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RESEARCH

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# Experiences and impacts of psychological support following adverse neonatal experiences or perinatal loss: a qualitative analysis

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## Abstract

**Background** Poor parental mental health in the perinatal period has detrimental impacts on the lives and relationships of parents and their babies. Parents whose babies are born premature and/or sick and require neonatal care or those who experience perinatal loss are at increased risk of adverse mental health outcomes. In 2021 a North-West charity received funding to offer psychological support to service users of infants admitted to neonatal care or those who had experienced perinatal loss, named the Family Well-being Service (FWS). The FWS offered three different types of support – ad hoc support at the neonatal units or specialist clinics; one-to-one person-centred therapy; or group counselling. Here we report the qualitative findings from an independent evaluation of the FWS.

**Methods** Thirty-seven interviews took place online or over the phone with 16 service users (of whom two took part in a follow-up interview), eight FWS providers and 11 healthcare professionals. Interviews were coded and analysed using thematic analysis.

**Results** The analysis revealed two themes. *'Creating time and space for support'* detailed the informational, contextual, and relational basis of the service. This theme describes the importance of tailoring communications and having a flexible and proactive approach to service user engagement. Service users valued being listened to without judgement and having the space to discuss their own needs with a therapist who was independent of healthcare. Communication, access, and service delivery barriers are also highlighted. The second theme – *'making a difference'* – describes the cognitive, emotional, and interpersonal benefits for service users. These included service users being provided with tools for positive coping, and how the support had led to enhanced well-being, improved relationships, and confidence in returning to work.

**Conclusion** The findings complement and extend the existing literature by offering new insights into therapeutic support for service users experiencing adverse neonatal experiences or perinatal loss. Key mechanisms of effective support, irrespective of whether it is provided on a one-to-one or group basis were identified. These mechanisms include clear information, flexibility (in access or delivery), being independent of statutory provision, focused on

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individual needs, active listening, the use of therapeutic tools, and positive relationships with the therapist. Further opportunities to engage with those less willing to take up mental health support should be developed.

**Keywords** Neonatal, Perinatal loss, Mental health

## Introduction

Perinatal mental health refers to mental health during pregnancy or within the first year after having a baby [1]. It is estimated that up to 20% of women experience poor mental health such as antenatal or postnatal depression, anxiety, post-traumatic stress, or other complications such as postpartum psychosis [1]. Two key areas that can impact perinatal mental health relate to having a baby admitted to neonatal care, or experiencing a perinatal loss (such as miscarriage, stillbirth, or early neonatal death). Both situations induce similar responses but for different reasons. The need to promote positive parental health is well-reported due to the links between poor mental health and parent relationships [2] and poorer infant and child social, emotional, behavioural, and cognitive developmental outcomes [3–5].

Having a baby admitted to neonatal care can be a devastating experience for parents [6] due to experiencing a traumatic birth, concerns over infant viability and the unfamiliar and technological nature of the neonatal environment [7]. A recent systematic review and meta-analysis to explore prevalence rates of depression and anxiety for mothers and fathers of preterm infants reported depression rates of 29.2% for mothers and 17.4% for fathers, and anxiety rates of 37.7% and 18.3% for mothers and fathers respectively [8]. Mothers of premature infants have also been found to experience higher rates of post-traumatic stress when compared to fathers [9]. Perinatal loss is also reported to have profound and lasting effects on the mental health of parents due to feelings of intense grief manifested through feelings of sadness, anger, guilt, and emptiness [10–12]. Individuals who have experienced perinatal loss are also at increased risk of trauma symptoms, such as flashbacks and nightmares [13] and developing, or exacerbating depression and anxiety [10]. Both having a premature and/or sick infant or a perinatal loss can induce guilt due to parents blaming themselves for their baby's prematurity or untimely death [10, 11, 14, 15]. These parents can also experience social isolation through feeling disconnected from friends and family due to a lack of understanding [10, 16].

Interventions for perinatal mental health are crucial to ensure the well-being of the parents and infants. Within neonatal care, interventions can include family-centred care [17, 18], skin-to-skin [19] and education programmes [20]. An integrative review focused on interventions designed to improve the psychosocial needs of parents of premature and/or sick infants identified 36 different studies/interventions including creative activities,

peer support, relaxation/mindfulness, spiritual/religious and psychotherapeutic support [7]. This review found varying results with a general lack of effectiveness trials and wide heterogeneity within similar interventions; mechanisms of self-care, relaxation and social opportunities were highlighted as important [7]. A further systematic review and meta-analysis of 17 psychosocial interventions for individuals experiencing perinatal loss found significant impacts on reducing depression, anxiety, and grief; with most interventions offering either counselling or structured debriefing sessions [21].

