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Article

“You Have No Idea How Much ‘Just Get the Shot’ Is Triggering Me”: Experiences of COVID-19 Vaccination in Individuals with Psychosis and Schizophrenia

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Abstract: The COVID-19 pandemic has presented those with experience of psychosis with a number of additional challenges. In the present study, we extend previous literature on this subject to explore experiences of COVID-19 vaccination in those with psychosis or schizophrenia. We analysed 38 posts from three popular Reddit sites for individuals with experiences of psychosis and schizophrenia. We employed reflexive, inductive thematic analysis and identified the following two themes: (i) facilitators for COVID-19 vaccination uptake, and (ii) barriers to COVID-19 vaccination uptake. The facilitators consisted of (i) trust in science/fact-checking, (ii) fear of the virus/vulnerable status/personal experience, (iii) help from trusted people, (iv) others becoming vaccinated, (v) rationalising fears/paranoia, and (vi) moral decision/contact with vulnerable people. The barriers consisted of (i) lack of trust (in doctors, government, science), (ii) psychosis about things inserted into the body/fear of adverse reactions, and (iii) increased paranoia because of the coercive tone of discussions around the vaccination. It is clear that public health guidance can be problematic for individuals who have lived experience of psychosis. We recommend employing experts by experience in the design of public health campaigns that aim to reduce the fear around COVID-19 vaccinations.

Keywords: COVID-19; online forum; pandemic; psychosis; schizophrenia; vaccination



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1. Introduction

The impact of the COVID-19 pandemic on the physical and mental wellbeing of the general population is well-documented (del Rio et al. 2020; Hossain et al. 2020), though people with pre-existing mental health conditions have been disproportionately affected by COVID-19 (Brewer et al. 2022). In particular, though causal mechanisms remain unclear, research indicates that people with psychosis or schizophrenia have an increased risk of COVID-19 related morbidity and mortality (Mohan et al. 2021). A range of factors may contribute to this increased susceptibility, including lower levels of health literacy, increased incidence of risky health behaviour (such as smoking) or comorbid conditions, and difficulties accessing the stable housing required for social distancing (Kozloff et al. 2020; Shinn and Viron 2020).

Symptoms of mental distress may also be exacerbated by the COVID-19 pandemic. For example, patients with schizophrenia who have experienced COVID-19 in the previous 12 months report more psychological distress and worse psychological recovery than those who have not (Caqueo-Urizar et al. 2021). However, experiences are highly variable (Hudon et al. 2022), with other research suggesting that outpatients with schizophrenia have coped well with the pandemic (Kotlarska et al. 2022). Such studies typically focus on the overall experiences of COVID-19, though some aspects of the pandemic may be more problematic than others. For example, Patel et al. (2022) highlights the extent to which the pandemic impacted the community participation of young adults with early psychosis. In the present

study, we aim to extend the previous literature on this subject and explore experiences of COVID-19 vaccination in those with psychosis or schizophrenia through qualitative analysis of online forum posts.

A sizeable proportion of the population (around 20–70% depending on the specific country) hesitate or refuse to accept a COVID-19 vaccination (e.g., [Murphy et al. 2021](#); [Nemat et al. 2021](#); [Sallam et al. 2021](#); [Solis Arce et al. 2021](#)). It is essential to understand the reasons for this hesitancy, which limits the success of vaccination programmes (see [Salali and Uysal 2021](#)). Some of the many factors behind vaccine hesitancy include concerns about COVID-19 vaccine side effects and safety ([Lockyer et al. 2021](#); [Solis Arce et al. 2021](#)), distrust in governments ([Tram et al. 2022](#)), and conspiratorial beliefs ([Allington et al. 2021](#); [Jennings et al. 2021](#); [Sallam et al. 2021](#)). COVID-19 vaccine hesitancy has been intensively studied in the general public (e.g., [Khubchandani et al. 2021](#); [Murphy et al. 2021](#); [Perveen et al. 2021](#); [Taylor et al. 2020](#)). However, we have less knowledge of experiences of vaccination in vulnerable populations, such as in individuals with experiences of severe forms of mental distress. In this study, we add to the existing literature on COVID-19 vaccination hesitancy by exploring the issues faced by those who self-identify as having lived experience of psychosis or schizophrenia.

