



Review

Perinatal palliative care education: An integrative review

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ARTICLE INFO

Keywords:

Education
Health care professionals
Integrative review
Perinatal palliative care
Training

ABSTRACT

Objectives: The aim of this review was to analyze the effectiveness of teaching healthcare professionals in perinatal palliative care, methods of evaluating the teaching, and the teaching strategies used.

Design: An integrative review.

Methods: A systematic search was conducted for English language peer reviewed publications of any research design via SCOPUS, Medline/PubMed, EBSCOhost, Science Direct, ERIC, Web of Science, Wiley, Nursing Ovid, and ProQuest databases. Fourteen research papers published between 2002 and 2017 that met the selection criteria were included in the review.

Findings: All 14 studies considered perinatal bereavement education to be effective. Eight studies reported statistical improvements in knowledge, security/comfort in providing end-of-life care, or increased perceptions of the emotional care needs of bereaved families, after attending an educational program. Questionnaires or interviews were used to evaluate the educational programs. Innovative teaching strategies, in particular, were evaluated positively (e.g., simulation, discussion, and arts-based methods).

Conclusion: Perinatal palliative care education is essential in pregraduate education for midwives and neonatal nurses. Other research is vital for finding out the effectiveness of this education for pregraduate nursing students. Perinatal palliative care education programs need to be available in postgraduate education for professionals who encounter perinatal death and bereaved families in hospital and community care.

1. Background

Perinatal palliative care (PPC) involves the planning and provision of supportive care prenatally or postnatally to a baby (a fetus, or newborn) and their family when a child has been diagnosed with a defect or disease that is inconsistent with long-term survival, or when the prematurity of the child limits the possibility of saving its life (Leuthner and Jones, 2007; British Association of Perinatal Medicine, 2010). Ideally, holistic care is provided by a multidisciplinary palliative team, whose members may be an obstetrician, midwife, geneticist, neonatologist, pediatric nurse, psychologist, chaplain, and other health or social workers (Leuthner and Jones, 2007).

Over the past decade, much attention has been paid to care for parents who have experienced perinatal loss. Healthcare providers' support can have a decisive effect on a family's response to their baby's death (Engler et al., 2004; O'Connell et al., 2016). The research highlights the need for staff education and training that reflects the parents' needs and evidence-based practice (Bakhbakhhi et al., 2017; O'Connell et al., 2016).

The purpose of this integrative review was to analyze the effectiveness of the teaching healthcare professionals in PPC. We also investigated the teaching methods that are used to prepare health professionals and students for the care of grieving parents after perinatal loss, and the tools that are used to evaluate PPC teaching.

2. Methodology

An integrative review methodology is the most comprehensive approach, and allows the inclusion of experimental and non-experimental studies in order to fully understand the analyzed phenomenon (Whittemore and Knafl, 2006). We used Whittemore and Knafl's five-stage approach (2006): *problem identification, literature search, data evaluation, data analysis, and presentation*.

2.1. Study selection criteria

A systematic search was conducted to identify and find relevant sources. The search was conducted across SCOPUS, Medline/PubMed,

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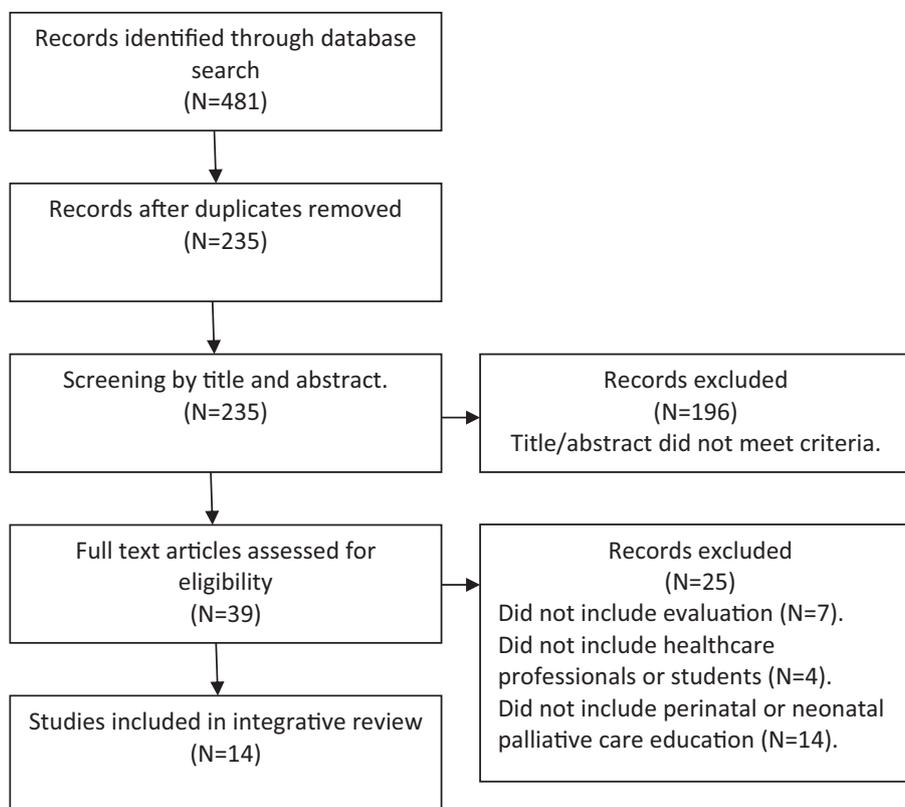


Fig. 1. PRISMA flow diagram.

EBSCOhost, Science Direct, ERIC, Web of Science, Wiley, Nursing Ovid, and ProQuest databases. The last search was conducted on May 15, 2018. The keyword search terms used were: ‘perinatal palliative care’ OR ‘perinatal loss’ OR ‘stillbirth’ OR ‘neonatal/perinatal death’ OR ‘bereavement care’ OR ‘end of life care’ AND ‘education’ OR ‘training’ OR ‘teaching’.

The identification and selection of research studies for this review are detailed in a PRISMA flow diagram (see Fig.1). In the database search phase, titles and abstracts were reviewed by three authors.

2.2. Eligibility criteria and quality assessment

Inclusion criteria were qualitative, quantitative and mixed method studies dealing with the evaluation of teaching that focuses on care for grieving parents after perinatal loss, perinatal palliative and end-of-life care.

