



## Understanding palliative care learning: A narrative inquiry exploring health care professionals' memorable experiences



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### ABSTRACT

Palliative care is an emotionally evocative domain of care, the complexities of which are not well understood. Palliative care has been described as a cultural shift in healthcare away from disease focused interventions toward a holistic and patient centered approach. Concerns have arisen around a lack of preparation for this approach to care following formal education programs across a variety of health professions. Demographics in many areas of the world demonstrate an increasing need for healthcare providers (HCPs) who are competent, confident, and engaged with this practice. Using narrative methodology to consider visual and verbal forms of storytelling, we explored memorable palliative care learning experiences of rural HCPs in Canada (2018–2019) to broaden understanding of how palliative care learning happens. HCPs across a variety of professions drew and recounted emotionally rich narratives that revealed personal and contextual dimensions as central to learning, inclusive of relationships, settings, and cultures. HCPs across professions recounted experiences that followed a common narrative arc that we call the 4Ds: difference, discomfort, disruptive, departure. This narrative arc is compatible with viewing learning as an ongoing process of transformation or becoming. Through considering the 4Ds and its implications for education, providers and educators can attune to opportunities to support students and colleagues as they emerge and grow as HCPs. Conversely, not attending to difficult, disruptive, and emotional aspects of learning may perpetuate hidden aspects of healthcare culture with possible negative impacts on provider experience and notions of professional identity.

### 1. Introduction

Palliative care is an emotionally evocative domain of work, the complexities of which are not well understood. Palliative care has been described as a cultural shift in healthcare away from disease focused interventions of acute care and chronic disease management toward a holistic and patient centered approach (Canadian Hospice Palliative Care Association, 2015; Brighton et al., 2019; Funk et al., 2017; James & Macleod, 1993; Kasman et al., 2003; Lin & Fan, 2020; Rhodes-Kropf et al., 2005; World Health Organisation, 2011). Concerns have arisen from healthcare providers (HCPs) across a variety of professions, documenting a lack of formal preparation for this unique approach to care (Bickel-Swenson, 2007; Croxon et al., 2017; Gibbins et al., 2011; Shaw et al., 2010). Critics have also argued that traditional educational models fail to adequately address the emotions inherent in HCPs learning (LeBlanc et al., 2015; McNaughton, 2013; Shapiro, 2011). Little is known about how HCPs' experiences, inclusive of emotion, shape both the learning and practice of palliative care (McConnell & Eva, 2015, pp. 181–192; Rhodes-Kropf et al., 2005).

The World Health Organisation (WHO) defines palliative care as "... an approach that improves the quality of life of patients ... and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual." (World Health Organisation, 2020) Despite its common usage, the term 'palliative care' suffers from a lack of conceptual clarity, and can represent varied meanings and models of care in different jurisdictions, cultures, and contexts (O'Connor et al., 2010; Ryan et al., 2020; Sawatzky et al., 2016). In this paper, we follow the WHO definition and conceptualize palliative care as an approach that is beneficial at all stages of an illness trajectory, from diagnosis of a life limiting disease through to death, and is practiced across health professions, ages and stages of life, diseases and organ systems, and places of care (Canadian Hospice Palliative Care Association, 2015; Sawatzky et al., 2016). Palliative care happens in all healthcare settings: well-resourced urban environments with access to specialized providers and teams, and rural and remote places which have fewer and more widespread resources. The rural context often entails the provision of health care services by

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<https://doi.org/10.1016/j.ssmqr.2022.100098>

Received 17 October 2021; Received in revised form 1 May 2022; Accepted 5 May 2022

Available online 20 May 2022

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providers within a generalist scope of practice (Strasser, 2016). They may be known community members and not anonymous strangers, thus potentially compounding the complexity and emotional nature of this work (Simpson & McDonald, 2017). To ensure that palliative care is accessible to all patients, particularly those in rural areas with fewer resources and generalist models of care, it must be firmly embedded in primary care interprofessional training and practice (Canadian Hospice Palliative Care Association, 2015; World Health Organisation, 2020).

HCPs describe feeling under-prepared for the practice of palliative care. Several reasons have been cited as contributing to feelings of unreadiness including: limited exposure during formal education, interpersonal challenges, emotional distress, uncertainty, and lack of confidence in the ability to cope with the phenomena of death and dying (Croxon et al., 2017; Deravin-Malone & Croxon, 2016; Gibbins et al., 2011; Kasman et al., 2003; Potter et al., 2015; Redman et al., 2017; Tedder et al., 2017). Formal health professions education programs are often biomedical in orientation: organized around body systems and disease processes. A palliative approach to care transcends these constructions, thus rendering its place within existing curricular structures challenging. Furthermore, most health professions learning is situated within acquisition and participation learning frameworks (Bleakley et al., 2011; Cruess et al., 2014; Jarvis-Selinger et al., 2012; Sfard, 1998). While neither framework is completely exclusive in its focus, each privileges a perspective: acquisition underlining individual cognition and agency, participation favouring social interactions within cultural structures (Mann, 2011). Conceptualizing learning as a process of becoming overcomes the limitation in the focus of the acquisition and participation models by acknowledging that learning is the intentional and unintentional interaction between individuals, social relationships, and cultures (Hager & Hodkinson, 2011). Transformative learning, described by Mezirow, can be thought of as a process of becoming: effective learning involving the individual, immersion in the context, and participation in the world (Mezirow, 1991; Van Schalkwyk et al., 2019). The transformative process is social, relational, and emotional whereby experiences trigger a disorienting dilemma, a challenge, or a struggle that brings into question prior assumptions and perspectives (Van Schalkwyk et al., 2019; Yacek, 2020).

