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**Knighting, K, Kirton, J, Silverio, SA and Shaw, BNJ (2019) A Network Approach to Neonatal Palliative Care Education: Impact on Knowledge, Efficacy, and Clinical Practice. Journal of Perinatal and Neonatal Nursing, 33 (4). pp. 350-360. ISSN 0893-2190**

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# **A NETWORK APPROACH TO NEONATAL PALLIATIVE CARE EDUCATION: IMPACT ON KNOWLEDGE, EFFICACY AND CLINICAL PRACTICE**

## **ABSTRACT**

Over 80,000 babies are admitted to specialist neonatal units in the United Kingdom every year, with approximately 2,109 neonatal deaths a year; 98% in hospital. A common element in guidance and pathways to facilitate the provision of palliative care to infants and their families is the importance of good education and training to develop high quality staff and services. This paper presents a mixed-methods, sequential, explanatory design evaluation of one day palliative care education workshops delivered using a network-wide approach to multi-disciplinary professionals. Workshops were delivered by healthcare professionals and bereaved parents, and evaluated using questionnaires, adapted for neonatal staff from standardised measures, and follow-up interviews. The workshop content and shared learning approach resulted in significant improvements in participant's knowledge, attitude, self-beliefs and confidence in neonatal palliative care, enhanced awareness of services, and improved links between professionals. Participants cascaded their learning to their teams and provided examples of changes in their clinical practice following the workshop. Parent stories were identified as a very powerful component of the training, with lasting impact on participants. Formal, integrated palliative care education programmes for perinatal and neonatal staff, and longitudinal research into the impact on practice and the experience received by families is needed.

## **KEY WORDS**

Neonatal; education; evaluation; palliative care; end of life care.

## **PRECIS**

A shared learning approach across a clinical network enhanced relationships between teams and significantly increased knowledge, clinical skills and confidence to deliver neonatal palliative care.

## INTRODUCTION

Together for Short Lives [TfSL] describe palliative care for foetus, neonate or infant with life-limiting conditions as *“an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child and support for the family. It includes the management of distressing symptoms... and care through death and bereavement.”*<sup>1[p38]</sup> Between 2007 and 2015 the number of babies admitted to a specialist neonatal unit in the UK for care rose from 37,235 to 96,556;<sup>2</sup> with approximately 2,109 neonatal deaths a year, 98% of which occur in hospital.<sup>3,4,2</sup> To support the care of a growing number of babies requiring palliative care TfSL produced the Neonatal Care Pathway for Babies with Palliative Care Needs pathway.<sup>5</sup> The pathway aims to support professionals and families when planning care for young babies, up to 28 days old who have life-limiting or life-threatening conditions to ensure that appropriate care and resources are available and that where appropriate, babies can be transferred to their family’s home or local hospice, with appropriate support if wanted by the family. In response to a recognition that palliative care is increasingly being introduced during antenatal period, the pathway was revised and extended in 2017 with the launch of the Perinatal Pathway for Babies with Palliative Care Needs.<sup>4</sup>

The Department of Health,<sup>6</sup> National Institute for Health and Care Excellence,<sup>7-9</sup> Together for Short Lives,<sup>1,4,10</sup> and the British Association of Perinatal Medicine<sup>11,12</sup> have all developed recommendations, pathways, quality indicators and standards to facilitate the provision of palliative and end-of-life care to infants, children, and their families. A common and consistent element in these documents is the importance of good education and training, to develop high quality staff and services. However, the initial recommendations were not perceived to be supported by a sufficient increase in educational initiatives for paediatric palliative care,<sup>13</sup> despite

the demonstrated importance of education in helping staff to effectively implement recommendations and pathways.<sup>14</sup> The literature reported gaps in the knowledge and skills of health and social care staff.<sup>15,16</sup> The requirement for comprehensive and effective education was demonstrated by reports that staff continued to feel inadequately prepared to confidently provide neonatal palliative care.<sup>17,18</sup> Parents also reported dissatisfaction with the palliative and end-of-life care received for their babies.<sup>19</sup>