The reasons for investigating experiences of COVID-19 vaccination in individuals with psychosis are compelling. Due to higher COVID-related morbidity and mortality, there has been a call for prioritising people with severe mental illness in vaccination programmes ([De Hert et al. 2021](#); [Mazereel et al. 2021a](#); [Warren et al. 2021](#)). However, quantitative evidence on the uptake of vaccination is varied. Some studies have reported that psychiatric disorders are not necessarily linked to increased hesitancy around the COVID-19 vaccine ([Jefsen et al. 2021](#); [Mazereel et al. 2021b](#)), whereas others have found that individuals with a schizophrenia diagnosis may be less likely to accept the vaccine than people from the general population ([Bitan 2021](#); [Bitan et al. 2021](#)). It seems that the findings from one study population cannot be generalised to other populations. In order to understand the specific issues faced by individuals with psychosis, it would be beneficial to employ a bottom-up approach, utilising a qualitative method in investigating experiences around the COVID-19 vaccination.

There are several potential barriers and facilitators to COVID-19 vaccine uptake in people with psychosis. First, lack of trust in scientists, medics, and the government ([Allington et al. 2021](#)), as well as belief in conspiracy theories ([Allington et al. 2021](#); [Bertin et al. 2020](#); [Burke et al. 2021](#); [Freeman et al. 2020](#); [Sallam et al. 2021](#); [Soveri et al. 2021](#)), relate to vaccination hesitancy in the general population. These could be prominent barriers for vaccination uptake specifically in people at the higher end of the psychosis continuum, who may already have low trust (e.g., [Ratcliffe 2015](#)) and conspiratorial beliefs ([Georgiou et al. 2019](#)). Indeed, the pandemic could play a role in increased distrust, paranoia, and conspiracy beliefs in individuals with experiences of psychosis ([Lyons et al. 2023](#)), and this could later translate into refusal to accept the vaccination.

Second, much of the discussion around COVID-19 vaccination has involved debates around mandatory versus voluntary programmes (e.g., [Pennings and Symons 2021](#)). The care for individuals with psychotic experiences is peppered with examples of coercive care, where people comply out of fear rather than their own volition (e.g., [Wade et al. 2017](#)). Having a choice and control in one's own healthcare is crucial for individuals with experiences of psychosis (e.g., [Wood et al. 2019](#)), and the coercive tone around the COVID-19 vaccination could increase paranoia and hesitancy. Third, some factors could facilitate the uptake of COVID-19 vaccination. For example, people who have vulnerabilities that could increase morbidity and mortality are more likely to take the vaccination ([Aw et al. 2021](#)). Psychosis relates to multiple physical and psychosocial vulnerabilities increasing COVID-19 related risks (e.g., [De Hert et al. 2021](#)). Knowledge of these vulnerabilities could be a reason for accepting the vaccination for individuals with psychosis.

In the present study, we were interested in exploring experiences and opinions around COVID-19 vaccination in individuals who self-identify as having a psychosis/psychotic

disorder. To investigate this topic, we collected posts from three popular online discussion forums on Reddit, aimed at people with schizophrenia, psychosis, or schizoaffective disorders. Online discussion forums can be an important and reliable source of lived experiences and have been successfully used in researching lockdown experiences in people with psychosis (Lyons et al. 2023), as well as other forms of mental distress (Brewer et al. 2022). We analysed the data using an inductive thematic analysis, with the broad question “What are the experiences of COVID-19 vaccination uptake in individuals with psychosis and schizophrenia”.

2. Materials and Methods

2.1. Selection of Forum Posts

We utilised a popular online discussion forum platform, Reddit, which contains user-generated “subreddits” populated by people with similar interests. Almost half of the forum traffic comes from the United States, with over one third of Reddit users in the 18–29-year-old age group (Statista 2021). For the present study, we collected data from three subreddits for individuals with experiences of psychosis (31,000 users), schizophrenia (44,000 users), and schizoaffective disorders (10,000 users at the point of data collection). We searched the subreddits using the words “vaccination, vaccine” in order to identify and retrieve relevant posts.

