Novel Applications of Virtual Communities in Healthcare Settings

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Chapter 2

Socialization or Social Isolation?

Mental Health Community Support in the Digital Age

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ABSTRACT

This research project specifically examines the experience of online community support groups as reported by users. The project began out of concern that healthcare providers in the Global North are directing people with mental health problems to online services, without seemingly understanding the impact that this may have on the individuals. The research findings will be of particular interest to mental health practitioners and service providers in the UK and elsewhere in the Global North, and aims to influence decisions made for policies around developing new online mental health services.

INTRODUCTION

There are many people living and surviving in the community with mild to severe mental health problems who do not have easy access to professional health and social care services. Globally, we have started to see a demand for more choice in how healthcare provision is provided, however constant cuts to healthcare budgets in the Global North mean that options such as telehealthcare and online services are seen as a cheaper alternative, and are often billed as a more effective solution

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(Chambers *et al*., 2016). This is despite much research showing that there is little to no benefit of this method of support, particularly that of peer to peer online support communities (Eysenbach *et al.,* 2004).

This chapter specifically examines the experience of online community support groups as reported by users. Twenty-five participants answered between one and six open questions posted on three different mental health forums. The research began out of concern that healthcare providers in the Global North are directing people with mental health problems to online self-care or peer to peer support services, which may not be suitable for all mental health patients. Despite a paucity of research showing completion rates of professional online therapeutic support interventions are rare (Simco *et al*., 2014), those that do complete the set programmes have been found to benefit from the support (Learmonth *et al*., 2008). However, statistics released in January 2017 by NHS Digital (the UK National Health Service) show that more people than ever are turning up at hospital emergency departments in the UK to receive support for mental health issues (NHS Digital, 2017). Since 2011, the numbers of people going to emergency hospital departments because of their mental ill health has increased by over 50%, and this is also the case for those under the age of 18 (NHS Digital, 2017). This shows that despite a growing number of professional and peer to peer online support services, there may still a growing need for face-to-face intervention.

This chapter suggests that through the identification of positive experiences of online mental health support forums, suitable resources can be developed cheaply and effectively in order to reduce the effects of mental illness, and support those who are unable to find support elsewhere.

BACKGROUND

Worldwide the spending is disproportionately low on mental health (between approximately 2 and 50 USDs per capita), and the lack of financial support has resulted in cuts to services, especially public sector services that support people with mental health problems within their local communities (WHO, 2015). Others are unable to access such support, perhaps due to living arrangements, or because of the negative stigma associated with mental health (Corrigan *et al.,* 2005; Link *et al*., 1999; Star, 1955). Globally, one in ten people are estimated to have a mental health issue, yet up to two thirds of these do not access any type of support services (WHO, 2015). It is of great concern that budget cuts and negative attitudes to mental health issues may lead to an increase in people isolated through lack of professional service support, so it is vital to understand the social factors that shape the way people may seek support in different formats.

The wellbeing of people with mental ill health is highly related to the experience of social isolation and the lack of social support (Corry 2008; Steptoe *et al*. 2013). More recently, there has been a shift in thinking when it comes to treatments with many patients (in general) taking an active role in deciding on the best method of healthcare provision for themselves (Allen *et al*., 2016). Brown and Calnan (2016) found that the level of trust between providers and service users was of vital importance. If trust is lost, it can exacerbate mental health issues and increase isolation (Heyes, 2017). However if trust is fostered, then the result is likely to be positive and isolation is reduced. Therefore, it is important that service users have a choice regarding their preferred method of care in order to get the best possible outcome for the individual (Allen *et al*., 2016; Heyes, 2017).

User-led initiatives (which can also be organised around other health and lifestyle issues), such as cancer support groups and bariatric surgery patient support groups, are part of a wider sociological phenomenon of social movements around self-care and peer patient support (Das & Faxvaag, 2014; Tanis, 2008). These groups are usually informally created, such as individuals with mental ill health issues setting up their own peer to peer support groups, or backed by non-governmental organisations. The central aim of these is to bring users together for mutual support and to reduce isolation (Barak *et al*., 2008; Mind, n.d.). Therefore, there is a need to examine the specific mechanisms that make up social support to understand who is benefitting from the current provisions (Kawachi and Berkman, 2001; Eysenbach *et al*., 2004). There are also a great deal of online mental health professionally led community support groups, although there has been less analysis of these (Eysenbach *et al*. 2004). It is apparent that there is a paucity of academic knowledge in this area, which demands research attention in order to maximise the effectiveness of such groups in the wider context of social and health care support (Eysenbach *et al*. 2004).

