

End-of-life conversations about death and dying from volunteer perspectives: A qualitative study

Original Article

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Abstract

Objectives. Although often unrecognized, volunteers fulfill many essential roles in hospices and other end-of-life care settings. Volunteers complement the actions of professionals in fulfilling many extra care needs, such as delivering newspapers and tidying bedsides. We explored end-of-life conversations about death and dying between hospice volunteers and terminally ill people, with a particular emphasis on any expressed desire to die. Our 2 research questions were as follows: (1) What is the nature of end-of-life conversations between hospice patients and hospice volunteers? and (2) How do hospice volunteers experience conversations about death and dying with patients who are at the end-of-life?

Methods. We conducted semi-structured interviews using an interpretive phenomenological analysis. We recruited hospice volunteers from 4 hospices in Calgary, Edmonton, and Red Deer; 3 larger cities in the province of Alberta, Canada.

Results. We interviewed 12 participants to saturation. Four themes emerged: (1) trusting conversations about death and dying in the context of a safe place; (2) normalcy of conversations about death and dying; (3) building meaningful relationships; and (4) end-of-life conversations as a transformative experience. Our results emphasize the importance of preparing volunteers for conversations about death and dying, including the desire to die.

Significance of results. The safe environment of the hospice, the commitment to patient confidentiality, and the ability of volunteers to meet the basic and emotional needs of dying people or simply just be present without having formal care duties that need to be completed contribute to volunteers being able to participate in timely and needed conversations about death and dying, including the desire to die. In turn, hospice experiences and end-of-life conversations provide a transformative experience for volunteers.

Introduction

Volunteers fulfill many essential roles in end-of-life care settings (Delaloye et al. 2015; Luijckx and Schols 2009; Wilson et al. 2005). Volunteers complement the actions of professionals in fulfilling many extra care needs, such as delivering newspapers to patients, tidying bedsides, telephone calling, writing, religious duties, helping patients eat meals, turning patients in bed, or helping with food preparation (Vanderstichelen et al. 2019; Wilson et al. 2005). Hospice volunteers may also provide companionship, friendship, and emotional support (e.g., a listening ear). In the context of end-of-life physical and psychological suffering, it is not unusual for hospice patients to talk to volunteers about their own death (Somes et al. 2018).

Death, even in privileged settings such as hospices and palliative care units in hospitals, is often still a taboo subject, as it is difficult to talk about it. Evidence has shown that health-care providers lack competencies to conduct conversations around death, terminal diagnoses, advanced end-of-life care planning, or patients' possible desire to die (Crespo et al. 2021; Granek et al. 2013; Numico et al. 2009). Even if death occurs in a hospital or hospice, weeks or months of end-of-life care will normally have taken place in a home or another community setting such as a nursing home. It is therefore likely that these dying people will talk to family members, neighbors, and other laypeople, such as community organization volunteers, about their impending death, dying, and related matters such as a desire to die.

Not unsurprisingly, a systematic review highlighted that laypeople are frequently involved in sensitive end-of-life conversations (Somes et al. 2018). In any calm environment, death-related topics can emerge and be discussed. Our study explored end-of-life conversations between hospice volunteers and dying people about death and dying, including the desire to die, from the volunteer perspective. Additionally, we investigated the impact of these conversations on the volunteers. The research questions were as follows: (1) What is the nature of end-of-life

conversations between hospice patients and hospice volunteers? and (2) How do hospice volunteers experience conversations about death and dying with patients at the end-of-life?

Methods

Procedures

All methods were carried out in accordance with the principles of the Declaration of Helsinki. Research ethics approval for this study was received in advance of all research procedures from the University of Alberta's Health Research Ethics Committee (Pro00087952). Forty-one hospice institutions were approached to gain organizational approval to approach volunteers for their participation in this study. The study was explained to hospice managers who were willing to take part in this study, and ultimately suggested volunteers for interviewing.

Participants

We recruited and interviewed volunteers from 4 hospices in Calgary, Edmonton, and Red Deer (3 cities in the Canadian province of Alberta). Purposive sampling was used to ensure ideal informants. The inclusion criteria were adult (18+ years old), fluent in English, current active hospice volunteer (inpatient or home), and a signed informed consent form after a discussion of the contents of a letter of information about the study had taken place. Thirteen volunteers were approached, and 12 participated to reach data saturation. No further hospices were then contacted to suggest volunteers for possible interviews. Data were collected over 1 spring and summer, at a time when Medical Assistance in Dying (MAiD) had just been made legal in Canada.

Data collection

The interview guide contained 3 core foci: (1) The nature of end-of-life conversations about death and dying; (2) Their experience with people expressing a desire to die; and (3) The impact of these conversations on them (see Table 1). Semi-structured interviews, based on these 3 questions, were conducted from March to May 2019. The participants were encouraged throughout each interview to add further information if they wished to do so and also to talk about what they were comfortable with sharing.

Participants chose a preferred time and location for their interview. Each interview was audio-recorded and then transcribed for data analysis. All interviews were performed by the same researcher, a person with experience in qualitative data collection and analysis.

Data analysis

Interpretative phenomenological analysis (IPA) (Smith et al. 2009), a qualitative approach designed to understand individual feelings and thoughts pertaining to the studied phenomenon, was used for this study. This approach was considered and found to be ideal for understanding individual experiences and thoughts about end-of-life conversations. IPA enabled us to focus on interpreting and revealing the implicit meanings of the participants' experiences.

