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A Descriptive, Retrospective Study of After-hours Calls in Hospice and Palliative Care

Yun Jiang, MS, RN and Amanda L. Gentry, MPH

School of Nursing, University of Pittsburgh, Pittsburgh, PA, USA

Margaret Pusateri, BS, BA

School of Medicine, University of Louisville, Louisville, KY, USA

Karen L. Courtney, RN, PhD

School of Health Information Science, University of Victoria, Victoria, BC, Canada

Abstract

Aims—Few studies have described after-hours calls in hospice patient care. This retrospective study examines the timing of after-hours telephone triage services; the reasons for access to after-hours hospice and palliative care services; and the predominant nursing interventions offered in after-hours calls in hospice and palliative care.

Methods—A fixed coding scheme was used to code a de-identified after-hours triage phone log of all calls between July 2005 and June 2006 (n=4,434) from a Pennsylvania hospice and palliative care services organization. Descriptive statistics were used to identify call timing pattern, call reasons, and predominant nursing interventions.

Results—Triage services were utilized most frequently to request assistance with signs and symptoms control (25.7%), report death (17.8%), and to request a home visit (15.3%). The top nursing interventions included updating case managers or supervisors about the needs of follow-up (29.5%), coordinating home visits (20.5%), and instructing caregivers or patients on how to control new signs and symptoms (19.8%).

Conclusions—A better understanding of when and why patients and their family caregivers utilize after-hours hospice triage services can assist in the design of future proactive interventions to improve care, and enhance training for new and existing hospice triage nurses.

Keywords

After-hours care; palliative care; hospice care; triages; nursing

Introduction

Research has shown that if given a choice, most terminally ill patients would choose to die at home^{1,2}. Commonly, they value the ability to continue life with their family and friends, preferring to receive hospice and palliative care in an environment in which they are comfortable³. The goal of hospice and palliative care is to maintain the highest quality of

Corresponding Author: Yun Jiang, MS, RN School of Nursing University of Pittsburgh 3500 Victoria Building Pittsburgh, PA 15261
Phone: 412-973-7640 yuj10@pitt.edu.

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life possible for patients with terminal illnesses, and their family members. Achieving this goal rests on five principles of care: respecting the choices of terminally ill persons, supporting their medical, emotional, social, and spiritual needs, supporting the needs of their family members, helping them access the health care resources they need, and building the programs to provide them with the best care⁴.

Family members often serve as the primary caregivers for home hospice patients. They play a major role: comforting patients, monitoring their condition changes, controlling their symptoms, and communicating with health care providers about both the patients' needs, and their own⁵. The patients' quality of life is significantly associated with family caregivers' quality of life and caregiver burden⁶.

Hospice and palliative care services are encouraged to focus on the needs of both the patients and their families. Current hospice care philosophy and Medicare regulations support the multidisciplinary home care team to create a care plan for each hospice patient. Team members make routine visits during business hours to provide care for patients, and support for their family caregivers. However, most hospice programs offer limited in-home visits "after-hours" (weeknights between 5PM and 8AM, weekends, and public holidays)⁷. After-hours hospice care is usually coordinated and provided by triage nurses through telephone services. Family caregivers rely on hospice nurses for care and resources, seeking out information, advice and comfort from the after-hours services^{8,9}. The majority of patients and caregivers have found that discussing their concerns with the nurse over the phone reduces their anxiety and provides comfort¹⁰. Patients and caregivers are sometimes hesitant to use these call services because they are afraid to disturb the nurse's sleep¹¹. In such situations, patients and caregivers may feel isolated and helpless when professional support is not available¹². It can be extremely difficult for family caregivers to respond to medical problems, and rapid changes in the patient's condition on their own¹³.

Although it is recognized that providing 24-hour professional support is essential for hospice and palliative care, there is a limited body of literature describing the after-hours call services in hospice and palliative care^{9,12-17}. Sample sizes in the existing literature tend to be limited. For example, in a 12-month study auditing 106 palliative care patient and caregiver after-hours calls, symptom control and medication questions were the major reasons cited for the calls¹⁴. Another descriptive study of a 24-hour hospice telephone and home services (n= 79) found that medical or medication questions, nursing care issues, technical equipment (such as IV pumps) questions, and emotional support needs were the top call concerns¹⁸.

