

Girl's and women's experiences of seeking mental health support for symptoms associated with psychosis. A Narrative Review

RUNNING TITLE: Women help-seeking for psychosis: A Review

¹ **Sarah Roberts**, Faculty of Health and Medicine, Lancaster University, ORCID: 0000-0002-8878-5898

² **Dr Sarah Parry**, Faculty of Health and Medicine, Lancaster University, ORCID: 0000-0002-5666-1997; Corresponding author: s.l.parry@lancaster.ac.uk

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Abstract

BACKGROUND

Women are more likely than men to experience symptoms associated with psychosis, such as voice hearing, and more likely to seek mental health support. However, little is known about the emotional experiences of girls and young women who seek help for symptoms of psychosis to inform gender sensitive services and access routes. The current review offers the first focused insights into barriers and facilitators relating to help-seeking for girls and women experiencing symptoms of psychosis.

METHODS

OneSearch, PubMed and PsychINFO databases were searched for suitable papers in relation to the research question between November 2021 and February 2022. 139 papers were found, of which eight met the inclusion criteria for review.

RESULTS

Across the eight papers reviewed, participants were aged 15-71-years-old. From the participant numbers available, data from a total of 54,907 participants from a range of demographic groups were included in the review. Results and findings sections from the eight papers were reviewed for themes, and four overarching themes emerged: (1) the emotional cost of seeking help, (2) voice-hearing for girls and women, (3) side effects of treatment, (4) facilitators to accessing support.

DISCUSSION

Engagement in talking therapies can be difficult when services minimise the experience of psychosis related symptoms. Women may be more likely to have their symptom-related distress diagnosed as a mood disorder, rather than symptoms of psychosis being identified, preventing timely tailored intervention. Normalisation, psychoeducation, social support and validation were recommended as helpful interventions.

Key words: Girls, Women, Help-seeking, Mental Health, Psychosis

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Practitioner Message

1. Women and men experiencing symptoms of psychosis may present differently. It is important women's presentations are understood within a gender context, rather than simply different to men, with men's symptoms considered as 'typical'.
2. When women's symptoms of psychosis are overlooked in favour of diagnoses of mood disorders without an explanation, this can feel invalidating.
3. Women may be more likely to experience voice hearing, particularly aggressive and distressing voice hearing, due to gender-based violence and oppression.
4. Therefore, understanding of trauma-informed care and consideration of trauma-related antecedents are important.
5. Elements of talking therapies such as psychoeducation, normalisation and peer support may be particularly helpful for women.

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Young women aged 16-24-years-old are almost three times more likely to experience mental health difficulties compared to men of the same age (McManus et al., 2016). However, only 15% of young women experiencing mental health distress receive timely mental health support (Lubian et al., 2016). Presently, 31.3% of people with symptoms of psychosis access mental health services (Jaeschke et al., 2021), despite a 29% increase in referrals for a suspected first-episode psychosis between 2019 and 2021 (National Health Service [NHS], 2021). It has been ten years since Seeman (2012) highlighted why it is important that services develop tailored support for women with symptoms of psychosis in particular, although progress has been slow. The most recent review of how adult women experience psychosis spectrum conditions indicated women experience additional mood symptoms compared to men, have double the odds of physical comorbidities, may be more likely to be misdiagnosed causing delays in treatment, and at higher risk of side-effects from pharmacological interventions (Mazza et al., 2021). The current review aims to holistically explore experiences of help-seeking for girls and young women to identify barriers and helpful next steps during this critical developmental period, where early intervention could make a significant difference.

Psychosis can be characterised by multi-sensory hallucinations (Toh et al., 2021), delusions, paranoia, and a distorted view of reality (Marie, 2020). The usual period of onset for women is during one's late-twenties (Li et al., 2016). Psychosis is associated with decreased quality of life and life expectancy (Šimunović et al., 2020), which is why early intervention and support is so important. Suicide is also a significant cause of death for

people with psychosis (Aydın et al., 2019), potentially related to the hallucinations and delusions experienced (Bornheimer et al., 2020) and the stress of associated stigma (Pyle et al., 2015), which can influence one's self-concept clarity (Noyman-Veksler et al., 2013).

Psychosis remains a highly stigmatised mental health condition (Huggett et al., 2018). Fears of stigmatisation can be a significant barrier to help-seeking for psychosis (Haavik et al., 2019), with 73.5% of individuals with suspected first-episode psychosis waiting over the recommended time to seek help (NHS, 2021).

