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EMPIRICAL STUDIES

Teaching about death and dying—A national mixed-methods survey of palliative care education provision in Swedish undergraduate nursing programmes

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Abstract

Background: In coming decades, the number of people affected by illnesses who need palliative care will rise worldwide. Registered Nurses are in a central position in providing this care, and education is one of the necessary components for meeting coming requirements. However, there is a lack of knowledge about palliative care in undergraduate nursing education curricula, including the extent of the education provided and the related pedagogical methods.

Aim: The aim was to investigate the extent, content and pedagogical methods used and to explore lecturers' experiences of being responsible for teaching and learning about palliative care for undergraduate nursing students on nursing programmes at Swedish universities.

Setting: All 24 universities responsible for providing undergraduate nursing education in Sweden participated.

Participants: One lecturer with in-depth knowledge about palliative care or end-of-life care education participated in the quantitative ($n = 24$) and qualitative ($n = 22$) parts of the study.

Method: A mixed-method research study with an explorative design was used. Descriptive statistics were used to analyse quantitative data, and content analysis for qualitative, with both also analysed integratively.

Results: Few undergraduate nursing programmes included a specific course about palliative care in their curricula, however, all universities incorporated education about palliative care in some way. Most of the palliative care education was theoretical, and lecturers used a variety of pedagogical strategies and their own professional and personal experience to support students to understand the palliative care approach. Topics such as life and death were difficult to both learn and teach about.

Conclusions: There is a need for substantial education about palliative care. Lecturers strive on their own to develop students' understanding and increase the extent of palliative care education with innovative teaching strategies, but must compete with other topics. Palliative care teaching must be prioritised, not only by the universities, but also by the national authority.

KEYWORDS

death and dying, palliative care, qualitative approaches, quantitative approaches, undergraduate nurse education

INTRODUCTION

The World Health Organization (WHO) has estimated that nearly 57 million people in the world need palliative care (PC) each year, and that only 1 out of 10 people who need PC receive it [1]. By 2060, this need for PC is expected to nearly double [1–3]. Stjernswärd et al. [4] presented four components to guide governments in integrating pain relief and successful PC within all levels of a country's health care system: (1) appropriate policies, (2) adequate drug availability, (3) education of health care workers and the public and (4) implementation of PC services at all levels throughout society. As recently as October 2021, the WHO published a refined set of consensus-based indicators and an updated PC development conceptual model [1]. The conceptual model includes the same four components as Stjernswärd et al. presented [4], with an additional two components: research; and empowering people and communities [1]. An education component is included in both models and demonstrates the need of PC to be integrated into the curricula for undergraduate health care professional education programmes.

BACKGROUND

There is a global increase in the ageing population, accompanied by a growing prevalence of multi-morbidity, incidence of chronic progressive illnesses with long disease courses and occurrence of complex symptoms. All these aspects will generate an increased need for PC provision and increase the value of earlier referral to PC [2, 3]. Murtagh et al. [5] have calculated that 69%–82% of all persons who will die will benefit from PC in the future. For many patients, where the outcome has been uncertain, or when it has been known that the person will not survive, the provision of high-quality end-of-life care (EoL) or PC could have been beneficial. EoL care and PC are terms that are often used synonymously to represent care in the final days, weeks or months of an individual's life and such care is often assumed to be less active than that provided in curative care. However, PC is a highly active form of care [6], which can meet the needs of patients with several different serious conditions and from an early stage of the disease; hence, PC provision needs to be intensified in the coming years [2, 3]. Stjernswärd et al. proposed in 2007 [4] that PC education and training for healthcare workers and of the public is essential in meeting the future need for PC. The same year, the Swedish National Council of Palliative Care identified a large discrepancy between the extent of PC training modules for undergraduate students: physicians had between 2 h and 2 weeks of training; Registered Nurses (RN) had between 3 h and 5 weeks; Nurse Assistants (NA) had between 5 hours and 5 weeks; and, for other healthcare professionals, only a few hours of training in PC were included [7]. This variation between education programmes must be considered alongside the knowledge that delivering PC is a complex and advanced task [6]. These results are in line with a recent publication showing a global lack of opportunities for medical students to learn about and to practise PC [8]. There is also shown to be a large variation in content about PC in nursing education programmes across Europe [9]. These variations were found both across and within countries. A US initiative to create comprehensive online training for faculty members who are responsible for undergraduate nursing education shows that there are still problems in including this in education programmes, due to the following: (1) difficulties in convincing policy makers to integrate the content into the curriculum, (2) costs and (3) convincing policy makers of the importance of providing essential education on PC in nursing education [10].