Political Framework

Understanding a particular political framework when discussing mental ill health is important, as it is often the case that the whole discourse around mental health is a result of political decisions (WHO, 2005). UK social policy focuses on enabling people to live and manage symptoms, as far as possible, within the community and providing that they have the mental capacity to cope (Mental Capacity Act, 2005; The Care Act, 2014; The Mental Health Act, 2007). However, the majority of people with mental ill health living 'within the community' do not benefit from the resources available to them (Morris, 2012). Isolation from meaningful community engagement often leads to loneliness and further co-morbidity issues, such as depression or substance misuse, particularly if subjected to discrimination and abuse (Link *et al*., 1997). Crabtree and Haslam's (2010) study on positive and negative implications of group identification demonstrated that a group support setting could reinforce supportive frameworks, and that this could outweigh the negativity felt by stigmatisation by non-group members. They recommended that a qualitative study should be conducted to explore the causal variables of relationships within the group settings and the effects that these may have on each individual (Crabtree and Haslam, 2010). There is a vast amount of knowledge about how community support groups are perceived by service users, whether they find them useful and in what ways they are helpful (Cruwys *et al*., 2013; Steffens *et al*., 2016; Welbourne *et al.,* 2013), yet there is still little understood about how people utilise online support for mental health issues. Welbourne *et al.,* (2013) suggest that this may be because motivations are often different for other online peer to peer patient groups, so research findings in one online health support area may not necessarily translate to others.

The most recent policy in the UK, The Care Act (2014), was launched on 1st April 2015. The Act focuses on the wellbeing of the individual with care needs, and also that of the carer (as long as they are not a paid service). By signposting these individuals to face-to-face community support services, there is a reliance on creating sufficient support systems in the local area. The cost objectives to creating these communities is to save money in the long run through 'fixing' problems that could arise from isolating people with care needs initially. Often carers of people with disabilities (physical or mental) suffer from mental health problems or physical ill health as a result of their caring role, consequently having to seek expensive health provisions for themselves (paid for through public funding) (Whybrow and Heyes, 2016). Therefore, social connections are important in preventing further or future health issues.

A study by the NIHR (Pinfold *et al.,* 2015), focused on the effects of communities on individuals with severe mental health issues (SMI). This exploration found that the family network can be viewed in many different ways, and these are not always positive, despite good intentions. The findings suggest that those with little familial interaction, but regular interaction with stable service providers (social services/ support worker/ priest and so on) were the happiest in their environment, and were likely to have a better health outcome than those with close family ties and/ or inconsistent relationships with service providers (Pinfold *et al*., 2015). The lack of understanding around mental health has also lead to some people being segregated from family and friend connections, which could lead to further isolation or seeking identity in other ways, such as within online communities (Link et al, 1999; Pescosolido, 2010).

Isolation and Stigma

Isolation continues to be a significant risk factor for morbidity, across the age spectrum (Holt-Lunstad *et al*., 2015). There are many people for whom isolation is not an option, but something that is forced on them through age or ill-health, and a vast number of those people may not get the help they need (Hawkley and Cacioppo, 2010; Uchino, 2006). Online support may mean that vastly more people get access to the support they need as and when it is required rather than having to wait for a GP or counselling appointment (Learmonth *et al*., 2008).

The stigma surrounding mental ill health is still concerning, particularly as it has been found to have a detrimental effect on help-seeking (Clement *et al,* 2015). Recent data collected by Schomerus *et al.* (2016) showed that even when members of the general public expressed understanding of mental ill health, attitudes towards acceptance of people with mental health issues are not altered. Although this experiment was a relatively small sample (n=1679), the findings show how important it is for mental health professionals to approach public attitudes in the future. Similarly, a recent study by NSUN (National Survivor User Network) for mental health in the UK (Beresford *et al*., 2015), found that service users believed that stigma was still evident in social dealings on a daily basis. The general belief held, was that stigma around mental health was formed by an outdated understanding of the medical model (Beresford *et al*., 2015).

Mental health issues, tend to be predominantly diagnosed using the medical model of the Diagnostic and Statistical Manual of Mental Disorders (DSM), however there are many people living and surviving in the community with mild to severe mental health problems who do not have access to medical or psychological support and/or would not welcome professional labelling or intervention. It is not fully understood what causes mental illness, or indeed if mental illness really exists (see Szasz, 1961, for arguments around this). Frances (2013) argues that the DSM is a way of creating control within society and of the medical profession, maintaining governance over what is normal and abnormal. The DSM is not necessarily an accurate portrayal of mental ill health, but it is generally accepted as the diagnostic criteria for most of the world's mental state (Frances, 2013).

Medical approaches to treating individuals with mild to moderate mental ill health issues in the UK can vary from involuntary incarceration, to providing signposting information about charitable services that can help with grief or suicidal thoughts, medication, and referral to counselling or online support services. However, Evans-Lacko *et al.,* (2013) argue that despite this range of possible medical actions, in general, medication is relied upon in general practice and in hospital care. They go onto note that mental illness should be treated as seriously as physical illness and that this need for dealing earnestly with mental health issues is increasingly important (Evans-Lacko *et al.,* 2013). However, there is a dominant and continuing lack of will in treating and understanding mental ill health, both socially and medically (for example see Maclure, 1988; Cuijpers, 2003; and Frances, 2013). It is therefore important to understand how individuals feel about their own mental health, and their choices and preferences in how they want to receive help and support (Heyes and Whybrow, 2016; The Care Act, 2014).

