Palliative and Supportive Care

cambridge.org/pax

Impact of an education program to facilitate nurses' discussions of existential issues in neurological care

A. Ozanne, PH.D.[1,2], I. Henoch, PH.D.[1], J. Öhlén, PH.D.[1,3,4], B. Jakobsson Larsson, PH.D.[5,6] and C. Melin-Johansson, PH.D.[7,8]

[1]Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden; [2]Department of Neurology, Sahlgrenska University Hospital, Gothenburg, Sweden; [3]University of Gothenburg Centre for Person-Centred Care, University of Gothenburg, Gothenburg, Sweden; [4]Palliative Centre, Sahlgrenska University Hospital Västra Götaland Region, Gothenburg, Sweden; [5]Department of Global Health and Caring Sciences, Uppsala University, Uppsala, Sweden; [6]Department of Neuroscience, Neurology, Uppsala University Hospital, Uppsala, Sweden; [7]Department of Nursing Sciences, Mid Sweden University, Östersund, Sweden and [8]Department of Health Sciences, Ersta Sköndal Bräcke College, Stockholm, Sweden

Original Article

Cite this article: Ozanne A, Henoch I, Öhlén J, Jakobsson Larsson B, Melin-Johansson C (2022). Impact of an education program to facilitate nurses' discussions of existential issues in neurological care. *Palliative and Supportive Care* **20**, 630–636. https://doi.org/10.1017/S1478951521001620

Received: 9 March 2021
Revised: 17 August 2021
Accepted: 19 September 2021

Key words:
Education; Existential; Neurology; Nursing; Spirituality

Author for correspondence:
Anneli Ozanne,
Institute of Health and Care Sciences,
Sahlgrenska Academy,
University of Gothenburg,
Gothenburg, Sweden.
E-mail: anneli.ozanne@gu.se

Abstract

Objectives. Discussing existential issues is integral to caring for people with acute, progressive, or life-limiting neurological illness, but there is a lack of research examining how nurses approach existential issues with this patient group and their family members. The purpose was to examine the experiential impact of an educational program for nurses designed to facilitate discussions of existential issues with patients and family members in neurological wards.
Method. Nurses in inpatient and outpatient care at a neurological clinic in Sweden were invited to participate in an education program about discussing existential issues with patients and their family members as related to neurological conditions. The evaluation of the program and of the nurses' view of discussing existential issues was conducted through focus groups before and after participation. The data were analyzed by qualitative content analysis.
Results. The program gave nurses a deeper understanding of existential issues and how to manage these conversations with patients and their family members. Both internal and external barriers remained after education, with nurses experiencing insecurity and fear, and a sense of being inhibited by the environment. However, they were more aware of the barriers after the education, and it was easier to find strategies to manage the conversations. They demonstrated support for each other in the team both before and after participating in the program.
Significance of results. The educational program gave nurses strategies for discussing existential issues with patients and family members. The knowledge that internal and external barriers impede communication should compel organizations to work on making conditions more conducive, for example, by supporting nurses to learn strategies to more easily manage conversations about existential issues and by reviewing the physical environment and the context in which they are conducted.

Introduction

Neurological diseases are often progressive, with physical and sometimes mental deterioration. They can also lead to death, although patients more often die from other causes (Koekkoek et al., 2014; Oliver et al., 2016). This means that patients and family members might experience that their earlier existence and lives are threatened and as a result, existential issues can arise for them both. This could, for patients, manifest in experiences of existential loneliness with death anxiety, feelings of unfairness, guilt and shame, and searching for meaning, and family members might feel lonely and isolated, which they can have a need to discuss (Ozanne et al., 2013, 2015). For healthcare professionals (HCPs), adopting an open approach to meeting patients and family members to discuss existential issues early on and not only at the end of life can be regarded as part of a health promotive palliative approach (Cohen and Deliens, 2012; Sawatzky et al., 2017). However, despite awareness that certain issues are important to patients, HCPs do not always invite discussion about these concerns because of fear, and the lack of knowledge and time (Strang et al., 2001).

Existential philosophy reflects on human existence and its limitations (Tomer et al., 2008). Questions about meaning, freedom, loneliness, and death (Yalom, 1980) are existential issues that persons with diseases deal with, but there is a lack of education in this area (Eriksson et al., 2015). In order to provide person-centered care (Britten et al., 2020) or person-centered palliative care (Öhlén et al., 2016; Österlind and Henoch, 2020), it is important to listen to the patient's expression of existential issues.