Registered Nurses are globally the largest group of healthcare professionals [3], and are often the profession of contact for patients and relatives, with an increasing responsibility for providing care as a person approaches death, which has also been shown in Swedish contexts [3, 6, 11]. To become a RN in Sweden, a 3-year (six semesters, 20 weeks each semester and 180 European Credit Transfer System [ECTS] credits) Bachelor of Science programme in nursing is required. The education programme is quality assured nationally by the Swedish Higher Education Authority, with set education standards and

clearly defined learning objectives for nursing education. However, the curricula for PC education can, in Sweden, as in other countries, differ between universities and each university can choose the extent of its PC training content, and whether to include clinical training within this specific topic [9, 12]. Research to explore undergraduate nursing students' reasoning about death and dying made it clear that they see caring for the dying and the dying phase itself as a RN's working responsibility and duty; however, in considering their own insufficiency and lack of experience, they also perceive that death and dying is a frightening experience [13–15]. Attitudes towards caring for dying patients are found to be more positive among older students, Swedish-born students and students who have had previous care education, care experiences or experiences of meeting a dying person [12]. One longitudinal study, which followed undergraduate nursing students over three years, showed that students' attitudes to caring for dying patients improved during the entire educational programme. Changes in attitudes were associated with the length of the theoretical element of the programme, as students who received courses in PC education to a greater extent changed their attitudes positively towards caring for a dying patient. Furthermore, students felt prepared for caring for a dying patient, but not for caring for a dead body or meeting relatives [16]. Similar findings about nursing students' attitudes towards caring for dying patients are also described by Dunn et al. [17], Iranmanesh et al. [18, 19], Arslan et al. [20] and Grubb and Arthur [21].

Both theoretical and practical training components are important for developing knowledge about PC among undergraduate nursing students [12, 16]. As RNs are situated in a central position to improve the delivery of PC, and because education is one of the components needed to meet the coming requirements of PC, the optimum extent, content and pedagogical methods for PC education must be explored. Obtaining such knowledge will contribute to determining the most effective means of establishing appropriate levels of competence in PC for undergraduate nursing students. The aim was therefore to investigate the extent, content and pedagogical methods used and to explore lecturers' experiences of being responsible for teaching and learning about palliative care for undergraduate nursing students on nursing programmes at Swedish universities.

DESIGN AND METHODS

A mixed-method research, with an explorative design, was used in this national survey.

Sample and setting

All 24 universities responsible for undergraduate nursing education in Sweden were invited to participate by approaching a lecturer with in-depth knowledge about the education of PC or EoL care. The lecturers were identified by the universities' web pages or by contacting representatives in each specific department responsible for the provision of undergraduate nursing education, who helped us identify the individual(s) who was/were responsible for any teaching in the appropriate area. If there were several lecturers at the same university who were responsible for this part of the curriculum, the initial contact was asked to assess who was best suited to participate and respond to the questions. An email was sent with information about the study along with an invitation to participate. One week after the initial invitation was sent, a follow-up email was sent to ask for their participation.

Data collection

The mixed-method design was inspired by Creswell et al. [22] and chosen because neither qualitative nor quantitative methods alone were considered sufficient to obtain a broad and deep understanding of lecturers' experiences about the extent, content and pedagogical methods used in PC education across Sweden. The reason for the explorative design was to use qualitative data to explain quantitative data [22]. In this study, a quantitative questionnaire was completed by the lecturer and collected in phase one, and the individual quantitative data that called for additional explanation partly guided the second phase, the collection of qualitative data. In this second phase, additional questions were posed to the lecturer to further deepen the understanding about the extent, content and pedagogical methods they used and to explore the lecturers' experiences of being responsible for teaching and learning about PC. Finally, the researchers interpreted to what extent and in what ways the two sets of data diverged or related to each other to create a more comprehensive understanding in response to the study's overall aim [22]. To further confirm an understanding of the PC education at each university, the programme syllabus for the undergraduate nursing education programme was collected from the university's web page.

