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Barriers to Discharge: A Retrospective Medical Record Review Examining Potential Barriers to Patient Discharge at the End-of-Life

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Abstract

It is estimated that 70% of Americans would prefer to die at home, but less than one-quarter do so. Patients near the end of life often face several barriers that prevent them from successfully transitioning from an acute care setting to their preferred place of death. These barriers include but are not limited to a lack of trust between facilities and community care providers, ineffective communication, delayed discharge planning, difficulty accessing medications and supplies, lack of control, feelings of uncertainty, and feelings of burden. This study utilized a survey of 102 medical records of patients who died in the hospital to identify barriers experienced by end-of-life patients in one Midwestern acute care hospital.

Highlights

- Most Americans at the end of life prefer to die at home, but less than one-quarter do so.

- Barriers to discharge include inadequate provider knowledge of palliative care guidelines, delayed discharge planning, ineffective communication between hospital and community care settings, difficulty accessing medications and supplies, patient's feelings of uncertainty, burden, and loss of control.

- Supporting patient preference related to the location of death can be viewed as a quality-of-care measure.

Keywords: End of life, place of preference, barriers to discharge

Cover Letter

Pauline Felker and Kelly Purdy are graduate nursing students pursuing their Doctorate of Nursing Practice at the University of Nebraska Medical Center, in Omaha, Nebraska. Dr. Lynne Buchanan is the supervising faculty for this project. She is a professor and board-certified Advanced Practice Nurse Practitioner specializing in telehealthcare delivery and substance use disorders.

The researchers share an interest in palliative care, leading them to investigate why many patients die in the hospital when they would rather die at home. This article discusses the results of a retrospective chart review that aimed to find barriers preventing end-of-life patients from discharging to their preferred location.

The mission of the American Academy of Nurse Practitioners is to empower Advanced Practice Providers (APNs) to advance the quality of health care through practice, education, advocacy, research, and leadership. This manuscript supports this mission through the teaching of physicians and APNs regarding practice recommendations and guidelines for end-of-life patients. It advocates for patient rights at the end of life by promoting effective leadership skills that reinforce the need for early assessment and referral as well as promoting discharge to the patients place of preference.

This manuscript has not been and will not be submitted elsewhere for publication.

Barriers to discharge: A retrospective medical record review examining potential barriers to patient discharge at the end-of-life

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Introduction

A good death is one that is "free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards".[1] When reviewing a patient's end of life preferences, it was found that 70% of Americans would prefer to die at home,[2] but less than one quarter do so.[3] Multiple studies support the belief that most individuals at the end of life would prefer to die at home.[4,5] Patients near the end of life often face several barriers that prevent them from successfully transitioning from an acute care setting to their preferred place of death. This study seeks to identify those barriers at a local hospital and discuss ways to modify such barriers.

Background and Significance

Most Americans would prefer to die in their home, but less than one-quarter do so. According to Lusardi et al,[8] at least 60% of the people who die each year in the United States will die in the hospital. Of that 60%, more than half will have spent time in the intensive care unit (ICU) in the three days prior to death. The longer a patient stay in the ICU the higher the rate of mortality and resource utilization. It has been found that patients who stay in the ICU longer than 7 days accounted for the use of more than 50% of the ICU resources. It was also found that 32% of ICU resources are spent caring for patients who survive less than 100 days after discharge.[8]

These numbers are important to consider when discussing healthcare costs and the possibility of discharging patients home. Currently, in the United States, elderly patients account for 42 to 52% of ICU admission and 60% of all ICU days.[9] Caring for ICU patients takes up 15-25% of hospital costs. With the aging population growing, costs can be expected to rise. Being able to discharge a patient home to die could be a significant source of cost savings for a facility. In one study, a hospital was able to transfer 7 out of 456 dying ICU patients to their homes over the course of one year. This provided a total cost savings to the hospital of over $40,000.[8]

In addition to financial burdens and utilization of resources, there are also the experiences and concerns of the family. One retrospective study found that families reported patient quality of life during the last week of life was higher when the patient died at home versus in the hospital. On a scale of 0 to 10, with 10 being the highest quality of life, families rated the patient's quality of life at home at a 7.3 versus a 5.0 when in the hospital.[10]

A review of the literature shows that several common barriers affect patients' ability to discharge from the acute care setting to their preferred place of death. These factors include: the presence of an advance directive document, patient diagnosis, provider involvement, functional status, and demographic and socioeconomic status.

