The complex lived experience of schizophrenia diagnosis: a thematic analysis of online forum posts

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Abstract

Receiving a diagnosis of schizophrenia can be a life-changing experience with both negative and positive consequences. Previous research has identified important aspects of diagnosis, such as disagreement with the label, diagnostic shifts, stigma, and communication of the diagnosis. There is, however, relatively little research from the lived experience perspective. In this study, we investigated the lived experiences of receiving a schizophrenia diagnosis utilising a popular Reddit discussion forum. We used inductive thematic analysis to consider posts from 105 unique usernames and identified five themes. These were (i) Denial and acceptance; (ii) Stigma of diagnosis and selective disclosure; (iii) The complicated process of diagnosis; (iv) Losing, maintaining, and finding a sense of self; and (v) Receiving, finding, and providing support. Diagnosis is a complex personal experience where the same person can simultaneously accept and reject the diagnostic label. Greater attention is required to the lived experience of this diagnostic journey.

Keywords Diagnosis · Identity · Lived experience · Online forum · Schizophrenia · Stigma

Introduction

Schizophrenia is typically characterised as a serious, life-long, biomedical mental disorder (Magliano et al., 2020; Pickersgill, 2023) and a diagnosis of schizophrenia can be life changing. Diagnosis can lead to both negative (e.g., disempowerment, labelling, social exclusion) and positive (e.g., access to care, naming the problem, externalisation) outcomes, depending on the individual and the context (Eads et al., 2021; Howe et al., 2014; Pitt et al., 2009; Rose & Thornicroft 2010). Relatively few studies have, however, considered the impact of diagnosis from a lived experience perspective (e.g., Perkins et al., 2018). The present study extends our understanding of this subject by examining personal experiences of schizophrenia diagnosis in online discussion forum posts.

Previous research demonstrates that diagnosis can be contradictory and complex for the individual. This is even further complicated by heterogeneity of the diagnosis (Allsopp et al., 2019), which means that individuals with the same label can have completely different experiences. For example, in a sample of seven British participants, Howe and colleagues (Howe et al., 2014) found that diagnosis was useful in promoting access to support but harmful in leading to stigma and social exclusion. Similarly, a systematic review and meta-analysis of lived experience concluded that diagnosis can be understood as a process that includes profound shame and a sense of loss, but also the creation of new identities (Walsh et al., 2016). Despite the complexity of this experience, existing research has typically focused on a specific aspect of diagnosis, such as disagreement with the diagnostic label (Forgione, 2019), experience of diagnostic shifts (O'Connor et al., 2022), stigma (Hamilton et al., 2014; Huggett et al., 2018), or communication of the diagnosis (Loughland et al., 2015; Milton & Mullan, 2015).

In the present study, we aim to deepen the knowledge of this complex issue, focusing more broadly on the lived experience of receiving (or being in the process of receiving) a diagnosis of schizophrenia, and the impact of this

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diagnosis on the service-user. We utilise Reddit, a popular online discussion forum platform with 430 million (monthly active) users, divided into communities (known as subreddits) united by similar interests (Widman, 2022). User-created content is organised into nested systems of commentary, including initial posts, replies to the initial posts, and responses to the replies (Amaya et al., 2021; Caplan & Purser, 2019). The platform has become a popular and effective tool for qualitative investigations on a range of sensitive topics (Proferes et al., 2021), including substance use (e.g., Gage et al., 2022) and involuntary celibacy (Maxwell et al., 2020).

Online social networking sites can be valuable in establishing and maintaining social relationships, especially for users experiencing severe mental distress (Highton-Williamson et al., 2015). Indeed, research indicates that discussion forums have several therapeutic benefits (Smith-Merry et al., 2019). For the researcher, discussion forums can provide a valuable insight into lived experiences of mental distress. The posts are driven by poster experience rather than researcher agenda and anonymous posting encourages openness rather than socially desirable comments. Indeed, telling personal stories is an important aspect of Reddit posting (O'Neill, 2018). Consequently, Reddit has been effectively used to investigate the first episode of psychosis (Spikol & Murphy, 2019), and experiences of the COVID-19 pandemic in individuals who identify as having psychosis/schizophrenia (Lyons et al., 2021; Lyons & Brewer, 2023). The current study aims to expand our understanding of the lived experience of schizophrenia diagnosis, utilising an inductive thematic analysis of these online forum posts.

