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Advanced Practice Nurse Service Provision During the Last Week of Life

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Abstract

This secondary data analysis of a randomized clinical trial describes the contacts made by advanced practice nurses for long-term ventilator patients who were not receiving hospice services during their last week of life and for matched patients on long-term ventilators who did not die. The contacts were examined for a total of 64 patients (32 patients during their last week of life and 32 matched patients). There was a statistically significant difference in the total number of contacts for long-term ventilator patients during their last week of life compared to the matched patients. Most contacts in both groups were initiated by advanced practice nurses. The type, reason, and outcomes of contacts are described. Accessible and coordinated care during the last week of life is important for patients on long-term ventilators after discharge from the hospital, especially for those who are not receiving hospice services.

Keywords

advance practice nurse; descriptive; end-of-life; long-term ventilator

Care at the end of life is multifaceted and broadly encompasses physical, emotional, and spiritual components. The importance of one or more of these multifaceted aspects of end-of-life (EOL) care has been reported by patients, families, and healthcare providers.^{1–3}

Multifaceted care is provided by many different members of the healthcare team, and maintaining continuity and coordination of services is paramount. To provide continuous, coordinated services at the end of life, healthcare providers need to be accessible to patients and families across multiple care settings.

Continuity, accessibility, and coordination have been identified as important aspects of care at the end of life.^{4–9} In one study, focus groups consisting of patients, families, physicians, and other healthcare providers were surveyed to determine aspects of medical care that were necessary to provide quality care at the end of life. Accessibility and continuity were among the most frequently identified aspects of care by patients and families. Healthcare providers (nurses, social workers, and physicians) identified team communication and coordination as one of the most important physician responsibilities.⁶ One component of accessibility and continuity was ensuring that a healthcare provider is accessible to the patient and family in a

timely manner.^{5,6} Some components of team communication and coordination included letting the patient/family know who to call for problems and helping them get consistent information. Finally, “coordination and continuity of care” is a domain that was noted in more than 50% of EOL guidelines on quality EOL care.¹⁰

Data about preferred EOL care from interviews and focus groups have reflected the views of healthcare providers, patients, and families at varying times before or after the death of a person; however, little is known about the care actually delivered during the last week of life. Specifically, no studies have described the number and type of contacts delivered through an individualized care delivery program in the last week of life.

Patients who have undergone prolonged periods of mechanical ventilation, described as “long-term ventilator (LTV) patients,” have high mortality rates during hospitalization and within the first year postdischarge.^{11,12} LTV patients who live to be discharged from the hospital often have extensive and complex needs that require care from numerous medical specialties and other supportive services. In this way, they are similar to many other patients with life-limiting diseases, such as cancer and advanced heart failure. Because of the complex care needs of discharged LTV patients, many of whom will die within 1 year, it is important to have an accessible healthcare provider who can facilitate continuous care and coordinate needed services. However, actual use, unrestrained by insurance or economic factors, has not been reported. Because discrepancies exist between healthcare needs and healthcare that is actually delivered, data on the nature and amount of care would be useful to determine the best way to meet the complex care needs of the LTV patient.

In a disease management intervention (DMI) trial, LTV patients and caregivers were randomly assigned to an advanced practice nurse (APN) case manager who was accessible 24 hours per day, 7 days per week, to coordinate care and provide support. The purpose of this article was to describe the type of contacts made during the last week of life for LTV patients and compare these with contacts made during a matched week for discharged LTV patients who did not die.

METHODS

Design and Sample

This was a secondary analysis of quantitative data from a National Institutes of Health–funded randomized controlled trial, Disease Management of the Chronically Critically Ill (N = 1041). The DMI study was designed to test the effectiveness of a postdischarge disease management program on outcomes during the 2 months after discharge for LTV patients and their families/caregivers. The sample for this report comprised LTV patients who were randomized to the intervention group (APN case manager) of the parent study. Only patients in the intervention group who died and their matched cases who did not die were used in these analyses. Patients who were in the control group were not included in this analysis because they did not receive APN care.