Subsequently there have been examples of locally delivered neonatal palliative care educational provision. For example an education programme of a single four hour workshop with groups of multiple professionals demonstrated that a relatively short training intervention changed attitudes to palliative care among participants; increasing both knowledge of services and confidence to refer patients appropriately.<sup>20</sup> It also suggests that providing training locally had many advantages; facilitating knowledge of local services outside the unit and providing opportunity for staff to discuss their own approaches and concerns about caring for babies with palliative care needs with their colleagues.<sup>20</sup> However, there were also key areas attendees felt would be useful for future training such as communication skills and ethical issues around withdrawal of intensive care.<sup>20</sup> Other education models such as monthly hour sessions, online courses, and blended learning programmes linked to professional registrations have also been proposed or evaluated, each with strengths and weakness, and demonstrating the continued importance of evaluating how any changes in staff knowledge and confidence translates into their clinical practice.<sup>21,22</sup>

Neonatal units have always provided care and support to neonates who may go on to die within their care but with technology and medical advances the number of infants requiring palliative and end-of-life care in neonatal units, as well as those who are not expected to live beyond one year or may require longer term care, is steadily increasing.<sup>2,11,12</sup> Neonatal care has been evolving

in response to the changing demand with development of specialist nursing roles dedicated to palliative care and increased collaborative working between teams and services, such as neonatal link nurses between hospices and neonatal units.<sup>22</sup> These changes along with the literature and policy drivers and pathways of the last 10 years aimed at improving the quality of palliative care within neonatal units, including the support for the family, strengthen the need for development and evaluation of further education programmes to increase staff awareness, enhance their knowledge of neonatal palliative care, and develop collaborative working, both in the UK and international.<sup>22-27</sup>

In the North West of England approximately 330 neonates will die of a condition that may require palliative care<sup>28</sup> (Cochrane et al., 2007). The Northwest Children and Young People's Palliative Care Network [NCYPPCN] Strategy and Workplan for 2011-2014 made recommendations for the provision of palliative care for children and provides information on the current levels of provision in the Northwest.<sup>29</sup> One of the three objectives of the strategy is the 'enhancement of existing services through education and training'. To support this objective the specialist palliative care team at a children's hospital sought funding to develop an education programme and training materials to enhance paediatric palliative care in the region. One aspect of this programme was a series of education workshops on neonatal palliative care. This paper presents the evaluation of the workshops including their impact on the participants' perceived efficacy in caring for the dying neonate (self-efficacy), perceived attitudes and outcomes in caring for the dying neonate (thanatophobia/effectiveness), along with any longitudinal impact on their clinical practice.

## **METHODS**

### **Education Programme**

The programme was designed and delivered by core professionals from across the neonatal network including an Advanced Neonatal Nurse Practitioner, Medical and Paediatric Specialist Palliative Care Consultants and a Nurse Specialist. The programme was delivered free of charge as a full one day workshop which enabled sessions to be interactive, with use of scenarios and group work, as well as presentations. Local services were also present at the breaks to showcase their resources.

The learning outcomes of the programme were to improve staff's efficacy and confidence to provide care for the dying neonate by increasing (i) their knowledge of neonatal palliative care, (ii) their confidence to provide palliative care and (iii) confidence in managing difficult conversations with the family, and (iv) awareness of the local services and resources that could be utilised to enhance the support for family members and choice for place of death. The programme is outlined in Table 1.

INSERT TABLE 1

The one day workshop was delivered three times over 24 months at a hospital with the largest Level 3 neonatal unit in the network; with a 12 month follow-up evaluation period (2012-2015). Staff from neonatal units in the nine hospitals of the network were invited to attend, along with other appropriate professionals working across the area including those from the children's hospices.

### **Evaluation**

The evaluation was a mixed-methods, sequential, explanatory design<sup>30</sup> with two phases consisting of administering pre- and post-workshop questionnaires to participants on the day of

the workshop (Phase 1) and follow-up interviews with a sub-sample of participants regarding the impact of the workshop on their practice when providing end-of-life care to a neonate (Phase 2). Prior to the workshop participants were sent an information sheet about the evaluation including the phase 2 interviews. The study was approved by the Faculty Research Ethics Committee of the university evaluation team. National Health Service (NHS) management permissions were received from the nine NHS Hospital Trusts in the Neonatal Clinical Network.