Experiencing, understanding and managing one's own emotion is integral to both the being and becoming a HCP, and has been underscored as an important component of the learning and the practice of palliative care (James & Macleod, 1993; Kilbertus et al., 2018; Lin & Fan, 2020; Rhodes-Kropf et al., 2005). Emotion can impact cognition, self-regulation, motivation, critical thinking, and notions of identity (McConnell & Eva, 2015, pp. 181–192). Events are often considered as memorable or important by virtue of the strong emotions evoked by the experience (Bohanek et al., 2005; Helmich et al., 2012). They are an important part of both therapeutic and interprofessional relationships and can influence HCP resilience (Jiménez-Herrera et al., 2020; McConnell & Eva, 2015, pp. 181–192; McNaughton, 2013; Weng, 2008). The study of emotions is a vast domain and for the purposes of this study we understand primary emotion as a response to an event resulting in psychological, behavioral and/or physiological consequences. Primary emotions can be triggered by a something related (integral) or unrelated (incidental) to the task at hand. Self-conscious emotions such as shame, guilt, embarrassment, or pride, can arise from introspective inquiry stemming from thoughts, feelings, or events that prompt self-reflection (Bynum & Artino, 2018; Nguyen & Bynum, 2021). The generation and experience of self-conscious emotions may trigger challenges to the ideal and actual representations of the self: what is and what could be (Bynum & Artino, 2018).

Demographics across many countries dictate the need for a healthcare workforce competent in a palliative approach to care (Canadian Hospice Palliative Care Association, 2015; World Health Organisation, 2020). While supporting and developing the capacity of the healthcare workforce to provide quality palliative care has been identified as a priority in both urban and rural settings, questions remain about how this can be

reasonably accomplished (Kelley, 2007; Kelley et al., 2004; Mahtani et al., 2015; Redman et al., 2017; Reymond et al., 2005; Shaw et al., 2010). Recognizing this, we seek to deepen our understanding of how HCPs learn palliative care by eliciting and engaging with narratives of memorable palliative care learning and inviting HCPs to critically reflect upon their experiences. This understanding will help health professions educators design and implement strategies that better support HCPs in becoming both competent and capable in the provision a palliative approach to care.

## 2. Methods

This study was undertaken using narrative methods, both visual and spoken texts, to elicit memorable palliative care learning experiences for rural health care providers.

### 2.1. Ontological and epistemological considerations

Grounded in interpretivist ontology and constructivist epistemology, we consider learning a process of becoming: a continuous, emergent interweaving of individuals, social interactions, and workplace cultures in a manner that can be transformative (Hager & Hodkinson, 2011; Van Schalkwyk et al., 2019). We utilized narrative methodology for this research study because of its focus on capturing personal experience over time. As learning is complex, nuanced, and personal, individuals' stories of palliative care learning can serve as authentic sources of knowledge for extrapolating the complexity and ambiguity of the human condition (Bleakley, 2005; Riessman, 2008). Our participants used oral and visual methods to tell their stories thus enabling them to construct their narrative, think about, and communicate their learning in different ways. Furthermore, accessing multiple ways of telling a story can broaden the researchers' view of the complexity of living through memorable palliative learning experiences (Keats, 2009).

### 2.2. Participant recruitment

#### 2.2.1. Practice context

This study was undertaken in a rural setting in northern Canada, an area of about 3,000 square kilometres. In this context, rural HCPs have a wide range of practice, large workloads and responsibilities, and work in relative isolation (Strasser, 2016). Healthcare services in this area are provided in a generalist model. Specialist care is accessed by travelling over 100 km to a referral center, or virtually through a telehealth network. In this setting, palliative care is provided by primary care HCPs in homes, long-term care facilities, hospice, and hospital settings within the community. Unique ethical issues can arise when work is undertaken in rural communities, where HCPs live and work alongside those they serve. Prior to beginning recruitment, research ethics approval was obtained from ethics boards governing this geographic region who were aware of the particularities of healthcare practice and research in rural communities.

#### 2.2.2. Participants

Participants were recruited from the approximately 100 formal HCPs working in multiple agencies across the region. Email requests for volunteer participants emanated from a local academic physician leader, supportive of, but not part of the research team. Recruitment posters were displayed in local healthcare facilities. Those expressing interest in participating in the study were invited to attend an individual interview with one member of the research team (KK), who was not in a position of authority or influence with respect to potential participants. Participants received a \$10 (Cdn) gift certificate for a local business in appreciation for their time. Seventeen rural healthcare practitioner participants, male ( $n = 4$ ) and female ( $n = 13$ ), drew and recounted narratives of memorable learning (NMLs) for palliative care. Participants came from 4 health professions: registered practical nurse (RPN  $n = 2$ ), registered nurse (RN

n = 4), nurse practitioner (NP n = 1), family physician (MD n = 10). Length of time in practice varied from less than 10 years (n = 5), 10–20 years (n = 1), 20–30 years (n = 4), 30–40 years (n = 6), to 40–50 years (n = 1).

