

“Human information behavior in hospice care volunteerism in the Southeastern Appalachian region” - Sheri Edwards

Introduction and Background

End-of-life care in the US, often referred to as “hospice care,” has seen an explosive growth in the last decade, with almost 42% of all deaths in 2010 in the US, occurring while under the care of a hospice program, as reported by the Centers for Disease Control and Prevention (CDC). A central aspect of hospice care is (unpaid) volunteer work, which typically involves assisting patients with personal care, but can also include other tasks and responsibilities like clerical work and fundraising. However, hospice volunteer work is unique among other types of volunteer work in that it is strictly regulated by the Medicare hospice benefit, in which 94% of all hospices currently participate, and that requires that volunteers who work in a hospice program perform at least 5% of the total patient care hours undertaken by paid staff (e.g., social workers). Moreover, unlike other organizations that utilize volunteers, hospice care organizations are required by the Medicare hospice benefit to document the cost savings provided by volunteers.

The sensitivity of hospice work can create emotional difficulty for some volunteers, and volunteer retention continues to be of concern within hospice organizations. Statistics show that like all volunteerism, hospice care experiences fluctuations in volunteer participation: in 2006, approximately 400,000 people nationwide volunteered in hospices, and, by 2008, that number had increased to approximately 550,000. In 2009, however, the number of volunteers in hospice care experienced a downward trend by falling to 468,000, though the US Bureau of Labor reported a half percent decline in volunteerism overall in 2010.

Nevertheless, many hospice programs continue to employ (paid) volunteer coordinators to train volunteers in various aspects of hospice care. Studies that have explored the training of volunteers in hospice care have found that volunteer coordinators are the primary source of information for volunteers, and that hospice volunteers rely heavily on the information they receive in coordinator-led training programs in order to meet their responsibilities. However, volunteers reportedly often struggle with whom to turn to for information and guidance within a hospice agency. Moreover, a 2003 needs assessment survey of more than two hundred hospice volunteer coordinators found that hospice volunteer training programs are significantly lacking in various types of informational training materials, and that the information contained within available training materials can be incomplete or inaccurate. This can be a highly problematic situation, since a lack of ongoing, comprehensive training and education of hospice volunteers has been found to have a direct impact on the length of time in which a volunteer participates in hospice care; short stays in hospice work by volunteers have been reported as detrimental to the overall quality of patient care. This last point is particularly salient, since hospice care has been found to prolong the lives of some terminally-ill patients. Compounding the situation is the monetary cost of training hospice volunteers. Since more than 50% of hospice volunteers assist in direct patient care, an extensive amount of time and money is required to train them. Therefore, retention and productivity of hospice volunteers is an important consideration in terms of cost. As such, effective and continuous volunteer training is vital to the endurance of hospice volunteer programs. Undoubtedly, then, volunteer coordinators’ ability to provide insight into the development and implementation of complete and accurate information for the

purposes of training and retaining volunteers is directly related to the coordinators' information behavior and the factors that could help or harm it, since those same factors could also help or harm volunteer training and retention, and thus heavily impede a hospice organization's ability to maintain a quality level of service to its patients.

Conceptual Framework

This study adapts Robert Taylor's concept of the information use environment (IUE) in order to identify and explore those factors that enable and constrain the information behavior of hospice volunteer coordinators. To paraphrase Taylor's definition of the IUE, it is a set of elements that affect the flow of information within an organization and that provide the criteria for judging the value of that information. The IUE emphasizes the social context of all routine action related to information use, which is well-suited to this study, given the necessary social interaction between volunteer coordinators and volunteers; and it has been identified as a major conceptual development in information behavior studies. Moreover, the IUE recently has experienced a re-awakening in LIS, most notably by Rosenbaum, as well as by Durrance and her colleagues. According to Taylor, the IUE is comprised of four dimensions: people, problems, problem resolutions, and settings. "People" refers to classes of professionals whose need for and use of information is highly similar. A "problem" is an uncertainty from which an information need arises, and which is multi-dimensional. A "problem resolution" refers to the process of collecting information until a suitable solution is discovered. Finally, "setting" can be one of three types: geographical; intellectual/cultural; or organizational, and the enablers of and constraints to information use therein; organizational setting is the focus of this study. The IUE functions as the conceptual framework for this study by orienting the hospice care environment to the four components of the IUE so as to provide a meaningful and relevant context for information behavior as it occurs amongst hospice care volunteer coordinators.

Research Questions

This study is guided by the following research questions: 1) Who is the overseer of the volunteer in a hospice care setting and what is his or her work-related profile? 2) What are the information needs of the overseer of a volunteer in a hospice care setting? 3) How does the overseer of a volunteer in a hospice care setting seek information? 4) In what way(s) does the overseer of a volunteer in a hospice care setting use information? 5) What enables the information behavior of an overseer of a volunteer in a hospice care setting? 6) What constrains the information behavior of an overseer of a volunteer in a hospice care setting?

