

Issues of identity, perceptions and isolation: An interpretative phenomenological analysis of women's experience of Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome

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Abstract

The objective of this study was to explore the personal experience of women with MRKH, a rare condition characterised by congenital abnormalities of the genital tract. There are very few qualitative studies into the lived experiences of women with MRKH. Interviews were conducted with 13 women with MRKH and analysed using interpretative phenomenological analysis. Four superordinate themes are discovered: maintaining a viable female identity; acceptance and coping; normality, secrecy and shame and the isolating impact of a lack of knowledge amongst the medical profession. This study also suggests that societal ideals of a 'normal woman' are influencing how MRKH impacts on the self-experienced psychological health. It is suggested that the psychological wellbeing of women with MRKH could be improved with continued multidisciplinary support beyond the initial diagnosis and alongside any vaginal correction.

Keywords

amenorrhoea, disorders of sexual development, identity, interpretative phenomenological analysis, MRKH

Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome is a rare congenital disorder, named after the four physicians who first diagnosed the condition (Patnaik et al., 2015). It affects approximately one in 5000 women worldwide (Morcel et al., 2007). Type I is characterised by uterine and vaginal aplasia – a partial or complete lack of development of the uterus or vagina. In type II non-formation of the vagina and uterus is accompanied by other malformations such as renal, skeletal and cardiac abnormalities (Fontana et al., 2017). The formation of the ovaries is normal in both types and external genitalia are normal (Morcel et al., 2007).

MRKH is the most common cause of primary amenorrhoea (the absence of menstruation by age 15) and hence this is the point at which it is most usually diagnosed (Heiman, 2009). It is classed as a disorder of sex development (Barbaro et al., 2011) and is also known as

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Müllerian Aplasia, Vaginal agenesis and Müllerian agenesis.

Irrespective of whether women with MRKH have type I or type II, they are all unable to engage in penile-vagina intercourse without treatment, have an absence of periods and are unlikely to carry a pregnancy and bear children (Leithner et al., 2015). Therefore, women diagnosed with MRKH receive medical treatment to create a functional neovagina. This is offered in the non-surgical form of dilators to increase vaginal depth and width, or alternatively through surgery (Brucker et al., 2020). Dilators are the most common method of treatment, with surgery regarded as a secondary option (Cheikhelard et al., 2018).

Much of the existing research into MRKH syndrome has overwhelmingly been conducted within a medical framework studying the aetiology of the condition in an effort to identify the genes involved (Fontana et al., 2017), examining the differing anatomical symptoms (Boruah et al., 2017; Morcel et al., 2007), discussing sexual wellbeing (Dear et al., 2019) or contrasting and comparing vaginal dilation with vaginoplasty and other neovagina constructions (Adeyemi-Fowode and Dietrich, 2017).

Sexual functioning before and after treatment is an area that has been explored through quantitative surveys (Kang et al., 2020; Marcel et al., 2013 **JAQ: 21**) using measures such as Female Sexual Distress Scale-Revised (FSDS-R) and Female Sexual Function Index (FSFI). Whilst these quantitative surveys are a good indicator of sexual function and wellbeing, they do not seek to understand the emotional impact that treatment places on women. Where psychological symptoms are mentioned, the findings are secondary to their primary exploration (Brucker et al., 2020; Kimberley et al., 2011; Pastor et al., 2017) and do not take into account the lived experiences.

There is a paucity of qualitative research into MRKH (Herlin et al., 2020). Past studies have focused on the transition from childhood to adulthood when the diagnosis is typically received. Adolescence is a critical period in life as puberty is a time of intense biological

changes and identity development (Farid et al., 2019). Therefore, it is unsurprising the limited qualitative studies have focused on reactions to diagnosis, targeting the focal point of women receiving life-changing information, when the building blocks to a woman's identity are being created (Patterson et al., 2016).