### 2.2.3. Data collection

Narrative data was collected in both verbal and visual forms: individual interviews and ‘rich picture’ (RP) drawings (Cristancho & Helmich, 2019). Verbal narratives can be limited to one or few aspects of an experience, often procedural, while visual descriptions can capture multiple facets of a situation (Cristancho, 2014). Visual depictions can stimulate the expression of emotions, beliefs, and unconscious ideas thus having potential to reveal more intimate and less-sanctioned aspects of experience (Cristancho et al., 2015; Helmich et al., 2017). Employing this combination of verbal and visual narrative afforded a broader view of memorable learning by inviting participants to reflect on the personal, social, cultural, and systemic dimensions, in addition to the technical aspects of their professional practice.

In-person interviews with all 17 participants took place between September 2018 and October 2019. Prior to starting, the interviewer (KK) reviewed the informed consent process. All 17 participants provided written consent; no one declined to draw a RP nor chose to end the interview or withdraw consent. Sixteen of the 17 interviews were facilitated by one research team member (KK). A personal relationship was identified between one participant and the main interviewer (KK), raising an ethical conflict of interest. The primary investigator (FK), who was not in a position of authority or influence with that participant, undertook that interview.

Interviews followed 3 distinct steps (Appendix 1):

- 1 Eliciting background information on participant's professional practice and education.
- 2 Inviting participants to draw a RP about a memorable palliative care learning experience with detailed instruction and a choice of materials.
- 3 Conducting a semi-structured interview based on the narrative depicted in the RP (Rees et al., 2013).

Participants were allotted 30 min to complete their RP with most participants taking between 25 and 30 min. The RP was used as an elicitation tool and reference for the verbal narrative. Interview length varied from 30 min to 2.5 h, with most interviews lasting between 45 and 60 min. The interviewer asked questions informed by both interview content and iterative review and discussion of previous interviews amongst the research team. Participants were offered a digital photo of their RP and invited to contact the interviewer should they have any additional questions about the study. Immediately following each interview, the interviewer recorded an audio-memo capturing non-verbal observations, as well as their initial reflections to participant narratives. These audio-memos were later transcribed for reference and review. All interviews were transcribed, omitting identifying information. All interview files (audio recordings, transcriptions, and demographic details) were de-identified using participant codes (e.g., P 001). All research materials were stored on a secure drive within the local hospital, accessible to all research team members. Only the interviewer (KK) had access to personal information for the development of participant codes.

### 2.2.4. Data analysis

Data analysis began with local research team members (FK, KK, SR) immersing themselves in the first 6 interviews by reviewing the RPs in tandem with multiple close readings of transcripts. The RPs provided a visual expression of participants' experiences and were not analysed separately. The entire research team met regularly to discuss their initial impressions of the interviews including thoughts and ideas from multiple perspectives: inside the rural community (FK, KK, SR), outside the community (SB, SC); clinicians with palliative care experience (FK, SR),

non-clinicians, (KK, SB, SC); educational researchers (FK, SB, SC); narrative specialist (SB); in addition to individual personal reflections. KK and FK maintained personal reflective memos throughout the analytic process. Guiding questions on how to approach each narrative were developed based on the first 6 interviews. Thematic review of the first 6 interviews was undertaken by FK, KK, and SR, then discussed with the larger research team. A code book was developed and negotiated to understand themes common to these interviews. The process was repeated iteratively with regular research team meetings to inform ongoing interviews. Once interviews were completed, we took a more holistic approach to each participant's recollection of their memorable palliative care learning, considering the over-arching story present in each participant's narrative account. FK and KK started with one example interview that represented breadth and depth of content to create a general storyline or plot to capture the perceived learning trajectory of the participant. This storyline was then structured into themes, using transformational learning as a sensitizing concept. Following review with the whole research team, FK and KK analysed each interview separately using the themes discerned from the storyline, meeting and comparing analyses regularly, and negotiating differences based on the meaning of a contested quotation or the relevance of interview excerpts to themes. The results were reviewed with the research team using multiple examples for discussion and consensus. After a negotiated consensus by the research team regarding how storyline themes were applied to individual interviews, coded interview segments were reviewed by KK and FK individually to discern storyline sub-codes and further describe commonalities or patterns across all interviews. KK and FK then discussed their respective observations and insights, coming to an agreement on dominant narrative threads that could be represented to convey the learning trajectory of participants.

### 2.2.5. Development of a composite narrative

In contrast to presenting results in the form of interview excerpts and exemplars, a composite narrative was constructed for three main reasons: 1) to preserve anonymity of participants; 2) to present the richness of storied experience that would otherwise be lost by a deconstructed form of data presentation; 3) to share findings in a manner that aligns with a narrative interview approach (Todres, 2007). A composite narrative seeks to preserve the richness of individual experiences described by participants while demonstrating generalities across narratives, as discerned through thematic analysis of interview transcripts (Todres, 2007; Wertz et al., 2011). Through combining dominant narrative threads to draft a plot and using the thematically coded interview transcripts to structure the narrative, KK created a composite story that illustrates aspects of participants' experiences. The settings were fictional, to protect anonymity, but were generated based on rich descriptions of events and circumstances shared by participants. Though characters were created, descriptions about experience and perception come directly from participant interviews. We have embedded both direct and paraphrased quotes from interview transcripts throughout the composite narrative. Similarly, the plotline is structured by themes discerned from interviews. Literary devices (e.g., internal monologue, imagery, and dialogue) were used to shape the composite story, to promote reader engagement, and evoke understanding. Justification for all segments of the composite narrative were documented in a heavily annotated version of the composite text demonstrating links to the original NMLs. A draft composite story was presented to the research team to determine how it resonated with their understandings of the interview data. Following initial feedback, the annotated version of the text was shared with the research team for final agreement.

