COMMUNITY CARE AFTER STILLBIRTH AND SECOND TRIMESTER MISCARRIAGE FINAL PROJECT REPORT

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WARWICK MEDICAL SCHOOL

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Summary

• The quality and availability of community care after a stillbirth or second trimester miscarriage is extremely variable.
• Women and their families are often left unsupported, and in a position where they have to seek out their own support
• Communication with healthcare professionals is often inconsistent, insensitive and lacking empathy.
• There is a need for holistic community care, which covers a woman's physical and mental health and that of her partner. More research is needed to establish what this should consist of and how it should be delivered.

Background

Stillbirth (which refers to a baby not born alive after 24 completed weeks of pregnancy) and second trimester miscarriage (a miscarriage occurring between 12 weeks and 24 weeks of pregnancy), are devastating events for parents. In 2021 the rate of stillbirth in the UK was 4.1 per 1000 live births (1). The annual rates of second trimester pregnancy loss are not routinely collected and reported in the UK, but the rate of second trimester loss is 1-2% of all pregnancies (5), which would equate to approximately 20,000 a year in the UK based on the 2020 conception rate (6). Women from black, Asian and other ethnic minority groups are at increased risk of stillbirth and twice as likely to experience a stillbirth than white women in the UK (2); they also have an increased risk of miscarriage (3). There is also an increased risk for women living in the most economically deprived areas. The rate of stillbirth amongst the socioeconomically most deprived in England is 5.6/1000 live births compared to 2.7/1000 for the least deprived (1). There is significant geographical variation in rates of stillbirth across the UK, with the West Midlands having some of the highest rates.

The National Bereavement Care Pathway (7) for stillbirth and pregnancy loss, launched in 2017, promotes best practice for care after a loss and during the next pregnancy. However, there is a lack of evidence for effective interventions in the period between pregnancies to improve subsequent pregnancy outcomes and women's long-term physical and mental health.

Current RCOG guidelines recommend an appointment in secondary care with a consultant Obstetrician in the weeks after a stillbirth or second trimester miscarriage to review possible causes and arrange relevant investigations. Medical conditions, and other factors such as smoking, which increase the risk of stillbirth and miscarriage, may be identified in pregnancy and considered with the woman at an appointment with a consultant in secondary care following a pregnancy loss. The longer-term care of their physical and mental health, however, takes place in primary care, and at present guidance is lacking about how this should best be delivered. There is currently little evidence, and a research gap, to determine what interventions should be implemented in primary care to improve maternal health and reduce future rates of stillbirth and second trimester miscarriage.

Methods

This was an initial knowledge gathering study looking to build on four objectives for future larger scale research priorities. For this purpose, objectives were to create infrastructure and capacity by way of linking with primary care networks in the West Midlands region. Additionally, to build links with national groups and identify gaps in current care.

Ethics approval was granted by the University of Warwick Biomedical and Scientific Research Ethics Committee. Ref no. BSREC 89/21-22

To achieve these objectives, we had three main project strands.

1. National stakeholder group

We formed a national stakeholder group consisting of 27 participants including GPs, midwives, health visitors, pregnancy loss charity representatives, professionals working in mental health and those with lived experience of pregnancy loss. We held two online stakeholder meetings, the first in September 2022 and the second in January 2023.

2. Patient and Public Involvement (PPI)

We asked members of the public who have had personal experience of stillbirth and second trimester miscarriage to participate in workshops to discuss what they feel could be improved, what care they would like to see developed and what they think future research should look like.

Knowing that stillbirth and second trimester miscarriage is more common amongst women from black and Asian ethnic backgrounds and women who live in more deprived areas of the UK, we wanted to make sure that these women were represented. To do this, we worked in partnership with three not for profit organisations 'FWT-MAMTA', 'South Asian Health Foundation' and 'Egality' to recruit members of the public to participate in the workshops.

We established a PPI network of 13 women with lived experience of stillbirth or second trimester miscarriage (n=13). Six of the participants identified as white British, two as black British/Caribbean, two of Arabic ethnicity and three identified as South Asian. They all had either experienced a stillbirth or second trimester miscarriage ranging from within the last year to 25 years previously. Each PPI member attended two groups, one between October and November 2022, and the second between January and February 2023.

3. GP trainee survey

We also wanted to consider the experiences of GPs of the community-based care they provide to patients who have experienced a stillbirth or second trimester miscarriage; what is currently happening, what they think would be useful in the future and what could be done better. To gather this information, we asked GP specialty trainees to conduct a survey of their colleagues in the practice they worked in.Recruitment was through West Midlands GP training schemes and in total 15 GP trainees conducted a survey of current practice care provision following a second trimester miscarriage or stillbirth.

