

## Profound Learning of End of Life Caregivers

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**Abstract:** This study explores the learning of volunteer end of life caregivers (EOLCG). Using the profound learning framework, the researchers will use a grounded theory approach to generate transferable characterizations of how learning occurs for EOLCGs and what the content of that learning is. As a unique population of adult learners who perform an essential and sacred service for those passing through a mysterious and difficult time of life, there is much to be explored. The study seeks to understand how profound learning happens for EOLCGs.

*Keywords:* end of life care giving, end of life care learning, hospice training, hospice learning

This exploratory, theory-building study seeks to understand whether profound learning happens for end of life caregivers. This study focuses on caregivers and their profound learning during their experiences. This group was chosen because of conditions and experiences the researchers suspect are fertile ground for profound learning. The researchers' goal in this study is to provide qualitative, conceptual descriptions of the profound learning of EOLCGs. The research questions center around the practices, motivations, and processes of profound learning that takes place in the experiences of end of life caregivers. The results of this research will contribute to the existing scholarship of profound learning.

### Literature Background

Grounded theory methodology suggests differing approaches to the timing of a literature review (Charmaz, 2014). One approach is to not include a comprehensive review until after the data has been gathered and analyzed so that researchers will not be unduly influenced prior to their initial conclusions. Another approach is to have a full review prior to the study so there is a deep understanding before interviews are conducted, data is collected, and coding proceeds. The research team for this study decided to take a middle approach, looking for only an initial collection of literature, which will be supplemented and integrated, along with other related sources, as the research analysis proceeds. A search was conducted of the following databases, JStor and Academic Search Premier, using these keywords: end of life caregiving, end of life care learning, hospice training, and hospice learning. Articles were gathered and assigned to members of the research team, who developed annotated summaries inserted into a project spreadsheet. This information will not be developed into an integrated review until the findings are completely interpreted.

Literature collected so far does not make clear connections between deep learning of volunteer caregivers and their end-of-life experiences. While there are several anecdotal descriptions, there are few empirical studies from which to draw. Several the articles discuss professional

caregivers, such as nurses, and their experiences and challenges (Ives-Baine et al., 2013; Lindsay et al., 2012; Rivera-Romero et al., 2019). Several findings and theoretical concepts found in the literature may be useful in later analysis, including relationship which is at the center of caregiver and patient (Ives-Baine et al., 2013); the importance of debriefing after a patient passes (Kelly & Nisker, 2010); the meaning-making process, including reflection (Lindsay et al., 2012); paradoxes, including sadness-happiness and individual-collective needs, and the importance of multiple perspectives brought by multiple participants involved (Loisell & Sterling, 2012); death and dying communication apprehension (Pagano, 2016); the sense of time, including the relationship of finitude and learning (Russell, 2008); learning the value of silence and presence (Foote, 2006; Sanders & Swails, 2011); the processes of meaning reconstruction and reorganized personal identity for the caregiver (Foote, 2015; Supiano & Vaughn-Cole, 2011); the need for ritual (Running et al., 2008); the narratives hospice volunteers use to reflect upon and to interpret their experiences, the idea of what “good death” means, and the way a hospice volunteer can become a hospice educator (Wittenberg-Lyles, 2006); the idea of anticipatory grief and a feeling of an uncertain future (Berinato, 2020); the concept of front-facing regions of a hospice workers (caring, compassion, professional) and back-facing regions (morbid, dark humor, detachment from death and dying, strategies to change patient and family behaviors) and how they divide time and space (Cain, 2012); and the process of censoring, an adaptive process which is used by nurses to allow themselves to continue as the patient moves toward death (Curcio, 2017).

### **Profound Learning**

Profound learning has been recently conceptualized by Carr-Chellman and Kroth (Carr-Chellman & Kroth, 2017; Kroth & Carr-Chellman, 2018, 2020a), with initial theory-building studies (Carr-Chellman & Kroth, 2019; Kroth & Carr-Chellman, 2020b). Kroth (2016) originally conceptualized a profound learner as “someone who pursues deeper knowledge over time” (p. 29), and as someone who “has an ongoing proclivity and practice of seeking deeper learning . . . and are intentional about deepening as a way of life” (p. 29). Carr-Chellman & Kroth (2017) began to develop a framework for profound learning, suggesting that practices, or disciplines, are one approach for individuals to intentionally develop profound learning as a way of life instead of, or perhaps in resistance to, the shallow path that the internet and current society are pushing toward.

These authors suggest that qualities of profound learners are pursued over time, and so it would include but not be limited to transformative learning experiences; that profound learners “seek to open up, to ask, and to continually reveal rather than to close down, to answer, or to completely discover (p. 29); that extraordinary learning comes from the ordinary; and that “ordinary people can become profound learners, and profound learning can be found in the ordinary” (p.30). Carr-Chellman and Kroth continued to add substance to the conceptualization of profound learning by proposing three “building blocks” for a profound learning pedagogy (2018), which are: 1) that such an approach assumes that completely correct answers cannot be found and that the pursuit of truth can only be asymptotic and thus is a continuing exploration rather than an accomplishment; 2) that, ergo, there is no endpoint in the pursuit of deeper learning, such that learning capacity continues to develop over a lifetime; and 3) that developing practices such as disciplines, routines, and habits, are essential to intentionality, draw out one’s full potentiality, and pursue depth over a lifetime.

Most recently, Kroth & Carr-Chellman utilized metaphor to develop more substantive ways of looking at what profound means rather than simply “deep”. Metaphors for profundity included looking at profundity as a milieu and as moving toward a center. Qualities of milieu included being interconnected with everything, as being immersed and integrated with all that surrounds; and as moving from separateness to oneness. Profound learning includes structures and processes that can be returned to, where new ideas can be mixed with existing knowledge, but can never be filled; and is a path of discovery.