## 3. Results

### 3.1. The Weight of Accountability Overview

The data from the 17 participant NMLs for palliative care are presented below as a composite 3-act play entitled ‘The Weight of

Accountability'. This composite narrative seeks to preserve the richness of individual participant experiences, while honouring the commonalities discerned across participant interviews, affording opportunities for the reader to both engage with and reflect on the complexities of palliative care learning.

### 3.2. The Weight of Accountability

#### 3.2.1. Act 1: Ruminations

The subtle sound of the engine rumbling was barely audible as she watched the road ahead. She had tried listening to the radio, but as her attention continually wandered, she opted for the near silence of driving. If only she could find a similar quiet in her mind. It had been weeks since it happened, but she couldn't stop thinking about it. The look in her patient's eyes as she lay in distress; the feel of her patient's hand grasping her arm, reaching for relief. Within that moment—she couldn't forget—was the suffering of the family as they watched their loved one struggle toward end of life; and herself, the physician who couldn't help, sinking in her feeling that she was contributing to the suffering. That feeling had not gone away as the days and now weeks passed. Indeed, she seemed to feel worse as her ruminations drew on, now acutely aware of all that had happened before and what might have been done differently.

Though her care decisions had been routine, and she recognized that she couldn't have known where things would lead, she couldn't stop the now familiar refrain in her head: *"If only I had of ... Why didn't I ... ? ... It was not my best work ... It's my job to relieve suffering ... I let them down ... I let myself down ... How can I face the family? ... I could have done better ... I should have ..."* Her rational mind tried to keep things in perspective, but she felt the weight of her decisions, nonetheless.

She had experienced other traumatic deaths over her nearly two-decades as a family physician ... the misalignment of goals and expectations with patients and families; the conflicts with colleagues; the sense of compromise; the guilt. But this felt different. She couldn't recall ever feeling so defeated as a care provider. She certainly didn't feel like the doctor she wanted to be.

Turning on to her street, she held the wheel with intention, letting her shoulders drop and acknowledging the need to set these thoughts aside for now. Her husband and daughter would likely be home, and she wanted to be present with them, undistracted.

#### 3.2.2. Act 2: A beautiful expression of gratitude

Arriving home, she got out of the car next to her husband's empty parking space, feeling somewhat relieved to have more time to herself. Walking up the driveway, she looked to her flower beds which needed tending and hoped such activity would keep her mind off things for a while. As she knelt down to remove the remnants of last year's plants, she uncovered new buds on the emerging spring perennials. She would plant more this year, she thought, considering the possibilities.

Hearing a car slowing on the road, she turned to greet her husband and daughter, but was taken aback to see Jason, her patient's husband, pull in the driveway. She hadn't seen him since his wife died, and she felt her self-consciousness growing as he turned off his car and moved to get out. *What was he doing here?* As he closed his door, she saw the bouquet of flowers in his hand and the smile on his face. Time seemed to slow.

"I hope it's okay that I've come to your home," he said as he walked towards her. "I just really wanted to say thank you and seeing as I'm just up the road ..." Handing her the flowers, he added, "My family and I, we're so grateful for everything you've done for us. My wife, she ... she was so thankful to have you as her doctor. She told me that. Said she felt comfortable with you, that you were kind and understanding ... And me, well ... I don't know what I would have done without you. I ... I wasn't prepared for how hard it was going to be. You helped me through that, and ... we could always rely on you."

His voice grew shaky as he spoke and she felt her own tears coming as she listened, feeling overwhelmed by this beautiful expression of gratitude. He had no idea how much she had been struggling lately, and here he was, gifting something of greater significance than he could have known.

As she listened to his words, she remembered the look on his face when she arrived at their house the night before his wife passed: the anxiety, the stress. She had put her hand on his shoulder to reassure him that they would get through it. Feeling the bouquet of flowers in her arms, she realized that she had forgotten about that moment on the doorstep. Those times which he now alluded to had been buried by her thoughts and memories of what she felt had gone wrong. With that thought, the painful memories started rolling back and the heaviness returned. She suddenly felt abashed, like it wasn't rightful to receive his thanks.

"This is very kind of you Jason, it means a lot to me ... I appreciate your coming here and these flowers are lovely ... I just ... I wish things had gone better ... I mean, it wasn't perfect ..." she said, not knowing what to say.

There was a brief silence and she felt strained to keep eye contact.

"You were there every time we needed you ... the whole way through," he replied, sensing her uncertainty. He remembered that last night she came to the house, when things felt out of control, and wondered how it had affected her. "Moments are only part of the journey, and certainly don't define it," he added, feeling a need to be there for her now, as she had been there for him.

Breathing in, she smiled, grasping the bundle of flower stems. "Thank you, Jason," she said with a nod, feeling she could accept what he was giving her.