Method

Selection of forum posts

We identified a popular subreddit community (with over 50,000 users) for individuals with personal experience of schizophrenia. We then searched for relevant posts using the term "schizophrenia diagnosis". The search was restricted to a recent 12-month period (29th June, 2021 29th June, 2022) following recommendations by Caplan and Purser (2019). This search identified 249 initial threads. The research question "what are the lived experiences of receiving a schizophrenia diagnosis" guided the subsequent selection of posts for analysis. For inclusion, posts were required to (i) focus on the poster's own personal experience; (ii) discuss personal experience of schizophrenia diagnosis before / after their diagnosis took place, (iii) relate directly to the diagnosis itself, rather than other aspects of schizophrenia (e.g., living with the symptoms). Posts that were deemed

to meet the inclusion criteria were saved on a word document, together with relevant usernames and links to the post. In order to protect the identity of the posters, this file is not available publicly. We identified 36 relevant threads (i.e., initial posts) together with responses from other users, which were analysed if they also met the inclusion criteria. We analysed posts or the replies associated with 105 unique usernames, resulting in a datafile that was 20,590 words in length.

Demographic information

Demographic information (country of residence; age; gender/gender identity; diagnosis) was collected where possible. Country of residence could not be identified for 62 posters. Most (n = 26) lived in the United States; the remaining posters were from Australia, Canada, Denmark, Finland, Ireland, Mexico, Netherlands, Poland, and the United Kingdom. We could not determine the age for 67 posters. Four were below the age of 18; 19 were aged 18–24; 22 were 25–39; and 5 were aged 40 or over. We could not determine gender/gender identity for 47 posters. For those that could be identified, identities included: 23 men, 25 women, 3 transgender men, 1 transgender woman, 3 genderqueer, 1 gender fluid, and 2 non-binary. The posters discussed the following current diagnoses: 69 schizophrenia; 10 depression; 9 bi-polar disorder, 7 autism; 6 obsessive-compulsive disorder; 6 schizoaffective disorder, 4 personality disorder, 2 attention deficit hyperactivity disorder.

Analysis of forum posts

The research team consisted of two academics and four postgraduate students. Collectively, the research team members have the following strengths: lived experiences of schizophrenia and other diagnoses; experience of caring for a person with a diagnosis of schizoaffective disorder or symptoms of psychosis; experience of discussion forum/ qualitative research; and extensive research and teaching experience in clinical psychology. The team reflected on and discussed positionality throughout the analysis, taking into consideration potential biases.

We analysed data using inductive thematic analysis (Braun & Clarke, 2022). Posts were initially read independently by five members of the research team: two faculty members and three postgraduate students. Each member took notes and suggested initial codes for subsequent analysis. The team then held a meeting to discuss the similarities and differences between coders. Following the meeting, it was decided that one researcher (VG, postgraduate student and an expert by experience) would take lead in combining the codes and drafting initial themes. These initial codes

and themes were central to our original research question. The initial codebook devised by VG was revised during the coding process by ML, who also highlighted potential quotes that could be used in representing the themes. After the inductive coding, the final codebook was used by four team members (AO, GB, ML, PB) who each coded twenty posts deductively. This was organised so that two team members coded the same posts; leading into coding of forty posts in total. During this process, we refined the codes and the themes in order to make sure the overlap between the themes were minimal.

Ethical issues

Though most studies utilising Reddit have not required ethical approval (e.g., Proferes et al., 2021), we acknowledge the complicated ethical issues associated with online forum research (Adams, 2022), and secured ethical approval (Institutional Review Board Ref number). The forum is open without registration, and community members post to tens of thousands of online strangers. Therefore, we consider the posts to be public, rather than private (see also Smedley & Coulson, 2021, for ethics discussions). Despite the public nature of the data, we sought to protect the anonymity of Reddit posters by slightly changing the wording of quotes and entering them on an internet search engine and the Reddit site to ensure that they cannot be traced back to the original source (Reagle, 2022). Although there are questions over analysing posts without seeking consent (e.g., Adams, 2022; Smedley & Coulson, 2021), asking for consent from thousands of individuals is not practical, and would prevent the research from taking place. We carefully considered the lack of informed consent and decided that the benefits of the findings outweigh any potential harms.

Results

We identified five themes centred on the impact of diagnosis: (i) Denial and acceptance (three sub-themes: Denial of diagnosis; Acceptance of diagnosis; Conflict between denial and acceptance); (ii) Stigma of diagnosis and selective disclosure; (iii) The process of diagnosis, (iv) Losing, maintaining, and finding a sense of the self (two sub-themes: The lost self; Constructing and maintaining a sense of self), and (v) Receiving, finding, and providing support.

Figure 1 shows a created a diagram on the potential connections between the themes and subthemes. The process of diagnosis spans the entire experience and has a bearing on denial, conflict and acceptance. Stigma also feeds into denial, conflict and lack of identity. Acceptance of a diagnosis is heavily based on the experience and process of healthcare services, and through supportive peer spaces that reinforce and maintain a clear sense of self/identity.

Theme 1 Denial and acceptance

This theme related to the denial or acceptance of a diagnosis of schizophrenia. The theme was divided into three sub-theme - denial, acceptance, and a conflict between denial and acceptance.