### **Methodology**

Grounded theory research studies social psychological processes in the context of a particular experience generating an explanation of that process in new theoretical terms, elaborating the properties of the theory, illustrating the conditions under which the process materializes (Charmaz 2014). Following Charmaz’s (2014) constructivist grounded theory approach, the researchers will apply an inductive lens to emergent conceptual categories present in the data to generate meaningful characterizations of the phenomena. A more robust understanding of profound learning, generally, as well as profound learning for EOLCGs more specifically, should result. As a guiding interest, the characteristics of profound learning will shape our data collection and analysis. Concepts such as disciplines, practices, and habits will provide points of departure. Likewise, the notions of formation, identity development over time, and agency will inform our methods. It is common for grounded theorists to begin research investigations with sensitizing concepts and guiding interests like these core concepts of profound learning.

Two empirical studies have been completed to date. The first was an inquiry into teachers’ experiences of profound learning (2019). Here, profound learners were found: 1) to have depth of thought; 2) to be emotionally wise; 3) to take life seriously; 4) to be adventurous in thought and deed; 5) not constrained by age, ideological perspectives, or level of education, thus transcending structural identity and therefore able to consider matters holistically; and 6) to be humble. The second empirical study was an exploratory Delphi study which sought to find consensus among a number thought leaders in the field of adult education. Among the findings were qualities of profound learning, categorized into themes, which included: 1) deeply reflective, 2) a deepening process, 3) consequential, 4) a change process, 5) progress toward a more authentic truth, and 6) integrative. Also found were qualities of profound learners, which included themes of: 1) looks beyond their own existing knowledge, 2) is a deep thinker, 3) pursues on-going growth over a lifetime, 4) is open-minded, 5) is engaged in the world around them, 6) pays attention, 7) explores, and 8) is mature in their approach to life. The grounded theory study discussed here is intended as another step in this theory-building process.

### **Data Collection**

In grounded theory, researchers are focused on gathering rich data to elaborate and address the research question. As such, the researchers drew on Seidman’s qualitative interviewing techniques. This two-interview sequence draws on Seidman’s (2006) three-interview structure for phenomenological data collection. All interviews are phenomenological, so Seidman’s characterization doesn’t necessitate that his sequence or structure be used only in the service of a

phenomenological study. All interviewing requires an understanding of both the context and the meaning one's participant associates with that context in light of the research question/purpose. Seidman's structure helps navigate the researcher into a participant's background, their experiences and the meaning they make of the research topic. Seidman also helps facilitate strong rapport as well. Interview one establishes the context of the participant's experience. Interview two allows the participant to reconstruct the details of their experience within the context in which it occurred. Interview three encourages the participant to reflect on the meaning of the experience.

For our two-interview structure; we collapsed Seidman's three interviews into two. Interview one began moving out of biography/history and into the participant's current lived experience with the topic. Interview two will begin with additional questions about the participant's current lived experience, transitioning into the meaning of that experience. Interview two will finish by establishing closure with the participant. Interviews were conducted using research pairs consisting of an academic researcher and a doctoral student, following an apprenticeship model. Initial interviews were conducted by the academic researcher and later interviews were conducted by the doctoral students. All interviews were 60 to 90 minutes in length, were conducted over Zoom, and then recorded and transcribed.

### **Study Participants Selection and Recruitment**

The sample frame consists of volunteer end of life caregivers. The context for their work is caring for people who are in the final stages of life or actively dying. Using a purposeful sample of convenience to generate the richest possible data about our research question, our participants came to the study in multiple ways. We worked with gatekeepers at hospice organizations and hospitals who facilitated contact with potential participants. We also pursued a snowball sample as some participants provided contacts of others who might be interested in participating.

Participants for this study were recruited from a population of hospice volunteers. The rationale for this decision was to focus on those who choose to do this work and are motivated by a desire to provide hospice care without compensation. The sample goal for this study was initially set by the team at a minimum of 16 participants for the two-interview grounded theory study. However, that number is fluid depending on the data analysis process. Data collection is ongoing. Initial contact was made to volunteer coordinators at hospice centers and programs throughout the Treasure Valley of Idaho. Both hospital hospice programs and separate hospice entities were identified and contacted. This study was approved through the University of Idaho Institutional Review Board. However, two of the hospital hospice programs required additional institutional review and approval by their own hospital review boards. Recruitment efforts began during February and March 2020, which coincided with an Idaho state lockdown during the COVID-19 pandemic. This required the team to abandon face-to-face contact and to limit all recruitment and interview contact efforts to phone, email, and virtual conversations.

An email with research study details was sent to program volunteer coordinators after initial phone contact and conversation. Once volunteer coordinators approved the study, a recruitment email was sent on to hospice volunteers through the coordinators. This meant that participants were recruited by volunteer coordinators rather than by researchers. However, once the

volunteers responded to the research team contact, there was no further communication with the volunteer coordinators. Volunteers who responded via email directly to the team were sent additional information about the study either by email or through a phone conversation. None of the volunteers recruited were known to the team members prior to this research study. Participants were chosen using a convenience sample. All hospice volunteers who indicated an interest in the study, and agreed to be interviewed, were included in this study. A few of the hospice volunteers who initially indicated interest in the study voluntarily withdrew for personal reasons prior to the first interview.

### Researcher Description

The research team consists of six members, three faculty and three doctoral students. The study emerged as part of the University of Idaho's doctoral research apprenticeship program. As such, it is part of and continuation of a larger body of research work on profound learning. The *a priori* guiding interests and sensitizing concepts include profound learning and the constituent elements of that theory.

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