Recurrent Miscarriage in Northern Ireland
Position Statement as at 31 September 2016

Introduction

Since 2014, the Patient and Client Council (PCC) has been supporting women in Northern Ireland who have suffered miscarriage to ensure their voices are heard by decision makers. Of particular concern is the care provided to women and their partners who have experienced recurrent miscarriage. This paper aims to provide an overview of the current provision of recurrent miscarriage services in Northern Ireland.

Definition and incidence

Miscarriage is the spontaneous ending of a pregnancy before 24 weeks gestation and occurs in between 20% and 25% of pregnancies.[1] By far the majority of miscarriages happen in the first trimester, ie, before 14 weeks of pregnancy. [2]

Most women who miscarry do so once or twice, and it is not uncommon to have a mix of miscarriages and live births.

Recurrent miscarriage is usually defined as three or more consecutive miscarriages.[3-5] It is much less common, affecting about one in every 100 couples trying to conceive.

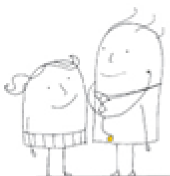
In the UK, data from 2012 showed that more than 50,000 hospital admissions each year are due to miscarriage.[6] Hospital episode statistics for Northern Ireland show 2,166 initial admissions for miscarriage recorded across all five HSC Trusts in 2014/15 (excluding readmissions in the same pregnancy).[7]

In both instances, these numbers are an underestimate of the actual incidence of miscarriage as many such losses will not result in hospital treatment or admission and will, therefore, go unrecorded.

There are no figures available for those women who have suffered recurrent miscarriage, although the PCC has requested the number of women, in the past financial year, who have presented for treatment within each HSC Trust, where they had a record of three or more miscarriages.

Impact

For most women and their partners, miscarriage represents the loss of a baby, and the hopes and plans invested in that future child. Feelings of loss and grief are



common, along with guilt (*Was it something I did?)* and anxiety (*What if this keeps happening?*).[5,8]

For those with recurrent miscarriage the cycle of pregnancy and loss is frequently both physically and emotionally draining, and can place a great strain on even the strongest of relationships.[8] It can be difficult, if not impossible, to maintain hope for the next pregnancy, and women and their partners understandably seek both explanations for their losses and treatment to prevent recurrence.

The case for specialist services

Appropriate care, investigations and evidence-based treatment are most likely to be found in a specialist recurrent miscarriage facility where there are appropriate skills, knowledge and expertise, as well as links to, if not involvement in, clinical research.[9-11]

The Royal College of Obstetricians and Gynaecologists (RCOG) notes: 'Ideally, a couple should be seen together at a dedicated recurrent miscarriage clinic and given accurate information to facilitate decision making about future pregnancies.' [4]

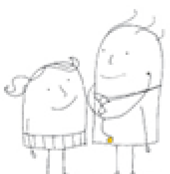
> There is no specialist, dedicated recurrent miscarriage service in Northern Ireland.
>
> Referral for investigations depends on the views and practices of individual clinicians, while access to specialist, evidence-based investigations and expertise is very limited.
>
> Currently, women have to qualify for a referral to a specialist centre in England. Figures obtained from the Health and Social Care Board (HSCB) show that only six women in Northern Ireland qualified for such referrals in 2014/15. Others will have to pay for private treatment, as well as the costs of travel and perhaps accommodation.

Guidelines

The RCOG provides clear guidelines for the *investigation*, *treatment* and *care* of couples with recurrent miscarriage.[4]

Investigations

The RCOG recommends that investigations into the possible causes of miscarriage should be routinely offered to women who have had three (or more) consecutive first trimester miscarriages. This is because first trimester miscarriages especially are often due to chance rather than an underlying disorder.[5]



They recommend offering investigations to women with *one or more second trimester* miscarriage(s) as these losses are much less common and a cause is more likely to be identified.

Some doctors will offer investigations at an earlier stage to women who are in their late 30s to 40s (because the risk increases with maternal age) if it has taken a long time for them to conceive (because this is also a factor in miscarriage risk) and/or if there is a medical history suggestive of a likely cause.[4,5]

Diagnosis and Treatment

After specialist recurrent miscarriage investigations, somewhat less than half the couples tested will be found to have a specific problem, or problems, likely to have caused their losses. The most common of these – the clotting disorder antiphospholipid syndrome (APS) – has an agreed treatment pathway that greatly reduces the risk of a subsequent miscarriage. Other disorders, such as a parental chromosome abnormality, have less defined treatment pathways, but genetic counselling can offer advice for the future.