Patterson et al. (2016) focused on five women, aged 18–22 years. The researchers were interested in the transitional period from adolescence to early adulthood. An interpretative phenomenological analysis (IPA) study identified these emerging themes: a desire to break free from the control of family members; feelings of being different to others; struggles with disclosing their diagnosis to potential partners and the challenge of maintaining their female identity. The participants were young women; hence it does not speak of the lived experiences of older women. A more recent mixed methods Malaysian based study by Hatim et al. (2021) was conducted with a slightly larger sample size (12) and age range (24–40) but the qualitative analysis whilst generally illuminating was Thematic and therefore in this case had less focus on the lived experiences and sense making of individuals with MRKH, and more focus on general issues. Whilst as an approach Thematic Analysis can be flexible and allow for a focus on individual experiences in some of the past literature this was not always maximised in past MRKH research. Nor does it have the clear focus on the lived experiences of individuals that IPA would provide. This was reflected in themes such as issues with delayed diagnosis and the role of medics.

This study seeks to address the gap in research by examining the experience of older women, and, in contrast to existing research, the current study focuses on the complete lived experience of an individual rather than on specific parts of the phenomenon under investigation (such as just diagnosis or disclosure). With relatively little qualitative research undertaken in the area it is hoped that this larger study (the biggest known qualitative MRKH sample to date) using IPA will contribute significantly to our

understanding, broadening what is known about the lived experiences of women with MRKH.

Method

Participants

Thirteen individuals were recruited by placing an advertisement on the social media pages of *MRKH Connect*, which is the UK’s leading charity supporting women with MRKH, as well sending the invitation out via the charity’s mailing list. Forty-one women volunteered to participate in the research. In keeping with IPA methodology, the aim was to recruit a small sample of participants (Smith et al., 2009), allowing for detailed scrutiny of individual accounts and facilitating meaningful cross-case analysis.

Of the 41 volunteers, 20 were contacted at random. From these 20 invitations; 13 went on to be successfully interviewed, two withdrew following technology problems, four did not reply to the invitation email and one replied to the invitation after the collection of data had ended. Participants were aged between 18 and 59 (see Table 1). Inclusion criteria were that participants should be 18 years or over, not currently being treated for mental illness and able to speak and understand sufficient English to be interviewed.

Each participant was interviewed using Microsoft Teams, the choice of using the camera was left to the participant as the interviewer elected to be guided by the participant to what would make them feel most comfortable. Participants elected to have a visual interview ($n=4$), see the interviewer but not been seen themselves ($n=2$) or record audio only nine ($n=7$). The interviews lasted between 45 and 90 minutes with the average length of an hour.

Materials

The interview schedule was designed to start with general, ice-breaker questions about diagnosis before building up to challenges that participants faced. Prompts and follow-up questions are interwoven to generate rich responses. The questions are open-ended to elicit detailed responses and descriptive with introductions to show awareness of the sensitivity of such direct questions (Dickson-Swift et al., 2007). Questions such as ‘Can you tell me about any challenges you have faced?’ allow the participants to direct the topic so that the interviewer will not bias or control the direction of the replies (Pietkiewicz and Smith, 2014; Smith et al., 2009). The interview schedule had flexibility

Table 1. Participant demographic information including current age, age of investigation and diagnosis and location.

Pseudonym	Age at interview	Location	Age underwent initial investigations	Age received diagnosis of MRKH
Lily	18	UK	17	18
Alexandra	23	Greece	15	22
Ella	25	UK	17	18
Doutzen	33	Netherlands	19	19
Jessica	37	USA	13	15
Stephanie	38	USA	17	38
Zuri	41	Mozambique	30	35
Shamalia	42	UK	18	37
Rachel	44	UK	17	18
Dawn	44	UK	17	17
Lauren	48	UK	16	17
Jennifer	49	UK	16	47
Valerie	59	UK	16	56

and was not followed in a rigid way but rather a process of reflecting on the dialogue and delving deeper was adopted giving the participant every opportunity to retell their story in their own words and have their opinions voiced and considered.

Procedure

Ethical approval was obtained from the University ethics board. Following consent from the Director a recruitment advertisement was placed on the social media pages of a *MRKH charity* inviting women with MRKH to contact the interviewer. In addition, the Director sent out an email to the women on the *charity* mailing list with the recruitment advert.