In 2021 a North-West charity received government funding to develop and evaluate a two-year (April 2021–March 2023) Family Well-being Service (FWS). This service involved three types of support. (A) Ad hoc emotion-based support provided to service users while their babies were admitted to neonatal care or attending specialist clinics following perinatal loss. (B) Person-centred one-to-one therapy (~10–12 weeks) delivered over the telephone or face-to-face to service users whose infants were admitted to neonatal care, had experienced perinatal loss and those attending foetal medicine clinics due to their infants experiencing complex health conditions. (C) Group support, via a 6-week face-to-face guided bereavement course designed by two of the FWS therapists for service users who had experienced perinatal loss. Group support was initially introduced as an interim measure to enable service users to receive support while they waited for one-to-one therapy. The FWS was provided to service users who received care from any of four maternity Trusts in one North-West region. Here we report some of the qualitative findings from the evaluation to highlight the experiences and impacts of the FWS on service users. This work complements existing research by offering qualitative findings of a therapeutic-based intervention for those experiencing perinatal mental health difficulties following adverse neonatal outcomes [22]. It also extends the current literature by providing insights into an ad hoc form of therapeutic support delivered during a sensitive period of infant admission.

## Methodology

### Design

An exploratory descriptive approach was undertaken due to this study focusing on a new area of service delivery [23].

During the evaluation, we planned to collect demographic and outcome data from all those who received one-to-one therapy from the FWS (with this information not routinely recorded for those who received ad hoc or group-based support). The service users were asked by the FWS therapists

to provide consent for data-sharing purposes. Overall, less than a third of service users who received one-to-one therapy over the evaluation period provided consent. As this meant that only a partial, and potentially unrepresentative data set was available, this information has not been reported (a full copy of the evaluation report that includes all data and outcome analyses is available from the lead author). The reason for non-consent was not recorded in case this had a negative impact on the FWS therapist-service user relationship.

As part of the evaluation, we undertook interviews with the FWS therapists who provided the therapeutic support; wider healthcare care, e.g., neonatal nurses/staff who work on the neonatal units - to capture their perceptions about the FWS being delivered at the units; and service users who had received support (ad hoc, one-to-one therapy, group-based counselling) from the FWS. In this paper, we report on insights from the qualitative data that describe the experiences and impacts of the FWS on service users.

#### Data collection

Data collection involved interviews with the FWS therapists, wider healthcare professionals and service users. Service users were also invited to participate in a follow-up interview ~6 months later to assess for longer-term impacts of the FWS and whether any additional support had been accessed. While different semi-structured interview schedules were created for the different population groups (see overview of topics for each participant group in Table 1), all involved exploring experiences of the FWS and recommendations for service development.

All interviews were undertaken remotely via telephone or Microsoft Teams and were video and/or audio recorded. At the start of the interview, consent statements were read out by the researcher, with participants asked to verbalise their agreement to each. The consent recording was then stored separately from the interview recording. Service users were offered a £10.00 voucher for each interview completed. All interviews were between 20 and 60 min (average of 50 min) in length and were transcribed in full for analysis purposes.

#### Recruitment

Recruitment of FWS therapists involved the FWS project lead sending an invitation to all appropriate staff. To recruit wider healthcare professionals, FWS therapists were asked to provide contact details of relevant healthcare professionals (those who were aware of the FWS) for the evaluation team to invite. Any service user aged 16+ years who had received support from the FWS was eligible to take part. Service users were invited (via FWS therapists) by being asked to complete an Agreement to Contact form to receive further information about the evaluation. Posters about the evaluation were also displayed in key locations (e.g., neonatal unit, location where therapy or group support was provided) for service users to contact the evaluation team directly.

On all occasions, participants received an invitation email, an information sheet, and a consent form, and asked to respond to the evaluation team within two weeks if they wished to participate (with reminders issued ~3/4 weeks later).

#### Analysis

Qualitative data were analysed using a reflexive thematic approach [24]. This involved the first and second authors creating an initial coding framework using MaxQDA qualitative software. The second author then continued to use this framework to code the remaining documents with codes added, re-named, or merged as appropriate. All the authors reviewed and agreed on final analytic decisions.

