

## Article

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Balaam, Marie-Clare and Thompson, Gillian

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# Sharing and modifying stories in neonatal peer support: an international mixed-methods study

Gill Thomson PhD (Associate Professor)<sup>1,2</sup>  and Marie-Claire Balaam MA (Senior Research Assistant)<sup>3</sup> 

<sup>1</sup>Maternal and Infant Nutrition & Nurture Unit (MAINN), School of Community Health and Midwifery, UCLan, Preston, UK, <sup>2</sup>School of Education, Health and Social Studies, Dalarna University, Falun, Sweden and <sup>3</sup>Research in Childbirth and Health, UCLan, Preston, Lancashire, UK

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## Sharing and modifying stories in neonatal peer support: an international mixed-methods study

While shared personal experiences are a valued prerequisite of the peer supporter–service-user relationship, they have the potential to create harm. There are challenges in peer supporters being emotionally ready to hear the experiences of others, and how much personal information peers should disclose. As part of an international study that aimed to explore how peer supporters who worked in a neonatal context (providing support to parents whose infant(s) has received neonatal care) were trained and supported, new insights emerged into how peers' personal stories were used and modified to instil boundaries in peer support services. In this paper, we report on a secondary analysis of the data to describe how peer supporters' stories were valued, used, assessed and moderated in neonatal peer support services; to safeguard and promote positive outcomes for peers and parents. Following University ethics approval, a mixed-methods study comprising online surveys and follow-up interviews was undertaken. Surveys were distributed through existing contacts and via social media. Thirty-

one managers/coordinators/trainers and 77 peer supporters completed the survey from 48 peer support services in 16 different countries, and 26 interviews were held with 27 survey respondents. Three themes describe variations in the types of stories that were preferred and when peers were perceived to be 'ready' to share them; the different means by which sharing personal accounts was encouraged and used to assess peer readiness; and the methods used to instil (and assess) boundaries in the stories the peers shared. In neonatal-related peer support provision, the expected use of peer supporters' stories resonates with the 'use of self' canon in social work practice. Peer supporters were expected to modify personal stories to ensure that service-user (parents) needs were primary, the information was beneficial, and harm was minimised. Further work to build resilience and emotional intelligence in peer supporters is needed.

**Keywords:** premature birth, parents, social support, mixed-methods, peer support.

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## Introduction

Peer support is a unique social support intervention that is used in many health- and social care-related contexts. Peers are a created social network who offer support (information, practical, emotional and social) to others with whom they have a shared experience (1). Peer support services are provided by national organisations or local services, with variations in the scope, training and supervision of peer supporters (2,3). The theoretical underpinnings of how peer support can influence salutary outcomes in others are outlined by Salzer (4). These

relate to how positive psychosocial interactions with peers based on mutual trust and respect (social support) can influence positive outcomes; how individuals are more willing to accept support from peers with whom they share similar characteristics (social comparison); how peers operate as credible role models for others to emulate and model (social learning) and finally how peers' 'experiential knowledge' of the stressor enables them to demonstrate empathy and to normalise concerns (4).

Peer support is often provided on a voluntary basis and motivated by altruistic intentions (5,6); peer supporters want to use their personal knowledge of a certain stressor (e.g. mental health, disability, HIV, premature baby, etc.) to good effect by encouraging and enabling positive outcomes for others (5,6). Altruism is commonly described as actions being undertaken to enhance the welfare of

### Correspondence to:

Gill Thomson, MAINN, School of Community Health and Midwifery, UCLan, Preston PR1 2HE, UK.  
E-mail: GThomson@uclan.ac.uk

others without the expectation of reward. However, it can be argued that while altruistic acts are prosocial behaviours, not all prosocial behaviours are purely altruistic. For instance, individuals may be motivated to help others due to 'vested interests' (7,8), whereby the support has reciprocal benefits for self and others, or by 'direct reciprocity' (9), where the intention is that recipients will feel obligated to provide the same help for others. Altruism however, can also take a more negative form called 'pathological' altruism (10), which can involve harm (for the peer and service-user) through peers becoming overburdened, or having an unhealthy focus on the needs of others at cost to themselves.