The interviews were carried out over Microsoft Teams at a time of the participant's choosing when they felt free to talk with privacy and without interruption. Prior to the commencement of the interviews and the recording, the interviewer talked through the information sheet and the process of the interview. It was explained to the participant that they could withdraw without any reason, at any point, and afterwards, up until the results had been written up. Consent was gained from all participants before the interview began and they signed an electronic consent form to confirm that they felt able to talk about MRKH without lasting damage and understood the purpose and conditions of the study. A pseudonym was agreed with the participants to attach to their recording and transcript in case they wished to withdraw.

At the end of the recorded interview, the interviewer talked through the ideas of the participant to check that the interviewer was construing appropriate meanings from their comments and debriefed the participant before sharing further details of support groups or sign posting women towards services.

Data analysis

Analysis followed the IPA process outlined by Smith et al. (2009), rather than later versions. This approach was taken as it is concerned with

a person's perception of a phenomenon and the meaning they give to it. Thus, the individual voices of women with MRKH can be heard, understood and analysed, providing an authentic insight into how social and cultural contexts can influence the creation of an individual's identity following diagnosis. As mentioned above some past research had considered the impact of general issues in relation to MKRH but perhaps not the individual impact and sense-making involved as these issues were navigated. The current research and IPA approach allowed for an increased focus on individual lived experiences first, and the interaction and sense-making involved in any more general issues (such as the act of diagnosis). Each transcript was re-read multiple times and analysed individually. The researcher then made initial notes. Phrases and paragraphs were highlighted which held particular interest. The transcripts were coded by searching for points of linguistic, descriptive and conceptual note and emergent themes were identified. The researcher moved from individual passages to the whole transcript, before refocusing on particularly resonant sections of the interview. After separate analysis, the interviews were examined together to find areas of convergence and divergence. Initial themes were clustered to create subordinate themes, which were then in turn clustered to make superordinate themes. These were discussed and agreed by the research team.

Results

Four superordinate themes emerged in the data. Three of the themes have a strong link to the research area: maintaining a viable female identity; normality, secrecy and shame and acceptance and coping. The fourth theme, the discussion of diagnosis and the isolating impact a lack of knowledge amongst the medical profession has a weaker link but given the importance IPA attributed to the emic perspective of participants (Smith et al., 2009), it was necessary to include the findings. Some overlap and interaction between the superordinate themes was noted,

with issues around how female identity is defined having close links to the experiencing and navigation of shame. **[AQ: 3]**

Maintaining a viable female identity

This was a strong theme within the transcripts. The symptoms of MRKH; lack of periods, sexual dysfunction and being unable to carry a child, brought femininity and gender to the forefront of women's minds. The women struggled with their perception of gender and with questions raised by other people. They reported the insensitivity of others asking them about their condition and their own need to justify that they warrant the label of 'woman':

I think that for a long time my sense of femininity was totally gone, and it was questioned. You know, am I a real woman? Because people had always said to me, like since I was diagnosed and they knew, especially younger people, they said, "Ah [Lily], you're not a real woman." Like, you know, "You're a fake woman," and stuff. [Lily]

Lily raises here the concept of authenticity in regard to femininity, with the repeated use of 'real' and contrast of 'fake'. Repeated questioning here at an early age appears to have reduced the sense of femininity Lily was able to experience. Similar issues around the concept of femininity or womanhood were raised by Shamalia.

...my sister's reaction straight away was, "Oh! So you're not even a woman? What are you then?" and her words, further made me feel like okay, "I'm definitely a freak" the gynaecologist had also said, "It's just a freak of nature" [Shamalia]

The questioning in this case was distressingly from a family member and refers again to those with MRKH not being a real woman, or even a woman at all. This challenging of their womanhood left Shamalia considering what alternative label to apply to their identity, and they settled on the suggested (by a medical professional no less) label of freak. Freak suggesting a severe deviation from the normal feminine identity. This is additionally problematic

considering the use by a medical professional, suggesting an othering and isolating impact.

