

## **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 39% of all deaths in 2008 in the US, occurring while under the care of a hospice program, as reported by the Centers for Disease Control and Prevention. 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, 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; 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) What are the information needs of hospice volunteer coordinators?; 2) What is the information use environment of hospice volunteer coordinators?; 3) How do hospice volunteer coordinators seek information in a hospice care environment?; 4) How do hospice volunteer coordinators use information in a hospice care environment?; 5) What enables the information behavior of hospice volunteer coordinators?; and 6) What constrains the information behavior of hospice volunteer coordinators?

## **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 is used to ask the volunteer coordinator 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 a volunteer coordinator.

Interviews have taken place in East Tennessee and in northern Georgia so as to identify and explore coordinators' information behavior-related similarities and differences within the same overall geographic region (i.e., Southern Appalachia, 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). Fifteen of twenty planned interviews have been conducted. A discussion guide that adapts the critical incident technique (CIT) is used to provide some structure to the interview so as to have a basic framework for gaining insight into memorable episodes in order to elicit a coordinator's success or failure while in a specific information behavior-related situation. Additionally, the volunteer coordinator is 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 incorporates 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 uses 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 is informed by structuration theory, which focuses on social interaction as it occurs within a social structure according to rules and 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.

## **Preliminary findings**

Thus far, this study has found that participants seek information from a variety of sources: company manuals; colleagues, including coordinators in other states, as well as other members of the hospice care team (e.g., physicians, organization directors); online resources, either chosen

by or developed by the hospice organization; medical textbooks; relevant databases; and inter-company chat services. Colleagues and company manuals have been the overwhelming information source of choice. Chat service, though widely available, is rarely used, mostly because it is new and therefore outside the range of the coordinators' habitual information behavior. The rules and (re)sources that govern information behavior within a hospice care environment both enable and constrain the coordinator's information behavior, depending on when and why an information is needed and the extent to which that source is useful, and whether organizational rules allow for that use.