A key effective feature of peer support is that peers, by virtue of having 'been there', can connect on a more mutual, empathic basis and through which more meaningful support can be provided (6,11,12). A recent meta-synthesis of 34 qualitative papers to explore the impact of providing peer support for peer support workers was undertaken by MacLellan et al. (6). This review highlights how sharing stories (peers and service-users) reflects a therapeutic model of care. Sharing stories increased the peer supporter's sense of responsibility to service-users and self. This in turn had a simultaneous impact on the quality of the peer's relationships with service-users and colleagues, and a positive reframing of the peer supporter's identity (6). However, other literature included in the review identified how peers can face tensions in how much personal information to share with service-users due to concerns of overstepping the boundaries of 'professional' into 'friend' (13-17). Peers can face personal costs when sharing and hearing others' stories, such as through triggering painful memories or through emotional contagion (e.g. when one person's emotions trigger similar emotions in others) (13,17). While it is argued that peer support organisations should help peers to develop and utilise boundaries when providing support to others (14,17), currently there is little known about what and how the peers' experiential accounts should be used and shared.

In our recent international study, we collected insights from 48 neonatal-related peer support services (where peer supporters provided support to parents of sick and/or premature infants) to explore how peer supporters were trained and supported in their roles. As part of this study, we identified new insights into how peer supporters' stories were used and moderated in neonatal peer support services. In this paper, we report on a secondary analysis of the data to describe when and what types of peer stories were preferred; how the sharing of personal accounts was used to assess peer readiness, and how peer stories were adapted and supported to instil boundaries in peer-parent contacts. These findings offer important insights into how stories can be used to safeguard and promote positive outcomes

for peers and parents and offer important lessons for peer support practice.

## Methods

While full details of study methods are reported elsewhere (18), an overview has been provided. This was a mixed-methods study comprising online surveys and follow-up interviews with peer support services who provide neonatal-related peer support. We developed a definition of peer support to specifically target services who provided 'some' training to peer supporters and where the peers offered direct support to parents (whether face to face or online) (see Table 1).

We developed two online surveys – one for managers/coordinators/trainers (MCTs) and one for peer supporters. Surveys were hosted on the Bristol Online secure platform and were developed based on wider literature (e.g. Hall et al. (19)) and the authors' prior research into perinatal peer support. The surveys were piloted with six academics/professionals with a peer support and/or neonatal care background. Both survey versions contained predefined and open-text questions related to the nature and types of peer support offered, and the training, supervision and support provided to peer supporters. Additional questions were included in the MCT version to capture background information and peer recruitment procedures. (Full copies of the surveys are available from

**Table 1** Peer support definition

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*All of the criteria in point one AND any of the criteria in point two.*

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- 1) Peer supporters (parent supporters/parent counsellors/parent mentors/parent veterans) are parents:
    - awho have had a sick/premature baby that was cared for in a neonatal unit
    - bwwho provide support to parents who are experiencing high risk pregnancies and/or whose infants are currently being cared for on the neonatal unit or have been discharged
    - cwwho provide support to parents (which could include giving information, practical, emotional and/or social types of support)
    - dwwho offer support via face to face, telephone/text or social media
    - ewwho offer one-to-one or group-based support in hospital or community settings
    - fwwho have received 'some' training/guidance to provide support to other parents
    - gwwho may provide support on a voluntary or paid basis
  - AND
  - 2) The peer support service/programme is organised/coordinated/ provided by any of the following:
    - aNational/local services or organisations (such as parenting, breastfeeding or voluntary organisations)
    - bHospital staff
    - cOther health and social-care professionals
-

the first author). All participants willing to take part in a follow-up interview (in English) were asked to record their contact details.

Methods to distribute the survey included the following: (i) an introductory email sent to existing UK, European and international contacts in peer support organisations, international neonatal and maternity care research networks and to neonatal parent-related organisations identified via internet searches; (ii) the study was advertised via social media (Facebook and Twitter); and (iii) snowball methods involved participants sharing the information with other services/organisations as appropriate. Once it was clarified that the peer support service met the definition (Table 1) participant information (information sheet, links to surveys) was forwarded in English or if needed, in translated form, together with a request for the information to be distributed to MCTs and peer supporters as appropriate. Colleagues and volunteers translated participant information into Spanish, Portuguese, French, Danish and Finnish, with accuracy checked by another native speaker.

Follow-up interviews were undertaken with a purposive sample of survey respondents. We selected individuals who had different roles (e.g. MCTs, peer supporters) from different models of peer support (e.g. national or local organisations/services) in different settings. A semi-structured interview schedule was developed with questions designed to expand on survey responses. Both authors shared the work of undertaking the telephone or Skype interviews. All interviews took between 30 and 78 minutes to complete and were audio-recorded and transcribed in full. Transcription was undertaken by a research assistant from the research support team at the authors' University.

