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Pain management and the African American hospice caregiver: A case report

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Introduction

Although African Americans' use of hospice has increased (8.9% of all hospice patients were African American in 2010 as compared with 8.7% in 2009), their underutilization of hospice services continues,¹⁻⁴ demonstrating there is still much to be learned about the African American hospice experience. A lack of knowledge and trust are considered primary barriers to hospice use among African Americans,^{2,5-8} and education has been recommended as a standard strategy for overcoming these and other barriers.⁹⁻¹² Education about pain management and assessment is critical, as prior research has identified barriers to pain management are related to demographic characteristics such as culture^{2,13-16} and race.^{2,3,17-20} Family caregivers who are tasked with assessing pain and administering pain medications report fear of opioid side effects,²¹⁻²³ fear of addiction,²¹⁻²³ fear of legal euthanasia,^{24,25} and lack of knowledge regarding pain medication.^{23,26} The purpose of this case study is to explore one African American caregiver's experience with hospice pain management.

Method

Semi-structured bereavement interviews with family caregivers were collected as part of a study exploring caregiver participation in interdisciplinary hospice team meetings. Further

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Authors' Disclosure Statement

Conflict of interest

The authors report no conflict of interest.

details on the larger project are available elsewhere.²⁷ During interviews, caregivers were given an opportunity to express themselves freely about their hospice experience with pain management and overall hospice satisfaction. This case provides a unique contemporary perspective of one African American caregiver's dissatisfaction with hospice pain management despite her personal knowledge of hospice and her level of education. The institutional review board of the supporting university approved this study.

Results

One African American female caregiver, Mrs. Smith (pseudonym), age 54, participated in the study for 20 days. The patient, her 81-year-old mother with stomach cancer, had been relocated from her home in a nearby state to a long-term care facility within four miles of her daughter's home. Mrs. Smith was married and employed full-time as an associate professor in addition to her caregiving responsibilities. Despite prior hospice experience with her father, during Mrs. Smith's interview, she expressed dissatisfaction with and distrust of hospice owing to her observations of poor communication between the hospice staff and the nursing home staff and neglected concerns about over-medicating her mother.

During the bereavement interview, Mrs. Smith noted problematic communication between the hospice staff and the nursing home staff. She reported:

There was a definite breakdown. Neither of them seemed to be aware of what the responsibilities of the other one was...as soon as the nursing home nurses found out she [mother] was going to be moving to hospice, they dropped everything.

Mrs. Smith felt that there was no collaboration between hospice and nursing home staff, especially as it concerned pain management responsibilities.

Several of Mrs. Smith's comments referenced the possibility of hospice hastening her mother's death. She "didn't want her in any pain," however she was concerned about the ethical use of pain medication in hospice care. Although Mrs. Smith rated the quality of her mother's death moderately high (8 on a 0–10 scale, with 0 = terrible and 10 = almost perfect), she emphasized the role of pain medication when further discussing her dissatisfaction with the quality of care, explaining that her mother "was given morphine when she didn't want morphine...I would have to say it was a possible problem."

Frequent references to her mother's pain medication demonstrated concerns about its use. At different points in her interview, Mrs. Smith speculated about a connection between Dr. Kevorkian, assisted suicide and hospice. Mrs. Smith commented:

[look at] what we have accepted as helping the patient, then at the same time [we] aren't willing to look at things like Dr. Kevorkian...for the people who are living, it's very disconcerting because it's almost like assisted suicide; the person's body sort of shuts down. They're no longer communicative.

When asked if she was able to discuss any of her concerns about the use of pain medication with the staff, Mrs. Smith replied, "And she [Mrs. Smith's mother] would always say, 'I'm ready to go whenever God takes me,' but I don't think she wanted any help from any hospice people..."

Mrs. Smith also compared the death process and hospice care to childbirth. She explained,

We give women epidurals for pain, we give *Pitocin* to speed the process...and I likened that whole morphine/pain medication issue to *Pitocin*. You really are almost speeding the birth of the child with *Pitocin* and trying to make the mother

more comfortable and in the same respect – only with death – you’re doing that with the hospice patient with morphine-like painkillers.

In summary, analysis of this case indicates that poor communication between the hospice and nursing home staff, as well as Mrs. Smith’s unease about her mother’s pain management, contributed to a lack of trust in the hospice experience. Reflecting on her mother’s last hours, Mrs. Smith explained, “Now, I’m not saying that last dose killed her, but I often wonder, did she really need something?” Mrs. Smith was also asked to consider her hospice experience and then rate herself in different areas regarding pain management: her personal knowledge and skills, her understanding and comfort with her mother’s pain medication, and her overall satisfaction with the hospice team’s management of her mother’s pain. Mrs. Smith rated her personal knowledge and skills related to pain management as moderate (7 on a 0–10 scale, with 0 = no skills or knowledge and 10 = tremendous knowledge and skills), her overall satisfaction with hospice’s pain management as moderate (7 on a 0–10 scale, with 0 = not at all satisfied and 10 = tremendously satisfied), but rated her personal understanding and comfort with her mother’s pain medications as low (3 on a 0–10 scale, with 0 = not at all comfortable and 10 = tremendously comfortable).

Discussion

Hospices use five clinical approaches to medication management—establishing trust, promoting self-confidence, offering relief, and assessing caregivers’ understanding and performance,²⁸ and yet hospice family caregivers continue to struggle with issues of trust and confidence surrounding pain management and caregivers’ desire to provide comfort for their loved ones.^{29,30} In the case of African Americans, trust issues with the medical profession are well documented^{31,32} and trust is recognized as an essential element in medical care.³³ Once caregivers become aware of dissension between healthcare professionals, as in Mrs. Smith’s case, trust in healthcare professionals is jeopardized. Any outward manifestation of lack of cooperation between hospice and any other type of care facility or staff creates uncertainty in the caregiver, neither promoting self-confidence nor offering relief, therefore affecting the caregivers’ perception of the quality care itself.³³ For Mrs. Smith, this perception was illustrated in her frustrations with the communication between the staff and nursing home and may have also influenced her perception of her mother’s pain management.

The prevailing remedy for overcoming pain management barriers is increased knowledge,^{21,23,26,34,35} yet despite Mrs. Smith’s previous hospice experience with her father, her high literacy and doctoral education,³⁶ she remained conflicted about her mother’s pain management. Mrs. Smith’s comfort with and understanding of the use of pain medication may have been inhibited by her lack of trust in hospice’s pain management. Furthermore, we acknowledge that without further investigation, Mrs. Smith’s concerns about her mother’s pain management may have been legitimate.

This case study contributes to the existing literature on caregivers and African American caregivers in several ways. First, the impact of cooperation through good communication between health care professionals should not be undervalued, particularly in situations where trust has already been established as a significant barrier to medical care. Second, studies support the assumption that an educated caregiver has fewer barriers to pain management and yet, this case study suggests that fewer barriers does not equate to no barriers, thereby challenging hospice care education assumptions for the educated caregiver. For the caregiver, having pain management knowledge and skills do not equate necessarily to the understanding of and comfort with pain management, and therefore, have the potential to affect the caregiver’s overall satisfaction with hospice’s pain management. Finally, African American cultural beliefs, beliefs about medical care, and the resultant potential

conflicts therein about pain management may create an even more significant barrier than previously thought and therefore, requires greater level of monitoring, education and support for the African American caregiver. Moving beyond predictors of hospice use means recognizing that hospice use by any minority group such as African Americans is only the beginning. Higher monitoring and continuing education through the African American hospice experience may be necessary to ensure that the caregivers' experiences reflect the highest standards of the hospice mission.

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