Social connection and online engagement: Insights from users of a mental health online forum.

Abstract

Background: Over the past two decades, online forums for mental health support have emerged as an important tool for improving mental health and wellbeing. There has been important research which analyses the content of forum posts, studies on how and why individuals engage with forums, and how extensively forums are used. However, we still lack insights into key questions on the effectiveness of medical and health Internet tools, how they are experienced by their users, and how they might be best configured and deployed – especially in rural and remote settings, outside major cities and towns.

Objective: The aim of our study was to study the dynamics, benefits, and challenges of a peer-to-peer mental health online forum, from a user perspective. In particular, to better explore and understand user perspectives on connection, engagement, and support offered in such forums, information and advice they gained, and what issues they encountered. We studied both consumer and carer experiences of the forums.

Methods: In order to understand the experience of forum users, we devised a qualitative study utilising semi-structured interviews with 17 participants (12 women, 5 men). Data were transcribed, coded, and analysed via key themes.

Results: The study found that participants: experienced considerable social and geographical isolation which the forums helped to address; sought out the forums as a way to find social connection that was lacking in their everyday lives; used the forums to both find and provide information and practical advice.

Conclusions: The study confirms that online peer support provides a critical, ongoing role in providing social connection for mental health consumers. In addition, the research shows forums also provide crucial information and advice for many in this study, especially those living in rural and remote areas. Key to the success of this online forum was careful configuration of moderation, deployment of professional support and advice.

KEYWORDS

Online health forum; mental health; peer support; social connection; engagement; mental illness; consumer experience
Introduction

Web-based interventions for mental ill-health are increasingly becoming a part of policy frameworks for community mental health (e.g. by the Australian Government [1]). Internet-based supports and services make sense for governments given the number of people who incorporate the online into their social worlds, and the considerable difficulties services and supports have accessing people face-to-face due to distance and other forms of social isolation.

Online forums are promoted as an important form of online support [2] and large and popular forums have been developed in most countries. This paper reports on interviews with people who are members of the SANE Forums [https://saneforums.org], a popular Australian online forum run by the non-government mental health organisation SANE Australia. The research is part of a wider study exploring experiences of engagement with and use of the SANE Australia online forums with funding provided by the National Mental Health Commission. The aim is to understand the experiences and motivations of people using online mental health forums.

Background

Existing research on online forums for mental health support can be broken down into that which analyses and understands the content of forum posts, and that which attempts to understand how and why individuals engage with them. A small amount of research also examines how extensively forums are used.

A study drawing on 264,431 responses to the representative US National Survey of Drug Use and Health (2004-2010) found that 0.3% of the population overall used online forums to access peer support for mental ill-health [3]. Studies of people with severe mental illness have found that a small but significant number of people access online forums for peer support. An Australian study surveyed 100 people with severe mental illness accessing a community-based support service and found that 33% of participants were online forum members [4]. Of this group of forum users approximately half read forum posts at least once week and one quarter posted to forums. An earlier German study of psychiatric patients in a hospital-based program found that 19% of patients utilised online forums for support and information [5].

While the numbers reported in these studies are small, they are significant because the overall number of people able to regularly access the internet amongst this group is generally lower than the general population.

Content-based research

Research on the content of online forum postings has attempted to understand illness experiences (e.g. [6]) including of obsessive compulsive disorder [7], cannabis addiction [8], dual diagnosis [6] and eating disorders (Kendal et al, 2017). Other content analysis has sought to determine whether forums help or hinder people’s recovery. Kavuluru and colleagues [9] have developed a system to identify the helpfulness of comments on Reddit forums for mental health. Similarly, Cohen et al [10] drew on content from the Australian-based Reachout.com forums to develop a matrix identifying harmful content so that it could be targeted and addressed more easily by forum moderators. Several studies have also attempted to
characterise the types of posts that are made (e.g. [11-13]. A paper by Mazur and Mickel [14] coded content according to purpose and found that 86% of posts in a carer forum were about seeking advice or information on a specific topic and 20% were seeking support for the poster’s situation. Very little previous research has focused on carer or family use of forums. Those that have are mainly content analyses of the experiences of parents with children with mental illness to understand what they are asking about online [14, 15].