### **Phase 1 – Quantitative Assessment**

The pre-workshop questionnaire contained a mixture of Likert scale, open-ended and multiple choice questions in four sections asking for (1) demographic information about professional role and experience of palliative and neonatal care; (2) perceived educational and clinical needs of the workshop and self-reported knowledge, confidence and clinical skills in neonatal palliative care; (3) self-efficacy and (4) attitude and perceived outcome effectiveness of providing neonatal palliative care. Section 3 and 4 used two standardised questionnaires. The post-workshop questionnaire also contained four sections asking for views and ratings on (1) content and delivery of the workshop; (2) how the workshop met their educational and clinical expectations; and (3&4) the two standardised questionnaires. The two standardised questionnaires were:

- (i) *The Self-Efficacy in Palliative Care Scale (SEPC)*<sup>31</sup> is a 23-item scale with three distinct subscales to assess communication (8 items), patient management; pain and symptom control (8 items), and multi-professional team work (7 items). The scale has a 100mm visual analogue scale. This scale has been validated and used with staff primarily working in adult palliative care, so a small number of items were rephrased and piloted with staff working in a neonatal unit prior to the evaluation in order to

ensure that the wording of all questions was appropriate to discussions taking place with the patient's family (and not with the patient, as in adult palliative care). As a result 1 item was unchanged, 6 items deleted, 16 items reworded to use the term 'baby' rather than patient, and 3 new items added resulting in an adapted scale of 19 items. These amendments were agreed with the developer of the original scale.

(ii) *Thanatophobia Scale (TS)*<sup>32</sup> is a seven-item scale which assesses attitudes towards caring for palliative care patients on a seven-point Likert scale. This scale had one item removed ('It makes me uncomfortable when a dying patient wants to say goodbye to me') as this was inappropriate for a neonatal patient resulting in an adapted scale of 6 items.

The revised scales are available from the corresponding author.

### **Quantitative Data Collection**

At the beginning of the workshop, a short presentation about the study was given by one of the researchers with an opportunity for them to ask questions. Each participant received an evaluation pack consisting of the questionnaires and an expression of interest form for the interview phase. Questionnaires were marked with a unique number and letter combination to enable them to be completed anonymously but be matched for each participant (e.g. 1a and 1b = Participant 1). Participants completed the pre- and post-workshop questionnaires at the beginning and end of the workshop respectively, with forms collected in at each time point during the day. Participants who wished to take part in a future interview completed the form with their contact details and their unique number from their questionnaires if they were happy for the data from their questionnaires to be used to inform their interview. All questionnaires and forms were collected by the research team.



## **Quantitative Analysis**

All questionnaire responses were entered into IBM SPSS Statistics for Windows (Version 22.0 Armonk, NY: IBM Corp.) Wilcoxon signed ranks tests were used to compare pre- and post-course ratings for the Likert scales of self-reported perceived knowledge, confidence and clinical skills in neonatal palliative care, and to compare agreement with the statements on the TS. Paired-samples t-tests were conducted to identify any significant change between pre- and post-scores for each SEPC sub-scales.

## **Phase 2 – Qualitative Assessment**

Phase 2 consisted of semi-structured interviews which asked participants' some general demographic details to confirm their role, employer and length of service , and then seven open questions about: (i) their general neonatal or palliative care experience, (ii) their experience of neonatal palliative care, (iii) their views on the workshop content including anything they felt was missing, (iv) whether they had disseminated any learning from the workshop with colleagues, (v) any impact or changes to their clinical practice, or that of their team since the workshop, (vi) their experiences of providing palliative care to a neonate since the workshop, including any challenges they may have faced, and (vii) any recommendations for future training.

## **Qualitative Data Collection**

Participants were contacted by letter or email to invite them to take part in a telephone or face to face interview at a convenient time to them, at three, six and nine months after the workshop. If a participant met the criteria and agreed to take part in the interview they completed and returned a consent form which also included consent to use their questionnaire data completed

in the workshop for the case study and for permission to contact them again at the next time point.

Interviews were conversational in style, and semi-structured to allow the interviewer to address themes relevant to the research questions whilst allowing them to follow relevant avenues of inquiry opened by the participants. All interviews were digitally audio recorded, transcribed verbatim, anonymised, and entered into Nvivo 10 for analysis.