Patients with an advance directive in place at the time of admission were more likely to receive a palliative care (PC) consultation.[11] Stilos et al.[13] showed that discussions pertaining to goals of care were frequent precursors to a hospice referral. Yet, only the involvement of specialty palliative care services predicted transitions out of hospitals for end-of-life care. This may be related to discussions from specialty palliative care having occurred earlier in the illness trajectory or their communication of options for community-based services or a setting of care. A study by Williams et al.[12] showed that there was an increase in preference and decision documentation closer to death, particularly in the last week of life. These studies show while accurate and up-to-date preferences should be recorded, it is just as important to hold these discussions as early as possible so that the patient is able to fully participate in expressing their end of life wishes. Likewise, it is helpful to family members when preferences have already been decided upon so that decisions are not clouded by the pain and grief that losing a loved one can cause.

A patient's medical diagnosis is another factor that affects their discharge goal and the likelihood of discharging to their preferred place of death. According to Martz et al.[11] palliative

care recipients are more likely to be women with a diagnosis of sepsis, pneumonia, cancer or "other". Having cancer and living with others was associated with a preference of dying at home.[14] Individuals dying from cancer are more likely to die in a hospice setting then those individuals dying from kidney disease or dementia.[13] One theory behind this phenomenon is that those with cancer have been found to have more discussions regarding end-of-life issues and have an awareness of their preferred place of death.[15] Billingham and Billingham[15] found it is easier to recognize impending death and to predict someone's disease progression when they have cancer. They recommend measures to improve early recognition of the terminal phase and suggest the provision of services for end-of-life care should be opened to non-palliative care specialists and clinicians in order to increase access to palliative care services for patients with all diagnoses.

This leads to provider involvement. The level of provider involvement can affect the patient's ability to discharge to their place of preference as it is the physician who is oftentimes in charge of choosing the best care and treatment options for their patient.[12] One study found that there was a reluctance by many clinicians and families to discuss end of life preferences for fear of causing the patient distress and worsening their condition.[12] Stilos[13] noted the subjective nature of the term "end of life" and discussed the difficulty in recognizing when a patient is entering the last days of life. They found referring physicians may focus primarily on the most pressing symptoms (such as relieving pain and discomforting symptoms), leaving the palliative care team to assess symptom management rather than allowing them to partake in end-of-life discussions and goal setting. Another study by Reyniers et al.[16] provided physician insight into admission practices and reasons behind the hospital admission. Results of the study showed potentially avoidable admissions may have been prevented if providers would have given better support to family caregivers or communicated with the patient about their limited life expectancy

and the possibility of palliative care.

Functional status and preferring treatments aimed to improve quality of life were also associated with dying at home.[14] However, Gill et al.[17] found patients at end- of- life often go to the emergency room when palliative care services are unavailable in the community. If strong support is not readily available, some caregivers will not be able to bear the strain and unplanned hospital admissions may be necessary. Billingham & Billingham[15] proposed these crises can be avoided if patients and caregivers are well prepared and support is available. This could be achieved through early referral to a palliative care team, initiation of outpatient palliative care services if available, or increased provider training in primary palliative care.

Demographic data also influences place of death. Independent factors associated with increased chance of dying at home rather than in a hospital include increasing age, female gender, certain ethnicities, receipt of home palliative care, and having fewer co-morbidities.[5,14] Individuals with lower socioeconomic status or who live in poorer areas are less likely to die at home. Also, culture and ethnicity can affect place of death.[14]

Purpose

This study examines the modifiable barriers identified at one acute care organization and discusses how they can be managed so that an individual at the end of life can discharge from the acute care setting to his or her place of preference. To identify modifiable barriers to discharge at the end of life the following question was developed-of a population who died in an acute care hospital system in 2019, are there barriers that can be identified and modified so that strategies can be developed to assist healthcare providers in facilitating an appropriate discharge to the patient's place of preference at the end of life?