#### Reflexivity

All authors have a psychology-related background. The lead author has over 20 years of undertaking research with perinatal populations, and the other two have been undertaking research in this area for ~5 years. All the authors are parents. All authors consider that emotion-based support for parents who have faced these adverse situations is crucial due to the potential for negative impacts on parents, infants, and families. The second author who was responsible for data collection and analysis had experienced neonatal care with her first child and had previously worked as a volunteer with the

**Table 1** Topic areas explored during the interviews with the different participant groups

Healthcare professionals	FWS therapists	Service users
Knowledge and experiences of working with the FWS	Background and role in the FWS; involvement in FWS development.	Views on information received about the FWS
Identifying mental health issues and making referrals to the FWS	Issues and challenges in FWS referrals	When and how support was accessed
Perceived impact of the FWS on service users	Experiences of FWS delivery including communication with other FWS/healthcare staff	Relationships with FWS staff
Recommendations for service development	Experiences of training and supervision (within the FWS)	Whether and how well-being was impacted
	Recommendations for service development	Recommendations for service development

**Table 2** Demographics and characteristics of service users

Demographic characteristic	N (%)
<b>Ethnicity</b>	
White British	13 (81.3)
White British American	1 (6.3)
Indian	1 (6.3)
Latin American	1 (6.3)
<b>Marital status</b>	
Married	10 (56.3)
Single	6 (37.5)
Civil partnership	1 (6.3)
<b>Reason for referral</b>	
Miscarriage	4 (25.0)
Neonatal death	4 (25.0)
Still born	4 (25.0)
NICU baby	2 (12.5)
Birth trauma and tokophobia following perinatal loss	1 (6.3)
Birth trauma/neonatal unit admission	1 (6.3)
<b>Parity</b>	
No children	6 (37.5)
One child	6 (37.5)
Two children	3 (18.8)
Four children	1 (6.3)

charity. Care was taken to ensure that this prior relationship did not overtly bias data collection, or the interpretations generated – this was achieved through working closely with the project lead (first author) to review the transcripts and when analysing the data set. As listening to others' experiences of neonatal care could trigger personal memories, regular check-ins were provided by the project lead for reflection and sign-posting purposes.

### Ethics

Ethics approval for this study was received from the Health ethics committee at the University of Central Lancashire (project no: 0262). All participants received a detailed information sheet and provided informed consent. As it was recognised that the interviews could elicit upset, a distress protocol was developed. This involved advising participants (in the information sheet and verbally) that the interview would be paused should they become upset, and a decision made together about how to proceed. All service users were provided with contact details of organisations where they could seek further support as needed. All information sheets noted that confidentiality would be broken should experiences of harm (to self and others) be disclosed.

### Results

A total of 37 interviews with 35 participants were undertaken, 35 interviews were completed via Microsoft Teams and two interviews were audio-recorded telephone calls. Participants included eight FWS staff, 11 healthcare

**Table 3** Types of support received by service users

Types of support	N (%)
Telephone counselling	8 (50.0)
Telephone counselling and group counselling	2 (12.5)
Group counselling	2 (12.5)
Ad hoc support in the neonatal unit and telephone counselling	2 (12.5)
Ad hoc support in the neonatal unit	1 (6.3)
Group counselling and ad hoc support at the rainbow clinic <sup>1</sup>	1 (6.3)

<sup>1</sup>Rainbow clinic provides specialist maternity care to women who are pregnant and who have suffered a previous stillbirth or neonatal death

professionals and 16 service users (of whom two were interviewed twice). The demographics and characteristics of service users are displayed in Table 2.

All service users identified as female and were aged between 25 and 40 years, with a mean age of 33. Most service users were White British or White British American ( $n=14$ , 87.5%), over half were married or in a civil partnership ( $n=11$ , 62.5%) and the rest were single ( $n=6$ , 37.5%). The age of the service users' youngest child ranged from 10 weeks to 4 years (with the average child age being 15 months). Reasons for referral varied and were due to several different types of adverse neonatal experiences or perinatal loss (see Table 2). The types of support that the service users received are detailed in Table 3. These data highlight that one service user had only received ad hoc support on the neonatal unit; the remainder had all received more prolonged support via one-to-one or group-based therapeutic support (four of whom also had received ad hoc support at the neonatal unit or specialist clinic).

The FWS staff interviewed included seven psychological therapists ( $n=7$ ) and the project lead. Healthcare professionals who participated in an interview held different roles including neonatal nurses, ward managers and sisters, education leads and mental health neonatal nurses. The healthcare professionals' length of service ranged from 9 months to 14 years.

