

Hospice Social Workers' Perspectives on Place of Death Congruence: A Qualitative Study

by Florence Wright

Editor's Note: Florence Wright, MSW, LGSW currently serves as the clinical social work fellow at the University of Minnesota Medical Center/Fairview. She works with patients and families in both the inpatient hospital setting and outpatient palliative care clinic. She is a graduate of the University of St. Thomas/St. Katherine's University in Saint Paul, Minnesota. During her graduate school program she was an Area of Emphasis in Aging Scholar, co-authored published research regarding attrition in psychotherapy, and completed a clinical practicum with a hospice agency. Florence's areas of clinical interest include: grief and loss, advance care planning, behavioral interventions for symptom management, and treatment of medical trauma. Florence also serves on the MCDES Board.

We have heard it before; home is where the heart is and there's no place like home. Even the word "home" conjures feelings of connection, familiarity, and normalcy. Home represents a place where people feel safe and a sense of belonging. Our homes have the ability to shape our very identity and provide an essential sense of comfort, consistency, control, and ease (Brazil, Bedard, Krueger, & Heidebrecht, 2005; Tang & McCorkel, 2001). Knowing this, one might assume that home is the preferred place to be, especially at end of life.

As a caregiver for my grandmother, I witnessed the ways in which care from a hospice team enabled her to die at home in a supported and dignified way. As a MSW graduate student with an interest in geriatrics and hospice I wondered about the significance of being at home at the end of life. Do people want to die at home? Are people able to die where they so choose? What influences where people die? What can I do to help people die in the place they prefer? These were the questions that interested me, so much so that I made the decision to devote nine months of research to place of death congruence.

Place of death congruence is a term used to describe the agreement between where people prefer to die and where they actually die (Bell, Somogyi-Zalud, & Masaki, 2010; Tang & McCorkle, 2003). In other words, one can say that they have achieved

place of death congruence if they die in the place where they prefer. Place of death congruence is important for health care professionals, families, and policymakers to consider and has been identified in current literature as "an essential component in terminal care" (Bell, et al., p.591). My research specifically focused on the perspective of hospice patients, as spoken by hospice social workers.

I used a qualitative research method that included nine, 30-minute, semi-structured interviews with hospice social workers. Four Metro Area hospice agencies were represented in the sample. The interviews were audio recorded and later transcribed word-for-word. Then, I completed content analysis to address my research questions. As you might imagine, this was a tedious process. But when themes started to emerge, it was exciting.

The results of my study indicate that patients generally prefer to die in a place they call "home," which can include private residences, skilled nursing facilities, assisted living facilities, and/or residential hospice homes. Although "home" may be the preferred place of death, it's well understood that home deaths are not always achievable. My work indicates that several factors are important determinants in achieving a home death including: culture, type of terminal illness and associated symptoms, safety, and finances.

One of the strongest themes? My results indicate that caregivers are the most critical factor in achieving a home death. Ideally, you'd have at least three. Not only must caregivers be willing, available, informed, and competent, they also must have the ability to flex their roles within the family system in order to make dying at home possible. No easy task!

Another theme in the research results: hospice social workers often act as caregiver coaches in enabling home death by maximizing caregiver strengths and by building networks of support. Hospice social workers aim to enhance place of death congruence by completing effective assessments, providing a variety of supports, educating, and providing and exploring realistic options for patients and

Perspectives continued on page 7



Florence Wright

Perspectives continued from page 6

families. Hospice social workers must also provide education and translation in order to assuage potential concerns, address the individualized needs of the patient and family, and recognize and amend potentially dangerous or unfavorable situations.

My findings present some interesting implications. As advocates involved in the care of our steadily increasing aging population, we must understand the barriers to dying at home and how to support patient and family preferences related to place of death. Future policy decisions should consider issues of cost efficiency surrounding dying at home versus dying in an institution, such as a hospital or nursing home. As professionals working with people at end of life, we must know how to best support caregivers! Achieving place of death congruence at home is rarely possible without them. Although end-of-life decisions are complex, emotional, and obscure, my research sought to offer some direction for future study and to enhance quality of life for individuals facing terminal illness.

Read the full article here: http://sophia.stkate.edu/cgi/viewcontent.cgi?article=1548&context=msw_papers.

References

- Bell, C. L., Somogyi-Zalud, E., & Masaki, K. H. (2010). Factors associated with congruence between preferred and actual place of death. *Journal of Pain and Symptom Management, 39*(3), 591-604. doi:10.1016/j.jpainsymman.2010.07.004.
- Brazil, K., Howell, D., Bedard, M., Krueger, P., & Heidebrecht, C. (2005). Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliative Medicine, 19*(6), 492-499. doi:10.1191/0269216305pm1050oa
- Tang, S. T., & McCorkle, R. (2001). Determinants of place of death for terminal cancer patients. *Cancer Investigation, 19*(2), 165-180. doi:10.1081/CNV-100000151