Most prior studies have focused on services provided by primary care teams instead of dedicated hospice and palliative care agencies^{13,17,19-22}. Limited reports have described services provided by hospice palliative care staff. An out-of-hours telephone service, Palcall, was reported to provide palliative care support and advice to patients, their carers and health professionals by senior palliative care nurse in the United Kingdom²³. In Canada, dying patients and their families accessed hospice palliative care services through B.C. NurseLine, a partner of the British Columbia Ministry of Health and the Fraser Health Hospice Palliative Care program²⁴. One retrospective study¹⁵ has explored after-hours triage calls to a community palliative care service during 1996 and 1997 in Australia. All calls were triaged through an inpatient hospice unit. Of the 629 calls made by 244 patients or caregivers to the after-hours service, almost 70% of calls were transferred to the on-call community palliative care nurse. The rate of call referral was directly related to the triage nurse's specific skills in telephone assessment and support provision. Many of the calls transferred to the community palliative care nurses were actually handled by follow-up telephone calls rather than in-home visits. Common call reasons that resulted in follow-up

in-home visits (n = 251) or telephone calls (n=186) were medication-related, pain, and nausea/vomiting. About 37% of phone calls were made because the patient wanted to speak to or get advice from a nurse¹⁵.

Although most patients and their families prefer to receive care at home with hospice services²⁵, their needs may require support that is unavailable from hospice and palliative care agencies after hours. Current the literature has not provided a very thorough description of the after-hours triage services provided by home hospice and palliative care agencies. This retrospective study aimed to better understand the utilization of after-hours triage services by hospice and palliative care patients and their family caregivers. A greater understanding of the timing and reasons for use of the triage services will assist in the design of proactive interventions to improve care for families and patients, and will help identify important outcome measures for future studies. The specific aims of this study were: 1) to describe the timing of after-hours telephone triage services; 2) to describe the reasons for access to after-hours hospice and palliative care services; and 3) to describe the predominant nursing interventions offered in after-hours calls in hospice and palliative care.

Methods

All procedures were reviewed and approved by the University of Pittsburgh Institutional Review Board prior to study implementation. Retrospective data analysis in this study was based on a prepared de-identified data set. Due to a lack of available descriptive classifications for home hospice triage calls in the literature, a coding/classification scheme was developed by the research team to describe the caller, the reason for the call, and the call disposition prior to data analysis.

Data sources

Data were derived from the existing telephone and medical records of a local hospice and palliative care organization which serves approximately 3,500 families annually in western Pennsylvania. For this organization, after-hours calls were managed by a team of hospice-trained nurses dedicated solely to after-hours telephone hospice triage. These nurses did not have an on-call or home-visit role. This study was only of retrospective records and the nurses were unaware of any plans for future research using these records during the study inclusion period.

An honest broker process was used to create the data set for analysis. In this process, the research team provided the organization with the inclusion/exclusion criteria and a list of desired variables. An organization staff member then extracted the relevant data from the after-hours telephone log and patient medical records and created a de-identified data set, which was subsequently provided to the research team.

In order to be included in the data set, telephone records had to: 1) concern an adult hospice and palliative care patient (ages 18 and over), 2) have taken place between July 1, 2005 and June 30, 2006, and 3) have occurred on weekdays between 5:00 pm and 8:00 am, weekends, or holidays when after-hours triage care was provided by the organization. Records for patients who were still receiving hospice or palliative care services at the time of the data extraction were excluded to minimize missing data and to protect patient confidentiality.

For each call that met the eligibility criteria, the following information was extracted from the original telephone record: 1) date of call; 2) day of the week of call; 3) time of call; 4) whether or not the call took place during a holiday; 5) caller category (patient, caregiver, others); 6) reason for call; and 7) disposition of the call. The disposition of the call refers to the nursing intervention provided on the phone. Call disposition data was obtained from the

call log filled out by the nurse. Some nurses also documented their follow-up interventions or updates after the call and included them within the call record. Holidays were defined as: within 7 days of Thanksgiving, Christmas, or New Year's Day, or if the caller stated the call was within 7 days of a holiday they normally celebrate. For each call, the following information was recorded from the patient's medical record: 1) admission date; 2) date of death; and 3) patient diagnosis. If the information was available, further data was collected and recorded for some calls, including: 1) number of days between admission date and phone call date; and 2) number of days between the phone call date and the date of death.

