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Nursing Support of Home Hospice Caregivers on the Day of Cancer Patient Death

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Abstract

Purpose—In this study we add to a sparse literature describing nurse-caregiver communication on the day of cancer patient death.

Design—A descriptive secondary analysis of 44 audiotaped home-hospice, day of death, nursing visits.

Setting—Nine hospices across three states.

Sample—42 caregiver-cancer patient dyads; 27 hospice nurses.

Methods—Audiorecordings were coded for supportive nursing communication and relative time spent in physical, psychosocial and spiritual discussion.

Variables—Tangible, emotional, informational, esteem and networking supportive communication; Caregiver religious affiliation.

Findings—Nurses reported their communication skills were less effective when discussing difficult topics as compared to their overall communication effectiveness. Eleven patients died before the nursing visit, three died during the visit, 30 died post-visit. Nurses primarily engaged in discussions facilitating caregiver emotional, tangible, and informational support. More informational support was observed when patient death occurred during the nursing visit. Time spent in general conversational categories showed that physical care conversations predominated (80% of the average overall amount of conversation time), lifestyle/psychosocial discussions 14%, spiritual discussions 6%. Spiritual discussions were observed in only 7 of 44 hospice visits. Spiritual discussions, although short and infrequent, were significantly longer on average for caregivers without a religious affiliation.

Conclusions—Nurses support caregivers on the day of cancer patient death using multiple supportive communication strategies. Spiritual discussions are minimal.

Nursing Implications—Communication skills programs can potentially increase self-reported communication effectiveness. Emerging acute spiritual concerns, especially for caregivers without

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a previous religious affiliation, should be anticipated. Spiritual support is included in the hospice model of holistic care.

Keywords

Hospice; Support; End of life; Family caregivers; Cancer communication

Introduction

Over the past five years hospice use has increased by almost 20% with most home hospice patients receiving care provided by informal caregivers, often family members and friends (National Hospice and Palliative Care Organization, 2015). Taking on a caregiving role can be physically and emotionally burdensome and has serious implications for caregiver physical health and well-being (A. L. Williams & McCorkle, 2011). Advanced cancer hospice patients often experience a rapidly deteriorating physical status contributing to caregiver burden (Teno, Weitzen, Fennell, & Mor, 2001). Research has shown that supporting the caregiver can reduce the burden of caregiving (Epstein & Street, 2007; Hebert, Schulz, Copeland, & Arnold, 2009; A. L. Williams & McCorkle, 2011).

Caregiver support at the very end of a cancer patient's life often comes from an informal network of family and friends who support the caregiver by assisting as needed with physical care of the patient, performing household tasks, and who also provide emotional support. Despite good intentions, other family members and friends may not have the previous experience or skills to provide all types of needed caregiver support needed during the actual day of patient death. For example, they may not understand the dying process thus providing inaccurate information, or are unfamiliar with post death tasks and requirements (Hebert et al., 2009).

Understanding what to expect as patient death approaches can be facilitated by communication with health care providers and has been associated with improved quality of death and patient dignity at end of life (McLeod-Sordjan, 2014). As such, caregivers often turn to their hospice nurse as an expert resource and also as one who has intimately known both the caregiver and the patient during end of life care. The holistic care nurses provide in this situation often effects lasting caregiver impressions. For caregivers, memories of the final nursing visit, events occurring on the day of death, and the quality of patient death may be remembered for many years (Higgins, Garrido, & Prigerson, 2015; B. R. Williams, Lewis, Burgio, & Goode, 2012).

Hospice nurses often develop close relationships with the families they care for due to the personal and intense nature of end of life care. Within these relationships, nurses are in a position to support the patient and caregiver by addressing questions and concerns (Strang, Henoch, Danielson, Browall, & Melin-Johansson, 2014). This can include practical issues such as explaining the physical dying process and what to do after the patient dies, as well as addressing emotional issues for example distress, uncertainty, and anxiety for both patients and their caregivers (Adelbratt & Strang, 2000; Clayton, Reblin, Carlisle, & Ellington, 2014; Hebert et al., 2009; Strang et al., 2014). In addition to practical and emotional needs, many caregivers and patients have spiritual needs during end of life care. Facilitating spiritual care is considered a component of optimal end of life care (Lynch & Dahlin, 2007; National Consensus Project for Quality Palliative Care, 2013), but is a topic that has been found to be more difficult for nurses to address (Molzahn & Sheilds, 2008; Reblin, Otis-Green, Ellington, & Clayton, 2014).