Health research is also still fixated on the idea of the medical model, with little psychological research into online mental health forums utilising a social constructionist approach (Burr, 2015). However, some health researchers (Link et al, 1999; Pescosolido, 2010), focus on interpersonal dynamics and social networks which highlight the issues of social withdrawal and link to community theories. Yuill et al., (2010) advocate the idea that a true perspective on health can only come from a consideration of both medical and social models for mental health, creating a pathway for multidisciplinary research in mental health.

Online Communities

Online forums have become commonplace amongst internet users worldwide. The number of worldwide users hit 3 billion in 2014, and is now approximately 3.5 billion in 2017, which is approximately 46% of the world's population (internetlivestats.com, 2017: online). Several hundred thousand forums now exist on the internet, with the number growing exponentially on a daily basis (Carroll, 2014). In Japan in 2007, the top discussion forum, 2-channel, was receiving in excess of 2.5 million posts per day (Carroll, 2014). This has since closed down, but currently one of the most popular worldwide sites, Reddit, receives approximately 1.5m users per day, with around 40,000 subscribers to their mental health threads (Reddit.com, 2015: online).

The idea that society has easy access to everything because it is on the internet may be a misnomer. The NHS in the UK (for example) puts information on the internet to make sure that it is easily and readily accessible, most businesses have websites that are 'user friendly', and adverts tell us to look online for further information. However, it is not easily accessible to the 54% of the world's population that do not have internet access. There are also varying reasons as to why the 46% that could in theory access the internet, may not. Illiteracy, learning difficulties, and fear, are just a few reasons that may prevent online activity. Those who are comfortable with using the internet are therefore given options about how to utilise the choice given to all consumers, whether that is which healthcare services to use, or where to buy their groceries. The people in society that may already be able to gain information from multiple sources are choosing whether to consume information online, and this can be for convenience, personal preference, or accessibility. However, those who do not find online information accessible may miss out, as it may be assumed that information has reached everyone because of its online presence.

Patient forums have gained in popularity (Blank and Adams-Blodnieks, 2005; Neal *et al*., 2007). The idea of the expert patient in the UK means that those with health needs are encouraged to learn about their conditions so that they can be best placed to manage them (Coulthard *et al*., 2013; Davidson *et al*., 2012). There are now many thousands of Mental Health community support groups online, and they provide various methods of information and support. The majority of the specialised forums will link (via 'click through' hyperlinks) to easy to read information produced by public health bodies. However, some rely on the information provided by their members, with potential problems such as misinformation being an issue (Neal *et al.,* 2007). Consumer choice means that people can search the various forums and decide which one they wish to participate in. In order to participate, the consumer must feel as though they will learn to trust the forum, trust the other users, but most importantly, they need to feel as though they can participate and get some support (Easterbrook and Vignoles, 2013; Hornsey and Jetten, 2004; Guo and Cheng, 2016). Noelle-Neumann's (1974) Spiral of Silence theory states that people within society needed to gauge public opinion in order to understand how they can interact on a similar level to avoid isolating themselves. Therefore, it is imperative that the forum chosen by the consumer is one that shares similar ideas and opinions as themselves. As with offline support groups, if the user does not feel as though they are part of the ingroup, they may refrain from the group, and isolation may continue (Tajfel and Turner, 1979). The similarity to offline groups can also mean that those who struggle to participate in offline face-to-face interactions may also struggle to participate in online communities.

Definitions of community vary greatly, however they tend to focus on community being a group of people with a common interest or that are geographically linked (Delanty, 2010, McMillan and Chavis, 1986). Using a virtual platform that does not feel as constricted as face to face contact may enable vulnerable people to explore support systems that they may feel unable to access in the 'real' (offline) world (Bell, 2007). For example, those who hide their mental health issues in everyday society may feel as though they can be open and honest with those in a virtual capacity due to the anonymity of the sphere (Suler, 2004). Most beneficial to users is the anonymity of being online (Daine *et al.,* 2013), particularly if the stigma of having a mental health problem is something that they are trying to escape. However, forums that are receiving 1.5 million hits per day tend to have so many threads added every minute, that it can be difficult for all posts to be seen by users. The consequences of this could be that someone who is asking for help for the first time may be missed, and they will think that they are unwelcome, ignored and therefore, become further isolated (Daine *et al*, 2013).

Woong Yun and Park (2011) looked at the relationships of participants of online communities, and found that often people act the same way within forums as they would do in offline ('real') life. This means that if they are open and trusting in the offline environment, they will be the same online. However, Schiel (2005) states that a person who is not really known to us cannot be a friend and therefore must not be trusted. Blanchard *et al.,* (2011) believed that trust was an important aspect of fostering relationships within virtual communities, and generally, people followed normal social practices expected in an offline community. They found that sanctioning behaviours when someone had acted inappropriately were also an important aspect of fulfilling normal social practices, so when members could rely on others to sanction inappropriate behaviour, trust within the community would grow (Blanchard *et al.,* 2011). However, trolling has become an issue in recent years, particularly within social media, and along with this research, has been shown to decrease trust within virtual spheres, and therefore may increase negative online experiences for users (Herring *et al.,* 2002; Heyes, 2017; Phillips, 2015; Rafferty, 2011).