Other content-based forum research utilises forums as a methodological tool to understand naturally occurring chat for groups that may be difficult to engage with through traditional research. Two studies, for example, analysed men’s mental health, including a study which focused on depression [16] and another on eating disorders (Wooldridge et al 2014). Some researchers also create forums for understanding forum interactions around a specific intervention (e.g. [17-19].

Impact of forum involvement

The impact of involvement in mental health-related online forums is shown to be largely positive [20, 21], but negative impacts need to be actively addressed to maintain this.

A small number of studies have warned of an increase in self-harm or mental distress due to forum use (e.g. [22]. This is seen as particularly concerning in relation to unmoderated forums [23, 24] and those that discuss eating disorders or suicide where techniques for harm are discussed [25]. Another study found that negative forum experiences came from poor interactions with other forum members or disagreements with forum moderators [11]. Interviews with people using a post-natal mental health support forum, for example, found that women could sometimes become more unwell because they were talking about the issues more [26].

Horgan et al [19] conducted a survey with 118 university students aged 18 to 24 with depression who had been chosen to join a peer support forum. They found no benefit in symptom alleviation from involvement in the forum. However, studies that focus on symptom alleviation may miss the purpose of such forums, which are focused more on peer support for people moving towards recovery [27]. Recovery in this context does not mean to get better, but to live a meaningful life with or without the symptoms of mental ill-health [28]. Peer-support is an important component of recovery because it allows for modelling of recovery and provides hope for people who may be struggling with their mental ill-health [29]. A meta-analysis of papers reflecting on online forums for people who self-harm used the CHIME recovery framework to determine the recovery orientation of the forums and determined that the forums did support participants’ recovery [30](Deering and Williams 2017).

Motivations for use

A much smaller number of papers have examined the motivation of participants engaging in peer support via online forums, or what they perceive they benefit from involvement. A survey reported by Seward et al [13] characterised the motivations of forum participants into three groups – those who sought online professional help, those who sought online anonymous help, and those that sought both online help and friendship. One paper provided a content analysis
of posts to determine the utility of an online forum for participants by examining posts which reflected on the forum itself [11]. This study found that users believed that their involvement resulted in positive “personal change…. social interactions and support”. Moore and Ayers [26] drew on interviews with forum users seeking post-natal mental health support in the UK. They found that many forum users do not seek help in real life because of stigma but found the online forums helpful because they were anonymous, provided connections with others with similar experiences and were non-judgemental. A survey by Jones et al [31] of young people accessing the self-harm forum, SharpTalk, found that participants preferred to discuss self-harm anonymously online than with friends and family.

What emerges from this examination of existing research is that there is a lack of understanding of what motivates those with mental health issues to seek connection, peer support, and information via online forums -- on a continuing basis. This paper provides insights into this question by offering an understanding of the motivations for ongoing forum involvement amongst registered users of a large moderated forum for carers and consumers. The findings of the paper are significant, given the limited attention in the academic literature to motivations for forum use.

There are two further innovations in the paper. Firstly, the paper offers insights into why carers of people with mental illness engage with online forums, why they persist in doing so, and what benefits and issues they report that it brings them. The research is the first we know that to add carers into the participant cohort. Secondly, the study offers crucial insights into rural and remote mental health consumers, and their motivations and experiences in using online forums. This study is based in Australia – a country which is highly urbanised, but includes a large minority of people living in very sparsely-populated regions who often lack local support services for mental health. This seems an obvious rationale for deploying online forums, but, as the paper reveals, there are also important issues to be understood for rural and remote consumers using online forums over time.

**Methods**

**Context and research aims**

The research presented here is part of a wider study exploring experiences of engagement with and use of the SANE Australia online forums.

In order to understand the *experience* of forum users, a qualitative design utilising semi-structured interviews was adopted in order to allow for a back and forth dialogue to foster and develop an understanding between participant and interviewer [32]. Interview questions focused on why participants used the forum, how they used it, what they liked and did not like about it, and how these issues could be addressed in forum design. All interviews were conducted by phone at a time convenient to participants. Each participant received AU$30 gift card as thanks for their time in participating in the research. Ethics approval was gained from the University of Sydney Human Research Ethics Committee (approval no. 2016/717).
The forums used by participants in this study are operated by SANE Australia, are free to access and are intended for Australian participants, although in practice are accessed by people worldwide. There are separate forums for carers and people with lived experience of mental ill-health, though this does not restrict who can publish on the forums. Within each forum there are a number of sub-categories of posts, with the Lived Experience forum including, amongst others: “our experience and stories”, “looking after our wellbeing”, “social spaces”, “something’s not right” and “what’s new: services, research and technologies”. There are also special forum sessions offered each week for discussion around particular topics that SANE identifies.