The link to a 'normal' female identity was often physical or functional. Female reproductive organs were important as they were viewed as physical objects that linked women to womanhood. Dawn mentioned how even saying the word 'vagina' made her uncomfortable:

I wanted to be like everybody else. [. . .] I felt like a freak. [. . .] Not having a vagina was a real problem, for me. That was where I was like, "Oh my God, I just want to be normal." [Dawn]

We again have the term 'freak' being used when considering how individuals felt or identified. Whilst similar to the wording of Shamalia we can see here how Dawn links this normal/freak binary identification to genitalia, with the lack of a vagina being the root of this identification. 'Normal' feminine identity being anchored to the perceptions of normal physiology.

A further link between the physiology and identity was apparent with Jessica. Jessica was diagnosed with ovarian cancer and talked about her 'tenuous grasp on womanhood' being destroyed the day that she learned her ovaries would have to be removed:

I only really essentially had ovaries, and that's what I felt tied me to womanhood. I was like, I have nothing else but ovaries. I have this partial, non-functional, annoying neovagina, just not really offering me anything. And I was like, "And I have ovaries," and then I get ovarian cancer, and that was horrifically hard. [Jessica]

The use of tied by Jessica is interesting. Though reproduction is often very difficult in individuals with MRKH the link to womanhood here is with internal organs involved directly in reproduction. In contrast to Dawn the vagina was secondary when considering their identity. This is perhaps because of the very direct links between ovaries and fertility often made in discussions around gender and womanhood. Some may use the vagina as the link to femininity, whereas others like Jessica may use related

links such as ovaries or children. This is perhaps reflected in some of the discussions around fertility and family expectations by the participants.

Fears were exposed about a woman's role to have children and how this would be received by potential partners. Four of the women had partners who were infertile, and they expressed relief that it removed a reason for their partner to reject them:

And my husband, he can't have children too, so for us, it's not, I'm not the only one, there's no imbalance. So actually, it's terrible but it's also a relief that he can't leave me because he hates the fact that I can't have children. [Doutzen]

The use of the word imbalance suggests that the ability to have children adds power or legitimacy to a relationship for a woman. The relief mentioned is framed not in terms of common experiences or feelings around infertility but instead around not being left by their partner. This is suggestive of beliefs around the role of women in a relationship, and therefore womanhood, being centred around child bearing. Some women had fears over their identity given the importance that their culture places on fertility. Shamalia explained what it meant being unable to fulfil that destiny:

It's a given that a woman's role is to be a wife and then to be a mum, those are the two main things. Even in my religion, I'm Muslim. So, in my religion, it's also the predominant cultural or religious thing in my culture. It's been embedded that a woman's role is as a wife and as a mother, so it was very hard for me to know who I was as a person. My self-identity. I had like a massive identity crisis as it were, "What is my role in life? Who am I?" [Shamalia]

Here Shamalia explains how those concepts of womanhood may be culturally derived but still centre around motherhood. Much like the labelling of individuals such as friends, family members and medical professionals mentioned above identity is framed in terms of being able to meet these expectations. The individual

experiences, labelling and identity crises mentioned by the participants were often connected to fertility or proxies for that (such as elements of physiology) as a result.

Normality, secrecy and shame

There was a strong element of shame and secrecy to the transcripts. The women felt that they were lacking normality in their lives. This shame and lack of normality can often be linked to some of the above issues around identity and challenges to identity. We could perhaps link some of the examples below to dissonance between identities. Jessica in particular spoke at great lengths about how the diagnosis meant she would not 'cross the same thresholds' as her friends. Being different to the ideal of the perfect woman, or even being unable to meet the same standard milestones, left many of the women feeling ashamed.

Stephanie explained how her shame was not from other people. She had support from her husband and family and her shame originated from 'within herself':

I was ashamed, and I didn't understand, and I viewed myself as not really a woman, like, what was I like? Where did I fit in? [Stephanie]

This is perhaps in contrast to some of the stark labelling mentioned in the previous theme such as being a 'fake' woman or a 'freak'. In the case of Stephanie, we can see a real focus on their own internal sense or view of self. With that shame appearing to derive from that lack of feminine identity they felt.

This linked to Valerie, a widow, who had a very loving marriage and supportive husband, she was equally unable to understand her feelings when she was in such a supportive background:

Even though I had the most marvellous man and he treated me so well, I still do have this shame I suppose, and I don't know why. [. . .] overridingly, I have a sense of shame and I can't tell people; I wouldn't tell people. [Valerie]

Much like Stephanie, Valerie's experiences of shame seem to be internally driven. Even with support in place there's an avoidance. There are some parallels here with the later theme around coping.

