

REFLECTIONS ON HOSPICE RESEARCH

Suzanne Y. Bushfield, Ph.D., Arizona State University

Research demands both an ability to look ahead and imagine what could be, as well as a firm grounding in what is. The author of this narrative never set out to be a researcher, but the longer she practiced social work, the more she wanted to know about what works and why. She developed an appreciation for building evidence and theory in order to contribute to her profession. Her first attempt at research as a hospice social worker was a positive learning experience. Practice-based research is a great place to start—but now she knows more about how to finish the job.

Introduction

I confess: I love research. While others may groan at the thought, my experiences as a hospice social worker laid the groundwork for my love of research. I now know that good decision making is based on sound research; my practice-based goals of doing the right thing while doing things right rely on good research. Every day as a hospice social work supervisor, I struggled with multiple concerns and issues: managing my day-to-day patient workload, planning for the future and anticipating needs, troubleshooting the barriers to providing good care. In today's practice environment, everyone must ask: Is it working? Is it helpful? Is it necessary? Is it cost effective? I believe that within every good, reflective practitioner there is a competent researcher waiting to emerge. Perhaps my own experiences are the best evidence for this premise: they have taught me what not to do, as well as guided me to successful outcomes. With many lessons learned, however, there are some experiences which may not need to be repeated. So, I will offer my own story as a beginning researcher in hospice involving the rewards, frustrations, and tribulations of an early attempt at research.

Hospice Practice

Hospices are designed to provide care for patients with terminal illness, and the target of care is the patient and family unit. There are two, sometimes competing, goals for hospice. The first goal is to provide palliative

care and comfort in the least restrictive environment for those who are dying. The second goal is to conserve resources by reducing unnecessary expenditures at the end of life. Hospices have been successful in pain and symptom management and in assisting patients and families with the tasks of dying. By focusing on palliative rather than curative care, hospices have also been successful in forgoing expensive treatment unless the goal is remediation of pain and suffering. Still, many hospices struggle with cost containment, particularly when expensive and so-called aggressive treatments also offer palliation of symptoms. Because of the method of financing hospice care, in which a daily reimbursement scheme rewards hospices for conserving resources and patient expenses, hospice workers often find themselves suggesting and supporting interventions of comfort that are most cost-effective. In particular, in-home care rather than institutional (hospital, nursing home) care is most frequently the venue of hospice care. There is tremendous pressure on hospices to make decisions based on fiscal realities. This is often in direct conflict with the philosophy of hospice care, which focuses on the psychosocial needs of patients and their families and emphasizes the role of the interdisciplinary team in providing hospice care.

As a hospice social worker, I saw first-hand the benefit of early, regular, and frequent involvement of the social worker in hospice care. While social work in hospice is

established and authorized through mandated standards of care (National Hospice Palliative Care Organization [NHPCO], 1997), the way in which social work services are incorporated into hospice care can vary greatly. In some organizations, nurses may be assessing the need for care and then referring to social work when it seems necessary. Unfortunately, this may contribute to social work involvement coming too late. Since bonding with the family may more effectively occur with frequent and regular contact (Greif & Bailey, 1990), infrequent or delayed social work contact can negatively impact the ability to establish needed relationships. Comprehensive psychosocial care cannot be adequate if it occurs only at intake, only with the patient, or only with reference to psychopathology (Dush, 1988). Therefore, many hospices now use social workers on the intake visit and for identified work with the family. However, consistent hospice social work involvement was not the norm a decade ago when I was on the front lines of social work.

Hospice has been hailed as a program which is most true to the principles of bio-psycho-social-spiritual care, expanding the scope of disease care to encompass psychological, social, cultural, and spiritual components (Phillips & Benner, 1994). As death has grown less simple and less familiar (Callahan, 1993), even hospice has not been able to address the pervasive ambivalence toward death, manifested by a series of small hopeful (and often costly) choices intended to fight death.