CAMBRIDGE UNIVERSITY PRESS

To achieve such person-centered care, HCPs may need to adjust their attitudes to patients with existential issues. A randomized intervention aiming to assist HCPs in this regard has shown to be effective (Morita et al., 2009). Other interventions have shown that HCPs who care for patients with untreatable cancer are more comfortable communicating with patients about existential issues after the intervention (Henoch et al., 2013; Udo et al., 2014), and it is easier for them to identify situations where existential issues are visible (Browall et al., 2014). Moreover, they can reflect on how to be open to conversation and make use of both words and silence to good effect (Strang et al., 2014). With such approach, HCPs are also reported to experience less work-related stress, (Udo et al., 2013) and increased perceived knowledge, awareness, and preparedness (Sand et al., 2018).

Nevertheless, few studies examine how HCPs address existential issues that arise for patients with neurological diseases and their family members. The severity of many neurological diseases, with deterioration over time and life-limiting or acute impediments, indicates that attention should be given to existential issues for patients and their families' right from admittance to the neurological clinic. The purpose was to examine the experiential impact of an educational program for nurses designed to facilitate discussions of existential issues with patients and family members in neurological wards.

Methods

Design

The design of the study is a qualitative evaluation of an educational program facilitating nurses' discussion of existential issues with patients and their families. The evaluation was conducted before and after participation, with data generated in focus groups.

Participants

All registered and enrolled in- and outpatient care nurses at a neurological clinic at the Swedish university hospital were invited to participate in an educational program where they discussed existential issues. They received verbal and written information about the study from one of the researchers and 18 nurses approved participation. Written informed consent was obtained from all participants.

A total of 18 nurses (13 from the outpatient clinic and 5 from the inpatient clinic) approved participation, which resulted in two groups from the outpatient clinic and one group from the inpatient clinic (Table 1).

Education program

The nurses took part in a program of education (Table 2) on how to discuss existential issues with patients affected by neurological diseases and their family members. The program included existential issues as Freedom, Relationships and Loneliness, Life and Death, and Meaning, which all are questions Yalom (1980) describe as essential in existential questions in patients with lethal illnesses. This program was developed from a training intervention in conversations about existential issues for nurses working with patients with cancer (Henoch et al., 2013, 2015). As family members might be affected by their family member's illness (Olsson et al., 2010; Ståhl et al., 2020), the program also included questions related to their situation.

Table 1. Participants' background

Participants	*n*
Total no. of participants	18
Registered nurses/enrolled nurses[a]	15/3
Female/male	18/0
Total no. of groups	3
Participants in each group	7/6/5
Total no. of times each group were included in data collection	3
Total no. of group discussions	9
Mean age years (min–max)	45.4 (24–62)
Experience of working in health care: mean years (min–max)	20 (1–44)
Years employed at current work place: mean years (min–max)	14.8 (0–37)

[a]Undergraduate nurse education includes at least 3 years university education and qualifies for a national licence. Enrolled nurse education includes at least 1.5 years at a secondary education/college education level.

Table 2. Characteristics of the educational program

Educational topics	1. Freedom (session 1) 2. Relationships and Loneliness (session 2) 3. Life and Death (session 3) 4. Meaning (session 4) 5. Personal experiences of conversations about existential issues and evaluation of the program (session 5)
Program duration	10 weeks (sessions were held every second week)
Session duration	90 min
Written educational material	Text describing each topic
Working methods	• *Before each session*: reading a text about the existential topic they were going to discuss • *At each session*: Group discussions about the meaning of the existential topic were conducted in a dialogue format • Emphasis was given to creating an open atmosphere that enabled the participants to share experiences and learn collaboratively

Data collection

To evaluate nurses' reflections before and after their training in discussion of existential issues and to examine their experiences of the program, focus groups were carried out with each group before and after the program. The interviewer (SS) and the observer (IH) carried out the focus groups before and 6 months after the program. They are both researchers with solid experiences of interviewing and of focus group methodology. A semi-structured interview guide was used (Table 3) with questions about experiences of discussing existential issues with patients and family members and reflections about the program. The guide has been developed based on the aim and to gain more knowledge about the participants views on existential issues and how they handle these conversations before and after the education. In addition, session five of the program was included since the participants then could evaluate the program in direct

https://doi.org/10.1017/S1478951521001620 Published online by Cambridge University Press

