HHS Public Access

Author manuscript

J Hosp Palliat Nurs. Author manuscript; available in PMC 2017 April 01.

Published in final edited form as:

J Hosp Palliat Nurs. 2016 April 1; 18(2): 124–130. doi:10.1097/NJH.0000000000000222.

Communication with Residents and Families in Nursing Homes at the End of Life

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Abstract

Communication with residents and their families is important to ensure that the end-of-life experience is in accordance with resident's wishes. A secondary analysis was conducted to determine: (a) who should communicate with the resident/family about death and dying; (b) when communication should occur around death and dying, obtaining a "DNR" order, and obtaining a hospice referral; and (c) what differences exist in communication about death and dying between Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and unlicensed staff.

Greater than 90% of staff (N=2,191) reported that the physician or social worker should communicate about death and dying with residents/families, but only 53% thought that direct care staff should talk with them. Weighted scores for "When communication should occur about death and dying and obtaining a 'DNR' Order" revealed significantly ($p < .01$) lower scores for unlicensed staff than RNs and LPNS (i.e., licensed staff), indicating that licensed staff were more likely to initiate conversations on admission or at the care-planning meeting, or when the resident's family requested it. No differences were found between staff on communication about obtaining a hospice referral.

The identified gaps in perception about who should be communicating can assist in developing appropriate interventions that need future testing. The potential for training regarding communication strategies and techniques could lead to higher satisfaction with end-of-life care for residents and their families.

Keywords

Communication; Terminal Care; Interdisciplinary Communication; Nursing; Nursing Home

Background

With the number of elders increasing who are admitted to nursing homes for the final days of their lives, death is occurring more often in nursing homes. Currently, 25% of all Americans die in nursing homes, and this number is predicted to rise to 40% by 2020[1]. While communication has been identified by families, residents, and health care providers as

an essential factor in end-of-life care[2–4], little research describes communication among the nurse, patient, and family at the end of life[5]. There also is a gap in the literature regarding information about direct care nursing staff (i.e., Registered Nurses [RNs], Licensed Practical Nurses [LPNs], and nursing assistants) perceptions about when communication should occur, especially related to "Do Not Resuscitate (DNR)" orders, hospice referrals, and who is responsible for communication about end-of-life care.

Family members of deceased residents identify communication as essential when talking about what makes a good death[6–8]. In these studies, open communication between healthcare workers, family members, and residents had a strong, positive correlation with high satisfaction with end-of-life care for the resident. However, despite the need for good communication, direct care staff, nursing home residents, and family have identified many barriers that resulted in missed conversations. These include: (a) perceived difficultly in having conversations related to end-of-life care, (b) feelings that staff did not have enough knowledge for the conversation, (c) assumptions that the preferences were already known, (d) presence of an advanced directive, and (e) inquiries never occurring[9]. Livingston identified another weakness in that the direct care staff (e.g., RNs, LPNs, and nursing assistants) and physicians did not see themselves as a team; this led to poor communication with each other and the resident's family[10].

Due to the limited number of systematic approaches to elicit and communicate information about resident life preferences, many staff members may be uneducated about how to handle the communication leading to residents' wishes and preferences not being fulfilled[11]. These missed opportunities for communication can affect progression of patient's care.

Because direct care staff provide substantial care to residents at their end of life, more research is needed to understand their perceptions about communication. Additionally, exploration of licensed (i.e., RNs and LPNs) and unlicensed staff perceptions of communication about death and the end-of-life processes could enhance understanding and contribute to interventions that could lead to improved and more satisfactory experiences for residents and their families during the resident's dying process.

The purpose of this secondary analysis is to identify communication used by direct care staff when residents and their families are preparing for the end of life. The following three research questions were explored: (a) Who communicates with the resident and family members about death and dying in the nursing home? (b) When should communication occur about death and dying, obtaining a "DNR" order, and obtaining a hospice referral? and (c) Are there differences in communication about death and dying, obtaining a "DNR" order, and obtaining a hospice referral between Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and unlicensed staff (certified nursing assistants [CNAs], certified medication assistants [CMAs], and restorative aides)?

