



Published in final edited form as:

J Pain Symptom Manage. 2017 July ; 54(1): 27–34. doi:10.1016/j.jpainsymman.2017.03.011.

“I Just Felt Like I Was Stuck in the Middle”: Physician Assistants’ Experiences Communicating with Terminally Ill Patients and their Families in the Acute Care Setting

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Abstract

Context—Terminally ill hospitalized patients and their families consistently rank effective communication and shared decision-making among their top priorities. Advance Practice Providers such as Physician Assistants (PAs) are increasingly providing care in the hospital setting and are often called to communicate with patients and families. A first step to improving PA communication is to better understand PAs’ current experiences in their daily practices.

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Disclosures

None of the authors has competing financial interests.

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Objectives—This study aimed to explore: 1) roles PAs serve in communicating with terminally ill patients/families; 2) PAs' attitudes and opinions about communication roles and 3) perceived barriers and facilitators of communication with patients/families in the hospital setting.

Methods—Five focus groups were conducted with PAs practicing on adult medical services at three acute care hospitals of an academic medical center in the Bronx, NY. An open-ended question guide was used. An inductive thematic analysis strategy was used to examine the data from transcribed audiotapes of focus group sessions to identify emergent concepts and themes.

Results—The overarching theme that emerged was being *Stuck in the Middle*. PAs experienced 1) ambiguity around their roles and responsibilities in communications between the medical team and patients and families; 2) gaps in knowledge and skills and 3) organizational or structural deficits in the patient care systems that placed them in uncomfortable situations.

Conclusion—Interventions aimed at improving PA communication with terminally ill patients and their families should target institutional structures, systems and culture around roles and responsibilities in addition to skill and knowledge gaps in order to be most effective.

Keywords

Palliative Care; Health Communication; Hospital Medicine

Introduction

In the United States, almost a quarter of all deaths occur in acute care hospitals and about 1/3 of all decedents spend time in an intensive care unit (ICU) during the last month of life.¹ Terminally ill hospitalized patients and their families consistently rank effective communication and shared decision-making among their top priorities.² However, the quality of communication in the inpatient setting remains very poor.³ For well over a decade, the End of Life Nursing Education Consortium has provided communication skills training for bedside nurses,⁴ and there has been abundant research on communication skills training for physicians.^{5–13} However, there remains a dearth of programs geared to advanced practice providers (APPs) such as Physician Assistants (PAs) and nurse practitioners (NPs).¹⁴

APPs deliver front-line care on medical, surgical and intensive care units. They often perform communication tasks that arise acutely. At a minimum, these clinicians should be able to provide “initial discussions about benefits and drawbacks of treatment options and what to expect in the future as well as preliminary advance care planning.”¹⁵ PAs are medical professionals licensed to examine, diagnose and treat patients. Licensure requires a master's degree from an accredited educational program. In 2013 about 30,000 PAs were employed in hospitals.¹⁶ Since hospital employment of PAs continues to grow, they will be increasingly called on to communicate with terminally ill patients or their families on behalf of the medical team.^{17–19} The Accreditation Review Commission on Education for the Physician Assistant requires “instruction on interpersonal and communication skills,” and as of 2010, instruction in “palliative and end-of-life care” is also required.²⁰ However, these requirements are broad and not standardized, thus communication skills may not be geared to needs of terminally ill patients and the palliative curriculum may not emphasize

communication. PAs trained before 2010 may not have received any palliative care training at all.

Previous studies have identified family conflict and lack of communication skills training as barriers to communication among nurses and physicians.^{21–25} In addition, physicians have cited time constraints and patient and family fears, emotions and lack of knowledge as barriers.^{21,26,27} They have also cited their own emotional bonds with patients and feelings of failure.²¹ In contrast, bedside nurses identified unclear communication roles and difficulty prognosticating as barriers.²⁵

Understanding PAs current experience will help develop training programs to fit their needs. It is unclear what roles PAs are currently fulfilling in communicating with patients with terminal illness and their families in the acute care setting. They are in a unique position as a non-physician representative of the medical team without the same bedside relationship with the patient as the nurse. We aim to explore how they perceive their role, how comfortable they feel with the roles they are currently playing, and what barriers and facilitators exist for providing quality communication using qualitative, focus group study.