Quantitative data

A study-specific questionnaire was compiled by the research group, including 17 questions, with closed and

open-ended answers, partly used in an earlier survey conducted by the Swedish National Council for Palliative Care [7], with additional questions formulated to deepen the knowledge about the education provided, how it was provided and how it was experienced by lecturers and, from the lecturers' point of view, for students. The questionnaire included demographic questions and information about the undergraduate nursing education programme, with predetermined choices listed and space provided for individual free-text comments, for example: whether PC was included in the syllabus; if so, how PC and EoL care were defined; and how PC was labelled, that is to say, PC, palliative nursing, palliative medicine, nursing with a specific focus on PC, or EoL care. Questions were also asked about the extent of, and at which point during the programme that PC education was included; the type of pedagogical methods (with both predetermined responses and space for recording individual responses); and the extent of these; the aim of the lecture; competencies used; academic competencies about PC within the university; whether the education was clinical-, theoretical- or/and scientifically grounded; the area of focus in the lectures (with both predetermined responses and space for individual comments); examination forms; and, if PC was not included in the education programme, the reason for this.

Qualitative data

To obtain a deeper understanding about the extent, content and pedagogical methods for PC education at each university, individual interviews were performed by telephone with participating lecturers. The interviewer based the interview on each specific teacher's responses to the questionnaire. All interviews started with: 'Can you tell me how you perceive teaching, and which pedagogical methods you use in teaching, about caring for severely ill and dying people'? Specific topics were explored, including: which different areas are included in the teaching about PC or EoL care (theory—which areas; practice—to what extent); whether there were any areas that were more difficult than others to teach about concerning PC or EoL; how the lecturer perceived that the education programme affected the students; whether there were any areas that the lecturer experienced that the students found difficult to learn about; whether the lecturer lacked any resources for their teaching; and whether they had considered other forms of teaching about PC or EoL. The interviews were performed by three of the authors, and one RN, who has a PhD degree, member of the Swedish National Palliative Care network. All the researchers who performed the interviews have a long history of experience of working in clinical PC, and of performing research and teaching in this area. The interviews were, after obtaining the participant's permission, audio-recorded and lasted between 14 and 60 min (md = 30).

Data analysis and integration

Quantitative data were analysed using the IBM SPSS Statistics for Windows, Version 22.0 software package [23]. The results are presented as descriptive statistics with mean values (m), median (md), standard deviations (SD) and minimum (min) – maximum (max).

Qualitative data, drawn from both the open-ended survey questions and individual interviews, were analysed using qualitative content analysis [24]. As a first step, the quantitative data and qualitative data from the open-ended survey questionnaires were analysed. Thereafter, the audio recordings were divided between three of the five researchers, with each allocated those interviews not performed by themselves. The audiotaped interviews were listened to in full, to obtain an understanding of their content. Thereafter, the first four interviews were transcribed verbatim, while 20 of the audio recordings were listened through again, with each researcher writing down memos, parts or sentences according to the aim of the study [25]. In this step, we compared the initial analysis of the transcribed text with what emerged from the memo notes made during the listening to ensure that this allowed us to similarly capture the content of the interviews. This was then compared and discussed. Here, we observed that going back and forth between the memos and the listening to the recordings allowed the analysis to advance by strengthening and adding to the findings, so the work continued in this way. Analysing the qualitative data made it possible to further explore the quantitative data, using summaries and quotations. The results were checked against the interview text and written memos to ensure that the content correctly represented what the lecturers had said. Text from the programme syllabus from each of the 24 undergraduate nursing education programmes was audited to determine whether there was a course entitled 'PC' or clearly described content covering PC. It was also noted when PC was included in the educational programme.

ETHICAL CONSIDERATIONS

An information letter was emailed to an identified representative from each university with the aim and procedure of the study presented and with confirmation that their participation was completely voluntary and could be terminated at any time until the data were processed and compiled. For the collection of qualitative data, telephone

interviews were chosen to enable participation from universities and university colleges across the entire country. The telephone interviews were recorded after obtaining each participant's agreement. The Swedish Ethical Review Authority was contacted, and they advised that there was no need for ethical approval according to the Swedish Law (SFS 2003: 460) on the ethical review of research involving people.

RESULTS

All universities in Sweden providing undergraduate nursing education participated in the quantitative section of the study by collecting questionnaire responses from one responsible lecturer ($n = 24$), and individual interviews were held with 22 of the lecturers. The length of experience as a lecturer varied in total; from between 1 and 36 years (md 12), and, within each specific university, between 1 and 30 years (md = 11.5). The compilation of the university syllabuses showed a variety of content, including PC as an individual course, as an area of another course, or not described at all, as described in further detail below.

