A national survey of women's experiences of recurrent miscarriage care

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Background

Recurrent miscarriage (RM) affects 1-5% of the reproductive population[1,2]. RM is now defined as the loss of two or more pregnancies (ESHRE)[1,3,4]. Quality in healthcare is shaped by the experiences and engagement of patients, families, caregivers, and professionals[5]. Clinical practice guidelines for RM describe investigations and treatments, but they do not provide mechanisms to ensure patient-centred care is guided by the values and needs of women/couples. As the patient experience is multifaceted[6], learning what matters to women/couples during RM is essential to inform future care practices. Previous national and international surveys have examined inpatient stays, maternity care, and care experiences around pregnancy loss, but there is little focus on RM care[7,8].

Aim: To explore the experiences of women and men who have received RM care in the Republic of Ireland and identify patient-centred care factors linked to the overall RM care experience.

Methods

A cross-sectional study using an anonymous online survey to examine the experience of those who interacted with the maternity services following RM. Women and men over 18, who experienced two or more consecutive first-trimester miscarriages in the last ten years 2010-2021 and who received care for RM in the Republic of Ireland were invited to participate

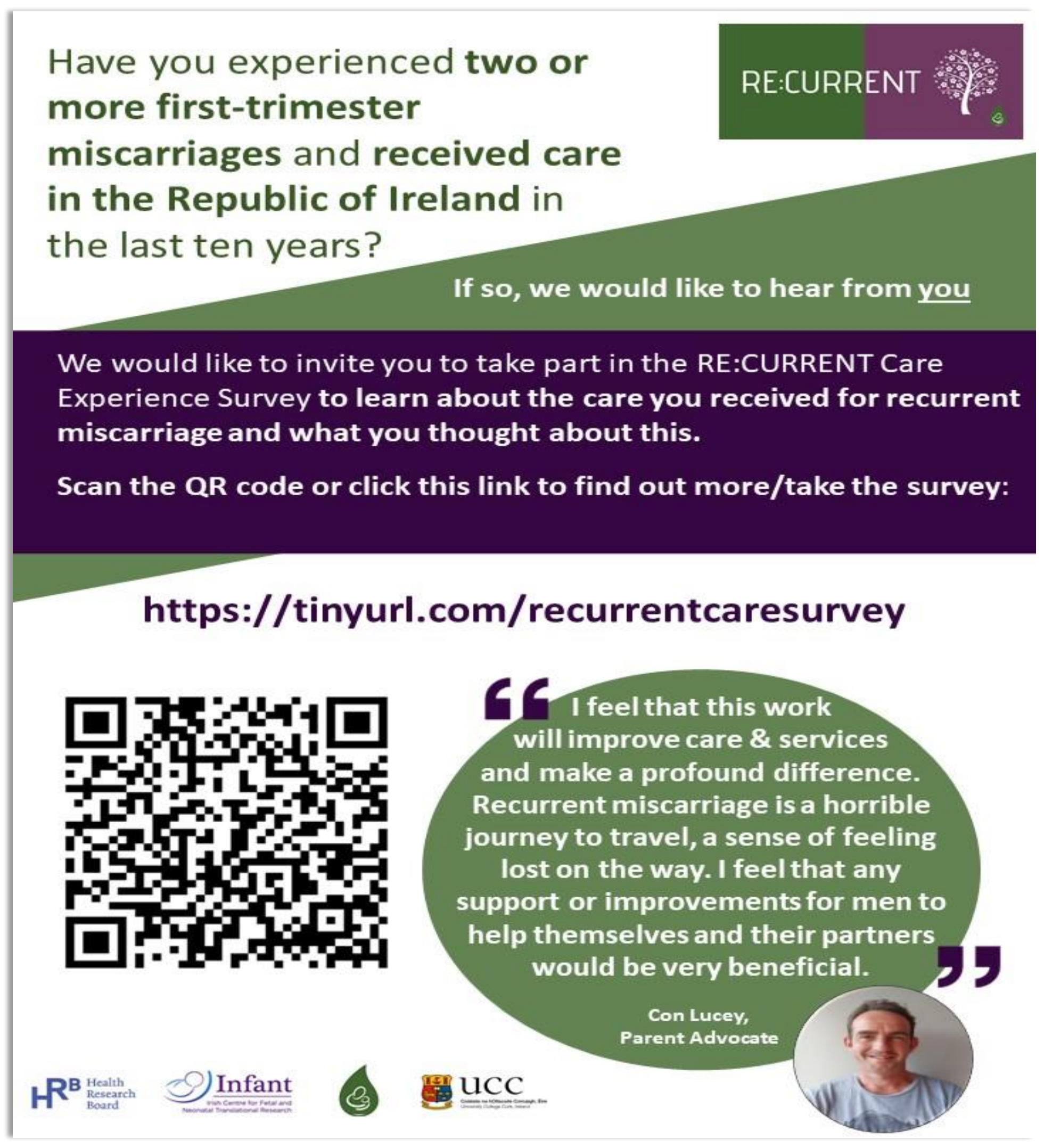
In consultation with key stakeholders, including parent advocates from the RE:CURRENT Research Advisory Group a questionnaire consisting of 10 sections, 165 questions were purposefully designed using relevant literature.