Table 3. Interview guide before and after education

Interview guide before and after education	1. What do existential issues mean for you? 2. On which ways do you meet existential issues in your work? 3. What kind of existential issues do patients and their relatives ask about? 4. How do you meet these questions? 5. Do you have any tools to manage the existential issues you receive? 6. How do you invite to conversations about existential issues with patients and their relatives? Give examples of your own experience of such situations. 7. If you don't, why do you not invite to talk about existential issues? 8. Do you feel safe to talk about existential issues with patients and their relatives? If not, how do you think you could feel safer in these conversations? 9. What are the prerequisites and possibilities for you to talk about existential issues? 10. What are the hinders for you to talk about existential issues? 11. Thinking about existential issues, what is most important for you?
Complementary questions after education	1. Is it something else you want to talk about? 2. Do you feel safer to talk about existential issues after the education? 3. Have the education made you more confident to talk about existential issues with patients and their relative? If yes, on which way? If no, why not?

connection to it. In this way, data were obtained before the program, directly after and after half a year. The course leader delivering the education (CB) collected data during the fifth session of the program, which was structured by the participants' own experiences of conversations about existential issues and their experience of participating in the program. CB is an experienced course leader and a clinical nurse specialist and teacher with expertise in palliative care and supervision of nurses and nursing students. Sessions one to four were part of the education programme and not included in the analysis (Figure 1).

The first group started in January 2016 and the last was completed in November 2016. All data collection took place at the hospital in an undisturbed room, with interviews and discussions audio-recorded and transcribed verbatim.

Analysis

Data were analyzed with an inductive approach using qualitative content analysis (Graneheim and Lundman, 2004; Graneheim et al., 2017; Lindgren et al., 2020). All interviews were read several times to reveal emerging patterns. Data from the focus groups before and after the program, as well as data from the fifth session of the program, were first analyzed separately. The first author (AO), divided the text into meaning units, and each meaning unit was then condensed, abstracted, and labeled with a code. Codes with similar content were thereafter abstracted and sorted into subthemes. This process was then discussed with the last author (CM-J) until consensus was reached. The authors have a strong background in the methodology. In this phase, it was obvious that content from all the interviews could be sorted and abstracted into the same subthemes, and within each subtheme differences before and after the education were analyzed. In this way, all the subthemes were built up with data from all interviews, both before and 6 months after the program and from the fifth session. The subthemes were then abstracted into two themes, which were then abstracted into a main theme. To ensure stringent and trustworthy interpretations, the analysis moved back and forth between the steps: meaning units, codes, subthemes, themes, and main theme, and between the parts and the whole text. All authors reflected and discussed the analysis until consensus emerged.

Ethical considerations

The Research Ethics Committee approval was obtained from the Regional Ethical Committee in Gothenburg (Dnr. 426-08).

Results

Remaining difficulties but with a deeper understanding

The main theme "Remaining difficulties but with a deeper understanding" illuminates how the nurses found strategies to manage

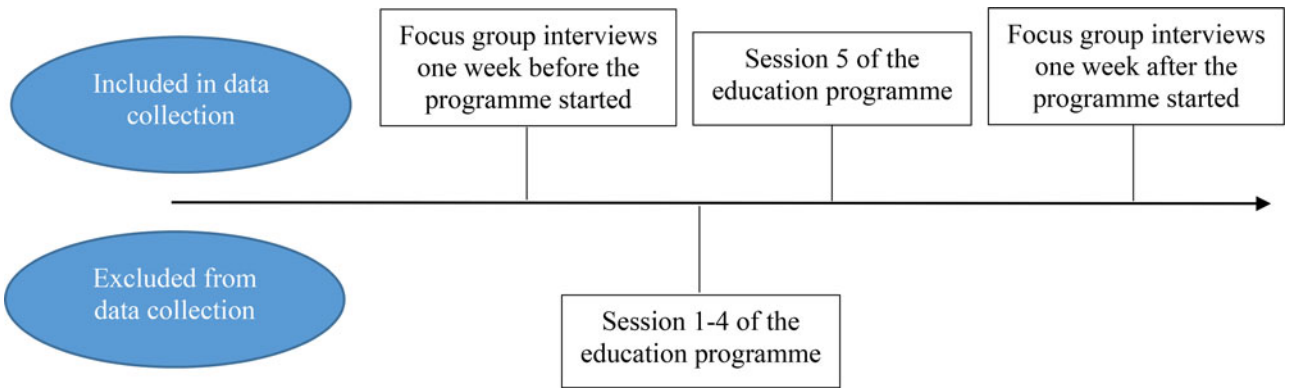

Fig. 1. Data collection. The focus group interviews before and after the program lasted for around 60 min and the focus group discussion in the fifth session lasted around 90 min.

