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WE'RE THE EYES AND THE EARS, BUT WE DON'T HAVE A VOICE: PERSPECTIVES OF HOSPICE AIDES

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Abstract

Hospice aides are integral to the delivery of home hospice care and play an essential role in the effective communication and collaboration of the hospice interdisciplinary team. Despite their critical role, little is known about hospice aides' perceptions of their role in providing hospice services. This qualitative study explores hospice aides' perspectives of their work, their relationships with patients, families and interdisciplinary team members, and their contributions to end-of-life care. Two focus groups of hospice aides ($N = 13$), and 16 hours of observation of in-home caregiving were conducted. Focus group data were inductively and iteratively coded, and three themes were identified: 1) "We're the eyes and ears", 2) "We're kept out of the loop", and 3) "We have no voice." Aides described themselves as front-line providers based on the close relationships they formed with patients and family members, yet felt under-recognized by members of the hospice team. Observational field notes were reexamined with themes to confirm convergence of qualitative and observational data. Better understanding of their role could enhance integration of aides into patient- and family-centered team interactions, leading to both improved patient and family outcomes and retention and support of this critical component of the hospice workforce.

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Conflicts of Interest

The remaining authors have no conflicts of interest to disclose. For the other authors, none were declared.

Keywords

Hospice aide; interdisciplinary treatment team; end-of-life care; interdisciplinary communication; qualitative research

Hospice aides are integral members of the hospice interdisciplinary team (IDT) which typically includes physicians, nurses, social workers, chaplains, aides, and volunteers. Hospice aides usually spend the most time with patients and are vital to the achievement of hospice care goals.^{1,2} In addition to providing basic nursing care, such as assisting patients in activities of daily living and direct personal care, hospice aides also provide emotional support and comfort to patients and families at a particularly stressful time and often develop close relationships with patients and family caregivers.^{2,3}

Hospice aides' relationships with families may provide them with unique insights into patients' changing health status and family caregivers' needs, thus providing invaluable information to guide care planning.⁴ In fact, communication of essential patient information to families and to the IDT has been identified as a core competency of the home health aide's role.^{2,5} Effective delivery of hospice care is dependent on communication and collaboration among IDT members,⁶ yet research on hospice aides' collaboration with IDTs is scant. Seminal articles on hospice IDT communication, collaboration, and shared decision-making have been published, but these articles were based on a single interventional study that did not include hospice aides as part of the IDT.⁷⁻⁹

The lack of research on home hospice aides is likely due to two factors: the decentralized nature of this workforce¹⁰ and because hospice aides are not often recognized as professional members of the IDT. A recent review of communication processes within hospice IDTs reported on 34 studies of routine IDT meetings in the United States.¹¹ The majority of the IDT attendees in these studies consisted of physicians, nurses, social workers, and chaplains, with a few also including family caregivers and volunteers; none described the attendance of hospice aides. Regular attendance at meetings can facilitate enrollment in research¹² and the absence of aides at regular meetings makes this a more difficult population to sample.

The marginalized status and lack of recognition as professionals is also a barrier to the study of hospice aides, despite comprising almost a fifth of the hospice care workforce.^{13,14} Hospice aides are integral to the deliverability and sustainability of hospice care, yet they have substantially lower salaries compared to the rest of the IDT; the median pay of nursing aides in 2016 was a rate of \$12.78 per hour.¹⁵ Both female gender and racial or ethnic minority status have been associated with lower compensation and appraisal of skill level among health care workers in past studies.¹⁶ Over 90% of the nursing aide workforce is female, and 45.6% are identified as members of racial and ethnic minority groups.¹⁷ Additionally, hospice aides—like nursing assistants who provide care in other care settings and situations such as hospital-based care, home health, and long term care—have been consistently described in the literature in comparison to being less skilled than nurses.¹⁸ Although many nursing aides receive training and/or certification as nursing aides, aides continue to feel undervalued as healthcare professionals.¹⁹

Objective

This study explored the role of hospice aides in providing in-home care for patients and families and as members of the IDT, and aides' perceptions of interactions with patients, families and other team members. Knowledge gained from eliciting and understanding their roles and contributions from their own perspective has potential to inform their improved integration into the IDT and thus enhance team communication, collaboration, coordination, and ultimately the delivery of improved patient and family care.