In one case the shame was cultural. Shamalia spoke of how her family tried to 'push' her into an arranged marriage to cover up her diagnosis:

I was told by my older sister, "Make sure you never talk about this with anyone, it will bring shame to the family. What are people going to say? What are people going to think?" [Shamalia]

In this case we have evidence of external pressures to not disclose rather than being internally driven. Though this is in keeping with external cultural and social pressures mentioned earlier by Shamalia.

A couple of the women distanced themselves from the stigma. Lily recalled her initial reaction was to reject the idea that she might find some common ground with women in the support groups:

So, I was in denial at first. Then I remember going out for coffee with one of my Mum's friends and she said, "Have you found any support groups?" And I said, "Yeah, but I'm not going to go." And she said, "Why not?" And I said, "Well I'm not like them, I'm. . .you know, they're not like me." [Lily]

Interestingly this feeling of difference and isolation experienced by Lily lead to even a rejection of talking to similar individuals. There are some similarities here to the cultural pressures not to share, or the shame driven motivations of individuals like Stephanie and Valerie. A feeling of difference here, or not fitting in, seems to persist and limit interactions with others. Maintaining secrecy and shame as a result.

Acceptance and coping

Whilst identity issues persisted, and feelings of shame were initially present for many of the

participants there was a strong sense of working towards coming to terms with the diagnosis over a long period of time.

In their struggle to make sense of their life, blaming fate was used to cope and prosper. For some women, in the absence of having children, they tried to fill their lives with a 'greater purpose' (Doutzen):

I asked if this was what God wanted because I always wanted to be a career woman and this was like a match, not having a baby could be a match. [Zuri]

The use of 'career woman' here suggests the replacement of a female identity governed by fertility and childbearing with one around alternative goals. Career woman is often used as an archetype that combats more patriarchal, traditional or even misogynistic views of femininity. The method of coping and acceptance here is one of a shift in identity or identity goals over time. A processing that goes beyond the initial diagnosis.

Processing the information that they have been given is challenging and five women likened it to grief:

It's grief for the future, it's grief for the child you can never carry in your belly, and it's grief for the secure future, the vanilla future that I always wanted. . .of, get a job, get a degree, get married, have children. That's what I always wanted and now that's not how I see my life. Yeah, I think it's grief. [Lily]

Some of this grief outlined by Lily refers to elements that directly contradict that stereotypical and fertility driven view of womanhood mentioned in previous themes. The use of vanilla is interesting as this is often used to refer to normal yet unexciting experiences or practices. Those there is acknowledgement of grief and what was originally wanted this use of vanilla is suggestive of holding this future in lower esteemed than it once was. An indication maybe that part of this grief processing has involved a revaluation or renegotiation of what is important to them.

A further example of this can be seen in Jessica's account. Jessica took what she referred to as 'self-conditioning' to the extreme. She recognised that she had to make some tough decisions at a young age and her transcript contained the repetition of the words '15-year-old brain'. Jessica convinced herself she would be a 'terrible mother' and reinforced to herself that she would be happy without children:

My fifteen-year-old brain just decided that the best possible option was to make myself dislike children. And so, it did. Like systematically, over the next few years, I just made myself really, really, dislike children, to the point where I know now, even if I didn't have this, I wouldn't choose to have children. [. . .] So, I devised this plan, I executed it. It worked perfectly. [Jessica]

Though a little more specific than Lily's account of grief we can see a similar renegotiation of wants and expectations. The grief of likely not being able to have children was navigated by reframing that possibility as being unwanted and undesirable.

Though there were occasional examples of humour being used to cope most of the participants used avoidance of conversations or long-term relationships as a coping strategy and controlled their emotional environment by minimising pain and damage they might face. In some cases, this involved self-destructive or harming behaviours.