### Data analysis

Descriptive (frequencies of Likert/forced choice response questions) analysis was undertaken using SPSS v.24. Thematic analysis of the qualitative data was undertaken using Braun & Clark's (20) approach, supported by MAXQDA (www.maxqda.com). Five key themes 'background/infrastructure of peer support services', 'timing, location and nature of peer support', 'recruitment and suitability of peer supporters', 'training provision' and 'professional and emotional support' that summarise key findings across the whole data set are reported elsewhere (18).

For this paper, we undertook a secondary analysis of the data to focus on insights that concerned the value, assessment and modification of peer stories. This focus had not been the original intention of the study, and rather it emerged when we were analysing the whole data set. Therefore, in line with the purpose of secondary analysis, we aimed to answer a different research

question of the same data (21), an approach widely used with both quantitative and qualitative research (21).

All qualitative data (interview data, open text included in the surveys) were re-uploaded to MAXQDA. Braun and Clark's (20) inductive thematic approach was undertaken that included all the data being read in its entirety to identify any issues that concerned the use, value and moderation of peer stories. These data were organised into codes, and codes merged into sub-themes and overarching themes that reflected the data set. Both authors were involved in all analytical phases. After the themes had been agreed, some of the descriptive survey data were integrated to provide a wider context, for example in the range and types of methods used within the peer support services.

### Ethics

Ethical approval was granted by an ethics sub-committee at the lead author's institution. Survey participants had to read and agree (by ticking a box) to consent statements to confirm they understood the purpose of the study, the voluntary nature of participation, withdrawal procedures and confidentiality. Consent to take part in a telephone interview was re-established at the start of data collection.

### Findings

One hundred and eight survey responses were received from 31 MCTs and 77 peer supporters. Respondents were from 48 different peer support services from 16 different countries: England (n = 7), Scotland (n = 2), Northern Ireland (n = 1), Republic of Ireland (n = 1), Finland (n = 4), America (n = 8), Canada (n = 4), Australia (n = 6), New Zealand (n = 3), Belgium (n = 1), Spain (n = 4), Mexico (n = 1), Rwanda (n = 1), Denmark (n = 1), Lithuania (n = 1) and Estonia (n = 2)). One service provided online peer support only. Twenty-six interviews were undertaken with 27 participants (13 MCTs and 14 peer supporters).

Most peer support services had been in operation for 5+ years and were provided by parenting/voluntary organisations. Approximately 69% of peer support services were provided by volunteers, and while all services recruited peers who had direct experience of neonatal care, ~58% of services *only* recruited those who had personal accounts. The numbers of peer supporters actively providing support in the services ranged from 2 to >1000. Overall, there were wide variations in relation to the funding, format of peer support, training, supervision and types/availability of support for peer supporters.

Here, we report three themes that describe how peers' stories were valued, used, assessed and moderated. The first theme, '*Types and timing of stories*', reports on

variations across the services in the types of stories that were desired, and when the peer supporters were deemed to be 'ready' to share their stories with parents. The second theme, 'Assessing for emotional readiness (via storytelling)', describes the different means by which sharing personal accounts was encouraged and used to assess peer readiness for a peer support role. The third theme, 'Modifying and monitoring stories in peer-parent encounters', identifies the different methods that were used to instil (and assess) boundaries in the content and types of stories being shared with parents. Participant quotes have been included with an identifier to indicate their role (MCT or peer supporter), country, project number and data source (survey or interview).

### Types and timing of stories

The value of receiving support from a peer with experiential knowledge was a recurring underlying ethos across the services:

It's just that shared understanding of what it felt like. Or just what it felt like to have to leave your baby in a hospital under the care of somebody else. That fear of bonding with your baby in case it's worst-case scenario. That feeling of failure that you did something wrong and that's why your baby ended up like they did. It's all that very personal stuff, and we can actually say in a way that just hits home with parents. (Peer supporter 13\_Australia\_6\_Interview)

However, the acceptability of certain 'types' of stories varied. For instance, MCTs from some of the included services reported that parents who had a negative experience (e.g. poor infant prognosis) would not be suitable for a peer support role due to the potential for negative impacts for themselves and others. Whereas other services specifically targeted peer supporters that had endured extreme and tragic experiences such as having a very premature infant or infant bereavement. One MCT from a service in the United States considered that these parents make the best peer supporter due to peer support becoming their 'personal crusade'.

