End-of-Life Caregivers and Profound Learning: A Grounded Theory Study

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Abstract
This study developed a deeper understanding of profound learning as experienced by volunteer end-of-life caregivers. This paper shares preliminary results of the study, including the following findings: Kinds of Knowledges; Tools; Engages the Human Condition; Relational.
Keywords: profound learning, hospice, end-of-life caregiving

This study investigated ways adult learners experience and develop profound learning through the work of volunteer end-of-life caregiving. Death is a portal into deep love and deep suffering, and therefore is an ideal opportunity to study how end-of-life caregivers learn deeply during another person's once-in-a-lifetime experience. This empirical study focuses on individuals volunteering as end-of-life caregivers (EOLCGs) to help us understand the learning that occurs leading up to, during, and after their experiences with those, and those close to, who are in the process of transitioning. Specifically, this study seeks to contribute to emerging profound learning theory development. These participants were chosen because the researchers suspect their roles, conditions, and experiences are fertile ground for profound learning. The research questions center around the preparation, practices, motivations, and processes of profound learning that take place for volunteer end-of-life caregivers. The findings of this grounded theory study include the following: Kinds of Knowledges; Tools; Engages the Human Condition; Relational.

Perspective or theoretical framework including relevant literature

Profound Learning (PL) is in exploratory stages and is built on the qualities and characteristics of continuous and deliberate formation which integrates meaningful experiences into an explicitly designed, cultivated, developmental process occurring over time or a period of time, and resulting in continuing, durable, rich, deepening learning and development.

Profound learning is understood as ever-deepening learning, evidenced through learner practices and attributes by which insights are gained, substantial knowledge and meaningful learning are accomplished, perspectives evolve, relationships blossom, values are questioned, and paradigms are tested (Carr-Chellman & Kroth, 2019a; Kroth & Carr-Chellman, 2020). The key component of PL is the development and application of practices, meta-practices, and meta-skills that, consistently actualized, frame the learning transaction as formation over a lifetime (Kroth et al., 2022). This component of PL provides a foundation for lifelong learning that is holistic and agentic, rather than dualistic and passive. While it is not framed as a panacea theory, it does enable significantly improved learning experiences; the effective application of PL to learning design is intended to lead to human flourishing.

Human flourishing, as an element of PL, is understood as the ways in which we experience happiness, self-actualization, depth of human growth, and fulfillment. Founded on traditions of Aristotle (2009), Aquinas (1274;1981) and Nussbaum (2001), human flourishing is

not seen, in the PL frame, as an end-state, but it is instead seen as a socially constituted and intermittent experience that can be enhanced and accentuated through practices, meta-practices, and meta-skills.

Perhaps the most compelling characteristic of PL is the clear, simple recognition that deep learning can become a disposition developed over time that can be practiced, learned, and taught. PL, "emphasizes shifts and deep changes occurring incrementally and occasionally over a lifetime through experiences and ongoing explorations that seek insight, depth, and breadth through practices or disciplines" (Carr-Chellman & Kroth, 2019b). A key aspect of PL is the recognition that people can learn to be profound learners. PL connects with the construct of "deepening" which is defined as depth of growth, complex thinking, and multiperspectivity over a lifetime.

The qualities of profundity, profound learning, profound learners, and profound living have been explored and certain themes associated with each of these has begun to be moved beyond mere ideas to design blueprints. Profundity is particularly associated with deep, provocative, and substantive qualities. Profound learners are marked by reflection, deepening, consequential, and change-oriented processes, while profound learning similarly is associated with deep reflection, deep processing, and consequential learning. Profound living is understood as living meaningfully, practicing ongoing reflection, working toward richer understandings, and being intentional, authentic and integrative (Carr-Chellman & Kroth, 2019a; Kroth & Carr-Chellman, 2020).

Precisely because PL is focused on the deep reflective unfolding of the learning experience, the sense that one is never completely "done" with learning, and the formative nature of learning, it is well-aligned with the experiences of EOLCGs. Through the lens of PL, the learning and formation of end of life caregivers provides greater clarity about the iterative, action-oriented learning that is continuously refined and tested and is foundational to reflective practice. In a related thread, current PL research connected to human flourishing is becoming grounded in justice-oriented, community-based contexts while building a shared symbolic universe through virtue-oriented growth. Finally, because this study reveals a two-way communication/relational pattern to learning, PL also connects well to design thinking and formative design.

Several empirical studies have been conducted to date and several more are in-process. The completed, published, studies include a Delphi study (Kroth & Carr-Chellman, 2020) and an investigation into teacher's experiences of PL (Carr-Chellman &Kroth, 2019a). Research is on-going in three separate empirical investigations: PL and leadership, PL and end-of-life caregivers (this study), and PL and practices of living. Preliminary results from these studies have been presented at conferences and published in conference proceedings. Additionally, an integrative literature review examining leadership practices grounded in PL has been published (Scott et al., 2019). Lastly, there are three published theoretical explorations of PL (Carr-Chellman & Kroth, 2020; Kroth & Carr-Chellman, 2020; Kroth & Carr-Chellman, 2018). Next steps for research include further connections with other fields including design thinking, community building, and organizational capacity building.

Research Design
The research design for this study has been elaborated in two previously published proceedings manuscripts (Wigdorski et al., 2020; Daniels et al., 2021). An abbreviated description is included here.

Following Charmaz' (2014) Constructivist Grounded Theory approach, the researchers applied an inductive lens to emergent conceptual categories present in the data to generate meaningful characterizations of the phenomena. Data collection is complete and analysis is ongoing. Results-to-date are included in this paper. We have already observed and experienced deep learning just from our interviews, review and analysis of the transcripts, and discussions about them. As a guiding interest, the characteristics of profound learning have shaped and will situate 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.