### **Qualitative Analysis**

In the second phase of this sequential explanatory evaluation, qualitative data were analysed using Thematic Analysis<sup>33,34</sup> in a consultative and inductive manner, using cross-checking in an effort to maintain rigour and ensure generalisability of the data. To do this, transcripts were coded independently by two researchers [KK, JK] who then brought initial thematic concepts together to define and refine themes. During this process themes were sometimes presented differently, but the meaning and supporting quotations indicated the analysts had identified the same central organising concept and therefore theme names were negotiated and/or collapsed. Any unresolved or disputed thematic concepts or subsequent themes were arbitrated by a third researcher [SAS], who further refined the order of presentation and the supporting quotations, resulting in a final agreement of six themes.

### **PARTICIPANTS**

A total of 73 professionals attended the three workshops from 15 locations and services across the neonatal network area in Phase one. Many of participants were nurses working in neonatal services (See Table 2). All participants completed at least one of the questionnaires. Of these, 70

participants completed both the pre- and post-workshop questionnaires; 43 of whom also completed an expression of interest form for the interview study. Any missing responses or individual surveys were entered as missing data. The participants for the interview study of Phase two were a sub-sample of those who completed the expressions of interest form. Participants were eligible to take part in a follow-up interview if they have been involved in the care of a baby around the time of its death since the workshop. There were challenges for recruitment to the interview study. Four participants completed interviews within the 12-month period of completing one of the workshops. One participant responded both at 6 and 12 months following the workshop. Participants were a Neonatal Transport Nurse (ID17, 6 & 12 months), a Social Worker based at a children's hospice (ID24, 6 months), a Children's Nurse at a children's hospice (ID3, 6 months) and a Paediatric Registrar working in a neonatal unit (ID32, 3 months). The findings reported here focus on the participants' experience of the workshop and its impact on their knowledge, efficacy and clinical practice.

INSERT TABLE 2

## **FINDINGS – Phase 1**

### **Impact on Perceived Knowledge, Clinical Skills and Confidence**

Participants reported their perceived knowledge, confidence and clinical skills in neonatal palliative care on an eight point Likert Scale with (0) indicating 'no knowledge' to (7) 'very knowledgeable' The scores significantly increased for the majority of participants following the workshops across all three areas (See Table 3).

INSERT TABLE 3

### **Impact on Perceived Attitudes and Outcomes in Caring for the Dying Neonate**

There was improvement in perceived attitudes and outcomes for the majority of participants between the pre-workshop and the post-workshop Thanatophobia Scales (median 5 versus median 5.75,  $p < .001$ ). All individual items on the TS showed a statistically significant improvement from pre- to post-course (Table 4).

INSERT TABLE 4

### **Impact on Self-perceived Efficacy in Caring for the Dying Neonate**

The mean scores reported for each of the SEPC sub-scales increased indicating significant improvements in participants' perceived efficacy across each area (Table 5).

INSERT TABLE 5

### **Potential Use of New Knowledge and Skills**

Participants were asked how they would use the knowledge and/or skills gained during the workshop in their practice. Their responses suggested they saw the potential for enhanced practice in the following areas:

- Communication skills with colleagues and parents, including having difficult conversations and breaking bad news;
- Awareness and understanding of the care provided in neonatal units;
- Confidence and understanding of how to provide best care for a dying baby;
- Importance of discussing palliative care options earlier to facilitate parallel planning, support for families and exploring options for organ donation;
- Awareness of other end-of-life care and post-death care options available, including use of children's hospices and charity organisations;

- Awareness and understanding of ethical and legal issues around palliative and end-of-life care for neonates and babies, including withdrawal of care;
- Importance of understanding parents' needs and wishes for palliative and end-of-life care, including the opportunity to make memories.

### **Further Training**

All participants reported they would like to refresh their learning, typically every six to twelve months. Key areas for future research included: parallel planning; spiritual care; choices for palliative and end-of-life care at home; medicines; communication; and the legal aspects of post mortem.