Enrollment criteria for the parent study included the following: all adult patients older than 18 years who had been on mechanical ventilation for more than 72 hours and lived to be discharged from the hospital. Additional eligibility criteria included the ability to speak English and a discharge location within 80 miles of the study hospital. This distance was chosen to exclude patients who would probably receive follow-up care elsewhere. Patients were ineligible if they were on home ventilation before admission, were a solid organ transplant recipient, or were discharged with hospice services.

Procedure

Approval for this study was obtained from the institutional review board at University Hospitals of Cleveland. After informed consent was obtained from the patient and caregiver, patients were randomly assigned to an intervention or control group. Patients in the intervention group were assigned to an APN who would work with the patient and caregiver for 2 months after discharge from the index hospitalization or until the patient died. The intervention was a disease management program led by an APN who coordinated services and collaborated with a variety of healthcare providers to meet the patients' needs.

According to the study protocol, the APN was responsible for meeting the patient and/or caregiver just before discharge to establish rapport and complete the research questionnaires. The APN had access to the inpatient medical record and inpatient healthcare providers to learn about the patient's clinical course and ongoing care issues. The clinical course was summarized by the APN and distributed to the discharge facility and healthcare providers involved in the post-discharge care of the patient. This clinical summary was updated throughout the 2-month period as clinical conditions or plans changed. The APNs knew about current clinical issues, which would need ongoing attention after hospital discharge, and ensured that continuity of care was an explicit aspect of the plan of care.

The study protocol directed the APNs to contact the patient and/or caregiver two times during the first week and at least once per week thereafter. For patients whose discharge location was within 30 miles of the hospital, the APNs were to visit "in person" two times during the first week and at least once weekly throughout the 2-month study period. Patients and caregivers who were discharged within the 30- to 80-mile range were contacted by telephone. Patients and/or caregivers were given the APN's pager number, voice mail, and e-mail address for any questions or issues. The APNs were available to patients and families 24 hours per day, 7 days per week. All intervention patients who died during the 2-month postdischarge period and those patients who did not die were matched on sex, age, and discharge location and were included in this secondary data analysis.

Measures

All contacts were recorded by the APN on a researcher-designed contact log. All recorded contacts involved the APN; either the contacts were initiated by the APN or the APN was contacted by the patient, family, or other member of the healthcare team. The research team met frequently with the APNs to discuss what constituted a contact and how it should be recorded. All APNs were familiar with the contact logs and had used them for several months before the contacts included in these analyses. The log included the following: the specific dates of the postdischarge study period, the number of contacts, the type of contact (in person, telephone, or others, which included e-mails and faxes), who initiated the contact (patient, caregiver, APN, or others, which included nurses, social workers, or interdisciplinary team meetings), who was contacted (patient, caregiver, physician, others, which included APN, nurses, social worker, or interdisciplinary team meeting), the nature of the contact, and the outcome of the contact (continue plan of care or change plan of care). For the outcome, the APN could only select either "continue" or "change" but not both. The nature of the contact encompassed three categories: Category 1—monitoring, assessment, support, medication review, coordination of any services and/or providers; Category 2—direct care, problem management or problem advice; and Category 3—discharge planning. Discharge planning included any care activity involved with the transition of the patient from one location to another. The APN could choose one, two, or all three categories to describe the nature of a contact.

The first contact was recorded after discharge from the index hospitalization. According to the study protocol, the first day of the intervention started on the day after discharge. For patients who died, data on contacts were taken from the last 7 days of life. The last week of life was chosen to describe the nature and number of contacts for a group of patients with a high mortality risk after hospital discharge. The patients who died were then matched by sex, age, and discharge location with patients who did not die during the 2-month study period. These parameters were chosen because there could be differences based on sex and age in the need for someone to help coordinate services. Discharge location was used as a proxy for severity of illness because patients who were discharged to an institutional setting were more likely to have greater care needs than those discharged to home. To compare the number and nature of contacts for patients with potentially different care needs, data were collected from the same week for patients who did not die. For example, for a patient who died on the day 14 of the study period, contact data included days 8 through 14, and contact data for the matched patient were also used from this same postdischarge period.