Conversations on the actual day of patient death can be especially challenging, and are known to be extremely important to caregivers and families, but are not frequently studied, likely due to the difficulty in systematically capturing these events (B. R. Williams et al., 2012). Effective end-of-life communication using a relationship based care approach that encompasses biopsychosocial support, especially during the last week of patient life, has been associated with better caregiver bereavement outcomes and quality of life (Hebert et al., 2009; Wright et al., 2008). When the patient is actively dying most supportive nursing communication is directed at the caregiver as most patients are unable to fully respond (Morita, Tei, & Inoue, 2003). Home hospice nurses engage in supportive discussions on the day of patient death with caregivers to facilitate caregiver support and meet caregiver needs. In this observational study we present a highly unique investigation of hospice nurse-caregiver communication occurring on the day of patient death.

Methods

Design

We conducted a descriptive secondary analysis of 44 audiotaped home-hospice nursing visits occurring on the day of patient death representing 42 caregiver-patient dyads; two patients received two home visits on the day of patient death, accounting for the additional two audiotapes. These visits were previously audio-recorded as part of the Nurse Caregiver Communication project from the multi-site longitudinal Cancer Caregiving Study-I that investigated hospice nurse-family interactions from hospice enrollment until patient death (NCIP01CA138317; PI Mooney). This study was approved by the Institutional Review Board. After informed consent was obtained demographic and descriptive data from both hospice nurses and caregiver-patient dyads was collected at enrollment in the parent study.

Procedures

A directed content analysis was conducted by two trained coders to identify and describe nursing supportive communication processes on the day of patient death (Hsieh & Shannon, 2005). Both coders had extensive professional end of life care experience. To avoid bias and achieve consensus and rigor, weekly team meetings were held to review coding decisions. Moreover, regular meetings ensured that selected codes were representative of the data and important content was captured. An audit trail was created to record modifications that were made to the codebook and reflect coder notes and general visit impressions.

To capture supportive nursing communication on the day of patient death we operationalized Cutrona and Suhr’s (1992) descriptions of the types of support needed by spouses during stressful events by adapting Williams and colleagues (2012) descriptions of effective end of life communication to reflect supportive day of death conversations. This resulted in five codes, presented in Table 1; 1) Emotional support (e.g., providing comfort or reassurance);

2) Esteem (e.g., validating feelings, caregiver compliments); 3) Informational Support (e.g., offering explanations of the dying process or post-mortem care); 4) Network Support (e.g., facilitating awareness and/or connections with other services); and 5) Tangible support (e.g., discussions related to ensuring patient comfort and dignity). This framework and coding approach did not include spiritual support. Due to the recommendations of the National Consensus Project For Quality Palliative Care (2013), and our own previous research and clinical experience, we added spiritual support to our coding approach (Table 2).

Analysis

Audiotaped conversations were coded using Noldus Observer event logging software (Noldus Information Technology, 2013). A comment field was used to summarize general visit impressions and capture words, phrases, and concepts that contributed to the general impression of events during each visit (Saldana, 2012). Ratios of the type of support across all visits, and by patient status (died prior to visit, died during visit or actively dying) were calculated. Overall, codes represented broad domains of supportive communication offered by nurses to caregivers and patients on the day of patient death.

Data were analyzed descriptively to characterize the sample of nurses and caregiver-patient dyads. Based on categorizations of optimal end of life care defined by the National Consensus Project For Quality Palliative Care (2013), generalized linear models were created to assess differences in the relative amount of time spent in general physical, psychosocial, and spiritual discussions, and for spiritual discussions by reported caregiver-patient religious affiliation versus no affiliation (McCullagh & Nelder, 1989). Calculations were performed using SAS software (v9.4, SAS Institute Inc., Cary, NC, USA). Results were considered statistically significant if $p<0.05$.

Results

Descriptive data about nurses, caregivers, and patients is presented in Table 3. Across the 44 recordings of 42 caregiver-patient dyads (2 patients had a visit both before and after death), 11 audiotaped visits were to homes where the patient had died immediately before the nursing visit, 3 patient deaths occurred during the hospice nurse home visit, and 30 recorded home visits captured conversations for patients who were actively dying during the nursing visit but died after the hospice nurse had left the home.

Nurses represented 9 hospices across 3 states. Six nurses held certification as Certified Hospice and Palliative Nurses. Overall nurses felt their communication skills were not as effective when discussing difficult topics as compared to their overall communication effectiveness, although none felt they were ineffective communicators (Roberts et al., 2005) (Table 3).