We hosted a webinar event detailing how to conduct the survey and take informed consent and follow good clinical practice. The trainees worked across diverse practices from different socioeconomic regions. Using the National General Practice Profiles - OHID (phe.org.uk) 9 of the 15 practices had a deprivation score of five or less, meaning they were in more socioeconomically deprived areas.

Study themes

First round of meetings

The first stakeholder group and PPI groups were held in the later part of 2022. For this part of the project, we were interested in finding out about what existing care consists of.

First stakeholder group

In the first stakeholder group meeting, we asked for the group members thoughts on the following:

- Identification of gaps in care once women are discharged from hospital care.
- Ideas about how these gaps can be broached.
- Recruitment of black and South Asian women.

The following is a summary of themes that came from this meeting.

Post discharge care

Following discharge from secondary care, there may be a delay in discharge information being sent to the GP or it may not reach the GP at all. Information that is shared, may be incomplete and GPs and community midwives may be unaware that a pregnancy loss has occurred. The level of care that is offered in the community is also typically less intensive than that offered in a hospital setting. There is often little or no follow-up plan and women and their families are often left feeling unsupported. Healthcare staff described the way women on leaving the hospital-based maternity system 'fall off a cliff' as there is little support following this.

Offering a 6-8-week check

The stakeholder group discussed the process of the 6-8-week postnatal check notification. It is the discharge of the baby that triggers this in primary care, rather than discharge of the mother so in the case of a stillbirth, the trigger for notification may not occur. This means that often women are not offered a routine 6-8-week postnatal check.

Continuity of care

Even in situations where a discharge summary has been received in a timely fashion and/or a follow up appointment has been offered in primary care, healthcare staff may not have been through the notes prior to appointments. This may be more of a problem in larger practices where women and their partners are unable to have appointments with a 'usual' doctor.

Care pathways

There is substantial variability and no uniform approach between GP practices. The 'normal' pathway following birth is a 6-8-week postnatal check but in stillbirth and second trimester miscarriage, there is no standard care provided. Some GPs may offer routine follow up, whilst others offer opportunistic care and others offer no care at all. Stakeholders felt there should be standardised follow up in place as there is following a livebirth. It was also highlighted that the most vulnerable women are most at risk of receiving no care at all, due to multiple adversity, an increased risk of moving frequently or language barriers.

Women and partners can be referred to perinatal mental health services but there is a lack of consistency in referral criteria, service provision, referral pathways and eligibility to access care across the country.

Healthcare providers are often not aware of the services available for women to access in their area and this means that there is a lack of signposting to additional support.
There are bereavement midwives in some locations, but these are not present in all hospitals. Bereavement midwives' remit varies between locations, with some of them able to carry on providing care for a prolonged period of time after discharge into the community whilst others only provide support in the initial period after a loss.

First round of PPI groups

We asked the PPIE groups the following questions.
1) When you think about the care you received in the community (outside of the hospital) following your stillbirth or pregnancy loss, what do you think was done well?
2) When you think about the care you received in the community following your stillbirth or pregnancy loss, what do you think could have been better?
3) Did you receive any care in the community (out of hospital) to help you plan for a future pregnancy or improve your overall physical or mental health?
We found themes arising from the first PPI group round to be very similar to those of the stakeholder group.

Continuity of care

Issues with a lack of continuity of care were raised for example where notes may not have been read prior to appointments. One woman had to explain her pregnancy loss history from the start to multiple healthcare staff and found the process of having to go over her medical history repeatedly a difficult experience. We heard from more than one PPI member about how their GP/midwife was not aware they had had a stillbirth. Women found repeating their stories again and again both exhausting and distressing. Many felt there was a culture amongst healthcare professionals of not reading notes and informing themselves prior to contact with a patient.

Communication

Women and partners felt there was a lack of sensitivity in the language used by healthcare staff. There was also a sense of awkwardness in staff not knowing how to act or what to say.

For example, the partner of one woman was asked by the midwife – 'are you the father of the dead baby'. Another woman felt that the GP didn't know how to act with her and didn't follow up.

One woman felt that staff should have acknowledged her baby even if it made them uncomfortable. Simple questions like asking the baby's name were omitted by staff for fear of saying the wrong thing. They felt that just saying something rather than nothing was important.

Women also found they were concerned about upsetting others and making other people feel uncomfortable; "You don't know who to talk to, or what to say, without making someone else feel bad".

Post discharge care

Where there was a bereavement midwife, women often reported positive experiences. As well as being looked after while in hospital, signposting advice was also given. One woman spoke of how the bereavement midwife from the first pregnancy was there for the second and helped get her an early scan. She also rang her to chat and made it clear she was there for her when needed. Another woman spoke about how from a few hours after the death of her son, the bereavement midwife was consistently with her for the next few days, even changing shifts so she would be in. The midwife enabled her to understand the process of what was going to happen in terms of a post-mortem and burial.