Just then, she saw her husband's car slowing down as he and their daughter came up the road.

"Oh, there's my cue!" said Jason, noticing the need to move his car which blocked the driveway entrance. "Enjoy the lovely evening doc," he added with a smile and a wave.

She waved goodbye, hearing his words again in her mind. As her family walked up the driveway, she smiled in awareness that for the first time in weeks, she didn't feel the need to hide how she was feeling—she felt good right now.

#### 3.2.3. Act 3: Growth

[a few years later]

"That's all I have for today," the physician said as she put her pen down, "You?"

"That's everything on my list," replied Mel, a new nurse practitioner who recently joined the practice.

They had been discussing patient and administrative matters during their weekly meeting, sharing a pot of tea in the team office, as they usually did. With no patients booked for the rest of the afternoon, the physician thought that now might be a good time to check in with Mel: she'd been uncharacteristically quiet over the past few days, and seemingly removed at times.

"Is everything okay Mel? You seem a little ... down," she asked, hoping she wasn't prying.

Mel looked surprised for a moment, then looked away saying, "Yeah, actually ... I ... am feeling pretty badly about Tom ... You know, he ... died a few days ago."

The physician nodded her head; she had heard during hospital rounds the morning prior. She knew his situation had been complicated and that

his palliative course had been difficult to manage. Mel had taken him on as a new patient shortly after starting her practice here; his diagnosis came soon after and things progressed rather quickly. She recalled Mel sharing her worry about him as he descended deeper into loss, suffering in ways that challenged her sharply. She wondered if she had been supportive enough as Mel went through this, and if she should have checked in sooner.

“I just feel badly how it all turned out ... like, I should of ... it should have been different ...,” Mel started, trying not to cry.

The physician felt for her, offering a subtle expression of understanding. Mel continued, “I just felt so powerless ... like I couldn't do anything to help ... I always thought there'd be something I could do; that every symptom could be managed in some way ... and here, I just felt kind of lost ... like I wasn't accomplishing anything ... I ... I didn't ever think it would be like this ...”

As she listened, the physician saw herself in her younger colleague, remembering her experience from a few years ago: the sense of guilt, shame, and defeat; and the subsequent struggle with identity. For a moment, she reflected on the apparent clash between the reality of this work and the professional ideals that seem to set providers up for feeling like failures when things inevitably get beyond one's control. She knew her understanding of doctorhood had changed over the years, though not without labour.

“You know, this is reminding me of a patient I had a few years back, and how hard it was on me,” she began. She told Mel about the moments she couldn't forget, the heavy ruminations, and the gift she received. She shared her reflections and what she learned, hoping it would be helpful: “It took taking a different perspective, but ... I eventually realized that I was still the doctor I wanted to be, even though I felt that I ... missed the mark. I suppose ... asking what ‘the mark’ is in good end of life care is the question ... like, what are we aiming for? ... The more I thought about that, the more I felt that being a real doctor—the essence of it—is being present ... being there.”

The two were silent for a moment, each in their own thoughts.

“I'm so grateful that my patient's husband came to see me that day. I'm not sure how things would have unfolded for me if he hadn't ... I mean, if you don't learn from these guys, you don't belong in health care,” she remarked. Smiling, Mel nodded in agreement.

“He helped me to recognize how much a steadfast presence can mean to people ... It may seem subtle or even passive within a certain view of medical practice, but ... sitting with people—being available and able to listen—can have big impacts, including on us ... I think, one of my biggest learning points through all of that was recognizing the importance of humility ... It's a way of being with others, but also with ourselves ... like, we can't control everything; we can't predict everything, even though we like to try. And, certainly, we're going to be wrong sometimes, and unaware of things, even within ourselves. For me ... being pensive about these things has helped me build resilience ... and broaden horizons in my relationships. I guess what I'm trying to say is, humility invites growth ... and ... I want that growth, though it's often difficult ...” Pausing for a moment, the physician added, “There are lots of situations in health care where we're vulnerable to vicarious trauma, and we pretend that our professional boundaries protect us from that ... We need to take care of ourselves and support each other, and maybe, if we're honest about how this work affects us, the weight we shoulder can lessen ... hopefully anyway ...”

Nodding to her colleague, Mel felt a sense of relief, like talking about this had been what she needed. Reflecting aloud, she said, “Listening to your story has got me thinking about my time with Tom and his family ...

about the good parts ...” Mel felt a sense of optimism; that she would find a way forward and become something new.

After telling her colleague more about her experience with Tom and his family, Mel got up to leave and said, “I think I'm going to call Tom's partner and see how she's doing. It's something I usually do after a death, but I admit that I've been avoiding it ... just feeling vulnerable, I guess ... and, afraid of what she might say ... But, I think now is a good time to check in.” The two exchange a smile and look of understanding.

“Thanks,” Mel said, pausing for a moment, with her hand on the door.

“Of course, anytime,” replied the physician assuredly, feeling thankful herself. “And Mel ... thanks for sharing all of this with me, and for listening. It ... keeps me learning,” she added.

“I guess it never stops, does it?” replied Mel, thinking of her own learning. The physician nodded, smiling again.