We analyzed the data from an initial descriptive approach to a more in-depth interpretative outlook. All transcriptions were read

Table 1. Semi-structured interview guide

- Can you tell me how you started volunteering or helping other people?
- Why did you start volunteering?
- Are some of the topics they talk about really sensitive or private? Such as they are dying or have been told they are terminal or got a diagnosis that is fatal.
- Have you ever talked with a person who told you they wished to die? Or they were ready to die? Or they knew they were dying and wanted to die soon?
- Were other people (health-care providers, family, friends, ...) aware of that person's wish?
- Can you tell me about one case where someone wanted to die?
- Why did they want to die?
- Do you think that this is a way for them to maintain control?
- How did you feel when a person expresses a wish to die?
- How do you think these conversations influence you?
- Do you need support to manage these situations?
- In your experience, do you think that patients feel more comfortable talking about sensitive topics (such as their impending death and dying) with volunteers as compared to family members or health-care professionals?
- Would you like to say something else about this subject?

and manually coded line by line to identify significant statements and the meanings associated with them. Codes were assigned to each meaning that emerged. These codes were classified into categories based on conceptual similarity and ultimately grouped into subthemes and then themes. Triangulation within the research team corroborated the interpretation of the data. The methodological quality of the study was verified using the Standards for Reporting Qualitative Research (O'Brien et al. 2014). The interview transcripts were managed using Atlas.ti v.9 qualitative data analysis software.

All interviews were anonymized, and only 2 researchers had access to the recordings. We created a chart showing the categories that emerged from the studies (more descriptive level), and this served as the basis for developing themes from the interviews (more interpretative levels that encapsulated the categories found in different interviews).

Results

Of the twelve12 participants, all were female. Their differing sociodemographic characteristics are described in Table 2.

The data analysis identified 137 codes that were grouped into categories, and then classified into 4 themes: (1) Trusting conversations about death and dying in the context of a safe place; (2) Normalcy of conversations about death and dying; (3) Building meaningful relationships; and (4) End-of-life conversations as a transformative experience. Table 3 shows the categories and themes that emerged from the studies, and Table 4 contains representative quotations.

Theme 1. Trusting conversations about death and dying in the context of a safe place

All the volunteers considered that the special environment of a hospice generates trust and security that facilitates honest conversations with patients. Training to perform tasks as end-of-life volunteers and the unconditional support of hospice managers provided the volunteers with the necessary tools to manage their work, including having end-of-life conversations with patients who

Table 2. Characteristics of the participants

Participant	Age	Sex	Time of interview	Setting	Occupation	Length of service
P1	75	Female	60 min	Senior center/hospice	Retired	5 years
P2	28	Female	14 min	Hospice	Graduate nursing student	1 year
P3	29	Female	19 min	Hospice	Social worker student	1 year
P4	45	Female	11 min	Hospice	Massage therapist	1 year
P5	65	Female	49 min	Hospice	Retired	7 years
P6	67	Female	49 min	Hospice	Retired	9 years
P7	58	Female	27 min	Hospice	Missed data	Not reported
P8	64	Female	70 min	Hospice	Retired	5 years
P9	80	Female	27 min	Hospice	Retired	14 years
P10	74	Female	29 min	Hospice	Retired	10 years
P11	34	Female	23 min	Hospice	Computer scientist	4 years
P12	54	Female	33 min	Hospice	Retired	10 years

Table 3. Main themes and categories

Theme 1. Trusting conversations about death and dying in the context of a safe place
A lot of people don't know how to relate
Allowing feelings to be aired without judgment
Death as part of life
Easier to talk with a stranger
Hospice as a place where death is not seen as a taboo
Hospice as a place where discovering the person
Hospice as a place where the person is considered as a whole
Hospice as the place to be yourself (not an illness)
Importance of confidentiality to have conversations
Hospice as a safe place to speak about death and dying
Theme 2. Normalcy of conversations about death and dying
Conversations about family
Conversations about being afraid of dying
Conversations about faith and religion
Conversations about the desire to die (acceptance of dying, being ready)
Conversations about the wish to hasten death
Dealing with patients who ask for MAiD
Helping patients to find out purpose
Talking about unresolved problems
Theme 3. Building meaningful relationships
Accommodating to each person
Allowing all kind of thoughts and free expressions
Becoming friends
Being compassionate
Coping strategies to manage situations provided by health-care professionals
Importance of allowing silence

(Continued)

Table 3. (Continued.)

Importance of presence
Investing time with patients
Theme 4. End-of-life conversations as a transformative experience
Embracing life because facing death
Experience of fulfilling because of their work as volunteers
Hospice as a place of profound experiences
I am different person because of my involvement in the volunteer
Impact of accompanying people in end-of-life processes
Impact of meaningful conversations
Learnings from patients
Reflective on the own situation
Valuing meaningful relationships with patients
When a person dies it's also a loss for you

initiated such conversations. Some participants referred to the fact that outside the hospice context, it is difficult to have conversations about death or the end-of-life. The fact that death and dying are normalized in the hospice and that death is not seen as a taboo subject favored open conversations on these issues.

All participants affirmed that due to the commitment to confidentiality, the patients felt safe sharing intimate aspects of their lives with them. Hospice was a safe place in terms of allowing feelings to be aired without judgment.