<center>**Methods**</center>

Design

A retrospective cohort study was performed on a random sample selected from a population of 1,012 medical charts. The cohort consisted of adults, ages 19 and older, with a variety of admitting medical diagnoses. The study design was reviewed and approved by the institutional review board that governs research on human subjects. The DNP proposal was also reviewed and approved by the Nursing Research Council at the site of the study and the Professional Graduate Nursing Affairs Committee at the university.

Subjects

The subjects for this study were adult patients ages 19 or older who were admitted to and died in a large midwestern hospital during calendar year 2019. Subjects were randomly selected from a database using a random numbers table developed by a statistician at the university. Subjects were excluded if they are 18 years or younger or had a diagnosis of Covid-19, or unexpected or sudden death.

Setting

The project took place in an urban, acute care facility. The organization services 15 acute care hospitals, 2 specialty hospitals, 2 behavioral health facilities, over 120 outpatient clinics, and multiple health services across Nebraska and Western Iowa. For the purposes of this study, the investigators focused on patient charts from the 5 acute care hospitals in the local area. Each

hospital offers different services from level I trauma center and academic medical center to heart and vascular care, emergency services, surgery, maternity, cancer care, specialty spine care, orthopedics, women's care, diagnostic imaging and others.

Tools

A tool to guide the retrospective chart review was used to facilitate discovery of barriers to discharge (Appendix 1). This tool was developed by the investigators and reviewed by four experts in palliative care. The experts included a palliative care APRN, a statistician, and two palliative care certified physicians. The tool was used to gather information from patient charts such as presence of advance directives, admitting diagnosis, identification of a primary care provider, functional status, demographic information, and whether a palliative care referral was placed. The investigators used identical data collection templates and were trained to use the same collection technique in order to decrease bias and promote uniformity in data collection measures.

Results

Using the investigative tool created by the researchers, data was collected from a random sample of 102 medical charts. Descriptive statistics were used to analyze the data associated with the cohort. In the individuals who died in one day or less (N=47), it was found that not enough medical information was available to provide significant insight into the potential barriers to discharge that may have existed. Therefore, the results of the data were focused on the remaining 55 individuals who had a length of stay greater than one day.

This population of patients was found to be homogenous with 87.3% of the patients being Caucasian. The cohort consisted of an almost equal split between genders assigned at birth with 52 % male and 48% female. The mean age for this group was 69.07 (SD 14.607). Place of residence prior to the terminal admission was found to be private residence or dwelling (67.3%) followed by assisted living, independent living facility or skilled nursing facility (21.8%). Most individuals in the sample, 96.4%, were covered by insurance with 61.8% identifying Medicare as their primary insurance. 23.6% of those admitted had private insurance. While the demographic data showed clinical significance between groups there was no statistical significance (see Table 1). For example, it is important for providers to know the population they are serving. The demographic data that was gathered was important in defining the population served at this facility, but no statistical significance was found between these variables.

The average length of stay for those admitted for greater than one day was 10 days (SD 9.479). On average, a patient was hospitalized for 6 days prior to receiving a palliative care consult. Patients who identified barriers to discharge demonstrated a longer length of stay with an average of 15.24 hospital days (SD 14.708). Those who did not identify barriers to discharge had an average length of stay of 4.15 days (SD 4.581).

The palliative care team evaluated 67% of the 55 patients admitted for more than one day. Of this group, 84% did not have an advance directive document on file and 69% did not have a Power of Attorney for health care specified (Table 2). Females were more likely to have a Power of Attorney compared to males (34.7% compared to 17% of males). Despite the majority of patients that were evaluated by palliative care, 99% had an unknown preferred place of death. Only 1% of the records indicated the patient's preferred place of death.