DATA ANALYSIS

Descriptive statistics, Wilcoxon signed ranked tests, and χ^2 were used to compare characteristics of patients who died with those who did not. Descriptive statistics were used to describe the type, frequencies, and reasons for contacts. A paired sample *t* test was used to compare the total number of contacts during the last week of life for patients who died and their matched cases during the same week of the study period.

RESULTS

Thirty-two patients who died during the 2-month postdischarge study period were matched to 32 patients who did not die during the 2-month postdischarge period. All patients (*N* = 64) were part of the intervention group so they were assigned to receive services from an APN. The 32 patients who died were matched with 32 of 141 patients who were randomized to the intervention group but did not die in the 2-month postdischarge period. The lowest study identification number of the 32 patients who died was matched starting with the lowest patient ID number of the 141 patients who did not die and who met the criteria for sex, age cohort, and discharge location. All patients matched on sex. Twenty-five of the 32 patients matched age within 5 years, and the remaining seven patients matched age within 10 years. Patients were matched based on specific discharge location (nursing home, long-term acute care [LTAC], or rehabilitation). All but five of the patients matched on exact discharge location; however, these five patients matched based on the fact that they were discharged to some type of institution (nursing home, LTAC, or rehabilitation).

The characteristics of all patients who were randomized in the parent study (*N* = 344), those who died (*n* = 32), and their matched cases (who did not die) (*n* = 32) are described in Table 1. Because patients in this study were matched on sex, age, and discharge location, these characteristics were similar for both groups. In general, most patients in this analysis were females in their late 60s, and most caregivers were females, approximately half of whom were adult children of the patients. Most patients were discharged to either a nursing home or LTAC, with the fewest discharged to a rehabilitation facility. There were no statistically significant differences between patients who died and patients who did not die in variables associated with severity of illness: hospital length of stay, ICU length of stay, length of mechanical ventilation, and number of pre-existing conditions. However, patients who died had longer lengths of in-hospital mechanical ventilation and ICU and hospital stays. There were also no statistically significant differences between the two groups in caregiver age, sex, or relationship to the patient; the distance of the discharge location from the study site; the need for full ventilatory support (24 hours per day); or cognitive impairment at the time of discharge from the index

hospitalization. There was a statistically significant difference ($P < 0.05$) between the number of readmissions and transitions to different settings between those who died and those who did not die. The patients who were readmitted were either still hospitalized from a previous readmission or readmitted during their last week of life. The mean number of days from discharge until death was 25 days, so most contacts were taken from the third to fourth week after discharge from the hospital.

Total Number of Contacts

Overall, there were more contacts made for patients who died than for those who did not die. There were 356 total contacts made for patients during the last week of life and 205 total contacts made for patients in the matched group. The mean (SD) number of total contacts for patients who died was 11.13 (10.56), compared to the matched group's mean (SD) of 6.4 (5.33). Using a paired sample t test, the average difference in contacts between the two groups was 4.719 (95% confidence interval, 0.266–9.172). There was a statistically significant difference between the groups in terms of total number of contacts ($P = .039$). The nature and frequency of contacts are shown in Table 2.

Type and Frequency of Contacts

For both groups (patients who died and matched patients who did not die), most contacts made were either face to face or by telephone. A total of 174 (49%) face-to-face and 169 (47%) telephone contacts (out of 356 total contacts) were made for patients during their last week of life. For the matched patients who did not die, there were a total of 94 (46%) face-to-face contacts and 88 (43%) telephone contacts (out of 205 total contacts). There were few other contacts. The APNs initiated 77% ($n = 273$) of the contacts for patients who died and 74% ($n = 151$) for the matched patients who did not die. Caregivers of patients who died initiated 6% ($n = 22$) of the contacts to the APN and caregivers of matched patients initiated 2% ($n = 4$). No contacts were initiated by the patients during their last week of life, and only two contacts were initiated by patients in the matched group.