### Findings

In the following sections, we present two themes and associated sub-themes. The first theme - 'creating time and space for support' - details the informational, contextual, and relational basis of the FWS service, as well as barriers to service delivery. The second theme - 'making a difference' - describes the cognitive, emotional, and interpersonal benefits of the FWS for service users. Illustrative quotes are included with identifiers that use the abbreviations SU – service user, FWSS – Family Well-being service staff, or HCP – healthcare professional. Additional identifiers that signify the type of support the service user received are also included using the codes A (ad hoc support), G (group counselling) and O (one-to-one therapy).

### Creating time and space for support

In this section, we describe how the FWS therapists worked to facilitate time and space for therapeutic support across six sub-themes - 'tailoring the communications', 'a flexible and proactive approach', 'being listened to without judgement', 'independent from others', 'not just about the baby' and 'shared experiences'. A final sub-theme reports on the 'barriers to service delivery'.

#### Tailoring the communications

FWS staff used various communication modes - verbal, leaflets, email, telephone, or text - to inform and communicate with service users. Some service users spoke positively about the incremental information received and how valuable it had been to tell them 'everything I could expect' (SU4:O&G): this, together with the perceived 'non-pushy' approach of the FWS staff enabled them to make their own decisions and to access the support on their terms, 'I just read through it [leaflet] because it wasn't kind of like it straight away, we're gonna refer you. They said have a think' (SU16:O). Another service user reported:

*It was a lot of like, what's gonna fit for me really. Like I wasn't just kind of told, this is what you're going to do and that kind of thing. Like, every step of the way I was asked, like, do you want to do this? Do you want to try this? You know, do you think that would work for you? And it felt really personal. (SU4:O&G)*

Service users also appreciated the immediacy of contact from the therapists, 'found it really good, they contacted me really quick' (SU9:O), once a decision to receive support had been made.

A further means by which FWS staff helped to tailor communications and support service user engagement was via data sharing. Several service users highlighted the benefits of the FWS staff sharing their information with others in the service, thereby mitigating the need for repeating painful accounts:

*She [FWP therapist] was aware that I was gonna be contacting. I think it is helpful that they already knew my background because it can avoid questions that you don't particularly want to answer, or things that you don't want to have to repeatedly go over. (SU3:G)*

Those receiving ad hoc support were all encouraged to take up formal therapy following infant discharge. However, the therapists also offered a text message contact for service users who were not receptive to receiving more prolonged therapeutic support during their infant's neonatal stay, e.g., 'six weeks after you've been discharged just to check in'

(FWSS1). For some, this delay in service offer was considered 'perfect' as it meant that they accessed support that they 'would not have accessed' but has 'helped me no end' (SU7:A&O). Although one of the FWS staff reflected that whilst this follow-up approach was not always successful, it provided 'peace of mind' (FWSS5) to know that it had been offered.

#### A flexible and proactive approach

Participants who accessed different forms of therapeutic support from the FWS spoke very positively about the flexible and proactive nature of the service. Proactive ad hoc support on the neonatal unit enabled service users to receive support while being with their babies. Healthcare staff felt parents were unlikely to prioritise their own mental health needs when 'all they are concerned about is the baby' - proactively approaching them 'where they are' was therefore perceived to be the 'best way of doing it by far' (HCP8). Ad hoc support was also considered important in preventing service users from 'slipping through the net' (HCP5) by expecting them to join a waiting list for an appointment that they then decide not to access.

Flexibility in how the one-to-one therapy was provided (i.e., by telephone or face-to-face) was highly appreciated. Telephone appointments were valued for practical reasons such as childcare - 'I can't attend in person with two children' and wider work commitments. Accessing support from home also allowed service users to feel comfortable in their own space, which in turn enabled them to be more open with their therapist:

*You're in your space. I was comfy, I had my coffee and then I just felt like, I don't know if I'd have opened up so much if I was in a room and it felt like counselling, like therapy (SU6:O).*

Flexibility in service users being able to change appointments, 'they changed every appointment that I needed changing [...] it was brilliant' (SU1:O) or delaying appointments 'she didn't mind me texting and saying I'm running 5-10 minutes late' (SU6:O) was highly valued. Service users also appreciated the freedom to go at their own pace: 'if you wanted to contribute [during the group counselling], you could do, if you didn't, you didn't have to' (SU10:O&G). One service user reflected on how this personalised approach stimulated reciprocity in terms of individuals being able to 'get out' what they 'put in' (SU15:G). This flexibility was also echoed in the bereavement groups, with the discussion topics being based on the needs of the group rather than a prescribed plan:

*[Group therapists] had something as sort of an idea for each session but they would always ask if there*



*was anything that we as a group or individually wanted to focus on or cover. (SU3:G)*