Another factor to influence help-seeking and the severity of symptoms appears to be gender. When seeking support, women have reported being perceived as 'overdramatic', 'attention seeking' and having symptoms underestimated by practitioners (Ferrari et al., 2018, p. 358). Women are also more likely to be misdiagnosed, causing a delay in receiving appropriate care (Mazza et al., 2021). Women can also experience specific gendered features of distressing auditory hallucinations, such as persecutory male voices, perceived as abusive and infantilising, appearing to reflect oppression against women in areas of society (McCarthy-Jones et al., 2015). The voices heard by women can also express derogatory sexual comments that are gender-specific, demonstrating gender prescriptions placed upon women around sexual conduct (Mitropoulos et al., 2015).

To explore the challenges, barriers and facilitators to timely mental health support, this narrative review aimed to explore the experiences of girls and women seeking mental health support for symptoms associated with psychosis. This timely review of primary and secondary research will identify important factors specifically relevant for supporting women and girls with symptoms associated with psychosis.

Method

Eligibility Criteria

For inclusion, the studies needed to focus on symptoms of psychosis, whether this be a clinical diagnosis or symptomology, for example voice-hearing, hallucinations and unusual sensory experiences. Studies also needed to include, but not be limited to, the experiences of girls and women aged 13-24-years-old seeking mental health support for symptoms associated with psychosis. Publications were required to be peer reviewed and published in English.

Search Strategy

An initial exploration through OneSearch facilitated the mapping of the field of literature in relation to the research question. Search terms employed were: “psychosis”, “schizophrenia”, “voice-hearing”, “hallucinations”, “unusual experiences”, and “help-seeking”, “support”, “mental health services”. These differing terminologies were used to ensure a comprehensive search of the literature, as often different terms are used to represent symptoms associated with psychosis. A second string of “girls”, “women”, “female” was added to ensure identified literature was relevant to girl’s and women’s experiences of help-seeking.

Throughout the second phase, PubMed and PsychINFO databases were systematically searched using the aforementioned terms. The filter function was employed to source publications with girls and women aged 13-24-years-old. This age range was used due to the higher likelihood of young women experiencing mental health difficulties (McManus et al., 2016), which peaks during the often turbulent transition through adolescence from childhood to adulthood (McGorry & Mei, 2018). Even with this specific focus, it was challenging to

source publications specific to adolescence, suggesting further research is needed with adolescents.

This search produced 139 results, which were then carefully reviewed to determine their relevance in relation to the research question. A large number of studies (102) were excluded following a review of the abstracts as they were not specifically focused on experiences of help-seeking. The remaining 37 studies were then read in full to establish suitability, of which 29 were excluded due to the focus being on carers of individuals, rather than people with direct lived experience of help-seeking for symptoms associated with psychosis. Finally, eight studies were identified as meeting the inclusion criteria.

Data Extraction and Analysis

Of the eight studies selected for review, the content was reviewed carefully and summaries written of each paper in relation to the research question of the review. The summaries were then analysed for common themes in relation to the research question, attending specifically to experiences of girls and young women within the texts. Overarching themes were then checked against the original manuscripts to ensure the integrity of the original reporting had been maintained throughout the synthesis and thematic interpretation. Four themes emerged relating to (1) the emotional harm caused by seeking help, (2) voice-hearing for girls and women, (3) side effects of treatment, (4) facilitators to accessing support; cumulatively offering the first focused insights into factors relating to help-seeking for girls and young women experiencing symptoms of psychosis. The selected studies for review included six reviews and two sources of primary research, one qualitative and one quantitative, published across eight separate journals.

TABLE ONE: *Summary of Selected Studies*

Study author(s)	Summary	Participant demographics
Ferrari et al. (2018)	Qualitative study exploring gender differences in routes to care within young people with lived experience of psychosis. Using focus groups and individual interviews	25 individuals of all genders, African-origin, Caribbean- origin, European-origin, service users of early intervention psychosis services, aged 19 – 27 years
Ferrara & Srihari (2021)	Literature review, exploring factors which may impede women regarding access and quality of care within first episode psychosis services	2,774 individuals of all genders with first-episode psychosis, European descent, aged 23-41 years
Mazza et al. (2021)	Narrative Literature Review exploring gender differences within schizophrenia spectrum disorders	51,859 individuals of all genders, with schizophrenia and related psychotic related disorders, European descent, aged 18-65 years
Ochoa et al. (2012)	Literature review summarising significant findings regarding gender differences in first episode psychosis and schizophrenia	All genders, individuals with schizophrenia and first-episode psychosis, wide range of cultures globally