Methods

Study Design

This descriptive, qualitative study was conducted using focus groups and an observational ethnography. The focus group guide was developed to elicit hospice aides' own perceptions, based on the assumption that how aides think and feel about their work influences their communication with patients, families and other IDT members. Observation provided a more objective view of these interactions. The unique mixed-method design allowed for the triangulation of aides' reports with naturalistic observations.²⁰ All study procedures were conducted under institutional review board (IRB) approval.

Setting and Sample

A purposive sample of nursing aides were recruited from a non-profit home health and hospice agency in an urban region of the western United States. Both certified and non-certified aides were eligible to participate if they provided care for patients who were on hospice services, were age 18 or older, and could speak and understand English.

Procedures

During two monthly scheduled in-service meetings, hospice aides were approached and introduced to the study with permission from hospice administration (no administrators were present or informed of aide participation). Participants who consented to participate completed a brief self-administered survey prior to the focus group discussion including sociodemographic information, prior experience, hours spent providing patient care, and current modes and frequency of communication with hospice IDT members. They then participated in one of two focus groups facilitated in a private conference room at the hospice agency.

Each focus group was led by one researcher (initials removed to preserve the integrity of the review process) using open-ended questions and prompts (Table 1), while another researcher (initials removed to preserve the integrity of the review process) observed and took notes regarding group dynamics and non-verbal interactions. Both focus groups were audio-recorded.

After the completion of the focus groups, two aides were selected to be "shadowed" by members of the research team (i.e. directly observed providing in-home hospice care) between March and May 2015 by two members of the research team (initials removed to preserve the integrity of the review process), a clinical psychologist and a nurse, resulting in

16 hours of observational data. Aides were chosen based on their relative experience, patient assignments, scheduling and availability. While shadowing, researchers took detailed field notes on how the aides communicated and interacted with family caregivers and other patient care providers. Informal conversations with aides and formal debriefing with the research team afterwards helped contextualize insights, identify patterns and clarify questions about the relation of observations and focus group data.

Analysis

Focus group data were professionally transcribed, and transcripts were compiled with shadowing and debriefing field notes and imported into NVivo 10 for management and coding. In the initial phase of coding, two members of the team (initials removed to preserve the integrity of the review process) read transcripts and field notes multiple times before performing line-by-line inductive coding, producing 90 initial descriptive codes. Annotations clarifying codes and emergent relationships between codes were also made at this time. Initial codes were then compared, discussed, and hierarchically organized by conceptual and topical similarity so that the grouping of sub-codes within higher order categories helped identify and define characteristics and dimensions of the broader categories.

Increasingly higher-level categories were then compiled into three main themes reflecting the central focus on hospice aides' perceptions of their roles and their interactions with patients, families and the IDT. Throughout, research team consensus was sought through discussion of the process. Analysis and interpretation of results were guided by the study aim of describing the role of hospice aides providing in-home care for patients and families from their perspectives, including their perceptions of communication and interactions with patients, families and other members of the IDT through a process of constant comparison.²¹

Field notes were reexamined with themes to confirm convergence of qualitative and observational data and to provide additional context regarding aides' interactions with patients, families, and other IDT members or care providers in the clinical setting.²²

Results

All 13 eligible hospice aides consented to participate in focus groups ($n=9$; $n=4$). During consent, aides indicated their willingness to be shadowed on future home hospice patient visits. Out of the 13 eligible aides, 10 consented to be shadowed on their shift. Two aides were selected for observation based on criteria described above.

Table 2 presents demographic characteristics of the focus group participants (shadowed aides are not identified to protect participant privacy). All participants saw both hospice and home health patients. All participants were female with an average age of 45 years. Forty-six percent of participants were Hispanic/Latino followed by non-Hispanic White (31%). The majority of the participants listed a high school certificate, General Education Diploma (GED), or technical diploma as their highest level of education. Almost half of the participants reported an annual household income of between \$15,000 and \$25,000.