Being previously unknown to the hospice patients was another communication facilitator. Wanting to protect already grieving family members led patients to avoid topics of conversation that could hurt them. Because volunteers were commonly seen as not being involved in direct care, patients could also think of them as people with whom they could discuss any topic without fear of the impact on the volunteers. Moreover, almost all participants advised that, in their experience, they thought the patients could be more open up with volunteers than with some health-care professionals.

Many discussions emphasized the normalization of death, which fostered an appropriate atmosphere for spontaneous

Table 4. Significant quotations

Theme 1. Trusting conversations about death and dying in the context of a safe place
So it's just regular conversations like I would have with anybody else which I think is what they are looking for the day program [...] Just for them just to feel like themselves and not be the sick person and the stigma around that and being treated like fragile (P2).
In our groups we are allowing all these feelings with any judgment, there is no right or wrong way of grief. So we are allowing a safe place for someone to express their feelings of loss without any judgment or how to guide which I think for individuals who's having a hard time sharing with outside members who don't understand they can come here and people get it (P3).
And they talked about it all the time every time they were talking "what were gonna do" when I'm gone now, this has to be done, it was ... awesome! When you see that side and when you see the other side when no one is talking about anything. I think this is the side you need to be at, I think we need to talk about it, it's a natural part of life, we all are aiming at the same direction, some people is just not good with it (P7).
And you know lots of people would talk to a stranger versus their family, and you know this is one thing that in Grand Prairie that I noticed was that, lots of times family just came in and said nothing, just sit, and that's ok but then when they leave, you know, then I go in and I say "you need water, you need whatever" "no [bis]," and all of the sudden yes they say something and the conversation starts and you just roll from there, right? And so you ... for me, it was like "why?" [bis] why, don't they talk to their family? (P7)
I think there's a lot of things people want to talk about, and I think you lose a lot of inhibitions, too, when you know that you're dying.... You could talk about pretty much anything and not have to think "Oh!." And she could tell me stories about friends of hers, and she could tell me that because I don't know any of her friends. I don't know any of these people. So, like she'd say, 'if I talk about this, it's between you and me'. Like, "I don't even know any of your friends! You can tell me, and I won't say anything!" So, I think that confidentiality, too, is big, and to show weakness when we're not supposed to. Moms, grandmothers don't show weaknesses. I'm sure it's the same with men. You don't show weaknesses. You just toughen up and ... Right? (P8)
They know that this place exists for this for this experience, the death experience. And they know that everybody here is either trained or trained for helping them with this experience ... even us as volunteers we go through some training too. So, it's a place where they often express when they are doing the grief group, they feel safe ... (P10)
It's confidential, it's a safe place sharing what they share it doesn't go outside of these walls ... and I think that facilitates more honesty and openness I'm not saying that they don't do that with the professional counsellors here because we don't witness that and they are all say that they have been ... some of them have had some bridging here with the counsellors ... that really help them (P10).
Theme 2. Normalcy of conversations about death and dying
Sometimes I've just been asked to go in and just to be there but most times I've been asked when someone is still pretty alert and wanting to chat and just another time something I did for a bit is sitting out, there is a table out there and often we wheel them out and I've gone and they ask me sometimes but I can just see a spot when I've had nothing to do and I'll just go in and talk about their life where they have been at or what they've done ... One fellow he read poetry, and he gave me a piece of poetry he read and ... I didn't realize he was actually a cowboy poet so things like that, just to be alert ... you know, there is time and we can help out there and they are greatly open (P5).
Lots of talks are about their families, lots of them. You know, all this people that don't have family, lots of them are afraid to die, some are conversations about religion, you know? Whatever I have many conversations with many people, a couple of younger ... when I was volunteering there was a young fellow ... he in particular wasn't afraid to die. He was ready, he was ready to go, he wanted his father to be done with this, and his watch what his dad has gone through, and he was 20 years old! It was, he was quite interesting actually, yeah, so I've got a whole different perspective on that from him, I learnt a lot from him, yeah (P7).
Yeah, I've had a lot of conversations about it. I want to know where people are at (laughs) I am inquisitive, right, so ... you know, I think it helps people to talk, you know? Some people are pretty shut down but if you know how to get around that, you know, people would open up, and would talk, and you know lots of people would talk to a stranger versus their family (P7).
He was ready to die and he'd mentioned that on several occasions, he said could be the day, today could be the day, I could just have a heart attack and that would be in. And I would say to him, so are you ready to die? And he'd say: Oh yeah, I am ready, I was ready yesterday, what happened yesterday? I am still here ... (P7)
But she was at the point where other than family and myself, she really had no interest in seeing anybody. A lot of people don't know how to relate to people who are dying. They don't want to talk about it. They just want to hear that everything is OK. And this individual, she wanted to talk about everything and anything. But she kept things from her family. Like near the end, I said to her "Do your kids know where you're at? Do they know where you're at, at this stage in your life?" and she said "No, no they don't." Because she held it back. She didn't want them to worry. That's what mom's do. That's what grandmas do. But she could tell me. We would cry together. We laughed together, we cried together. We talked about everything from sex to ... you know? And then I would tell her silly stories that were going on, and she would tell me silly stories that went on, like it was just ... I think the laughter. I think that was a big part of what I try to bring in. I'm not trying to belittle what they're going through at all. I don't mean that at all. But it's just to get their head out of where they are (P8).
Because she was very much, as most women are, protectors. You don't want to talk about things that are not comfortable. But with a volunteer, which, if you have a good relationship ... I mean, we had a great relationship, we can talk about those things. Like I'd go there some days, I'd go over there some days, and I'd bitch about my husband: "you'll never guess what he did today." You know? And she was telling me things I should be doing, making him do (P8).
The conversations can just really be small talk ... if I get the sense that they wanna have more of an in-depth conversation, I would sit with them, and I'd have a conversation about their life, their work, how their family is like, reminiscence about the past; sometimes they would like to talk about end of life and so ... yeah ... it really depends on the situation. I usually let them ... the patients kind of dictate more, take the conversation; I don't try to direct at all (P11).
Theme 3. Building meaningful relationships
That's why that table out there is so important too because volunteers sit there, the staff sit there occasionally and the residents and seems that they are put there for us to talk to and encourage and we can get encouraged too, so ... But I've been doing the same like reading sometimes just sitting quietly ... would you like to talk or you just want to be quiet? Just some of them want to be quiet but the one that I went to see a lady and she said to me "I am a Christian, but I am not so sure if I believe anymore, what should I do?" [laugh] so we have a really good discussion, and I can't tell her what to do but yeah, it was a challenge some of them are scared, some of them don't want to be alone (P6).