There is, however, a sense of community created by a shared identity (Ren *et al.,* 2012). In the case of mental health forums, people may be seeking information and advice from people who have had similar experiences (Ren *et al.,* 2012; Tate and Zabinski, 2004). This help may boost self-esteem if the individual has found a community that they can identify with (King and Moreggi, 1998; Ren *et al.,* 2012). The 'field' of virtual community support groups may therefore be a platform that can replicate face-to-face community support groups, and the security of the individuals' identity within this (Tate and Zabinski, 2004; Wood, 1989; Yalom and Leczcz, 2005).

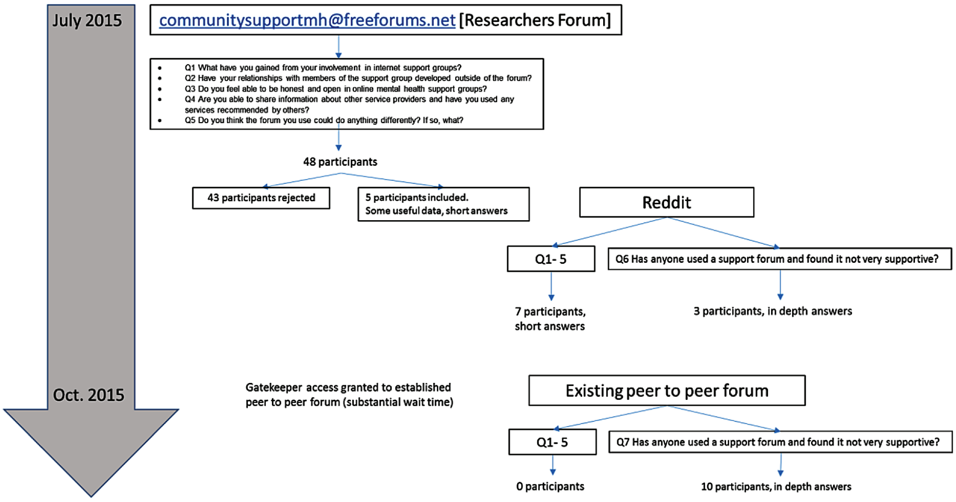
Although the study of online community support groups is somewhat different to the offline groups, the comparison between online and offline is necessary in order to fully understand if there are significant differences. Richardson (2015) ascertains that online and offline should not be considered as completely different entities, as both are communities built through complex multi-dimensional relationships. The on and offline segregation should perhaps therefore be reconsidered as different ways of forging relationships, these being within different social spaces (online) and via different modes (through forums, blogging sites or social media). These different fields may then require different research methods, or the adaption of existing methods in order to revolutionize community psychology and social theory research (Kozinets, 2010).

Baym (1995) had been a participant of an online group before deciding to conduct her research. Over three years she asked questions, took surveys and analysed the text, her method being an ethnographic one that progressed over time, alongside her own understanding of the group. The idea of virtual research evolving as it happens is also supported by Chandler (2016). She found that the lack of rich data in some forums meant that her data collection methods needed to evolve alongside the researchers understanding of forum participation. Chandler (2016) found that in order to maximise the participants to her work on self-harm, she utilised the mass forum Reddit. This provided an inordinate amount of participant responses and yielded some interesting and good quality data. This type of ethnographic research has been termed virtual ethnography, and is a growing phenomenon in online research (Rheingold, 2003). In this particular research (Heyes, 2017), virtual ethnography also involves the idea of the researcher being a 'tolerated observer' (Hine, 2010: 10), a presence that is apparent to the participant, but does not hinder the information given. Markham (2004) believes that ethnographic research in general has flaws, however, the lack of physical cues in virtual ethnography could actually add to, rather than inhibit the analysis of the research.

METHOD

A virtual ethnography study was conducted over a three month period between July 2015 and October 2015. Sixty-five participants answered between one and six questions on one of three forums: 1) a forum created for the purpose of the research called communitysupportmh.freeforums.net; 2) threads set up within Reddit's mental health section; and 3) a peer to peer community support forum that wished to remain anonymous (See Figure 1). No further information was taken about the participants, and there was no follow up contact (apart from to remind them that