However, women often found they were left to find their own support. They found the first two weeks after discharge were 'adrenaline fuelled' and so something is needed after this when other people start to forget. Very few women were offered follow up with their GP after discharge or had contact with a community midwife. For those that did the experience was often not a positive one. For example, one woman received a call from the midwife asking if she wanted to talk but didn't want to at the time. It was too soon as she had only just left hospital. She felt that one call was not enough and would have liked her to say she would call back again in a weeks' time. Whilst another spoke of how at a 6-week check at the practice the "GP asked where the baby was".

Women and partners wanted a more holistic approach where both their physical and mental health was addressed. One woman spoke of how only physical health help was offered from her GP even though they were aware of her anxiety and previous miscarriages. Another woman said that during the pregnancy following her stillbirth, she was offered extra scans, but no emotional support – "just dished out antidepressants".

Signposting and third sector support

Once discharged from maternity care participants felt that signposting to available services was often inadequate. For example, one woman spoke about leaving hospital with a box rather than a baby. The box contained signposting leaflets, but she did not read any of this info. She thought that this should be followed up after a couple of weeks of being back at

home when questions such as "what do I do now?" arise.

Participants often had to find these services for themselves, but once they did access services they found they were invaluable. Often these services were provided by faith, community and third-sector groups, rather than the NHS. One of the PPI members spoke about how finding some peer support through a charity was a lifeline. Peer support can help address and normalise common concerns such as fears about bonding with a subsequent new-born baby following a stillbirth. This sort of group support is good for validation, confidentiality, and worries about being judged by those who may not understand.

Second round of meetings

The second stakeholder group and PPI listening groups were held in January and February of 2023. The general focus was on what care should be provided and how and where this could be delivered.

Second stakeholder group

We asked the stakeholder group the following questions.

1) What examples of good practice and interventions have you seen that could work in this context?

2) Your own ideas of an intervention

- What it looks like
- Who is it for?
- When is it used?
- How is it accessed?
- When would it be accessed?
- Does it address mental health/physical health or both?

Key themes in this workshop were discussions on where care should be provided. Having family/women's health hubs providing holistic care or within a GP surgery were both options that were discussed.

Where care should lie

Family/women's health hubs were suggested for holistic care – but sensitivity needed for appointment/group timings e.g., not mixing new parents and parents with loss.

Intervention

When it came to discussing suitable interventions, it was felt that there was a need for further evidence-based co-design work, on a larger scale, to develop a pathway or intervention to improve care for women and p in this population. Without this, it was unclear what form this pathway or intervention should take. However, there was consensus that where possible care should be flexible and tailored to the needs of the individual.

Second PPI group

We asked the PPIE group the following questions:

Which parts of the care journey once discharged from hospital could be made better.

- Where would you access it?
- Who would you like to provide it?
- When would you first want to access it?
- How often and for how long?
- When would you want to be offered it?
- What things would you like covered (mental / physical health)?

In this round we spoke to 11 women, two on the telephone, two in person, and the remainder via online video. A summary of themes generated are below.

Continuity of care

Women spoke of wanting to see improved continuity of care from secondary to primary care. This should include healthcare professionals sharing knowledge about the patient, and reading notes to ensure that there is no need for a woman to have to tell her story repeatedly.

Individual preference

It was evident that there is no 'one size fits all' care model. Women spoke of care in the community needing to be holistic and address both mental and physical wellbeing. Opinions on the most appropriate timing for offering and providing care was variable, however support offered needs to be open-ended, and offered more than once even if the first offer is not taken up.

Preferences for the person most appropriate to deliver support was varied; for example, a bereavement midwife in the hospital, or the GP were suggested options. There was consensus that care should involve women and their families, and should include signposting to additional services where available.

GP trainee survey themes

Audit results and GP awareness of pregnancy loss occurring

Trainees ran an EMIS search to identify how many stillbirths had occurred in each practice in the past 5 years; 11 of the 15 practices had coded that at least one patient had a stillbirth in the previous 5 years. They were unable to run a search for second trimester miscarriage, as there is currently no GP notes code for second trimester miscarriage.

GPs were also asked if they were aware of any stillbirths or second trimester miscarriages that had occurred in the past 5 years. At some of the practices there was a mismatch etween the results of the search and the information given by GPs, with some GPs being unaware that losses had occurred.