Audio-recordings averaged 52 minutes (SD=32.8 minutes). Although we initially coded supportive nursing communication to both the caregiver and the patient, nursing supportive communication comments were collapsed for this analysis because the vast majority of supportive comments were directed only to the caregiver. Overall, the ratio of specific types of supportive communication behaviors to all supportive nursing communication demonstrated that conversations about the provision of tangible support were most prevalent (35% of total overall supportive communication) followed by emotional support (25% of total overall supportive communication), informational support (23% of total overall supportive communication), offering esteem (15% of total overall supportive communication), and finally facilitating networking opportunities (3% of total overall supportive communication). Not every type of support was found in every visit. Examples of supportive communication between nurses, caregivers, and patients are presented in Table 2. Examining how the ratio of types of support changed in relation to patient time of death showed that nurses varied the support they offered to caregivers and patients based on patient status (Table 4). On average tangible supportive comments remained the most common type of nursing support, especially when the patient had died just prior to the nursing visit. Informational support increased relative to other types of support when the patient died during the visit, although this finding should be interpreted with caution as only three audiotapes represented cancer patient death during the nursing visit. Assessing the amount of time spent in general conversational categories showed that overall conversations about physical care predominated, representing 80% of the average amount of conversation time during a hospice home visit occurring on the day of cancer patient death, lifestyle and psychosocial discussions represented 14% of the average amount of talk, and spiritual discussions represented 6% of overall average amount of visit talk. Spiritual discussions were observed in only 7 of 44 hospice home visits. Using a mixed-effects model for trends about the relative time spent in spiritual conversations, those previously declaring no religious affiliation had a significantly increased duration of spiritual conversation (β= 119.16, s.e. = 36.73, p= 0.0032; no affiliation mean=30.0 seconds, SD=50.7; religious preference mean=3.7 seconds, SD=14.4).

Discussion

The recognition of the critical association between communication processes and caregiver outcomes make it essential to better understand communication on the day of patient death. To that end, we have described a unique and extremely understudied event: home hospice nurse supportive communication of caregivers and patients occurring on the day of cancer patient death.

Current national guidelines describing optimal end of life care suggest that nurses must effectively acknowledge and inform family members of the processes of death including the inevitable occurrence of symptoms, share symptom management plans, educate and support caregivers and patients who are imminently dying, provide information about the availability of spiritual care services as well as assist in making spiritual care available, and provide a plan for future bereavement support (Lynch & Dahlin, 2007; National Consensus Project for Quality Palliative Care, 2013). Thus, communication is one of the primary ways optimal and supportive end of life care practices are implemented (Hebert et al., 2009). Hospice nurses play a critical role on the day of patient death by providing informational and tangible support that helps cancer caregivers and family members to understand what is happening, make informed decisions, and assists the caregiver in making the patient is as comfortable as possible. Nurses also have an important role in the provision of other types of support, such as emotional support, to help caregivers and families to manage distress and uncertainty, and networking support that facilitates connections to additional services as appropriate, helping to meet caregiver current and future needs.

Similar to findings of caregiver and patient support across the overall hospice trajectory, hospice nurses visiting on the day of cancer patient death frequently engaged in discussions of task-based tangible support related to patient care and comfort; emotional and informational support were also prevalent (Reblin et al., 2015). Discussions of networking opportunities for caregiver support from additional services was observed much less frequently, as were discussions related to spiritual concerns. Our findings also support studies investigating the relative amount of overall time spent in general physical, psychosocial, and spiritual discussions across the longer hospice trajectory, showing that physical care conversations predominate and spiritual conversations are exceptionally minimal across the patient's hospice trajectory (Ellington et al., 2015). The overall predominance of conversation time related to physical care and the minimal amount of time spent in spiritual discussions did not change for conversations occurring on the day of patient death.

Spirituality may be considered an additional type of needed caregiver support, and a form of support that is provided much less frequently by nurses. It is possible that nurses are somewhat uncomfortable or feel less effective discussing spiritual matters (Molzahn & Sheilds, 2008; Reblin et al., 2014). It is also possible that other hospice team members such as chaplains or the family's spiritual advisors engage in these conversations with patients and caregivers, and as such nurses feel that they can focus on different caregiver and patient needs. Our findings that nurses spent slightly more time discussing spirituality on the day of cancer patient death for those without a previously declared religious affiliation may indicate the emergence of new and acute spiritual concerns about death that should be addressed.