Palliative care education

The lecturers described PC as an area incorporated in one way or another into the undergraduate nursing education programme at all 24 universities; the concept used was either EoL or PC, and the education was mostly delivered to students in the fifth ($n = 15$), second ($n = 13$), or fourth or sixth ($n = 10$ each) semesters. The PC education was delivered as a specific compulsory course ($n = 4$), with a variety of between 7 and 14 ECTS credits; as part of an overarching course ($n = 2$, 3.5 or 6 ECTS credits); as an elective course ($n = 1$, 7.5 ECTS credits); or included in the general nursing education programme together with other areas (Table 1). The education was primarily theoretical ($n = 22$), although two universities reported that their compulsory courses included clinical palliative education, with 7 and 7.5 ECTS credits, or approximately 160 h. Otherwise, the clinical education for PC was included in areas corresponding in one way or another to PC, for example, care of older people. The lecturers were asked to highlight which areas, from the pre-formulated topics, that they deliver in the undergraduate nursing programme and whether the topic was directed towards PC and/or the education in general, Table 1. Here it is notable that all of the topics were integrated in both PC and in the education programme in general. Symptoms common in PC or EoL care were included in the education of PC, but more often in the general education programme. However, most topics were more common in the general education programme rather than being specifically connected to PC, for example, dementia, neurological diseases and transcultural care, with each having a low correspondence with PC (Table 1). The extent of time devoted to the PC education varied; from one university reporting 4 h in total, to two universities reporting 160 h each (Table 2). Thirteen universities reported having clinical education corresponding to PC without presenting the number of hours. The reasons given for not delivering a specific course about PC were described as: a concurrence about subjects in the education programme; and that there was not enough time in the current curriculum without the reduction or removal of other educational elements. One lecturer described this as: 'If PC is to be included, something else needs to be reduced or removed' (no. 2).

Several lecturers perceived that PC education in the nursing programme is sparse. They reflected on how students need extensive knowledge of PC for their future profession, as they soon need to face the reality of PC as RNs. Lecturers experienced that many of the students are worried about meeting patients and relatives in EOL care. The importance of illustrating what PC means, theoretically, and also of demonstrating PC in clinical practice and in different care situations as clearly as possible, was explored. Lecturers expressed that it would be optimal if it were possible to perform follow-ups with the students throughout the undergraduate nursing educational programme, but their experience is that this possibility often does not exist.

Competences of the educators

The lecturers had clinical skills and a variety of different academic degrees, which enabled them to relate theory and practice. Priests and deacons, physiotherapists, social workers, occupational therapist, funeral directors, relatives of persons with incurable illness and physicians were sometimes invited to give a lecture, and this made the subject real for the students.

> The most important tool in this subject is us and the experiences we can share based on patient cases that we discuss with the students. It is a strength and asset that you as a lecturer have worked in palliative care and end-of-life care and thus you can use yourself and own experience.
>
> (no. 21)

TABLE 1 Teaching content in the undergraduate nursing programme related to education about palliative or end-of-life care and/or to the nursing education programmes in general

Education area	In the palliative care area[a]	In the general education programme
Explicit palliative care		
Palliative care philosophy	11	6
Organisations of palliative care or end of life care	11	7
Hospice	10	6
Symptoms common in palliative care or end of life care	7	9
Other areas (alphabetically)		
Behavioural theories	1	9
Cancer	5	9
Children	4	9
Crisis reactions	5	10
Communication	5	8
Complementary care	4	5
Clinically applicable nursing care of common symptoms	6	8
Death and dying, Thanatology	7	9
Dementia	2	10
Ethics	5	6
Euthanasia	4	6
Existential issues	6	9
Grief	5	7
Laws	4	10
Lung diseases	3	10
Neurological diseases	2	11
Nursing care theories	3	10
Pharmacological treatments	5	8
Philosophy	1	11
Professional approach	4	10
Relatives	6	7
Teamwork/professional roles	5	7
Transcultural care	3	13
Other*	2	N/A

Abbreviation: N/A, Not applicable.

[a]Each lecturer could report more than one area.

*'Other' was described as being the conducting of a literature review according to a special patient's needs.

Course development

The courses in PC are constantly developed and the participants described how, 'as a lecturer, you try different current ideas'. To further develop the PC education programme, it was suggested that it should be made a compulsory element instead of being highlighted in certain semesters during the programme, or that the number of hours should be extended, and also that PC should be taught in smaller groups during the education programme.