McCarthy-Jones et al. (2015)	Literature review exploring historical understanding of women hearing voices. Interdisciplinary, mixed methodology study of women's experiences of hearing voices, using interviews and Interpretative phenomenological analysis	Qualitative study: 8 women who experience voice-hearing, aged 18-65 years, European, Australian, African-Caribbean and African descent. Quantitative study: 197 individuals of all genders, aged 15-63 years who experience voice hearing, culture not specified
Haarmans et al. (2018)	Quantitative study exploring the effect of gender-role strain on psychotic experiences of women, using a series of questionnaires	44 women with a diagnosis of schizophrenia spectrum disorder and with no clinical diagnosis, from a white and minority ethnic background. Age range 19-71 years
Seeman (2020)	Literature review exploring women's experiences of schizophrenia and treatment	All genders, individuals with schizophrenia, wide range of cultures globally
Haarmans (2019)	Literature review exploring sex and gender differences within psychosis	All genders, individuals with schizophrenia, from White, European and Asian descent

Findings

Theme 1: The Emotional Harm Caused by Seeking Help

A common theme identified across four papers related to the adverse emotions felt when attempting to access support. For instance, in Ferrari et al.'s (2018) qualitative study, women described feeling ignored, mistrusted, and judged by services. Their diagnoses had also been denied due to them being perceived as 'too functional' by practitioners. Although women in general present as functioning relatively well alongside psychotic symptoms compared to men (Mazza et al., 2021), this presentation does not indicate less distress or the severity of symptoms. Further, being labelled with gender stereotyped terms such as 'drama queen' also led to delays in treatment. One woman expressed that she still did not receive support after a suicide attempt. Overall, negative experiences and rejections from mental health services led to women feeling self-doubt around their symptoms and mental health. Women felt as though they were "not sick enough", only able to receive support when they "reached rock bottom", which impacted women's readiness to talk about their symptoms, and their ability to continue seeking help.

These findings were replicated by Ferrara and Srihari (2021), through which women were perceived to have better overall functioning during the onset of their symptoms, which could lead to feeling undervalued as someone in need of care and treatment delays. Ferrara and Srihari also noted another specific disadvantage faced by women when help-seeking. Typically, symptoms associated with psychosis are often clinically recognised later in women compared to men (Mazza et al., 2021; Ochoa et al., 2012), potentially due to the tendency for mood symptoms relating to psychosis, such as depression and anxiety, being more common for women's presentations (Comacchio et al, 2020; Ochoa et al., 2012). Therefore, the emotional response to the symptoms, the symptom-related distress, may be the focus for diagnosis, as opposed to the symptoms themselves. Mazza et al. (2021) and Ochoa et al. (2012) echo Ferrara and Srihari's crucial point that women are more likely to be

diagnosed incorrectly with a mood disorder, which can exclude women from early intervention services for psychosis.

This postponement in receiving support leads to adverse outcomes relating to psychosis later in life, with more severe and resistant symptoms (Drake et al., 2020), decreased social functioning, and quality of life (Murru & Carpiniello, 2018; Penttilä et al., 2014). Overall, due to women and men presenting differently with psychosis symptoms, perhaps especially younger women, opportunities for early intervention are missed for girls and women (Høye et al., 2011).

Theme 2: Voice-hearing for Girls and Women

The nature of voice hearing as reported across the reviewed studies indicates a significant gender effect relating specifically to how and what women hear. Voice-hearing is more common for women than men (Riecher-Rössler et al., 2018; Seeman, 2020), demonstrating another pre-existing vulnerability faced by women. McCarthy-Jones et al.'s (2015) qualitative study explores how women were perceived when accessing support for voice-hearing from mental health services. McCarthy-Jones et al. outlines that historically, hearing voices was labelled as "hysteria" by male physicians if the voice-hearers were women, which seems to bear resemblance to experiences today. Women reported feeling that modern psychiatry focussed on biomedical explanations for voice-hearing and interventions such as antipsychotic medication conceptualised their experience in a reductionistic fashion, ignoring the role played by negative life experiences and the emotions these may cultivate. Experiences in which society and services reattributed women's frustrations, exposure to adversity, and repression to indicators of mental illness were seen as another barrier to help-seeking.