Methods

Design

A descriptive, secondary analysis of data from the National Institute of Nursing Research (NINR)-funded study, "Impact of Quality End-of-Life Care in Nursing Homes," was used for this study[12]. Using Unruh and Wan's expanded structure, process, and outcomes systems framework[13], the primary study was used to examine the quality of care, life, and death in nursing homes. This study focuses on the direct care staff perceptions of communication with family and residents at the end of life.

Setting and Sample

One hundred nursing homes from two Midwestern states randomly were selected from 180 facilities that met the criteria for enrollment in the primary study; 85 facilities agreed to participate and completed the study. The nursing homes had an average bed size of 89 (*Range*= 39–254), about two-thirds (63%) were rural, and more than half (53%) were for-profit (non-profit = 38% and government-owned = 10%). Within the nursing homes, the sample consisted of 2,191 direct care staff (see Roles in Table 1). The original data included 2,932 staff members, but was reduced to 2,191 after non-nursing personnel and non-direct care staff members were eliminated.

Procedures

Nursing home administrators were informed about the study and consent was obtained for their participation. Direct care staff members working in the nursing homes consented and completed study questionnaires in person during on-site visits by the research team. Although data were collected at two time points (the beginning of the study and the end of the study) only end-of-study data are reported here. Data were de-identified for use by the researcher and determination of non-human subjects research was made by a Midwestern academic medical center.

Measures

Survey questions—For this study, four items were used from one subconstruct, Planning/Intervention, of the *Palliative Care Practice* construct of the Palliative Care Process Measure (PCPM). Reliability and validity was established for the PCPM by Thompson and colleagues[14]. After being presented with a case study of a dying resident, the direct care staff were asked to respond to survey questions related to the case study that made up the four items representing the *Planning/Intervention* subconstruct.

Responses were yes (1) or no (2) to the first survey item, "Who will talk about death and dying with resident's family member?" for each of the following care givers: (a) any direct care staff, including CNAs, (b) resident's physician, (c) social worker, (d) charge nurse, (d) director of nursing, (e) chaplain, or (f) others. No additional information was solicited for the other category.

Table 2 summarizes the times (varied by question) when responses (never, sometimes, often, and always) were asked for the next three survey items: (a) When would you communicate

about death and dying? (b) When would you communicate about obtaining a "DNR" order? and (c) When would you communicate about obtaining a hospice referral? Weights from zero to five were assigned for each response option (never to always) for each of the times listed for each survey question (see Table 2). Scores were created by summing across the weights assigned for each of the times within each survey item. Summed scores ranges for the three survey items were: 0 to 12, 0 to 10, and 0 to 14, respectively, for each item.

Demographic data—Table 1 presents the categories for each of the demographic characteristics that were reported by direct care staff. Information was collected about: (a) age categories; (b) gender; (c) race; (d) highest level of education; (e) number of years in the current job title; and (f) number of years working in the nursing home.

Data Analysis

Data were analyzed using IBM Statistics SPSS Version 22.0. The first question, "Who communicates with the resident and family members about death and dying in the nursing home?" and the second question, "When should communication occur about death and dying, obtaining a "Do Not Resuscitate" order, or obtaining a hospice referral?" were analyzed using descriptive statistics. The third question, "Are there differences in communication about death and dying, obtaining a "DNR" order, and obtaining a hospice referral between Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and unlicensed staff (certified nursing assistants [CNAs], certified medication assistants [CMAs], and restorative aides)?" was analyzed using ANOVA to test for differences between the three groups (RNs, LPNs, and unlicensed staff) on the weighted summed scores for each of the three items from the *Planning/Intervention* subconstruct of the PCPM. Assumptions for violations of homogeneity of variance were tested using Levine's test; follow-up tests were conducted using Dunnett's T3 test to determine group differences following a significant (p <.05) Levine test.