The forums operate under the three broad principles of respect, safety and anonymity and posting guidelines also limit the content of posts. Participants are encouraged to “share helpful content, focussed on wellbeing, recovery and help seeking behaviours” [33]. Forum members are unable to post information about specific harmful behaviours and must not provide details of medication. Any information provided must be from personal experience or trustworthy sources with links provided. Participants must use pseudonyms and must not share personal details about themselves.

The forums do not offer crisis support but are constantly moderated by mental health professionals who monitor content and offer advice.

Sampling

An initial survey, advertised to forum members by SANE, was conducted to understand who the SANE forum members were and how they used the forums (the survey results are reported elsewhere). Consumers and carers were able to identify on the survey whether they were interested in participating in an interview. One-hundred and four survey participants indicated their willingness to participate in an interview. A purposive sampling strategy was then used to identify a broad, but not statistically significant, range of consumer and carer participants, ensuring that participants were included who were from both rural and metropolitan areas and a range of Australian states, genders and ages.

Participants were excluded if they were not based in Australia, did not provide valid contact details, or did not respond to researcher invitations to participate. Where too many participants in a particular grouping identified as wishing to participate they were randomly selected. Characteristics of the 17 participants are listed in Table 1 below. Only 12 men offered to participate so the final number of male participants was lower (the remaining seven were either not from Australia, or did not provide contact details). Several people identified as both a carer and someone with a lived experience of mental ill-health and so used both forums. Only three of the participants who indicated they were interested in being interviewed who were aged 61 years and over were contactable. Of the three, we were able to interview one. Interviews concentrated on those who used the lived experience forum but we also interviewed three respondents who used the carer’s forum and three people who indicated they used both forums.

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<th>Table 1: Participant Characteristics.</th>
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<td>Metropolitan South Australia (SA)</td>
<td>Lived Experience</td>
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<td>31-35</td>
<td>Rural New South Wales (NSW)</td>
<td>Carers</td>
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<td>Metropolitan Queensland (Qld)</td>
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<td>41-45</td>
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**Analysis**

Data were transcribed verbatim and entered into NVivo 10 where they were coded by hand. An open-coding approach was used which generated a large number of codes. After nine of the interviews were coded, the initial coding was reviewed and these codes grouped together into broader categories with sub-themes, based on similarities and differences in content of codes. These broader categories and sub-themes were then used to code the remaining eight transcripts. All coded data was then reviewed to produce a final thematic structure by moving backwards and forwards between coded data extracts and the transcripts.

**Results**

Analysis of the data revealed findings clustered around three key themes

- participants experienced considerable social and geographical isolation which the forums helped to address;
- participants sought out the forums as a way to find social connection that was lacking in their everyday lives;
- participants sought out the forums to both find and provide information and practical advice.

**Experience of mental illness: social isolation and geographical isolation**
Yeah, you know, you have the loneliness, you don’t know where to go, don’t have support … those stories just keep popping up. It’s scary how consistent it is. (C08)

**Social isolation:**

Participants described lives of loneliness and social isolation, stigma, exclusion, and workplace discrimination. Many participants felt unable to discuss mental illness in their everyday lives and communities because they felt that people were not interested, did not understand, or might hold prejudices and stigmatizing attitudes towards them. Several participants described feeling unable to leave the house due to their mental health symptoms, or how these symptoms might appear to others.

They felt that people in their lives who hadn’t experienced mental ill-health could not understand their experiences and therefore could not offer support:

...other than professionals, I haven’t had many people I can have conversations about mental illness with in my life, because unless they’ve been through it, they don’t really -- they can’t relate to it at all. (C11)

You can’t just talk to anyone about mental health issues. They just don’t get it .... They just don’t get it because their lives are so full. (C03)

For others, this was related to stigma in their own communities or workplaces (C01; C05; C15):

... after they find out I had a mental illness, they don’t want to be friends anymore. (C15).