Figure 1. Method timeline

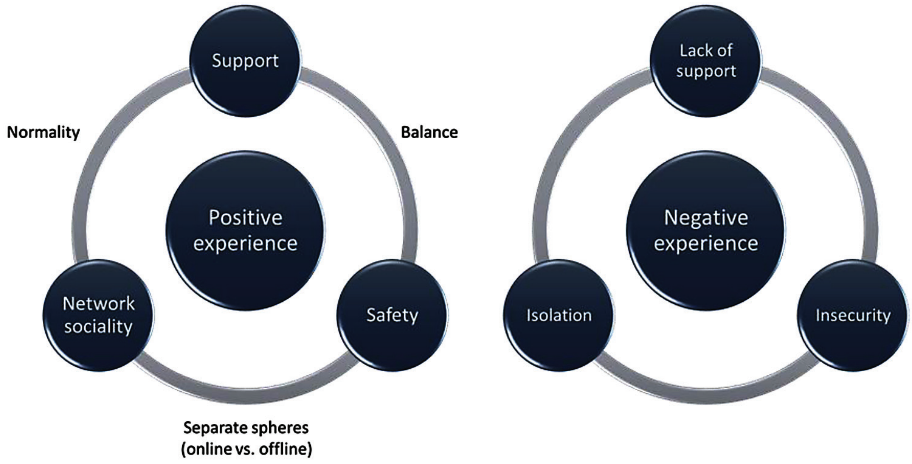


they could withdraw from the study if they wished). Forty-three participants were disqualified from the research due to giving identifying features or not meeting the criteria (i.e. when asked what they gained from being part of a support forum, replied that they had never used one). Gender was not deemed an important factor within this research, and as such, names of the participants were anonymized using an online name generator (http://myusernamegenerator.com/) to avoid gender bias. Open questions were posted as individual threads on each forum in order to create free flowing dialogue. Ethical approval was granted by Manchester Metropolitan University Ethics committee in July 2015.

FINDINGS

The research data was analysed manually using thematic analysis (Boyatzis, 1998; Braun and Clarke, 2006), and second coded using NVivo 11. Through coding, several themes began to emerge. These were reduced to three main issues: safety; support; and network sociality. Minor themes included balance, normality and separate spheres (of offline and online worlds). It emerged that if at least one of the main themes was in place, the participant was likely to have a positive experience of online community support, and therefore, an increased feeling of socialization. If all of the themes were negative, the experience is likely to be negative, and the result would be an increase in social isolation. The minor themes were present in the positive experiences; however, further research needs to be conducted to find the relationship between these themes and the negative experiences (see Figure 2).

Figure 2. A model of online support experiences



DATA ANALYSIS

The analysis of the themes that emerged can be put into three main categories: Safety, Security and Network Sociality. These encompass a number of other areas that were brought up, including trust, the balance between on and offline life, and how normal the person feels. This section shows how the data were analysed in order for the researcher to defend these three main themes.

Safety

As discussed in the literature review, and confirmed by Brown and Calnan's. (2016) study and Blanchard *et al.*'s (2011) model, trust can be an issue for members of online communities, however, this does not necessarily deter them from online social engagement. Not being able to participate in real life means that alternative methods of group participation are sought, however it may not be identified as 'true' interaction but a 'disembedded subjectivity that is somehow 'lifted out'' (Giddens, 1984, cited in Wittel, 2001: 51), a concept that can help some of the participants feel safer.

Online communities are an unknown entity, and trying to build a sense of a shared social space can be difficult when the participants may have different notions of culture and societal norms (Ostrum, *et al.*, 1993). Safety therefore comes from a sense of 'good' culture within an online mental health community: one that is supportive; offers help and advice; and has participants with similar (perceived) social capital.

However, even when praising one of the forums, many participants still brought up issues and bad experiences they had had previously with other forums. The majority of people still struggled to trust other online participants, being wary of 'exploitative' and 'sneaky people', whilst also expressing defeatist attitudes towards expecting policies to be followed, or for moderators to do anything. The shared culture of the community can then turn into a bad experience and threatens the individual's idea of a safe environment.

Part of online forums is the fact that there are moderators or senior members keeping users safe from harm, which in Urowa's case (names are generated from an online name generator) did not seem to help or keep the participants from harm. Some of the participants gave examples of forums that had started well, but then went on to destroy the trust that people had in them. Unayi, describing it as:

Unayi: *[A forum] was 100% anonymous. The sneaky people trying to squeeze people for personal details happened every few sessions I connected to in the last few weeks it was open. Creepy.*
Trusting anonymous people on the internet is not recommended in any situation. [Reddit, Q6]

The experience of having their safety compromised reminded several participants of experiences of offline interactions. Seven of the participants stated that they do not trust people outside of the internet either, with Unayi admitting that they would not trust their spouse or their friends 'to act in my best interest'. Schiel (2005) agrees, stating that people cannot be treated as friends if they are an unknown entity. The idea that the online community is made up of people that may have no real similar offline capital, means that they could never be trusted as they probably have an ulterior motive (Schiel, 2005).

However, there were many participants who felt as though it was easier to trust people on the internet that those offline, particularly on the basis of their shared identity (Tate and Zabinski, 2004; Suler, 2004):

Udefwl: *(I am) More honest than I can be face to face with people* [Researchers Forum, Q3]

Poufi: *Far more honest than I could be with friends and family* [Researchers Forum, Q3]

Vafez: *I have made some really nice friends on here and they have not judged me for being different.* [MHF, Q7]

Those who feel unable to be open and honest in their offline relationships (perhaps due to the nature of their mental health issues), can find it easier to be open and honest with strangers who share similar health issues, and also easier to offer support. The safety of these interactions comes from the anonymity that may make other people fearful of online interaction (Daine *et al*., 2013; Guo and Cheng, 2016), and this can cause conflict for the participants when trying to find a safe community in which they feel comfortable enough to become a permanent part of. If they do not feel a sense of safety in online interactions, they are unlikely to feel supported in an online community support forum.