(i)   Denial of diagnosis

Denial of diagnosis included feeling like an imposter, denying the existence of the condition, feeling that personal experience is not consistent with the diagnosis, and reluctance to be labelled / put 'in a box'. Imposter syndrome was apparent in individuals such as Poster 1, who disclosed that *"I was in total denial for about a year or two. I did not think my symptoms were severe enough to be a schizophrenic"*.
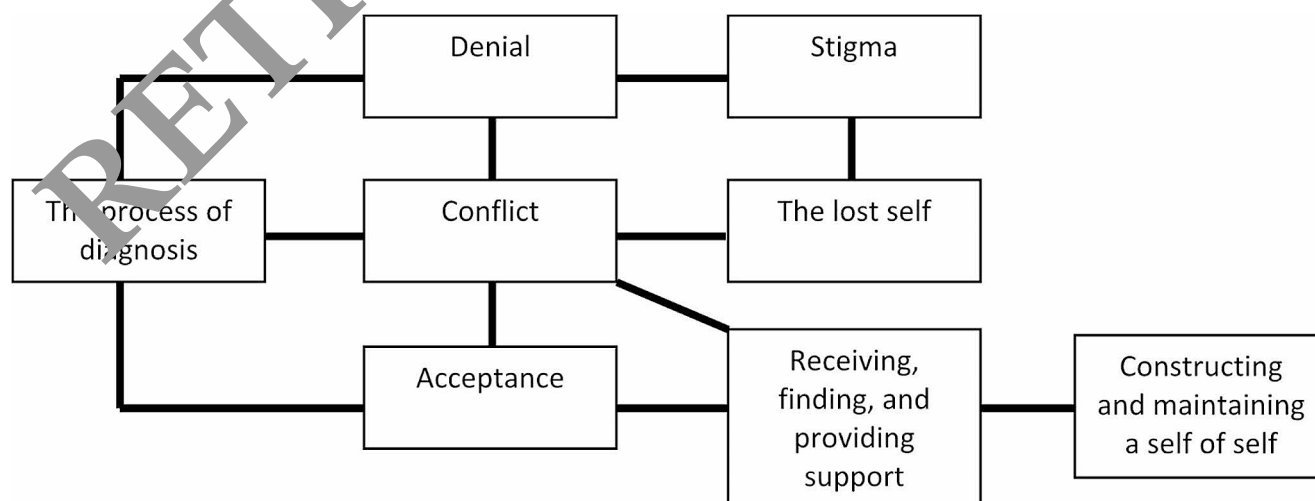

Fig. 1 Diagrammatic presentation of the relationship between the themes and subthemes

Many others perceived schizophrenia to be a serious, life-changing illness and did not feel that their experiences were consistent with the label. For instance, Poster 26 stated that they *"... can't shake the feeling of faking it for attention. I have been in the hospital several times but this thought keeps coming up"*. Shame and fear were apparent in many of the posts, such as a reply to Poster 26 who noted that…*" I am so terrified that I actually do not have any mental illnesses and I'm just faking it all"*.

Some posters also had difficulty accepting the diagnosis because their voices were insisting that the hallucinations were real. For instance, a response to Poster 1 stated that *"Am I the only person struggling to accept the diagnosis because the voices insist they are real people? My voices do a lot of mind reading and respond to my thoughts. If I try to remind myself I'm having delusions, one of the voices says "I'm not letting you walk around thinking you have schizophrenia"*. In addition, some posters doubted the credibility of the DSM diagnosis. They discussed their dislike for having complicated experiences put 'in a box', and talked about how psychiatry had a limited capacity to understand people. For instance, a response to poster 21 stated that *"I am diagnosed as having schizophrenia. However, I think that psychiatry is a feeble attempt to understand something that is simply beyond its limitations as an institution*."

(ii) Acceptance of diagnosis

Posters who accepted their diagnosis reported that diagnosis was a good fit with their experience and how the benefits of diagnosis (e.g., validation of experiences; increasing understanding of self; and aiding in healing) outweigh any potential costs. In addition, many reported that accepting diagnosis can take time, but the acceptance is crucial for accessing help. Posters commented that they accepted their diagnosis and felt bad for others who were in denial. For instance, a response to Poster 21 stated that *"Sadly, I am certain I have this sickness. Weird and sad when other people question their diagnosis and are not aware they have schizophrenia"*.