> Smaller groups would be good and to meet the students several times. Don't just start a lot of thoughts that you cannot follow up. If there are many students in the seminars, it will be difficult for them to open [up]and talk.
>
> (no. 13)

Lectures experienced, from the written and oral evaluation of PC education programmes, that nursing students often were satisfied with the assignments and content of PC

TABLE 2 Pedagogical methods used for the education of palliative and end-of-life care with the duration of time in hours

Pedagogic strategy (answers)	Mean hours	SD	Median hour	Min hour	Max hour
Lecture ($n = 21$)	7.5	8.3	6	0	35
Seminar ($n = 23$)	3.8	4.4	3	0	20
Clinical education ($n = 18$)	18	51.7	0	0	160
Team-work ($n = 21$)	1.8	4.1	0	0	18
Movie ($n = 23$)	1.5	2.2	1	0	10
Clinical visits ($n = 23$)	0.9	2.2	0	0	8
Simulated education ($n = 22$)	0.5	1.4	0	0	6
Case ($n = 23$)	0.9	1.6	0	0	5
Supervision ($n = 23$)	0.6	1.6	0	0	6
Workshop ($n = 23$)	0.3	1.0	0	0	4
Other ($n = 23$)	0.1	0.6	0	0	3

education, and that the PC education made a difference in their future profession.

Areas in theoretical education

The WHO definition of PC, including its physiological, psychological, social and existential dimensions, was most frequently utilised. In Sweden, the term 'four cornerstones', that is symptom relief, family support, teamwork and communication, is described in national guidelines and was used in the PC education. Other important areas of knowledge include how PC is organised, methods for communication and how to identify and analyse needs in PC. Specific areas and key theories, such as the lifeworld concept, different breaking points in PC (e.g. when care changes from curative care to PC) and phenomena such as intersectionality, ethics in EoL care, philosophy and ideology, were included to support the students' understanding of the patients' and relatives' situation and were used to link the course objectives together.

> ... when we have the course in palliative care, we are not talking about end-of-life care but only palliative care ... End-of-life care can be provided anywhere without having any basis in any approach ... But palliative care has its own basis to stand on.
>
> (no. 14)

Pedagogical methods

There was a diversity of pedagogical methods used by the lecturers (Table 2), with lectures, seminars and clinical education being the most common. The least frequently reported were workshops, clinical visits, supervisions and simulated training. Web lectures about PC were used as a learning opportunity more often than in-person lectures, where students were able to view a recorded lecture and its content several times and thus concentrate on specific sections. There were also differences between the extent in time of each learning activity and in the various pedagogical methods applied (Table 2), with the most time spent on clinical education and the least on clinical visits, and simulation or other methods, for example performing literature searches.

Lectures

Theoretical lectures were common and were usually short but were considered effective. For example, a short lecture could be a 1- to 3-h lecture linked with care of the older person and EOL, death and the dying process. Lectures also concerned both the early and late palliative phases, the concept of total pain, EoL discussions, existential issues and symptom control. At these lectures, it was obvious that the students thought a lot about how their own reactions might be when encountering and interacting with dying persons.

> ... many students are young, and they have not been affected by this naturally in life. Their grandparents are often still alive and, in some way, [this is] a protected environment where they are not faced with death. There are several students there who express that, oh, should they die too, we had not expected that.
>
> (no. 11)

Theoretical lectures were often performed before clinical education in universities having clinical education.

Reflective seminars

Reflective seminars, based on the literature, including person-centred care, different understandings of hope and meaning, were based on different patient experiences and what these looks like in 'reality', to provide an in-depth understanding about PC. The group dynamics were important, as personal experiences and empathic thoughts and feelings contributed to making the subject manageable for the students. Reflective supervision was also promoted, as a kind of supervision in nursing that strengthens the profession on a personal level and aids in the development of critical thinking skills.

Simulation

Simulation in different care settings was experienced as a form of support for making situations in PC real. The lectures could include various patient cases that were discussed, and to draw knowledge from certain literature and care programmes related to PC. Students were often proud to simulate EOL situations, including symptom relief and basic nursing care, such as washing a patient, being present when a patient died, and communicating with relatives. Simulation scenarios usually concluded with a reflection session with groups of students.

> The simulation scenarios are very good, and the students take them very seriously. Worse when students do not show how they feel. It does not always go on track and some do not want to participate in simulation exercises.
>
> (no. 17)

Examinations

Written examinations in the form of a patient history with a focus on total pain, and individual tasks about communication associated with materials and films were common. Presentations were also common, for example students interviewed persons about death and dying and made an oral presentation to fellow students and the lecturer. Other examinations included, for example, a written bachelor's thesis in nursing, where students could write about PC or EoL issues, taking examinations during PC clinical education or taking a national clinical final examination.

> Those who are examined by us [from a university having a mandatory course] are probably relatively well prepared to care for patients in the palliative care stage.
>
> (no. 17)

Among the different teaching methods and educational tools related to PC, lecturers expressed that panel debates and seminars could be arranged to better prepare the students for facing the PC context and for encountering seriously ill and dying persons.