Regarding exclusion criteria, no limitations were set for publication date. However, a limitation was set on language. Papers written in a language other than English were excluded due to lack of translation resources. Papers other than primary studies were also excluded. Duplicate publications were removed. Papers focusing on individuals other than healthcare professionals or students were excluded.

To measure quality, we used the Mixed Methods Appraisal Tool (MMAT) - Version 2011, which was designed for the appraisal stage of complex systematic literature reviews that include qualitative (QUAL), quantitative (QUAN), and mixed methods (MM) studies. The MMAT was used to assess all 14 selected studies, by means of a quality scoring system of zero, 25%, 50%, 75%, or 100%; with a higher score indicating higher quality (Pace et al., 2012; Pluye et al., 2009). Two researchers scored articles independently, and then discussed the differences. Consensus was achieved on all discrepancies.

2.3. Data analysis and synthesis

Data were extracted using a specifically designed data extraction table (see Table 1), and examined and compared independently by the authors. The following information was extracted from the texts: study design, study location, study population, data collection, study aims, teaching methods, the content of teaching, key findings. Reduced data were encoded. A content and thematic data analysis was performed according to Joffe and Yardley (2004). Outcomes were categorized into common themes, using a color-coding method to highlight similar findings across the literature (Taylor et al., 2006). First we categorized and quantified the basic characteristics of qualitative data. Then we systematically identified and described the topics and patterns in a qualitative data set. For synthesis of data based on the included studies, we selected a sequential explanatory design, in which the QUAN synthesis is followed by, and informs, the QUAL synthesis; and QUAL synthesis helps explain some results of the QUAN synthesis (Pluye and Hong, 2014).

3. Findings and discussion

Fourteen studies met all the inclusion criteria and were included in the integrative review (see Table 1). They were published between 2002 and 2017, and come from various English-speaking countries (the United Kingdom, Ireland, the USA, and Australia). One study is international (Australia, Vietnam, Fiji, and the Netherlands). The sample size of respondents ranges from $n = 6$ to $n = 758$.

The integrative review includes six descriptive QUAL studies, seven QUAN studies, and one MM study. Two studies (Hollins Martin et al., 2014; Hollins Martin et al., 2016) detail separately the results of the same research, describing QUAN data and QUAL data respectively. The quality of five studies was assessed by MMAT at 100%, seven studies at 75%, and two studies at 50%. MMAT is a tool that permits to appraise the methodological quality of studies. The most common drawback of

Table 1
Summary of studies included in the review.

Author, year, location	Research design	Sample	Data collection	Study aims	Teaching methods	Key findings	MMAT scores
Anspacher et al., 2017, USA	QUAN	Members of the pediatric hospitalist division (n = 12)	NCC PC pre and posttest (objective knowledge measure), and postmodule evaluation (7 items, 5-point Likert scale)	To examine the self-study tool. To determine the effectiveness of the modul (utility, learners' knowledge)	Computer based self-study tool: a PowerPoint slide show with a script in the notes section. Using the presenter mode allows the learner to simultaneously view the slides and read the script for instruction.	The average posttest score was 96% compared to pretest scores of 90% (unpaired t-test p = 0.058). The module was highly rated for meeting the learning objectives, usefulness for teaching small groups, and appropriateness of the format of the activity. The lowest rating was for change in clinical practice.	50% Not representative sample, not standard instrument
Barry et al., 2017, Ireland	QUAL	Undergraduate midwifery students (n = 6)	Face to face semi-structured interviews	To explore the influence of the Amulet artwork and exhibition on midwifery students' perceptions of caring for bereaved parents.	Visit of the exhibition the Amulet. It is a collaborative artwork and exhibition which was initiated and produced by artist Marie Brett, who worked with women exploring the hidden world of infants loss.	The performance and reflection of the works of art and the Amulet show have increased student awareness and insight into the non-linear nature of the process of mourning and meaning to maintain the path of sympathetic care for parents experiencing perinatal death.	75% Researchers' influence unclear
Cartwright and Read, 2005, UK	QUAL	Health visitors and midwives (n = 21)	Pre and post-workshop questionnaires (10 open questions), focus groups	To explore the gaps in knowledge and service provision; and evaluate the importance of post-registration support and training.	Workshop (6–8 participants), two half-days, which included a variety of interactive teaching and learning methods: formal data presentation; case analysis and directed exercises.	Six themes emerged from the analysis: emotional impact, content and delivery, strengths, weaknesses, impact upon practice and further educational needs. Workshops helped to increase participants' knowledge, awareness and confidence in raising difficult topics with clients and their families and also with other associated colleagues.	75% Researchers' influence unclear
Colwell, 2017, UK	QUAN	Undergraduate pediatric nursing/ midwifery students (n = 16)	The post-session evaluation form consisted of a Likert Scale followed by open questions (self-report knowledge measure)	To examine the use of simulation as part of a modern training approach in neonatal bereavement education.	Four discussion sections and two simulated scenarios in the simulation suite.	Simulation could be utilized more in infant bereavement education as a valid and credible educational method and deserves expansion and elaboration. 100% students learn a lot from this session, 87% feel an increase in confidence in the management of this situation.	50% Not representative sample, not standard instrument
DiMarco et al., 2002, USA	QUAN	Health care professionals (n = 128)	Pre and posttest, ECI questionnaire adapted for use in this research (Three vignettes, 14 items per vignette, 7-point Likert scale) (self-report measure)	To examine the differences in health care professionals' perception of emotional care delivered to parents experiencing perinatal loss.	Two different types of bereavement classes: a 1-day information session (lecture, case presentations, panel discussions) and 3-day bereavement counselor training session. Used methods: lecture, small group discussions, role play, case presentations, panel presentations	Posttest scores for each of the vignettes and for the total scores were significantly higher (p = 0.000) than pretest scores. The miscarriage vignette had the largest change scores and the lowest mean scores on the pretest and posttest, which indicates that professionals still viewed miscarriage as not as significant a loss as stillbirth and neonatal loss after attending the conferences. Health care professionals' perceptions of the emotional care needs of families experiencing perinatal loss were significantly increased after attending an educational program. There was no difference in scores between the 3-day and 1-day attendees.	100%

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Table 1 (continued)

