospice certified nurses. Previous research describing how hospice nurses learn to prepare families for death has indicated that new hospice nurses learn how to prepare families from the written materials provided by the hospice for families, from their personal experiences with death, and from their clinical experiences with death {Kehl, 2009 #34}. Perhaps those with less experience in hospice and palliative care have less experience to draw on. Yet, one would think that after 3-6 years in hospice nursing, the most common range of deaths would be experienced. Tailoring is important because it provides the FCG with information that is directly applicable to their situation. An untailored message is likely to include content that is not pertinent, such as information on symptoms that a particular patient is not likely to experience. Untailored messages may also miss information that might be crucial to a specific individual, such as giving information on managing increased temperature to the FCG of a patient who is dying with an infection.

Recommendations

The recommendations of this report fall into three categories: clinical practice recommendations, research recommendations and clinical education recommendations.

Clinical Practice Recommendations

In most circumstances, it is preferable to tailor preparation information and support to a specific FCG. Clinicians should learn the range of signs and symptoms that are likely to present with different diseases and trajectories of death and tailor their preparation and support in the final days to target what is most likely to occur for a particular patient and family. Clinicians need to assess learning readiness and FCG information and support needs to determine content and timing. Assessment of FCG understanding should be assessed with every visit.

Research Recommendations

One question that deserves additional scrutiny is whether something about the process of hospice certification, such as the review for the exam, affects the nurses' knowledge and use of tailoring. Little is known about what family caregivers would find most helpful in preparing and supporting them during the final days. There is no accepted standard of preparation and little knowledge, prior to this study, of how nurses tailor preparation. Eventually, research examining the efficacy of tailored versus standard preparatory messages would be useful, although it is premature at this time. Much additional research needs to be conducted before we have a tested, effective means to prepare families. With the inconsistencies in how hospice nurses decide what and when to prepare families for the final days, a comprehensive assessment of family caregiver needs that focuses on their needs during the active dying or imminently dying phase should also be developed and tested.

Research discovering how hospice nurses learn practices like preparation and support of family caregivers is much needed. What little research exists shows a patchy system of precepting and learning from experience that does not provide new hospice nurses with confidence in their practice. It also means that the experience of the patients and families is

largely dependent on the training practices of an individual hospice and the experiences of their primary nurse.

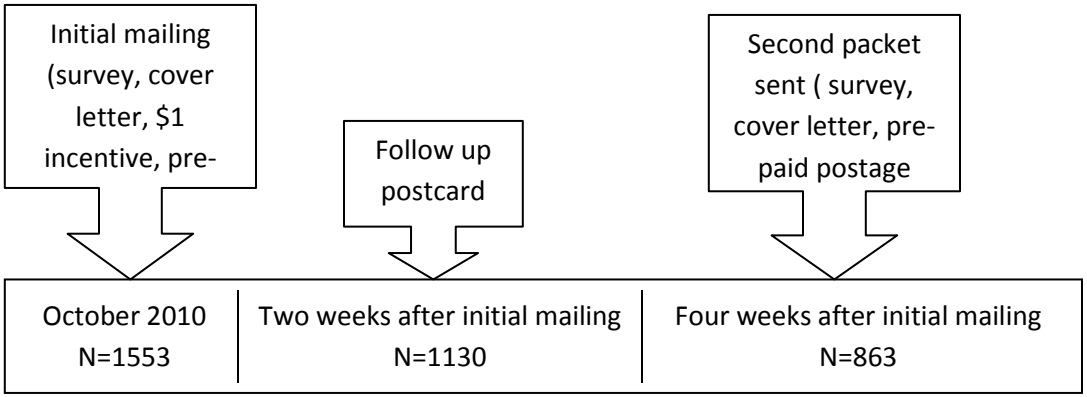
Clinical Education Recommendations

While there is little empiric knowledge of how to prepare families for the final days and death, it is clear that experienced nurses are willing to share their clinical knowledge and expertise. Staff training programs need to be further developed to use the expertise of the experienced and hospice certified nurses so that their sophisticated practices can be taught to other staff. A national educational program aimed at newer hospice nurses and concentrating on knowledge and support needs of family caregivers in the last week of life would fill a serious deficit in the training of many hospice nurses, and would provide more consistency of care.

Financial summary

The original budget was based on the total needed funds for the project. Since the total cost of the project exceeded the amount available from HPNF, additional funding was to come from the PI's research funding through the UW-Madison Institute on Clinical and Translational Research. SRSS services were very efficient and managed to lower the costs from what was originally budgeted. The primary expenses for this study were the amount needed for SRSS to administer the surveys and was personnel. Research staff included a paid research assistant and a student hourly administrative assistant. Hours for these staff members that were above the budgeted amount for the grant were covered by ICTR. In addition, four students who were for scanning the surveys and verifying data accuracy were not paid, but participated as part of a research practicum.

Figure 1 – Mailing schedule



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