Participants used the initial hardship to make themselves stronger. They recognised how their lives could be worse and there were references to MRKH being 'life-changing' but not 'life-threatening' MRKH was compared favourably to other illnesses and disabilities to shape the participants positive frame of mind. Across many participants the finding of support had a huge impact on healing. There was a feeling that professionals were unable to help the women in the same way that they could help each other:

You see it's about what we have in common, we've got that bond and we just get it. It's not like we have to explain ourselves or justify ourselves. [Rachel]

Finding other women with the condition was a crucial psychological need for all participants (even though it wasn't shared by all initially). Three participants until then had believed they were the only one in the world with the condition:

I was like, "Yes! There's a whole community out there, it might not be local, it's worldwide but I'm not alone" and that was such a big deal for me, to know that I'm not alone anymore and I didn't need to feel alone all those years. [Shamalia]

A repetition of the use of 'alone' drives home the isolating nature of such a rare and at times stigma carrying condition. An important and common referred to element of this was the knowledge that others shared this experience rather than perhaps more practical elements of information sharing. No longer being the 'only' person with the condition was a positive revelation. The narrative of a positive community, or bond, is at odds with the narrative of negative othering and labelling from others including family members and medical professionals.

The isolating impact of lack of medical professional knowledge

An initial lack of named diagnosis and knowledge, coupled with a later lack of support and information from medical professionals was often considered isolating. Some women had taken years to learn the name of their diagnosis. Others knew the name but struggled to say it or asked the researcher to remind them of the longer form. It appeared to be an unconscious strategy to give MRKH less power over them if they failed to acknowledge it as important. Those who thought they were the only one with the condition, had to come up with their own terms:

I called it, 'my no-womb thing' or my other way of saying it was 'my no-womb condition' but mostly, I called it 'my no-womb thing' because there was no name for it then. [Shamalia]

We have an example here of Shamalia applying their own label (which contrasts significantly with the label of ‘freak’ applied by others). Interestingly though this is a less extreme or obviously negative label it is still one tied to biological and fertility related cues mentioned earlier.

For many it was painful not having a name for the condition, and a lack of forthcoming information from a medical profession had the impact of isolating individuals from the broader community and diagnosis:

I think that had I had any doctor in twenty years give me, I mean it's shameful to me, to give me the name of what I had, and then I wouldn't have been alone, you know (cries). Um, that would have definitely made a huge difference to me. [Stephanie]

Stephanie's account again makes reference to the impact of feeling alone or isolated. In the previous theme the positive impact of the realisation of not being alone was clear. Here we have further confirmation of the negative impact of feeling alone, this time through doctors being unable to give a name or diagnosis. The isolation being enforced through a lack of naming. Thus denying access to solace and support through the wider diagnosed community.

Even those that had a name for it discovered that after the initial medical treatment, they were left with questions. In their search to try and find answers, all of the women went online for help.

Four participants had used the internet to discover their own diagnosis. Yet even those who had been given a diagnosis felt that they were left to get on with life by themselves and placed themselves as the central person to have dealt with their medical treatment. The loneliness of the diagnosis in terms of support and medical help was clear:

Once I was diagnosed, they said, "Look, we can't look after you anymore because you were born with it and you haven't developed it, so we can't treat you." So, they were like, "You have to

leave," basically. So, they just discharged me, and I was left to figure it out for myself. [Lily]

The diagnosis here is clearly only part of the journey for Lily, and the need to consider what comes after (or ‘figure’, whether medical or psychological), is a real challenge for individuals. Diagnosis and the initial reaction is important part of their lived experiences but it is an initial part of a process. Only one participant was offered counselling. Doutzen explained how her counselling made her feel worse because the counsellor made her feel abnormal by enjoying the rarity of her condition, as though it were entertainment:

And they were asking me questions but in a very silly way, and it was more like interested, "Oh, how did you make the vagina? Oh, that's really wooooo." I felt really stupid and embarrassed. [Doutzen]

In some ways we have a contrast here to the positive impact no longer feeling alone had. Participants who knew they were not the only person to have MRKH no longer felt isolated, no longer were the odd ones out as they had a community. Doutzen's experience with the counsellor instead frames them as an oddity again.

The treatment was broadly seen as surgery or dilator treatment. The women spoke of how they were dismissed by the medical team and left to get on with the dilation themselves.