Results

Our study included 2,191 participants who worked in nursing homes. The participants were predominantly female (94%) and Caucasian/European American (79%). More than half (51%) reported being in their job title for more than five year, with 41% reporting they had been at this nursing home for 1 to 5 years. Approximately 42% were 25 to 44 years of age, and 58% had a high school or GED as their highest level of education (see Table 1).

Descriptive statistics for the first research question, "Who communicates with the resident and family member about death and dying in the nursing home?" can be found in Table 3. Greater than 90% of direct care staff thought that the professional healthcare team members (i.e., physician, social worker, or charge nurse) should communicate about death and dying with residents/families, but only 53% thought that direct care staff, including CNAs, should talk with them. While 59% of direct care staff selected "Other" for who would talk about death and dying with the resident's family member, direct care staff were not provided an option to specify who "other" was.

When communication should occur related to death and dying, obtaining a "DNR" order and obtaining a hospice referral (research question two) can be found in Table 4. Approximately 75% of direct care staff would talk to the resident's family member about death and dying when the resident is terminal or when the resident's family member wants to talk, while only 40% of direct care staff would talk about death and dying on admission. About three-fourths of direct care staff would talk to the resident's family member on admission about obtaining a DNR order. Only 26% of the direct care staff would communicate about obtaining a hospice referral for the resident on admission, but 84% would talk about hospice referral when the physician orders it.

For the third research question, the overall test from the ANOVA revealed significant differences between groups for when communication would occur about death and dying ($F_{(2,1868)} = 7.99$, $p < .001$), and when communication would occur about obtaining a "DNR" order ($F_{(2,1892)} = 40.67$, $p < .001$). There were no significant differences ($F_{(2,1867)} = 2.09$, $p = .124$) between RNs, LPNs, and the unlicensed staff for when communication would occur about obtaining a hospice order. Follow-up tests using Dunnett's T3 revealed that the unlicensed group (CNAs, CMAs, and Restorative Aides) reported significantly lower weighted summed scores ($M = 5.87$, $SD = 4.38$) than the RNs ($M = 6.84$, $SD = 3.93$) or LPNs ($M = 6.61$, $SD = 4.10$) for "When would you communicate about death and dying". Similarly, "When would you communicate about obtaining a 'DNR' order" resulted in lower weighted summed scores in the unlicensed group ($M = 6.44$, $SD = 3.71$) in comparison to RNs ($M = 7.96$, $SD = 2.80$) and LPNs ($M = 7.96$, $SD = 2.59$). For both questions there were no significant differences between the means for RNs and LPNs. The lower scores for unlicensed staff indicated that they were less likely than RNs or LPNs to initiate conversations on admission, at the care planning meeting, or when the resident's family asks for it.

Discussion

This study presents the perspective of NH staff about communication with residents and families at the end of life. The results showed that most all of the direct care staff (90%) thought that the professional healthcare team members (i.e., physician, social worker, or charge nurse) should communicate about death and dying with residents or their families. Although more than half (53%) thought that direct care staff should partake in conversations about death and dying with residents and their families, this is not adequate to meet the needs of the end-of-life needs of residents. While all direct care staff deal with situations that involve death and dying, they may not perceive that these conversations are their responsibility. This could be due to lack of training, lack of time, or discomfort in having conversations about death and dying. This important finding may be the result of diffusion of responsibility; direct care staff, especially unlicensed staff, may believe other professionals have more experience in how to have these conversations. Direct care staff often are focused on the completion of tasks[15] and may not think that they have time for discussion, especially if they are uncomfortable with the topic. Realizing the importance of having conversations about death and dying and the impact on the quality of care provided to the residents and their families is essential to changing the expectations for communication from the direct care provider.