### 3.3. Exposition of the script *The Weight of Accountability: the 4 D model*

Participants in this study drew and narrated complex and rich experiences of memorable palliative care learning. These experiences, across various health professions and at different stages of professional life, unfolded along a trajectory of transformative learning (Van Schalkwyk et al., 2019). Learning involved an ongoing entanglement of factors: the individual's knowledge, actions, and emotions; their social relationships with patients, families, colleagues, community members, and loved ones; and the unique physical, cultural, and geographical contexts in homes and across a variety of health care facilities. Multiple facets of experience and context contributed to participants' meaning making influencing how they saw themselves and how they felt perceived by others: their emerging and evolving professional identity. We describe this trajectory as the 4 D model: **different**, **discomfort**, **disruptive**, **departure**. As evident in our composite narrative, the 4 Ds were not necessarily sequential but interwoven through the participants' recounting of their experience. Illustrative examples taken from participant NMLs succinctly show how elements of the 4Ds were expressed within participant NMLs are set out in Table 1 [see Table 1: Illustrative examples of the 4Ds] We define the 4D model as follows:

**Different:** The context of learning involved something notably different from other professional experiences. This aspect of novelty or unfamiliarity in turn sparked reflection and contributed to participants' memorable learning.

**Discomfort:** There was a sense of mental or physical uneasiness in the NMLs which was both described and often relived in the telling. Many participants demonstrated strong emotion during the interviews, for example crying, during the recounting.

**Disruptive:** The verbal and visual narratives depicted moments of disruption causing participants to challenge or doubt the mental representation they held of themselves and their work. This happened through personal reflection and often involved engagement with others. Examples of disruptive or disorientating moments involved questioning decisions in care, how the care was enacted and evolved, the impossibility of perfection in care, the inability to act in a way they aspired, the need to make and accept compromise, the importance of presence or ‘being’ as opposed to action or ‘doing’.

**Departure:** Participants' experience of disruption led them towards a transformation or departure from how they saw themselves prior to this memorable learning. In some instances, this reflection and departure was immediate and in others the process took more time, sometimes many years. The transformation related to changes in understanding of self (e.g. purpose, acceptance, tolerance of uncertainty); others (e.g., accepting others, negotiating compromise, being as opposed to doing in therapeutic relationships); and context (e.g., how systems and cultures influence choices and care). Participant narratives underlined not only a

**Table 1**  
Illustrative examples of the 4Ds.

<b>DIFFERENT</b>	<p>“Learning this idea that there could be a completely rational person who had done every possible thing to address her symptom and for it to be wholly unsuccessful was something new to me. That there was actually somebody with a problem that we could do nothing for ... Before her ... I would have thought ... that there was no symptom I couldn't manage.” P 11</p> <hr/> <p>“She was in her bed, in her house, on her farm property ... She had all her people there, and I realized that I get to deal with ... four generations of one family. This was not something I ever experienced in the city ... And the fact that life was just going on as normal ... This was my first experience in what I felt should be the way we do things.” P 17</p> <p>“He had been recently diagnosed ... and I had no past understanding of [this illness] ... no background, no education ... I pretty much had him on my own ... That was new for me, to have that level of responsibility without kind of understanding the care plan.” P 7</p>
<b>DISCOMFORT</b>	<p>“It was a very sad time, the end of someone's life, it was really happy too because ... you could feel the love in the family ... and there was lots of crying, lots of grieving but it was just really nice. I think it was a good end of life ... when you are going into someone's home you are more vulnerable and they are way more vulnerable” P 9</p> <p>“This is the moment you don't forget ... He grabbed me and pulled me over that day and ... he said ... he found [the medication] really frightening, and the nightmares, and the way the drug made him feel ... My angst comes from what happened in his psyche and his emotions ... how much did he suffer?” P 7</p> <p>“I felt that ... I was in jail with her, because there was nothing I could do to help her, and I felt helpless ... I couldn't say the right things. I couldn't do anything. So, this little figure [referring to drawing] has no mouth and has no arms ... I felt powerless ... like my hands were tied.” P 11</p>
<b>DISRUPTIVE</b>	<p>“My identity as a family doctor is a person who is with my patients through thick and thin ... I am like the consistent person ... Continuity of care [is] ... really essential to my idea of a primary care physician ... The disconnect about treatment I think I was not prepared for ... Maybe it's partly like I feel my patient doesn't trust me.” P4</p> <p>“This is me bringing my baggage to the table and that shouldn't happen ... I had to realize that I was putting my own values ahead of the patient's in that decision-making process ... sometimes you don't realize that you are being obstructive ... No one gave me the concept that ... I would have to juggle how I felt strongly about something in order to provide good care ... I just didn't realize that could happen or would happen.” P 3</p> <p>“It's my job to relieve suffering, and I couldn't relieve her suffering ... I just felt ... that we were contributing to her suffering ... and that we were failing her.” P 11</p>
<b>DEPARTURE</b>	<p>“I really think the part that was most useful for the family ... was me being in the room ... I think getting the feedback from the family was really critical for that ... to realize that I had been doing the right thing ... Active listening and the presence was as useful if not more useful than any of the medical information or techniques that I was able to provide.” P 10</p> <p>“I think that learning needs a little bit of humility ... I [learned] to really be aware that it is hard to have a good understanding of somebody and their wishes early on in your doctor/patient relationship, and so you need to make that extra effort ... making sure they feel comfortable telling [you] what's important to them ... I already knew that I had some biases ... but I really need to work hard to not let that get in the way of the doctor/patient relationship.” P 4</p> <p>“This was a big growth moment for me, because when you're kind of an A-type personality and an achiever, to not do well ... it's hard on your psyche ... And forgiving yourself and learning we're not all perfect. I think I thought I was supposed to be ... It made me stronger.” P 7</p>

P: participant code

process of reflection but reflexivity: how memorable learning experiences changed ideas, behaviors, thoughts, emotions, and actions moving forward.