### **Being listened to without judgement**

Service users repeatedly spoke of how much they valued feeling 'heard and listened to and valued' (SU5) by the FWS therapists; with these accounts provided by service users who had received ad hoc, one-to-one, or group-based support. One service user also felt that while the therapist was 'paid to listen' it was the fact that she seemed to 'want to listen' that made a difference (SU1:O). Several service users reflected on how the therapists' active listening and person-centred non-judgmental approach meant they 'found her really easy to talk to, it's a really good relationship' (SU12:A&G), and was someone who they 'could be completely open with' (SU6:O):

*The most helpful thing is having someone to listen to me and that has no judgment whatsoever, I have to say when I went on, she was calm, she was soothing and never felt one bit of like, oh my God, I can't believe that's happened [...] There's no judgment, [...] she was there for me and only for me. (SU14:O)*

Feeling listened to and having a good relationship with their therapist gave service users a sense of being 'wholly seen' and a safe space to be 'able to feel safe and valued and respected' (SU5:A&O). Some service users described how it was like they were talking to a friend who was 'there for me':

*It was just like talking with an old friend, if you know what I mean. And even though I've never met the lady before, she was very friendly [...]. So it was nice. (SU13:O)*

### **Independent from others**

Whilst service users appreciated the friendliness and authenticity of their therapist, they also talked about how helpful it was to receive regular support from the same therapist who was independent of friends, family, and healthcare professionals. Several participants who received one-to-one or group-based support considered this to be helpful as it meant they could openly share how they felt without feeling like a burden:

*I was really worried that when I was talking to like my husband or my mum and my sister or anything that that I was saying was just going to end up upsetting them and having someone to talk to or just felt like I can say whatever I want, [...] Like it's not gonna ruin their day, I can just say what I want, it was just so helpful really (SU4:O&G).*

The positives of the therapists being separate from clinicians were related to challenges in the relationships between healthcare providers and parents due, e.g., to life-saving care being administered to their babies which was uncomfortable to watch:

*So, it's quite nice that they have that extra person to talk to who isn't the person that just stuck a gastric tube down your baby and made him cry or, you know, or that just cannulated your baby (HCP1).*

Healthcare professionals also spoke of how parents could attempt to 'hold it together' during interactions with healthcare staff, due to not wanting to give the 'impression that they're struggling' (HCP6). Support from an 'outsider' perspective was therefore perceived to be crucial in breaking down these barriers and offering dedicated needs-led support.

### **Not just about the baby**

Another reason service users felt they could talk openly about their feelings and experiences was due to the support being focused on their needs as individuals, rather than being about the baby, or being a parent:

*It helped me in a lot more ways as sometimes it was nothing to do with being a mum or [baby] and yeah, it just worked really well' (SU6:O).*

Service users acknowledged the need to process their negative experiences but also the necessity of talking about other things that were affecting their mental health and their ability to cope:

*I had to grieve with what had happened in the past. Cause normally I just push everything down and deal with it, I just get on with the next day. So, we [therapist and service user] went backwards for me to be able to move forward. (SU14:O)*

'My helping hour' (SU6:O) as one service user who had received therapy described, and mirrored in others' narratives, related to how much they appreciated and looked forward to taking time out each week to think about their needs:

*When you've got a newborn and you're wrapped up with, especially with someone with a condition and wrapped up with a feeding schedule, medicines, nappies, sleepless nights, blah blah, blah blah blah. I would never have then thought, you know what? Let's take care of you. Let's have an hour that's just for me. (SU7:A&O)*

### Shared experience

Some service users who received support on an ad hoc, one-to-one or group basis spoke of how receiving support from a therapist who had faced a similar experience had *'definitely helped'*. One pregnant service user who had had a previous miscarriage reported the benefits of receiving one-to-one support from a therapist who had faced their own experiences of infertility and subsequent in vitro fertilisation:

*She'd gone through pretty much a very similar experience to me. She'd had very similar infertility issues, and she's also gone through losses herself. So, it was easy to bond with her very quickly because you do when someone's gone through that same experience (SU11:O).*

Others referred to how receiving support from therapists who had *'been through it all the same'* (SU1:O) helped them to feel *'normal'* and *'I wasn't being dramatic or crazy'* (SU8:A). Whereas for others, it was receiving support from a therapist who understood the realities of parenthood that mattered:

*Motherhood is hard, you know, like and my counsellor was a parent as well, so really helped to, like, justify those feelings are rational and just rationalise. (SU5:A&O)*

Opportunities for group support also enabled service users to normalise and validate their experiences *'with other people who have all gone through the same thing and have the same feelings'* (SU4:O&G).