From the point of view medically, now when I look back on it now, it was very archaic and uncaring, nobody was there to support me, there was nothing there to support me [. . .] so I just trundled on by myself and I was the one who had to go and ask if I could have this operation, rather than the dilator. [Valerie]

The use of ‘nobody’ and ‘nothing’ here seems to highlight that both medical professionals and systems were absent in support. Valerie was isolated on an individual level as well as a patient within a larger system. The impetus to suggest positive medical life changing option had to come from lone non-medical

individuals indicating a practical impact of the isolating experience.

Participants reported feeling like a nuisance. Jennifer reported being ‘passed around like pass the parcel’ and other participants reported feeling that their opinions were dismissed. Additionally, the patient/doctor power imbalance is raised conveying a sense and experience of being oppressed:

So, feeling, you know, pushed around, pushed away, like you're worthless, like you're not listened to, like you don't have a place, like you feel stupid. You feel really worthless. And MRKH brings that anyway, because, you know, you feel a little bit rubbish, because it's not an easy thing to deal with. Erm, but then, when doctors don't do their job on top of that, it makes it ten times worse. And they have a lot of power, it's just how they choose to use it that really affects you. [Lily]

The isolating impact of poor interactions is quite clear from Lily's account. The use of ‘pushed away’ in addition to ‘around’ is quite striking as it suggests the creation of distance between medical professionals and MRKH individuals.

This issue of a power imbalance extended into the desire or need to find further information. Questions remain for the women over their diagnosis and with many individuals having negative experiences with medical professionals the information was sought elsewhere. Though this was often inadequate or poorly targeted. Stephanie highlighted how older women are unable to find adequate resources to support their treatment:

There's a really good website from Boston Children's Hospital that I found but again it's really talking about when you're seventeen and you have the diagnosis, not when you're thirty-eight, or even when you're in your twenties and thirties and have gone thought different things and are at a different point. [Stephanie]

Discussion

The aim of this study was to explore women's lived experiences of MRKH, particularly

beyond diagnosis and disclosure, and in a larger and older sample than has previously been engaged with. All themes within the results are underpinned by the participants' search for a place within society where being a woman is equated with motherhood (Baruch et al., 1983 [AQ: 4]). Moreover, the congenital absence or underdevelopment of their vagina exerts a damaging psychological impact on women, as they face challenges in their life. Whilst there was some overlap with the findings of Patterson et al. (2016) such as threat to the identity of being a woman, there are novel findings here in regards to the ongoing feelings of shame, strategies for coping and the long term isolating impact caused by a lack of medical professional knowledge and support. Further novelty is evident in the in older age of the participants, and their lived experiences of navigating MRKH beyond initial diagnosis.

Participants described how MRKH impacts on their intimate relationships and psychological wellbeing. The cause of shame and secrecy surrounding their condition links to societal constructions around womanhood and sex. Feminine research equates motherhood with femininity (Chang et al., 1994 [AQ: 5]; Rich, 1976; Weaver and Ussher, 1997), hence it is unsurprising that the women feel on the periphery of societal norms. Russo (1976) describes motherhood as women's ‘raison d'être’ (p. 144) further supporting the rationale behind the participants' feelings of failure to fulfil the societal expectation of gender ideals. Feminists identify menstruation as ‘the uniting entity between women’ and hence a phenomenon that all women share (Kitzinger and Willmott, 2002). Whilst this appears a positive view of menstruation and womanhood, it fails to account for women with MRKH. Whilst our results did identify initial links made to fertility or indicators by most participants, we also observed some accounts of shifts and renegotiations of identity. In some cases, this was through the involving of alternative feminine archetypes or through the challenging of expectations around being ‘good at’ or enjoying activities relating to motherhood. This is something that appeared to

be processed over time, with the initial reaction to diagnosis being akin to grief. It is only through having a sample with older individuals who have experienced MRKH for longer that these processes can be revealed. **[AQ: 6]**

Importantly Patterson et al. (2016) suggested, rightly, that the difficulties posed by a MRKH diagnosis may be particularly relevant at a young age of diagnosis because of the impact on identity development during the transition to adulthood. Our results suggest that this impact can still occur in those diagnosed much later but that such challenges posed by diagnosis can be processed. Mitchell et al. (2021) suggest that adult identity integration or development has two core stages, maintenance and reestablishment. Reestablishment process attempt to manage disruptions or challenges to established identity. This can involve the exploration of new possibilities or the use of accommodation (the changing of goals and priorities, Whitbourne et al., 2002). We can arguably see evidence of this in the way participants explored new identity possibilities like 'career woman' or changed the expected value or enjoyment of motherhood.

