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Title: Exploring perinatal death with midwifery students' using a collaborative art project

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Summary

Objective: To explore the influence of the Amulet artwork and exhibition on midwifery students' perceptions of caring for parents experiencing perinatal death.

Design: A descriptive qualitative design involving face-to-face semi-structured interviews following institutional ethical approval.

Setting: A regional Maternity Hospital in Ireland which hosted the National Artwork and Exhibition exploring the hidden world of infant death.

Participants: A purposive sample of six consenting post registration midwifery students who had attended the Amulet artwork and exhibition.

Findings: Four core themes emerged and these were i) entering the mother's world and hearing her pain; ii) the journey of grief and connecting with the bereaved parent's unique experience; iii) facing the challenge of providing effective perinatal bereavement care; iv) maintaining a journey of compassionate practice

Conclusion and implications for practice: Exposure to, and reflection on the Amulet artwork and exhibition increased students' awareness and insight into the non-linear nature of the grieving process, and to the importance of maintaining a journey of compassionate care for parents experiencing perinatal death. The findings suggest that the use of creative women-centered strategies promote affective learning in relation to perinatal death and so may be of use to educators and maternity care providers.

Introduction

Bereavement is part of life, and bereavement and death associated with stillbirth is recognised as a time when there may be only one chance to get it right (Downe et al., 2013). As Schott and Henly (2007) emphasise, memories may be the only things that parents have to take home, and most of those memories will involve the care they receive. In the Amulet artwork and exhibition, the amulets are special object signifiers, particular to infant loss; protecting the bereaved parent's memory of their deceased infant (Brett, www.amulets.ie). Caring for bereaved parents has been influenced through the years by women, their stories, voluntary organisations and pioneers in the professional field, so that care can be based on a firm knowledge base, standards of care, education and training and a partnership approach. In 1981, Myles highlighted the importance of kindness and compassionate care for bereaved parents, acknowledging how the midwife facilitates this through her words and actions. These factors continue to be recognised as fundamental to contemporary midwifery care. Individualised care and the manner in which staff behaved was of key importance in a UK national survey of parents after stillbirth or the death of their baby (Redshaw et al., 2014). Downe et al. (2013) in their study on bereaved parents' experience of stillbirth suggest that an ethos of care at all levels of the organisation is central to positive staff caring behaviours. Hospital policy and meeting training needs of staff has a positive effect on attitudes towards bereavement care, demonstrated by Chan et al. (2004). Caring for bereaved parents has been described as stressful for health care professionals, and there is a growing awareness of the importance of the emotional needs of health care professionals as well as parents (Kenworthy and Kirkham, 2011). Midwifery students may well find themselves supporting bereaved

couples experiencing perinatal death, and they will certainly be faced with the situation as newly qualified midwives.

There is a lack of discussion and debate in the literature on how midwifery students are prepared to care for bereaved parents (Mitchell, 2005). Begley (2003) and McKenna and Rolls (2011) refer to the importance of developing strategies to support students as they acquire the skills necessary to deal with bereaved parents. Facilitation of affective teaching and learning strategies in the context of bereavement is challenging within the university setting, where the emphasis can tend towards didactic teaching (Laporte Matzo et al., 2003). An evaluation of perinatal bereavement education found that midwifery students' most positive comments related to hearing the women's stories and the involvement of user groups, with limited value attributed to the theoretical input (Mitchell 2005). Hollins Martin et al. (2014) found the use of a work book to be an effective method of teaching bereavement care to midwifery students. In their account of using a creative approach to the teaching of spirituality to students, Mitchell and Hall (2007) conclude that educationalists need to further investigate how students can be facilitated to learn the art and science of midwifery, within the constraints of a formal curriculum.

The Amulet: Anamnesis is a collaborative artwork and exhibition which was initiated and produced by artist Marie Brett, who worked with women exploring the hidden world of infant loss. 'Anamnesis' is a Greek word meaning to recall to memory, referring to a patient's account of their medical history and amulets are small objects, often worn, thought to give protection or to bring good fortune. Photographs of family amulets together with bereaved parent's stories describe their amulet's meaning (Brett, www.amulets.ie). The Amulet exhibition tour, funded through The Arts Council Touring and Dissemination of Work Award 2014, was brought on site to the University Maternity Hospital, Limerick in September 2014. This qualitative descriptive study explored the influence of the Amulet artwork and exhibition on midwifery students' perceptions of caring for bereaved parents.