One result of the growing awareness of the social context of health has been increased demands for social work services (Browne, Smith, & Ewalt, 1996). Previous research indicates that social workers play a critical role in the integration of services for families (Moore, 1990), and that when families are experiencing multiple crises, social workers are the professional of choice for many

(Vosler, 1990). Social workers have been found to play a pivotal role in understanding how relationships, programs, and interventions impact caregivers and patients (Monahan & Hooker, 1995). For hospice patients in particular, perception of social support has been found to be a significant causal factor in psychological adaptation and well-being (Dobratz, 1995). Social workers in hospice perform many roles, and one objective of social work is to maximize the potential of resources to meet the needs of clients (Moore, 1990).

As a member of the interdisciplinary team, I often felt as if I had to continually market my services, which included helping patients and families see the use of a social worker not as an indication of their failure, but as a resource; helping nurses and clergy see my involvement as supportive to their care, rather than competing for patient and family loyalty and spiritual care; helping physicians communicate what was needed by the patient and family as opposed to communicating for physicians. At the heart of social work practice is a reality filled with both concrete and symbolic meaning (Allan-Meares & Lane, 1990). It was a very concrete concern that guided my entry into applied research.

On-call access to hospice staff is essential to hospice care in order to provide 24-hour access and reassurance to patients and families (Gentile & Fello, 1990). However, staffing and planning for on-call responses can be difficult and costly and leaves gaps in consistency of care. Many hospices have relied on volunteers to fill gaps, but on-call professional services still must be available according to hospice standards of care (NHPCO, 1997).

My Practice Experience Leading To Research

I worked for a not-for-profit, hospital-based hospice, with a budget of \$1.5 million, and located in a rural mid-western state. The

hospice experienced steady growth, expanding to five rural sites in three years (1989-92). The patient load served by this hospice grew by 78% during that period, from 6,453 to 11,500 patient days.

My research experience began by asking simple quality improvement questions based on high-volume, problem-prone, and cost concerns: what is the frequency of use of the hospice's on-call telephone calls and visits, and what are the reasons for the high on-call demand? This led to the second quality-improvement question for consideration: what is the reason for the frequent and unexpected number of hospitalizations experienced by hospice patients? These were very practical concerns, since planning for staff use and on-call availability has implications in both cost and job satisfaction. In managing the bottom line, additional costs of hospitalization—which is frequently the “quick fix” when home care giving fails—can be devastating to hospices struggling to make ends meet.

We suspected that the reasons for both hospitalizations and on-call requests were primarily psychosocial in nature, and that a proactive approach that increased the use of social work visits might prevent calls to on-call nursing staff and reduce the number of unexpected hospitalizations. We began tracking on-call contacts beginning in 1991, including the date, whether a visit or phone call was required, and the focus of the call (psychosocial or medical or other). When the call was psychosocial, we asked the on-call nurse to record comments regarding the specific concern. All nursing staff were instructed to complete the log as part of their on-call duty. All hospitalizations were also recorded and reviewed for the reason for the hospitalization.

Continuous quality improvement indicators that were also monitored at this time included nursing productivity, as measured by the length of the visit, number of visits, and hours per visit; social work visits per patient;

and follow-up customer-satisfaction responses. Data were monitored quarterly and compiled yearly. Granted, this data collection process was somewhat primitive by today's standards: we tabulated everything by hand and spent lots of time reviewing patient charts.

Research Leading to Knowledge of and Changes to Practice

In examining reasons for hospitalization, the majority of incidents were due to psychosocial problems, especially those with the primary caregiver or having no caregiver available. After monitoring for a short time (one quarter) and retroactive chart reviews (five years), it was decided that most hospitalizations and many on-call requests were, in fact, due to psychosocial concerns. After team meetings and analysis of the data, we decided to implement social work involvement on the admission visit (a nurse and a social worker went together for the admission visit). The social worker then followed up as needed, with the standard of care set at a minimum of one visit every two weeks. Continued analysis of this “fix” yielded a number of interesting results.

The first and most obvious impact was noted in the on-call usage: telephone calls to on-call nursing increased by 47% even though the patient workload only increased by 18%. However, the number of calls to on-call that necessitated a visit were reduced by 3% from 1992-1993, and reduced again by 2% from 1993-1994. This finding suggested that urgent issues were perhaps being identified earlier through social work intervention, and fewer complicated emergencies that needed a visit were taking place. The change was noticeable: morning reports were shorter and often less complex.