Methods

A focus group methodology was chosen for exploratory research. This approach facilitates discussion of local culture and group/collective norms and allows for comparison of similarities and differences in participants' opinions and experiences.²⁸

The Albert Einstein College of Medicine Institutional Review Board evaluated this protocol and deemed it exempt from review. We used convenience sampling of PAs working on adult medical services at three acute care hospitals of an academic medical center, which collectively provide 1,500 beds to an urban, racially and ethnically diverse population of patients. Over 100 PAs provide front-line care on medical, surgical and intensive care units. Similar to how PAs function in many hospitals, they serve as primary provider and responder for inpatients. They round with attendings, write all orders, interact with consultants, hold discussions with and update patients and families as needed. PAs work in twelve-hour shifts around the clock and are present to provide care when attending physicians are not physically available in the hospital. Recruitment was by email from the principle investigator (PI) through institutional email lists. Lunch or dinner was provided but there was no other compensation for participation. Five focus groups were conducted between December, 2015 and April, 2016 at all three hospitals and during both day and night shifts.

The research team consisted of the PI, who is a palliative care physician and qualitative research fellow, a PA, two critical care physician-researchers, a palliative care fellow and a medical student. Focus groups were led by the PI and a palliative care fellow. A loosely structured interview guide was developed using standard iterative processes. The interview guide was piloted for content and clarity with a group including resident physicians, one PA and one NP. Open-ended questions were used to explore the broadest scope of responses regarding experiences, roles, barriers and facilitators of communication, and to allow PAs to express their unique perspective (table 1).

PAs were assured that their responses would be kept confidential and would not affect their clinical relationships in the workplace. Focus groups were one hour in length and were audiotaped and transcribed. The data were examined and categorized using an inductive thematic analysis strategy.²⁹ The first two focus group transcripts were read in-depth by two of the researchers (E.C. and G.K.) who independently identified coding categories. These readers then arrived at a consensus set of codes. These revised codes were then applied independently by two researchers (E.C. and R.L.) to the remaining transcripts, and the initial two transcripts were re-coded. The data were coded in the Dedoose™ software program (Hermosa Beach, CA). Differences in coding were resolved with discussion.

Once the coding was completed, the immersion/crystallization approach³⁰ was used to look for emerging patterns related to communication in the data. The process of immersion followed by crystallization was repeated (E.C., R.L., G.K.), alternating with group reflective analysis with the research team (E.C., R.L., G.K., A.A.H., J.B., M.N.G.), until all the data had been examined and the meaningful patterns and themes extracted and described. The interviews were then re-read to identify any disconfirming data (E.C. and R.L.).

Preliminary data analysis showed that data saturation had been reached after five focus groups with no additional themes emerging from the final group.

Results

The five groups consisted of 5–8 participants each (average 6.8) for a total of 34 participants. Ten (29%) were men, and the average age of participants was 37.7 (median 33, range 25, 62). Participants had a wide range of work experience as a PA. The average years in practice was 9, median 6, range 0.5 years to 28 years.

The main theme that emerged from this analysis was being *stuck in the middle*. PAs described uncertainty due to role ambiguity; skills and knowledge gaps that strained their role as when acting as emissary between physicians and patients/families; and deficiencies in patient care systems that complicated their role in coordinating between patients/families and the medical team (figure 1).

Stuck in the Middle: Role Ambiguity

There was wide variation in how PAs' perceived their role. Some PAs felt that discussing diagnoses or prognosis and engaging in shared decision-making were within their scope of practice.

“PAs are...ready to take the responsibility of explaining things to patients, but to have that backup...you want to make sure the doctor you're working with has the same thoughts about the plan.” [Female, Focus Group 1, two to five years experience]

Whether due to the urgency of the situation or due to the practices of the attending physicians, PAs were often thrust into the role of the primary communicator with the patient and family.