Findings for “When communication occurs” reveals that communication most likely will occur when the direct care staff feel confronted with the situation directly. Direct care staff are most likely to talk to the resident’s family about death and dying when the resident is terminal or when the resident’s family member wants to initiate the conversation. Being comfortable initiating conversations about death and dying takes training and practice. Doing that before the resident or the family is faced with the resident’s impending death is helpful in determining what their expectations and desires are. Additionally, providing support to terminal residents and their families is an essential element of care that would be expected since many residents spend their last days in the nursing home.

Talking to the resident’s family member about a DNR order is most likely to occur when it is part of the intake and assessment process, such as on admission, either by the nurse or possibly a social worker who is responsible for those activities. Consequently, unlicensed staff often would not consider this as part of their responsibilities. However, they may be privy to conversations with the family closer to the end of life, especially if the resident’s condition is deteriorating. Thus, understanding their role in reporting resident and/or family wishes is important.

The direct care staff in this study reported that a hospice referral should be made when the physician orders it or when the resident’s family member asks for it. Having direct care staff advocate for hospice referral earlier in the process is beneficial not only for the residents and their families but also for the direct care staff. Hospice personnel are trained in end-of-life care and can facilitate conversations between the direct care staff and the family, and enhance the end-of-life experience, which has been shown to improve care[16].

It is important for direct care providers to identify cues from the residents and their families who want to have conversations about death and dying. These could occur as part of the daily life of the residents with the direct care providers who spend the most time providing their care. If these cues or conversations are missed, the residents’ and families’ full wishes may not be fulfilled. It also may lead to higher levels of stress and a rushed decision because time may not be available for thorough conversations to occur about these topics during the final days of life.

Findings from this study suggest that there are differences in direct care staff perceptions of when communication about end-of-life care occurs. Examining the weighted scores for “When communication should occur about death and dying, obtaining a ‘DNR‘ order, and obtaining a hospice referral, RNs and LPNs (licensed staff were more likely to initiate conversations on admission, at the next care planning meeting, or when the family asked for referral to hospice care than unlicensed staff. However, it may not be the unlicensed provider’s responsibility to initiate communication during these times given the current environment in nursing homes. Often the unlicensed staff are with the residents and their families and have opportunities to respond to conversations that may be initiated by families. Education and training would be interventions that could assist all direct care staff during these crucial conversations.

The lower number of staff with a Bachelor's or higher degree (6.9%) whose education should include development of interpersonal skills also impacts the communication with residents and their families. Because of the differences in responses based on educational level, it may be important to provide on-the-job training to ensure that all direct care staff have knowledge about end-of-life communication so they can assist and provide support to each other in this process.

Study Limitations

The limitations of this study include the lack of diversity of the direct care staff working in these Midwestern nursing homes in comparison to the typical nursing home throughout the country. Direct care staff in this sample reported being in their roles and in the nursing home longer than one would expect given the high turnover in nursing homes. Additionally, based on the sample of smaller nursing homes in rural areas for this study, data may not be generalizable to the other nursing homes across the U.S. Further research should be completed in order to replicate the findings in populations with more diverse backgrounds and should include more detailed questions about end-of-life communication. Because this was a secondary analysis, only variables that were included in the primary study were available, and there may be other information that was not collected that would be beneficial in interpreting the findings.

Conclusions

Findings from this study provided baseline knowledge of direct care staff's views about end-of-life communication. Identifying the differences between the licensed and unlicensed staff is important in determining gaps in communication about death and dying. This includes obtaining information about a DNR order or asking family about referral to hospice care. Nursing home administrators should assess staff members' perceptions on end-of-life communication to assist in determining appropriate interventions that promote quality end-of-life communication for all direct care staff. Future studies should include testing of interventions that could provide knowledge about appropriate end-of-life communication techniques as well as strategies to assist direct care staff with quality end-of-life communication.

Acknowledgments

The authors gratefully acknowledge Dr. Sarah Thompson, Principal Investigator, for contributing the data for this study from her NINR-funded study, "Impact of Quality End-of-Life Care in Nursing Homes" (NR009547).