I get really upset about it because where I previously worked, they knew what happened to me while I was in hospital and they said, we don’t care, we’re not interested, we should have sacked you. (C01)

The consequence of the isolation caused by a lack of understanding was profound, leading to loneliness and further mental distress. For these participants, the forums were a space where they could step out of the stigmatisation and loneliness that they experience in their everyday lives, into a community where mental health was accepted and understood. This is discussed further below.

Social isolation and inability to talk about mental illness appeared to be compounded for participants who lived in rural communities (C02; C05; C06; C07). One participant spoke about the necessity to “hide” their illness and the lack of resources available to address mental ill-health in their own community:

When you’re in a country town you have to sort of hide it because people are not tolerant ... I don’t have access to a lot of stuff and there’s nothing really out there to communicate with other people about your mental health. (C05)

For this participant the forums offered an alternative space for connection that helped to reduce the social isolation they experienced in their rural community:
I think it’s helped me because it’s a connection ... I’m in a restricted country area and I’ve hurt my back so I don’t work in nursing. So I’m home all day. It’s just company to know that there’s other people out there. (C05)

Rural participants faced additional barriers in accessing supports in their area. This was true for carers as well as those with a lived experience of mental illness (C06). In one instance, a participant mentioned that although services were available in her area, she knew all the psychiatrists because she used to work in mental health so did not feel comfortable accessing them (C04). She therefore had to travel to a capital city to access support. Another mentioned that the only face-to-face social support groups in his area were for people with specific needs and did not cater for chronic mental illness (C02). Another said that in their rural area there was only one support group and timing was not appropriate for those with young children (C06). For these participants, the forums offered a support group that they could access when they wanted and for their own specific needs.

Social connection

... I can always get online and so that’s the beauty of it. (C05)
... for me it’s a real connection. I’m not the only one with bipolar disorder. (C07)

As these quotations demonstrate, for participants who were socially isolated and unable to speak about mental illness or connect with anyone with similar experiences in their own communities, the forums offered an important opportunity for social connection. The forums also provided an opportunity reframe experiences, receive support and give back or help others who were struggling with the same issues.

Participants described accessing the forums in an attempt to ameliorate their social isolation. The forums presented an opportunity to discuss the reality of their situation when it was not possible or appropriate to discuss their experiences with others. They spoke of “struggling” (C12) to speak to family members or worried about ‘pestering’ their relatives and friends (C14). One participant spoke about the forums being an antidote to their social isolation but that they were less important when they were able to speak to their friends in person (C10). For these participants the forums played a powerful role in their lives by allowing them to speak and connect with people how and when they needed it most.

For some participants, the opportunity to connect with others provided a context in which they could understand or reframe their own experiences, and develop hope for the future (C01; C10).

I remember there was one guy that used to say, it does get better. It gets a lot better and I know that this is an awful feeling now, but it does get better -- and that was really big. That was life-changing. (C10)

Participants also described others offering new skills or perspectives that they could then put to use in their own recovery and contextualise their experiences (C09, C11).

This practical support is discussed in detail in a later section of the results.

Similar experience:
A strong theme reported among the respondents was the ability to connect with others who shared similar experiences. All but one of the participants spoke about the utility of the forums being tied to the feeling that others had the same experiences as themselves. The participants felt that there was a large group out there that they could connect with, which made them feel less alone and allowed them to share with others who would understand their experiences—something that was rare in their everyday lives (C03; C04; C07). This can be seen in the following quotation:

I wanted to be surrounded by people that know my experience rather than don’t know but want to help ... Not therapists, not my best friends who has understanding but doesn’t have experience of it. (C04)

This shared experience was a strong motivator for initial engagement with the forums. Ongoing engagement came from a sense of personal connections being made and a shared community around these experiences, which alleviated loneliness, developed a sense of belonging and contributed a range experiences and coping strategies. One person went as far as to liken the connections they felt with people on the communities to the connections they had with their own family members (C12). Seeking out those with similar experience was also a means to normalise the experience of having a mental illness:

... it’s more the sense of other people relate to what you are saying and they can say yeah, I know exactly how you feel because this happened to me. You feel better about it all of a sudden. (C11)

When I first went to hospital ... I was feeling very isolated and very -- pretty dysfunctional. Just like I was the only one and I just couldn't cope or function as an adult. I went on there [the forums] and I had people say, you know what, we've been through this too and we’re better -- and it does get better. (C10)

To find others with similar experiences participants searched through forum threads to identify those that they most related to and which they could draw on for comfort, strategies, or a sense that someone understands (C01; C08). While many of these accounts spoke about receiving support from others, participants also spoke about the importance of providing support. This offered a way to use one’s experiences and knowledge to give back to others who supported them (C07; C08; C12). It was also viewed as being ‘therapeutic’ (C02) for the person providing the support.

For some it was the connecting that was important rather than the content of what was discussed. The forums provided an opportunity to have a chat or socialise online with people who had something in common for people whose social isolation in the physical world meant that this type of day-to-day interaction was not otherwise possible. Participants spoke about forum events or get-togethers such as themed chat, ‘fun Fridays’ (C15) or an ad hoc ‘party’ (C04) amongst online friends. One participant spoke about treating the forum as if they were chatting with friends or family over coffee:

... if you were living with somebody you would just say hi and here’s a coffee, whatever, so I feel like [the forum has] become that for me. If I sit down and have a coffee I'll log on and that might be four times a day. Just the talking every day helps ... chatting.
Lifeline [a telephone based support service] isn’t always terribly helpful and they’re always in a rush. (C03)

For this participant), this type of human, informal, interaction was not available from formal mental health services which are more oriented to outcome and pressured for time. Another participant contrasted these types of interactions with in-person support groups, who they described in negative terms:

I used to go to pity parties, which are better known as support groups. They sit there and compare each other’s scars … I actually prefer the computer forum (C09).

Such interactions on the forums contributed to the connectedness of participants in their wider, offline communities (C04; C10).

It’s been a big help in motivating me when you see people post tomorrow I’m going to go down and have a coffee. What are you doing tomorrow … I think I’ve learnt to speak better to people and that of course creates better relationships. (C04)

Being able to actually articulate those experiences within that [online] community makes me more able to go out and talk about it to the broader community … It was a lot easier with something like bipolar to articulate it to the forums first before going out and talking to other people that really don’t understand it. (C10)

As these quotations show participants spoke not only of an increased a community connectedness, but also a strength in communicating about the experience of mental illness and greater compassion for others in the community who may also have mental illness.

Boundaries, anonymity and authenticity:

While the forums offered an opportunity for meaningful social connection, participants also recognised the need for boundaries. More than half of the participants mentioned that reading about other people’s circumstances could on occasion be difficult and could potentially ‘trigger’ (C03; C04) their own mental ill-health.

It can be quite draining to read that much about other people’s problems … I want to be there and I’m happy to do it, but it can be quite exhausting and it’s quite easy to burn out if you read too much of the forums at any one time. (C10)

This meant that participants might need to establish and negotiate boundaries around how they used the forums, including allowing others to respond to certain posts rather than responding themselves, or even staying off the forums, especially if they were feeling unwell:

I do self-regulate, because if it’s a similar situation sometimes it can be really beneficial and other times you’re just not in the headspace to hear someone else’s story the same. (C01)

Participants also negotiated boundaries around what they were either prepared to discuss, or were able to discuss due to restrictions on the posting of certain kinds of content by the site.
moderators. One carer participant (C17) mentioned setting boundaries around what he would post, because he was unsure if people should hear it.

Another participant described her inability to share suicidal ideation with someone in her community and then reflected that she could also not share this information with people on the forums. She reflected that having to negotiate the boundaries on what could be shared had the potential to be “tiring” and restricted her ability to be ‘open’:

You have to really think about how you share it. It gets a bit tiring when you’re not well. (C03)

In addition to negotiating boundaries around difficult content, the requirement for anonymity imposed another boundary on participants. One participant called the requirement for anonymity a “double-edged sword” because it allowed them to “let a lot more out” but they had “to be a lot more careful about who knows who you are” (Participant C08).