“If the family or patient comes to you and asks you the question, you can’t just be like, ‘Well, this isn’t my job.’” [M/G2/ 10Y]

“The start of the night shift happened and the patient’s blood pressure was low and she was actively dying right there...The whole family was in the room, and so I’m assessing the patient, I’m explaining to them, ok the blood pressure is this, her breathing really doesn’t look good, we’re heading down the road of just calling a rapid response and intubating her...it was hard being in limbo and trying to be on the front lines and communicate...just help them with their decision-making, offering them any guidance.” [M/G2/ 10Y]

While most PAs endorsed an active role, several felt that the attending should lead and manage these communications.

“... the attendings are in charge of the patient care, ultimately. We don’t make the final decisions. So I don’t think it should be considered the PAs’ responsibility to initiate the goals of discussion. I think it should come from the attending. We can definitely follow-up ...If anything, I do it on a daily basis, but it’s just like out of respect.” [F/G3/ 10Y]

Sometimes patients and families questioned the role of the PA, and several PAs voiced support for the patient’s and family’s right to hear from a physician.

“They hear our point, we are the first to come and bring the worst news to them. And they say, ‘Okay, can I speak to the doctor?’” [F/G5]

Many PAs described frustration at having to manage circumstances when they felt the attending should have addressed goals of care earlier in the hospitalization.

“They [the family] got very upset that he’s been here over two weeks and nobody ever said anything about him not getting well or not doing well or deteriorating.” [M/G1/2-5Y]

PAs reported that their roles shifted, depending on which attending physicians they were working with.

“When we work with [one group of attendings], we usually have a good backup at least during the day. [They] are good about at least reaching out to the families on a daily basis and keeping them informed. But when we are working [with a different group]...most of the care, palliative or not, falls on us as far as decision-making goes. And a lot of the times, it’s just us informing them about what we’ve already done.” [F/G4/<2Y]

“So the attending was a neurosurgeon, and she was very busy...I just remember I was starting maybe a few months before. She told me to go in, tell the family that this is what the lesion is in the brain, this is why she’s having the weakness, and the prognosis. And I absolutely refused. I wasn’t going to tell them that their significant family member is going to probably die within six months to a year.” [M/G2/ 10Y]

“I felt the need to call palliative care, and I did, and then you know it came back to me, the attending called me was very upset, “Why did you call palliative care?””
[M/G1/ 10Y]

In addition, PAs frequently found themselves in the role of emissary between the physician and the patient and family. This caused frustration when the messages of the attending and the PA were not well-coordinated.

“The trust issue is when the family says, ‘Please have the attending call me back,’ and the attending does not call ... in spite of you telling them.” [F/G1/ 10Y]

“The family would keep coming and asking me, ‘Are we doing this [artificial nutrition]?’ The attending kept telling me, ‘Let’s hold off on feeding.’ To what extent the family doesn’t understand. The family was totally lost.” [F/G1/2-5Y]

“And they [the family] feel uneasy about the care here because they’re like why isn’t everyone on the same page?” [F/G1/2-5Y]

PAs struggled with discussing and explaining previous care that was not provided by them and medical decisions that they themselves had not made.

“A lot of families are angry, especially they’re like well why wasn’t this done, why wasn’t that done? I mean there’s probably a very logical reason why, but you’re seeing this patient for the first time, and sometimes the family is pretty well-informed and sometimes they’re right...So it becomes difficult to calm them down. And of course you’re at the point of no return, now the patient’s already dying, but they’re angry, they want answers.” [M/G2/ 10Y]

PAs sometimes found themselves in the middle of a conflict within the family.

“I got in contact with the health care proxy, and the health care proxy wanted to do everything aggressively to treat this new finding. And I said, ‘Well, he [the patient]’s not interested.’ And she said, ‘Then force him to be interested.’ So I just felt like I was stuck in the middle.” [F/G1/ 10Y]

Stuck in the Middle: Uncertainty due to Gaps in Knowledge and Skills

Despite many PAs recounting instances of successful bedside communication, PAs experienced uncertainty when communication tasks were beyond their knowledge or skill.