Thematic Analysis

Three core themes described the aides' perceptions of their roles and interactions with hospice patients and families and the IDT: 1) "We're the Eyes and the Ears", 2) "We're Kept out of the Loop", and 3) "We Have No Voice". Each of these themes described unique but related aspects of how aides see themselves as integral but often unrecognized members of the hospice IDT.

"We're the Eyes and the Ears."

Aides described close contact with patients and family members that allowed them to gain insight into patient needs: "We see these patients all the time and we know when things are happening with them". Successful communication of patient needs to the IDT was seen as averting problems and improving the quality of care.

Hospice aides reported having the most contact with patients and family caregivers of any member of the care team. They provided physical care, monitored patients, and developed emotional rapport with patients and family members. During shadowing, aides appeared familiar with patients' preferences and dislikes; family members also expressed positive feelings and appreciation for the aides, confirming aides' perceptions of the closeness of their relationships for whom they provided care. Hospice aides were observed as being actively engaged in monitoring patients' clinical trajectories and their responses to interventions delivered through hospice services. This intimate and intensive interaction with patients and family caregivers contributed to aides' self-described function as the "eyes and the ears" of the hospice IDT.

Communication with the IDT, primarily nurses, to report changes in patient's status or emergent problems occurred by email, text, or phone. As one aide stated, "'I communicate a lot. I tell the nurses, I send emails out to them and let them know what's happening.'" In focus groups, aides expressed that relaying information to the IDT was an important aspect of their job, and that their frequent contact with patients and families allowed them to identify salient information, to watch for potential problems and changes in status, and to serve as a catalyst for interventions when problems occurred. One aide discussed how a patient's family was reluctant to control a patient's pain with prescribed medication. Initially the aide did not directly intervene with the family as she felt it was not within her scope of work. Eventually she became pivotal in changing the family's mind about giving the prescribed pain medication and helping to advocate for better pain management. She recalled:

I don't know how many weeks the nurses couldn't get them to get their morphine. Nobody could get them to do it because they thought it was cruel. But then finally when I told them how she is suffering because you could see in the way she was acting, the body and everything...when they were ready for the morphine I called the nurse and told them to come and talk to them again.

In another example, an aide became suspicious that her cognitively impaired patient was not receiving timely incontinence care from the assisted living facility where the patient resided. One Friday before she left her shift, she drew a line down the back of the incontinence brief

with a permanent marker. When starting her shift the following Monday, she saw that the brief had not been changed over the weekend. The aide relayed this to the hospice nurse, who then discussed the issue with the facility's nurse, which resulted in improved patient care.

Aides also described alerting the hospice team when they felt that their home health patients were becoming appropriate for hospice. Aides reported their roles placed them in a strategic position to identify and intervene in patient care and affect patient outcomes: "We clean them. We visit with them. We have so much more contact... We're the most important people."

"We're Kept Out of the Loop."

Sharing key information was seen as vital for supporting collaboration between hospice aides and other team members and coordinating patient care. Aides shared examples of when information-sharing with the IDT worked well, but also described instances when they were "kept out of the loop", and thus felt compromised in their ability to provide the best care possible.

Aides indicated that they usually initiated contact to report on patient care as part of their daily duties, but occasionally nurse care managers initiated communication to share information. Most nurse-initiated communication entailed asking aides to monitor for patient changes, especially after a procedure was performed, for example insertion or changing of a urinary catheter, or when there were anticipated changes in patient status.

While aides perceived that it was important for them to relay vital information about patients to the hospice team, they also perceived that this was inconsistently reciprocated. When receiving a new patient, aides felt that having a verbal report of the patients' background would help them be better prepared: "You're sending me in somewhere in the dark and I don't need to be told every little thing about every patient, but I like when ... I go in knowing. It's gonna make my visit so much easier if I'm aware." Another aide described how having nurses provide verbal reports on new patients was particularly helpful and led to aides feeling acknowledged and supported. Aides also reported valuing patient status updates or news about a patient's death. Unfortunately, such reports from nurses were described as the exception, rather than the norm.

Aides generally felt that they had the least amount of background information on patients compared to other members of the IDT. Information was often limited to written documentation and through personal communication with informal caregivers. Aides were often not able to easily and directly access patient information in the electronic record, unlike nurses or other members of the IDT. An aide reflected, "They have access to everything, you know, their med lists, their visits, their summary, the assessment, everything. With the aides, it just comes on their phone." Another aide adds, "Name, address, phone, that's it."