### Barriers to service delivery

Overall, there were some challenges and barriers reported in relation to communication, access, and service delivery. First, in relation to communication, some service users referred for one-to-one or group support complained about a lack of information about when it would be received:

*So, it was a bit frustrating waiting and not knowing whether it was then gonna be like weeks and weeks, or months, or whether it was gonna be like a few days. (SU4:O&G)*

Several service users also described communication difficulties about the delay in follow-up after the initial assessment (when referred for formal therapy). This delay meant they had to *'unravel'* the *'worst parts you are struggling with'* and then *'putting the phone down'* with *'no follow-up plan or coping mechanisms'* in place (SU10:O&G). The gaps in support provision were also expressed from within the service: *'it's not great, because those mums and*

*dads are waiting, and they've reached out, and that's when they need the help'* (FWSS7).

Despite the benefits of ad hoc support, access-related issues were raised about therapists being unable to provide support for practical as well as emotional-based reasons. From a practical perspective, the therapists only had limited time on the units which meant *'some people may not see her'* (HCP1), and if parents did not live in the catchment area, then support could not be offered. Healthcare staff were not always notified about the FWS therapists' availability at the unit. This information was considered important to ensure effective signposting to, *'just to say to a parent, well if you want to speak to anybody, we've got our counsellor in on such-a-day'* (HCP6). From an emotional perspective, it was recognised that therapeutic support was not suitable for all, such as those *'who are very closed down'* (FWSS1) or *'scared'* of disclosing negative emotions particularly *'the ones where there are social issues'* (HCP6).

Regarding service delivery, while several service users made positive comments about the flexible nature of support, in terms of access, delivery and amount received, some wished the sessions had been longer. One also spoke of an *'awkward finish'* when the one-to-one sessions were ending:

*[So, it can be like] ohh sorry, I think I've lost track of time a little bit, I think we're gonna have to pull it up there and we're gonna have to end. So, I'll be like, alright, OK, right, yeah fine. And it can be a bit clunky in the way that it finishes rather than it drawing naturally to a conclusion. (SU10:O&G)*

### Making a difference

In this section, we describe service users' reflections on the psychological, cognitive, behavioural, and social benefits of FWS support. Four sub-themes are detailed - *'tools for positive coping'*, *'enhanced well-being'*, *'improved relationships with others'* and *'confidence in returning to work'*.

#### Tools for positive coping

Several service users described how the therapeutic tools they were taught as part of their therapy sessions either on the ward, one-to-one, or in the group provided positive coping mechanisms to help with ongoing adversities: with one describing them as a *'toolbox'* to draw on when needed (SU4:O&G). The techniques were reported to have helped them understand and articulate how they were feeling, *'to unpick, how it was that I was feeling what I was struggling with'* (SU10:O&G) and the breathing and distraction techniques enabled them to *'stop blaming myself and start breathing'* and to *'do something else to try*



take my mind off it' (SU2:O). Other service users referred to how the support had helped them to know 'more about their triggers' which helped them to feel strong and to retain a sense of control during uncontrollable and uncertain situations:

*The tools just to step back and be like right, [...] write down everything I can't control and everything I can control of what my memories are and then cross everything I can't change. Like I can't control how sick she is. I can't control her temperature, but what I can control is her feeds and being her mum and stuff like that [...] They made me feel the strength that I've not felt in about 5 years. (SU5:A&O)*

The therapeutic techniques provided by the therapists were an ongoing source of support to help service users in the extreme circumstances of the neonatal unit as well as in day-to-day life:

*I relied on one of the meditations she sent me, and it just really, really centred me at night, even as I was feeling overwhelmed, just like putting my headphones in and just saying to my husband, if he wakes up and you just see to him, and that just helped me so much. (SU6:O)*

### **Enhanced well-being**

Many service users described how the FWS support had improved their psychological well-being, using terms such as feeling 'lighter', more 'optimistic' and a 'stronger person'. Some service users referred to how the therapist had provided important crisis management. For one participant who received one-to-one therapy, this related to how the support helped to 'pull her back' from an emotional crisis each week, associated with the threats of a further potential pregnancy loss:

*If I didn't have [therapist] once a week, I dread to think where I would have been. It was kind of like, yeah, like each week she'd pull me back in, and then I'd probably go a bit crazy again, and then she'd pull me back in. (SU11:O)*