“It’s very nerve wracking when you’re asking all these questions. ‘What’s wrong with them? Why aren’t they getting better?’ And you’re just, oh my God, like how do I answer this if you don’t know everything about the patient. Whereas the attending would know.” [F/G3/2-5Y]

“I didn’t feel like I gave them a very good explanation as to this is what we can do, but is this really what we want to do? Like are you more concerned with the quantity or the quality of life?...I guess I’m just not very well trained in that.”
[F/G2/<2Y]

“How do you know you’re making the right decision? How do you know that you are actually—I mean am I playing God by saying that this patient can’t make it?”

Sometimes I have little difficulties grappling with am I actually convincing them of the right thing.” [M/G2/ 10Y]

PAs used various strategies to navigate around their skills and knowledge gaps and reduce uncertainty.

“I’ve reached out to other colleagues that are more senior and have been around longer...because they’re always available to help. And if we have a night hospitalist I’ve reached out to them, even for private patients sometimes. I just can’t wrap my head around everything and need a second opinion and second eyes.” [F/G2/2-5Y]

“And the first couple times we’ve had to break bad news or talk about the death of a patient, you know, I remember just looking up things on the Internet, like journals, there’s so many research studies on different ways to approach a family.” [F/G1/2-5Y]

“I ended up calling the consults involved in the case and said, ‘This is the finding. I need you to document what are his chances of being treated?’” [F/G1/ 10Y]

Stuck in the Middle: Uncertainty due to Organizational or Structural Deficits in the Patient Care System

Given the variability in medical training and clinical experience, PAs are especially sensitive to issues such as lack of continuity and poor documentation in the chart. Handovers of patient care are frequent, necessitating reliance on the documentation of other clinicians.

“There’s no continuity in the record... You can’t follow what happened. And then you’re being asked these questions...and you don’t want to go and look stupid in front of the family...It takes you three or four hours to go through what happened, and even more, and then you have to speak to the family.” [M/G1/ 10Y]

They identified improving teamwork as a key organizational component to promoting successful communication.

“It’s a team effort when it comes to goals of care and I feel like a lot of the times, it’s just the PAs talking about all this, when it’s just very overwhelming and I think that we really do need the attending to take responsibility...Or even reinforce. Help us.” [F/G3/<2Y]

“How about [the nurse could say], ‘You know what, Mrs. So and So is not doing so well.’ And then when they get into more questions you can say, ‘They’re very sick, they have pneumonia, they have this.’ And then when they get more into it they say, ‘You know what, let me get the PA.’ And then the PA will come in and say ‘Yes, Mrs. So and So is not doing so well, this is why they’re not doing so well.’ Then you have two people who have already said to you, ‘This person’s not doing well.’ And then hopefully when the attending does come...and says, ‘Mrs. So and So’s not doing so well,’ then I feel like that would also start getting them thinking, okay, everybody’s telling me that my mom’s not doing well, maybe I should start thinking about goals of care.” [F/G1/2-5Y]

“We focus in IDT [Interdisciplinary Team] rounds on discharges all the time... What happened to this sick patient, what are we doing for him? Is critical care seeing this patient? Was palliative care called or was comfort care and quality of life discussed? That should be included in the IDT rounds.” [M/G1/ 10Y]

Discussion

This study shows that PAs are engaged in multiple communication tasks with terminally ill patients and their families. When family members or patients request to “speak to the doctor,” they now often encounter an APP. All clinicians face communication barriers caused by limited time, unpredictable work load and family conflict.^{21,25–27} However, PAs have the added burden of role ambiguity. This is important because provision of care perceived to be futile, coupled with a belief that their communication skills are inadequate, is associated with PA burnout.³¹

Oncology and ICU nurses also report role ambiguity.^{32–34} However, nurses described being able to assess patient and family readiness to hear prognostic information and using this skill set to facilitate communication between the physician and patient/family unit.³⁴ PAs in our study did not describe this assessment skill, making it more difficult to resolve role ambiguity.