In over 50% of the peer support services, there was an expected minimum time-period between the peers' own experience of neonatal care and providing support to parents. While this timeframe differed across the services (range: 6 months-3 years), the rationale was that peers needed to have some distance from their experience, and an acknowledgement that the period post discharge from the neonatal intensive care unit (NICU) could be particularly challenging; 'A lot of people can go on auto pilot to get through the NICU, and it is post NICU they fall apart' (Peer supporter 67\_Spain\_41\_Interview). There were also concerns about the peer's capacity to offer support in the early postnatal period, and particularly if there were

issues related to compromised/poor health. A recurring reflection across the services, however, was that the time between experiences was only one indicator of suitability and that further means to assess peer readiness – 'to see if they need the mentor or if they're ready to be a mentor' (MCT 8\_USA\_10\_Interview) – was essential.

### Assessing for emotional readiness (via storytelling)

Peer selection was based on positive intra- and interpersonal qualities such as empathy, compassion, confidence in social interactions and good communication skills. However, an essential factor of peer suitability expressed by one MCT from United States, but reflected across the services, was: 'Do you [peer supporter] believe that you have successfully dealt with your own experience?' The key method used to assess the peer's emotional readiness for the peer support role was via their responses and reactions to their own and others' stories.

Almost all the peer support services held a formal interview with the peer supporters. MCTs referred to how they would use probing questions to elicit the peer's personal experience of neonatal care, their motivations for peer support, current coping mechanisms and responses to potential challenging situations (e.g. providing support to a parent with an infant who has a poor prognosis). Peers were encouraged to share their own stories during the initial training programme (75.5%, n = 34/48), and different scenarios were used during role-plays to observe peer responses: '[to] get a sense of where the parent is at in terms of their [emotional] processing' (MCT 17\_Canada\_20\_Survey). In one service, peer supporters accessed the training first, followed by an interview, as in this way, 'if we hear unresolved negative feelings in their story telling, we explore it further in their interview' (MCT 1\_Canada\_1\_Survey). In another service, the peer supporters were interviewed and subsequently engaged in email correspondence to ensure he/she was 'capable of sharing both their story by written and by mouth' (MCT 19\_Canada\_24\_Interview). Some services also provided training over separate days with stories shared throughout or during the last session only. As indicated in the quote below, a prolonged approach was designed to enable honest and open disclosures and self-reflection:

At first I was a little concerned that it was broken up into two days but after sitting through it, I've realised that that first four hours of hearing everyone's stories is just so taxing that I think you really need that little break to be able to gather yourself, to gear up what kind of questions that you might have and then come back- which we do a week later. [...] That way they can decide again if it's a good fit for them or if they're ready for it. (Peer supporter 45\_Canada\_27\_Interview)

Listening to other peers' stories was perceived to be invaluable to expose peer supporters to the divergent realities they may face in practice, and enabled MCTs to identify those who required further follow-up and support.

#### *Modifying and monitoring stories in peer-parent encounters*

Almost all the training programmes included instruction on the nature and content of stories that should be shared with parents, with this learning reinforced, for example during supervision, ongoing training. The need to regulate what was shared during peer-parent interactions was deemed important for parents' experiences to be the primary focus of peer-parent contacts. This was in order to prevent peers providing support for purely self-cathartic means; *'the volunteering in itself shouldn't be a cathartic process, it should be about trying to help others'* (MCT 7\_England\_8\_Interview) and in recognition of how unheeded disclosures of peer's personal accounts could cause harm: *'it was a mother who frightened parents with phrases like "that's nothing, you'll see", "when you leave it's worse"'* (MCT 23\_Spain\_28\_Survey). The potential negative impact of inappropriate disclosures for parents' future use of peer support was highlighted:

You have to have the right attitude, because if you have one person, a volunteer, that has a nasty attitude then that could potentially turn away a lot of people who actually need your help and your services, but because they had one bad encounter they don't really see you as something that will fit their needs. (Peer supporter 61\_USA\_35\_Interview)