https://doi.org/10.1017/S1478951521001620 Published online by Cambridge University Press

Table 4. Description of main theme, themes, and subthemes

Main theme	Remaining difficulties but with a deeper understanding	
Themes	Counteracting internal and external barriers	Finding strategies to manage conversations about existential issues
Subthemes	Feeling insecurity and fear	Addressing questions without answers
	Being inhibited by the health facility environment[a]	Being together in difficulty[a]
		Creating time for conversation[a]
		Supporting each other in difficulty[a]

[a]The participants gained a deeper perspective on things after the program. Internal and external barriers to communication, as well as strategies for managing conversations about existential issues, existed both before and after the program, but the nurses found it easier to find relevant strategies to use in the conversations after participating.

existential issues in difficult conversations, at the same time working to counteract internal and external barriers to communication. Finding these strategies was easier after participating in the program, as the nurses felt more comfortable asking about existential issues, were more at ease being quiet and showing that they did not always have answers, and were calmer about staying with the person in their time of need. The experiences of nurses discussing existential issues varied. It was considered a difficult part of work, but the education gave them a deeper understanding of the area and strategies to use in conversations. The main theme, themes, and subthemes are shown in Table 4 and in the text below.

Counteracting internal and external barriers

Nurses described trying to counteract internal and external barriers to discussions with patients and family members about existential issues both before and after participating in the program. Obstacles included feeling insecure and fearful in the conversations and that the health facility environment was not conducive to conversations, for example, due to lack of time and privacy.

Feeling insecure and fearful

The nurses felt insecure and fearful about discussing existential issues both before and after the program. It was difficult to know what to talk about and the nurses' insecurity increased if patients did not want nurses to talk with family members or if family members avoided conversation, even though they probably needed it.

Such insecurity and fear was worse among less experienced nurses who were prone to self-criticism. They wished they had managed situations differently with more control, and had been able to give answers, even though that was impossible and it was more important to listen. They found it difficult to initiate conversations as they were unsure if the person actually wanted to talk.

> Group 3 before education: *IP1: I think it's difficult too, if we get, for example, a patient with ALS who has deteriorated — maybe has pneumonia or something — then I don't feel, I don't know if she or he wants to talk about existential issues// You feel you like, you might get it wrong, or if I just say like, "Have you thought about death?", She or he might not want to talk about it, but just be treated here and now.// IP2: I prefer the patient to say something himself so you don't put your foot in it, assuming that you probably want to talk about it because you are so ill.

*I, interviewer; IP, interview person.

By avoiding the subject, it was easier to pass responsibility back to that person and focus on practical tasks, such as giving an infusion.

Feelings of insecurity and fear were less frequent after the program, which is described in subthemes below the theme "Finding strategies to manage conversations about existential issues".

Being inhibited by the health facility environment

The nurses felt that the health facility environment inhibited conversation about existential issues, with no difference before and after participating in the program. Lack of time and privacy to talk and having to cover for each other were examples of barriers. They felt that it was degrading to the person if they started a conversation but had no time to listen, so they avoided it.

> Group 3 before education: IP3:I think that such questions need time, that you have time to sit down, but unfortunately that time doesn't exist. //IP2: That's also something that means you might not initiate it [a conversation], because if you start talking, then I might not have time to sit down and answer or listen to what you want to say, and then I think it's degrading to that person.

They felt guilty when conversations about existential issues took time, but they gave it higher priority after the education.

Finding strategies to manage conversations about existential issues

The nurses found it difficult to address and start conversations about existential issues with patients and family members, and looked for strategies to acknowledge their questions without having answers, while staying with them in their time of need. The nurses tried to create time for the conversations on the basis of the resources available to them. After the program, the nurses still found all these aspects difficult, but the reflections and strategies they took away from the course sessions helped them come to a deeper understanding of how to address and manage the conversations.