Others accepted the diagnosis, but with a degree of scepticism. For example, Poster 6 discussed how they *"…believe that the diagnosis is right for my experiences. However I still believe that my experiences are real, and that rather than illness, schizophrenia label is just one way to categorise real experiences"*. Posts like these demonstrate how accepting the diagnosis is a complicated process. Some individuals talked about working actively to accept their diagnosis. For example, one response to Poster 1 discussed how they *"…actually had to do 6 months of therapy to accept the diagnosis as I was told I should. I still don't feel it's accurate, but it does not matter."*

Posters also reported that diagnosis validated their experience, was related to increased understanding and accepting that one needs help. A response to Poster 3 said that they would *"…feel invalidated if I don't have anything to label myself with"*. Another response talked about how *" After my second hospitalisation, I did some research and found out that schizophrenia affects you way before you have an episode. I found that it explains a lot of why I am the way I am. I have learned to embrace it and it is really healing"*. The benefits of accepting the diagnosis were articulated in a response to Poster 22, who thought that the benefits outweigh the downsides of the diagnosis *"...you know what is going on. You have a handle on your warning signs and symptoms. The doctors can treat you accurately and your health team knows immediately how to help you. You will have a better understanding of yourself and how your brain works. It was such a relief to get the diagnosis, because I finally felt in control and in the know.*" The feeling of being in control, understanding what is going on, and accepting help were positive sides of accepting schizophrenia diagnosis.

(iii) Conflict between denial and acceptance

Many of the posters changed position between acceptance and denial, suggesting that acceptance is a complex process, where people periodically change between accepting and doubting the diagnosis. This switching between acceptance and denial was clear in Poster 26, who wrote that *"On one hand, I feel like it's not severe enough and on the other hand I feel it's really severe. My mind keeps going from one idea to the other periodically and it is exhausting. I wish I could accept the diagnosis without constantly doubting it"*. Some posts also demonstrated how it is possible to simultaneously accept and reject the diagnosis. Poster 6 stated that *" I believe the diagnosis is correct for my experiences but I still firmly think that my experiences are real and happening. The label is a way to categorise real experiences and not an illness…Although I do have short periods of thinking of it as an illness. Schizophrenia is a scary diagnosis to have…but I do feel thankful that I have a name to my experiences as it feels much easier to cope with and explain. It's just really scary.*"

Other posters reported that they avoided 'overthinking' the diagnosis, preferring to focus on adherence to treatment, and not letting the diagnosis define who they are. For example, a response to Poster 1 stated that *"Whatever is wrong with me, I need to take my medication. I need to move on with life. This is the right mindset- try to be better rather than try to find out which box you fit in. I will probably never know anyways"*. Indeed, though many posters doubted their diagnosis, it was associated with access to medication and

recovery. Although many doubted the long-term benefits of medication, they were unsure how to cope without it. For example, a response to Poster 10 commented *"I doubt my diagnosis a lot of the time, but taking medication seems to keep me out of the bin. I agree that in the long-term, medication is poison to your brain. I just don't know how to deal with psychosis without it"*. Poster 16 was in the process of receiving a diagnosis and was doubtful about the utility of diagnosis when care is accessible without it *"I understand that diagnosis could help me to get better treatment. I don't know what else can be done as I'm already on antipsychotics and see a psychiatrist and a therapist. I just can't see what more can be done"*.

Theme 2: Stigma of diagnosis and selective disclosure

The stigma theme related to discussions of self-stigma, behaviour to avoid other-stigma, and mental health professional refusal to give a diagnosis because of stigma. Other posters reported that that they were content, if not 'loud and proud' to share their diagnosis openly in order to reduce the stigma associated with the schizophrenia label.

People often revealed mixed feelings about the potential for discrimination. For example, a person responding to Poster 5 stated that *"although I don't think you should worry about discrimination for being schizophrenic, I would not go around telling people I'm schizophrenic. It may scare people off, and I would personally keep it confidential"*. Therefore, though people may not believe stigma is widespread, concerns may still prevent disclosure of the diagnosis.

The posters discussed self-stigma and other-stigma as a downside of receiving a diagnosis. Many posters felt like they were a failure, with few future prospects. In the words of Poster 22, the schizophrenia label resulted in *"feeling utterly worthless and defective"* and that any other label would be better such as *"bipolar diagnosis is better than getting anything with the word schizo in it"*. Posters also raised concern that they would be discriminated against by friends, relatives, colleagues, and healthcare professionals if disclosing their diagnosis. For instance, Poster 36 speculated that they would not be believed by their doctor because of the diagnosis, *"when I visit my family doctor and they look at my record and see I have schizophrenia, are they just going to think I'm crazy and delusional and whatever I'm feeling is not real?"*. The potential for diagnostic overshadowing' during visits to the doctor on issues unrelated to schizophrenia diagnosis was a cause for concern.

Concerns relating to preconceived ideas of schizophrenia were evident in response to Poster 13, who discussed their experiences in a psychiatric ward *"There is a massive stigma that people who experience psychosis are all drug users living off benefits. You can tell this by the treatment in psychiatric wards. They don't expect people to be working or running their own businesses."* Consequently, posters were concerned about how the stigma of diagnosis could negatively affect their professional and family lives. For example, Poster 7 was concerned about how the stigma of diagnosis could affect multiple aspects of life, *"I'm currently in the medical field. My licence is under review because my old boss reported me as "medically unfit" he just hated the decisions I made. I am now scared that I will lose my licence permanently. I want to become a doctor. I am a parent, and I don't know how this will affect my life now"*.