Methods

Study design and sample

A qualitative descriptive approach was used, facilitating the opportunity to gain in-depth knowledge of participants' perceptions of the Amulet artwork and exhibition. This approach enabled the researchers to stay close to the data, as it aimed to describe participants experiences rather than explain them (Sandelowski, 2010) and was identified as appropriate to meet the needs of the study (Sandelowski, 2000).

The study population comprised of post registration students on the eighteen month midwifery programme (n=9). As part of the students' theoretical module prior to final practice placement, students were facilitated to attend the Amulet artwork and exhibition in Sept. 2014. Purposive sampling was used and six student midwives participated in the study.

Ethical approval to conduct the study was granted by the Educational and Health Science Education Committee at the University of Limerick. The following steps were taken to address ethical concerns of involving students in faculty research (Ferguson et al., 2006). Participation in the study was completely voluntary and took place after all theoretical assignments had been completed. Students were invited to participate in the study three months after attending the Amulet artwork and exhibition. Information on the study was provided to the students via e-mail by a member of faculty not teaching on the programme and the students were asked to reply only if they were interested in participating in the study. The information sheet for potential participants set out the details of the study and that a copy of the transcript would be made available to participants if requested, the student's right to withdraw from the study at any time, the benefits of the study, and the next step to take if the student chose to participate. Written consent was obtained before the commencement of the interview.

Data collection

Data were collected between January and March 2015 via semi-structured interviews, as the questions can be open ended enough to allow interviewees to express their perspectives on the topic but also facilitate comparison across the participants (Savin Baden and Howell Major, 2013). The interviews were facilitated by lecturers of midwifery. The interview guide was informed by Gibbs (1988) framework of reflection focusing on description, thoughts and feelings, evaluation, conclusion and action plan. All participants were asked to discuss their perceptions of the Amulet artwork and exhibition and to reflect on what it meant to them, and how it might affect their practice in the future (see Box 1). Paraphrasing and cues such as 'can you tell me a little more about that' were used. All interviews were transcribed verbatim by two members of the research team.

Data analysis

The data from the interview recordings were analysed using Burnard's (2006) content analysis framework. Three members of the team identified codes and early themes. Further review of themes was conducted with the lead researcher and an expert in the area of bereavement and loss, where themes were defined and named. All members of the team including the artist Marie Brett reviewed the final themes and report. A clear audit trail was maintained of how data were managed and how findings were derived.

Findings

Four core themes emerged: i) entering the mother's world and hearing her pain; ii) the journey of grief and connecting with the bereaved parent's unique experience; iii) facing the challenge of providing effective perinatal bereavement care and iv) maintaining a journey of compassionate practice.

Entering the mother's world and hearing her pain.

The students described their preconceived ideas prior to entering the exhibition space, and then their thoughts and feelings as they became engrossed in the Amulet artwork and

exhibition. The women's voices and their amulets created a special place where students and other health care professionals could reflect on their role, and the impact they have on bereaved parents' journey.

One student spoke of having

"...a black frame in my head and dark picture about death and then found that it was so different to what I thought in my head." (P1)

Other students weren't sure that a maternity hospital was the right place to show the exhibition:

"... for myself and student midwives and for a lot of women they may have been thinking "what are they doing in a maternity hospital talking about bereavement and death"."(P3)

When they entered the room that normally provides parent education classes, in what is a very busy maternity hospital, they were so struck by the transformation, a bright space; calm music; the art installation; and a separate tranquil relaxation space. They saw the benefits of having such an exhibition in a maternity hospital where it was accessible to staff:

"We met paediatricians, we met everyone from the girls in the canteen to labour ward staff ,that was important too." (P1)

The students spoke in reverential tones about the artwork installation and the atmosphere that was generated:

"There was just this beautiful calmness and serenity in the room. It felt like you were coming into... almost like a church. That kind of sense of just sanctity and, you know, it was really special." (P2)

The voice of each woman as she told her story of infant death had a profound effect on the students:

"We were very moved, everyone was very moved. The whole idea of listening to the tapes, I think that was probably the best bit. I think you could walk into an art gallery with all these pictures and I don't think it is the same as listening to the human voice. You could hear the pain in some people's voice, you wouldn't get across in a picture. Very good yeah it was a brilliant idea, very powerful." (P3)

At times the students found the women's stories overwhelming and they took a break and availed of the relaxation space where they spoke with each other. They also spoke about going to a private space themselves as they connected with their own life stories. The students engaged with the mother's stories through the audio visual installation and became immersed in the world of infant death.