Author, year, location	Research design	Sample	Data collection	Study aims	Teaching methods	Key findings	MMAT scores
Forster and Donovan, 2016. Australia	QUAL	Undergraduate nursing/midwifery students (n = 10)	Debriefing session	To explore the impact of a simulated neonatal resuscitation on nurse/midwife students' perceptions of their preparedness to provide bereavement support.	Students participated in groups of 3–4 students in two simulated neonatal resuscitation scenarios. The total duration for both simulations was 30 min. The simulation was videotaped and immediately following it students participated in a debriefing session.	Four themes emerged from the analysis: feeling unprepared, communication changes, the value of the simulation and personal reactions to neonatal death. The findings indicate that this simulation can assist students to develop and reflect upon their bereavement support skills in the context of unexpected neonatal death.	75% Researchers' influence unclear
Gardiner et al., 2016. International	QUAN	Health care professionals (n = 758)	Pre and post-workshop questionnaires (16 items, 5-point Likert scale) (self-report knowledge and confidence measure)	To determine the effectiveness of the program (knowledge, confidence, satisfaction) and suitability for international use.	IMPROVE program: workshop (introductory lecture, six learning station, a formative assessment), small group (4–9 participants). Used methods: hands on, skill-based and dynamic rotating teaching stations utilizing tell-show-do-feedback methodology. 30 min at each station. The workbook is in a self-directed learning format and was developed to be interactive (it is interleaved with thirty activities), designed to apply theory to practice. Student midwives completed the workbook in a pre-organized classroom day.	Evaluations showed a significant improvement between pre- and post-program knowledge and confidence in all six stations and overall, and a high degree of satisfaction in all settings. The IMPROVE program has been well received in Australia and in three different international settings. The significant main effect of mean pre-intervention UBET scores against post-intervention scores (p = 0.001) evidences that the workbook was effective at equipping student midwives with knowledge to underpin clinical skills that relate to bereavement care. That is, student midwives perceptions of their knowledge and understanding of perinatal bereavement care was markedly higher post-workbook completion.	100%
Hollins Martin et al., 2014. UK	QUAN	Undergraduate midwifery students (n = 179)	Pre and post-workbook completion test, UBET questionnaire 7 items, 5-point Likert scale) (primarily self-report knowledge measure)	To develop a workbook and evaluate it for effectiveness at delivering learning objectives.	The workbook is in a self-directed learning format and was developed to be interactive (it is interleaved with thirty activities), designed to apply theory to practice. Student midwives completed the workbook in a pre-organized classroom day.	Three themes emerged from the analysis: increasing classroom interaction (need to include group activities in the classroom that allow students to explore their thoughts and feelings about perinatal bereavement), the importance of reflecting on emotions (some of the students appreciated the importance of discussing emotional components as part of equipping them with some experience), and need for experience. Five main themes emerged from the analysis: dealing with death and bereaved families, anxieties and fears, teaching strategies, user representation and preparedness for practice. An integrated curriculum for pediatric and perinatal palliative and end-of-life care can demonstrate an increased knowledge in a small convenience sample of nursing students when compared to a control group not	100%
Hollins Martin et al., 2016. UK	QUAN	Undergraduate midwifery students (n = 179)	Qualitative data gathered in the open-ended comments sections under each of the UBET questions	To explore qualitative data provided by student midwives who evaluated the workbook to explore their views of potential teaching strategies.	The workbook is in a self-directed learning format and was developed to be interactive (it is interleaved with thirty activities), designed to apply theory to practice. Student midwives completed the workbook in a pre-organized classroom day.	Three themes emerged from the analysis: increasing classroom interaction (need to include group activities in the classroom that allow students to explore their thoughts and feelings about perinatal bereavement), the importance of reflecting on emotions (some of the students appreciated the importance of discussing emotional components as part of equipping them with some experience), and need for experience. Five main themes emerged from the analysis: dealing with death and bereaved families, anxieties and fears, teaching strategies, user representation and preparedness for practice. An integrated curriculum for pediatric and perinatal palliative and end-of-life care can demonstrate an increased knowledge in a small convenience sample of nursing students when compared to a control group not	100%
Mitchell, 2005. UK	QUAL	Undergraduate midwifery students (n = 45)	Verbal feedback and students' comments in the form of reflective writing	To evaluate preparation student midwives to care for bereaved parents.	One day session. Used methods: lecture, discussion, exploration of feelings and thoughts, watching video, interview with the leader of the local SANDS group.	Five main themes emerged from the analysis: dealing with death and bereaved families, anxieties and fears, teaching strategies, user representation and preparedness for practice. An integrated curriculum for pediatric and perinatal palliative and end-of-life care can demonstrate an increased knowledge in a small convenience sample of nursing students when compared to a control group not	75% Researchers' influence unclear
O'Shea et al., 2015. USA	QUAN	Undergraduate nursing students (n = 59)	Pediatric Palliative and End-of-Life Care pre and posttest, (50 items) (objective knowledge measure)	To evaluate the effect of an integrated curriculum for palliative care on nursing students' knowledge.	didactic hours over 14 weeks with 42 clinical hours, per course. Used methods: power point, lecture,	An integrated curriculum for pediatric and perinatal palliative and end-of-life care can demonstrate an increased knowledge in a small convenience sample of nursing students when compared to a control group not	75% Small convenience sample

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Table 1 (continued)

Author, year, location	Research design	Sample	Data collection	Study aims	Teaching methods	Key findings	MMAT scores
Patterson et al., 2016, UK	QUAL	Undergraduate midwifery students (n = 35)	Questionnaire (qualitative commentary) and focus group	To evaluate the use of poetry (Elegy for a Stillborn Child) and to establish its impact on the emotional insight of midwifery students in relation to pregnancy loss.	discussion, case studies, and simulated scenarios using role-play. Using literature as a teaching method. Students were asked to read the poem and discuss the insights and understanding that they gained and the implications these might have for practice. The session followed immediately after a teaching session of Pregnancy and Loss.	exposed to the same curriculum. The experimental group's knowledge scores increased from pretest (M = 34.78, SD = 4.42) to posttest (M = 37.78, SD = 4.96)6, while the control group's scores did not change from pretest (M = 37.42, SD = 4.06) to posttest (M = 37.00, SD = 3.28). Students' comments clearly support the suggestion that use of this poem has enhanced emotional intelligence. The data also indicates that vicarious experience gained through reading this poem has helped to nurture sensitivity and professional insight into the impact of still birth on a father.	75% Researchers' influence unclear
Twamley et al., 2013, UK	MM	Healthcare professionals (n = 264)	Pre and post-workshop questionnaires (open and closed questions, 7 domains) (primarily self-report knowledge measure)	To evaluate a half day educational program and to establish its impact on the knowledge and attitudes towards palliative care.	A four-hour education workshop on the principles, practice and resources in palliative care. Used methods: lecture, discussion, case studies.	Over 79% of respondents reported that the workshop completely met their learning needs. Post-session 80% of respondents felt confident referring to palliative care services, compared with 46% before (p < 0.001). Analysis of open and closed text responses revealed a shift in attitude after the sessions from a focus on dying/end-of-life, towards integrating palliative care as part of a holistic treatment plan.	100%
Zhang and Lane, 2013, USA	QUAN	Neonatal nurses (n = 63)	Pre and posttest, BEACONNS questionnaire (55 items, 3 domains) (self-report knowledge measure)	To evaluate the effect of a bereavement seminar on the attitudes of nurses regarding end of life and palliative care of neonates.	An eight-hour bereavement seminar. The seminar focused on dealing with ethics issues and improving communication skills, on developing strategies to support the caregiver and family in dealing with their grief and to utilize support services in the community and hospital.	After bereavement seminar, the seminar attendees had higher levels of comfort in providing end of life care than nurses in the control group (T = -0.214; P = 0.04). Nurses who came to the workshop were less satisfied with their previous end of life/bereavement care training than those who did not come (t = -2.21, P = 0.03).	75% Groups not comparable