Some of the stigma-related concerns centred on perceptions of dangerousness and losing autonomy. For instance, a person responding to Poster 13 complained how they are *"terrified of people knowing I'm schizophrenic because nine times out of ten either treat you like an incompetent child, or as if you were dangerous. I am neither, I'm a functioning adult! But people just assume you cannot be an adult if you are mentally ill"*. Although the majority of posters were reluctant to disclose a diagnosis, some were 'loud and proud'. A response to Poster 11 reported that they are happy to talk about the diagnosis to everybody because they are *"trying to destigmatize it and talk about the "scary" mental illnesses. Most people are okay with it. My partner's mom doesn't like me tho partially cuz of that but it's whatever"*. Others were shy to disclose at first, but not ashamed of the diagnosis once people knew. A response to Poster 11 said that *"when people know, I wear it like a badge of honor. I'll even make crazy jokes on occasions. It took many years to reach that level of comfort. I used to just say "it's under control with medication" and never say anything else about it"*.

Stigma also resulted in strategic disclosure, where individuals shared the diagnosis in some instances (e.g., places of education) but not others (e.g., when meeting new people). A person replying to Poster 13 wrote that "*I don't mind if people know. I don't advertise it but I chose to share it with my university. I didn't with my last university. The more I do the easier it becomes"*. When meeting new people, the same individual discussed how they like to get to know their friends before disclosure and gauge their attitudes towards mental illness. For example, "*Not all my friends know though. I like to get to know someone first. Mental illness often comes up in conversation anyway, which gives me a chance to gauge their reaction and thoughts on it"*. Stigma also impacted on health care professionals' willingness to provide a diagnosis, even when the person preferred to have the label. For instance, Poster 20 stated how *"my hospital team discussed how they want me to achieve my goal of becoming a doctor one day, and they don't want me to have*

the stigma of a psychotic illness". Posters who talked about being denied a diagnosis because it is stigmatising generally thought that it was a negative experience.

Theme 3: The complicated process of diagnosis

The diagnostic process was, for most, a long and complicated journey. Sometimes, this was because mental health professionals were unsure about the correct diagnosis or lacked clarity in communicating the diagnosis. Indeed, some posters had an experience of receiving a diagnosis or a diagnostic shift without their knowledge, which often came as a surprise. Many discussed a journey of diagnosis shifts, and the length of time that it took to receive a diagnosis that the person could identify with. The process of diagnosis was also coloured by lack of trust in doctors.

For many, it took years before they were provided with a diagnosis that they felt reflected their experiences. According to Poster 6 *"The journey from the start of my psychosis to a clear diagnosis was 9 years"*. During the diagnosis journey, diagnostic shifts were common. Many posters reported multiple diagnoses, sometimes from multiple healthcare providers, and sometimes from the same doctor. For example, Poster 35 was confused after receiving multiple diagnoses from the same doctor " *I am currently hospitalised and they told me that my diagnosis has changed to Schizoaffective. I was in the same hospital a month ago and my discharge paperwork said acute psychosis, schizophrenia, and bipolar 1. I have been to the hospital 9 times and the diagnosis is never consistent. Am I doing something wrong, or is it a lack of insight from the Doctor? He seems to change diagnosis every visit"*.

A response to Poster 6 outlined how they would like to receive a clear diagnosis that would help communication with healthcare professionals, but how they are *"...still on that roller coaster honda. I've had depression with psychotic features, cluster a personality disorder, and now my psychiatrist says maybe schizoaffective and my psychologist says maybe delusional disorder"*. The lack of diagnostic consistency impacted on the perceived credibility of psychiatry. For instance, discussing diagnosis from two separate psychiatrists, Poster 7 reported *"my previous one said I have schizoaffective disorder (depressive type) and the current one said I have psychotic depression. The problem is that neither diagnosis fits neatly. . I guess I am just disappointed that psychiatry is not objective science, with multiple answers to the same situation"*.

Some posters were denied a diagnosis because they presented as articulate or high functioning. They reported that their input was ignored and healthcare providers based decisions on how the person looks, sounds, or whether they are in employment. For instance, Poster 32 shared how they were *".told I could not be schizoaffective because I did not look sick and I have always had a job"* . Similar experiences were echoed by a responder to the post who said how they *".have all the symptoms of schizophrenia but can't get diagnosed because I can talk properly and I have good social skills. I don't " seem psychotic". It is so wrong"*. Further, professionals made clinical decisions after brief consultations, with the potential for stereotypes to influence diagnosis. According to Poster 13, *"I wanted to finally get someone to give me the diagnosis. The new doctor talked to me on the phone ONCE and ended up concluding that I'm too articulate. People with schizophrenia don't speak as well as I do"*. The posters often commented that it was difficult to be taken seriously by the healthcare providers.

