

Description

Miscarriage Support Tool: Equity of Care

Rebecca Sweetman – Senior Digital Health Project Manager, University Hospital Coventry & Warwickshire

Professor Siobhan Quenby – Professor of Obstetrics, University of Warwick and Consultant Obstetrician, University Hospital Coventry & Warwickshire

Social @s-quenby

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Summary

Large disparities in miscarriage care are experienced by women belonging to ethnic minorities and those living in deprived areas of the UK, with Black women having a more than 40% increased risk of miscarriage than White women. Too many women, especially those from disadvantaged backgrounds, do not get enough information, support or care following a miscarriage. The Miscarriage Support Tool aims to tackle the unjust inequalities facing these women through personalised support and advice, to empower them to advocate for their own care. We aim to give these groups equity in access to care, otherwise unavailable, and reduce their risk of miscarriage.



Introduction

Miscarriage is generally defined as the loss of a pregnancy before 23 weeks gestation and is the most common pregnancy complication. One in five women will experience a miscarriage,[1] one in 20 will experience two miscarriages, one in 100 will experience three or more miscarriages.[2] Currently in the UK, pathways of miscarriage care can vary greatly depending on locally available services and their referral criteria. It also depends on those in primary care settings having up-to-date knowledge and information on the tests and treatments recommended by National Institute for Health and Care Excellence (NICE) guidelines.

A landmark series of research papers,[1,3,4] found large disparities in miscarriage outcomes and care experienced by women belonging to ethnic minorities and those living in deprived areas of the UK, with Black women 40% more likely to miscarry than White women.[1] Too many women, especially those from disadvantaged backgrounds, do not get enough information, support or care following a miscarriage in the UK today.[5]

Research recommends a graded model of care where childbearing women and people are seen by a healthcare professional after their first miscarriage,[3] not having to wait until they have three consecutive miscarriages which is commonly the case at present. Online tools have also been recommended to give families access to preconceptual advice, online resources, peer-to-peer support groups and health and lifestyle advice.

Practice challenge 1

Do you feel confident recommending the latest tests and treatments for those who have experienced one or more miscarriages? Are you aware of local referral criteria and how this may differ from services in other regions?

Miscarriage and mental health

The consequences of miscarriage can be both physical and psychological. While the physical trauma of miscarriage is perhaps more obvious, adverse psychological effects have been displayed in women and birthing people who experience miscarriage such as depression, increased anxiety, sleep disorders and post- traumatic stress disorder (PTSD).[1,6] Those who have experienced miscarriage may want to understand why this has happened, if there was anything that could have been done to prevent it and if it will happen again. Disparity in miscarriage care and common misconceptions about miscarriage do little to alleviate this problem, with women and birthing people who have experienced miscarriage often feeling as though they have done something wrong, as well as feeling ashamed and alone.[7]

Psychological effects of miscarriage can often go unnoticed by healthcare professionals, family and friends. Those who

feel guilty and ashamed may conceal their loss. This is especially true given the unspoken rule that pregnancies should be announced after approximately 12 weeks, when the greatest risk of miscarriage has passed. If no one has been told about the pregnancy, this limits those who can support and care if a miscarriage does sadly occur. Given this concealment, the psychological effects of miscarriage are often underestimated.

Recent research has also shown how different groups of women and birthing people may be more at risk of adverse mental health outcomes after early pregnancy loss. It has been reported that the risk of major depression in Black women who experience early pregnancy loss is twice as high compared to non-Black women.[8] Women and birthing people with higher socio-demographic deprivation have also been reported as being particularly vulnerable to mental health problems after miscarriage, with the level of care they receive being an important factor in protecting against this.[9] Therefore, mental health support is a vital component in miscarriage care but often overlooked.

Practice challenge 2

Can you reflect on a time when a woman or birthing person in your care needed mental health support – is this something you were able to provide, or did you know what services to refer to or recommend?

Planning for a next pregnancy

Pre-conceptual optimisation of women and birthing people's health is important to improve, not only to reduce miscarriage risk but also to reduce risk of other pregnancy complications. This means our philosophy is that a miscarriage is an opportunity to improve health in terms of lifestyle, diet and optimising medical co-morbidities. Lifestyle and health factors are changeable and have the potential to decrease the risk of further miscarriage. However, studies have shown less than half of those planning a pregnancy seek health advice.[10]

Practice challenge 3

In your workplace do you feel equipped to advise women and birthing people of health and lifestyle changes? Consider what information or training may be beneficial to discuss this.