The likelihood of voice-hearing can increase significantly if the individual has experienced rape (Bentall et al., 2012) or childhood abuse (Chaiyachati & Gur, 2021). Women are more likely to experience child abuse than men (1 in 4 women vs. 1 in 6 men; Office for National Statistics, 2020). Women are also more likely to experience rape than men (1 in 5 women vs. 1 in 71 men; Black et al., 2011), suggesting these traumatic experiences pose a significant vulnerability for women. Research typically characterises 'adverse life experiences' as being isolated occurrences, such as an attack, neglect, or bereavement. However, it is important to note that abuse also occurs systemically and over the long-term, particularly for women (Haarmans et al., 2018), such as the consistent oppression of women within a patriarchal society (McCarthy-Jones et al., 2015). Consequently, considerations of adversity such as harassment, marginalisation and disempowerment should inform formulation and decision making in relation to care planning.

McCarthy-Jones et al. stresses that purely biological explanations for voice-hearing discount the relationship between trauma and voice-hearing, which is now widely accepted. McCarthy-Jones et al. states that the association between trauma and voice-hearing should promote the view that voice-hearing for women is not simply a symptom of pathology, but potentially a result of a patriarchal society that has continuously assumed control over women's bodies.

Further, Haarmans et al. (2018) proposes that adverse life experiences can result in negative self-beliefs, which evidence suggests can lead directly to the onset of voice-hearing. Various models of self-criticism also propose that critical self-thoughts are a result of a negative self-view (Beck, 2011; Young et al., 2003), which can be reflected in voice content (Beck & Rector, 2005; Paulik, 2012). Although, analysis of voice content is still

developing and additional research is required (Scott et al., 2021), influences on content and self-concept seem particularly important to explore in relation to the female experience of voice hearing.

Similarly, Haarmans et al. (2018) suggests people from disadvantaged positions in society are more susceptible to developing symptoms associated with psychosis, such as voice-hearing. These disadvantages can include social inequality and discrimination, which women often face. This emphasises the importance of mental health services considering potential antecedents leading to the development of symptoms associated with psychosis, facilitating collaborative formulation and understanding.

Women in McCarthy-Jones et al.'s (2015) study described that oppressive practices in healthcare services left them feeling prohibited from listening to or interpreting their voices, thereby limiting their own self-understanding. Even women who experienced comforting voices felt distress due to internalised stigma, leading to feelings of shame and being silenced. Women also felt disempowered due to their symptoms being pathologized, and feared being further stigmatised or discriminated against, conversely feeling forced to rely on mental health services for support. This seems paradoxical, as it is the practices of these services which have contributed to this adversity. Overall, women described internalising the narrative around their voice-hearing being part of an 'illness', experiencing damaging and long-lasting effects in several aspects of their lives. Women also felt an added detriment was the gender stereotypes placed on them as women voice-hearers. One woman stated she was worried about being viewed as "that strange mad woman", and another expressed: "you're up against it as a woman in the first place... hearing voices ain't gonna do you no favours". Haarmans et al. (2018) discussed how gender roles contribute to women's negative self-beliefs, such as perceived failure to adhere to gender norms.

Theme 3: Side Effects of Treatment

Evidence from Mazza et al. (2021), Ochoa et al. (2012) and Seeman (2020) suggest that even when women are able to overcome barriers to accessing help, women are more likely to experience adverse side effects from antipsychotic medication. Seeman (2020) provides an in-depth discussion, highlighting the extensive list of serious potential side effects, such as loss of menstruation, impacts upon appearance, and increased risk of stroke, pulmonary embolisms, osteoporosis and breast cancer. Cross-sectional studies have estimated the prevalence of side effects to be up to 75% of women compared to 42% of men who are receiving antipsychotics (Kinon et al., 2003). These side effects have been seen particularly within young women (O'Keane, 2008), indicating that clinical trials need to be explicit about gender representation of participants (Howard et al., 2017) when informing the evidence base on the safety and efficiency of anti-psychotic medication.

Theme 4: Facilitators to Accessing Support

In terms of what helped women access support, participants across the studies spoke of social relationships, support groups and voluntary organisations being helpful, through which comprehensive peer support and psychoeducation helped with managing symptoms and stigma (Haarmans, 2019; McCarthy-Jones et al., 2015). Further, Schön (2010) describes how gender roles can be advantageous for women, with increased acceptance around relying on family support. Overall, there was little mention of helpful approaches mental health services were taking to support young women in particular, highlighting the urgent need for more research in this area. General facilitators included normalisation (McCarthy-Jones et al., 2015), tailored care for women, focusing on addressing negative

self-beliefs, which may be gender-specific (Haarmans et al., 2018; Mazza, et al., 2021), critical evaluation of societal gender roles, expanding to a systemic level of support to decrease self-blame for young women who experience symptoms associated with psychosis (Haarmans et al., 2018; Haarmans, 2019). Overall, a culture change is needed within mental health services to recognise differences in the presentation and needs of young women, which are still in need of further research.