" ...when you put on your headphones you had plenty of space to kind of mull it over. As in, you had your picture in front of you, you had your CD player and your earphones and you

could just stay in your own little world. You weren't really catching eye contact with anyone else kind of distracting you, which was nice, because of the way it was set up."(P5)

The students listened to the mothers describe what their special object or amulet meant to them. Some of the amulets included a pouch of breast milk that had been stored for a very long time, two identity bracelets, a song, a butterfly, a blue cardigan and a letter from a midwife. The students were struck by having breast milk as an amulet.

"Some of the amulets that were there were very I suppose "nice" amulets and then there were some that were very... that felt quite visceral, like the women's breast milk." (P2)

One of the women gave birth in the 1980s and had never seen her baby:

"... her name was Helen and her baby was buried in her grandmother's grave, and she never got to see the baby or what the baby was dressed in and so she had the blue cardigan. That one hit me, that one was the one that stuck with me." (P4)

The students were very moved and while different amulets resonated with each student the letter sent by the midwife stayed with all the students.

"There was a lady who had received a letter from a night sister as well, and I think that was the most moving actually, that there are people out there that care and they do give women a lot of support I thought that was the most touching one for me." (P3)

The journey of grief and connecting with the bereaved parents' unique experience

The students connected with the women's stories and gained insight into the hidden world of death and how women grieve. The students learned about perinatal death in a way that would not be possible using formal teaching strategies.

"I think as a student the two hours I got to spend there it was worth any lecture. It was really worth any lecture, nobody could have stood up there and told us about bereavement and death and then we went in there and figured it out and that is important too." (P1)

"Just how they dealt with it. Just how something small like that [amulet] could ease their pain...It gives you more of like what to expect, to think about what she is feeling."(P4)

"When I saw the CD I thought Oh God that is someone my age. You just have an immediate connection then..." (P1)

The women's stories helped the students to reflect and gain insight into the importance of the student's role in caring for bereaved couples.

"They remember everything that you say." (P5)

"I suppose I am more aware now than I was, from listening to all the women. I am more aware myself that it is not something that can be brushed off. That you do listen to it, that you

do feel something from someone's experience, a lived experience, it is very sad. I wouldn't have had that thought about it before."(P3)

Viewing the Amulet exhibition helped the students to delve beneath the surface of perinatal death and gain insight into the importance of individualised care.

"She is going through a lot more than we will ever know. So it is good to have seen the amulet project, it makes you think as a student midwife how you can help that woman and what you can say and what not to say." (P6)

The students connected to the journey of grief and all were struck by the non-linear nature of grief and the individual nature of the journey.

"I just presumed that everyone grieved the same. What we learned about the steps of grief it didn't seem to be like that. Some of the people, they struggled so so long and some of the people moved on at the same time and that was quite nice to hear."(P1)

"You're hearing about their journey through grief and what things have meant to them, and I think that is the biggest thing for me, the fact that I could see that it was a journey, that it is a journey for women and that it's different for everyone and different things are important to different people when you're grieving, and just to be cognizant of that really, you know..."(P2)

The students connected to midwifery practice and gained insight into the importance of the role they play and realized how they too become part of the bereaved parent's story.

"It is so so important like the small things, like things that we do and we do hurriedly to get in and get out, to get it done. Like people remember this and that it is just such a short piece of time that they have with their babies after they have passed away so to be more aware." (P6)

There was recognition of the important connection between a bereaved woman and a midwife that is sometimes both personal and professional.

"Obviously that was what happened between that woman that lost her baby and between the midwife that wrote that letter. That little window of, I suppose of commonality" (P2)

Facing the challenge of providing effective perinatal bereavement care

All of the students tried to make sense of their own experience of caring for parents experiencing perinatal death.

One student described her coping strategy for caring for a stillborn baby and wondered if it was hard for her, what must it be like for the woman.

"I don't know for myself, I feel that the baby is still alive if that makes sense. When I had to handle the baby and put little gown and little socks and all that and I was kind of just talking

to the baby as I was doing it with the other midwife. I did look over at one stage and she did smile and you know the way I thought it was hard enough [for me]." (P3)

While being present with women experiencing perinatal loss is challenging for the students, it is also rewarding as one participant recounts:

"I'd been caring for her during the day and I found her in the bathroom crying and she had passed a gestational sac into a piece of tissue, and she said it was relief, that she felt a big relief. She was crying with relief rather than grief which I found not strange I suppose, but I was happy for her that she was feeling something. That lady now did give me a lovely hug, and she was like, "Please stay in this profession." And I was like, "Aw, that's really nice!" (P5)

The students acknowledged that providing perinatal bereavement care is hard and even though they had experienced death and dying as nurses, they hadn't thought of this aspect in relation to midwifery care.