Other healthcare providers (nurses, social workers, physicians) and other family members initiated 17% ($n = 61$) of contacts to APNs for patients who died and 11% ($n = 23$) of contacts for patients who did not die. Interdisciplinary team meetings were also counted as other healthcare providers contacts. For patients in their last week of life, APNs made 63 (18%) contacts to patients, 58 (16%) contacts to caregivers, 36 (10%) contacts to physicians, and 210 (59%) contacts to other healthcare providers (APNs, nurses, social workers, respiratory therapists, or interdisciplinary team meetings). For matched patients who did not die, APNs made 47 (23%) contacts to patients, 47 (23%) contacts to caregivers, 26 (13%) contacts to physicians, and 100 (49%) contacts to other healthcare providers (APN, nurses, social workers, respiratory or physical therapists or interdisciplinary team meetings). Often more than one person was contacted when the APN initiated the contact.

Reason and Outcome for the Contact

The most prevalent reason for the contact for patients in both groups was Category 1 (monitoring, assessment, support, medication review, and coordination of services and/or providers), with 71% ($n = 251$) Category 1 contacts for patients who died and 66% ($n = 136$) Category 1 contacts for patients who did not die. Category 2 (direct care, problem management, or problem advice) contacts were made for 42% ($n = 151$) of patients who died and 55% ($n = 113$) of patients who did not die. Fifty-nine (17%) Category 3 (discharge planning) contacts were made for patients who died, and only two contacts were made for Category 3 (discharge planning) of patients who did not die. There were frequently multiple reasons for a single contact. The most prevalent outcome for both groups was to continue the plan of care with

86% (n = 306) for patients who died and 80% (n = 163) for patients who did not die. The outcome for the remaining contacts for both groups was to “change the plan.”

DISCUSSION

The fact that LTV patients need much care and support after discharge from the hospital is reflected not only in their high postdischarge mortality rate but also in their need for some type of institutional care. None of the patients who died in the postdischarge period were discharged to their homes, and none of these patients were discharged with hospice services (per study criteria). To understand one aspect of multifaceted care, we described and compared the contacts made by APNs for LTV patients after discharge from the hospital. In this study, the APNs who were available 24 hours per day, 7 days per week were a continuous link between the inpatient and discharge setting and were available to coordinate needed services and support. Research on EOL care has supported the need for accessible, continuous, and coordinated care.^{4–9} There have been no other reports of the nature or frequency of contacts during the last week of life for patients who have undergone prolonged mechanical ventilation and ICU days; thus, we were unable to compare our findings to other research.

Although patients who died had more days on mechanical ventilation and longer ICU or hospital stays, there were no statistically significant differences in clinical characteristics related to severity of illness, discharge location, or cognitive impairment, so it is likely that both groups had similar care needs at the time of discharge. There were also no statistically significant differences in key caregiver characteristics such as age, sex, and relationship to the patient, which further supports similarities between patients who died and patients who did not.

It was not surprising that the total numbers of contacts were greater for patients during their last week of life because it is likely that more changes in clinical condition occurred in the last week of life. When patients experience a change or decline in their clinical condition, there is the need to contact a healthcare provider to determine the cause, treat symptoms, and modify the plan of care. Because none of these patients were receiving hospice services, there may not have been a plan in place to address the evaluation and/or treatment of symptoms. Furthermore, families and healthcare providers may not have expected the patient to die, so there may have been many questions and concerns, including the need for decisions about aggressiveness of care.

Another explanation for more contacts made to patients during their last week of life might be related to the distance of their discharge location. Although not statistically significant, the discharge distance was less than 30 miles from the study site for 26 patients who died versus 22 matched patients. There may have been more contacts made to patients based on their discharge distance, hence allowing the APN to visit patients and caregivers in person and meet healthcare providers at the facility. Perhaps caregivers felt better able to rely on a healthcare provider with whom they had more physical contact and thus contacted the APN for help.