A sense of connection and community was both enabled and constrained by the need for anonymity. This was closely linked to the concept of authenticity. For some participants, the sense of being part of a genuinely supportive community was still authentic, despite anonymity. One participant indicated that although she did not know people’s real names, she still felt like they were her friends (C04).

Participants described the anonymity of the forums as "useful" (C10) and facilitating somewhere they could be more “real” (C03) and described impersonal nature of online social connection helpful for sharing personal information (C06).

While anonymity made some feel they could be more real, it conversely made others feel that the connection to others was less real and the online anonymous format limited the extent to which they experienced a sense of connection and community (C02; C08; C14; C17). This can be seen in the following quotations:

I don't find it overly helpful to post there or talk there because it is remote. So something I've been looking for recently is a group in my town that we can go -- and even if we just go and have a cup of coffee and you've got people in front of you to talk to. (C02)

I've never really counted people I've met on the internet as people in my life ... That's not [the forum's] fault. That's just how I think about the world. (C08)

For these people the forums played an important role, but did not supplant their need for offline social support.

Practical advice and information

I would rather, because of the face to face factor, take the advice of [my] case manager ... I'd be more than likely to consult her as far as possible advice is concerned. But, as I say, real life people and real life set ups like that, aren't always available. In those circumstances in particular, [the] Forum can be excellent. (C14)

Participants were directly asked about the importance of practical advice and information received via the forums. In addition to seeking social connection from people with similar
experiences, participants stated that they accessed the forums to seek or provide practical information and advice (C01; C02; C03; C04; C08; C10; C11; C14).

Receiving help for specific questions:
The forums were used to ask or provide advice on specific questions. These questions were often practical in nature, and related to how to navigate the mental health system, private healthcare (C01) or how to navigate other bureaucratic systems (C02). People also asked advice about other practical issues, which were impacted on by their mental ill-health, such as finding employment or housing:

At one stage I was investigating the concept of moving to Supported Residential Service Accommodation. I asked people on the Forum if they had any experience ... I got interesting feedback and useful feedback from that. The long and the short of it was that I didn’t end up moving. (C14)

Greater understanding of mental ill-health beyond their own experiences:
Participants mentioned that the forums had given them a greater understanding of mental illness, symptom management and about where to get help (C03; C04; C08; C10; C11). This came from reading other people's posts, information and links posted by moderators, and information/discussion sessions linked to the forums:

I've got my two brothers are unwell. Just listening to how [people with] schizophrenia talk about their experiences. It just helps me understand my brothers a bit. (C03)

I think it’s given me better insight into the diversity of experiences that can come under one diagnosis. I had quite a good understanding of mental health generally before that, having a lot of family members with different issues and also a mother who trained as a psychologist. I grew up reading the DSM IV. I had a reasonable understanding, but this really gave me a bit more insight into the experiences. (C10)

I read people's experiences across the board. I also look at links people have posted. That can be really educational. That’s made me do broader research on the internet, reading articles about mental health and all that kind of thing. (C11)

This knowledge was often not directly relevant to their own personal experience, but developed a valuable wider understanding of mental illness (C04; C08). This breadth of knowledge helped with understanding others’ experiences, and could be used to put one’s own experience into perspective.

However, others indicated that they already knew a great deal about mental illness and about the kinds of help available (C02). For these participants the responses to their posts were supportive but not of much practical use. For some individuals, who had sought advice about specific issues, this could be disappointing, but for others social connection was more important than advice and involvement in the forums fulfilled other support roles in their lives (C11; C13; C15):

What’s useful is mainly just knowing people are out there and they are compassionate ... It’s just knowing that there are people out there who can relate to what you are going
through, that is supportive within itself ... I don't know if I really need advice as such. (C11)

_Professional versus peer advice:

In discussing the quality of advice and information provided through the forums, participants set up a distinction between peer advice and the advice provided by moderators. The forum moderators were viewed as a very important part of the forum experience through providing oversight and more ‘professional’ support (C04; C07; C08). One participant felt reassured that she could call on the moderators when she felt that another forum user might need more professional advice or a user had over-disclosed.