Unjust inequalities

In 2022, The Miscarriage Support Tool was created to tackle the unjust inequalities facing disadvantaged and underrepresented women who experience a miscarriage across England. By supporting them with personalised advice and empowering them to advocate for their own care, we aimed to give these groups equity in access to care otherwise unavailable and reduce their risk of miscarriage.

This project aligned with the Lancet 2021 Miscarriage Matters series,[1] which recommends specific and personalised care pathways for women who have an increased chance of miscarriage. We wanted Black and Black mixed-heritage women and women from low socio-demographic groups to:

- Feel empowered to advocate for their own care.
- Feel more knowledgeable and confident about their health and the healthcare they are entitled to.
- Feel supported and reassured by personalised advice and help.
- Be more likely to make positive lifestyle changes.
- Access pathways to better mental health if needed.

Aims of this project

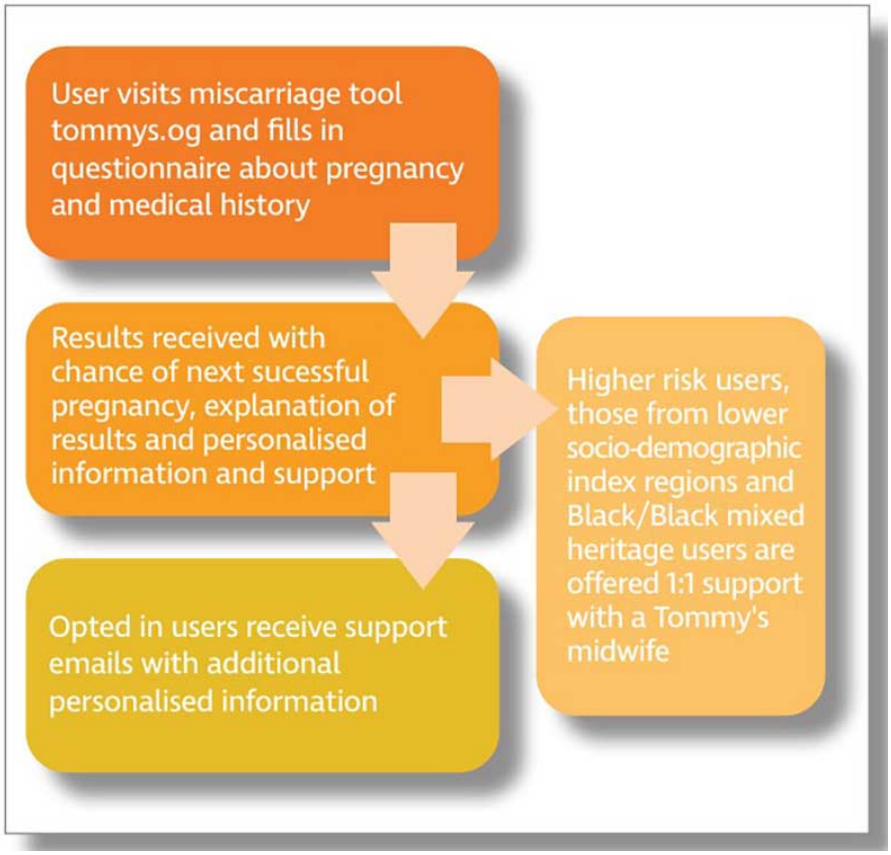
Our aims for our Miscarriage Support Tool were to:

- Reach and support women and birthing people with a higher risk of experiencing another miscarriage, specifically Black and Black mixed-heritage women and women from low socio-demographic groups.
- Provide useful, personalised information to parents after a miscarriage to inform future care.

For those who have experienced miscarriage, anxiety around trying again can be an obstacle to a successful pregnancy. We hoped that with this tool, users would be encouraged to try to conceive again and feel informed and supported as they consider a next pregnancy.

To address these concerns, the Miscarriage Support Tool (MST) was created. The MST is an online tool that uses an algorithm developed by the University of Warwick as part of research in conjunction with the National Centre for Miscarriage Research. The tool has been developed for people who have had one or more miscarriages (this includes late, early, molar, chemical and missed/silent miscarriages) and are considering a next pregnancy. The tool uses the data collected as the user goes through an online questionnaire to give a percentage chance of successful next pregnancy as well as personalised advice on support and available treatments.

Figure 1: Miscarriage Support Tool



The information delivered through the tool incorporates updated NICE guidelines for miscarriage care, for example informing women about the appropriate use of progesterone. This enables users to have tailored information on how their clinicians should help them next, based on the latest evidence- based recommendations.