The similar pattern of face-to-face and telephone contacts may reflect the fact that much coordination and support were necessary to organize care and support patients and caregivers for all discharged LTV patients. However, the similar pattern of APN initiated contacts for both groups was surprising. It seems that changes in clinical condition would occur in the last week of life, which would prompt the APN to initiate more contacts to assess the patient, support the caregiver, and collaborate with other healthcare providers to determine the cause, treat symptoms, and modify the plan of care.

Only 2 patients were able to initiate contacts to the APN (from the matched group) probably because they were too sick or cognitively impaired; approximately one-third of patients in both

groups were cognitively impaired. More caregivers of patients who died contacted the APN than did caregivers of patients who did not die, which suggests the need for greater support of caregivers during the last week of life. The fact that other healthcare professionals (physicians, nurses, social workers) initiated contacts to APNs was encouraging because they are not accustomed to communicating with a healthcare provider (APN), who was not part of the outpatient or inpatient healthcare provider group.

The overall frequencies of contacts made by APNs to patients, caregivers, physicians, and other healthcare professionals indicated that much care, support, and coordination were necessary for both groups. The APNs were responsible not only for making contacts to coordinate needed services but also for communicating changes in the plan with patients, caregivers, and other members of the healthcare team. More contacts were made consistently by the APNs to other healthcare providers including nurses, social workers, or interdisciplinary team meetings during a patient's last week compared to matched patients because more coordination of services may have been needed to support the patient and family and address changes in clinical condition.

It was not surprising that most contacts were categorized as Category 1 (monitoring, assessment, support, medication review, and coordination of any services and/or providers) for both groups because of the multiple complicated care issues for discharged LTV patients. There were more contacts categorized as Category 3 (discharge planning) for patients who died, which was likely related to the fact that these patients had been readmitted to the hospital or transitioned to a different facility during their last week of life. Approximately one-third of patients who died had readmissions, and none of the matched patients were readmitted.

We cannot explain why there were more contacts for which the outcome was to continue the plan of care for patients in both groups because it would seem that a change in plan from treating to providing comfort would occur more frequently, especially for patients during their last week of life. This may have been related to how the APN defined activities that constituted a change in plan.

LIMITATIONS

Although our sample size for this analysis was small, it was representative of the larger LTV population, as shown in Table 1. Patients did match on age cohort, sex, and discharge location. A larger sample size in the parent study would have permitted further statistical analysis of the contacts and more precise matching with variables such as reason for mechanical ventilation, cognitive and functional status at discharge, and selected caregiver characteristics (ie, functional status and depression). Although the APNs were experienced in the study protocol and several team meetings were dedicated to contacts, there may have been differences in how each APN defined and recorded certain contacts. Further articulation to include the amount of time spent on a contact, the nature of the contact, and the outcome of the contact would have been helpful; however, the contacts were not a major outcome of the parent study. We know anecdotally that some contacts made to patients, caregivers, and/or other healthcare providers lasted a few hours, and some contacts made to the other category were actually interdisciplinary team meetings.

Lastly, we do not know if patients/caregivers and other healthcare providers consistently contacted the APN when there were clinical issues; they may have relied on the other more familiar forms of support such as the home healthcare nurse or their primary care physician. We do know that APNs were required to make at least two contacts during the first week after discharge and a minimum of one contact for every week thereafter. Despite these limitations, this study provided some initial evidence on the actual nature of contacts for LTV patients not only after discharge from the hospital but also during the last week of life.

Multifaceted posthospital care is needed for LTV patients who live to be discharged from the hospital. This study adds new information about types and frequencies of contacts delivered through an individualized care delivery program, which were reflective of continuous, coordinated, accessible care, especially during the last week of life for patients without hospice services. The results were limited by the fact that this study reflected actual delivery of services by APNs based on patient needs unrestricted by insurance and economic factors. Postdischarge care for LTV patients and their families may need to be organized so that a case manager can be accessible to coordinate services and care across settings. Because LTV patients are often not recognized as terminally ill, they do not receive appropriate coordinated hospice services in their last week of life.

Further research is needed to focus on the nature of contacts that provide continuous, coordinated, and accessible care. Recording specific activities about each contact could provide rich data about the nature of care needed.