Some posters reported that diagnoses and diagnostic shifts were not communicated to them by healthcare professionals, which eroded any trust that the service users had in the providers and diagnostic processes. According to Poster 7, *"I had to get my medical records for something and I noticed my paranoid schizophrenia diagnosis had been changed? No one told me. Apparently it's schizoaffective now? I don't care that it was changed. It's just the fact no one bothered to tell me! I'm scared that they hid it from me on purpose. Otherwise, why not tell me? I don't understand"*. The secretiveness and lack of communication was a cause of concern and distress for the posters.

Theme 4: Losing, maintaining, and finding a sense of the self

The theme was comprised of two sub-themes, The lost self and Constructing and maintaining a sense of self. These reflected both reports from Posters who felt that they had lost their old identities and mourned for their former self, and shoes who discussed creating and maintaining new identities.

(i) The lost self

Posters discussed the loss of their former self. For example, Poster 17 reported *"I'm so sad because I miss the happy go lucky, strong woman I was…And now I'm a shell of her. You know? It's definitely miserable."* Identity loss was also related to career plans, also discussed by Poster 17 *" I just can't help but feel crushed. I had hopes and dreams. I was very accomplished in my career for my age and I had to resign due to these issues. People have been saying I can be whatever I want but I can't lol."* The lost self was also discussed in relation to lack of self-care and loss of control of one's own life. Poster 15 noted that *"I do enjoy my life, but I am just so tired. I don't go out anymore. I don't cook fancy meals anymore. I am not the person who I was six months*

ago…Is becoming a lazy piece of garbage a symptom of schizophrenia?" The change in identity was exacerbated by the changed perceptions of loved ones after the diagnosis. For example, a response to Post 1 commented, ".*I still want people to see me as the person I once was. I went from being the most outgoing person in the room to saying literally nothing around anyone. It's hard when you have an image of who you're supposed to be & subconsciously monitoring every little decision you and others make*".

(ii) Constructing and maintaining a sense of self

Many posters discussed actively working towards the construction and maintenance of a new sense of self. Poster 24 commented *"...I attach emotional significance more to some labels than to others. Schizophrenia for me carries a lot of weight. Remember you are the one who knows best your symptoms and experiences. You can choose how to identify with the labels".* For some posters, schizophrenia was framed as a spiritual human experience. A response to Poster 21 explained how they believe that*"... what the people around me label as "psychosis," is a natural spiritual journey for me. I only accepted the diagnosis and everything because I wasn't in the mood to resist. So, yes, I often think I don't have schizophrenia... I simply don't care anymore as I no longer suffer from the same symptoms that previously troubled me."* The idea of psychosis as a spiritual journey was also reflected in another response to Poster 21 where the individual had very little faith in psychiatry and the diagnostic categories. They stated how *"...The DSM is just an over glorified dictionary that describes the states that people find themselves in. Of course this is not to detract from the intensity of the symptoms in psychotic episodes. But I have learned this- it comes down to your focus and what ideas you feed. I personally believe for some of us the barrier between things seen and unseen is thinner".*

Theme 5: Receiving, finding, and providing support

Posts frequently discussed support from a range of sources including the Reddit community, friends, family, and health care professionals. People discussed their experiences of receiving support, shared advice on how to find support, and actively provided support to each other.

The importance of the Reddit community was clear. Writing one's story in the discussion forum was perceived to be as useful as receiving help from a medical professional. For example, Poster 15 shared their story about receiving a diagnosis, and wrote how *"...it feels so good to have a community like this. I will talk to my doctor, but writing that out and posting it gave me the same effect".* Many posters reported that the Reddit community provided a source of

hope and a place where personal stories could be shared. Indeed, Poster 17 requested inspirational stories from other community members to support their own diagnostic experience, *"I was wondering if anybody else was as bothered as I am over coming to terms with this diagnosis? If anyone has success stories, please share as I would love to read some happy stories. Any advice on how to accept this would be greatly appreciated".* On receiving these stories, they posted *"Thank you so much for sharing your story. You were a lovely teacher and you are still continuing to make a difference in people's lives…This gives me a lot of hope especially as I want to pursue a career in psychology and be some type of school councellor, therapist or social worker. Congrats on your job- I'm sure you are making a positive difference in those people's lives"!*