I love the fact that when I have concerns about a person ... I can instantly send an email message and one of the [moderators] will then handle that. I can just say so and so, I’m concerned about their post, have a look ... We know that there is someone professional out there that will get straight on and [remove their] phone number and their real name. (C04)

However some participants found the involvement of moderators, or the posting guidelines too restrictive, which they felt limited the utility of the forums (C02; C05), for example:

You can’t talk about this or that or treatment or anything like that. So there is quite a restrictive -- I find it constricted but at least it’s an avenue for people to communicate to each other. (C05)

Another participant reflected on the limits of boundary setting on the forums which they felt had not gone far enough after a bad experience where moderators did not step in when needed (C07).

For another participant, the professional advice offered by one of the moderators was one of the highlights of the forum (C08). However, for this participant, it was important that the forum retain its function as a community of peers, rather than as a site in which people could access advice from professionals:

I think if you have too many people doing it you’ll just turn people away a little bit, it’s meant to be a community for like-minded people. So you don’t want psychologist after psychologist in there. (C08)

Several participants were concerned that the advice offered by peers was incorrect and felt that people with mental illness were not the best people to be giving advice on how to live well (C03; C05; C07; C09).

One participant mentioned that she did not like it when people “play doctor”(C09) and another was concerned that advice might be confusing, because it was offered by “everyday people” with mental illnesses rather than professionals (C07). Participant C05 wished to connect with individuals on the forum with a similar diagnosis but was concerned about the ability for someone who was unwell to offer support:
Because we are really isolated sometimes and I guess that’s when we’re unwell and probably we shouldn't be communicating to another unwell person [laughs]. I don’t know. (C05)

This shows that despite the use of the forums for social support a number of the participants demonstrated a mistrust of lived experience and expressed stereotypical views about the ability of people who are mentally unwell to provide advice.

Discussion

The overwhelming message that emerged from the data was that the forums functioned as a site of connectedness through peer support. There were three key components of this connection. Firstly, participants experienced considerable social isolation which the forums helped to address. Because of this isolation they sought out the forums as a way to find social connection that was lacking in their everyday lives. Finally, participants utilised the online connections to both find and provide support, information and practical advice.

The interviews underscore that the participants experience considerable social isolation and stigmatisation, associated with their experiences of mental ill-health. This sense of isolation was especially acute for those participants in non-metropolitan locations. The isolation compounded the pain, marginalization, exclusion, and other challenges that these participants experienced in relation to their mental ill-health. This isolation also cut participants off from the crucial social connection they felt that they needed and, which research has shown, will promote recovery [34]. Participants also struggled to find the equally fundamental requirements of meaningful communication and information. In the face of isolation, a lack of information and a paucity of people with whom to talk and share experiences of illness and variable health and well-being, participants sought out the forums to find social connection that was lacking in their everyday lives. The opportunity to regain social connection through the forums was a way for participants to reframe often difficult experiences of mental illness. The strong sense expressed by participants of sharing recognizably similar experiences with other participants in the forums was key to this sense of connection.

Social connection on the forums may be particularly valuable to people living in rural and remote areas. Although Australia is a largely urbanised country, many live in rural and remote areas where services and supports are provided over long distances to small numbers of people, which means that all but the most essential medical services rarely operate outside of urban areas or major regional centres. These interviews show that it is not just a lack of appropriate services which lead to social isolation, but both stigma and the familiarity of small rural communities that stopped people connecting and receiving support for mental ill-health. An anonymous forum therefore made sense to these participants, because it was not place-based and they were free to speak without people knowing who they were. This supports the findings of a relatively small, preliminary study of forum users in Australia which found that online connections were able to address the isolation felt by people with mental ill-health in rural and regional areas [35].
The bedrock sense of social connection and shared experience in the forums was strongly underpinned by the rule of anonymity. The participants expressed a range of views on anonymity and how it helped, or detracted, from their experience in the use of, and attitudes towards, the forums. For the majority, anonymity allowed them to express themselves in ways they were not able to do elsewhere -- to be more “real” or “authentic”. This perception aligns with systematic reviews of the benefits of anonymous online self-disclosure [36]. For some however, the anonymity, especially with an online platform, meant that they felt that the experience was less “real”. Previous research has also highlighted these two faces of anonymity [26, 31]. One antidote to this is to see the forums as one important element within a broader set of physical, virtual, and mixed environments of support. While it may be tempting to move all services online for this isolated community, online forums are not a panacea and services must complement rather than replace face-to-face services.