Abbreviations: BEACONNS - Bereavement/End of life Attitudes About Care of Neonatal Nurses Scale; ECI - The Emotional Care Instrument; NCC PC – Newborn Care Curriculum Palliative Care, MM - Mixed method design; QUAL - Descriptive qualitative design; QUAN - Quantitative design; SANDS - Stillbirth and neonatal death charity; UBET - Understanding Bereavement Evaluation Tool.

QUAN studies was not using a representative sample and a standard instrument. On the other hand, QUAL studies did not meet the criterion of reflexivity of researchers (their influence on findings) most often. As our aims also focused on aspects other than assessing the effectiveness of teaching (teaching content, teaching methods, evaluation tools), we found useful even studies that received e.g. only 50% of the MMAT evaluation (Anspacher et al., 2017 and Colwell, 2017).

The aim of the studies was to evaluate educational programs and events in the field of perinatal or neonatal palliative/bereavement care, and to establish the influence of teaching on respondents' knowledge, attitudes to, and readiness for PPC. Most studies also monitored respondents' satisfaction with the educational program. QUAN studies were evaluated using mostly pre- and post-tests, while QUAL studies were assessed by analyzing data obtained through interviews, focus groups, or qualitative written comments.

All 14 studies consider perinatal bereavement education to be effective. Eight studies reported statistical improvements in knowledge, security/comfort in providing end-of-life care, or increased perceptions of the emotional care needs of bereaved families, after attending an educational program (key findings see Table 1). Since the evaluation tools used in the studies differed, it was not possible to determine which program was most effective. Only four studies (DiMarco et al., 2002; Hollins Martin et al., 2014; O'Shea et al., 2015; Zhang and Lane, 2013) used a validated questionnaire for teaching evaluation. Only two studies used an objective evaluation of the increase in knowledge by the questionnaire (Anspacher et al., 2017; O'Shea et al., 2015). In a study by Anspacher et al. (2017), participants criticized excessive simplicity of the knowledge Newborn Care Curriculum Palliative Care Module test.

O'Shea et al. (2015) used a comprehensive and validated Pediatric Palliative and End-of-Life Care Test (see Section 3.2). Other studies mainly used a self-report measure.

Qualitative data provide more detail on the benefits of educational programs for knowledge development, commenting on the effectiveness of individual teaching methods, and participant satisfaction. Participants in the qualitative studies (Barry et al., 2017; Cartwright and Read, 2005; Forster and Donovan, 2016; Hollins Martin et al., 2016; Mitchell, 2005; Patterson et al., 2016) reported a number of outcomes from participation in the educational program: an awareness of the need for a safe environment conducive to the sharing of emotions in lessons, the gaining of new knowledge and communication skills, an awareness of the benefits of PPC teaching in practice (i.e., increased confidence, awareness of the parents' needs, and understanding of the grieving process), an awareness of the need to be able to cope with stress, the forming of positive attitudes towards palliative care, an appreciation of active participation in lessons, and positive evaluations of participation in PPC training (especially regarding postgraduate education).

The main results of the content and thematic analysis are explained in the following section.

3.1. PPC teaching methods

In the studies included in the review, a wide range of PPC teaching methods was used.

Lectures, slide presentations, or written texts were the most common teaching methods used in the selected studies (Anspacher et al., 2017; Cartwright and Read, 2005; DiMarco et al., 2002; Gardiner et al., 2016; Hollins Martin et al., 2014; Mitchell, 2005; O'Shea et al., 2015; Twamley et al., 2013). The verbal component of teaching remains one of the main tools in the cognitive process. The participants in educational programs most valued and appreciated dialogical methods, especially *discussions* (Cartwright and Read, 2005; Colwell, 2017; DiMarco et al., 2002; Mitchell, 2005). In the discussions, participants could share their experiences from the past and learn about other participants' experiences (in some curricula, even interdisciplinary

ones). They also had an opportunity to formulate and defend their ideas and attitudes regarding dealing with death. For such discussions, smaller groups of participants are preferable (Cartwright and Read, 2005; Gardiner et al., 2016), creating an atmosphere of trust and security, supported by the lecturers (Cartwright and Read, 2005; Colwell, 2017; Mitchell, 2005). It is necessary to create a supportive environment (e.g., to offer counseling, to have two lecturers, with one at the students' disposal), especially when working with students (Mitchell, 2005; Forster and Donovan, 2016). Matzo et al. (2003) state that a faculty should incorporate strategies necessary to develop a system of support in the teaching of end-of-life care. The aim of this supportive system is to enable students to explore and express feelings associated with anxiety, loss, and the grief experienced when caring for dying patients and their families.

Another important teaching method used in four studies was *simulated scenarios using role-play* (Colwell, 2017; DiMarco et al., 2002; Forster and Donovan, 2016; O'Shea et al., 2015). Simulation methods require student participation, enabling them to acquire skills, and to analyze and solve problems representing real-life situations. The studies mostly used a form of scenario-based learning that involved scripted or semi-scripted interactions between health professionals and patients, and between health professionals. The role-playing method is highly valued for its development of participants' communication skills (Bosse et al., 2012). Clinical simulation is a safe and effective method for students/midwives to experience and practice the use of language and discourse in challenging situations (Donovan and Forster, 2015). Gillan et al. (2014) recommend end-of-life care simulation as an innovative strategy that can help prepare nursing students to provide quality end-of-life care.