Similarly, a person responding to Poster 25 encouraged the poster to *"Hang in there. It can be challenging to have your whole trajectory affected by discovering a mental illness and receiving a diagnosis. Your normal life is whatever you make of it. Having schizophrenia can be challenging, but a lot of us find that we can still have fulfilling lives".* The same person found the Reddit community useful as a place where peer-support could be given and received, writing that *"I find that coming to this forum really helps me as I just a lot of people who go through similar situations as I do. There are all sorts of people here, and usually, there are going to be people who relate to what is going on".* A person responding to Poster 30 offered hope by writing that…*" I believe there is hope. It is a wild ride, but I'm sure you will see a light at the end of the tunnel soon".*

Friends, family, and health-care professionals were also identified as a source of support by many of the posters. For example, a person responding to Poster 21 talked about how *"...received a lot of therapy which has helped along the way, but the greatest element of help is just having good friends. They help me to normalise the situation and develop healthier patterns".* A response to Poster 23 reported, *"I am grateful for my therapist, who went to get specialised training so she could learn how to help people with schizophrenia".* Another person, responding to Poster 25, discussed how *"In therapy, I picked up coping methods such as CBT. I have also discovered an App that helps me to keep a routine".* Although posters discussed difficulties with family, friends, and healthcare professionals (as outlined in other themes), it was clear that they could be a substantial source of support.

Discussion

Thematic analysis revealed that receiving (or being in the process of receiving) a diagnosis of schizophrenia is a complex personal experience where the same person can, at the same time, both accept and reject diagnosis, trust and distrust doctors, and think that stigma does not exist but decline to the disclose diagnosis due to stigma. We identified five themes from these complex experiences, which we named (i) Denial and acceptance, (ii) Stigma of diagnosis and selective self-disclosure, (iii) The complicated process of diagnosis, (iv) Losing, maintaining, and finding a sense of the self, and (v) Receiving, finding, and providing support.

Acceptance of the diagnosis was a complex and often contradictory experience. The same person could simultaneously accept and reject the schizophrenia label or move between acceptance and rejection. Those who rejected the diagnosis typically felt that the label was too serious to reflect their experience or remained sceptical about the credibility of schizophrenia as a diagnostic category. This is consistent with previous research indicating that people may reject a diagnosis if they feel that the label does not reflect their personal experience (Forgione, 2019). Rejection of the label can also be indicative of a journey emphasising personal growth beyond the boundaries of psychiatry (Lawrence et al., 2021). In the Reddit community discussions, rejection of diagnosis due to scepticism toward psychiatry seemed like a distinctively different experience to rejecting the diagnosis due to feeling that one has the wrong diagnosis. Feeling like an imposter (i.e., perceiving schizophrenia to be a serious condition but concern that others think they are faking it) was commonplace. In part, concern that others might perceive a condition to be 'fake' reflected self-stigma and feelings of shame and fear, which can worsen the mental health of the individual who has received the diagnosis (Crumb et al., 2019).

Healthcare providers play an important role in reducing the feelings of being an imposter and validating the seriousness of the experiences. Communication between the healthcare provider and service user (i.e., information transfer and good therapeutic relationship) can promote acceptance (Schneider et al., 2004). This highlights the importance of listening and understanding people's own views about their diagnosis, especially as agreement with the diagnosis can be associated with worse mental health outcomes (Murri et al., 2015). Positive aspects of formal diagnosis included validation of experiences, which can help in the process of recovery. Naming the condition signals that symptoms are real, and provide explanatory power for the person (Hayne, 2003; Loughland et al., 2015; Pitt et al., 2009). Acceptance of the diagnosis also facilitated acceptance of help, although

the help was mostly discussed in terms of pharmaceutical interventions.

Mirroring findings from previous studies on stigma and diagnosis, posters discussed personal stigma (i.e., perceived/experienced stigmatisation and self-stigma; see also Gerlinger et al., 2013; Knight et al., 2003), and stigma from others (see also Zahid & Best, 2021). Stigma is one of the most substantial factors negatively influencing quality of life (Degnan et al., 2021) and preventing social inclusion and recovery (Pitt et al., 2009; Yanos et al., 2020). Self-stigma has also been associated with changes in identity following a diagnosis (Yen et al., 2020). Linking our themes of stigma and identity, Yen and colleagues (Yen et al., 2020) discussed how initial self-stigma (stemming from the self and others) can facilitate a process that results in better coping via change in identity.

Indeed, reconstructing a new self-identity is crucial for recovery and well-being (Roe & Davidson, 2005; Shea, 2010), but it can be a process that takes a long time. Identity changes related to grief for the former self, as well as to the process of reconstructing and maintaining a new identity after receiving the diagnosis. The Reddit posters discussed how the label 'schizophrenia' related to a drastic change in identity, resulting in feelings of loss and hopelessness (see also Berdardelli et al., 2019; Conneely et al., 2021; Hayne, 2003; Shea, 2010, for similar findings). However, identity change is part of a normal human experience, and does not need to be a negative event. Some of the posters were more open about their new identity, which seemed to be associated with better coping. These diverse experiences resonate with apparently contradictory research. Studies indicate that distancing oneself from the mental illness label relates to reduced stigma and increased coping (Marcussen et al., 2021; Yanos et al., 2010). However, identifying with the label via activism where internalised stigma transforms into empowerment can also improve coping (Marcussen et al., 2021; Sawaf, 2022). Our results support previous studies that show that either distancing oneself from the illness label, or proudly identifying with it can both be a positive way to deal with the diagnosis.