A second significant impact was found in the hospitalization rate. The number of hospitalizations due to caregiver problems was reduced. Surprisingly, the hospitalization rate

remained constant, despite the patient workload increase of 18%. This is further evidence that suggested that social work intervention identified and addressed caregiver issues before they became emergencies, and that appropriate arrangements for respite care were being made.

The third significant impact was identified in the data on RN productivity. The length of the nurse visit time decreased by 20%. I believe that nursing visits were shorter because the social worker was addressing more of the psychosocial issues, leaving the nurse to focus more on medical and symptom management. Nurses and social workers seemed to be working more effectively as team members, with clearer role definitions.

A final result was the increased cost of additional social work coverage. There were, of course, costs associated with the additional social work visits, but these were offset by savings in RN productivity and hospitalization costs. Armed with data, we could more easily argue for increased social work coverage.

Additional indicators for patient satisfaction were monitored during the process of review and implementation. Patient satisfaction for this hospice remained high. Family members were routinely sent a form to complete, which asked them to address the services received overall, and nursing, social work, and chaplaincy services. With an average rate of return of 49%, there was a change noted with respect to responses regarding social work. Comments were monitored. Before the implementation of regular, early, and frequent social work visits, comments regarding the social worker frequently were, "I don't know who the social worker was," and, "I only saw her once." After implementing regular and frequent social work visits, comments were direct and very positive regarding specific social workers. Letters, comments, and qualitative responses all indicated positive connections with the

social worker, resulting in benefits such as support, encouragement, comfort, information and referral, resources, planning, and problem solving. Characteristic comments included, "Our social worker was great. We couldn't have made it without her," and "[Social Worker] was very helpful in so many ways. She helped us access the things we needed, and to anticipate our needs."

The exciting conclusion to this study was that early and regular social work intervention may have an impact on hospitalization rates due to closer monitoring and anticipation of caregiver problems. Social worker involvement in admission visits may allow early identification of psychosocial concerns, which, through regular contact, may be monitored and addressed. Forming a connection with the social worker early on in the hospice stay may result in families contacting the social worker directly during office hours rather than using the on-call service. Reduction in after-hours calls for psychosocial problems also resulted in reduced costs for staffing 24-hour visits. Early, frequent, and regular use of social work may result in significant cost savings for hospices, which more than make up for the cost of additional social work coverage.

It was also exciting to receive encouragement from the Director of Hospice to submit this project for presentation at the national clinical conference for the National Hospice Organization (now NHPHO). When it was accepted for presentation, I was elated, and the trip to Miami Beach was only part of that!

Dissemination

The presentation was prepared and reviewed and well received. I was even more excited to learn that others were influenced by this study: a colleague went on to develop a nationwide survey of hospice social workers based on this initial project. My first venture at formal research was practical and

meaningful and had an impact on practice. As a turning point in my career path, I recognized that more research was needed to measure outcomes related to social work involvement in the delivery of hospice care. In particular, research was needed which might delineate the specific relationship of social work interventions to outcomes, such as safe and comfortable dying, self-determined life closure for the patient and all family members, effective grieving during and after the dying process. The social workers' contribution to the interdisciplinary hospice team may also be enhanced through their more frequent involvement in patient and family care, a topic that needs further research.

As reality set in, it was my social work practice that was full of life, full of demands, more interesting. No one seemed to care much about the final step in the research process, disseminating the results through publication. So, well-meaning plans to write about this important research went on the "back burner." I'm really not sure why I didn't pursue publication, but a number of speculations seem reasonable. As time passed, it seemed more important to work on new projects. I really believe that what was missing in my clinical setting was a mentor for research. I finally found that in an academic setting, where research is a valued and expected component of the social work faculty's role.

By the time I entered my Ph.D. program, I had relocated to another state and was working in behavioral health. I had not forgotten my passion about hospice and end-of-life care, but instead became involved in other topics. It was not until I re-connected with hospice practitioners that I realized the full impact of my first research projects. Looking back, I suspect that the best research really does grow from the partnership between practice and academe.