It is important to acknowledge that some of the subreddit forums stated their position on spreading misinformation about vaccines, with statements about removing posts and banning the posters disseminating false information. Therefore, the forum posts (and subsequent analysis) may not reflect the full spectrum of experiences of forum users in these communities. Misinformation about COVID-19 is prominent on online forums including Reddit (Cinelli et al. 2020) and moderation is heavily reliant on user feedback (Bozarth et al. 2023). As a consequence, social media users may be vulnerable to misinformation, especially in relation to the prevention or treatment of COVID-19, which can delay engagement with effective vaccination or treatment or lead to serious side effects. At present, it is difficult to determine the extent to which misinformation may be more or less common in subreddits targeted at specific users and future research should address this issue.

Only posts that discussed personal experiences (e.g., opinions, feelings, and behaviours) around COVID-19 vaccination uptake were included. Our approach provides an insight into those issues that are most important to forum users with psychosis/schizophrenia rather than issues prioritised by researcher agenda or interpreted through the perspectives of healthcare providers or family members. At times, the subreddits included arguments and personal insults between individuals with differing opinions, which were not analysed in the present study. In addition, many of the posts gave peer support and advice, which also were not analysed in the current study. The search identified 38 relevant posts with unique usernames. As well as the initial post, we included responses if they were deemed appropriate (i.e., respondents discussed their own experiences, rather than gave advice only). The posts were written between September 2020 and September 2021.

2.2. Ethical Issues

Although the study does not have participants in the traditional sense, we obtained ethical approval from the Institutional Review Board (ref: 7680). At all stages of the research, we consulted ethical guidelines and guides on internet studies (e.g., Smedley and Coulson 2021). We paid careful attention to the public or private nature of the information, benefits of the research outweighing the harms, and the lack of feasibility of seeking informed consent (Eysenbach and Till 2001; Roberts 2015). For example, as posts were added to subreddits with a large number of users (31,000, 44,000, and 10,000 members at the time of the study) rather than social platforms where users may share their thoughts and experiences with a limited number of people that they have personally ‘friended’, we considered that the posts were more “public” than “private” in nature. Though posts were addressed to a large number of online strangers in openly available Reddit communities (Eysenbach and Till

2001), we adopted a number of measures in order to mitigate potential harm, especially around anonymity. For instance, we assigned a number to each post and did not include the username. In addition, we altered the wording of the quotes so that they cannot be traced back to the original post. We think that the potential benefits of the study (i.e., understanding lived experiences around COVID-19 vaccination) outweigh the risks of the research.

2.3. Data Analysis

The research team consisted of two faculty members, both with extensive experience of qualitative and quantitative discussion forum research. In addition, one of the researchers (ML) has years of experience of teaching and researching psychosis, with a heavy emphasis on understanding lived experiences. The two researchers independently read the posts several times and started the initial coding of the data for reflexive inductive thematic analysis (Braun and Clarke 2022). The initial codes included ‘distrust of government’, ‘delusions on insertion of device’, and ‘fear of injections’. We chose this type of thematic analysis as we felt that it would best represent the multifaceted experiences of the online communities for people with psychosis. We also wanted to ensure that codes and themes were led by the experiences and opinions of forum posters rather than the agenda and priorities of the researchers. The researchers held a meeting where the codes were discussed and refined. ML organised the codes into themes, which both of the researchers agreed with, after extensive discussions. Because of the reflexive, inductive nature of the analysis, we did not calculate inter-rater reliability in coding, or adopt structured codebooks (Braun and Clarke 2022).

3. Results

We identified the following two main themes: (i) facilitators for COVID-19 vaccination uptake and (ii) barriers to COVID-19 vaccination uptake. Each theme contained a number of sub-themes.

3.1. Theme 1: Facilitators for COVID-19 Vaccination Uptake

Forum posters discussed several factors that had either already encouraged them to accept the vaccine, or positively impacted on their intention and willingness to accept the vaccine in the future. It was clear that the posters utilised a range of coping mechanisms that facilitated vaccine uptake and many of the coping strategies were informed by their previous experiences with psychosis-related paranoia. The facilitators consisted of (i) trust in science/fact-checking, (ii) fear of the virus/vulnerable status/personal experience, (iii) help from trusted people, (iv) others becoming vaccinated, (v) rationalising fears/paranoia, and (vi) moral decision/contact with vulnerable people.