"When you are starting off as a student midwife you are not expecting that side of it just the happy side of it so it is hard to experience that side of things". (P4)

Some of the students found that they were never assigned to care for bereaved women in labour, that it was the experienced midwives who cared for these women on the postnatal ward, and so they never really got to speak with the women. Those students found that the Amulet artwork and exhibition gave an important insight into the woman's journey of grief and also into the role of the midwife.

*"It was more the experienced midwives that would go in to them. So you never really got to hear the woman's story, as in like, you'd hear it in report and stuff and they might say, "She had a good night", "She had a bad night", or whatever, but we never really got to speak to the women so it was nice to hear their point of view and see the impact that the midwives had on them, because a lot of them spoke about the care they got."*P4

The lack of exposure to caring for couples experiencing perinatal death meant that the students worried about how they would face the challenge once qualified.

"I can just imagine the day I walk out and I put on the navy trousers and I am presented with this lady, now that I am going to have to look after as a midwife, your first is always going to be so hard. So I don't know how we can do it differently. I can understand why we are not in the room but in two, three months time when we do qualify and meet these women it is going to be very tough. It shouldn't be tough on us, as it is already tough on them." (P5)

The students recognised that the midwives found caring for bereaved couples challenging and the students observed the support that was extended by other midwives.

"...a midwife just came out to the desk for a few minutes to be on her own and have a breather herself. Quietly somebody did go over to her and ask "are you ok, do you need

anything done and have you had your break?'. So they are supportive and definitely supported." (P1)

Maintaining a journey of compassionate practice

The students reflected on the effect the Amulet artwork and exhibition had on their practice and the insights gained. The students acknowledged the difficulties of the busy clinical environment, but they also recognised the importance of finding the time and being with the woman.

"If you have twenty minutes just to go back in and if they want to cry, they can cry, if you have to cry you cry, do it all together. If you are able to be that person for them they will appreciate it so much. It is just so lovely to be that person...The time for someone to sit and put a hand on their hand. We are not going to fix it but we can help them talk through it. It is nice to be able to do that and we forget to do it."(P1)

The students reflected on the many changes in practices in relation to perinatal bereavement care and in particular Helen's story of practices in the 1980s compared to now.

"It was just so sad she never got to see the baby, she never got to see what the baby was dressed in. It wasn't really her choice, she wanted to see the baby, she wasn't given an option and that was like how many years ago, maybe forty." (P4)

"Like now in the hospital they bring in the photographer doing the hand prints, doing all the memory pieces. How important they are, like even bathing the baby, that might be the only time that parents might bath their baby". (P6)

The letter sent by the midwife to the woman really resonated with all the students from a personal and professional boundaries perspective, and they all reflected on what action they would take in the situation.

"That midwife obviously connected with the woman, it is nice to think that link is there. That woman and the midwife helped each other through that death" (P6)

"...And it's not something that is unprofessional. I think if anything, it's really professional because it shows that you're embracing what it is that makes you a midwife, you know?" (P2)

The absence of the male perspective in the Amulet artwork and exhibition made the students reflect on the needs of the partner in relation to perinatal bereavement care.

"...I think we don't look at male grieving at all, that just came into my head when I looked at the Amulet exhibition." (P1)

"...That is another thing I feel, that we seem to think that it is just a woman's thing and that's what captured for me as well with the exhibition that a male perspective would have been nice, I really feel that it would have benefited everybody."(P3)

“I know definitely we do our best but the man can be forgotten about in situations like this. The woman has carried the baby she has gone through labour and then the men can sometimes be forgotten.” (P6)