Couples with unexplained recurrent miscarriage are particularly vulnerable to offers of tests and treatments that are neither evidence-based nor part of a recognised clinical trial. Some of these treatments may be unsafe.[12]

Supportive care

The RCOG recognises that couples need information about possible outcomes of investigations, including the diagnosis of unexplained recurrent miscarriage. They may need specialist support regarding a particular diagnosis and treatment in considering whether to try again or during the next pregnancy, if there is one.

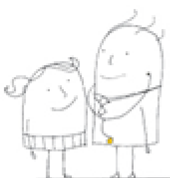
There is some evidence that supportive care alone can improve outcomes for women with unexplained recurrent miscarriage.[4,13]

Psychological support and counselling

Some women and couples will need professional counselling, be it from a bereavement nurse or midwife, or a trained counsellor. Many will appreciate the opportunity to talk through the psychological impact of repeated loss, as well as their options and concerns for the future.

Bereavement counselling services available in Northern Ireland

Specialist counselling for miscarriage and recurrent miscarriage is extremely limited and, in some parts of Northern Ireland, non-existent.



In November 2014, the HSCB and Northern Ireland Practice and Education Council (NIPEC) published the *Regional Bereavement Guidance on evidence-based, holistic care of parents and their families after the experience of miscarriage, stillbirth or neonatal death*. This was updated in December 2015.[14]

While acknowledging that 'all midwives and medical staff have responsibility in providing compassionate care and support', the guidance also highlighted the importance of having a dedicated bereavement midwife to provide 'consistent advisory support to professionals and vital counselling services to women and their families'.[14] The guidance also recommended that the services of an accredited counsellor should be offered to a small number of women.

Despite this, specialist counselling for miscarriage and recurrent miscarriage is extremely limited and, in some parts of Northern Ireland, non-existent. As part of our research, the PCC wrote to all HSC Trusts to find out what, if any, counselling or psychological support services were available to women who had suffered a miscarriage.

The Belfast HSC Trust is currently running a pilot scheme to offer specialist counselling to women/couples who experience a miscarriage. Flyers were distributed to promote the service, which is provided at the Regional Fertility Centre within the Grove Wellbeing Centre on the Shore Road.

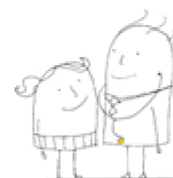
Southern HSC Trust, Western HSC Trust and Northern HSC Trust had no dedicated counselling/psychological support service for women who had experienced recurrent miscarriage. Northern HSC Trust said it provided written information on grief and bereavement, as well as signposting to other agencies, prior to discharge from hospital.

Western HSC Trust said it had recently brought this gap in service provision to the attention of the Local Commissioning Group, who felt that it required a regional, rather than a local, solution. Currently, the Well Woman Centre in Derry/Londonderry, which is part-funded by Western HSC Trust, takes referrals for counselling. The South Eastern HSC Trust is the only Trust with a trained bereavement midwife who provides counselling.

The Patient and Client Council and recurrent miscarriage

In June 2014, the PCC met with a group of women to listen to their stories and understand their experience of miscarriage.

The women told us that what was needed in Northern Ireland was a consultant who specialised in recurrent miscarriage and would be aware of the latest developments in tests and treatments.



They also wanted a dedicated clinic where women with recurrent miscarriage could undergo a range of specialist tests, as well as quick and easy access to laboratories for test results. They pointed out that one of the problems with current blood testing in Northern Ireland is that they were not always done under optimal conditions, which can affect the results. Having a dedicated laboratory would mean that more rigorous and uniform standards could be applied when conducting tests.

The women told us that, while most HSC Trusts offered a thrombophilia screen to test for an inherited blood-clotting disorder and a scan, the service varied from Trust to Trust. Some HSC Trusts used to offer karyotyping (chromosome analysis of fetus and/or parents), but this is now increasingly difficult to obtain through HSC.

The women also told us:

- Referral to a specialist recurrent miscarriage clinic at St Mary's Hospital in London can take up to nine months – even for a blood test. This was after a woman had experienced a minimum of three miscarriages, and many were conscious of the 'biological clock ticking'.
- Patients reported that they have never been offered a referral to a specialist clinic in the UK. Others commented that when they enquired about it they were told it would not make a difference. A couple of women at the meeting had attended St Mary's Hospital and, with treatment, had successful pregnancies. Success rates from St Mary's have been requested by the PCC.
- Patients who have been referred have reported that other medical conditions were detected at a specialist clinic that were not diagnosed in Northern Ireland.
- A number of tests are offered in specialist clinics that are not available in Northern Ireland. Other tests, such as APS, can be tested in a dedicated laboratory within one hour of the sample being taken, providing a more reliable result rather than a false position. A full list of tests performed at St Mary's Hospital has been requested by the PCC.
- Women in the PCC group referred to Complicated Grief Disorder (CGD), which standard counselling cannot address.[15]

They felt that, if a woman miscarried again after undergoing standard HSC investigations and treatment, there should be a willingness on the part of HSC Trusts to refer this relatively small number of women to recurrent miscarriage specialists in England. This would also provide opportunities to take part in clinical research and small-scale or large-scale trials. It is notable that no hospitals in Northern Ireland are taking part in multi-centre miscarriage trials due to the lack of a dedicated resource.