Clinical education

Clinical-based teaching and education was carried out in municipal health care and county councils, at hospices and in specialist PC units, and in specialist home care services, where the students combined clinical education with theory. The lecturers experienced that the students could transform theoretical knowledge into practical action.

> The students have learned so much (during clinical education). They have understood what knowledge you need to have as a nurse to be able to work with this and that you need all parts of the education to be able to work with palliative care. They get a kick out of it. They see that they need to use everything. They (clinical supervisors) take a great responsibility at the clinics when it comes to education. When they (students) are out in term 5, they let the students take the lead very much and withdraw themselves (clinical supervisors) and let the students work, even when it comes to care at home then.
>
> (no. 14)

The most rewarding learning situations were experienced when the students had the possibility to participate in different situations and to reflect upon what they had experienced, together with the lecturers and/or their clinical supervisors. This could be about the care performed for the severely ill and dying patients, about death and how to take care of a dead body. Pedagogical methods about PC could also consist of simulation exercises arranged to resemble clinical situations as closely as possible. These were delivered with computerised mannequins, as well as in medical technical education, complete with reflective seminars.

Challenges in PC education

During both the theoretical and the clinical education provision, lecturers found some areas especially difficult for students to understand, reflect upon and think about. Predominantly, this was related to the connection between life and death, for example how to create a good life despite knowing that death is imminent. These were also areas about which the lecturers themselves found difficult to teach.

> life and death, attitudes and communication are more difficult than teaching about teamwork, concrete nursing interventions and medical prescriptions.
>
> (no. 22)

Other areas that the lecturers found difficult to teach about included sexuality when receiving PC. This was difficult for both the lecturer and the students to reflect on and to learn how to talk about.

Understanding the palliative approach

The lecturers described that it was difficult for students to understand when PC should be initiated, that PC is not only about the dying phase, and that there are both early and late stages. They also perceived that it was difficult for students to relate to death and dying theoretically. Some students showed no interest in PC. They feared what they may face as a RN in terms of caring for dying patients and their relatives.

> It is difficult to really convey the feeling so that the students feel safe and, as in the encounter with life coming to an end.
>
> (no. 16)

Existential and ethical concerns

The lecturers perceived that PC evokes many emotions and affects the students in different ways, and it inspires students to work with existential issues and to think about dying and death as specific areas. At the same time, it could be difficult for students to talk about death and to accept that they themselves would die. Uncertainties, such as 'What must I do as a RN when patients and relatives ask about death'? and 'It is not just about performing nursing and medical tasks but also to open up conversations with patients and relatives' are explored during the learning activities about PC. Other difficult areas in the PC education include existential issues, such as meaning and meaninglessness, palliative sedation and euthanasia. Facing ethical dilemmas and dealing with life values were also difficult challenges, as students might lack enough experience to be able to cope with such issues and situations.

> It is important to constantly work with your own self-awareness about how I am, and that this also affects others ... I think this is important for both lecturers and students.
>
> (no. 5)

Communication about death and dying

Communication was sometimes perceived as an abstract issue. Reflection and active dialogue, including education in communication about death and dying, were found to be essential for raising awareness, as was as EoL communication, and how it was performed with patients and relatives. When death concerned young people, topics such as hope and faith, encountering patients from different cultures or with different religious beliefs, and how death was perceived, were areas that the lecturers experienced as being sensitive and private to communicate about, but were of great interest to the students.

> It is difficult when children are relatives or when the children are sick, and we have this in the education. Then it becomes apparent that it may be young people who die because they may have children as close relatives and some students think that is difficult and then you must try to meet them at their individual level.
>
> (no. 14)

DISCUSSION

All universities that provide undergraduate nursing education in Sweden participated in the present study by having one responsible lecturer complete the questionnaire, and all but two participated in a follow-up individual interview. This high response rate might reflect the lecturers' perspective that PC is of great importance in undergraduate nursing education. Furthermore, some lecturers emphasised that PC has a specific base, compared to EOL care, which could be performed anywhere.