Others described fundamental changes such as moving from a state of being unable to 'function properly' to being back at work and 'happy and getting on' and feeling 'like a different person' (SU4:O&G). Another service user also described how the one-to-one therapy had improved her well-being after a traumatic birth and neonatal stay to such an extent that she had become 'a better version' of herself:

*I just literally feel like me again, I suppose I think you just get so wrapped up with being mum and just being on all the time and as a mum you do normally lose your confidence and you do lose yourself so it's more like feeling like me but even a better version that I liked of me. (SU6:O)*

### **Improved relationships with others**

Service users who received one-to-one or group-based support talked openly about how their relationships with their partners and family had been enhanced due to the support the FWS had provided. One reported how the support had helped her and her husband to 'communicate with each other' and 'discuss how we were both feeling' (SU15:G). Another service user shared how the one-to-one telephone therapy had restored her relationship with her mother:

*I don't know what magic she's done but my mum and my relationship it's been really good to a point where before I couldn't wait to get my mum out of my house, but now, it's kind of like mum I need you and I appreciate you (SU16:O).*

A further way the FWS support influenced relationships with others was regarding a future conception. While following a traumatic birth, neonatal stay or loss of a baby, individuals can be hesitant to have more children [25], the FWS was reported to have helped service users' address these concerns. Bereavement group participants also reported finding hope for future family planning together, thereby enabling a futural peer support element to the therapeutic intervention:

*Hopefully, we'll be able to support each other, hopefully in the future through future pregnancies. Like it'd just be amazing if we all managed to get pregnant together and had our babies together that'd just be unbelievable. (SU15:G)*

### **Confidence in returning to work**

Service users who had received one-to-one support reflected on how the support had helped them to address their anxieties in returning to paid employment:

*[Baby] is going to nursery that was quite triggering [...] And I think if I had to deal with that a long time ago, like a few months ago, I'd have just blow my head there, I just couldn't have done that. But now, I've just been, like, really calm and just quite open to it and just, sort of kept my cool really. (SU6:O)*

Another service user who had experienced a neonatal loss reported: *'If I hadn't had had the support I wouldn't have gone back to work and I'd probably be in a much darker place'* (SU13:O). This woman reflected that working was positive for her emotional well-being, and how this would not have been possible without the support from the FWS.

## Discussion

In this paper, we present findings from an evaluation of a charity that provided ad hoc support, formal therapy and group support to service users who had a premature and/or sick infant or who had suffered a perinatal loss. We highlight the informational, contextual, and relational basis of how the support was experienced, and the cognitive, emotional, and interpersonal impacts of the FWS for service users. The findings of this paper contribute to the evidence supporting the need for emotional and psychological support for those who experience adverse maternity and neonatal outcomes in the perinatal period [3]. Overall, there appear to be key mechanisms - defined as the entities or activities responsible for the phenomenon (i.e., positive experiences and impact of FWS support) [26] - that underpinned effective support, irrespective of whether it was delivered on a one-to-one or group basis. These mechanisms include clear information, flexibility (in access and/or delivery), being independent of statutory provision, focused on individual needs, active listening, the use of therapeutic tools, and positive relationships with the therapist. Furthermore, while *'shared experiences'* are a key mechanism of group-based support, this was also evident in one-to-one therapy when service users received support from a therapist with a shared history.

A number of our findings echo those reported in a recent qualitative systematic review of women's experiences of specialist perinatal mental health services [22]. Similar findings concern the importance of the therapist-service user relationship, with the therapist's open, non-judgemental, and person-centred approach found to be essential to meaningful service experiences [22]. As reported in the review, and in our study, continuity was a key feature of relationship building that engendered safety and dependability [22] and for meaningful change. While some of the included papers in the review reported how women felt clinicians had real insight and understanding of perinatal mental health conditions [27–29], in our work, this also related to the therapists sharing their personal experience of perinatal mental health and/or loss. These findings resonate with those by Cleary and Armour who explored the dual identity of counsellors and therapists with experiential experiences of mental health issues [30] whereby self-disclosure enhanced the therapeutic relationship. They also concur with a qualitative study by Parker et al. who found counsellors having

a working knowledge of neonates and the neonatal environment was crucial [31].

Similar to the wider literature, we found that service users benefitted from receiving support independent of health care and focused on their needs as individuals [32, 33]. This finding further supports the need for independent specialist support such as provided within the UK-based specialist perinatal mental health and maternal mental health services [3]. While specialist mental health support has been found to help service users understand their infant's needs and develop parent-infant relationships [22, 27, 34], in our study, the benefits were more individualised and included enhanced personal and social well-being. Our findings of the positive impacts of group-based support also align with the wider literature regarding the value of receiving validation and reassurance from peers with shared experiences [29, 35, 36], as well as opportunities for ongoing social support after the groups had ended [35]. The benefits gained via support from the therapists and within the groups signal post-traumatic growth described as *"positive psychological change experienced as the result of the struggle with highly challenging life circumstances"* [37]. This was evidenced through women feeling stronger, developing new relationships, more able to cope with future adversities and with a new and improved outlook on themselves and their situation [37].