Support

Participants offered their comments as helpful support, even if they had no 'real' (professional) insights to offer. This could be that by providing a support mechanism to others by offering encouragement actually makes them feel better about themselves, rather than directly seeking help for their own issues. They do not feel that they are burdening others with their own stories and have the associated positive feelings of altruism (Brown and Calnan 2016). One of the participants specifically noted that writing their own posts made them feel anxious, but commenting on other people's posts made them feel good.

Other participants did not realise that they were participating to feel better about themselves. An example of this kind of interaction is that of Jaqdudi (Reddit), who had participated and lurked in several forums, was sceptical of the support that they offer. Some of these interactions were trying to show that they were actually part of 'normal' offline interaction, they were just passing by and happened to stop to comment.

Jaqdudi: *I don't honestly have many problems that can't be solved by Googling a specific question or maybe talking to my friends.* [Reddit, Q6]

However, interwoven in between this scepticism of receiving support through forums, they also try and act as though they would still be ok with receiving support – when asked if they have thought about using the forums for more than they already have, the reply was 'Sure, if the need arises'. It is interesting that they have felt the need to be lurking on a mental health forum, and also felt compelled to answer the research question even though they deny the need for support. Jaqdudi was one of the people that posted the most in terms of discussion about the use of forums, but also seemed to be unable to express (perhaps even unaware of) how they use support forums. Through being helpful and answering research questions and supporting others, they may not perceive themselves as needing support at all.

This need for reassurance of being normal was also seen in some of the other participants, expressing how many close friends or family members they have in the offline world, trying to give an air of flippancy to their answers. This guarded behaviour shows that participants such as Jaqdudi, like to be part of a community, but do not feel as though they can ask for support. This may be due to a lack of trust, or that they may be cautious about giving too much information about themselves on a platform that users are often told to be wary of giving too much information to, due to the few that abuse the system. This could drive the participants into becoming part of the out-group in the online communities, resulting in them becoming segregated from the community. However, it could also mean that they are receiving personal gratification through supporting others, and therefore do not need to divulge personal information in order to benefit from being part of the community (Welbourne *et al.,* 2013).

Network Sociality

Being social is something that comes naturally to some people, and as discussed in the literature review, is difficult for those who are seen as being deviant from dominant social norms around their health and wellbeing. Network sociality is not so much wanting to be part of a social community, but is the need for interaction in order to understand one's own identity (Wittel, 2001). Those seeking online health support communities generally want to find or exchange, informational and/or emotional support (Welbourne *et al.,* 2013). This identity and support seeking is evident throughout the data, and this section will explore isolation, identity and consumerism through the over-arching concept of network sociality.

Through the analysis, it is clear from the number of participants that had been part of multiple forums (at least 8), that the choice afforded by the amount of community support forums subjects users to (at least) as much consumerism as they would be offline. They can decide how many forums they wish to engage in, and whether to lurk, participate or go elsewhere. These choices are helpful to those who may not want to seek advice from a GP or offline services, however the possibility to use orthodox health and wellbeing services is still there for those who may wish to do so, and if necessary they can chose whether to use them concurrently. However, trying to find a supportive community that is right for the individual can prove difficult for people with mental ill health. The stigma of having a mental health problem in offline communities can be the cause of individuals seeking solace in the online world (Goffman, 1963; Link, *et al*., 1997). Therefore, participating in any community, online or offline, can cause feelings of anxiety and uncertainty about how one's posts will be received and responded to by others.

As one participant states:

Ripem: *Writing about my own issues as a new post gives me anxiety (probably the vulnerability aspect)[sic].* [Reddit, Q1]

The idea of disclosing personal information for someone with mental health problems can be fraught with fear of the consequences. For an individual to decide to disclose this type of information to a new community can be seen as a huge risk. This leads participants to describe a process of 'lurking' on the forums before actually making that crucial first post and connecting to an online community.

One participant mentioned quietly evaluating forums, prior to actively being involved through posting. Although the actual numbers of those who lurk online in forums and never post personal information is not known, the activity is commonly discussed in literature about the use of online forums (Schneider *et al.*, 2013; Rafaeli *et al.*, 2004). The participants want to become part of the community, so lurking can help them to assess if the people already contributing are similar to them, reducing the possibility of alienating themselves from the offset (Blanchard *et al.,* 2010; Bourdieu, 1990; Noelle- Neumann, 1977). Six of the ten participants of the established Mental Health Forum expressed that they were constantly fearful about isolating themselves from the offline world, rather than worrying about not fitting in with the online world.