Posters discussed complicated and long diagnostic journeys, consistent with previous research that has reported that the process of being diagnosed is far from straightforward (Rose & Thornicroft, 2010; Thomas et al., 2013). Diagnostic shifts were apparent in many of the posts. People often had their diagnosis altered, sometimes without their knowledge or consent. Although these shifts are very common among service users who have (had) a schizophrenia diagnosis (Lopez-Gastroman et al., 2019), there is a dearth of research investigating it from a lived experience perspective. A diagnostic shift can be distressing and confusing, especially if presentation of symptoms has remained the same, resulting

in distrust towards the services and credibility of psychiatry as a science (O'Connor et al., 2022; Perkins et al., 2018). It is important to deepen our understanding of how service-users perceive and respond to changes in diagnosis as it can have serious consequences to their wellbeing.

The theme receiving, finding, and providing support captured extremely positive posts. It was clear that many posters visited the Reddit forum with the intention of receiving and providing support in a safe and compassionate environment. Unstructured, naturally emerging online peer support communities can be a beneficial experience for individuals with severe forms of mental distress (e.g., Lyons et al., 2021; Lyons & Brewer, 2023; Naslund et al., 2014). In our analyses, it was obvious that the posters provided encouragement and solidarity to each other, which seemed to bring some relief to the stressors associated with receiving a schizophrenia diagnosis. Indeed, online platforms may provide a "system of mutual giving and receiving where individuals who have endured the difficulties of mental illness can offer hope, friendship, and support to others facing similar challenge" (Naslund et al., 2020, p. 248). Our results suggest that Reddit communities can provide a safe, non-judgemental peer support environment for discussions of issues surrounding receiving the diagnosis.

The posters also discussed how they received support from friends, family, and healthcare professionals. This support was important in terms of normalisation of experience and providing tools for coping. Indeed, other studies have found that social support from friends, family, and healthcare professionals provides positive emotions and reduces depression (Jameel et al., 2020). This can be of crucial importance especially during the process of coming to terms with a schizophrenia diagnosis. Overall, our themes are consistent with previous findings that have demonstrated how friends and family can be a source of both support and discrimination (e.g., Morgan et al., 2017).

Limitations and implications

Although the analysis of Reddit posts provides an insight into the lived experience of complex issues (Morrissette & Morrissette, 2023), the research has some important limitations. For example, it is not possible to analyse any intersectional issues as we do not have sufficient demographic information. Ethnic or racial identities (Misra et al., 2021; Wood et al., 2022) as well as sexual orientation (O'Connor et al., 2018) are among some of the important factors that influence the experience of stigma and help-seeking. In addition, experiences of diagnosis could be different depending on the location of the individual. There are cultural and country-level differences (e.g., Angemeyer et al., 2016; Mascayano et al., 2015; Ran et al., 2021) but also

similarities (Mascayano et al., 2015; Sarraf et al., 2022) in factors such as stigma. Due to limited information on the location of the Reddit posters, this is something that cannot be taken into consideration in our study. Future studies would benefit from interviewing individuals from diverse backgrounds to assess if experiences with schizophrenia diagnosis vary with different intersecting identities, cultures, and countries.

The study has potential implications for clinical practice. In order to communicate the difficulties of the diagnostic process (including potential diagnostic shift), clinicians should explain how diagnosis is not an exact and precise science, but that the label is often a best judgment that can change later. The diagnosis (and any changes to it) should be done in collaboration with the service user, allowing plenty of time to discuss and research the best-fitting options for each individual. After diagnosis, the person should be offered support by clinicians knowledgeable of how to deal with the sense of loss with identity (Buck et al., 2013).

To conclude, relatively few studies have considered the lived experience of receiving a diagnosis of schizophrenia. We conducted an inductive thematic analysis of online forum posts to expand our understanding of this important topic. The receipt of a diagnosis of schizophrenia was shown to be a complex and dynamic process. Five themes were identified: (i) Denial and acceptance (three sub-themes: Denial of diagnosis; Acceptance of diagnosis; Conflict between denial and acceptance); (ii) Stigma of diagnosis; (iii) The process of diagnosis, (iv) Identity and sense of the self (two sub-themes: The lost self; Constructing and maintaining a sense of self); and (v) Receiving, finding, and providing support. These should facilitate further study on diagnosis (e.g., including intersecting identities) and support collaborative discussion between clinicians and service users.

Declarations

Conflict of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

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