3.1.1. Trust in Science/Fact-Checking

Many posters reported that they trusted the science ‘behind’ vaccination, and actively sought credible information relating to the development of the vaccines. For instance, one person discussed how they are “... a scientist in the making. I don’t doubt the science behind the vaccinations and am generally not an antivaxxer” (Post 1). The posters acknowledged that the vaccinations may not be perfect, but believed them to be safe and functional, stating that “The vaccine isn’t perfect, but it’s decent enough to prevent or mitigate Covid infections” (Post 3), or “the evidence so far suggests that the vaccine is safe” (Post 16). Some went to great lengths when checking the facts, including investigating the background of the scientists who published research studies “Investigating the scientific researchers credentials also helped” (Post 24).

3.1.2. Fear of the Virus/Vulnerable Status/Personal Experience

One factor that facilitated vaccination uptake was that the fear of the virus exceeded the fear of vaccination. One person who had already taken the vaccination discussed

how it helped that they are “... as afraid of deadly diseases like Covid as I am of doctors. It is horrendous” (Post 1). Many talked about how their psychosis medication could actually make them more vulnerable to COVID-19, which should place them in a priority group for vaccination, and stated the following: “... wondering if any states give vaccine priority to especially those taking clozapine? I would like to get the vaccine, but I am not eligible. I am afraid of dying from covid because I’m taking clozapine” (Post 14). Personal experience of COVID-19, either through a loved one catching the virus, or the person themselves getting ill also facilitated uptake. For example, Poster 3 talked about how “Covid sucks ass. If anyone, I should know it, have had it twice ... took the vaccine too afterwards, because I really don’t want to get it again”.

3.1.3. Help from Trusted People

Trusted others (e.g., friends, partners, family) were an important facilitator for many posters. Their role was important in encouraging and reassuring vaccine uptake, as well as helping to organise and attend appointments. For example, one person wrote how “I was able to go the appointment by going together with my partner. I told myself that every thought I had was just the illness. My partner is smart and does not have this same illness so he knows, better listen to him. It was super hard but I did it and didn’t get side-effects from the vaccine” (Post 2). Trusted people arranging the appointments, and even receiving their vaccinations at the same time were especially helpful. Poster 24 praised their mother for being there at the same time to get her vaccination, stating the following: “It helped that my mother was there with me for both shots. Could have not done it on my own. This pandemic has fucked my mental health over. But she was there, getting the shots with me”.

3.1.4. Others Becoming Vaccinated

Observing and hearing about other people receiving the vaccination made it easier for people to decide whether to become vaccinated themselves. Friends were a good model for reducing hesitancy, demonstrated by the following statement: “... was so great seeing my friends take it, and be just fine” (Post 26). Many of the posters specifically discussed how the people they knew experienced very few side effects (that were not serious) after receiving the vaccination, with one example stating that “I know a few people who have had two doses of the vaccine and had no issues. One friend said the only thing was that she was a little tired after the second dose” (Post 36). Famous people were also identified as role models encouraging vaccination uptake. For example, Poster 35 mentioned how “Pope Francis and Queen Elizabeth are taking it, I’m taking it”.

3.1.5. Rationalising Fears/Paranoia

A common and effective tool for overcoming vaccination-related fear was the use of rational reasoning. Analytic thinking was applied, for example, in combatting paranoia about government conspiracies with the vaccination. Poster 21 wrote how “... if the government wanted to chip everyone, they would be selling these vaccines overseas like hot cakes. Instead, they hoard them for our population. If the vaccine itself was harmful, they would not do that. I hate getting shots, but feel that if someone was going to track me—and I’ve had that paranoia before—it would be in a different form”. In a similar way, Poster 3 advised that others should “... look up the size of the needles they use for microchips in pets. They are massive. The body does not produce enough current to actually power any sort of GPS broadcasting. Compare that to the vaccine needle ... itty bitty little thing, not physically possible for there to be anything ‘funky’ in there.” Others referred to previous paranoid thinking, and recalled how the government-related thoughts were proved false when tested against reality. It seemed that previous experience of paranoia was something that helped individuals to cope with vaccination related paranoias, demonstrated by the following statement: “When I find myself thinking like this, I try to remember similar past beliefs I had and moved past, I remember how they were never true” (Post 26).