The environment in which the simulated situation takes place (Colwell, 2017) and degree of authenticity are of great importance (Pike and O'Donnell, 2010). Simulation rooms can be used (e.g., NICU or a bereavement room), which allow participants to experience a realistic clinical environment and how the atmosphere can affect the experience of grieving parents.

Colwell (2017) describes two scenarios in which students learn to communicate with a mother and to take care of a dying baby. The baby's mother was played by a member of the faculty. Forster and Donovan (2016) also used a teaching staff member in the role of a grieving mother in a simulated situation. The psychological security of the environment is also important for participants. When teaching using the simulation method, a participant is often assigned the role of observer. Studies suggest that participants in the observer role benefit as much as those playing active roles (Kaplan et al., 2012; Tuxbury et al., 2012). However, in a study by Colwell (2017), 12.5% of learners reported they would have preferred to be able to actively participate in the simulated scenario.

In studies by Colwell (2017) and by Forster and Donovan (2016), a course of simulation teaching is described. Colwell (2017) informed the participants about the plan of the session, prepared them emotionally and explained to them that they could leave or stop the scenario at any time, which is strictly recommended by the standards of The International Nursing Association for Clinical Simulation and Learning. Forster and Donovan (2016) do not mention any information about pre-briefing. In their study, students reported that they experienced feelings of shock, confusion and increased awareness of their own grief in the course of the session. They might have not been prepared emotionally well enough for the situation. In both cases the simulation was followed by debriefing promoted reflective thinking and assimilation of new knowledge, skills, and attitudes.

Participants in educational programs can also use the *exposure method*, involving true accounts from parents of the loss of their babies (explored in more detail in selected studies). This included, for example, reading parents' stories, viewing photos at the collaborative artwork and exhibition (Barry et al., 2017), a video that details a particular family's experience of their baby's death (Mitchell, 2005), a

discussion with parents who had experienced perinatal loss (Mitchell, 2005), and a case-study presentation and analysis (Cartwright and Read, 2005; DiMarco et al., 2002; O'Shea et al., 2015). A case study allows the educator to stimulate critical thinking and to match the case to the goals of the training (Matzo et al., 2003). Parents' accounts can help participants acquaint themselves with the grieving process parents experience as a natural stage in coping with the loss of their babies. "The women's stories helped the students to reflect and gain insight into the importance of their role in caring for bereaved couples" (Barry et al., 2017, p. 3).

Three studies in our review used *arts-based palliative care training* in the teaching of student midwives. Two studies focused on the evaluation of a purely creative approach, namely a visit to an art project (Barry et al., 2017) and the use of poetry to provide vicarious experience and develop emotional insight (Patterson et al., 2016). In his poem *Elegy for a Stillborn Child*, Seamus Heaney (1972) sensitively captures the depth and extent of the emotional trauma suffered by both parents. Patterson et al. (2016) recommend this poem (and indeed similar works of literature) be used to complement standard midwifery teaching and to develop the emotional intelligence of healthcare professionals. In both studies, a creative approach was preceded by a teaching session on pregnancy and loss. Literature and poems can be used in the teaching of students to develop their practical wisdom, emotional intelligence, and moral imagination, which are clearly essential to good palliative care (Begley et al., 2011; Matzo et al., 2003). Hollins Martin et al. (2014) combine the transfer of information in written form with creative output in a workbook, encouraging students to draw their own symbol that might have been used for marking the records of a woman who has been experiencing a perinatal loss in one activity. The creative teaching method promotes active student learning, stimulates a meaningful and deep learning experience for students, and develops cognitive, social, and affective skills (Rankin and Brown, 2016).

Two studies used *self-study tools* in PPC teaching: a workbook (Hollins Martin et al., 2014; Hollins Martin et al., 2016) and an on-line presentation (Anspacher et al., 2017). In both cases participants increased their theoretical knowledge, but they missed interaction during a learning activity, especially discussion about individual topics and sharing their experiences. On-line teaching was satisfactory, however 92% of participants strongly agreed it would be beneficial in a small-group setting (Anspacher et al., 2017). Some students found using a workbook quite emotionally demanding in university environment and they would prefer working in a home environment. The authors consider a possibility to convert a workbook into an on-line teaching tool that incorporates discussion groups and activities (Hollins Martin et al., 2016).

3.2. Evaluation tools for PPC teaching

The evaluation tools used in the studies focused on the knowledge acquired, the perceived level of knowledge and skills, the attitude towards PPC, and the provision of emotional support.

In their study, O'Shea et al. (2015) used *Pediatric Palliative and End-of-Life Care Test*, focusing on students' knowledge of pediatric and perinatal palliative, and end-of-life care. It is a modified instrument from a published knowledge assessment tool End-of-Life Nursing Education Consortium Knowledge Assessment Test (ELNEC-KAT). ELNEC-KAT has been tested and found to be valid (Lange et al., 2009). The test is a 50-item, multiple-choice instrument, which O'Shea adapted to focus specifically on the care of children with life-threatening conditions and their families. The total score of the test ranges between 0 and 50 points. A higher score reflects a higher level of knowledge. Reliability analysis indicated good internal consistency (pre-test Cronbach's alpha = 0.75; post-test Cronbach's alpha = 0.74), test-retest reliability was also good ($r = 0.76$) (O'Shea et al., 2015).

The instrument known as the *Understanding Bereavement Evaluation Tool (UBET)* was designed to measure the effectiveness of workbooks in

the study by Hollins Martin et al. (2014, 2016). It measures participants' perceived level of learning before and after workbook completion. The UBET consists of six statements evaluated on a 5-point Likert scale. Scores range from 6 to 30, with a score of six representing the lowest subjective assessment of level of knowledge regarding perinatal bereavement care, and 30 the highest. Validity tests have shown that the UBET, (6-item version), can be considered a psychometrically robust instrument. Internal consistency was good (Cronbach's alpha = 0.78) (Hollins Martin et al., 2013). Principal components analysis identified that the UBET comprised two sub-scales: theoretical knowledge base and psychosocial elements of care delivery (Hollins Martin et al., 2013).