Changing Roles

Now that I am older and wiser, have completed my Ph.D., and am a faculty member in a social work department at a university, my research agenda is once again full of life. I have renewed my research in the field of hospice and end-of-life care. When I teach research, I describe the process of shaping a good project as "a whole lot of thinking followed by a little bit of writing," but now I wish my earlier endeavors had included a little more writing! My decision to pursue an academic career was influenced by a number of issues and several key people. I began to recognize that research and teaching really can make a difference. When research addresses practical, "real world" problems, it may have immediate applicable results. I also gained a sense of satisfaction from teaching, seeing the "fruits of my labor" as former students (from my years as a part-time faculty member) began to contribute to the field of social work. In addition, over the years I began to receive requests for the hospice social work outcomes paper, since it was cited in other related studies. I am sorry to say that the failure to complete the project to publication may also have prevented new evidence from being available to practitioners.

Still, when I attend hospice conferences, the talk among hospice social workers often returns to issues of workload, involvement of social workers upon admission to hospice, and cost effectiveness. I guess that is why our code of ethics says that we all are expected to be social work researchers so that the next wave of social work practitioners can have all the knowledge and skills they need to deal with the changing environment and, in addition, so that those patients and families struggling and suffering with end of life issues may find the hope and support they need. My ability to manage data is far more sophisticated now, but the simplicity of my data analysis in this first research attempt made the major results easy to identify.

As a researcher, I have had good support from mentors like Leola Furman and Dona Reese, whose leadership in research on social work and spirituality is an inspiration. Their encouragement has meant a lot to me and influenced my decision to concentrate on an academic career. I used to think the ideal job was one-half teaching and one-half practice. Now, I have discovered that research provides an insight into practice that carries a special appeal. It may be a lot of work to engage in research, but the rewards are great. Social work practitioners can generate good research by asking three simple questions: What am I doing? Why do I do it that way? How do I know it works? Who knows where answering those questions can lead!

Listening to patients and families helped me understand that each person's voice must be heard. Now, as a researcher, I am finding ways to give voice to those who may not have been heard.

References

- Allan-Meares, P., & Lane, A.B. (1990). Integrating qualitative and quantitative data collection techniques. *Social Work, 35/5*, 451-458.
- Browne, C., Smith, M., & Ewalt, P. (1996). Advancing social work practice in health care settings: A collaborative partnership for continuing education. *Health and Social Work, 21/November, 1996*, pp. 267-276.
- Callahan, D., (1993). *The Troubled Dream of Life*. New York: Simon & Schuster.
- Dobratz, M. (1995). Analysis of variables that impact psychological adaptation in home hospice patients. *The Hospice Journal, 10/1*, pp. 75-88.
- Dush, D. (1988). Psychological research in hospice care: Toward specificity of

therapeutic mechanisms. *The Hospice Journal, 4/2*, pp. 9-36.

- Gentile, M., & Fello, M. (1990). Hospice care for the 1990's. *Journal of Home Health Care Practice, 3/1*, pp. 1-15.
 - Greif, G., & Bailey, C. (1990) Where are the fathers in social work literature? *Families in Society, 71*, February, pp. 88-92.
 - Monahan, D., & Hooker, K. (1995, May). Health of spouse caregivers of dementia patients: The role of personality and social support. *Social Work, 40*, pp. 305-314.
 - Moore, S. (1990). A social work practice model of case management: the case management grid. *Social Work, 35*, pp. 444-448.
 - National Hospice and Palliative Care Organization (1997). *Standards of Care*. Alexandria, VA: NHPCO.
 - Phillips, S., & Benner, P. (1994). *The Crisis of Care*. Washington, D.C.: Georgetown University Press, pp. 21-35.
 - Vosler, N. (1990, September). Assessing family access to basic resources: An essential component of social work practice. *Social Work, 35*, pp. 434-441.
- Suzanne Y. Bushfield, Ph.D. is an Assistant Professor at Arizona State University (West Campus) School of Social Work. Comments regarding this article can be sent to suzanne.bushfield@asu.edu.

Copyright of Reflections: Narratives of Professional Helping is the property of Cleveland State University and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.