

Experiences of Women with Mayer-Rokitansky-Küster-Hauser Syndrome Accessing Fertility Treatment in the United Kingdom

S. Gilmer, R. Tarling, S. Roberts
Liverpool John Moores University, Liverpool, England



BACKGROUND

Approximately 1 in 5,000 women are affected by Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome, a rare congenital female reproductive condition characterised by the absence or partial development of the uterus and vagina, resulting in absolute infertility (Dube et al., 2023). Those with MRKH syndrome experience considerable psychological and emotional challenges when pursuing fertility treatment and surrogacy, particularly in the context of disparities in access to the National Health Service (NHS)-funded fertility services in the United Kingdom. Access to funding for fertility preservation and assisted reproductive technologies is often restricted and unequally allocated - exacerbating the emotional, social, and psychological burden experienced by this population during their family planning journey.

OBJECTIVES

This study examined how inequities in NHS-funded fertility services affect the psychological and emotional wellbeing of women with MRKH syndrome in the UK. It explored the impact of limited access to treatments such as In vitro fertilisation, as well as broader experiences across the family planning pathway, including interactions with healthcare professionals and efforts to access information and support.

METHODS

A qualitative design using semi-structured interviews was employed. Participants were women diagnosed with MRKH syndrome who were currently, previously, or planning to pursue fertility treatment in the future via the NHS. A total of 8 women (aged 22 to 40 years) were recruited. Data were analysed using thematic analysis.

CONCLUSIONS

- Individuals with MRKH syndrome face significant emotional, financial, and systemic barriers when accessing fertility treatments through the NHS, often leading to feelings of distress, frustration, and isolation.
- Inequalities in access to fertility treatments vary by region in the UK, forcing many to pursue costly private care.
- A lack of clear information and knowledgeable healthcare professionals adds to the psychological strain, whilst online communities provide support but carry risks of misinformation.
- Urgent NHS reforms are needed, including equal access to fertility treatments, expanded funding, and improved training for healthcare providers on conditions such as MRKH syndrome.
- Enhanced mental health support and accessible information are essential to reducing psychological distress and ensuring equitable, compassionate care for people with MRKH syndrome.

ACKNOWLEDGEMENT

The authors would like to thank all the participants for generously sharing their experiences, as well as MRKH Connect for their invaluable guidance and support.

RESULTS

Theme 1: The Impact of MRKH on Family Planning

MRKH syndrome has a significant impact on how individuals approach family planning. The diagnosis often brings emotional distress, medical trauma, and a sense of loss, while also accelerating reproductive decision-making. Many feel isolated in navigating their fertility options and face added challenges in disclosing the condition to partners, often under the pressure of uncertainty and limited reproductive pathways.

Sub-themes:

- Impact of diagnosis
- Family planning
- Partners

Participant quote:

"I'm 29 but I feel so much older than I am. I've been through a lot since I was 14, 15. I'm watching my friends start careers and live their lives without the same issues or panic I have. It's like my timeline is being rushed."

Theme 2: Interactions with Healthcare Professionals

Participants faced significant challenges with healthcare professionals who lacked knowledge of MRKH and fertility options, leading to frequent self-advocacy, emotional distress, and feelings of abandonment. Although some experienced empathetic care, such instances were rare.

Sub-themes:

- MRKH
- Fertility treatments
- Support

Participant quote:

"I think the level of self-advocacy required of me throughout the entire process, from IVF to surrogacy to birth to post-birth, was exhausting and added significant stress to what was already, objectively, a stressful situation."

Theme 3: Navigating the Fertility Process

Those with MRKH face clear systemic and structural barriers when accessing fertility services, especially within the NHS. Challenges such as complex eligibility criteria, long waiting times, financial constraints, and regional disparities contribute to feelings of frustration, helplessness, and inequity. The emotional toll is intensified by the need for persistent self-advocacy and uncertainty around treatment outcomes and funding.

Sub-themes:

- Funding
- The NHS
- Impact on Mental Health

Participant quote:

"It's not fair. It feels unfair to have this diagnosis anyway... to then have to come to terms with the fact you're also going to be stumping out thousands and thousands of pounds if you want a child at some point. It's a bit gut-wrenching."

Theme 4: The Biopsychosocial Impact of Fertility Treatment

Participants faced significant emotional, physical, and social challenges throughout fertility treatments. Stress, uncertainty, and lack of control were common, while social support - especially online - played a crucial but sometimes complicated role. This theme emphasised the need for holistic care addressing all aspects of the fertility journey.

Sub-themes:

- Egg Freezing Process
- Surrogacy Journey
- Social Support

Participant quote:

"We did it because we had to and we are eternally grateful that it worked out in the end, but it was tremendously stressful and not something I would ever have chosen, you know, if it wasn't medically necessary."

REFERENCES

Dube, R., Kar, S. S., Jhancy, M., & George, B. T. (2023). Molecular Basis of Müllerian Agenesis Causing Congenital Uterine Factor Infertility-A Systematic Review. *International journal of molecular sciences*, 25(1), 120. <https://doi.org/10.3390/ijms25010120>

CONTACT INFORMATION

psysgil1@ljmu.ac.uk
r.m.tarling@ljmu.ac.uk
s.g.roberts1@ljmu.ac.uk