This was also illustrated in their description of the necessity of theoretical education as a basis for practice. The lecturers experienced that students are interested, fascinated and frightened by the area of PC. Most PC education included theoretical elements in some way, and lecturers used a variety of pedagogical methods, as well as their own both professional and personal experiences, to support students to understand the PC approach and the area of life and death, although these areas were experienced as being difficult to teach about. These pedagogical methods are aligned with those of the European Association for Palliative Care (EAPC) [26], which emphasises that it is essential that teaching methods in PC are varied, including, for example, theory and clinical education, group work, reflection and feedback, role-play and self-directed learning. Furthermore, the results in the current study present one answer to Martins Pereira et al.'s [9] recent call about the teaching content and hours dedicated to PC education to further adapt the competence of RNs to be able to meet different levels and contexts of PC. The WHO's definition of PC from 2002 [27] was most frequently used in the undergraduate nursing education programmes when teaching about PC, along with an emphasis that PC must be person-centred and must ensure that the patient has the best quality of life possible during the life they have left. In 2020, a new definition of PC was proposed by the IAHPC [28]. During the extensive work that contributed to developing this new definition, it has been criticised for being too broad and that there is a risk that the concept of PC will thereby be diluted. That is a simplified definition cannot reflect what PC means and will not facilitate discussions about when and how PC should be provided. According to the authors [28], it will be a major change in how the new definition of PC is perceived politically and practised clinically. Based on the present study, we also see the need for educators to be included in developing the definition.

Although it is estimated that there will be an increased need of PC and EOL care in the coming decades [2, 3], the present study demonstrates that only a few universities include a specific course about this in their curricula, and even less include clinical education. Stjernswärd et al. highlighted over 10 years ago [4] that a public health strategy for PC, advocated by the WHO, must include the education of policymakers, healthcare workers and the public about PC. Sweden as a nation has been categorised as having developed PC as an advanced health system integration [29], and this is also shown in Martin Pereira et al.'s publication [9], with Sweden as one out of 12 European countries including education about PC at all levels. However, it might be argued that the national strategy for providing education about PC for undergraduate nursing students in Sweden is deficient. Martins Pereira et al. (2021) suggest that large variations between organisations in how education about PC are delivered within a country may have major implications for the delivery of effective PC education and practice in that country. It is also of great value that PC is included in the undergraduate education of nurses and other professions and not just made a specialist area. Being in the middle of the COVID-19 pandemic, the question about how well-prepared RNs, as well as other professionals, are, not only to meet this new disease itself, but also to meet death and the dying, needs to be raised. It has recently been acknowledged that RNs need several competencies to perform excellent PC, for example: competencies in collaborating with the patient, family and team; competencies in communication and cultural issues; clinical competencies; ethical and legal competencies; psychosocial and spiritual competencies; and competencies related to a nurse's professional role and leadership [30]. One can argue that these things are a necessity for all excellent nursing, but situations where patients know that there is a limited time in life, and that they will thereafter die, requires staff to have the knowledge and maturity to be by their side and support them and their relatives in the dying phase. This further emphasises the need to acknowledge the complexity of PC, which the participants in the present study argued for. In order to provide staff with the necessary knowledge to carry out this complex work, the universities need to include PC education in nursing programmes.

Palliative care puts life and death at the forefront and the care is associated with being able to meet physical, mental, social and existential needs. Undergraduate nursing students have described care for dying patients as a duty that they find frightening, and an area for which their own sufficiency and experience are of importance [13, 14]. The present study reveals that education about EoL and PC are foremost delivered as theoretical education throughout the country, and that only a few universities have a combination of theoretical and clinical training. Conversely, EoL and PC are also, to some extent, included in the general education curricula, which was possibly overlooked earlier when the participants were only asked about PC education. Both the pedagogical methods and the extent of the scope of PC education have, to a minor extent, increased, according to a report by the Swedish National Council for Palliative Care [7]. Earlier research has shown that the extent of education about PC, and that receiving a course of longer duration, of over 5 weeks, and including both theoretical and practical elements, improved students' attitudes towards the care of a dying patient and prepared students to care for a dying patient [16].

Lecturers in the present study used, in line with a review by Carmack and Kemery [31], a variety of