Lack of effective information sharing was a source of frustration, and aides stated that these issues affected their ability to do their jobs. An aide expressed, "Communication is what we

all need and if we don't have it, the patient doesn't feel like they're taken care of, the family doesn't feel like they're being taken care of, and I'm not doing a good job." Communication of important information was also closely related to aides' perceptions of IDT collaboration and teamwork, or lack thereof: "I don't feel like I'm part of the hospice team even though we're a big part of what is happening with the patient." Some, though not all, felt that inclusion of aides at IDT meetings would reinforce that aides were an important team voice: "I think at least giving us the option to participate. I mean maybe some aides don't want to be part of that but some of us do... If it's not, great, we at least tried it."

"We Have No Voice."

Aides generally felt that they were not given opportunities to voice their opinions on patient care, and when they did their opinions were not always welcome. This was expressed by the third theme, "We Have No Voice". Most aides felt there were clear communication expectations such as the reporting and documentation of care, patient changes in status, or problem identification during focus group discussions. Similarly, we observed frequent texting, emails and charting to communicate about patient care during shadowing. However, aides' sense of feeling unheard stemmed from the fact that they felt that, beyond simple reporting, input regarding opinions and insights were sometimes ignored:

See, now I feel like I have a situation where I felt like the nurse wasn't listening to me ... I said, why don't you cath this woman? ... it would ease a little bit of this situation when I'm coming to work on Monday morning and she's soaked from here to here... but they made that choice. She's the case manager.

This sense of feeling unheard was tied to job scope limitations. This aide continues:

She says, 'Oh we're not going to diagnose.' Well, you're really not diagnosing. You're just calling the nurse and you're suggesting these things, you know, these creams or whatever you need.'

Experienced aides prided themselves on their clinical knowledge gained through years of experience and believed this experience to be superior to "book smarts." Another aide recounted a situation where her caregiving experience and skill could have prevented an unwanted outcome, if it had been acknowledged and valued:

I'm bowel care certified so I'm able to disimpact and stuff. And I had this nurse at another company, she goes, 'You can't do disimpaction like I can.' And I was doing it three times a week. [The patient] had floppy bowel syndrome and so [the nurse] goes out there and she sends the patient to the hospital with a rectal bleed. 'Hmph, thank Heaven I can't do it like you can, honey.'"

Yet despite their pride in their clinical experience as hospice aides, some participants perceived that they were looked down on by other members of the IDT due to their lack of higher education and a professional degree, as illustrated by the following focus group exchange:

Aide 1: I think it's we don't have an RN [license]...our input isn't necessarily...

Aide 6: I think our input is very necessary.

Aide 1: I do too but to them I think it's not valued.

These perceptions led to aides feeling underappreciated in some cases. "I seriously think we're a huge part of what happens out there." Another aide summarized, "The nurses don't realize that we really do know what's going on and I don't think that we get as much credit for what we know of our patients that we should."

These discussions underscored a sense of dissonance between how aides saw themselves and how they perceived the IDT regarded aides. Feelings of inferiority and power inequality contributed to aide perceptions that they were not valued IDT members, which influenced and reinforced the way aides interacted with other members of the IDT.

Discussion

Historically, hospice research has paid little attention to hospice aides' perceptions of their communication and interactions with patients and families nor with other members of the IDT, despite the pivotal role of aides in providing direct care. This study highlights aides' own perceptions of their role as professional caregivers, their differential status relative to other team members, and opportunities for improved communication and collaboration.

According to a report by the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine (previously the Institute of Medicine), team-based care is based on five principles: 1) shared common goals; 2) clearly defined roles; 3) a shared reciprocal sense of trust among members; 4) open and clear channels of communication; and 5) accountability of team processes and achievements.²³ Study findings demonstrated that from their perspective, hospice aides were inadequately integrated into the IDT team identity and processes, and felt that their opportunities for meaningful communication with other IDT members were limited not only by practical constraints, but by how their roles were seen (or not) by other team members.