(Continued)

Table 4. (Continued.)

You have to be compassionate in order to do this ... forgiving ... If you cannot forgive yourself you cannot be with these people ... because there is this non-judgment thing, right? (P7)
But sometimes, and I've found, they can tell me they've had concerns with their family, or they're worried about this or they're worried about that, which they can't talk to their family about. Sometimes it's easier with a stranger that's got no vested interest in them. To speak and to just to listen. "I hear what you're saying," you know? (P8)
I've been called in in the middle of the night, that someone was close. Or, just anxious [with emphasis]. And all they want is somebody just to be with them. And I bring a book, and I sit, and I make sure.... Hold their hand once in a while, and I rub their shoulder "I'm here with you" and "just relax," you know? "Get some rest" [in tender voice]. [...] And I just talked with him, and I just used his name, and I reassured him that everything's looked after and everyone's fine, and "you can just relax," you know? And "everything's good." And just that reassurance, which I think I would like, if I were in that situation, I think I would like for somebody to say to me, "yeah, it's OK now, you know? It's OK." And he passed when I was with him. And it was very, very calm, and I was still holding his hand when he passed, and I went out and I told the nurses, "He's passed" (P8).
I feel it was helpful to them it seem to be a bit calmer especially when you talk a little bit about it if they show any fear you can kind of reassure then ... but [after 10 seconds] yeah, it's reworthy but I think if you can make them feel that they are still loved, that they are still cared for people and they are supported and whatever the journey is that they won't be alone that is always a big one, they don't wanna be alone, so they must feel that there is a need there to be allowed 15.20, to be accepted ... but yeah the levels of spirituality you know is always a big ... (P9)
Theme 4. End-of-life conversations as a transformative experience
But experienced a lot of great gifts from this people which was also very helpful for me in many ways I think everybody has a way to shine (P1).
Well, I don't know they bring me just to embrace life and enjoy it well, what the hell and ... so it's been very encouraging to me like to ... you know we are going to die some time but to enjoy the moments that you've gone and enjoy the rest of them ... (P4).
We are more open since I've been here, we are more open and the kids ... we plan ahead, everything is plan ahead, and they know what's gonna happen, there's gonna be stuff, they're gonna forget about whatever but it makes it so much peaceful for me to think about. When I'm gone, they can carry on with this they'll all gonna get this place down and down south, they're gonna to fire over, who's gonna go where and when. That will be fun [laugh] they can do that. But, yeah, that's a good think, and I've never thought about how important that is and how much easier it is, probably, because of being here (P5).
I'm learning to listen more and try to be more open minded to that, doesn't mean that I have to change my views, but I need to listen, so I think it's probably helping me to be a better listener (P5).
Even all these people are dying we can really learn from them. Maybe more prepared and talk to our families. I talk to them, especially to my husband but even with our kids; we talk about death and dying. They don't really like deep conversations, but we have lots (P6).
It really is an honor to be able to see someone when they are dying and when they die, it's a really special time because it's only one happened once to them and they are willing to it have you there. It's [bis] really a privilege (P6).
Absolutely, the young one really had an impact on me. I think it was just because he was so young and we just he was so ... Because you know, you deal with different kinds of personalities and people, and you get people that are just get mad out of the situation and: "Why me? Why me?" And then you get this young fellow, handsome, just a nice kid, he's ok of all of that so what makes ok with all of that with this other person is lived during years 19.30 that for me I just don' understand it (P7).
because seeing anybody go that you love is a heartbreak ... but they influence me in that ... I guess as I've said ... I embrace life more ... yeah. I don't feel a negative about death maybe that's partly my who, cause we, my husband and I have had to face so many of our peers dying and so I guess it's more become in our age a reality so if ... you face ... there's no choice you have to face reality at your age, so I don't want that to be ever be a negative thing. I don't want to be a negative thing for my kids, my grandkids so I think the best way that kind of influence me is to just enjoy, you know, live everyday as another opportunity (P7).
A lot of people ask me "how can you do what you're doing?" I was sitting with an individual here, a resident in here. I came into the room to sit with her, and it was a friend of mine from the golf course, it was his aunt, and he said, "I didn't know you did this," because he had to go to work and whatever, and I was coming in to sit with her because she wasn't doing well. And both of them still, every time I see them, they thank me, and they say "I don't know how you can do that. We do it because it's a family person. But I don't know how you do it." But it gives me, like, to me, I don't know. It's an honor for these people to share their time with me. It's an honor for me (P8).
Has been particularly very re-worthy compared to others because it's very special to sit when somebody is dying so yes has been close to my heart, for sure (P9).
I guess because I embrace life more, I've also left some friendships that I was feeding ... I feel that I need to spend more time with people ... and in places that feed my soul so I'm more at peace (P10).
Life is more about a privilege that I've never thought before it's a chance to ... to do, to ... not that I believe that you get points for what you do, it's not that but I love to think of maybe leaving the world a little better (P10).
I truly believe that was beautiful. That maybe led to that other question ... He said, as his wife drove into bed with him, two nights before he actually died.... He just had not being speaking, he just was very silent, and the conversation was over. But that night he got very alert, and he looked at her and he said, "I'm going to miss you." So that was the grief that I was talking about too, he knew he was going, and he was going to miss this world, I guess that was the conversation that I remember the most (P10).
I wasn't in charge of her and I was there to hug her as she left this world it was my most poignant experience that I've ever had because it was just such a relaxation of her body, I've just whispered in her ear, you know, "Elyse, you can go, you've lived enough," I've just felt that as I was whispering in her ear for a while and just felt her body relaxed and she was gone so those are the three experiences I had with death and probably all different (P10).