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Table 1

Participant Demographics (N=2,191)

Characteristics	*n (%)*
Sex	
Male	121
Female	1,933
Race	
Caucasian/European American	1,677 (78.7)
African American	83 (3.9)
Asian American	31 (1.5)
Hispanic American	54 (2.5)
Other	287 (13.4)
Age (years)	
< 24	405 (18.8)
25–44	899 (41.8)
45–64	771 (35.9)
65 or > 65	75 (3.5)
Years in job title	
< 1	283 (13.2)
1–5 years	771 (35.9)
> 5	1,092 (50.9)
Years at this nursing home	
< 1	417 (21.4)
1–5 years	804 (41.3)
> 5	725 (37.3)
Education	
Less than high school	67 (3.2)
High school or GED	1,241 (58.4)
Associate’s Degree	670 (31.5)
Bachelor’s Degree or higher	146 (6.9)
Roles	
Registered Nurses (RNs)	273 (12.5)
Licensed Practical Nurses (LPNs)	384 (17.5)
Staff Nurses	12 (0.5)
Certified Nursing Assistants (CNAs)	1,100 (50.2)
Certified Medication Assistant (CMAs)	369 (16.8)
Restorative Aides	53 (2.4)

Table 2

Assigned Weights for Summed Scores for items for “Communication about Death and Dying, Obtaining a ‘DNR’ order, and Obtaining a Hospice Referral”.

When would you communicate about death and dying?					
Time Options	**On admission**	**At next care planning meeting**	**When resident is terminal**	**After physician does**	**When resident’s family wants to**
Responses					
Never	0	0	0	0	0
Sometimes	0	0	0	0	0
Often	5	4	1	1	1
Always	5	4	1	1	1
Summed Scored across the 5 items *Range* = 0 to 12					

When would you communicate about obtaining a “DNR” order?					
Time Options	**On admission**	**When we noticed resident losing weight**	**When resident’s family brings it up**	**At next care planning meeting**	**After physician orders hospice or comfort care**
Responses					
Never	0	0	0	0	0
Sometimes	0	0	0	0	0
Often	5	1	0	4	0
Always	5	1	0	4	0
Summed Scored across the 5 items *Range* = 0 to 10					

When would you communicate about obtaining a hospice referral?					
Time Options	**On admission**	**When resident’s family asks for it**	**When physician orders it**	**After resident has lost weight**	**At next care planning meeting**
Responses					
Never	0	0	0	0	0
Sometimes	0	0	0	0	0
Often	5	3	1	1	4
Always	5	3	1	1	4
Summed Scored across the 5 items *Range* = 0 to 14					

Table 3

Descriptive Statistics for “Who communicates with the resident and family members about death and dying in the nursing home?”

Who will talk about death and dying with the resident’s family member?	***n (%)***
Any direct care staff, including CNAs	1,093 (52.9)
Resident’s physician	2,042 (97.5)
Social Worker	1,921 (92.1)
Charge nurse	2,030 (97.4)
Director of Nursing	1,901 (91.9)
Chaplain	1,895 (91.3)
Other (unknown)	953 (59.3)

Table 4

Descriptive Statistics for “When Communication Occurs?”

	Often or Always
When would you communicate with a resident’s family member about death and dying?	*n* (%)
On admission	790 (39.2)
At the next care plan meeting	1,073 (53.7)
When she is terminal	1,478 (75.0)
After her physician does	1,194 (60.9)
When the resident’s family member wants to	1,473 (74.9)
When would you communicate about obtaining a DNR order?	
On admission	1,610 (79.3)
When we noticed she was losing weight	854 (44.0)
When the resident’s family member brings it up	1,461 (74.7)
At the next care plan meeting	1,258 (64.3)
After the doctor orders hospice or comfort care	1,569 (79.1)
When would you communicate about obtaining a hospice referral?	
On admission	501 (26.0)
When the resident’s family member asks for it	1,450 (73.9)
When the physician orders it	1,671 (84.4)
Now that she has lost weight	757 (38.9)
At the next care plan meeting	997 (51.2)