### **FINDINGS – Phase 2**

#### **Experience and impact of the workshop**

Participants spoke about the comprehensive content of the workshop and feeling that they learnt a lot from attending:

*“I think we both came away feeling quite overwhelmed and quite ‘oh my god that was great’, ‘cos we did both really, really enjoyed it. I got loads from it even though some of it was obviously medical and clinical and it sort of went over my head slightly, but I just think the whole day was there really to look at the whole aspect of neonatal care, I didn’t feel at that time there was anything missing.”* (ID 24, Social Worker, 6 months post-workshop)

*“We’ve never had to go down the route of syringe drivers and lots of pain control, they tend to go quite quickly so ... withdrawing feeds and things, we haven't really had to make*

*that decision, so to hear about the ethical side of it, that's always a good thing to talk about it."* (ID3, Children's Nurse, 6 months post-workshop)

*"I would say it was very useful"* (ID32, Paediatric Registrar, 3 months post-workshop)

### **Impact of hearing from bereaved parents**

All participants reported the powerful impact that hearing from the bereaved parents had on them; one spoke of acting on what they heard:

*"I think the parents speaking was really useful, although I think I cried all the way through it ...but I thought their perspective was really useful because ... you sort of, almost forget about them sometimes."* (ID 17, Neonatal Transport Nurse, 6 months post-workshop)

*"..for me...the whole of the workshop was just so valuable. What was valuable for me was the parents that spoke, to hear their story, I was actually able to come back to [children's hospice] and query certain things here.....I found it really interesting how one of the mums said how important she felt seeing all of those faces that had cared for her child, and ... I was able to come back to management and say 'do you know what, this lady said how valuable she found to see all those faces, obviously we can't allow every member of staff to go to a child's funeral but I think we need to you know try wherever possible for the people who have had an impact on that family to be able to attend".* (ID 24, Social Worker, 6 months post-workshop)

### **Awareness of other services and resources to facilitate working together**

Participants spoke highly of hearing about other services or resources from facilitators and how they could use this in the future to support themselves and the families they work with:

*“I think hearing about the hospice stuff was good as well because I do think that’s a useful resource.”* (ID 17, Neonatal Transport Nurse, 6 months post-workshop)

*“there were other people there at the workshops that, like the Bereavement Team at [hospital], I spoke to a lady who said I could ring them for support if I needed it and I hadn’t known I could do that so that was useful.”* (ID32, Paediatric Registrar, 3 months post-workshop)

*“I think also other things, you know we do all of the memory kind of work, we sort of attain memory boxes and do those kind of things, but hearing about the websites, photographers, and you know those different kind of things, it’s given us more ideas of things we can do with families.”* (ID 24, Social Worker, 6 months post-workshop)

This in turn, highlighted to staff from children hospices a need to increase their awareness raising of the services they can offer to neonates, their families and the staff who work them which they described planning following the workshop:

*“I think for myself it’s looking at, getting...lots of local health visitors, midwives, hospital team, to actually come along to the hospice for a day. We’re having a palliative care day around the care for neonates, we’ve got some really good speakers, just to create those links, share those experiences, share those ideas to all come together as a team to be offering families that choice.”* (ID 24, Social Worker, 6 months post-workshop)

*“I think it just highlights that there’s still work to be done, we have a Neonatal Focus*

*Group ... in which we talk about all these problems and ...so we did come back from the workshop and talk about what had gone on and it's encouraged us to do something like that at [the hospice] too, we're thinking about inviting neonatal staff to come in for the afternoon to, you know look around and have a little mini sort of teaching session so it did spur us on to get that going...just working together, you know so we can help them and they can help us, you know I'm not saying "look we're the be all and end all" at all, but we do need to help each other and share education really." (ID3, Children's Nurse, 6 months post-workshop)*

### **Impact on clinical practice**

The communication session of the workshop was spoken about as a highlight by all participants. One participant gave a clear example of how it had impacted on their communication with a father during his child's end-of-life care and subsequent death:

*"I would say that after the workshop I had a different perception of discussing this with the family. Prior to the workshop I would have really, really, really struggled explaining things to the dad and saying "look, the outcome is going to be poor, this is in the best interests of the baby" and all of that, and I think from the workshop I learned that like it's more about providing information to the family and guiding them in taking decisions so you work as a team with them...I think the workshop helped me, in a way that you just have to be clear and be professional and empathetic so I would say that's the way it helped me in this particularly case." (ID32, Paediatric Registrar, 3 months post-workshop)*

Another session which impacted on the practice of this participant was that on parallel planning of active and palliative care:



*“subsequently I've been involved in other cases where..., I took what I learnt at the workshop in terms of offering the family palliative care much earlier when you can, or parallel care when you can see how things could go poorly.... In another case, together with the nurses we were able to provide more support right from the beginning rather than at a later point which meant the right care was in place right from the beginning.”* (ID32, Paediatric Registrar, 3 months post-workshop)

### **Dissemination of learning with colleagues**

Along with the direct impact on clinical practice or raising awareness of services as discussed above, participants spoke generally about using what had been learnt or how they disseminated their learning with colleagues:

*“I have tried to use what I had learnt in my practice.”* (ID17, Neonatal transport nurse, 12 months post-workshop)

*“I think it was a case of us going back saying, ‘right we’ve come back with all these ideas’...one particular query that one of our clinical nurses had was about medication used for neonates and from that day we heard about the use of sucrose in neonatal care now, so that’s a big element she’s been able to start to look to into with our pharmacists.”* (ID 24, Social Worker, 6 months post-workshop)

### **Unique training and support needs for staff**

One participant spoke about the unique nature of working with neonates requiring training and appropriate support for staff to increase knowledge and efficacy in practice:

*“I think in general it’s just being more aware of the issues, don’t get me wrong we’re dealing with tragedy and trauma every single day, but I think the care offered to a neonate*

*is so very, very different and it's just to be aware that yes, we had an incredible challenge with that little chappy that we had here, and it just proved to us that we do need to put different things in place and we do need some extra staff training...The consultants at the hospital on the neonatal unit are looking at possibility of training for our nurses, to boost confidence more than anything, I think because ,this little man was so incredibly tiny, it sort of did rock everybody slightly because we just haven't been used to that.....we do need to be more aware that on an emotional level for our team, it's gonna be incredibly difficult work and I think the whole training day gave myself and my colleagues so much to consider with setting up now this avenue for taking on referrals that we need to have specifics in place and I think that the emotional support is gonna be huge.” (ID 24, Social Worker, 6 months post-workshop)*

One participant spoke of the lack of appropriate courses being available:

*“I would like to undertake further training in neonatal palliative care. I have not been able to identify a suitable course or module.” (ID17, Neonatal transport nurse, 12 months post-workshop)*

## **DISCUSSION**

A new educational initiative was introduced in the North West of England for neonatal palliative care following the Department of Health<sup>6</sup> Together for Short Lives<sup>5</sup> and British Association of Perinatal Medicine's<sup>11</sup> recommendations that good education and training is required in order to develop high quality palliative care services. Evaluation of the efficacy of educational interventions in palliative care is particularly important as it had been reported that staff felt inadequately prepared to confidently provide neonatal palliative care.<sup>17</sup> The introduction of the

initiative provided the opportunity to evaluate the educational workshops and the network approach taken to shared learning which involved bringing together professionals from across the neonatal network area rather than delivering it to individual units.

The participants in this study were mainly members of nursing staff. As nurses play a key role in palliative care in the neonatal population, the results of this study should be generalizable to other neonatal units. The majority of participants completed all the questionnaires thus providing a substantial amount of data related to the knowledge, clinical skills, confidence and attitude of participants related to palliative care. However, a limitation of this study is the small number of interviews carried out as a follow-up to the education intervention. The small number was due to many workshop participants not being directly involved in the care of a neonate around the time of its death in the year following the workshop and therefore not fulfilling the inclusion criteria.

The workshop participants reported significantly increased levels of knowledge, clinical skills and confidence with neonatal palliative care, together with a more positive attitude in their ability to provided palliative care and deal with some of the difficult issues associated with this type of care. The subscales on the self-perceived efficacy questionnaire showed an improvement in all three domains of communication, patient management and multidisciplinary team work after the workshop compared to before. Free text responses revealed that participants believed they would be generally better equipped to deal with neonatal palliative care situations, but also that some obtained some very specific knowledge which they would use in future (e.g. a better understanding of the importance of organ donation and how to access children's hospices). The interviews and free text responses suggest that some of these specific learning points have been translated into behavioural and practice change for some participants which was felt to result in improved palliative care for neonates and their families. A social constructivist approach was also

utilised by some participants to transform their shared learning in the workshop and reflection into action learning within their workplace by cascading new knowledge and taking action with colleagues to improve services.<sup>35</sup> To maintain learning and further enhance the opportunity to cascade learning into action it could be suggested that a formal approach to longitudinal engagement be developed and tested in future training and evaluation studies. Previous research<sup>21,36</sup> has described self-reported improvement in knowledge and confidence following neonatal palliative care workshops but no evidence has been found with longer follow-up to show impact on behaviour and practice. The preliminary findings reported in this paper highlight the importance of longitudinal research to explore the impact of educational initiatives on behaviour and practice, and for longer-term engagement with on-going training.