Three of the participants were unclear on the role of online relationships within the context of broader social experiences, they noted the aim for online forums is to enhance interactions with others. Similarly, Jawodaza notes that interaction with others is important, but s/he struggles with friendships in the 'real world', so utilises the forum as a method of interaction and support without the emotional ties of friendship. S/he also states that having this form of interaction is better than nothing at all:

Jawodaza: *If you feel up for having 'real' company, but are choosing to go online instead, it probably is worth giving yourself a boot up the backside and start getting out a bit more.*
But sometimes it's not that straightforward. I don't have many friends, the friends I do have are older and have their own families/lives.
Though even if I had people to socialise with, sometimes it's really difficult.
So for me it's better to be on here than have nothing. X [sic] [MHF, Q7]

Getting the balance right between online and offline interaction was a common concern amongst the participants on all three forums. Argyle (1969) argues that human interaction is a necessity and Steptoe *et al.* (2013) back up this contention by stating that those who are isolated from physical interaction have a higher risk of mortality. However, Kendall (2002) and Hine (2004; 2008) believe that technology has moved on considerably in recent decades and that limited human face to face interaction may not be as mortifying as it once was. Younger generations have grown up with online social relationships, and therefore, these types of interaction may prove to be more beneficial than having no offline contact at all. Kendall (2002) also states that most people do not use the internet instead of living offline, blending the online and offline worlds provides benefits, without having to worry about one type of interaction dominating one's life.

In line with Kendall's (2002) vision of the benefits of a 'blended world', thirteen of the participants stated that they felt comfortable with a blending of worlds, by utilising online support when they feel as though they are unable to cope with human interaction:

Kabeegi and Exogu both expressed that they found it difficult to talk to people in the real world, particularly if they do not have experience of similar mental health issues. By seeking support online, they feel more comfortable and are able to be honest about their feelings. This could be due to the shared values created through previous interactions on the forums, or a shared illness (and therefore understanding of what each other may be going through).

However, two of the participants saw the interactions between offline and online as separate spheres that provide an alternative place to air feelings and ideas, with no other agenda:

Vafez: *...cant mix with real people outside,.... this forum is great and a life saver for me* [MHF, Q7]

Jaxuq: *i find them helpful as i cant do real interaction with ppl [people] except my parents who work [sic]* [MHF, Q7]

These posts from Vafez and Jaxuq, emphasise interaction online and offline as separate arenas, the online space providing unique opportunities for mental health discussion. There is an interesting theme here, which also emerged elsewhere in the data, of online interaction not being 'real'. However, it clearly is real in the sense that it achieves interactional imperatives in terms of relating to another person and is valued by these respondents. Being online though allows a sense of 'playing at' interaction and experience, the stakes are not so high as face to face. This idea of 'playing' at being online is similar to those who utilise online games to help escape from the real world into a fantasy one (Hine, 2004; Calleja, 2010). Escapism could be therapeutic, allowing some relief from mental health issues, and summoning up support from those who appear to understand you, in a non-threatening way (Calleja, 2010).

However, choosing a forum in which to participate can itself be a difficult task, and one that is not as simple as just lurking until the right one is found because of the emergent and fast-changing nature of these social spaces:

Unayi: *...good ones [forums] can go bad quickly. [A forum] was originally brilliant, then it started to fill up with [..] assholes along with exploitative people...* [Reddit, Q6]

Urowa: *Most of the listeners [through support chat on the forum] did their best to change the subject. Then there was one who first started telling me who I can and can't consider a friend and then gave me a nopology [opposite of apology] when I confronted him.* [Reddit, Q6]

The participants reported that forums could quickly change and 'go bad' with changes in who was using them, arguments and disagreements, breaking out or trolling. Participants were asked if they had had any negative experiences of forums and to expand on why these were not good. Four participants, similar to Unayi and Urowa's experiences in the quotes above, expressed that they had on occasion had disagreements with other forum members and were dissatisfied with the way that it was handled. In these cases, they typically went on to describe how they no longer trusted anyone online or offline, despite the fact that they claimed to have good friends and other social relationships. Urowa however, described their experience as unfortunate rather than confidence destroying, and was disappointed with the way that their particular issue was handled. In this case, the site moderators did not want to get involved, despite having a clear behaviour policy on the site. This is ultimately an illustration spanning all three of the main themes, and showing that they are indeed linked to whether or not a person has a positive or a negative experience of online community support.

Despite these difficulties, eight of the participants argued that identifying with the people in a community support forum can be the key to success and were positive about their experience. Knowing that there were other people having/ or had been through similar experiences seemed to give the participants a sense of relief in having found 'normality':

Imeifl: *I've gained happiness in finally reading about other people like me. I've heard they exist, but until I discovered [a forum], I could never know for certain* [Researchers Forum, Q1]

Thoqwhon: *For me, I can be the 'real me' on here. … I find it near impossible to let [my friends and family] know that I'm not good and I try to be smiley to deflect concerns.* [MHF, Q7]

These participants seemed to have found a sense of identity authenticity that they could not display elsewhere. Having a sense of being like others and sharing issues is important. They feel accepted within this community and they no longer have to pretend in order to fit into offline society's idea of normal. In the online support forums, the majority of the participants feel that they have become part of an in-group (Tajfel and Turner, 1979; Yalom and Leczcz, 2005; Tate and Zabinski, 2004; Wood, 1989; Bourdieu, 1985) which can boost self-esteem and reduce feelings of anxiety and isolation (King and Moreggi, 1998).