Nurses provide a supportive role that other members of the caregiver's support network may be unable to provide. For example, nurses may have intensively known the patient during end of life care when distant relatives were not present and as such can offer esteem and emotionally support the caregiver. Hospice nurses are also in a unique position to have experienced multiple patient deaths and have a familiarity with the physiologic processes of death. This enables hospice nurses to provide tangible and informational support to caregivers that is reliable and accurate, such as what is to be expected during the dying process and what to do after the patient dies. This type of support is extremely important to caregivers, helping to manage uncertainty about current and future events (Hebert et al., 2009).

Due to the intensive and intimate nature of the home environment nurses tend to build personal relationships with family caregivers (White & Gilstrap, 2016). In this study the personal relationship between nurses, caregivers and patients was frequently seen during the provision of emotional support and when offering esteem (e.g. providing encouragement, compliments and a compassionate ear). Additionally, nurses can provide emotional support by eliciting and addressing fears or concerns and providing appropriate reassurance. These emotionally positive and supportive conversations can ease the tension of the moment and may have increased importance to caregivers as they remember the day of patient death (Reis et al., 2010).

Unfortunately not all caregivers and patients receive a visit on the day of patient death, despite the fact that the hospice Medicare benefit does not restrict visit number and that patient symptoms are often exacerbated as death approaches (Teno, Plotzke, Christian, & Gozalo, 2016). This study reported on patients who did not receive a hospice visit within 48 hours of death, finding concerning disparities using an analysis of hospice administrative data (Teno et al., 2016). Patients who were black were 30% less likely to get visits, one in five persons dying in a nursing home did not get a hospice visit, and one in five dying on a Sunday did not get a visit (Teno et al., 2016). This precludes supporting caregivers and patients during a particularly vulnerable time. As Table 4 illustrates, there is much tangible support offered to caregivers surrounding death of the patient. When this does not occur, regardless of the reason, caregivers are left to independently navigate an unfamiliar event (death at home) that has legally required tasks and duties in addition to personally desired traditions and duties. These data point strongly to the need for future comprehensive examination of how we support imminently dying patients and their caregivers.

Implications for Nursing

Our findings suggest, in line with other research, that nurses communicate their support to caregivers and patients by primarily focusing on the emotional, informational and tangible care aspects of the dying patient. This is understandable given the nature of the home hospice visit and the tasks to be completed; however national guidelines include additional domains of end of life care such as addressing spirituality and facilitating networking with other supportive services that could be offered to caregivers to ensure optimal end of life care. These forms of support address important caregiver needs, offering additional ways to support the caregiver. For example, if requested, nurses could ensure that caregivers are aware of and connected to supportive services such as groups that offer support for those that have experienced the death of a spouse (facilitating networking) potentially assisting the caregiver during future bereavement, a service of hospice that is often perceived as less than optimal (Tabler et al., 2015).

Nurses need to be aware that spiritual support may be especially necessary for caregivers and patients without a previously declared religious affiliation as they may experience new and acute concerns regarding what happens to the patient after death. If requested by caregivers or deemed appropriate by the hospice nurse, engaging in spiritual discussions for those with and without prior religious affiliation can be accomplished by asking about family traditions and providing conversational “space” that allows the caregiver to explain and discuss religious and/or cultural practices, thus providing more holistic end of life care (Reblin et al., 2014).

Educational support and communication skills training can enhance the comfort and self-reported effectiveness of nurses and other healthcare professionals when engaging in caregiver and patient supportive conversations, including unanticipated spiritual support needs (Curtis et al., 2013). Coyle et al. (2015) demonstrated that nursing communication confidence about engaging in discussions of death, dying, and end-of-life goals of care could be increased after nurses attended an end-of-life communication skills training program.

Conclusion

As home hospice care increases, supporting caregivers at the end of patient life becomes increasingly important and relevant to caregiver well-being and adjustment to bereavement. Nurses provide caregivers and patients with many types of supportive communication on the day of patient death. This support is important to caregivers and becomes part of the events surrounding patient death that may be remembered for years. In this secondary analysis of 44 home hospice nursing visits to cancer patients on the day of death, nurses primarily provided emotional, tangible, and informational support, offering less esteem and networking support. Spiritual discussions with caregivers were very minimal, but more prevalent for those without a previously reported religious affiliation suggesting an emerging area to explore when considering how to best support caregivers on the day of patient death. Using enhanced communication skills, hospice nurses can anticipate or facilitate supportive conversations surrounding imminent patient death thus increasing communication confidence when managing emotionally laden discussions on the day of patient death.