In addition to offering support, the forums were important ways for participants to learn about mental ill-health, and in doing so challenge self-stigma. Two other studies have also noted this benefit to participation [26, 31]. Linked to this, several participants also stated that the online community of the forums helped them to be more involved with their own communities in the offline world. For these participants the “practice” of online discussion allowed them to develop a more powerful discourse of themselves and their mental ill-health which they could use to counter perceived discourses of stigma that had hitherto stopped them from speaking. This finding was also noted in the study mentioned above by Moore and Ayers [26] on forum use in post-natal mental ill-health which study found that the “virtual ‘voice’ ” which participants were able to express online “empowered them to disclose offline” [26]. This shows that the peer-support provided by these forums may promote social inclusion in new and unexpected ways.

Peer-support is a core part of the recovery journey for many people experiencing mental ill-health [37]. This study revealed that peer-support provided through the forums had three components: 1) individuals reflecting on the modelling of recovery or hope given by others sharing their stories (support of other to self); 2) the provision of support to others (support of self to other); 3) visualising individuals providing help to others on the forums (support of other-to-other). However, some responses demonstrated a mistrust of peer knowledge in favour of professional advice. Although not a common theme, the comments that criticised the advice provided by others on the forums destabilised the idea of a peer-support forum by restigmatising people with mental illness as potentially inappropriate sources of information, advice or social support more generally.

Another concern commonly raised by participants was the need to manage boundaries. Given the nature of online peer support, the burden falls upon consumers to manage themselves in various ways to make the best of the space, while minimising the potentially negative implications. Several participants spoke of how they needed to ensure they were able to cope with what can be distressing communication or information from others, especially at times when they felt particularly vulnerable. It may be appropriate for forums to provide increased guidance for participants on this difficult balancing act, perhaps in the form of collaborative advice provided by other forum users and staff.
The nature of the way information is circulated, and advice is proffered, raises issues for the consumers, especially in terms of accuracy, relevance, and appropriateness. Here the role of moderation, and the availability, deployment, and intervention of experts -- for instance, in the form of the moderators, specific advice from trained professionals, and opportunities for information sessions (such as webinars) -- were often mentioned as important. The interviews confirm that such authoritative and trusted experts play a crucial role in the architecture, success, and sustainability of the forums, precisely because they provide a well-supported, welcome way to leaven and balance peer discussion with professional advice. Several international studies have also pointed to moderation as an important factor in maintaining a positive culture on forums (e.g. [21]. Research which focuses on forums without moderation have emphasised the need for moderation to assist with participants who over-disclosed, broke forum posting rules, or were unkind to other participants [26, 38]. However, content analysis of posts has also shown that participants were sometimes unhappy about moderator influence on their posts [11]. Clearly there is a need for moderation, but it needs to be carefully crafted so that participants perceive it as a facilitator of support rather than a burden.

Limitations
The findings of this study must be considered in relation to several limitations. These results relate to two specific forums, and therefore participant responses relate to the structure and internal culture of those forums. Readers should peruse the forums to understand the context in which the study was written. Those that we spoke to were all registered users of the forums, as they had indicated their willingness to participate via a survey only sent to forum members. It is therefore likely that those people who received the survey invitation were those that were motivated to become members rather than just read occasionally. Interview content may therefore be positively biased towards forum use and does not represent the views of those who only 'lurk' or 'listen' to the forum conversations.

Conclusions
This research has offered important insights about the support and information seeking preferences and habits of mental health consumers and carers. It confirms that online peer support provides a critical, ongoing role in providing social connection for mental health consumers. These kind of online forums also provide crucial information and advice and that for many in this study -- especially those living in rural and remote areas -- this was something that they could not access in their day to day lives.

There are important directions from future research that emerge from this qualitative study. Work is needed especially to explore and understand mental health consumers living in rural and remote settings, not least in order to appreciate better what kinds of ways that online forum can be designed, promoted, maintained, and moderated -- and where such peer support online communities sit alongside and complemented the range of other available support, information, and interventions.
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Conflicts of Interest
At the time the research took place author [removed for blinding] was employed by SANE Australia. She was no longer employed by SANE Australia at the time the paper was drafted.
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