Addressing questions without answers

Both before and after the program, existential issues were described in terms of philosophy of life, meaning of life, questions of why, guilt, shame, fear, life and death, future, time to die, and arose irrespective of neurological disease. Broaching these subjects was difficult, so nurses sometimes avoided asking about them, as they seldom had any answers.

> Group 3 before education: IP3: Now I think it's much easier, after all these years I have learned, I think, and maybe also from experience and training I have done in this area, but from the beginning I didn't think it was so easy.//IP1: I think it's difficult and I think it's because I'm pretty new as a nurse. I think you're in a very vulnerable … I think it's very difficult to go to a patient who's just received a difficult diagnosis because there's so much pressure to feel you have to have control over everything and have answers to all their questions, yes, I think it's difficult and even though the patients probably don't expect you to have answers to the existential questions, I think the most important thing is to listen, but it's difficult when you feel you might not be that experienced … (All agreed.)

The nurses felt that honesty was important, even when no answers could be given, but some nurses withheld information to avoid frightening the person.

https://doi.org/10.1017/S1478951521001620 Published online by Cambridge University Press

When a conversation did take place, it often focused on existential issues in relation to how patients and family members managed their life situation and how the remaining time could be best used. Encountering people anxious about death was particularly difficult, and the nurses requested more knowledge about how to manage these conversations. After participating in the program, it became easier for the nurses to address these kinds of questions, for example, they began to ask counter-questions so the person could answer what they thought about the future themselves. The nurses also became more confident about not having answers and realized that silence could be the best response. Experience and long-running care relations also made conversation easier.

Being together in difficulty

The nurses emphasized the importance of being with the patients and family members in their feelings of sorrow, fear, anger, guilt and shame, and listening without judging, helping them with strategies to manage life. Sometimes, having separate conversations with patients or family members was relevant, as they wanted to discuss different issues. Some nurses thought it was important that the patient or family member navigated the conversation, while other nurses felt they should be the ones to actively ask about existential issues.

> Group 1 before education: I. As staff, do you introduce such existential questions yourself or is it the patients who do that?//IP1: Often you ask how they feel, then it's the patients, and then everything kind of comes out. (Several agreed). IP2: It's like, you open up a little to them and see what comes of it. IP3: In the case of epilepsy, you might, because sometimes, some say, I'm really scared, really scared of getting seizures. Then you might ask: "What are you afraid of? What do you think'll happen?" And then they might come out with it – "I'm worried about not waking up after a seizure, or that I still think I could die during a seizure".

More experience and knowledge made it easier to ask questions and stay with patients and their families in their difficulty. After the program, nurses reflected more on existential issues, felt more prepared and safe, and had strategies for asking questions. Their own responsibility became more visible, which also helped them to strategically manage existential issues in conversations. They had more courage to enquire more actively and use open questions, to address a person's questions directly and acknowledge their anxiety, and give them time to talk.

> Group 1 after education: IP4: I think we got suggestions for good questions we can ask (several agreed). I've written some down. IP5: And then safety, precisely that you feel secure and self-confident with these questions. I think what this education has given us is that we can talk and discuss.

In addition, the program drew the nurses' attention to the fact that existential issues also included positive aspects, so a more positive approach could be taken in regard to talking about meaning, life, and plans.

Creating time for conversation

The nurses created time for conversation even though there was none. They prioritized talking to newly diagnosed patients, those who were transitioning to a more aggressive treatment or whose condition had deteriorated, or patients who were afraid of something in particular. The nurses prioritized urgent conversations over other work tasks.

> Group 1 before education: IP6: You have to give time to patients who need to talk. It's … we don't have time, but for these patients we need to take our time. IP7: I think where we work, a number of us work with the patients at the same time, so if we see someone is with a patient who needs more time, we can solve it …

After the program, the nurses were more emphatic about existential issues being part of their work and that it had to be prioritized. They thought too little time was available for these conversations.

Supporting each other

One strategy for managing conversations about existential issues was for nurses to support each other in the team. They sought help from team members and supported each other by giving constructive feedback and backing each other up, allowing time for discussion about existential issues. This was easier in the outpatient care unit. Support from the hospital church was also appreciated.