end-of-life conversations between volunteers and hospice patients, as illustrated by the following quote:

We are allowing a safe place for someone to express their feelings of loss without any judgment, which I think for individuals who are having a hard

time sharing with outside members who don't understand that they can come here. [...] People just get it because everybody is there because they can't share with anybody else; that's the issue, why people come to us. (P3)

All interviewees referred to their hospice as "my place to volunteer," not only because of the support they received there but primarily because of the special mission of the hospice to help people in their last life moments. They could offer support, presence, and love through small gestures that convey dignity in these circumstances of maximum fragility, such as singing, offering warm sheets, or simply being silent and holding patients' hands. This context of normalcy, naturalness, and care contributed to patients viewing hospice as a safe place for serious end-of-life conversations where volunteers have time to "discover each person." Volunteers experienced hospice as a place where patients are treated as people (as whole persons) who are loved and cared for as they deserve, where death is conceived of as a normal and expected part of life, and where life and death can be discussed naturally without making loved family members suffer. Hospice was also seen as a place where everyone can be her/himself beyond their illness.

Theme 2. Normalcy of conversations about death and dying

The volunteers stated that many topics of conversation about end-of-life concerns and impending death emerged during their volunteer work. One of the greatest concerns shared by patients was about how loved ones would carry on after they had died. Being a burden on loved ones was thus revealed as a major source of suffering for them. Not being present during significant future moments of their loved ones' lives was another recurring concern among hospice patients. Yet, some hospice patients had no family members, or none who were obviously present, and the participants felt that these patients suffered from this lack. Moreover, some volunteers had patients who barely mentioned relatives throughout their hospice stay. The volunteers respected that they did not want to talk about their families, potentially due to unresolved or unresolvable family problems.

The conversations included many end-of-life topics that ranged from accepting death and being prepared to die, to fear of death. Conversations about faith, religion, and personal spiritual beliefs were also frequent. Some volunteers facilitated contact with a spiritual leader when a patient belonged to a religious group. Others encouraged patients to contemplate the meaning of their life. All listened attentively as they recognized that hospice patients would naturally talk about death and dying. When asked specifically whether they had experience with patients who had expressed a desire to die, 9 of the 12 interviewees answered yes, at least once. The expressed desire to die ranged from the natural acceptance of impending death and the desire to see loved ones who were already deceased to a direct request for death by euthanasia or assisted suicide (MAiD). The wish to hasten death was viewed by the hospice volunteers not only as a way of expressing end-of-life suffering or as a manifestation of hopelessness but also as a form of self-determination and control, as illustrated in the following quotation:

He was just ready; he just said, "I want this over. I am not going to make it out of this. Can I just go to sleep? Why can't I just make it happen?" This was the conversation with him every day.... I don't know. Maybe you are here for a reason, maybe you are here to talk to me, maybe you are here to figure my life out like ... you know, we have lots of conversations. (P7)

This talking about the desire to die was experienced in different ways by the volunteers. For some, it was a difficult or sad occasion,

while others said they felt comfortable with these conversations. For instance, 1 reported that these conversations made her feel privileged, which strengthened her sense of belonging to the hospice:

Maybe [she talked to her about her desire to die]... because she didn't know me. I wasn't part of her family. Maybe she just felt really free. And I don't really know if she was asking me ... necessarily why she wasn't gone. But she was making sure that I realized that she was annoyed' cause she was ready. I can almost imagine myself, ok, I've wasted a lot of time, come on, and I'm ready. I think that they are even more comfortable with someone maybe even more than with their family. [...] Which makes me feel very privileged. (P5)

Theme 3. Building meaningful relationships

The most prominent communication facilitator was thought to be an empathetic and compassionate volunteer presence. The volunteers explained that investing time with the patients allowed them to establish a bond of trust that often ended in strong friendships. In explaining their tasks, many stated that their role sometimes consisted of simply "being there" unconditionally and with no self-serving end. They did not have professional care duties that had to be fulfilled. Another important category related to the power of presence was attentive listening. The volunteers reported that allowing silence, actively listening to patients without judging them, and letting them express themselves freely facilitated a high level of communication:

I think it's really meaningful for me to just sit with people in silence sometimes and just kind of feel their presence to be really grounded in my own presence, and I feel like there is just the connection that happens in that silence, so I found that very meaningful. There was one case recently ... with a patient that was really, really anxious, and he was crying out loud [...]. A couple of the nurses asked me to sit with him, and so I did, and he was really anxious; he was breathing very rapidly, and I just sat with him. And I didn't say very much, and then, all of a sudden – he had been kind of unresponsive – he sat up and looked at me and goes, "Who are you?" and [...] I feel he was just kind of opening himself up in a way that he hasn't for a while [...] so he started to tell me about his life [...]. He had just completely changed, and I was quite moved by just the change in his breaths come down and seemed more settled, and he was able to sleep [...] I was moved by that. (P11)

Another common denominator was the importance of accommodating each person so that every individual could talk freely about what they wanted to express:

The conversations can just really be small talk ... if I get the sense that they wanna have more of an in-depth conversation, I would sit with them, and I'd have a conversation about their life, their work, how their family is like, reminiscence about the past; sometimes they would like to talk about end-of-life, and so ... yeah ... it really depends on the situation. I usually let ... the patients kind of dictate more, take the conversation; I don't try to direct at all. (P11)

Finally, the volunteers thought that the hospice patients could simply be themselves with the volunteers. They did not have to act brave or be good patients. The patients could go beyond their role as patients to speak openly about death, with some even talking humorously about death and dying. They could be treated as ordinary people in this favorable context where they could open up and talk freely. This context of friendship, compassion, and permission to express and share thoughts and feelings about any topic including end-of-life concerns favored the building of deep personal relationships between patients and volunteers. Although it

was not always easy to identify the limits of these relationships (3 participants stated that they had some moments of uncertainty about their role), the support of the hospice workers was stated as crucial in managing these situations. Building meaningful relationships was described as one of the most enriching experiences for a hospice volunteer.

Theme 4. End-of-life conversations as a transformative experience

Hospice volunteering and accompanying people who are engaged in end-of-life processes were described by the volunteers as a transformative experience for them, in which they had learned a lot about life and death, and it allowed them to consider their own future mortality and life situation. Moreover, it changed their perspective on important issues, as well as priorities (such as friendship, life objectives, and spending time with family and loved ones). Some of them also remembered and thus were struck by particular conversations that they had had with patients. These volunteers described such experiences as “an opportunity to embrace life.” Many quotations reflect these and other benefits of volunteering. For example, P12, who had worked in the oil and gas industry, stated, “I found that there was no sense of reality working downtown (at my oil and gas job), so I wanted to, I guess, get more in touch with what reality is, which is here [in the hospice helping dying people].”

Others affirmed that it was an honor and a gift to be a witness to the life and death of another. Accompanying someone in the last moments, even being present in the final dying process under a “no one dies alone” policy, was a unique experience.

Participants described this end-of-life process experience in terms of “beauty” or “privilege.” For instance, P1 said, “I was there just to comfort him, but it was a very moving experience, and he did it [died] with such ahh ... [takes time to think] beauty; it was amazing.” Volunteers also affirmed their learning through their hospice work; P7 said, “I’ve got a whole different perspective on that from him. I learned a lot from him.”

Some volunteers affirmed that the death of a hospice patient, when there was a certain relationship, was a personal loss for them. In these cases, hospice professionals supported the volunteers in handling these difficult situations, both in advance of the death and afterward when the volunteers were grieving.

Three of the volunteers reported hearing explicit requests by patients of a wish for help to end their lives or hasten their death. Ultimately, 2 of the hospice volunteers’ patients died of their illness, before Medical Assistance in Dying (MAiD) had become legal in Canada. The remaining volunteer accompanied a patient who had asked for MAiD and then died of it, after it had become legal and available in Canada for those who qualify. None of the volunteers experienced moral distress or other concerns in talking with patients about their wish to hasten death, nor were the volunteers uncomfortable talking about this or any other end-of-life topics. All subjects discussed were relevant to the patients, so they were considered acceptable and worthwhile topics of conversation.

Discussion

This study explored end-of-life conversations between hospice volunteers and dying people about death and dying, including an expressed desire to die, from the volunteer perspective. We also explored the impact of these conversations on the volunteers.

The first theme, trusting conversations in the context of a safe place, showed, in the terminology of Wong et al. (2013), that contextual influences generate certain outcomes. This explains that in terms of our research question on the nature of end-of-life conversations, many participants alluded to the “hospice” context as a safe space where the presence and “free” work of volunteers and recognition of the special humanity and dignity promoted by the hospice philosophy favored the emergence of conversations about the end-of-life.

We learned from the hospice volunteers, in line with some other studies (Somes et al. 2018), that the patients perceived them as peers and that they had time for “unhurried conversations,” which facilitated openness to spontaneous, confident, and insightful end-of-life conversations.

This study provides valuable additional information, however, on end-of-life topics of conversation that occur between volunteers and hospice patients. To our knowledge, this is the first study to address the experience of volunteers with patients who express a wish to die. Consistent with the framework proposed by Schroepfer et al. (2009), the volunteers identified different intentions in patients’ expression of this wish. Most volunteers said that conversations about wishing to die occurred naturally within the framework of impending death and thus were an accepted reality. As previous studies have revealed, the participants carried out routine tasks of hospice volunteers (Bloomer and Walshe 2020), but one of the most important actions reported by all volunteers in our study and others (Dodd et al. 2018) was just being present, listening to and to some extent participating in any talks about the end-of-life.