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Knowledge Translation

- Nursing supportive communication on the day of cancer patient death is understudied.
- Nurses can support caregivers by addressing caregiver needs across multiple supportive domains.
- The recognition of emerging acute spiritual concerns, especially for caregivers without a previous religious affiliation, should be anticipated and is included in a model of holistic hospice care.

Table 1

Types of support and associated nursing communication behaviors adapted for day of patient death discussions.

Types of Support Adapted from Cutrona and Suhr (1992)	**Nursing Communication Behaviors Adapted from Williams et. al. (2012)**
Discussions of Tangible or Instrumental Support	Facilitating and/or explaining final acts (e.g. saying goodbye; discussing the need for medication disposal) Honoring patient dignity (e.g. discussions of how to provide patient care and comfort)
Providing Emotional Support	Providing reassurance (e.g. offering comfort, reassurance, and solace) Being a compassionate presence
Providing Informational Support	Providing information to the caregiver, family and patient (e.g. explanations of the dying process; discussions of post mortem events and care)
Providing Esteem	Offering compliments and/or validation of perceptions and feelings
Facilitating Networking Opportunities	Facilitating engagement with, or referrals to, other services (e.g. ensuring caregivers are aware of the availability of pastoral support or grief support groups)

Table 2

Examples of Nurse Supportive Communication.

Support Code	Nurse to Caregiver	Nurse to Patient
Discussions of Tangible Support (35% of all supportive communication)	I will let the hospice team know he passed for you. Would you like to help me wash his body? Do you have the number for the funeral home? I need to get rid of his pain medicines now, I'll be right back.	I'm giving you medicine to make your breathing easier. We're going to give you a bath.
Providing Emotional Support (25% of all supportive communication)	I'll come back whenever you need me. How are you holding up?	It's going to be okay.
Providing Informational Support (23% of total overall supportive communication)	I think she's getting close. These are normal things you see when someone is dying.	More pain medicine would probably help you be more comfortable, I don't think it will knock you out.
Providing Esteem Support (15% of total overall supportive communication)	You're doing everything right.	You look beautiful. You're a fighter.
Facilitating Networking Opportunities (connecting) (2% of total overall supportive communication)	Did you know that [church] has a group for people whose spouses have died?	N/A
Spiritual Discussions (occurred in 7 of 44 visits)	We could pray together if you want. If you are asking me personally, yes I believe in the soul, in angels too.… We really don't know, but I have heard patients talk to family members that have passed.	You see your mother? How wonderful.

Note: The percentage of spiritual discussion in relation to overall support was not assessed as spiritual support was not part of the original nursing supportive communication coding scheme.

Table 3

Nurse, caregiver, patient descriptive information.

	Caregivers **N=42**	**Patients** **N=42**	**Nurses** **N=27** **9 Hospices** **3 States**
Mean Age (years)	56.7 (range 22–82)	66.9 (range 38–98)	45 (range 23–69)
Female	26	19	26
White	38	40	25
Black	0	0	2
Other	3	0	0
Unknown	1	2	0
(Hispanic)	8	1	2
LDS (Mormon)	22	22	12
Protestant	2	4	1
Catholic	6	3	2
Jewish	0	1	0
Other	3	3	3
No religious affiliation	8	8	9
Unknown	1	1	0
Hospice-Palliative Care Certification			6
Mean years of nursing experience			16.5 (range 1.5 – 46)
Mean years of hospice nursing experience			5.8 (range <1 year–20)
Communication Effectiveness Overall 5 option Likert type format (not at all effective to very effective)			missing: 1
Very effective			8
Effective			16
Neutral (midway between not at all effective and very effective)			2
Communication Effectiveness when discussing difficult topics			missing: 1
Very effective			4
Effective			17
Neutral (midway between not at all effective and very effective)			5

Table 4

Ratio of mean nursing supportive comments by visit in relation to patient time of death.

Patient Status	Tangible support (%)	Emotional support (%)	Informational support (%)	Esteem support (%)	Networking support (%)
Dead prior to visit (n=11 audiotapes)	46	21	16	15	2
Death During Visit (n=3 audiotapes)	33	24	31	8	4
Actively Dying (n=30 audiotapes)	32	24	25	16	3