After the program, the nurses pointed out the importance of reflection and receiving support from colleagues when faced with difficult conversations and in their daily work. Some nurses had previously received professional supervision and found it valuable, although they rarely found enough time for reflection at work.

> Group 2 after education: IP1: Given what we work with, all the time, and are more or less exposed to every day, it's really important that we discuss existential issues and receive guidance. That would pretty much be a given. (Several agreed). IP2: But there I think that … the team is an important part, because, if you feel secure in the team, you have your colleagues, they kind of substitute for reflection time in some way. IP3: That's exactly what I mean.

The program gave the participants new and deeper perspectives and strengthened their skills in managing existential issues, helping them to collectively reflect and listen to colleagues' stories. They also reflected more on conversations that had been less successful and how this could be avoided in the future. Some wished the program was longer and provided more reflection and tools to use. A few said they had not learned anything and that it had not changed their way of working.

Discussion

The impact of an educational program designed to facilitate the discussion of existential issues with patients and family members was studied from the perspective of nurses in neurological wards before and after participating in the education program. The results show that the program gave nurses a deeper understanding of existential issues and how to manage these conversations; it also increased their awareness of internal and external barriers that aggravated the conversations. Being aware of the barriers and receiving strategies of how to manage them made it easier to realize the conversations. Both before and after the program conversations about existential issues were perceived as taxing. However, training, deepening knowledge, reflections in groups, experience, and support from colleagues helped the nurses initiate and conduct these necessary interactions with patients and their families, which can be compared with other studies (Henoch et al., 2013; Strang et al., 2014). Working in a neurological in- or outpatient care unit demands a lot from nurses. Some patients need acute care, while others need long-term contact; some

https://doi.org/10.1017/S1478951521001620 Published online by Cambridge University Press

patients receive medical treatment with positive outcomes, while others simply receive symptomatic treatment, sometimes with focus on palliative care. Such varied circumstances made it difficult for the nurses to know when and if they should initiate conversations about existential issues, and the pressure of not knowing what to say, as well as the lack of time made this even more difficult. Although comparable results are found in palliative care contexts (Strang et al., 2014), managing conversations about existential issues may be more difficult in neurological care units, as these issues are not an obvious part of the care. The results showed that irrespective of diagnosis, existential issues appeared, but it seemed to be easier for nurses who worked with patients with lethal diseases to initiate this kind of conversation. Providing existential support independent of the stage of a disease can be seen as promoting and part of the integration of a palliative approach to care (Cohen and Deliens, 2012; Öhlén et al., 2016; Sawatzky et al., 2017).

Lack of privacy and time were environmental factors that made discussing existential issues difficult. These results complies with other studies (Strang et al., 2001; Browall et al., 2010; Keall et al., 2014). Even if the nurses tried to prioritize these conversations, limited resources and organizational difficulties remained. The environmental factors did exist both before and after the education and such limiting factors need to be addressed and resolved on both a collegial and organizational level. However, the education program made them aware of these problems and partly they re-prioritized the work after the program to improve the possibility of existential conversations. These results suggest that education in existential issues is important and might partly affect negative environmental factors.

Creating trust, giving time and attention, being sensitive, and asking questions are factors that have been shown to establish a deep relationship between nurses and patients in a palliative home care context (Hemberg and Bergdahl, 2020). This compares with our results, which highlight how nurses remained with the person in their difficulty, asked questions, and created time for conversations. Although the nurses in our study described this as difficult, it became easier to use these strategies after participating in the program. It is, therefore, relevant to consider whether education can be a way of supporting nurses at neurological care units in helping them manage conversations about existential issues.

A study comparing palliative care education in European countries found that it is not a mandatory subject within undergraduate nursing education (Martins Pereira et al., 2021). The impact of training in our study varies, which might be related to differences in the nurses' professional background. Some nurses had, for example, worked many years with patients diagnosed by ALS or brain tumor and they presented themselves "clinically trained" due to that. However, both the experienced and the more inexperienced nurses found the education helpful. Having participated in the program relevant to our study, the participants described receiving a deeper understanding of existential issues and strategies to more easily manage these difficult conversations. Other training interventions also found that the nurses became more comfortable talking about existential issues (Henoch et al., 2013; Udo et al., 2014), found it easier to actively initiate conversations, and were more comfortable accommodating silence in the conversations (Strang et al., 2014). Training in this regard has further been shown to increase knowledge, awareness, and preparedness (Sand et al., 2018). The program taught the nurses' new ways of addressing existential issues. They became more aware of questions patients and families might ask and were helped to initiate conversations earlier and pose more challenging questions themselves. They also learned to use silence as a tool in the conversation. By capturing opportunities for discussions, they felt more responsibility for addressing existential issues, and this compares with other study results (Browall et al., 2010). Indeed, a prerequisite for person-centered palliative care may well be a nurse's skill in opening up to conversations with the patient and listening to their life story. This may, in turn, be of importance for patients and/or family members reflections on their life (Öhlén et al., 2016; Henoch and Österlind, 2019; Österlind and Henoch, 2020).