In keeping with a previously proposed death wish taxonomy (Ohnsorge et al. 2014; Rodríguez-Prat et al. 2017), we identified various meanings of the wish to hasten death. One of the main identified meanings is when suffering is intense, the patient wants it to end. This wish may not be a genuine desire to die (nor suicidal ideation) but rather an illustration of suffering that has not been addressed (Kremeike et al. 2018).

Another identified meaning of the wish to hasten death is to end the suffering of others, such as beloved family members who were already grieving in advance of the death. Other qualitative studies have similarly described this desire to avoid being a burden to others as a trigger for a wish to hasten death (McPherson et al. 2007; Rodríguez-Prat et al. 2019). In our study, volunteers often self-identified as crucial in allowing patients to see that their life – in line with logotherapy (Frankl 1991) – still had meaning, not only for themselves but also for their loved ones.

Only 3 of the 12 participants had heard explicit requests for death or a wish to hasten death. In 2 of these cases, the patients who verbalized this wish died because of their illness, as the decriminalization of MAiD in Canada had not yet come into effect, and these requests were made before that date. However, after MAiD was legalized in Canada, 1 of the volunteers had a patient who requested and received MAiD. In this case, the participant had developed a close relationship with this patient, and her death had a great impact on the volunteer. However, most participants indicated that they had developed close relationships with a number of patients, and so all deaths of these people had a great impact on them.

Another crucial finding of our study was that volunteers built meaningful relationships with patients. This was done in part through discussions but also by silence. “Just listening” may be one of the greatest gifts that one person can give another. Unlike the findings of Somes et al. (2018), none of our participants reported anguish or distress when sitting in silence with hospice patients.

Rather, they considered listening by being silent as being valuable work.

Similar to the results of other studies, volunteers did not find it upsetting to talk about the desire to die (Crespo et al. 2021). They stated that this type of conversation could arise naturally due to the relationship of trust between them and more broadly at the hospice, where it was clear to everyone that the patients were dying. In no case was this conversation or the desire to die uncomfortable for either party. A study that compared the fear of death among paid staff and volunteers found that this fear was lower in volunteers (Zana et al. 2020). This difference can be explained by the altruistic motivation of volunteers in comparison to the professional duties of staff. Not having as much direct and daily contact with the burden of the disease and with death through full or part-time employment may also explain why the experience and well-being of volunteers could be described as better (Zana et al. 2020).

We also found beneficial and transformative effects of end-of-life conversations on the volunteers themselves. Similarly, in a study by Beasley et al. (2015), some participants referenced how participating in a hospice, and specifically talking with dying people, helped them grow personally. Other researchers mentioned that being with these people had helped volunteers in their own personal process of mourning or regarding their own mortality (Claxton-Oldfield et al. 2007).

One limitation of our study is that only female volunteers were interviewed. However, this circumstance is understandable, as Bloomer and Walshe (2020) found most people who perform this type of service are women. We were unable to recruit any male volunteers, in large part because so few are hospice volunteers. Their experiences and perspectives are therefore not identified, a gap for future research to address. Another limitation is that only English-speaking volunteers in 1 Canadian province were recruited. Other volunteers elsewhere may have different feelings and experiences.

Regardless, this study demonstrates the value of end-of-life volunteers as well as their need for initial and ongoing in-service education so they can perform a range of needed and highly valuable end-of-life duties. End-of-life conversations should be viewed as a major duty of hospice volunteers. In our study, all participants received an initial training that also included how to approach end-of-life conversations. Hospice volunteers felt prepared to participate in these conversations and valued the support received from hospice managers and health professionals if they did not know what to do. However, it is important to note that hospice volunteers in Canada are not to initiate conversations with patients about MAiD (Canadian Hospice Palliative Care Association 2017). Thus, it is necessary for them, not only to learn how to manage conversations about an eventual desire to die but to know the boundaries of what is permitted for them as volunteers. In this vein, in-service training about what is the desire to die, and what this desire can mean should be mandatory for those in contact (volunteers, health-care professionals, and family members) with people nearing the end-of-life.

Future research should address the value of silence and active listening, as well as helpful conversations. Moreover, research should determine what is most helpful when dying people are at odds with or not in touch with their families. Many people, when dying, have some form of conflict with their families (Wilson et al. 2020).

Conclusions

End-of-life volunteers clearly do essential work in hospices. The safe environment of the hospice, the volunteers' commitment to

care and confidentiality in relation to hospice patients, and the ability of volunteers to meet the basic and emotional needs of dying people or simply just be there contribute to volunteers having the potential to conduct timely and helpful conversations about death and the dying process, including the desire to die. These experiences and end-of-life conversations are also transformative for volunteers.