It is possible to suggest several strategies to reduce the social and psychological impact of MRKH. The lack of knowledge of GPs surrounding MRKH and the presentation of symptoms indicates that a better awareness is needed of the clinical features and manifestations of MRKH. Such initiatives can only be effective if there is a widespread education of all healthcare professionals who may be involved in the care and treatment of women with MRKH. Indeed, it is hard to speculate how global this issue is but all 13 women in the study reported that they regularly encounter healthcare professionals who are unfamiliar with MRKH, to the point of isolating them through a lack of diagnosis. A further common experience was that of a lack of compassion from healthcare professionals, and even less the professional conduct at times due to the rarity of condition.

Furthermore, the information received at diagnosis was reported by the participants as lacking in sufficient detail. All 13 women have

reported being left with questions or unknown elements to their diagnosis for which they are seeking answers. The women in the study have evidenced that more information is needed for patients explaining MRKH and informing them of the management of the syndrome and their available options. This should be provided in a written format which accounts for the fact that at the point of diagnosis, the women are unprepared to receive life-changing information and therefore are unable to process any details surrounding the implication. Though the participants varied in the ages at which they were diagnosed, there was consensus that lack of information-sharing amongst medical professionals concerning MRKH was a cause of on-going stress and feelings of isolation. Correlations have been found between effectiveness of patients' treatment and the quality of patient-professional communication (McCabe and Healey, 2018). However, most report a real benefit of finding or knowing that a community of MRKH individuals existed. The importance of such support networks to help, guide and reduce feelings of isolation mean that routes to these support groups and communities should be prioritised earlier in the diagnosis journey.

A limitation of the study is that the women were recruited through the UK's leading support group for MRKH. Therefore, they were self-selected and wanted to share their lived experiences. Indeed, to participate they had found the support site and are accessing support. They may not be representative of women who have chosen not to engage as they are secure in their identity, or who are unable to talk about their condition and still processing feelings of fear and shame.

Diagnosis and corrective treatment are not the end of the journey for women with MRKH. The real journey commences after diagnosis, once the women start to process the information and begin navigating societal ideals and expectations. The shame expressed by these women on receiving diagnosis and their resulting evasions when questioned by others is congruent with correlations identified between avoidance and psychological distress (Aldwin and

Revenson, 1987; Stanton et al., 2000). The route to acceptance for women with MRKH is a challenging one, identity formation is difficult along with managing relationships and investigating the experience of these women has shown that when diagnosis stops, there is a need for psychological support to begin.

Author note AQ: 7

The participants represented in the raw transcripts have been given pseudonyms, and had any directly identifying information redacted. Descriptive quantitative data is only included in Table 1 in the main document. No quantitative analysis has taken place, only qualitative. The steps taken for the data analysis, and the general procedure for the interviews, are included in the main document.

Data sharing statement

The current article is accompanied by the relevant raw data generated during and/or analysed during the study, including files detailing the analyses and either the complete database or other relevant raw data. These files are available in the Figshare repository and accessible as Supplemental Material via the Sage Journals platform. Ethics approval, participant permissions, and all other relevant approvals were granted for this data sharing.

Declaration of conflicting interests

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Ethics approval

Ethical approval was obtained from the Birmingham City University ethics board (Ref: PSY_MSc_Jun20_047). Following consent from the Director a recruitment advertisement was placed on the social media pages of a *MRKH Connect* inviting women with MRKH to contact the interviewer. In addition, the Director sent out an email to the women on the *MRKH Connect* mailing list with the recruitment advert. All participants gave informed consent.

Informed consent

As noted all participant gave informed consent.

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