Strengths and limitations

Existential issues should be noted in contexts other than cancer and end-of-life palliative care. These issues are as common among patients with neurological diseases. One strength of our study is that it focuses on education in existential issues for nurses in relation to the care of this patient group. Another strength is that it also focuses on family members. As the whole family's life situation is affected, existential issues might surface for them too. A third strength is the participants' diversity of age and work experience, as it gives a broader perspective than if the group had been homogenous.

One limitation is that the participants were self-selected and might be interested in existential issues even before the education. For this reason, further research is needed to explore the impact of the program for broader groups of health professionals. Another limitation is that most of the participants worked in an outpatient care unit. Due to the difference in care and time available for conversation, it would have been valuable to include more participants from the inpatient care unit. However, as the analysis focuses on all the data, their experiences have also been examined. Another limitation is the lack of male participants. Unfortunately, the few available male nurses did not wish to participate. Finally, it would have been advantageous to include several hospitals rather than just one.

Conclusion

Education in existential issues is relevant and important in the context of care for patients with neurological diseases and their family members. The results reveal that after participating in the education program, the nurses became more confident in discussing existential issues and in the contexts of both acute care and in-patient care for progressive diagnosis. The knowledge that internal and external barriers impede communication should compel services for patients with the long-term condition with risk for disability and/or progression. The knowledge of strategies and barriers could be used to adapt program of education. Although the tradition of including existential issues in conversations is not as great in neurological care as in palliative care, it is clear that these issues need to be addressed.

Acknowledgment. Our heartfelt thanks to Ulla-Carin Lindquist Foundation for ALS research, Institute of Health and Care Sciences, University of Gothenburg; Susann Strang, associate professor and focus group interviewer before and after the program, and Christina Berg, RN, leader of the program.

Conflicts of interest. None declared.

https://doi.org/10.1017/S1478951521001620 Published online by Cambridge University Press

Funding. This work was supported by the Ulla-Carin Lindquist Foundation for ALS Research, Institute of Health and Care Sciences, University of Gothenburg.

References

Britten N, Ekman I, Naldemirci Ö, *et al.* (2020) Learning from Gothenburg model of person centred healthcare. *BMJ* **370**, m2738.

Browall M, Melin-Johansson C, Strang S, *et al.* (2010) Health care staff's opinions about existential issues among patients with cancer. *Palliative & Supportive Care* **8**(1), 59–68.

Browall M, Henoch I, Melin-Johansson C, *et al.* (2014) Existential encounters: Nurses' descriptions of critical incidents in end-of-life cancer care. *European Journal of Oncology Nursing* **18**(6), 636–644.

Cohen J and Deliens L (2012) *A Public Health Perspective on End of Life Care*. Oxford: Oxford University Press.

Eriksson G, Bergstedt TW and Melin-Johansson C (2015) The need for palliative care education, support, and reflection among rural nurses and other staff: A quantitative study. *Palliative & Supportive Care* **13**(2), 265–274.

Graneheim UH and Lundman B (2004) Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* **24**(2), 105–112.

Graneheim UH, Lindgren BM and Lundman B (2017) Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today* **56**, 29–34.

Hemberg J and Bergdahl E (2020) Dealing with ethical and existential issues at end of life through co-creation. *Nursing Ethics* **27**(4), 1012–1031.

Henoch I and Österlind J (2019) Development of the 6S dialogue tool to facilitate person-centred palliative care. *Journal of Advanced Nursing* **75**(11), 3138–3146.

Henoch I, Danielson E, Strang S, *et al.* (2013) Training intervention for health care staff in the provision of existential support to patients with cancer: A randomized, controlled study. *Journal of Pain and Symptom Management* **46**(6), 785–794.