Data coding scheme

A coding or classification scheme was developed through the review of a selected sample of calls (training set $n = 2,500$ calls or 56.4% of the total data set). An initial list of hierarchical codes ($n = 326$) was obtained by reviewing the training set. Two trained research staff members independently coded a random sample of 26 calls using the developed coding scheme. Inter-rater agreement was assessed by a third member of the research team who compared the samples for agreement and rectified any discrepancies. Following the inter-rater agreement check (average 2.2 discrepancies per call), the two coders met to discuss common inconsistencies and review the coding scheme together. Following the first inter-rater reliability check, one new code was added to the coding scheme. This process was repeated three times until the coding scheme was determined to be acceptable and consistent (average discrepancies less than 1 per call).

The final codebook contained 542 hierarchical codes, divided into three categories: Basic call information, Call reasons, and Nursing intervention²⁶. A hierarchical approach was used in the codebook in order to classify data at the most atomic level possible (child code) and yet facilitate aggregation of data (parent code) for analysis when needed. For example, the child codes of COL1 (Pale), COL2 (Cyanosis) and COLoth (other color changes) can be counted individually or aggregated into the parent code of COL, which represents all patient color changes. The final codebook is available upon request from the corresponding author.

Basic Call information—This category included fifteen descriptive codes for call characteristics such as call date, call time, call day of the week, number of days after admission, number of days before death, and caller type. Callers had three sub-categories: Patient/family caregiver, Non-patient/family caregiver, and Unknown caller. The Non-patient/caregiver sub-category included seven sub-divisions: doctor, nurse, pharmacist, lab staff, social workers, health aide, and others.

Call Reasons—This category had eleven sub-categories, which included 79 parent codes (i.e. Bleeding) and 342 child codes (i.e. Nosebleed). The eleven sub-categories included: General call (i.e. Patient contact information update); Admission/Discharge; Visit Request; Signs and Symptoms; Lab; Medication; Caregiver Concerns (i.e. increased services request); IV Line and Other Tube Care; Supplies; Deceased; and Other Call Reasons.

Nursing Intervention—This category had seven sub-categories including 46 parent codes (i.e. Fever Control) and 163 child codes (i.e. Increasing Liquid Intake). The seven sub-categories were: General Intervention (i.e. Follow-up call); Admission/Discharge; Visit Arrangement; Line/Tube Care; Medication; Signs and Symptoms Control; and Other Interventions.

Data coding and data analysis

Six research staff members were trained and tested for consistency in coding before they began coding the entire data set ($n = 4,434$ calls). All codes were entered into PASW

Statistics 18 (IBM, Somers, NY) for analysis. Descriptive statistics were used to determine the frequency of call day, holiday calls, call time, number of days after admission, number of days before death, caller type, patient diagnosis, call reasons, and nursing interventions.

Results

Call Timing

All calls in the data set took place after hours (weeknights between 5:00PM and 8:00AM, holidays, and weekends) between July 2005 and June 2006. Call log data included 247 weekdays and 53 weekend days (no after-hour calls recorded in 40 days). There were 16 calls (0.3%) with a missing date. The mean number of after-hours calls was 370 per month and 14.8 per day. Figure 1 shows the monthly volume call distribution.

A total of 3,037 (68.5%) calls were made after hours on weeknights with an average of 12.3 calls per night. Among all weeknight calls, 73.1% were made between 5PM and 12AM and 26.9% between 12AM and 8AM (Figure 2 and Figure 3 show the hourly call distribution for weeknights and weekends respectively). Nearly one-third (31.1%) of calls took place on weekends (1,381) with an average of 26.1 calls per weekend day. Two hundred and eighty-one calls (6.3%) were made on holidays, an average of 14.8 calls per holiday.