RE:CURRENT CARE EXPERIENCE SURVEY ITEMS

- Sociodemographic information
- Pregnancy and pregnancy loss history
- RM care pathway: investigations, receiving results, treatment for RM and follow-up care
- Patient centre care items: patients' preferences, information and support, the environment and involvement of family and friends

Qualtrics survey software was used to format and manage the survey which was distributed online from Sept-Nov 2021 through existing professional, collegial and support networks. Recruitment materials included photos and quotes from those with lived experience of RM.

Analysis: Sample characteristics and care experience explored using χ2 test. Descriptive analyses were carried out through the RM care pathway. Unadjusted multinomial logistic regression was conducted.



Have you experienced **two or more first-trimester miscarriages** and **received care in the Republic of Ireland** in the last ten years?

RE:CURRENT

If so, we would like to hear from you

We would like to invite you to take part in the RE:CURRENT Care Experience Survey **to learn about the care you received for recurrent miscarriage and what you thought about this.**

Scan the QR code or click this link to find out more/take the survey:

https://tinyurl.com/recurrentcaresurvey

"I feel that this work will improve care & services and make a profound difference. Recurrent miscarriage is a horrible journey to travel, a sense of feeling lost on the way. I feel that any support or improvements for men to help themselves and their partners would be very beneficial."

Con Lucey,
Parent Advocate

HRB Health Research Board · Infant · UCC

Results

213 participants completed the survey. 74 participants were not eligible for this analysis as they did not experience a consecutive miscarriage (n=63) or did not receive care between 2011 and 2021 (n=11). Of the eligible participants (n=139), 97% were women (n=135). Due to the small number of men (n=4), results for women who participated are presented.

Women characteristics (n=135)

79% were aged 35-44 years (n=106); 84% were married (n=114); 39% had a postgraduate degree (n=53); 77% were employed full-time (n=104); 80% had PHI (n=108); 57% had two consecutive miscarriages (n=77); 24% were diagnosed with infertility (n=32)

RM care pathway

1. Investigations (n=135)
53% of women had investigations to determine a cause for RM (n=71)

62% of women had to request these investigations (n=44)

49% felt their HCPs did not do everything to investigate the cause of their RM (n=35)

35% waited between 3-4 months for their investigations (n=25)

2. Receive Results (n=71)
86% received the results of their investigations for RM (n=61)

28% had waited between 3-4 months (n=17)

51% felt the wait time was too long (n=31)

64% did not get answers for the cause of their RM

3. Treatment/ Care plan (n=135)
52% of women had a treatment plan in place for their RM (n=70)

42% did not feel their HCP did everything to treat their RM (n=23)

4. Subsequent pregnancy (n=135)
72% of women experienced another pregnancy (n=97)

39% felt their HCP did everything 'to some extent to support their subsequent pregnancy (n=38)

Overall RM care experience

"How would you rate your experience of the care you received for RM?"

44% Poor
39% Satisfactory
17% Good

"Thinking about the care you received for RM, was it:"

16% better
20% as expected
64% worse than expected

"Have staff in different places worked well together when caring for you?"

60% No
40% Yes

Patient-centred care items throughout the RM care pathway and overall RM care experience

For all aspects of RM care (investigations, receiving results, treatment and subsequent pregnancy care) women were more likely to rate a good RM care experience if they had enough information, received answers they could understand, had a healthcare professional they could talk to about worries and fears and if their partner could ask questions. Women who received a treatment plan for RM or those who were offered early reassurance scans were more likely to rate a good RM care experience.

Conclusion

This study provides an overview of women's experiences of care through the RM care pathway. Although efforts were made to involve men, only four participated. While overall experience of RM care was poor, women identified certain patient-centred care items that could improve the care experience; results provide a better understanding of the drivers shaping care experiences to help inform and enhance RM care in Ireland.

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