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References

- Beasley E, Brooker J, Warren N, et al. (2015) The lived experience of volunteering in a palliative care biography service. *Palliative and Supportive Care* 13(5), 1417–1425. doi:10.1017/S1478951515000152
- Bloomer MJ and Walshe C (2020) 'It's not what they were expecting': A systematic review and narrative synthesis of the role and experience of the hospital palliative care volunteer. *Palliative Medicine* 34(5), 589–604. doi:10.1177/0269216319899025
- Canadian Hospice Palliative Care Association (2017) Hospice Palliative Care and Medical Assistance in Dying (MAiD) in Canada. Guidance for health care professionals and volunteers in hospice palliative care and other settings. <https://www.chpca.ca/wp-content/uploads/2019/12/chpca-maid-booklet-eng-12page-final-web.pdf>
- Claxton-Oldfield S (2007) The impact of volunteering in hospice palliative care. *American Journal of Hospice & Palliative Medicine* 24(4), 259–263. doi:10.1177/1049909106298398
- Crespo I, Monforte-Royo C, Balaguer A, et al. (2021) Screening for the Desire to die in the first palliative care encounter: A proof-of-concept study. *Journal of Palliative Medicine* 24(4), 570–573. doi:10.1089/jpm.2020.0276
- Delaloye S, Escher M, Luthy C, et al. (2015) Volunteers trained in palliative care at the hospital: An original and dynamic resource. *Palliative and Supportive Care* 13(3), 601–607. doi:10.1017/S1478951514000169
- Dodd S, Hill M, Ockenden N, et al. (2018) 'Being with' or 'doing for'? How the role of an end-of-life volunteer befriender can impact patient wellbeing: Interviews from a multiple qualitative case study (ELSA). *Supportive Care in Cancer* 26(9), 3163–3172. doi:10.1007/s00520-018-4169-2
- Frankl V (1991) *El Hombre En Busca de Sentido Man's search for meaning*. Barcelona: Herder.
- Granek L, Krzyzanowska MK, Tozer R, et al. (2013) Oncologists' strategies and barriers to effective communication about the end of life. *Journal of Oncology Practice* 9(4), e129–35. doi:10.1200/JOP.2012.000800
- Kremeike K, Galushko M, Frerich G, et al. (2018) The DEsire to Die in Palliative care: Optimization of Management (DEDIPOM) – A study protocol. *BMC Palliative Care* 17(1), 30. doi:10.1186/s12904-018-0279-3
- Luijckx KG and Schols JM (2009) Volunteers in palliative care make a difference. *Journal of Palliative Care* 25(1), 30–39. doi:10.1177/082585970902500104
- McPherson CJ, Wilson KG and Murray MA (2007) Feeling like a burden: Exploring the perspectives of patients at the end of life. *Social Science & Medicine* 64(2), 417–427. doi:10.1016/j.socscimed.2006.09.013
- Numico G, Anfossi M, Bertelli G, et al. (2009) The process of truth disclosure: An assessment of the results of information during the diagnostic phase in patients with cancer. *Annals of Oncology* 20(5), 941–945. doi:10.1093/annonc/mdn709
- O'Brien BC, Harris IB, Beckman TJ, et al. (2014) Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine* 89(9), 1245–1251. doi:10.1097/ACM.0000000000000388
- Ohnsorge K, Gudat H and Rehmman-Sutter C (2014) What a wish to die can mean: Reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care* 13(38), 1–14. doi:10.1186/1472-684X-13-38

- Rodríguez-Prat A, Balaguer A, Crespo I, et al.** (2019) Feeling like a burden to others and the wish to hasten death in patients with advanced illness: A systematic review. *Bioethics* **33**(4), 411–420. doi:10.1111/bioe.12562
- Rodríguez-Prat A, Balaguer A, Booth A, et al.** (2017) Understanding patients' experiences of the wish to hasten death: An updated and expanded systematic review and meta-ethnography. *BMJ Open* **7**(9), 16659. doi:10.1136/bmjopen-2017-016659
- Schroepfer TA, Noh H and Kavanaugh M** (2009) The myriad strategies for seeking control in the dying process. *The Gerontologist* **49**(6), 755–766. doi:10.1093/geront/gnp060
- Smith JA, Flowers P and Larkin M** (2009) *Interpretative Phenomenological Analysis. Theory, Method and Research*. London: SAGE.
- Somes E, Dukes J, Brungardt A, et al.** (2018) Perceptions of trained laypersons in end-of-life or advance care planning conversations: A qualitative meta-synthesis. *BMC Palliative Care* **17**(1), 1–19. doi:10.1186/s12904-018-0354-9
- Vanderstichelen S, Cohen J, Van Wesemael Y, et al.** (2019) Perspectives on volunteer-professional collaboration in palliative care: A qualitative study among volunteers, patients, family carers, and health care professionals. *Journal of Pain and Symptom Management* **58**(2), 198–207.e7. doi:10.1016/j.jpainsymman.2019.04.016
- Wilson DM, Anafi F, Roh SJ, et al.** (2020) A scoping research literature review to identify contemporary evidence on the incidence, causes, and impacts of end-of-life intra-family conflict. *Health Communication* **36**(13), 1616–1622. doi:10.1080/10410236.2020.1775448
- Wilson DM, Justice C, Thomas R, et al.** (2005) End-of-life care volunteers: A systematic review of the literature. *Health Services Management Research* **18**(4), 244–257. doi:10.1258/095148405774518624
- Wong G, Greenhalgh T, Westhorp G, et al.** (2013) RAMESES publication standards: Meta-narrative reviews. *Journal of Advanced Nursing* **69**(5), 987–1004. doi:10.1111/jan.12092
- Zana Á, Kegye A, Czeglédi E, et al.** (2020) Differences in well-being and fear of death among female hospice employees and volunteers in Hungary. *BMC Palliative Care* **19**(1), 1–8. doi:10.1186/S12904-020-00550-Z