While some women said it can be upsetting to have to travel to another country for advice and/or treatment at a time when they felt vulnerable, it was equally distressing for them to have to compete for a referral based on the number of miscarriages they have had.

Two months later, in August 2014, the PCC established the Pregnancy Loss Steering Group (PLSG). Meetings were held every six to eight weeks, which proved productive and produced some initial results. These included:

- The PLSG was consulted over the development of a bereavement pathway that is currently being implemented by the five HSC Trusts.
- The PLSG helped write and design a new regional early pregnancy loss information leaflet for service-users, which will be issued to all HSC trusts in the summer of 2016.
- The PLSG played a key role in rewording a regional consent form regarding a histopathology (examination of a biopsy or surgical specimen by a pathologist) test. The women used this opportunity to address inconsistencies surrounding how the test was conducted and the results relayed to patients.
- A PCC representative sat on a HSC Pathology Network group to share views from the PLSG. These were used to develop a new pathway, ensuring consistency across all HSC trusts with regards to histopathology tests.

The PCC and PLSG worked with the UK-based Miscarriage Association on early pregnancy loss literature to highlight that the charity's services were available in Northern Ireland.

One thousand A3 posters and 10,000 booklets were printed and distributed to GP surgeries, HSC Trusts, libraries, community centres and Women's Aid offices.

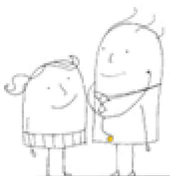
On 20 October 2015, the 'One in Four – Putting Miscarriage on the Agenda' event was held for HSC Trust staff and service users to share good practice, highlight any gaps in service provision and improve support mechanisms in Northern Ireland – an event that attracted widespread media coverage.

It included presentations from Ruth Bender Atik, National Director of the Miscarriage Association, and Dr Anne Kilgallen, Medical Director and Responsible Officer for the Western HSC Trust.

Ruth Bender Atik also held a GP training session, assisted by the PCC. Attendees were able to contribute to a set of six short educational videos produced by the Miscarriage Association. These have since been launched, and the PCC is raising awareness of this free online training resource to key HSC stakeholders in Northern Ireland.

On 9 March 2016, Ruth Bender Atik ran an information session for midwives as part of the Clinical Education Centre's early pregnancy bereavement awareness training. She ran a similar session at Antrim Area Hospital on 17 June 2016.

Arrangements are now in place for the Miscarriage Association to take an active role in further HSC early pregnancy awareness bereavement training through the Clinical Education Centre.



On 15 September 2016, a new support group for people affected by early pregnancy loss met at Antrim Area Hospital.

Recent developments

Miscarriage has been identified in the Northern Ireland Health and Social Care Draft Commissioning Plan for 2016/2017 as a specific issue. Section 5.3 on Maternity and Child Health states: 'Effective arrangements should be in place to ensure that women with more complex pregnancies are offered the best possible care in line with national evidence-based guidelines.'[16]

It recommended that HSC Trusts should work with the Public Health Agency (PHA) and HSCB to clarify and standardise the referral and clinical pathways for women who have had recurrent miscarriages. The Maternity Strategy Implementation Group has also agreed to work on this issue and it is included in the Action Plan for 2016/17.

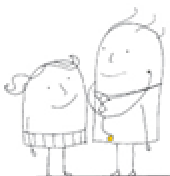
At the Northern Ireland Assembly Health Committee meeting on 15 September 2016, the PCC gave a briefing to members, during which it highlighted the need for specialist recurrent miscarriage services and psychological help for those who needed it.[17]

Conclusion

Northern Ireland requires specialist recurrent miscarriage services. Current services need to be reviewed with consideration given to the best option to meet patients' needs. Currently, women have to qualify for a referral to a specialist clinic in England or pay for private treatment. There is also a need for women and their partners to have timely access to specialised counselling services in Northern Ireland, if required.

After an initial scoping exercise, a meeting with key stakeholders to discuss solutions based on the needs of women and their partners is required.

In the meantime, the PCC will continue to increase awareness and knowledge among key decision makers, planners and commissioners in HSC organisations regarding the gaps in service provision for those women and their partners who experience miscarriage and recurrent miscarriage.



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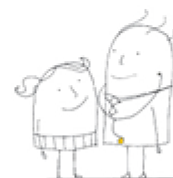

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