Using the information extracted from patient records and call logs, the average time between admission and death was 59.2 days, and the median time was 26 days. Information on the number of days since admission was available for 2,290 calls (51.6%). Among this set of calls, 0.2% took place before admission, 34.5% occurred within the first 5 days following admission, and 50.2% were within the first 11 days. Over two-thirds (67.1%) of calls (2,973) included information that indicated the number of days prior to death. Among this set of calls, 49.4% of calls occurred within three days of the patient's death, and 17.8% of calls actually reported a death.

Caller

More than half of all calls were directly from the patient or their family caregivers (57.1%), compared to 28.8% of calls from non-patients or non-caregivers, such as doctors, nurses or pharmacists. Among all non-patients or non-caregivers calls (1,276 calls), there were only 67 calls (5.3%) not related to patient care. These calls were either about health care staff issues or wrong number calls. Unknown callers accounted for 14.1% of all calls; the callers' identities could not be determined from the de-identified call log.

Diagnosis

Nearly two-thirds of calls (63.9%) were related to patients with cancer diagnoses. Patients with cardiac or blood vessel disorders accounted for 14.4% of calls. Pulmonary or airway disorders represented 8.1%, and brain, spinal cord or neural disorders represented 7.0% of call diagnoses respectively. Less commonly, calls were related to renal or urinary tract disorders (2.3%); immune disorders (0.8%); hepatic or gallbladder disorders (0.8%); infections (0.7%); bone, joint or muscle disorders (0.3%); psychiatric disorders (0.1%); or other disorders (1.7%).

Call Reason

Table 1 lists percentages for the top ten call reasons. The most frequent call reason was concerns over signs and symptoms (25.7% of calls). The signs and symptoms reported were either new, or an existing symptom that had worsened.

Of reported signs or symptoms, mental status or mood changes were most frequently reported and covered 8% of the total calls. The reported mental status or mood changes included: agitation; anxiety; restlessness; drowsiness; disorientation or confusion; responsiveness changes; or hallucinations. For example, "CALLER: X daughter from out of state, reported that patient is very agitated. Threatening to use his gun and very verbally and emotionally abusive..." In another example: "CALLER: X reported that patient is not responding and wanted to know how to tell when she is in a coma."

The second most common reported sign or symptom was respiratory problems, representing 7.4% of calls. Respiratory problems included: respiratory distress; cough; congestion; shortness of breath; labored breath or increased phlegm. For example, "CALLER: X reported that patient has a bad cough and has not slept for two days..." and "CALLER: X reported that patient is very anxious and short of breath..."

Other commonly reported signs and symptoms included: pain (5.5%); nausea or vomiting (3.0%); bowel movement problems (2.2%); urine problems (1.8%); skin or wound problems (1.4%); patient falls (1.2%) or fever (1.0%). One example for a call reporting uncontrolled pain was "CALLER: X reported that patient has increased hip pain. Neurontin 300 milligrams given early and Tylenol 500 milligrams (2 caps) for pain without significant relief". An example of the nausea and/or vomiting code: "CALLER: X reported that patient still vomiting with nausea most of the day. Patient has been on tube feedings but vomited after last two..."

Reports of the patient's death, or issues related to the patient's death accounted for 17.8% of calls. Issues related to a patient's death might include a request to return medical equipment. For example, "CALLER: X reported that patient ceased breath this morning ... Caller requested equipment pickup as soon as possible".

Requests for home visits were another popular call reason. Patients or caregivers literally requested a home visit (15.3% of calls) because of a perceived need for nursing follow-up or for concerns related to changing intensity of a problem, such as worsening symptoms (which was coded with both requesting a home visit and the specific symptom). For example, "CALLER: X requested home visit. Patient has a significant condition change and requested reassessment of patient status by nurse visit". Medication concerns (14.7% of calls) included: medication orders; delivery of prescriptions; refills; questions concerning medication administration; dosage issues; storage concerns; reports of adverse effects; and general medication information. Examples included: "CALLER: X reported that all meds were delivered today except for the pain patch", "Caregiver stated that the instructions for Decadron times are different now than they have been in the past", and "Caregiver stated that patient refused meds at times, even with evidence of pain".

Nursing Intervention

Table 2 lists the ten most common nursing interventions. The most frequent nursing intervention was to update the case manager or supervisor that the patient needed follow-up (29.5% of calls). The need of follow-up might be: a call (15.3%); a visit (8.4%); a medication status assessment (1.8%); or another specific follow-up request (10.3%).