The first theme, "We're the Eyes and the Ears," described how aides spent the most time with patients, a perception supported by observational data. Participants believed that the nature, amount and quality of this contact allowed them to better understand patients and family caregivers compared with other members of the IDT. Aides took pride in this role and in their work and caregiving skills.

The intensive and intimate context in which home-based direct care is provided also creates a unique situation in which aides sometimes serve as advocates for patients and family caregivers, and as a liaison between them and the IDT. For example, aides often described being the catalyst for getting a patient transitioned from home health to hospice care. This theme is consistent with previous research on hospice aides' perceptions of their professional roles and their influence on patient trajectories via communication with other members of the IDT.³ In alignment with the first two principles of effective team-based care, the hospice aides in this study also demonstrated knowledge of other IDT members' roles and responsibilities and a clear understanding of their professional role in relation, sharing the common goal of delivering quality patient care in this study.

However, the other two principles of effective team-based care-- mutual trust and effective communication, were not as frequently observed in our research. The second theme “We’re Kept out of the Loop” had negative implications for the principle of mutual and reciprocal relationships of trust within effective IDTs. Aides were situationally and systematically excluded from information sharing, exacerbating the sense that aides were periphery members of the IDT at best. The differential access to information led aides to perceive power inequalities, even among participants who reported a greater degree of respect and collaboration with IDT members. This inequality was observed to magnify their sense of having a lower status relative to other IDT members, and is consistent with previous research describing aide-nurse communication in skilled nursing facilities.²⁴

The third theme, “We Have No Voice,” further highlights the aides’ sense of inequality and demonstrates the perceived lack of respect within the hospice IDT of the valuable skills aides offer. A vital aspect of improving hospice aides’ integration into the IDT may be to improve communication and incorporating aides in team-based decisions. Previous research suggests that both role integration of hospice IDT members and having positive inter-professional relationships with other team members are associated with job satisfaction.²⁵ In other research, aides’ perceptions of support, empowerment, and engagement within the care team were increased when their patient assessments were integrated into post-shift debriefing, or when they were involved in care decisions.^{13,26} Similarly, improvement of nursing aides’ communication with other care providers has been associated with improved perceptions of quality of work life among aides.¹³ Such involvement in team processes may be an effective strategy to reduce aide turnover.²⁷

Previous work suggests that the majority of team reflection and communication occurs during IDT meetings.⁹ A study of IDT communication within team meetings found that 12.3% of IDT discussions made reference to an absent member—in this case, family caregivers—who could have supplemented discussions with needed information.²⁸ Likewise, hospice aides’ presence at IDT meetings could provide valuable team information. However, in an email query, hospice administrators ($N=7$) from different parts of the country noted that they did not include hospice aides in IDT meetings (M. Beck, written communication, April 2015).

In addition to improving retention of aides and enhancing team-based care, successful team collaboration in patient care may lead to improved patient outcomes and enhanced patient satisfaction.²⁹ A study conducted in 107 nursing homes in New York found that nursing aide communication was associated with improved end-of-life assessment performance.³⁰ Similarly, in this study aides referred to situations in which they were able to prevent escalation of problems or improve care for patients when they had the opportunity to engage in open communication with IDT members. Future research should explore the role of hospice aides in measurable patient and team outcomes, in line with the fifth principle of team-based care.

Finally, this study demonstrates the feasibility of engaging home hospice aides’ in end-of-life research. Despite challenges in recruiting hospice aides for research,¹⁰ participants in

this study were positive about the experience and appreciated the opportunity to be heard. As one aide stated, “It’s nice to know that the little guys is kind of important.”

Limitations

This study was limited by recruitment through a single hospice agency, thus conclusions may be less generalizable to other settings or geographical locations. Data may have been biased by conducting focus groups at the aides’ employment site, potentially creating an environment where negative or dissenting opinions were suppressed, despite the absence of administrators. Group discussion dynamics may also have been influenced by differences in participants’ comfort with active participation.