Discussion

The Amulet artwork and exhibition provided post registration midwifery students with the opportunity to gain insight into the journey of grief and caring for bereaved parents. Through reflection on the artwork and exhibition, the students have provided educators with a valuable insight into cognitive and affective learning in the context of perinatal bereavement and loss. When teaching about grief, death and bereavement Laporte Matzo et al. (2003) suggest that lectures alone are ineffective in identifying students’ perceptions and fears, and that an interactive process stimulates critical thinking and addresses the affective domain of learning. Reflective learning and the use of stories can help to develop knowledge and confidence in student nurses to provide compassionate relationship centred care (Adamson and Dewar 2015). Hall and Mitchell (2008) evaluated midwifery students’ creative work in relation to the meaning of birth and found that it was a way to approach and discuss the concept of spirituality. Students valued discussion over didactic teaching with the emphasis on individualised care rather than on theoretical frameworks of grief reactions in an evaluation by Mitchell (2005). In this study the use of artwork to enter the private world of infant death resonated with the students more than any lecture could have done: *'nobody could have stood up there and told us about bereavement and death and then we went in there and figured it out and that is important too'*.

Through connecting with the bereaved parent's unique experience the students realised that grief was a journey, and they gained insight into the complex nature of grief. The students were struck by the non-linear nature of grief: *'What we learned about the steps of grief it didn't seem to be like that'*. Arnold and Buschman (2008) study supports and expands on our understanding of parental grief as a continuing evolving process, with parents finding different ways to remain connected to their loved ones, using smell, sight, images and rituals. They suggest that the term acceptance must be reconsidered in light of the lifelong nature of parental grief. Arnold and Buschman's (2008) study did not include parents who experienced miscarriage and stillbirth, and while they could not generalise their findings to these deaths, the insights gained from exploring the influence of the Amulet artwork and exhibition on students’ views of caring for bereaved parents would support this understanding. The mothers’ stories validated the view of maintaining the bond with their dead baby in a new way. The participants in this study clearly picked up on this point and compared and contrasted this to the traditional theories of grief that they had learned.

The students reflected on clinical practice and their opportunity or lack of opportunity to care for couples experiencing perinatal death. Downe et al. (2013) emphasise that everyone involved in the care of parents experiencing stillbirth has only one opportunity to do the right thing, and that parental recovery is greatly affected by the attitude and caring behaviours of

staff. In a national review of support available for loss in early and late pregnancy it was found that midwifery students are generally protected from caring for women experiencing loss, and this could impact on their skills and confidence when qualified (Ottley et al., 2014). Begley (2003) recommended that students gain increased exposure to caring for bereaved parents under supervision. McKenna and Rolls (2011) recommended specific preparation for students prior to undertaking placements with clearly identified support structures. The importance of small group reflection early on in the curriculum in preparing students for dealing with death has been highlighted by Carson (2010). In this study the students who had the opportunity to care for bereaved parents demonstrated their capacity for sensitivity, compassion and the ability to be genuinely present. Those students who did not receive the opportunity to care for bereaved couples worried about how they would manage when they were qualified midwives.

Through reflection on the artwork and exhibition, students gained an insight into the importance of taking the time and being with the bereaved couple, regardless of the busyness of the unit. The students also gained insight and understanding into the importance of acknowledging the male partner's grief (McCreight, 2004). Kelley Trinidad (2012, p7) reported that for bereaved parents the most profound aspect of care occurred when obstetricians and midwives assigned time 'to sit with them look them in the eye and be present with them in their sadness'. As Downe et al. (2013) study shows it can be deeply upsetting for parents when their needs are not met at this time. Papadatou (2009) views relational care as the unique reciprocal influence that exists between the professional and the bereaved parents, and that an integral aspect of the care process is bringing something personal that transcends knowledge and skills. The letter from the midwife that was kept by the woman as her amulet resonated with all the students and made them reflect on the role of the midwife from a personal and professional perspective. Downe et al. (2013) conclude that the development of caring behaviour and empathetic engagement needs to be fostered through affective learning. Educators need to ensure that a wide range of learning strategies are used when preparing students for perinatal bereavement care. This study has demonstrated the benefits of exposure to collaborative art in gaining insight into the non-linear nature of grief and in maintaining a journey of compassionate care for parents experiencing perinatal death.

Conclusion and recommendations

Providing opportunities for exposure to, and reflection on projects such as the Amulet artwork and exhibition is a powerful means of fostering affective learning for midwifery students and other health care professionals, in caring for parents experiencing perinatal death. Educators need to facilitate creative learning strategies that focus on women's stories to increase awareness and insight into the non-linear nature of the grieving process. Midwifery students should be facilitated to gain confidence in supporting bereaved parents with the necessary support structures in place. This small qualitative study is based on a specific art project and the midwifery students taking part were registered nurses. The study

contributes to our understanding of student affective learning in the context of perinatal death.

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