Discussion

The current review indicates women experience many barriers when help-seeking for symptoms associated with psychosis. The four themes presented in this review demonstrate how women have felt dismissed and stereotyped by mental health services (Ferrari et al., 2018; Ferrara & Srihari, 2021); their symptoms are seen as atypical compared to men's or are misdiagnosed all together (Mazza et al., 2021; Ochoa et al. 2012), leading to delays and obstacles in care (Ferrara & Srihari, 2021). Women therefore miss out on timely mental health support, resulting in poorer outcomes later in life (Drake et al., 2020; Murru & Carpiello, 2018).

In particular, women who hear voices have experienced significant gender stereotyping and disregard in mental health services. Medicalised explanations and pharmacological interventions are less helpful for women than men (McCarthy-Jones et al., 2015). There are significant links between traumatic events and hallucinations, which women may be more vulnerable to due to gender-based violence and oppression (Black et al., 2011; Office for National Statistics, 2020), leading some women to be more likely to hear voices (Bentall et al., 2012; Chaiyachati & Gur, 2021). It has also been argued that negative self-beliefs produced by experiencing trauma can contribute to the onset of voice-hearing (Haarmans, 2018). Both of these elements do not always appear to be considered as

antecedents by mental health services (McCarthy-Jones et al., 2015; Haarmans, 2018), which can lead women to feel invalidated and misunderstood.

Overall, mental health support for symptoms associated with psychosis for girls and women should focus upon normalisation (McCarthy-Jones et al., 2015), consideration of trauma-related antecedents (Haarmans et al., 2018), and a critical evaluation of gender prescriptions placed on women to improve quality of support (Haarmans, 2019). The lack of studies available for review that have included girls and younger women who experience symptoms of psychosis demonstrates this is an area in desperate need of research, so the voices and experiences of younger age groups can inform gender sensitive access to timely and suitable support.

Clinical Implications

There are consistent barriers and challenges faced by women when accessing mental health support for symptoms associated with psychosis. Therefore, services should incorporate gender-informed practices as much as possible. For example, consideration of the specific traumatic events women may have experienced, particularly in relation to voice-hearing (Bentall et al., 2012; Chaiyachati & Gur, 2021). Gender-informed communication at the point of access to services could reduce feelings of dismissal and stereotyping. Further, guidance for clinicians on the differences in symptomology and impact of side effects of pharmacological interventions would be beneficial. This could reduce instances of misdiagnosis, delays in treatment and physical comorbidities.

Women internalising the narrative of their voice hearing being pathological, the dominance of the medical approach within psychosis and the misdiagnosis of women with psychosis as having a mood disorder indicate a diagnosis-centric framework within services. Rather than services labelling individuals with a condition that the individual may not feel

aligns with their experiences, services could explore symptoms within the context of experience and understanding (Dillon, 2013). For instance, instead of asking “What is wrong with you? What shall we call it?”, services should be asking “What happened to you? What do you need?” (Read, 2019). For people who do not feel as though a diagnostic label would be validating or beneficial for treatment options, this approach could facilitate collaborative formulation and reduce the risk of iatrogenic harm. For voice-hearing in particular, increased use of a wider range of psychological interventions as a primary treatment option may be beneficial. For example, Hallucination-focused Integrative Therapy (Jenner, 2016) has been shown to be effective in decreasing symptoms (Bighelli et al., 2018) and improving quality of life (Wiersma et al., 2004). The very early body of research exploring voice hearing in childhood and adolescence indicates that girls are more likely than boys and non-binary young people to experience distressing voice hearing and more likely to seek help from services (Parry, Lauren, & Varese, 2021). However, the current review has highlighted the many barriers girls and young women face in help-seeking, which is an area in need of urgent further study.

Limitations and Future Research

Although qualitative inquiry often provides rich data from people with lived experience, the small sample sizes of the reviewed studies limits generalisability. Additionally, the dominance of biomedical conceptualisations of psychosis in the Global North and over-representation of men in clinical trials for pharmacological interventions disadvantages exploration of how holistic and social support may be helpful for young women. For example, school and university communities could offer much in the way of normalisation, peer support and psychoeducation for girls in particular. Further, different cultures hold varying views regarding symptoms of psychosis, such as perceiving voice-hearing to be a spiritual occurrence (Perez, 2015), which carries less stigma. Further cultural exploration could provide new opportunities for exploring understanding and support, leading to a broader awareness of how symptoms of psychosis are experienced by genders and cultures.

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