Flexibility in rearranging appointments and the location of support being organised to suit individual service users encouraged access and an openness to share personal issues [22]. While complaints have been reported in the previous literature about service users being unaware of wider support provision and a lack of follow-up support [22, 36], in our study, we found that tailored information and communications provided at multiple points helped facilitate engagement. Although resource-related challenges concerning the availability of the therapists on the unit and a lack of communication as to when this support was available were noted. A further difficulty related to the reported time lag following an initial assessment: this signifies a need for ongoing contact to ensure service users gain access to the right support at the right time [38]. Proactive support is a central tenet of emotional-based care [39]. This was clear in our study as the proactive nature of the support was essential to provide parents with care at a harrowing time and to facilitate access to more structured support post-infant discharge. However, as some service users can be reluctant to disclose perinatal mental health problems, due to feeling overwhelmed or potential fears of stigma and negative reprisals [40], alternative methods to ensure that all parents receive timely support is needed. Furthermore, despite service users from minoritised ethnic communities being at increased risk of poor perinatal mental

health [41–43], they are less likely to access support [40, 43]. A recent systematic review to explore the reasons why minoritised ethnic women do not access mental health services identified barriers at the individual (stigma, lack of awareness), organisational (inadequate resources), sociocultural (language, cultural barriers) and structural (lack of clear policies) levels [44]. Therefore, while approaching parents in the neonatal unit may help to overcome some of these barriers, further work to elicit if and how this can influence access to specialist support amongst ethnically minoritised service users is needed.

The limitations of this study are that overall, only ~30% of service users who accessed one-to-one therapy consented to share their demographic and outcome data for the evaluation. However, typically studies involving mental health intervention have difficulties with recruitment and retention of participants and often achieve very low response rates [45]. It also suggests that further work on how to encourage consent and provide reassurance about how their data will be used may be needed. The intention was to interview ~20 service users, with only 16 recruited, despite numerous recruitment efforts. This may be due to asking service users to participate while still receiving support, and indicates that other potentially more sensitive methods, such as writing to participants after they have ended support with the FWS may have been more successful. Also, while all service users had the opportunity to be re-interviewed ~6 months later, only two took up this offer – both of whom had received one-to-one therapy. This low take-up may be due to symptom resolution or symptom continuation, both of which could be associated with concerns for re-triggering or magnifying negative emotions. More flexible ways, such as using a journal, may encourage long-term qualitative insights to be captured. A further limitation is that over 30% of the participants had received more than one type of support and any nuances in the experiences of the different support options were not fully explored in the interviews. Most of the participants were from a White demographic background, which may reflect wider barriers to access to mental health support in ethnic minority populations [40]. We also intended to interview more healthcare professionals, and the small number recruited is likely indicative of busy, time-poor professionals. Future research could include focus groups incorporated as part of existing professional-based meetings to maximise participation. However, despite the recruitment challenges, a total of 35 participants is a large sample for qualitative research, and generated rich, in-depth insights into the views, experiences, impacts, facilitators, and challenges associated with the FWS.

## Conclusion

This study describes how psychological support was provided for service users experiencing adverse maternity and neonatal outcomes and the impact of this support on

individual and familial well-being. This work complements existing research into perinatal counselling-based interventions and highlights the value of providing therapeutic support during a sensitive time. Despite study limitations, the findings signify the need for independent, timely, flexible, needs-based, proactive, well-resourced psychological-based support. They also emphasise how the therapists' open and non-judgmental approach and experiential knowledge are essential mechanisms of meaningful service provision. Implications for practice concern better communication regarding support availability, and timely follow-ups. Further means to engage those less willing to take up mental health support and who may have greater needs should be developed.

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## Author contributions

GT was project lead who designed the original study, with support from RN. LN conducted interviews. LN and GT developed a coding framework which was applied to the transcripts by LN. All authors reviewed analyses and agreed final analytical decisions. All authors read and approved the final manuscript.

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## Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

Ethics approval for this study was received from the Health ethics committee at the University of Central Lancashire (project no: 0262). All participants provided verbal consent to participate in the study, which was audio-recorded.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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