The *Emotional Care Instrument (ECI)* was used in a study by DiMarco et al. (2002), who adapted Reed's questionnaire to reflect perinatal loss in three different scenarios: miscarriage, stillbirth, and neonatal death. The ECI questionnaire measures three levels of emotional care (emotional seriousness of the event, priority of care, and emotional support). The revised ECI questionnaire had three vignettes (one for each of the loss scenarios) with 14 items per vignette. The statements are evaluated on a 7-point Likert scale, with one representing a very low and seven representing a very high score. The total score on the test ranges between 42 and 294 points. Internal consistency of the revised ECI was good (pre-test Cronbach's alpha = 0.72; post-test Cronbach's alpha = 0.82) (DiMarco et al., 2002).

Another tool used to evaluate educational programs is the *Bereavement/End of life Attitudes About Care of Neonatal Nurses Scale (BEACONNS)* by Zhang and Lane (2013). This instrument was developed to investigate nurses' perceptions of various aspects of bereavement/end-of-life care of critically ill and/or dying infants and infants' families by Engler et al. (2004). The BEACONNS questionnaire is a 55-item scale, containing four sections: the level of comfort in handling end-of-life and bereavement care (Comfort scale, 19 Likert-scale items, Cronbach's alpha = 0.95), role of propensity in providing end-of-life and bereavement care (Role scale, 18 Likert-scale items, Cronbach's alpha = 0.85), tendency to allow family involvement in providing end-of-life care (Involvement scale, 14 Likert-scale items, Cronbach's alpha = 0.85), and demographic characteristics (Engler et al., 2004). The statements are evaluated on a 5-point Likert scale. Reliability of the instrument when used in a descriptive study ranged between 0.81 and 0.95 (Engler et al., 2004).

Other questionnaires used in the selected evaluation surveys were mostly of the authors' own design without test reliability and validation.

3.3. PPC pregradual and postgradual education

In studies dealing with the evaluation of postgradual PPC programs (Anspacher et al., 2017; Cartwright and Read, 2005; DiMarco et al., 2002; Gardiner et al., 2016; Twamley et al., 2013; Zhang and Lane, 2013) we meet motivated participants from clinical practice who often have a professional experience with perinatal loss and who get in the program voluntarily. All of these training programs provide comprehensive content based on the PPC structure. The results of the evaluations show that health professionals are not satisfied with their previous education and readiness in PPC (Anspacher et al., 2017; Cartwright and Read, 2005; Zhang and Lane, 2013), which corresponds to the results of other research (Kain, 2006; Kilcullen and Ireland, 2017; Peng et al., 2013).

For midwives and neonatal nurses, PPC is actually the primary form of palliative care they can provide in practice. That is why it is logical that attention is paid to this form of care in university education. Seven of eight studies that deal with evaluation of undergraduate teaching PPC programs focus on undergraduate midwifery/pediatric nursing students. The content of each educational program is different. Hollins Martin et al. (2014, 2016) workbook is comprehensive in terms of content, but focuses primarily on cognitive aims. Some studies describe

teaching focused primarily on understanding parental grief, where affective aims predominate (Barry et al., 2017; Patterson et al., 2016). Simulation lessons that draw on selected situations from practice focus particularly on behavioral and social aims (Colwell, 2017; Forster and Donovan, 2016). In general, students considered PPC teaching as very emotive, intensive and challenging (Hollins Martin et al., 2016; Mitchell, 2005; Forster and Donovan, 2016) and they often did not know what to do with their feelings (Hollins Martin et al., 2016; Forster and Donovan, 2016). Paying much attention to self-care seems to be vital in the context of teaching students. Training regarding coping and managing responses to infant death has been identified as a priority for healthcare providers (Gold et al., 2008; Mander, 2009).

The O'Shea et al. (2015) study focuses on an educational PPC program in bachelor degree nursing students. It uses an enhanced pediatric and perinatal curricula adapted from End of life Nursing Education Consortium (ELNEC) project with a total of 35 didactic hours and 42 clinical hours (O'Shea et al., 2015). Students' knowledge improved in this content area. The authors recommend further evaluating sustained benefits of this curriculum.

4. Recommendations

PPC teaching has its own specific content (perinatal death through miscarriage, ectopic pregnancy, stillbirth, and newborn death) and differs from pediatric and adult palliative care. We recommend that undergraduate PPC education be provided to all nurses and midwives, but with a different level of attention to this topic and the number of lessons. For nurses, PPC is part of the whole comprehensive education in palliative care. American Nurses Association Board (2017) recommends that ELNEC curricula be used for undergraduate nursing students as the standard for primary palliative nursing education. ELNEC also contains a pediatric section, whose one module is dealing with PPC. Satisfaction with undergraduate nursing education in PPC and its effectiveness should be further researched.

On the other hand, for midwives and neonatal nurses PPC in undergraduate education is crucial and as such it should be given adequate attention. National Association of Neonatal Nurses (2015) considers palliative and end-of-life care for infants and their families as an integral component of neonatal care. The standards for midwifery education curriculum, developed by the International Confederation of Midwives (2019), define competences related to PPC (e.g. provide counseling and follow-up care for women and family members who experience stillbirth, neonatal death, serious infant illness, and congenital conditions, provide post-abortion care). Midwives can utilize PPC in the antepartum, intrapartum, and postpartum practice settings.

PPC has largely developed in recent decades (Balaguer et al., 2012) and is still developing and shaping. It is therefore necessary for PPC to be part of the lifelong training of professionals who encounter the issues of perinatal loss in practice. The analysis of studies on PPC post-graduate education programs shows that motivation for further education of PPC practitioners is their dissatisfaction with previous education.

We recommend that attention be paid to evaluations of individual educational activities in PPC. The postgraduate education programs we studied had comprehensive content based on the PPC structure. The knowledge of participants in training programs should be assessed equally both in a comprehensive and complex way. We recommend the use of measuring tools in evaluation studies to verify the objective knowledge of participants in PPC training programs. QUAN research should focus on having a representative sample of respondents and using a standard instrument. No research is available on other teaching methods, such as e-learning or blended learning in PPC.

5. Limitations

This is the first study to review comprehensively the efficacy of PPC education. One problem is that the same measurement tools were not

used for the evaluation of education in the studies. Only four studies used a validated questionnaire for evaluation of teaching. Most studies use self-report measure tools for evaluation, however, the students' opinions do not have to necessarily talk about the quality of educational program and knowledge acquired. Other methodological limitations were identified in MMAT scores, including selection bias and lack of comparison groups. In addition, the studies were conducted mainly in English-speaking countries. While the search strategy included a number of search terms and databases, it may not have identified all the relevant literature on this topic, such as unpublished literature.