CONCLUSION

This research sought to investigate and clarify what was important about the interactions within virtual mental health support groups and to provide an insight into these communities in order to influence policy and practice. By assessing the impact of online support networks for people with mental ill health, it has become clear that there are gaps in social policies and health care provision. Social constructions that surround mental ill health make it easy for vulnerable people to become invisible in society due to isolation (Corry, 2008; Steptoe *et al.*, 2013), and people can be reluctant to look at alternatives, such as online sources. Face to face mental health support groups, or negative experiences in online community spaces may have detrimental effects on people with mental health issues seeking alternatives.

The research found that there were benefits to most of the participants in terms of creating support networks that would take the place of, or supplement offline communities, and therefore as a result would reduce isolation. There were some negative consequences however, and the reluctance of some participants to fully immerse themselves into online communities meant that they used multiple sites without any affiliation to a particular community. This could make the individual feel further segregated from being supported by a community, and therefore more isolated than before initial online contact.

Users of the community support groups are generally positive about the support that they receive, and find it beneficial to communicate with people with similar experiences. However, the few who have had negative experiences reported that they no longer have any trust in the groups. Those with security issues however, keep using forums but err on the side of caution by not giving away too much personal information.

Good quality online support groups with a high level of peer support seem to be difficult to find, despite the number available. Forums that are successful usually have hundreds or even thousands of users daily, which makes them susceptible to exploitation. In turn, they either close down, or users may leave to find alternatives. They are useful in creating network sociality, providing a community in-group, and helping to boost self-esteem, thus enhancing quality of life for those who are isolated in offline communities. These are however, difficult to set up and can take a long time to attract members, which can be problematic in terms of creating the ideal solution for online community support for mental ill health. The model of online support, in Figure 2, aims to help with building understanding of the impact of this type of social support, although further research needs to be completed in order to recognise how this can be used to influence policy and practice.

One issue that should be addressed around information provided on the internet, is the assumption that everyone accesses it. With around 56% of the world's population still without access to the internet, this assumption can leave vulnerable people without the help they need. However, to those that are able to access it, the amount of information about mental ill health available online can be valuable to people, especially as cuts to funding look set to continue despite numbers of people diagnosed with mental health conditions rising. Lengthy waiting lists for counsellors and specialists may force people to seek alternatives, and those with access to online services may find their consumer prowess is vital in receiving alternative care. However, more research into the effectiveness of this is necessary, and will be a continual process over the coming years as the nature of the consumer changes.

It is also imperative that we do not assume that because the individual has access to the internet, that they will then wish to utilise this as their main method of treatment. Some people will continue to use face-to-face methods as their preference, or they may decide to refuse any treatment at all. Through offering choices in healthcare provision, we must ultimately respect the decision of the individual.

FUTURE RESEARCH DIRECTIONS

The idea of community being similar online to offline is something that has not been explored in great detail within social or community psychology, and it is therefore difficult to ascertain how best to utilise these communities or engage those who are still isolated. The changing nature of online also means that research needs to stay current. The changes in technology and the increase in the use of social media, predict that the interwoven nature of online and offline will become more complex, particularly when vulnerability such as mental ill health is taken into consideration, and where the individual is at in their life stage (Hine, 2008; Third *et al.*, 2014). Bridging to other support mechanisms has not been something that has been found within this research, and it is important that when seeking alternatives to conventional methods of support (i.e. offline), the participants of online support forums need to be careful that they are not self-diagnosing, or hiding a problem that needs medical attention. Therefore, the next stage of this research will be to conduct in depth interviews with users of online mental health community support to understand why they utilise online support, and if they felt it was beneficial.

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KEY TERMS AND DEFINITIONS

Ethnography: A method of research that involves non-participatory observation of participants in their normal environment, for example, at a weekly group meeting.

Expert Patient: The empowerment of a user of healthcare services, through the education of their condition and treatment.

Lurking: When users of online spaces watch, read or look at, but do not contribute to the discussion.

NHS: The National Health Service. This is the healthcare service that is provided in the UK. It is paid for with Government funds and is free at the point of access to residents of the UK.

Offline: Anything that happens when not connected to the internet.

Online: Anything that is accessed through, or actions taken, whilst connected to the internet.

Peer to Peer: Discussions or connections that happen with people of the same perceived status, such as users of forums. Medical doctors for example, may be a professional rather than a peer when participating in forum discussions.

Stigma: A negative association with social characteristics, traits or health issues.

Trolling: A means by which individuals attack others online through inflammatory comments.

Virtual Ethnography: A method of research that involves observation of participants in their online environments, for example, an internet chat room.