A LACE score is used to predict a person's chance for hospital readmission and/or death within 30 days of discharge.[18] A score greater than 10 indicates a strong likelihood for

readmission or death in the next 30 days. For those admitted for greater than one day the mean LACE score was 13.92 (SD 4.39). A Palliative Performance Score (PPS) is a tool used to help clinicians recognize a patient's functional decline and facilitate conversations regarding palliative care or end-of-life care possibilities. Scores range from 0-100, with 0 being patient death and 100 being patient is fully ambulatory and healthy. The mean PPS in this cohort was 51.2% (Table 2).

Table 1: Demographic Data Analysis

DNR -Do not resuscitate, DNI- Do not intubate
L-Assisted living, IL-independent living, SNF- skilled nursing facility, LTC- Long term care

	All patients (N=102)	Patients admitted for greater than 1 day (N=55)
Age	Mean 69.86	Mean 67.4
Gender assigned at birth	52 % Male 48 % Female	50.9 % Male 49.1 % Female
Ethnicity	89% Caucasian 9 % African American 2 % Hispanic 2 % Asian	87.3 % Caucasian 10.9 % African American 1.8 % Hispanic 0% Asian
PCP identified	84.3 % Yes 15.7% No	85.5 % Yes 14.5 % No
Insurance	94.1 % Yes (62.7% Medicare; 23.5% private) 6 % No	96.4 % Yes (61.8% Medicare; 23.6 % private) 3.6 % No
Code status	46.1% Not identified 13.7 % Full code 2% DNR/DNI 17.6 % DNR only 20.6% DNI only	58.2 % Not identified 10.9 % Full code 0% DNR/DNI 14.5 % DNR 16.4 % DNI
Residence prior to terminal event	72.5 % Private dwelling 15.7 % AL/IL/SNF 6 % LTC 6 % Other	67.3 % Private dwelling 21.8 % AL/IL/SNF 5.5 % LTC 5.5 % Other
Geographic location	16.7 % Northwest Omaha 7.8 % Northeast Omaha 4.9 % West Omaha 2.9 % Southeast Omaha 14.7 %Southwest Omaha 52.9 % Other	14.5 % Northwest Omaha 7.3 % Northeast Omaha 3.6 % West Omaha 3.6 % Southeast Omaha 12.7 % Southwest Omaha 58.2 % Other
ICD 10 codes	I46.9 Cardiac arrest, cause unspecified 22.5 % A41.9 Sepsis, unspecified organism 15.7 % J96.01 Acute respiratory failure with hypoxia 6.9 %	A41.9 Sepsis, unspecified organism 23.6 % J96.01 Acute respiratory failure with hypoxia 5.5% I46.9 Cardiac arrest, A41.5 Sepsis due to gram negative organisms, J96.21 Acute and chronic respiratory failure with hypoxia, or S06.5X9A Traumatic subdural hemorrhage with loss of consciousness of unspecified duration 3.6%

Summary of data pertinent to the Palliative Care team.

Table 2: Palliative Care Data Analysis

	All patients (N=102)	Patients admitted for greater than 1 day (N=55)
Average Length of Stay	6 days	10 days
Advanced Directive on File	20.6% Yes 79.4% No	16.4% Yes 83.6% No
Power of Attorney on File	25.5% Yes 74.5% No	30.9% Yes 69.1% No
Palliative Care Consult this Admission	36.3% Yes 63.7% No	67.3% Yes 32.7% No
Average # Days before Palliative Care Consult	6.31 days (SD 4.616)	6.3 days
End of Life Preference Documented	14.7% Yes 85.3% No	25.5% Yes 74.5% No
Preferred Place of Death Achieved	1% Yes 13.7% No 85.3% Unknown	1.8% Yes 21.8% No 76.4% Unknown
Palliative Performance Score (PPS)	55.2% (N=55)	51.2% (N=51)
Lace Score	13.62 (N=59)	13.9 (N=53)

Summary of data pertinent to the palliative care team.

Data was examined to determine if there was a difference between genders for those that were transferred to the ICU within 72 hours of dying. Results showed that a larger proportion of males, 65%, when compared to females, 35%, were transferred to the ICU within 72 hours of dying (Table 3). A chi-square goodness of fit was calculated comparing gender and tranfer to the ICU within 72 hours showing a significance of 0.034.