The triage nurse arranged or scheduled a home visit as a result of 20.5% of the total calls, and instructed caregivers on how to control reported signs and symptoms in 19.8% of calls. Solutions for medication-related problems comprised 12.3% of calls. A typical example of a nursing intervention for symptom control: the caller reported that "the patient has not had a bowel movement for 3–4 days despite Ducolax tablets," and the triage nurse instructed the caregiver "to administer two Ducolax tablets tonight and a serving of hot prune juice in the

morning.” In some cases, the caller would report something like: “the patient was very restless and lorazepam was not effective with recurrent agitation”. The corresponding nursing intervention on the call log would be marked: “VOICE MAIL UPDATE CASE MGR FOLLOW UP CALL/ VISIT TO REASSESS ALTERNATIVE MEASURES FOR MGT OF AGITATION.”

Discussion

This study describes a high volume of calls in after-hours hospice care (3,037 calls in two-year study period, averaging 26.1 calls per weekend day, and 12.3 calls per weeknight). The call volume in this study is much higher than that reported in previous studies^{14,15}. In addition, more calls took place on weekends than weeknights. One study in Singapore also reported a higher volume of calls on weekends and public holidays (16.7 calls on each of weekend day)¹⁶. However, the Singapore study focused on outbound calls (hospice care team *to* patients) rather than inbound calls (hospice nurses *from* patients or caregivers). In this retrospective study, each follow-up call made by the triage nurse to the patients/ caregivers was counted as a new call. If the follow-up call was to another nurse or healthcare provider, the call was considered part of the original call's nursing intervention. This treatment of follow-up calls could have artificially raised the call volume; however, the total number of follow-up calls was only 296 (6.7%).

The high call volume is representative of the high demand for hospice care support after hours. The call log of this study was provided by a hospice organization serving approximately 3,500 patients annually in eleven counties in Western Pennsylvania. Such a large patient population may be another reason for the high number of after-hours phone calls made to the hospice organization's triage service. Unfortunately, because call duration was not recorded in the call logs it was impossible to determine the true impact of the call volume on nurse workload. With the same data set, it was also impossible to track the patient, or the person who made the original call, specifically, not able to distinguish the calls from the patient or the family caregiver. This data limitation made it difficult to quantify the number of repeat callers, or to track the overall percentage of hospice patients and caregivers that utilized the service.

The distribution of call times in this study was similar to previous findings^{12,14,15,27}. Most calls took place at night between 5PM and 12 PM. Previous studies have suggested that hospice agencies should provide appropriate staffing arrangements during these time periods¹⁶ and develop proactive evening phone call services for patients who use the service frequently¹⁵; our findings also supports this.

In this study, almost half of all calls took place within the first 11 days of the patients' hospice admission, and within three days of the patients' death. It is understandable that patients or caregivers may require more support from healthcare professionals just after admission to the hospice program as processes and procedures are unfamiliar, and again when the patient's condition has deteriorated to the point that death is near. In the future, these patients and caregivers could be proactively identified as those most likely to need hospice triage services. Interestingly, this suggests that building an early rapport with the hospice care team, especially the triage nurses, may be beneficial. The average duration between patient admission and death was 59.2 days (median = 26 days), values which are consistent with a national average length of stay of 61.25 days, and a median length of 20.81 days as reported in 2006^{28,29}.

Reasons for after-hours calls as indicated in this study correspond to previous findings^{9,12,14–17,27,30}. Death report, symptom distress, and medication-related concerns

were common. As with this study, the most frequent reported symptoms were anxiety, pain, dyspnea, and nausea or vomiting. No previous study indicated a *request for a home visit* as a call reason, yet in this study, patients or caregivers requested the visit in 15.3% calls. Among these calls, 23.9% callers actually deferred the request after talking with the triage nurse on the phone. Despite this, the most frequent nursing intervention remained nurse coordination of a home visit. It should be noted that *coordination* of home visits occurred more often than *requests* for visits. A potential reason for the high number of intervention related home visits may be that either additional problem was identified by the triage nurse on the phone, or a home visit was the only appropriate action available.