3.1.6. Moral Decision/Contact with Vulnerable People

Many posters who had already received the COVID-19 vaccination talked about how they did so because it was their moral duty to protect others. For some, this was borne out of regular contact with vulnerable people. For instance, Poster 6 discussed how they “... got vaxxed as soon as I could. It was free, and I am in regular contact with people who are at high-risk of serious complications/death if they get it. It was a no brainer. Anything less would have been selfish, or even unethical.” Some of the posters were essential healthcare workers, who believed that it was their duty to vaccinate in order to protect others and be able to continue work, stating that “... if I choose not to get vaccinated and get sick, there will be one less healthcare worker. If I get vaccinated, I can meet our patients in their homes and interact with the populations that need my help. This is not grandiosity, people are crying every day because they need someone to just be kind to them” (Post 38). Posters discussed how it was the ‘right thing’ to do, and any risks around the vaccination were worth taking, as shown in the following statement: “I had paranoia, but did it for protecting myself and others, also others who are close to me. Even if it turns into a nightmare, I did it wanting something good” (Post 23). Many discussed how the potential harms around possible side effects and increased psychosis were outweighed by the potential benefits of protecting people from becoming ill or dying.

3.2. Theme 2: Barriers to COVID-19 Vaccination Uptake

We identified several issues that the posters perceived to be barriers to COVID-19 vaccination. In particular, it was clear that past adverse experiences related to low trust in medical professionals, and the coercive tone around vaccination campaigns increased fear and paranoia. The posters discussed barriers in terms of (i) lack of trust (in doctors, government, science), (ii) psychosis about things inserted into the body/fear of adverse reactions, and (iii) and increased paranoia because of the coercive tone of discussions around the vaccination.

3.2.1. Lack of Trust (In Doctors, Government, Science)

One of the recurrent topics focused on distrust of doctors due to previous coercive care practices. Further, many had previous experience with psychotropic medication that made them ill. According to Poster 3 who had a diagnosis of paranoid schizophrenia, “... I am very untrusting of any medical personnel or medication. Especially injections, as it took me almost a year to become comfortable with my paliperidone injections”. According to Poster 13, “I hate anything to do with drugs and doctors. I have such a bad fear of pills that I cannot even swallow when I put them in my mouth. Taking the vaccine is a huge step for me”. Coercive medical care for psychosis had made many individuals suspicious of doctors and medical professionals. They felt that they had been fooled or manipulated into complying with harmful medication in the past, which influenced their current decisions about the COVID-19 vaccination. In the words of Poster 37, “Before taking antipsychotics I trusted doctors and medicine. That trust has been shattered due to how I’ve reacted to medication-horrendous side effects and long-term issues. These are not stipulated when starting on these drugs. We are gaslit by the health industry to do as we are told, even when it could be to our detriment”.

3.2.2. Psychosis about Things Inserted into the Body/Fear of Adverse Reactions

Delusions and paranoias about medical procedures and inserting substances into the body were a significant barrier to vaccination uptake. Many had developed a phobia for needles because of past experiences and discussed paranoia about being injected with microchips or poison. Poster 4 wrote about their experiences with previous injections, saying that “I was delusional in the ER once. They held me down and injected me over and over. I thought it was radioactive poison. I now have a severe phobia of needles. I had to take an ativan before both covid shots, and still broke down and cried in the waiting room”. Posters were concerned about the influence of the vaccination in worsening their psychosis. Many were fearful that if they received the vaccine, they might not recover, with symptoms spiralling out of control. For example, “I am certain that if I get it, I will spend the rest of my life convinced that I

have been intentionally biochemically brainwashed by the government. This belief would be likely to drive me to kill myself, or to spend the rest of my life off my rocker in a psychiatric ward" (Post 20).