Most participants in this study noted the paucity of training and preparation for palliative care practice during their formal education. Memorable palliative care learning was unplanned, reflective, and rooted in experience. Learning was emotional and disruptive and challenged many established ideals of practice, such as absolute personal-professional boundaries, emotional non-attachment, and the centrality of medical expertise. The context of rural practice, often very different from where formal education or previous practice experience happened, was consequential: adding geographic and professional isolation, and/or socially entangled relationships within small communities that may not have been anticipated or experienced in other practice settings. Learning entailed emotional labour. Multiple NMLs were about the longstanding and lingering effects of the experience: rumination; a sense of compromise and failure, guilt, and shame; a focus on negative aspects of care; conflicts with patients, families, and colleagues; and suffering of patient, family, and provider. Several participants noted that a palliative approach and care at end-of-life challenged the concept of their professional role, which often privileged cure and disease-focused intervention over care and symptom management. Disease intervention was often described as ‘doing,’ whereas therapeutic presence was described as ‘being.’ At times, ‘just being there’ was uncomfortable, to the point of provoking feelings of powerlessness. In other instances, participants described ‘just being there’ as comfortable and easy, often correlated with an acceptance of dying by the patient and family. Bearing witness to suffering and emotional turmoil was both difficult and disruptive.

Participants noted that learning from these experiences involved self-reflection, discussion with others, and accepting feedback from patients and families. This was a deliberate process that often took time and supported the ongoing and lifelong nature of learning: the continual unfolding or becoming.

While most of the participants in this study recounted experiences that were emotionally difficult or challenging to endure, there were notable counternarratives. Learning that was memorable by virtue of how peaceful and calm the palliative care experience was for the dying person, their family, and the HCPs stood in contrast to a more common or familiar experience of ‘difficult deaths’. The trajectory of learning moved through the 4 Ds, however the discomfort experienced was not unease but rather a sentiment of tranquility which was novel in the circumstance of palliative care. This tranquility contrasted with previous experiences witnessing grim or arduous palliative or end of life care, serving as a catalyst for reflection.

#### 4. Discussion

Memorable palliative care learning for rural HCPs that is impactful, significant, and perspective altering is complex, unpredictable, holistic, and challenges traditional ideas of learning as acquisition. Participants in this study, representing rural HCPs from a variety of backgrounds and at diverse moments in their professional trajectories, followed a similar narrative arc while relating stories of memorable learning that were deeply personal, infused with emotion, immersed in both relationships and cultures, and influential in changing the way they saw themselves. While the process of becoming a health professional has been described

as the ongoing reflections, insights, experiences, relationships, and subsequent transformations (Fraser & Greenhalgh, 2001; Hager & Hodkinson, 2011), our data demonstrates that, for the practice of palliative care, these multiple elements are intertwined in complex ways and can have unpredictable impacts including both positive, negative, and distressing emotional reactions. Considering learning as this interplay between individuals, social interactions, cultures, and healthcare systems, where individuality and contextual embeddedness are inseparable, provides a way to illuminate and address that which may have been previously unseen to achieve the desired outcome: preparing and sustaining HCPs in their practice, in this instance, of palliative care.

As our participants described, memorable learning is embedded within the routine daily practice of health professionals, regardless of where palliative care is provided. Our data demonstrates that the personal and the contextual, inclusive of relationships, settings, and cultures, are central to learning and may take time to unravel and understand. This finding challenges the idea of focusing solely on formal and informal curriculum in health professions education, with the assumption that learners (HCPs at any stage of training) can move seamlessly from one setting to another and apply their acquisitions. It also contests the notion that training in one environment (e.g., urban setting) can be directly transferable to another (e.g., rural setting) without deliberate consideration of context. Transformative learning requires reflection, adaptation, and improvisation through the challenges and unpredictability of unique circumstances of health care provision.

The transformative learning trajectory, described in the literature and detailed in our participant NMLs as the 4D model, explicitly encompasses disruption or dissonance that challenges and disorients practitioners' sense of belonging and appreciation of the world and their role in it (Mezirow, 1991; Van Schalkwyk et al., 2019). Transformation, seen as a desirable goal of education and learning, emerges through the critical dialogue between prior assumptions and new experiences (Frenk et al., 2010). Participants recounted NMLs about experience in practice and in life that, while representing memorable learning, challenged many notions embedded in the culture of healthcare and education with which they were familiar: that the personal and professional can and ought to remain separate; that emotions get in the way of care; that 'good' care privileges the healthcare expert role through disease interventions over the value of therapeutic presence; or that an ideal of perfection in care exists. These ideas are perpetuated in many ways both obvious and hidden, in spoken and unspoken language and behaviors, and through educational and institutional cultures (Martimianakis & Hafferty, 2016). Given the depth of these notions within the culture of healthcare education and practice, arguably to the point of being invisible, HCPs at all stages of the learning trajectory may find this dissonance problematical (McNaughton, 2013).