Barriers reported by oncologists such as feelings of failure and close personal bonds with patients,²¹ were not found, suggesting that some aspects of the experience of PAs were more similar to bedside nurses’ experience than to the physicians’ experience, although their clinical role in the hospital is more similar to that of the physician. In contrast to other studies, patient and family difficulty understanding information, poor health literacy, or resistance to discussing difficult topics did not emerge as major themes.^{21,27}

There have been calls for increased communication skills training for nurses and physicians.^{21–24} This work adds to the literature by showing that PAs have similar or even greater needs. PAs act as fully functioning members of the healthcare team immediately upon graduating, frequently without post-graduate training. Attending physicians rarely have any responsibility to oversee their skills development. In addition, training and experience of PAs is likely to be very different from NPs, who enter practice from a patient-centered nursing background.

Implementation science theory suggests that efforts to improve communication practices will be successful if they target not only knowledge, skills and self-efficacy, but also institutional culture around roles and responsibilities and professional beliefs about consequences.^{35–38} PAs reported being able to communicate best when they had support from attending physicians and specialists, including shared understanding of the patient’s clinical trajectory and appropriate options for care and coordinated messaging to the patient and family. Given the fact that PAs are not likely to be trained to prognosticate complex cases and feel conflicted giving prognostic information, reframing communication skills training as a method to assess patient and family values and goals, in order to negotiate a care plan with the help of the attending and consulting physicians may ease their role

anxiety and make them more effective. PAs indicated that their roles shifted depending on the physicians they were working with. A need for coordinated communication with the attending physician was obvious. Additionally, deficits in the processes and norms around IDT rounds were noted. Educating all health care providers on interprofessional roles in end of life care planning and redesigning work flows including IDT rounds may encourage collaboration, support PA empowerment and reduce PA burnout.

Limitations of this study included convenience sampling which is likely to have selected for PAs with an interest in palliative care. At least one palliative care clinician known to the PAs helped facilitate each group. This may have limited the emergence of themes that could be seen to question the value of goals of care discussions or initiating palliative care. PAs were candid, however, in their descriptions of frustrations they experienced due to systems barriers and inadequate teamwork, suggesting that they were comfortable discussing their experiences. PAs were sampled from three different acute care hospitals and during day and night shifts in order to include as many different perspectives as possible. PAs are likely to have similar experiences of role ambiguity, knowledge and skill gap and organizational deficits regardless of their interest in palliative care. However, this study was based at a single institution and is informed by the culture of our institution. For example, PAs work with multiple attending physicians, which may hinder the development of shared understandings of roles and responsibilities. PAs working in smaller institutions that have a more longitudinal relationship with physicians may develop less ambiguous joint practices over time. However, educational gaps and ambiguity patient and family expectations are likely to be similar across institutions.

The insights will be used to tailor both educational and systems interventions to improve PA communication with terminally ill patients and their families. Prior to implementing educational interventions, meetings with PA, medical and nursing leadership to define roles and responsibilities and to develop standard policies around communication will improve the likelihood of success of educational interventions aimed at PAs.

Acknowledgments

This work was supported by the National Institutes of Health NHLBI project # UH3HL125119-02 (M.N.G.) and R03 AG050927 (A.A.H.).

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Fig. 1. Sources of uncertainty that PAs face in medical communication.

Table 1

Interview Guide for Focus Groups

Opening	1. Tell us your first name and how long you have worked as a physician assistant.
Introductory	2. Can you describe a time recently that you had to perform a difficult communication task with a patient with terminal illness or their family that stood out to you? 3. Can you tell me what this was like? Prompt: Examples are: breaking bad news, determining code status, discussing prognosis, discussing risks/benefits of treatment near end of life, “trial of ICU care”
Transition	4. What challenges have you faced communicating with patients and families of patients with terminal illness that you wish you had been better prepared for? Prompt: Are there system barriers, patient and family barriers, things that are difficult for you personally? Prompt: Are there others who should play a role in this communication instead of or in addition to clinicians like you? 5. Can you describe an instance when a difficult communication task went well?
Key question	6. What in your career or training helped you prepare for these challenges? Prompt: Do you feel your training was adequate?
Key question	7. What kinds of help could you have used to better prepare you for these challenges?
Ending	8. We are trying to design a training session to best serve you. What other suggestions do you have, or what other things would you like to be included in your training?