Our initial research questions were:

Research question: What constitutes profound learning?

Sub-questions:

What is the profound learning that happens as a result of the daily process of end-of-life caregivers?

What did they learn from their clients, from their own personal responses to their clients and their client's situations?

What is the formation process of becoming an end-of-life caregiver?

What actions/behaviors and practices generate profound learning?

For the interview structure, Seidman's (2006) three interview structure for phenomenological data collection was collapsed into two interviews. Interview one began with asking about the participant's biography/history, and then moved into the participant's current lived experience with the topic. Interview two was grounded in the themes which the team found after analyzing all thirteen first-round interviews, began with additional questions about the participant's current lived experience, and then transitioned into the meaning of that experience. 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, conducted over Zoom technology, and recorded and transcribed. Twelve second round interviews were conducted and transcribed. The research group is currently analyzing the transcripts in two smaller teams, bringing the results together to the larger group. The larger group then uses those emerging themes when analyzing the next set of transcripts, which is done again in smaller teams, and then with the whole team. To date, all but four of the transcripts have been analyzed with this approach. In this way, interrater reliability and triangulation are maximized to build trustworthiness.

Findings and conclusions

Having analyzed the first round of interviews to generate themes, the research team has now analyzed all but four transcripts from the second round of interviews and has generated inclusive themes for all of the data analyzed to this point. The following theoretical codes represent the provisional findings of our constant comparative process intended to generate a grounded theory for what constitutes profound learning: Kinds of Knowledges; Tools; Engages the Human Condition; Relational.

These themes appear to play important functions in shaping the caregivers across their life experiences and in their role as caregivers. These themes contribute to profound learning theory building. Our findings contribute to the ongoing research efforts to develop a deeper

understanding of profound learners; profound learning characterizations, development, and processes; and a more robust conceptualization of profound learning theory.

Kinds of Knowledges

In relation to existing research into profound learning, this theme engages a central epistemological question: how do we come to know the essential elements of being an end-of-life caregiver, which, as subsequent theoretical codes describe, also captures important elements of what it means to be human? This theme also characterizes the types of knowledge used by EOLCGs. The PL of EOLCGs is multivalent, meaning that there are different types and layers of knowledge, often overlapping and mutually supportive, that are essential to the work they perform, but that exist at different levels of abstraction and function. There is a layer at the level of skill development that can be trained and mentored for improvement. There is a layer of informal experiential knowledge that can't be trained or mentored, but is learned through practice and time. There is a layer of dispositions, often described by participants as a gift from God, signaling adaptability and an openness to the virtues and qualities that make one a better caregiver as well as a better person.

Engages the Human Condition

In relation to existing research into profound learning, this theme engages central anthropological and ontological questions: What are people for and what is most common and important to being human? What is the nature of reality that structures and contextualizes the purpose and meaning of being human? Fundamentally, PL in EOLCGs occurs in the midst of constant prioritization and reprioritization according to the continually evolving understanding of the patient's growth and identity development as a dying person. EOLCGs develop an acute sense of what is relatively important through the lens of someone who is progressively moving away from the selves they always knew into a self that is very different. The end result for many EOLCGs is an appreciation for the end-of-life miracle, the deep and meaningful transition, and the self-awareness, self-knowledge, and humility to be present, engaged, and supportive during this transition. Many EOLCGs described the nature of reality such that their intentions, beliefs, and feelings become inseparable from their effectiveness as caregivers.

Tools

In relation to existing research into profound learning, this theme characterizes a second central anthropological question: What characterizes the activity of an EOLCG? This theme expresses the finding that PL occurs through the use of tools: tools for providing comfort and easing suffering. In particular, the use of tools represents the fundamentally mediated and purposeful nature of human interaction. For example, music was described as a way to find the resonance with the patient, build the relationship, while emphasizing the distinction between music as performance and music as a relational tool.

Relational

Through the lens of existing research into profound learning, this theme characterizes a central cultural characteristic: profound learning is always relational. The qualities and attributes of EOLCGs were always expressed relationally. In particular, participants emphasized that one's ability to develop into a competent EOLCG was, more than anything else, a function of one's ability to put the patient first, focus on the relationship, and internalize the ethos that it's not

about you, it's about the patient. It would be difficult to overstate the prominence of this characteristic throughout our participant's interviews – it bleeds into every other theoretical code and shapes the experience of profound learning for EOLCGs.

Implications for adult education theory and practice.
The purpose of this study is to develop theory about profound learning in the context of end-of-life caregiving. Few events in life match the significance which occurs during the event of death, and those who care for those dying are arguably the closest a person might come to observing, experiencing, and mediating that profound learning event without dying oneself. EOLCGs are in the unique position of being educators - more like learning facilitators - of those dying and those closest to them. Further, volunteer EOLCG's, deliberately put themselves into this scenario, which places them within an existential, learning situation, unlike paid experts or the patient or family who have a greater obligation to be there. We were particularly interested in the formation process that occurs as a person begins to identify themselves as an EOLCG, and the intentional ways one is prepared for, practices to become, and then experiences learning over time. Profound learning is just becoming of interest theoretically, and this study contributes to the emerging empirical research conducted thus far. In addition to contributing to profound learning theory, this study will contribute to the body of knowledge around end-of-life caregiving and the professional development of the EOLCG practitioners and trainers. Important implications for professional development and identity formation include the role of trauma, the value of relationships and empathy, and the power of mediational artifacts such as music or animals to generate meaning and understanding.

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