A place for reflection and dialogue exploring the complexity of memorable learning can be planned and supported. This idea has repeatedly been suggested across health professions (Brighton et al., 2019; Clandinin & Cave, 2005; James & Macleod, 1993; Kasman et al., 2003; Lin & Fan, 2020; van der Zwet J., 2011; Van Schalkwyk et al., 2019). Teaching and learning opportunities that support psychologically safe spaces can be designed and presented as core curriculum. Novel strategies that support exploration of the intersection of the individual, their relationships, and workplace and institutional cultures have previously been proposed: formal role modelling, coaching and mentoring, narrative approaches and other humanities and arts-based activities (Charon, 2017; Sawatsky et al., 2020; Varpio et al., 2017). Our participants described the beneficial effect of participation in this study: an opportunity to illuminate and understand details and meanings of memorable learning, and sanctioning a place for safe exploration of thoughts and emotions that may have been buried or ruminated upon for many years. Thoughtful and deliberate application of teaching, learning, and assessment strategies that promote meaningful critical reflection and critical reflexivity for HCPs at all stages can support ongoing learning and professional identity development (Ng et al., 2019).

The presence of emotion in our participant NMLs: expressed visually through RP, orally through description, and frequently demonstrated through behaviors during interviews, is not surprising. What is remarkable in our participants' narratives is the widespread recounting of self-conscious emotion, mostly in the form of guilt and shame. The presence of self-conscious emotion was common in many NML and seemed to trigger subsequent and often longstanding introspection and reflection. This emotional response to oneself is complex and the consequences in health professions learning remains unclear, however the importance of self-conscious emotion has been linked to motivation to learn, the idea of perfectionism, professional identity formation, and resilience (Bynum & Artino, 2018). Our data demonstrates that dissonance between ideals of 'the provider I aspire to be' and realities of lived experience as a HCP are central to the difficult and disruptive triggers in the process of transformative learning.

There is an ethical imperative to support all learners, whether novice or seasoned, in their process of transformative learning. Discomfort, disruption and resulting emotions underlie memorable learning. The plea to create spaces for safe exploration of experience in palliative care specifically and in health professions education generally, have been ongoing. Our data further supports building legitimate and valued spaces for critical reflection and exploration across the HCPs trajectory of practice, as professional identity formation is ongoing and emergent. Recent events such as the global pandemic, and changes in legislation around medical assistance in dying in some countries underline that the context of clinical practice is not static, and HCPs will continue to experience different, difficult, and disruptive opportunities leading to departure from previous ways of thinking and being throughout their careers.

#### 4.1. Limitations

Participants for this study were currently practising in one rural area in northern Canada, although not all stories occurred in that geographic area. The recruitment process was limited by volunteer participation. We recognize that the voices of those who have left this domain of practice, who do not identify with or have been traumatized by palliative care practice, are not present. Their stories of memorable learning may have illuminated different themes and narrative trajectories. Whether this 4D model is transferable to other domains of care and contexts of practice will require further study.

#### 5. Conclusion

In this study we explored memorable palliative care learning among health professionals working in a rural setting. These HCPs entered clinical practice without feeling prepared for this domain of care but learned and adapted along the way. Their memorable learning was transformative, following the model we describe as the 4Ds: different, difficult, disruptive, departure. Through broadening the conceptualization of learning and probing the lived experience of HCPs using non-traditional methods, we deepen the understanding of learning and how to support ongoing and emergent professional identity formation. HCPs across professions and career trajectories share a common transformative learning pathway therefore legitimizing learning spaces that can be both interprofessional and transgenerational. Conversely, not paying attention to novel (different) or unexpected experiences that provoke physical or emotional unease (difficult) and disrupt previously held ideas or beliefs may result in missed opportunities to support the learner's subsequent departure or transformation. There is a danger in not appreciating health professions learning in this broader model: hidden and destructive aspects of healthcare culture may be perpetuated, with unpredictable or undesirable outcomes. Understanding the 4D learning process as complex and nuanced will help providers and educators move towards creative interventions that can be adapted and sustained within local contexts in support of a health care workforce that is competent and confident to engage in the practice of palliative care.

## Ethical statement

The lead author was the recipient of an AMS Phoenix Fellowship 2017 through AMS Healthcare. This provided funding support to undertake this study and there was no other influence from AMS Healthcare on the design nor undertaking of this work.

## Declarations of interest

Dr. Frances Kilbertus was the recipient of an AMS Phoenix Fellowship, 2017, which provided the funding support for this work through AMS Healthcare.

## Author statement

Frances Kilbertus: Conceptualization, methodology, formal analysis, writing: original draft and editing, funding acquisition.

Keely King: Conceptualization, formal analysis, investigation, data curation, writing: review and editing, project administration.

Susan Robinson: Conceptualization, formal analysis, writing: review and editing.

Sayra Cristancho: Methodology, formal analysis, writing: review and editing.

Sarah Burm: Methodology, formal analysis, writing: review and editing, consultant narrative methods.

## Ethics approval

Laurentian University Research Ethics Board: file number 6013850.  
Manitoulin Anishinaabek Research Review Committee (MARRC): certificate number 2018-14.

## Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ssmqr.2022.100098>.

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