Observation provided data verification, and although theoretical sampling was not conducted, data saturation was achieved with field data. Nevertheless, selection bias may have occurred with field observations. Participants who were more confident of their skills as a hospice aide may have been more likely to volunteer for shadowing. Despite these limitations, the research team, which consisted of bachelor’s-trained and advance practice nurses, clinical and social psychologists, and a hospice medical doctor, provided diverse perspectives in the analysis and interpretation of the research, thus reducing the possibility for researcher bias. In this study, 23.08% ($n=3$) of participants were hospice and palliative care certified, which is higher than the proportion of hospice and palliative certified nursing aides among Western states (16.82%), and is closer in proportion to other regions in the US (Midwest = 25.7%, Northeast = 26.17%, Southeast = 31.31%).³¹ However, due to the smaller sample size, it is difficult to ascertain if aides’ perceptions of team dynamics were impacted by certification, which is an area that warrants further study.

Conclusion

Hospice aides represent an essential component of the hospice workforce on which the ability to deliver quality care is dependent. However, instead of being partners in care, aides are often viewed as unskilled labor, which contributes to a sense of role invisibility, differential status and team exclusion. This perspective is detrimental to the delivery of team care,³² and fails to meet several core principles of team-based health care delivery.²³ Validating and integrating hospice aides as an IDT member (whether they physically attend the IDT meetings or not) and an agency’s core service culture is likely to improve the quality of patient and family care, and job satisfaction and retention among aides.³³ Future research should also evaluate how the role of hospice aides can be enhanced with improvements in the structure and processes of IDT collaboration and communication across all who interact to provide critical services.

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Table 1

Questions guiding focus groups and field observations

Topics	Focus Group Guiding Questions		Field Observation Focus	
Role of hospice aides in supporting families	1	What are your thoughts on the role of the hospice team in providing family support in home hospice?	1	Hospice aide support of family caregiver and secondarily of patient
	2	As a hospice aide, what do you do that helps support families?	2	Hospice aide professional role and role identity
	3	Are there other ways, in addition to providing direct care, that you support families? Can you give an example?		
	4	Compared to other members of the hospice team, including the nurse, the physician, the social worker, or the chaplain, how would you describe the kind of family support that you provide as a hospice aide? Is it the same or different? How so?		
Communication with Hospice Care Team	1	How do you communicate with other members of the hospice team? When? How often? How do you do this? Give examples.	1	Hospice aide coordination with IDT
	2	How important is communication between members of the care team in supporting families? Can you share an example of good communication? Can you share an example of bad communication?		
	3	How do you feel team communication can be improved? Do you have enough information to do your work well? Do you have enough time and opportunity to communicate with other team members?		
Engaging Aides in Research	1	The roles of nursing aides are not often studied in research. Why do you think that is so?	1	Hospice aide response to research shadowing
	2	If given the chance, do you think nursing aides would want to participate in hospice research? Why or why not? If not, what can we do to increase interest?		
	3	What are some motivators for nursing aides to participate in research?		
	4	What are some barriers for nursing aides to participate in research?		
	5	How did you feel about your participation in today's focus group?		

Table 2Participants' Demographic and Communication Characteristics (*N*=13)

	<i>M (SD), min-max</i>	<i>n</i>
Age	45 (11.23), 23–59	
Female		13
Race		
White		12
Native Hawaiian or Pacific Islander		1
Ethnicity		
Hispanic/Latino		4
Not Hispanic/Latino		9
Marital Status		
Married		9
Divorced		3
Other (e.g. Widowed, Separated)		2
Number of dependent children	1.91 (1.45), 0–4	
Religion		
Latter-Day Saints		6
Catholic		2
Christian		2
No religious affiliation		2
Annual Household Income		
< \$15,000		1
\$15,000 to \$24,999		6
\$25,000 to \$49,000		2
\$50,000 and above		2
Highest level of education		
High school or GED		5
Vocational or technical diploma		5
Associate's degree or some college		3
Training		
Certified Nursing Assistant		11
Certified Hospice and Palliative Nursing Assistant		3
Agency training		3
Other		2
Patients cared for per week		
1		3
2–3		3
4–5		1
Hours per week as a hospice aide		
1–20 hours		6
21–40 hours		4

	<i>M (SD), min-max</i>	<i>n</i>
41–60 hours		2
Number of years worked as a hospice aide		
<1 year		1
1 to <5 years		4
5 to <10 years		1
10 to <15 years		2
>15 years		1
Number of months working at current hospice	33.92 (52.72) 4–180	