Table 3: Transfer to ICU 72 hours prior to terminal event

		Yes	No	Total
Male	Count	26	27	53
	% within gender	49.9%	50.9%	100%
Female	Count	14	35	49
	% within gender	28.6%	71.4%	100%

Comparison of gender and ICU transfer prior to death.

Frailty was compared to whether the patient had ever had a palliative care consult at any point in their lifetime, to determine if there was a significant difference between the two variables. The data showed that as the frailty score increased (or the patient became more physically or cognitively ill), the more likely they were to receive a palliative care consult. The mean frailty score for those with a palliative care consult during the terminal admission was 6.25 (SD 1.538) compared to the mean of those who did not have a palliative care consult of 4.76 (SD 2.095). The mean frailty score for those with a palliative care consult at any point in their lifetime, was 6.8 compared to the mean of those with no record of a palliative care consult of 5.33 (Table 4).

Table 4: Palliative Care Consultation Correlation with Frailty

Frailty		Number	Mean	Std. Deviation	Std. Error Mean
	PC consult terminal admission	36	6.25	1.538	.256
	No PC consult terminal admission	21	4.76	2.095	.457
	Lifetime PC consult	8	7.25	.707	.250
	No lifetime PC consult	49	5.45	1.905	.272

PC= Palliative Care   Increased frailty associated with increased PC consult

Discussion

Previous research identified potential barriers to patient discharge at the end-of-life as the presence or absence of an advance directive document, patient diagnosis, provider involvement, functional status, and demographic and socioeconomic status. The data collected from this hospital system indicates that most patients do not have an advanced directive document on file. This could be considered a barrier to patient discharge as it prevents the patient's end-of-life wishes from being known to the care team. Also important is that the majority of patients were not asked if they had a preference of where they would like to be at the time of their death, nor were there identified barriers to discharge documented. It can be assumed that without knowledge of where the patient prefers to die, it will be difficult to identify the barriers preventing them from reaching their preferred place of death.

Patient diagnosis was not considered a barrier in this study as there was no single diagnosis that indicated the patient was more likely to die in the hospital compared to others. Most patients in this study had a primary care provider, however it is uncertain how involved their provider was in their care prior to their hospital admission.

The majority of patients had a functional status score (PPS) around 50%, indicating significant assistance will be required after discharge. This may or may not be a barrier for discharge. A downward trend in the PPS would indicate a functional decline for the patient, however it is unlikely that hospitals maintain longitudinal records of these scores for comparison. This may be a useful tool for patients requiring a longer hospitalization if the score is updated throughout the patient's stay and discharge plans adjusted accordingly. Because of the level of assistance required upon discharge, patients with a PPS of 50% or lower will require thorough evaluation and discharge planning from the entire care team. A low PPS paired with an elevated LACE score also indicates the need for significant discharge planning and end-of-life discussions

with patients and their family or caregiver. Demographic and socioeconomic status did not appear to be barriers in this group since it was a homogenous group of males and females and the majority (94%) had insurance.

Conclusion

Although there was no statistical significance found in the results, the clinical significance can still be useful. The barriers at this particular facility could be attributed to limited advance care planning, late palliative care consultation, limited provider knowledge regarding place of preference for end-of-life care, and quality of discharge planning received rather than patient demographic variables.

It is the authors' recommendation that the palliative care team receive consultations earlier in the setting of serious illness. This would prove beneficial in determining goals for care and discussions about end-of-life care preferences. It is also recommended that the palliative care team speak with patients and family members to specify the patient's place of preference at the end of life. Responses should be well documented and communicated with the care team in order to ensure appropriate discharge planning and potentially avoid hospital-prolonging treatments or procedures. This could also provide a potentially significant cost saving for the facility as well as the patient.

Limitations

The study was limited in that it only looked at one health care organization in the area. There are a total of three major health care systems in this metropolitan community. Collecting data from all hospital systems may have provided a more accurate representation of the population served and the barriers that are faced. It could also provide insight into what other systems are doing to meet their patient's discharge goals.