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Table 1

Subject Characteristics

	Parent Study (n = 334), Mean (SD)	Patients Who Died (n = 32), Mean (SD)	Matched Patients (n = 32), Mean (SD)	Z	P
Patients					
Age	61.0 (16.3), y	69.1 (13.1), y	67.1 (11.6), y	-1.93	.05
LOMV ^a	11.8 (10.7)	17.6 (15.1)	12.3 (9.3)	-1.55	.11
LOS (index)	24.0 (14.8)	31.0 (18.0)	24.9 (12.8)	-1.58	.11
LOS (ICU)	17.0 (13.5)	25.7 (17.4)	18.8 (11.6)	-1.86	.06
No. of preexisting conditions	5.5 (3.3)	6.3 (3.4)	6.1 (3.4)	-0.55	.58
Caregivers					
Age	52.9 (15.4), y	53.2 (12.6), y	53.6 (13.3)	-0.10	.91
	(n = 334), n (%)	(n = 32), n (%)	(n = 32), n (%)	χ^2	P
Patients					
Sex (female)	187 (56.0)	24 (75.0)	24 (75.0)	0.000	1.00
Discharge location				1.08	.58
Rehabilitation	68 (20.4)	3 (9.4)	4 (12.5)		
Nursing home	122 (36.5)	15 (46.9)	18 (56.3)		
LTAC	68 (20.4)	14 (43.8)	10 (31.3)		
Discharge distance				1.33	.24
<30 miles	259 (77.5)	26 (81.3)	22 (68.8)		
30-80 miles	75 (22.5)	6 (18.8)	10 (31.3)		
Discharged on ventilatory support	45 (13.5)	9 (28.0)	8 (25.0)	0.483	.78 ^a
Cognitive impairment	122 (38.1)	11 (36.7)	12 (38.7)	0.027	.87
Location changes after discharge					
Readmission	132 (39.5)	10 (31.3)	0	16.6	.00 ^a
Transition	224 (67.3)	4 (12.5)	3 (9.4)		
	n = 290, n (%)	n = 29, n (%)	n = 31, n (%)		
Caregivers					

	Parent Study (n = 334), Mean (SD)	Patients Who Died (n = 32), Mean (SD)	Matched Patients (n = 32), Mean (SD)	Z	P
Sex (female)	210 (72.4)	21 (72.4)	24 (75.0)	2.00	.65
Relationship					.88 ^a
Spouse	122 (41.7)	8 (27.6)	8 (25.8)		
Child	93 (32.1)	16 (55.2)	15 (48.4)		
Sibling	29 (10.0)	2 (6.9)	3 (9.7)		
Other	47 (15.7)	3 (10.3)	5 (16.1)		

Abbreviations: LOMV, length of mechanical ventilation; LOS, length of stay.

^aLikelihood ratio.

Table 2

Nature and Frequency of Contacts

	Patients Who Died (n = 356), n (%)	Matched Patients (n = 205), n (%)
Type		
Face to face	174 (48.8)	94 (45.8)
Telephone	169 (47.4)	88 (42.9)
Other	8 (2.2)	15 (7.3)
Who initiated contact		
APN	273 (76.6)	151 (73.6)
Caregivers	22 (6.1)	4 (1.9)
Patients	0	2 (1.0)
Other healthcare providers	61 (17.1)	23 (11.2)
Who was contacted		
Patients	63 (17.6)	47 (22.9)
Caregivers	58 (16.2)	47 (22.9)
Physicians	36 (10.1)	26 (12.6)
Other healthcare providers	210 (58.9)	100 (48.7)
Reason for contact		
Category 1 ^a	251 (70.5)	136 (66.3)
Category 2 ^b	151 (42.4)	113 (55.1)
Category 3 ^c	59 (16.5)	2 (1.0)
Outcome of contact		
Continue plan	306 (85.9)	163 (79.5)
Change plan	48 (13.4)	38 (18.5)

^a Monitoring, assessment, support, medication review, coordination of any services, and/or providers.

^b Direct care, problem management, or problem advice.

^c Activities related to discharge planning or transition from one location to another.