This risk seemed to be so great that it outweighed any perceived benefits of the vaccination. Indeed, some posters suggested that those with experience of psychosis or schizophrenia should be exempt from the vaccination if they wished, stating that " . . . a narrative being pushed that anyone who doesn't vaccinate is ignorant is at the end of the day ableist towards psychotic and schizophrenic people. Because people are not getting vaccinated for ignorant reasons it makes it harder for us who have valid reasons justified not getting it. Why is that my problem? Why should I have to risk hospitalization, suicide, or jail because people are unwilling to separate my disabilities from legitimately rude and inconsiderate people, due to the narrative the media is pushing around how to treat ALL unvaccinated people?" (Post 20). Indeed, people often perceived the media as a major contributor, dividing people into 'anti-vaxx' outgroups and vaccinated in-groups.

3.2.3. Increased Paranoia Because of the Coercive Tone of Discussions around the Vaccination

The coercive tone of the dialogue around the COVID-19 vaccinations increased paranoia in some posters, reducing the likelihood of vaccination. For example, " . . . something about this being shoved down our throats, and pushing people to hate unvaxxed people, makes me more paranoid. Maybe there is an unseen reason behind this? To me, personally, the equation doesn't really add up . . . You have no idea how much "just get the shot" is triggering me" (Post 20). The restrictions that many governments have put in place for those who are not vaccinated were problematic for those who experience psychosis. These restrictions also increased paranoia/conspiratorial thinking around the vaccination, demonstrated by the following statement: "Not being able to go to school, get mental health help, or go to work, and people being so fucking rude about me not being vaccinated is developing into some weird paranoia/delusion for me. I'm thinking like those Q conspiracy theorists. I honestly think that I will kill myself before having to get the vaccine . . . " (Post 31). It was clear that coercive discussions worsened the mental health of individuals with psychosis experience, decreasing their future likelihood of vaccination. The governmental restrictions for unvaccinated people had not just an adverse impact on paranoia, but also made it difficult for people to seek help and continue with their normal lives.

4. Discussion

Our research highlights the issues related to COVID-19 vaccinations that are important to those who have experience of psychosis. Using an inductive, reflexive thematic analysis, we constructed two broad themes around facilitators and barriers to vaccination uptake. It was clear that people in the Reddit community experienced several barriers to vaccination. These barriers were understandable, often stemming from previous adverse experiences with medication and health care professionals. The care for people with severe mental distress has historically been coercive in nature (Szasz 1989), with debilitating side effects from medications that are supposed to make the individual feel better (Read and Sacia 2020). It is not surprising, therefore, that the coercive tone of the discussions around the COVID-19 vaccinations increased feelings of paranoia and hesitancy.

There has been much discussion about the benefits of coercive and incentivised versus persuasive strategies in vaccination campaigns (Pennings and Symons 2021; Savulescu 2021). Our results demonstrate that coercive strategies can be detrimental to individuals with psychosis and schizophrenia, and this should be acknowledged in public health policies and vaccination campaigns. Additionally, people discussed concerns about the potential for the worsening of psychosis if they agreed to accept the vaccination. Many had previous paranoias about inserting harmful things (e.g., poison, tracking devices) into their body, and were fearful that these paranoias would spiral out of control. These barriers are serious, especially knowing that paranoia and suicidality are highly co-morbid, accentuated

by stressful life events (Carrillo de Albornoz et al. 2021). Those supporting individuals with psychosis or delivering the COVID-19 vaccination should address these concerns.

However, some of the facilitators discussed in the forums were also a consequence of the lived experiences of psychosis, suggesting that people in this community could provide important guidance for general populations who report fears and paranoia about the vaccination. For instance, rationalising paranoias is a strategy that individuals with psychosis use more widely (Aggelidou and Georgaca 2017) and was employed as a coping strategy around the COVID-19 vaccinations. Hence, knowledge and expertise of dealing with fear and paranoia could be useful when planning public health interventions and policies around vaccinations. Our suggestion is to employ people with lived experience of psychosis as experts when designing campaigns (see also Lyons et al. 2023).