Follow-up care

Follow up care from practice is variable

- The care received from a GP practice is extremely variable depending on which practice is providing care; ranging from nothing, to a standard post-natal check, to proactively sending a letter which offers support and signposting.
- Variability was also described within practices, with some GPs explaining that the level of care provided at their practice was dependent on which GP a discharge summary was seen by or which GP a patient consulted.

Care provision

- There was a lot of disagreement between who should provide the follow up care, at what point care should be offered, and where this care should happen.
- Some practices said that continuity could be achieved by having the bereavement midwife provide follow up from hospital and into the community. However, it was also acknowledged that GPs should offer at least one appointment in order to address any medical needs a patient may have, akin to the 6-8 week check currently offered after a live birth.

Adequacy of discharge summaries – handover of care from hospital

There was variability in the quality of handover and discharge summaries that GPs reported receiving. In general, GPs felt that the quality of discharge summaries and the timeliness and accuracy of handover from hospital was inadequate. Discharge summaries frequently contained minimal detail of events that occurred during a hospital admission, there was often a delay in summaries being received by the practice and they often contained little or no information about follow up requirements or plans.

Future care

There was consensus across the GPs interviewed that future care should be holistic, address and correct underlying health conditions, and cover mental and physical health. They felt that addressing medical co-morbidities, providing mental health support and follow up support as part of a multi-disciplinary team were all important. Signposting to additional services was also mentioned

There was a suggestion that information should be coded in both parent's notes and information on future care needs could be electronically highlighted if that is what a patient wanted.

Some GPs felt that an equivalent of a 6-8-week check would be an appropriate model, whilst others thought there should be provision of more than one appointment and involvement of the wider multi-disciplinary team, not just a GP.

Pre-conception care and future pregnancy planning

Eight of the fifteen GPs interviewed reported that their practice did not routinely provide pre-conceptual counselling. Of the GPs who did offer this, provision of care was again variable ranging from provision of advice on taking folic acid, through to offer of a full

pre-conception counselling appointment.

Additional suggestions for improving care

There were a variety of things GPs felt would help to improve care, these included:

- GP access to pre-pregnancy advice in a timely manner from secondary care.
- Access for patients to specialist care for pre-pregnancy management of existing co-morbidities
- Provision of support via social prescribers to help with weight management, smoking cessation and lifestyle advice
- Improved access to Mental health support in a timely manner
- A specific early referral pathway into secondary care for future pregnancies
- Better links with midwifery services
- Provision of continuity of care to prevent patient having to repeatedly re-tell their stories.
- Care for partners

Training needs or resources that would be useful to have.

- A few GPs felt that additional training may be useful
- Most GPs felt that additional training was not needed, especially given the current pressures on GPs' time, but they wanted access to resources when required.
- Access to information on local support services and additional resources for patients collated at a single point of access e.g. GP Gateway, which would allow GPs to signpost to additional support.
- One mentioned the possibility of access to a CPD module that GPs could opt in to

Next steps

The information from the three strands of the project will be used to design future research and decide on research priorities for care in the community for parents who have experienced stillbirth and second trimester miscarriage. The information gathered has already been used to design a research project with the aim to develop an intervention to improve the care that parents who have experienced stillbirth and second trimester miscarriage receive in the community.

Study outputs

1) NIHR Doctoral Fellowship application submitted January 2023
2) SW SAPC oral conference presentation 16th March 2023
3) Journal article discussing and reflecting on the project's PPIE process in progress
4) Lay summary infographic

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COMMUNITY CARE AFTER STILLBIRTH AND SECOND TRIMESTER MISCARRIAGE

RESEARCHERS AT THE UNIVERSITY OF WARWICK ASKED WOMEN IN THE WEST MIDLANDS WHAT HAPPENS WHEN THEY COME HOME FROM HOSPITAL AFTER A STILLBIRTH OR SECOND TRIMESTER MISCARRIAGE

THEY SAID....

they often had to find their own help

charities, faith groups and community groups provide a lot of support

"telling the story is exhausting"

the words used by doctors and midwives were often insensitive or awkward

there was no continuity

"you don't know who to talk to, or what to say, without making someone else feel bad"

it's difficult to remember and absorb verbal information

care needs to be flexible and individual

there was no NHS care for partners or families

community care is a postcode lottery

returning to hospital doesn't feel safe

"the GP asked where the baby was"

there was often little or no support or follow up from doctors and midwives in the community

care needs to be offered more than once

the hospital didn't communicate well with the GP

there was no care for physical health

"peer support can... normalise common concerns"

antenatal appointments need to be cancelled

need to be told what support is available

"felt dropped"

WHAT NEXT....

RESEARCH WORKING WITH WOMEN AND PARTNERS TO IMPROVE THE CARE THEY RECEIVE IN THE COMMUNITY

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