The study cohort was selected from only one year of data. Of the medical records that met inclusion criteria, only 10 % were used for this study. Although a random selection of medical records was used, it is possible that the medical records reviewed were not representative of the population at large. This study does not have power to make generalizations to all palliative care patients and the results are limited to this sample and organization.

Future studies examining whether outpatient end-of-life discussions had taken place prior to a patient's death and whether the patient's wishes were adhered to could provide insight into the need for and development of outpatient palliative care services in this area.

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Appendix 1

Data Collection Tool

Demographic Information

Pt identifier		___ ___ ___	___ ___ ___
Age (in years)			
Gender assigned at birth	0= Male 1= Female		
Ethnicity listed	0= Caucasian/white 1= African American/Black 2= Asian/Pacific Islander 3= Hispanic 4= American Indian/Alaska Native 5= Other/None listed		
Marital status	0= Single 1= Widowed 2= Divorced/ Separated 3= Married 4= Other (cohabitation, significant other, common law)		
Support system (outside the hospital)	0= Yes (is somebody present when the pt goes home) 1= No If yes, additional notes: (spouse, child, family, friend, neighbor)		
PCP listed	0= Yes 1= No		
Insurance listed	0= Yes 1= No		
Insurance Type	0=self-pay 1=Medicare 2=Medicaid 3=private insurance		
	4=other		
Geographic location	0= Northwest Omaha 1= Northeast Omaha 2= West Omaha 3= Southeast Omaha 4= Southwest Omaha 5= Other		

Functional Status

Prior to admission residence	0= Private dwelling 1= Hospice House 2= Assisted living/Independent living/SNF 3= Long term care facility (nursing home) 4= Homeless (car, tent, encampment) 5= Other (shelter)		
Functional status/Palliative Performance Scale (PPS) (decimal form)			
Frailty Index			
LACE Score			

Hospital Course

Hospital at time of death	0= Bergan Mercy 1= Lakeside 2= Midlands 3= Mercy 4= Immanuel		
Admission code status	0= Not identified 1= Full code 2= DNR and DNI 3=DNR only 4=DNI only		
Admission diagnoses and comorbidities (CPT code)			
Number of admissions 365 days prior to death			
Unit location at time of death	0=Medical/surgical 1=Progressive care unit 2=Intensive care 3= Other (2nd floor unit, observation)		
Transfer to ICU 72 hours prior to death	0= Yes 1= No		
LOS at time of death (# of days)			
Social Work involved in discharge	0= Yes 1= No		
Case Management RN involved in discharge	0= Yes 1= No		

Barriers to discharge identified prior to death (ie, financial difficulties, lack of support system)	0= Yes. If yes, list. 1= No		

Advanced Care Planning

Advanced directives on file	0= Yes 1= No		
Power of Attorney-Healthcare (POA-HC) on file	0= Yes 1= No		
Palliative care consult this admission	0= Yes 1= No		
Number of days before palliative care consult completed			
Palliative care consult lifetime	0= Yes 1= No		
End of life place of preference documented	0= Yes. If yes, list location. 1= No		
Preferred place of death achieved	0= Yes 1= No		

Authors' Biographies

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Kelly Purdy, RN, BSN. Prior to pursuing an advanced practice degree she worked as a specialty clinic nurse in an ambulatory care clinic at Nebraska Medicine in Omaha, Nebraska. She has previous nursing experience in hospice and med/surg inpatient care.

Lynne Buchanan, Ph.D., APRN-NP, BC. Dr. Buchanan has over 30 years of clinical nursing experience including roles as a critical care nurse, medical surgical nurse, and advanced practice registered nurse practitioner. She has experiences in technology use for substance use disorders, in use of the telehealth cart and peripheral tools for care delivery. She is a tenured professor and faculty at the University of Nebraska Medical Center in Omaha, Nebraska.

Leeza Struwe, PhD, MSN, RN, is a biostatistician in the Niedfelt Nursing Research Center where she provides research design and statistical analysis for the nurse researchers and doctoral students at the University of Nebraska Medical Center.