It is especially interesting to observe the rationalising of fears and paranoia in those with psychosis or schizophrenia in the context of previous research. In particular, in the general population, increased fear during pandemics is exacerbated by conspiracy theories that focus on the nature of the origin of the pandemic and government responses to it, often leading to emotional rather than rational responses (Freckelton 2020). It has been suggested that in general populations, delusion proneness (with cognitions and perceptions similar to those observed in psychosis spectrum disorders) (Acar et al. 2022) and paranoid ideation (Kuhn et al. 2021) are associated with COVID-19 conspiracy beliefs. Further research is required to understand the relationship between paranoid or delusional beliefs and endorsement of conspiracy theories in both clinical and general populations.

Our study is not without limitations. Due to the anonymous nature of the subreddits, we could not obtain background information of the posters. We could not verify important details such as country of residence, sex/gender identity, age, diagnosis, or severity of psychosis. As experiences of COVID-19 have been highly variable in this population (Hudon et al. 2022), additional research is required to identify the importance of diagnosis type and symptom severity, etc. In particular, our data do not allow us to distinguish between those who are responsive or resistant to treatment. These populations may differ in important ways, for example with respect to symptomology, lifestyle, and previous interactions with medical professionals (Nuciflora et al. 2019; Panov and Panova 2023; Sakinyte and Holmberg 2023). Future research should explore the lived experience of COVID-19-related issues such as vaccination in each clinical group. Similarly, as hesitancy to receive the COVID-19 vaccination is associated with other mental health conditions including anxiety and phobia (Payberah et al. 2022), additional research taking comorbidity of mental health conditions into account is required.

Similarly, because of the Reddit user demographics, it is possible that many of our posters were relatively young people from the US (Statista 2021), representing the experiences of a narrow subsection of those with psychosis. However, it is not possible to verify this. For future research, we suggest qualitative interviews with service users from different countries and backgrounds to see if the experiences with COVID-19 vaccination are unique to different circumstances. For instance, previous studies on schizophrenia and vaccination hesitancy have produced different results depending on the population under study (Bitan 2021; Bitan et al. 2021; Jepsen et al. 2021; Mazereel et al. 2021b), suggesting that the experiences are heterogeneous in nature.

In addition, we recommend employing experts by experience to implement service user-led research (e.g., Corstens et al. 2014) in order to gain the most accurate and authentic representation of the barriers and facilitators of vaccine uptake in people with experience of psychosis and schizophrenia. Despite the limitations of online forum research, the findings highlight an under-researched area that can form a basis for subsequent studies. Indeed, themes identified through the analysis of discussion forum posts (e.g., Lyons et al. 2023) have been replicated in subsequent studies (Kaltenboeck et al. 2023).

Though psychosis appeared to influence a number of unique facilitators and barriers, others were similar to those identified in general populations. For example, “doing the right thing” (e.g., Rieger 2020), modelling peers (Schneider et al. 2021), and the perceived

threat of COVID-19 (Khubchandani et al. 2021) were some of the common facilitators. Concerns about side effects (Taylor et al. 2020), and low levels of trust (Freeman et al. 2020; Lockyer et al. 2021; Murphy et al. 2021) were some of the common barriers. In many ways, individuals with psychosis had experiences that were more similar than dissimilar to the general population.

To conclude, we investigated the issues that those with psychosis discuss related to COVID-19 vaccinations, identifying a range of facilitators and barriers to vaccination. It is a complex issue. For example, whilst some posters discussed their need to be exempt from vaccination if they wished not to accept it, others discussed the need to be a high priority for vaccinations because of increased vulnerability to the virus. We recommend the employment of humane and empathetic public policies, where individuals with severe mental distress could both have priority, as well as exemption from vaccination without losing employment, care, or benefits. It is especially important to support those experiencing mental distress as scapegoating and discrimination occur during pandemics, often targeted at marginalised or excluded groups (Colet et al. 2015).

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Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board (ref: 7680).

Informed Consent Statement: Due to the nature of the data, it was not possible to obtain informed consent. See Section 2.2 for a full review of ethical issues.

Data Availability Statement: Due to the additional steps in protecting the anonymity of the discussion forum posters, we are not making our datafile publicly available.

Conflicts of Interest: The authors declare no conflict of interest.

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