Method

Since almost no formal knowledge exists in library and information science (LIS) about the information behavior within a hospice care environment, a qualitative methodological approach was chosen for this study in order to explore the dimensions of that behavior, as well any enablers and constraints that might govern it. In keeping with the naturalistic paradigm in qualitative research, a one-on-one, face-to-face, in-depth interview approach was used to ask the overseer of the volunteer in hospice care to describe in his or her own words and in his or her own natural setting the meaning of information behavior as it relates to working in the capacity of the overseer of the volunteer. Twenty-one interviews took place in East Tennessee, northern Georgia, and western North Carolina so as to identify and explore coordinators'

information behavior-related similarities and differences within the same overall geographic region (i.e., the Southern Appalachian region, which is defined by the Appalachian Regional Commission – a federally- and state-funded organization - as a cultural region comprised in part by East Tennessee and northern Georgia).

A discussion guide that adapts the critical incident technique (CIT) was used to provide some structure to the interviews so as to have a basic framework for gaining insight into memorable episodes in order to elicit an overseer's experience while in a specific information behavior-related situation. Additionally, the overseer was asked to characterize his or her information use environment and information behavior therein; whether, how, and to what degree one or more enablers and/or constraints existed to obtaining that information; and the nature of those enablers and constraints. The discussion guide was piloted in order to make necessary changes to the guide that the researcher did not anticipate in its initial design, and to ensure that the CIT is a suitable method of data collection for this study. The interview questions are open-ended and are of a general nature, and thus support the flexibility of qualitative research in general and of a grounded theory approach in particular.

Data Analysis

Data analysis incorporated a complementary approach using grounded theory and, to a larger extent, structuration theory; multi-method qualitative research has been found to offer complementary insight into social phenomena that might be overlooked by relying on a single method of analysis. As called for by grounded theory, the researcher used open, axial, and selective coding of the data in order to achieve the “constant comparison” method of analysis called for by a grounded theory approach. In addition to grounded theory, data analysis for this study also was informed by Anthony Giddens's theory of structuration (or, “structuration theory”), which focuses on social interaction as it occurs within a social structure according to moral and procedural rules and allocative and authoritative resources organic to that structure and that are transformed as social action takes place. Structuration theory was chosen as a complementary method of data analysis because it is a good fit for elucidating the IUE as a social context in which information behavior occurs, and because it provides a specific framework for identifying enablers of and constraints on human action. It must be noted that structuration theory is a sensitizing device that provides a loose framework for data analysis, and not a testable theory in the positivist tradition. Also worthy of note is that structuration theory, while highly applicable to LIS studies involving the IUE, as well as to other LIS-related phenomenon (e.g., information behavior), has received surprisingly little attention in the field.

Findings, Discussion, and Conclusions

This study has found that participants can work more than one role within hospice care and typically are known as “volunteer coordinators.” A total of twenty-eight information needs emerged from twenty-one critical incidents, along with fifty-four instances of information-seeking activity and sixty-three instances of information use activity. Information-seeking activity is enabled by twenty-one moral rules; thirty-two procedural rules; five allocative resources; and forty authoritative resources. Information-seeking activity also is constrained by Meanwhile, information use activity is enabled by four moral rules; five procedural rules; five allocative resources; and twenty-three authoritative resources.

On the other hand, information-seeking activity is constrained by eight oral rules; eighteen procedural rules; three allocative resources; and eight authoritative resources. Information use activity also is constrained by four procedural rules and twelve authoritative resources.

A large and expansive bureaucratic power structure within hospice care volunteerism emerged as the major finding of this study. Hospice care is ostensibly bound by the legal authority of the Medicare program, the nation's largest payer of hospice care. The unequal distribution and exertion of power within the relationship between Medicare and the hospice care agency limits the information behavior of the volunteer coordinator, and, by default, the volunteer, thus producing *unintended* consequences of that behavior which, in turn, produce and reproduce the social system that is hospice care, and determine the nature and type of social practices that occur between the coordinator and the volunteer. As such, while hospice care volunteerism continues to be under threat of extinction, Medicare produces and reproduces a (social) system of hospice care volunteerism that has a reportedly deleterious effect on the volunteer (e.g., lack of explicitly-known overseer of the volunteer; information gatekeeping), the very bureaucratic subordinate whom Medicare relies upon as a cost-savings measure (and thus potentially hospice care's own survival).

A second finding of this study is that a power structure emerged as a major component of hospice care volunteerism as an IUE. Rules and resources, a given component of the setting within the IUE as Taylor defines it, allow for power to flow among the social relationships that occur within an IUE (considered in this study as the information behavior of the hospice volunteer coordinator). While subordinates to the power structure are knowledgeable actors aware of the intended consequences of their information behavior as it occurs within the IUE, the exploitation of that behavior by the power structure produces unintended consequences of which those knowledgeable actors are unaware, further ensuring the production and reproduction of the power structure itself within the IUE. This revelation presents rich opportunities for LIS research involving human information behavior and the implicit power structure dimension of the IUE.