Peers were instructed to make general claims (e.g. *'I know how it is to be here in the unit'*) when introducing themselves to parents to demonstrate empathy and understanding. However, many participants highlighted how the parent's story needed to be the benchmark from which the peer supporter should judge, when asked, what level of personal detail to disclose. Active listening, silence to allow a reflective space for parents, deflection and reframing were considered key skills:

The more you talk the less you hear, and so I talked to the mentors about that - about how it's okay for there to be silence and to let somebody think about what they want to say to you. It's okay when they say they feel a certain way not to say "Oh I felt the exact same way" but to ask them a question like, "That's interesting. Tell me more about that". If the parent said "How premature was your child?"- "I had a baby born at twenty-six weeks." - that's the answer. You don't have to give them four years of information because that's not what they're asking for. (MCT 10\_USA\_8\_Interview)

Participants reported that while insights into the peer supporter's own experience of neonatal care could be

divulged, this was only when the information might help the parent's situation, and always with the proviso of not distressing parents. It was considered that while parents often want to hear stories with positive outcomes, participants emphasised that any disclosures needed to be tempered to prevent against false hope or causing unnecessary anxiety:

So if the parents ask afterwards "Why were you here? What's your story?" we will of course share it but not in detail. [...] I wouldn't go there and say that "I had preterm babies and one of them died" there might be parents who are really shocked, and they might start thinking maybe my child also dies, so I usually don't talk about that. (Peer supporter 72\_Estonia\_45\_Interview)

A few MCTs stipulated that peers should only share evidence-based information, whereas other participants highlighted that personal endorsements could be used, only if moderated by neutral and balanced qualifiers such as *'this does not always happen'*, *'every baby is different'* or *'this might help you, it might not, it's helped some'*:

Rather than saying "have you tried such and such, we found it great for our little boy", whatever, it's saying things in a manner of "some parents have found such and such useful, some parents tell me such and such" (Peer supporter 17\_England\_7\_Interview)

Various methods were used to assess the peer's ability to moderate self-disclosures when providing support to others. Just over two-thirds of the services provided shadowing (on a variable basis) to observe the peers in action, and ensure that the tone, and content of peer-parent communications were appropriate. Most services offered ongoing supervision (64.4%, n = 29/48), on a one-to-one and/or group basis for peers to reflect on and resolve any personal issues, such as facing challenging experiences in practice. Case study reflections were also used (in supervision or ongoing training sessions), whereby peers were asked to share what was discussed with parents to check whether for example *'they're talking more about themselves rather than the parents'* (MCT 7\_England\_8\_Interview). Furthermore, all the included services collected ongoing feedback on the peer's performance, for example from healthcare professionals, parents and/or other peer supporters.

On occasions when there were concerns regarding the peer supporters' capacity to offer peer support, additional counselling or further in-house support (e.g. additional shadowing opportunities) could be offered. The peers could also be directed to offer support in a less intense environment (e.g. group-based support), or within other areas of volunteering (e.g. fund raising). While the extent and nature of additional support was dependent on available resources within the individual peer support services, if supplementary support was not feasible, or the

peer supporters were unable to hone their skills, they could be counselled out of the service. Overall approximately 73% of the included services had faced situations when a peer supporter had been unsuitable. While this indicates an area where further support is required, it could also be, as reflected by one of the MCT's, *'there's a lot of people who cannot do it'*, due to the emotional, demanding nature of the peer support role.

## Discussion

In this paper, we provide insights from an international study of peer support in a neonatal context to highlight the value, use, assessment and modification of peer stories. Three key themes highlight that the services differed as to the types of stories preferred, and when these stories should be shared. Peer support services used various methods to encourage peers to listen to and share stories within a peer-to-peer context. Sharing stories served to facilitate healing, gauging the peer's emotional readiness for a peer supporter role and instilling boundaries in the content and types of stories to be shared with parents. Peers who were unable to operate within the expected confines of practice could be counselled out of the service or directed to less sensitive areas of practice.

The need for an expected minimum period between the peer's personal experience and providing peer support is reported by others, with a time-period of at least 12 months being advocated (19). The need for distance between a peer's own traumatic account and them acting to support others is in line with the 'physician health thyself' canon (22). We also uncovered new insights in that in some services 'certain' types of stories were preferred. Peers who had very negative personal accounts could be favoured as it was considered that this enhanced their altruistic desires to support others, or perceived as problematic due to the potential for pathological altruism with adverse impacts for the peer and/or parents.