6. Conclusion

Unfortunately, even in the field of obstetrics, midwifery and neonatology, caregivers encounter death. PPC education is essential in pregradual education for midwives and neonatal nurses. Further research is needed to find the effectiveness of PPC teaching in undergraduate nursing students. Education programs PPC need to be developed and made available in postgraduate education for professionals who encounter with perinatal death and the bereaved families in hospital and community care. Innovative teaching methods (simulated scenarios using role-play, discussion, art-based teaching, exposure method, etc.) and varied teaching approaches help participants to translate theory into meaningful clinical practice, and can also provide carers with feelings of greater confidence in and satisfaction with the care they provide. Death education is a life-long process; education in PPC can help healthcare professionals in their career development.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Ethical approval

Not applicable.

Declaration of competing interest

The authors have no conflict of interest to declare.

References

- American Nurses Association Board, 2017. Call for Action: Nurses Lead and Transform Palliative Care. ANA Professional Issues Panel. retrieved from. <https://www.nursingworld.org/practice-policy/health-policy/pro-issues-panel/palliative-and-hospice-nursing-panel/>.
- Anspacher, M., Burd, A., Stroth, J., Conroy, R., 2017. Newborn Care Curriculum: Palliative Care for the Newborn. pp. 1–5.
- Bakbakhhi, D., Burden, C., Storey, C., Siassakos, D., 2017. Care following stillbirth in high-resource settings: latest evidence, guidelines, and best practice points. *Semin. Fetal Neonatal Med.* 22, 161–166. <https://doi.org/10.1016/j.siny.2017.02.008>.
- Balaguer, A., Martín-Ancel, A., Ortigoza-Escobar, D., Escribano, J., Argemi, J., 2012. The model of palliative care in the perinatal setting: a review of the literature. *BMC Pediatr.* 12, 25. <https://doi.org/10.1186/1471-2431-12-25>.
- Barry, M., Quinn, C., Bradshaw, C., Noonan, M., Brett, M., Atkinson, S., New, C., 2017. Exploring perinatal death with midwifery students' using a collaborative art project. *Nurse Educ. Today* 48, 1–6. <https://doi.org/10.1016/j.nedt.2016.09.004>.
- Begley, A.M., Glackin, M., Henry, R., 2011. Tolstoy, stories, and facilitating insight in end of life care: exploring ethics through vicarious experience. *Nurse Educ. Today* 31, 516–520. <https://doi.org/10.1016/j.nedt.2010.09.004>.
- Bosse, H.M., Schultz, J.-H., Nickel, M., Lutz, T., Moltner, A., Junger, J., Huwendiek, S., Nikendei, C., 2012. The effect of using standardized patients or peer role play on ratings of undergraduate communication training: a randomized controlled trial. *Patient Educ. Couns.* 87, 300–306. <https://doi.org/10.1016/j.pec.2011.10.007>.
- British Association of Perinatal Medicine, 2010. Palliative Care (Supportive and End of Life Care). A Framework for Clinical Practice in Perinatal Medicine. https://www.bapm.org/sites/default/files/files/Palliative_care_final_version_%20Aug10.pdf.
- Cartwright, P., Read, S., 2005. Working with practitioners to develop training in perinatal loss and bereavement: evaluating three workshops. *Nurse Educ. Pract.* 5, 266–273. <https://doi.org/10.1016/j.nepr.2005.01.004>.
- Colwell, P., 2017. Building confidence in neonatal bereavement: the use of simulation as