Good communication is the keystone of hospice care via the telephone^{9,12,14,16}. A nurse with good communication skills may help comfort the patients and caregivers, and defuse crisis situations¹⁴. In a prior study, if more intervention was provided by the triage nurse over the phone, fewer referrals or home visits were ultimately required¹⁵. In this study, an *update of case to supervisors for follow-up*, and *scheduling new home visit* were listed as the top two nursing interventions. This indicates that a large number of cases could not be completely resolved on the phone. It is unknown if this lack of resolution was due to patients' unstable conditions or other factors. This leaves the potential for developing more in-depth patient assessments via the telephone.

Both callers seeking emotional support, and nursing interventions related to emotional support accounted for a relatively low proportion of the calls in this study. This may be due to a lack of documentation by the triage nurse as physical care may have been the higher priority³¹. Further, the assessment of emotional support needs on the phone can be difficult for nurses without special training because non-verbal expressions cannot be interpreted via a regular telephone. This indicates that formal, specialized training should be provided for nurses who conduct hospice triage care over the phone. This also suggests that the use of a videophone may improve communication between patients/caregivers and triage nurses working in after-hours hospice care as it would allow non-verbal clues to be taken into account³².

There were a few limitations in this study. First, because it was a retrospective study, there was no control over the initial data collection. For example, there was no record of call duration and no required documentation for emotional support assessment and provision. Second, the study used de-identified call log data leaving no way to track the number of calls made by individual patients. Without a verbatim transcription of each call, it is impossible to ascertain all the details of the conversations including the number of questions asked by callers, the number of questions posed by the nurses, as well as the responses of each party. It is possible that not all caller concerns, or nursing interventions, were represented in the call log. The nurses may have limited their documentation to the issues they perceived as most critical or urgent. They may not have consistently documented less "concrete" nursing interventions, such as providing emotional comfort or support.

In this study, there were no qualitative data to investigate the perspectives of service users, such as patient or caregiver satisfaction data or the triage nurses' perspectives of providing good after-hours hospice care. Future studies could be conducted to explore these aspects of hospice service delivery. In addition, it is necessary to include the patients and family caregivers who do not access these services. Future studies could assess any perceived barriers to the utilization of after-hours hospice care.

Conclusion

This retrospective study described the timing and reasons for hospice and palliative care patients and families to call the triage services after hours, providing a better understanding when and why patient and their family caregivers utilize after-hours hospice services. Also, the description of predominant nursing interventions offered in after hour calls may help hospice agencies assess the problem-solving and communication skills of triage nurses and identify the training needs for new and existing hospice triage nurses in the future. Although, the hospice triage codebook was developed for descriptive research purposes, it may have additional utility for future quality improvement efforts. For example, a periodic review of nursing triage documentation using a standardized classification could identify trends in caller needs and help in evaluating the effectiveness of existing interventions.

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Figure 1.
Volume of calls on weekdays by time of day

Fig 2.
Volume of calls on weekends by time of day

Table 1

Top 10 call reasons on after-hours triage calls (N=4434)

No	Call Reasons	n (%)
1	To express concerns over signs and symptoms	1138 (25.7)
2	To report a death	789 (17.8)
3	To request a home visit	680 (15.3)
4	To inquire about medication	653 (14.7)
5	To seek admission, discharge, or referral information	398 (9.0)
6	To report problems with IV line, Foley catheter, or other catheters	195 (4.4)
7	To seek emotional support	155 (3.5)
8	To request medical or personal care supplies	119 (2.7)
9	To update patient location or contact information	73 (1.6)
10	To change care plan	59 (1.3)

Table 2

Top 10 nursing interventions on after-hours triage calls (N=4434)

No	Nursing Interventions	n (%)
1	Update case managers or supervisors needing follow-up	1308 (29.5)
2	Coordinate home visits	911 (20.5)
3	Instruct how to control signs and symptoms	879 (19.8)
4	Resolve medication-related problems	546 (12.3)
5	Follow up calls	296 (6.7)
6	Instruct how to resolve IV lines & Catheter problems	141 (3.2)
7	Provide emotional support or assess emotional support needs	116 (2.6)
8	Provide admission, discharge, or referral information	111 (2.5)
9	Arrange supply provision or pick-up	78 (1.8)
10	Provide information for payment coverage concerns	17 (0.4)