All participants reported that they would like to refresh their learning and explore other issues related to neonatal palliative care. If this were to take place every 6 to 12 months, as suggested by participants, a large increase in resources would be required both for educational provision and for allowing nurses to attend these courses ensuring that their place of work was safely covered clinically.

The voices of the bereaved parents had a strong impact on participants and was perceived as a particularly valuable aspect of the workshop. Some of the parent's comments emphasised to the participants the parent experience and appears to have had a lasting effect for those participants that reported a benefit. No evidence could be found on the impact of parent voices in similar training but parent stories have been used to investigate and improve paediatric services.<sup>37,38</sup> The positive and lasting impact reported in this study suggest that the inclusion of parent's perspectives is to be valued as an integral part of continuous professional development for those members of staff who were involved in palliative care in order to maintain the whole family approach when caring for a dying baby. Engagement of parents in training supports the increasing

level of service user involvement in the development and delivery of training in health in the UK and the manifesto for public engagement.<sup>39-41</sup>

The presence of representatives from the children's hospices and charity organisations like SANDS (Still Birth and Neonatal Death Charity) at the workshops, together with the approach of bringing together professionals from across a variety of professional backgrounds and places of work across the neonatal network, provided a unique opportunity to develop further professional relationships and enhance shared learning experiences. This approach to learning supports the goal of growing a common understanding and set of values between teams.<sup>12</sup> Use of mixed discussion groups with interactive sessions working with real scenarios also enhanced the awareness and links, with the interview participants illustrating examples of the difference this has made to their referrals and utilisation of local palliative care services. This supports previous findings that nurses who have experience with palliative care services are more likely to refer before patients reach the final stage end of life care.<sup>42</sup> Along with a consistent recommendation in the literature to increasing collaborative working between organisations and professionals to enhance understanding and access to palliative care.<sup>43</sup>

One workshop is unlikely to be enough to maintain a permanent change in behaviour in the clinical area. It is known that skills and knowledge deteriorate after educational interventions, particularly if they are not used regularly.<sup>44</sup> Therefore follow on or refresher educational sessions or educational activities are important to maintain increases in neonatal palliative care knowledge, confidence and skills. Individuals have different learning styles and work within multi-disciplinary teams so drawing on situated learning theory to provide a range of educational experiences within their social contexts will support learning and further cascading of learning into wider teams of participants in different contexts.<sup>45</sup> Suggestions for further training include: repeating the day workshop to facilitate others to attend; having local regular workshops at the

place of work of participants to provide a work-base context for training; and providing action learning sets for participants across the network to maintain potentially more formal peer support and mentoring for participants of workshops on a regular basis.

## **CONCLUSION**

The evaluation has shown that the neonatal palliative care workshops with a shared learning approach of bringing staff from different hospitals and other organisations together from across a neonatal network can result in significant improvements in participant's knowledge, attitude, self-beliefs and confidence in neonatal palliative care, enhanced awareness of other services, and built links between professionals. The use of such workshops can achieve the aim of providing good education and training in relation to palliative care in parallel with the implementation of palliative care pathways.<sup>6,4,10-12</sup> The broad range of sessions covered in the all-day workshop ensured that key topics such as ethical issues of withdrawal of intensive care, symptom management, and communication skills were included; topics still being identified in the literature and guidance as important areas where training is needed.<sup>23-25</sup> The guidance which helped drive the development and implementation of the workshops of this evaluation has recently been updated.<sup>4,12</sup> The need for formal, integrated education programmes on palliative care for perinatal and neonatal staff remains an important goal. The future challenge will be to ensure resources are available to continue to provide this vital education, to identify on-going educational needs for those who have taken part in workshops or similar training to maintain and share their palliative care skills, and to conduct longitudinal research into the impact on practice of staff and the overall experience received by families.

## **Conflicts of interest**

The authors declare they have no conflicts of interest.

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