Henoch I, Strang S, Browall M, *et al.* (2015) Development of an existential support training program for healthcare professionals. *Palliative & Supportive Care* **13**(6), 1701–1709.

Keall R, Clayton JM and Butow P (2014) How do Australian palliative care nurses address existential and spiritual concerns? Facilitators, barriers and strategies. *Journal of Clinical Nursing* **23**(21–22), 3197–3205.

Koekkoek JA, Dirven L, Sizoo EM, *et al.* (2014) Symptoms and medication management in the end of life phase of high-grade glioma patients. *Journal of Neuro-Oncology* **120**(3), 589–595.

Lindgren BM, Lundman B and Graneheim UH (2020) Abstraction and interpretation during the qualitative content analysis process. *International Journal of Nursing Studies* **108**, 103632.

Martins Pereira S, Hernández-Marrero P, Pasman HR, *et al.* (2021) Nursing education on palliative care across Europe: Results and recommendations from the EAPC taskforce on preparation for practice in palliative care nursing across the EU based on an online-survey and country reports. *Palliative Medicine* **35**(1), 130–141.

Morita T, Murata H, Kishi E, *et al.* (2009) Meaninglessness in terminally ill cancer patients: A randomized controlled study. *Journal of Pain and Symptom Management* **37**(4), 649–658.

Öhlén J, Carlsson G, Jepsen A, *et al.* (2016) Enabling sense-making for patients receiving outpatient palliative treatment: A participatory action research driven model for person-centered communication. *Palliative & Supportive Care* **14**(3), 212–224.

Oliver DJ, Borasio GD, Caraceni A, *et al.* (2016) A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *European Journal of Neurology* **23**(1), 30–38.

Olsson AG, Markhede I, Strang S, *et al.* (2010) Differences in quality of life modalities give rise to needs of individual support in patients with ALS and their next of kin. *Palliative & Supportive Care* **8**(1), 75–82.

Österlind J and Henoch I (2020) The 6S-model for person-centred palliative care: A theoretical framework. *Nursing Philosophy* **22**(2), e12334.

Ozanne AO, Graneheim UH and Strang S (2013) Finding meaning despite anxiety over life and death in amyotrophic lateral sclerosis patients. *Journal of Clinical Nursing* **22**(15–16), 2141–2149.

Ozanne AO, Graneheim UH and Strang S (2015) Struggling to find meaning in life among spouses of people with ALS. *Palliative & Supportive Care* **13**(4), 909–916.

Sand L, Olsson M and Strang P (2018) Supporting in an existential crisis: A mixed-methods evaluation of a training model in palliative care. *Palliative & Supportive Care* **16**(4), 470–478.

Sawatzky R, Porterfield P, Roberts D, *et al.* (2017) Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis. *ANS: Advances in Nursing Science* **40**(3), 261–277.

Ståhl P, Fekete B, Henoch I, *et al.* (2020) Health-related quality of life and emotional well-being in patients with glioblastoma and their relatives. *Journal of Neuro-Oncology* **149**(2), 347–356.

Strang S, Strang P and Ternestedt BM (2001) Existential support in brain tumour patients and their spouses. *Supportive Care in Cancer* **9**(8), 625–633.

Strang S, Henoch I, Danielson E, *et al.* (2014) Communication about existential issues with patients close to death–nurses' reflections on content, process and meaning. *Psycho-Oncology* **23**(5), 562–568.

Tomer A, Eliason G and Wong PTP (2008) *Existential and Spiritual Issues in Death Attitudes*. New York, NY: Lawrence Erlbaum Associates.

Udo C, Danielson E, Henoch I, *et al.* (2013) Surgical nurses' work-related stress when caring for severely ill and dying patients in cancer after participating in an educational intervention on existential issues. *European Journal of Oncology Nursing* **17**(5), 546–553.

Udo C, Melin-Johansson C, Henoch I, *et al.* (2014) Surgical nurses' attitudes towards caring for patients dying of cancer — a pilot study of an educational intervention on existential issues. *European Journal of Cancer Care (English Language Edition)* **23**(4), 426–440.

Yalom ID (1980) *Existential Psychotherapy*. New York, NY: Basic Books.

https://doi.org/10.1017/S1478951521001620 Published online by Cambridge University Press