Support service

Users who receive a higher-risk result on the tool are offered a one-to-one call with a midwife. Black and Black-mixed heritage women and women from lower socio-demographic groups who use the tool are also offered the support service, regardless of their result. This specialist support service aims to address inequity and provide extra support to Black and Black-mixed heritage women and women from lower socio-demographic groups, who are at higher risk of miscarriage. Speaking to a trained midwife lets women and birthing people know what care and treatment they are entitled to as well as supporting them to access these services.

Topics discussed on the calls include antenatal care, referrals, tests and treatments, mental health support, baby-loss support, labour and birth, feeding and pre-conception advice. All of the users who have accessed this service have said that they would recommend it and over half (55 per cent) of users said they would make a lifestyle change based on the information they were given by the midwife.

Central themes that have emerged through these one-to-one support calls include women and birthing people from Black and Black-mixed heritage backgrounds not feeling safe. They are aware of the recent reports indicating they have a higher chance of miscarriage than non-Black women, and they understandably find this frightening. From speaking to the Tommy's midwives, they value this being acknowledged and understood and appreciate the honest and open conversation on how they can navigate this.

Miscarriage support tool impact so far

The MST went live in November 2022. In 14 months, the MST has been used over 110,000 times by over 83,000 individual users. Over 50,000 users have gone through to fully complete the tool and receive their results – over 1,000 of these have been from those considered to be at higher risk of another miscarriage. Nearly 23,000 users have signed up to receive further support emails detailing additional personalised recommendations and advice and over 400 childbearing women and people have used the support service offered to them and have received one-to-one video calls with Tommy's in-house team of midwives. The Social Deprivation Index (SDI) is used to measure deprivation and is a score that indicates the extent of social depravity in a small community (currently the MST is only linked to the English indices of deprivation, however we are currently working to include data to measure deprivation information for Northern Ireland, Scotland and Wales postcodes too). Small areas of similar population size are ranked from one to 32,844 on a number of set factors. All postcodes in England are then given a number one to five. Those ranked in the lowest 20% (most deprived) are given a score of one. Those ranked in the highest 20% (least deprived) are given a score of five.

Just over 30% of tool completions have been from the two most deprived groups (SDI one and two). This equates to over 13,000 individuals from the most deprived areas in England that have accessed the MST online and received personal information and support about miscarriage care. Over 5,000 of these users have also signed up to receive support emails, with further personalised information and support. Nearly 300 individuals from SDI one and two have also been offered the support service call with a Tommy's midwife.

Nearly 1,800 women and birthing people from Black and Black-mixed heritage backgrounds have used and completed our tool, 87 of which are suggested to be at high risk of another miscarriage. Over 900 of these users have also signed up to the support emails, to receive further personalised support and advice.

The MST data has enormous research potential. As we gather more data within the tool we hope to improve and refine the algorithm to take more factors into account that have an impact on the chance of a next successful pregnancy. We are currently collaborating with research teams to examine the data already gathered to discover patterns of interest that can yield information about the causes of miscarriage.

Our learning does not stop now that the MST is live. The online surveys we have built into the user platform have proven to be immensely valuable in gathering ongoing feedback to inform our content improvements.

What support is available?

Many couples find embarking on another pregnancy after miscarriage daunting because of the trauma associated with miscarriage. Recurrent miscarriage clinics and many NHS early pregnancy units will provide viability scanning in pregnancies subsequent to miscarriage in order to help couples manage their anxiety.

If couples have experienced three or more miscarriages there are tests and investigations their GP should offer, such as a full blood count (FBC) or a thyroid function test (TFT) as well as a referral to a recurrent miscarriage clinic.

NICE also now recommends the use of the hormone progesterone for those with early pregnancy bleeding to help prevent early miscarriage and give those with a history of miscarriage the best chance of a successful pregnancy.

Many couples will feel worried and anxious after having a previous miscarriage. No one can take away these feelings completely but there are lots of ways to manage anxiety after pregnancy loss. Tommy's website has information on

feelings and emotions after miscarriage. It may also be helpful to join a peer-to-peer support group such as the Tommy's Baby Loss Support Group on Facebook, as many women and birthing people often find talking with those with similar experiences helpful.

Conclusion

The Miscarriage Support Tool has made some progress in addressing the inequalities in healthcare experienced by couples who miscarry. No one should feel they are not being supported after experiencing a miscarriage, and no one should feel that the support they receive is inadequate. Everyone in the UK should have access to the same information and advice and all women and birthing people should be able to find out exactly what care they are entitled to after miscarriage. Data collected from the MST is also an incredible asset which will be used to develop the tool further and inform future research. **TPM**

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