Our findings concur with wider research in that opportunities for peers to share their personal accounts provided them with greater insight into their own and others' experiences (23,24). The review by MacLellan et al. (6) suggests that peer supporters in some areas of peer support practice are able to openly share their personal accounts with service-users. However, in our study, and as reported by others, there were boundaries instilled in the extent of peer disclosures (14,24). While the peer supporters in our study were encouraged to disclose and reflect on their personal experiences with other members of the peer support service, they were expected to provide moderated accounts when supporting parents. It has been argued that a professionalised peer support approach may jeopardise the peer-service-user relationship (5). However, in a neonatal context where infant

illness and uncertainty prevail, the need to regulate disclosures was considered essential to help reduce parental anxiety and to prevent against false hope.

How peer supporters are trained to use their personal experiences resonates with the 'use of self' canon within social work practice. While this term is considered a 'slippery and contested concept' (25), it is based on person-centred theory (26). 'Use of self' relates to practitioners using their personalities, beliefs and experiences to demonstrate empathy, validation and to build relationships to foster growth and positive change, but what is shared is a consciously mediated process that evolves and develops within the relationship (25,27,28). Similar to the findings in our study, the 'use of self' canon purports that while self-disclosure is inevitable, what is shared needs to be predetermined for service-users' benefit, to be of relevance, to be service-user rather than self-directed and to minimise harm (29). Social workers are evidently different from peer supporters as the nature of their relationship with clients is not 'altruistic' nor forged on shared backgrounds. However, social workers, similar to peer supporters, face potential challenges for emotional contagion, over-identification and blurring of boundaries when similar life stressors are reported (25,30).

The value of peer support in helping to resolve and normalise negative emotions and to direct parents to other areas of support is reported (19). However, as over two-thirds of the included services had experienced issues with peers being unable to undertake this emotion-based role, this suggests that additional support is needed. While our findings demonstrate that sharing personal accounts offers a therapeutic means to identify and promote emotional resolution, they also highlight the need for further means to develop resilience and emotional intelligence. A focus on emotional intelligence would concern training and support to enable the peer to be aware of, control and express their emotions and to use empathy in interpersonal relationships (31), whereas a focus on resilience concerns providing peer supporters with meaningful strategies and techniques that can help promote well-being while listening to and responding to adversity (32,33). Ongoing supervision is also needed to ensure that peer supporters remain within the established boundaries of their role and to support them in their ongoing work. Access or directing peers to counselling services should also be available for any peer supporters who feel this would be beneficial.

The strengths of this study relate to eliciting insights from a wide range of peer support services from different contexts and settings. In-depth interviews also enabled us to obtain richer insights than survey methodologies allow, although holding the interview in English may have been a barrier for some. While insights into the nature of peer and service-user interactions and

relationships feature in the wider literature, this is the first paper to consider how peer stories are used, assessed and modified in practice. Limitations relate to most of the services operating in high-income countries, despite concerted efforts to gain insights from other contexts. We also did not collect insights into the impact of peer support (on peers or parents). This means that we are not able to comment on how restrictions or modification of stories were internalised by peer supporters, nor how they had an impact upon the parents they supported. Member checking was not undertaken and would have helped to enhance the rigour of the findings. The focus on the use, value and modification of peer stories was not the original focus of the study. While we identified commonalities across the different peer support organisations, further research with a specific focus in this area should be undertaken.

## Conclusion

As part of an international study into peer support provision in a neonatal context, we provide new insights into the value, assessment and modification of peer stories. There were variations across the peer support services as to the types of stories preferred and when peer stories should be shared. Sharing stories via different modalities in the peer support services was used to aid healing, to assess peer's emotional readiness and to instil boundaries in the nature and content of information shared; peers who were unable to provide this emotion-based role could be counselled out of the service and/or directed to other areas of peer support practice. The expected model of practice resonates with the 'use of self' canon in social work practice. Rather than peers operating within an

egalitarian relationship with parents, based on mutuality and reciprocity, peers were instructed to consciously mediate and modify what was shared to ensure that parent's needs were primary, that the information served some benefits, and for harm to be minimised. The need for peer support among parents of sick and/or premature infants to help normalise negative emotions and to direct parents to other areas of support is highlighted. However, as many services experience difficulties in recruiting the 'right' supporters, further work to build resilience and emotional intelligence in peers is needed.

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## Author contributions

The first author conceived the study, and both authors were involved in data collection and analysis. Both authors were involved in writing the manuscript.

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