- an innovative educational approach. *J. Neonatal Nurs.* 23, 65–74. <https://doi.org/10.1016/j.jnn.2016.07.005>.
- DiMarco, M., Renker, P., Medas, J., Bertosa, H., Goranitis, J.L., 2002. Effects of an educational bereavement program on health care professionals' perceptions of perinatal loss. *J. Contin. Educ. Nurs.* 33, 180–186.
- Donovan, H., Forster, E., 2015. Communication adaptation in challenging simulations for student nurse midwives. *Clin. Simul. Nurs.* 11, 450–457. <https://doi.org/10.1016/j.ecns.2015.08.004>.
- Engler, A.J., Cusson, R.M., Brockett, R.T., Cannon-Heinrich, C., Goldberg, M.A., Gorzkowski West, M., Petow, W., 2004. Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. *Am. J. Crit. Care* 13, 489–498.
- International Confederation of Midwives, 2019. Essential Competencies of Midwifery Practice. ICM Education Resources. retrieved from. <https://www.internationalmidwives.org/our-work/education/education-resources/>.
- Forster, E., Donovan, H., 2016. Enhancing bereavement support skills using simulated neonatal resuscitation. *Int. J. Palliat. Nurs.* 22, 500–507. <https://doi.org/10.12968/ijpn.2016.22.10.500>.
- Gardiner, P.A., Kent, A.L., Rodriguez, V., Wojcieszek, A.M., Ellwood, D., Gordon, A., Wilson, P.A., Bond, D.M., Charles, A., Arbuckle, S., Gardener, G.J., Oats, J.J., Erwich, J.J., Korteweg, F.J., Duc, T.H.N., Leisher, S.H., Kishore, K., Silver, R.M., Heazell, A.E., Storey, C., Flenady, V., 2016. Evaluation of an international educational programme for health care professionals on best practice in the management of a perinatal death: Improving Perinatal mortality Review and Outcomes Via Education (IMPROVE). *BMC Pregnancy Childbirth* 16, 1–11. <https://doi.org/10.1186/s12884-016-1173-8>.
- Gillan, P.C., van der Riet, P.J., Jeong, S., 2014. End of life care education, past and present: a review of the literature. *Nurse Educ. Today* 34, 331–342. <https://doi.org/10.1016/j.nedt.2013.06.009>.
- Gold, K.J., Kuznia, A.L., Hayward, R.A., 2008. How physicians cope with stillbirth or neonatal death. *Obstetrics and Gynecology* 112, 29–34. <https://doi.org/10.1097/AOG.0b013e31817d0582>.
- Heaney, S., 1972. *Door into the Dark*, 2nd ed. Farber&Farber, London.
- Hollins Martin, C.J., Forrest, E., Wylie, L., Martin, C.R., 2013. The Understanding Bereavement Evaluation Tool (UBET) for midwives: factor structure and clinical research applications. *Nurse Educ. Today* 33, 1153–1159. <https://doi.org/10.1016/j.nedt.2012.11.019>.
- Hollins Martin, C.J., Forrest, E., Wylie, L., Martin, C.R., 2014. An evaluative survey to assess the effectiveness of using an interactive workbook to deliver bereavement education to undergraduate student midwives. *Midwifery* 30, 942–948. <https://doi.org/10.1016/j.midw.2013.05.004>.
- Hollins Martin, C.J., Robb, Y., Forrest, E., 2016. An exploratory qualitative analysis of student midwives views of teaching methods that could build their confidence to deliver perinatal bereavement care. *Nurse Educ. Today* 39, 99–103. <https://doi.org/10.1016/j.nedt.2015.12.023>.
- Joffe, H., Yardley, L., 2004. Content and thematic analysis. In: Marks, D., Yardley, L. (Eds.), *Research Methods for Clinical and Health Psychology*. Sage Publications, London, pp. 56–68.
- Kain, V., 2006. Palliative care delivery in the NICU: what barriers do neonatal nurses face? *Neonatal Netw* 25 387–92.
- Kaplan, B., Abraham, C., Gary, R., 2012. Effects of participation vs. observation of a simulation experience on testing outcomes: implications for logistical planning for a school of nursing. *Int. J. Nurs. Educ. Scholarsh.* 9. <https://doi.org/10.1515/1548-923X.2398>.
- Kilcullen, M., Ireland, S., 2017. Palliative care in the neonatal unit: neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. *BMC Palliative Care* 16. <https://doi.org/10.1186/s12904-017-0202-3>.
- Lange, J.W., Shea, J., Grossman, S.C., Wallace, M., Ferrell, B.R., 2009. Validation of the end-of-life nursing education consortium knowledge assessment test: an abbreviated version. *J. Hosp. Palliat. Nurs.* <https://doi.org/10.1097/NJH.0b013e3181b4cc54>.
- Leuthner, S., Jones, E., 2007. Fetal concerns program: a model for perinatal palliative care. *Am. J. Matern. Child Nurs.* 32 (5), 272–278. <https://doi.org/10.1097/01.NMC.0000287996.90307.c6>.
- Mander, R., 2009. Good grief: staff responses to childbearing loss. *Nurse Educ. Today* 29, 117–123. <https://doi.org/10.1016/j.nedt.2008.07.005>.
- Matzo, M.L., Sherman, D.W., Lo, K., Egan, K.A., Grant, M., Rhome, A., 2003. Strategies for teaching loss, grief, and bereavement. *Nurse Educ.* 28, 71–76.
- Mitchell, M., 2005. Preparing student midwives to care for bereaved parents. *Nurse Educ. Pract.* 5, 78–83. <https://doi.org/10.1016/j.nepr.2004.03.005>.
- National Association of Neonatal Nurses, 2015. Palliative and End-of-Life Care for Newborns and Infants. Position Statement 3063. retrieved from. <http://nann.org/about/position-statements>.
- O'Connell, O., Meaney, S., O'Donoghue, K., 2016. Caring for parents at the time of still-birth: how can we do better? *Women and Birth* 29, 345–349. <https://doi.org/10.1016/j.wombi.2016.01.003>.
- O'Shea, E.R., Campbell, S.H., Engler, A.J., Beauregard, R., Chamberlin, E.C., Currie, L.M., 2015. Effectiveness of a perinatal and pediatric End-of-Life Nursing Education Consortium (ELNEC) curricula integration. *Nurse Educ. Today* 35, 765–770. <https://doi.org/10.1016/j.nedt.2015.02.015>.
- Pace, R., Pluye, P., Bartlett, G., Macaulay, A.C., Salsberg, J., Jagosh, J., Seller, R., 2012. Testing the reliability and efficiency of the pilot Mixed Methods Appraisal Tool (MMAT) for systematic mixed studies review. *Int. J. Nurs. Stud.* 49, 47–53. <https://doi.org/10.1016/j.ijnurstu.2011.07.002>.
- Patterson, D., Begley, A., Nolan, A., 2016. An evaluation of a teaching strategy: the use of literature when teaching pre-registration midwifery students on pregnancy and loss. *Nurse Educ. Today* 38, 42–47. <https://doi.org/10.1016/j.nedt.2015.12.019>.
- Peng, N.H., Chen, C.H., Huang, L.C., Liu, H.L., Lee, M.C., Sheng, C.C., 2013. The educational needs of neonatal nurses regarding neonatal palliative care. *Nurse Educ. Today* 33, 1506–1510. <https://doi.org/10.1016/j.nedt.2013.04.020>.
- Pike, T., O'Donnell, V., 2010. The impact of clinical simulation on learner self-efficacy in pre-registration nursing education. *Nurse Educ. Today* 30, 405–410. <https://doi.org/10.1016/j.nedt.2009.09.013>.
- Pluye, P., Hong, Q.N., 2014. Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. *Annu. Rev. Public Health* 35, 29–45. <https://doi.org/10.1146/annurev-publhealth-032013-182440>.
- Pluye, P., Gagnon, M.P., Griffiths, F., Johnson-Lafleur, J., 2009. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *Int. J. Nurs. Stud.* 46, 529–546. <https://doi.org/10.1016/j.ijnurstu.2009.01.009>.
- Rankin, J., Brown, V., 2016. Creative teaching method as a learning strategy for student midwives: a qualitative study. *Nurse Educ. Today* 38, 93–100. <https://doi.org/10.1016/j.nedt.2015.12.009>.
- Taylor, B., Kermode, S., Roberts, K., 2006. *Research in Nursing and Health Care: Evidence for Practice*, 3rd ed. Cengage Learning EMEA, London, UK.
- Tuxbury, J.S., McCauley, P.M., Lement, W., 2012. Nursing and theatre collaborate: an end-of-life simulation using forum theatre. *J. Nurs. Educ.* 51, 462–465. <https://doi.org/10.3928/01484834-20120615-02>.
- Twamley, K., Kelly, P., Moss, R., Mancini, A., Craig, F., Koh, M., Polonsky, R., Bluebond-Langner, M., 2013. Palliative care education in neonatal units: impact on knowledge and attitudes. *BMJ Support. Palliat. Care* 3, 213–220. <https://doi.org/10.1136/bmjspcare-2012-000336>.
- Whittemore, R., Knaf, K., 2006. The integrative review: updated methodology the integrative review: updated methodology. *J. Adv. Nurs.* 52, 546–553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>.
- Zhang, W., Lane, B.S., 2013. Promoting neonatal staff nurses' comfort and involvement in end of life and bereavement care. *Nurs. Res. Pract.* 2013, 365329. <https://doi.org/10.1155/2013/365329>.