pedagogical methods and different professionals to illustrate the area of EoL and PC, and to cover difficult issues. These were often useful methods, but could depend on the responsible lecturer's own qualifications, and their opportunities to find and evaluate these methods. At the same time, as shown earlier, providing a PC education programme, including both theoretical and practical elements, did not prepare students to take care of a dead body or to meet relatives [16]. Working in PC requires an awareness of and compliance with the illness trajectory. This means being one step ahead to plan the care and to meet the needs of patients and relatives in the disease-dying process. However, despite the person-centeredness of PC, it is also important to realise how one's own experiences affect care and relationships. Therefore, continued reflection on one's own values and attitudes is essential for the professional role. Teaching about reflection within difficult areas was included in the nursing programmes, whether it was included in a specific course, an elective course, or implemented in other areas. This is in line with Slater et al. (2021), who argue that reflection upon experiences could lead to improvements in both competences to provide PC [32]. Thus, reflection was both possible and at the same time difficult, as the lecturers described that the students found the area of EoL and PC to be emotional demanding. There were some areas that challenged the lecturers more than others, for example existential aspects that could affect individual students. This might be difficult to counteract and depends on the specific situation, but shows the level of readiness that the teacher needs to have. The present study shows that EoL and PC are difficult for undergraduate nursing students to understand and for educators to teach. Further research, as well as the development of nationwide guidelines for PC education, is needed to prepare the healthcare system and members of society, as well as educators and RNs, for the future.

This study has its strength in that all universities providing undergraduate nursing education in the country participated, and that lecturers willingly shared their experiences. Furthermore, the mixed-method explorative design made it possible to integrate the quantitative and qualitative data and thereby deepen the understanding about the extent and content of the PC education. We do not claim that an overall picture of pedagogical methods in PC education in Sweden is covered. It must be acknowledged that the data related to only one lecturer's experiences and views from each of the universities, although it seems also to be common that these lecturers work independently in preparing the pedagogical methods for teaching PC. However, combining statistical and qualitative analysis contributed to obtaining a better understanding of the diversity of pedagogical methods utilised, and of the students' concerns in learning to care for dying patients. The different sets of data were collected separately and analysed by different researchers. At the beginning of the analysis, we used the content analysis as a way of describing qualitative data with different categories and sub-categories. This separated the data instead of weaving it together and then data were instead integrated, which enriched the analysis. That is, we could study the phenomenon from several different aspects and experiences, simultaneously being able to present the whole via quantitative data, and to see the details via qualitative data and be flexible by switching between text and numbers, respectively, which expanded and strengthened the study's conclusions. This study highlighted the lecturers' view of palliative care education provision, and it could not be assumed that the students' view of the education is the same. All authors' different pre-understandings contributed to the critical reflections and strengthened the analysis and increased the credibility [33]. We have made an effort to demonstrate the analysis process, using quotations in the results for readers to judge the trustworthiness of the study.

The technique of first listening to the audio-recorded interviews, and writing down memos, might be criticised. However, some interviews were transcribed verbatim, and the initial analysis was compared with what emerged from analysing the transcribed text and in listening and taking memo-notes. This was compared and discussed within the research group, who found that it was sufficient to use the listening and memo-taking in the analysis in the same way as the transcribed data. The decision to follow this strategy was made due to the aspects of using qualitative data in combination with the quantitative, and because the researchers have extensive experience from the field and experience in conducting qualitative research. Thus, taking memos was deemed as being sufficient, particularly as it is expensive and time-consuming to transcribe interview data verbatim [25]. To maintain a distance from the data, we did not analyse the interviews we conducted, thereby, other members of the research group were able to both critique and validate the analysis, and the results, which strengthened the trustworthiness of the study.

CONCLUSION

With an increasing need for PC worldwide, RNs need to be prepared for the complexity of PC and EOL care and, hence, there is a need for a substantial foundation in education in this area. It is therefore notable that only a few of the universities in Sweden include a compulsory course about PC and EoL care in their syllabus, and that this is up to the universities themselves to decide. This is contradictory to what Stjernswärd et al. [4] recommended to the government in

2007, which has recently been refined [1]. Lecturers strive to increase the content of the education about PC in undergraduate nursing programmes with new innovative pedagogical methods, although they also have to compete with other topics in the educational programme. The PC education provision at the different universities included a variety of pedagogical methods, with lectures and seminars being the most commonly used, and clinical visits and simulated training the least frequently used. The most challenging aspect for students, as experienced by the lecturers, was to provide an understanding of the PC approach, address any existential concerns and promote good communication with the patients. Although lecturers strived to develop pedagogical methods to improve the students' understanding of PC, there is still a shortage of learning related to PC in clinical education that includes sensitive guidance from lecturers and clinically experienced nurses. Additional research is needed to further explore the area of PC education from the students' perspective, as well as to develop and test pedagogical methods.

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CONFLICT OF INTEREST

Nothing to declare.

AUTHORS CONTRIBUTIONS

All authors have made substantial contributions to the study and were involved in conception and design of the study, drafting the manuscript and giving final approval of the version to be published. CLH, MB, CMJ, KE and JÖ were involved in acquisition of data. CLH, IH, CMJ, KE and MB carried out analysis and interpretation of data.

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