User Experiences of Online Community Support for Mental Ill Health

A thesis submitted in partial fulfilment of the requirements of the Manchester Metropolitan University for the degree of Doctor of Philosophy

Kim Heyes

Department of Social Work and Social Care

2018

Abstract

This doctoral study explores the use of online user-led community support forums for people with diagnosed and self-diagnosed mental ill health. The study is a qualitative analysis of three online forums and four semi-structured interviews incorporating twenty-nine participants. There is a lack of research into online communities using multiple methods, and my study uses two methods, virtual ethnography and semi-structured interviews, to ensure that there is a breadth and diversity to the research, allowing participants to choose different ways to participate.

The thesis is framed within the context of austerity measures in the United Kingdom, and cuts in funding for many aspects of mental health social care. Negative attitudes to mental health issues by members of society and policymakers can lead to an increase in people isolated through lack of formal service support. The study explores the use of a particular form of support, online community support forums, an area that is currently experiencing a growth in research.

My original contribution to knowledge is that peer-to-peer online communities enable people to construct their own mental health narrative by combining the lived experience of others with their own experience. By doing so, people can escape the social labelling, the stigma, and recreate a sense of self out of, or detached from, the medical and social discourses. This study highlighted how online forums can restore sociality and how online communities help people to clarify their own mental health narrative. As such, online forums and communities contribute to and are a new aspect of the health pathway. This research therefore, helps to inform gaps in health pathways, so that more suitable, cost-effective online resources can be created to reduce the effects of mental illness and support those who are unable to find support elsewhere.

"Cherish the past, adorn the present and construct for the future"

Clough Williams-Ellis

Dedicated to Gerald, Dodie and Clair.

Contents

Acknowledgements

There are many people that have been on this journey with me over the past 6 years. The most notable of which are Aiden, who was just 4 months old when I began, Keira, who was 8, and Liam who was 12. Now, at 6, 14 and 18, they have either never known a life without mum's PhD getting in the way, or can't remember when it didn't! My husband Paul and my step-children Kara, Heather and Matthew, have also been very patient and supportive through this process. Although I must admit I won't miss hearing 'when will your PhD be finished?' in that slightly moaning tone! Thank you for being so patient kids, my weekends are now (mostly!) yours.

My supervisors Jenny, Rebecca and Natalie have saved me from going down a big black hole over the last year, I have appreciated their support and guidance greatly. I have enjoyed our supervision sessions and I hope I have made you proud. I would also like to thank Geraldine, Rob and Marilyn who have supported me along the way.

I've been lucky enough to have a supportive network of friends and family, so thank you to my sister Karen, my Nana June, my fellow students Marie (aka 'the secret supervisor'), Karolina, Anton, Dave, Akunna, Loreen and Marcin, my good friends Anna, Kelly, Lucy, Fiona, Jo S., Adele, Alison, and Anne, the Mad Hatters Ros, Gill, Jo W and Tracy V., my favourite students turned colleagues Laney and Tracey W., and my IDS colleagues Deirdre, Orlagh, Lisa, Kathy, Nick, Maggie, P.J., Neil, Kirsty and Trish.

To the team of people whom I've only known for a year but feel like I've known for a lifetime, my fellow PERUvians: Andrew, Chris F, Chris O, Gavin, Jessica, Jordan, Kevin, Kirstine, Mark, Paula, Pete, Rachel, Steve and Sue, thank you a million times over for your support and camaraderie. I am so lucky to have such great colleagues and friends.

And lastly, thank you to my participants. You have so much strength through adversity. I hope that this thesis is the first step towards making mental health community support more easily accessible. I will keep trying, I promise.

Related Publications

Heyes, K. (2018). Mental Health: the dangers of the social media diagnosis. https://theconversation.com/mental-health-the-dangers-of-the-social-media-diagnosis-90717.

Heyes, K. (2018). *Socialisation or Social isolation? Virtual Ethnography and mental ill health.* Answering social science questions with social media data #NSMNSS one day conference, Wellcome Collection, London. 10th March 2018. (Funded).

Heyes, K. (2018). *Socialisation or Social isolation? Virtual Ethnography and mental ill health.* Poster presentation. Social Science and Mental Health Policy one day conference, Edinburgh University. 22nd March 2018. (Funded).

Heyes, K. (2018). Socialisation or Social Isolation? Mental Health Community Support in the digital age. In El Morr, C (ed) (2018). *Novel Applications of Virtual Communities in Healthcare Settings.* PA, USA: IGI Global. https://www.igi-global.com/chapter/socialization-or-social-isolation/190033.

Heyes, K. (2017). *Individual Illness – Narrative stories of people with mental ill health.* Paper presented at Overcoming Barriers and Minds, the 8th Together Against Stigma Conference, Copenhagen, 21st September 2017.

Heyes, K. (2017). *Using virtual ethnography to research vulnerable participants online: A case study of mental health online community support forums.* Online: SAGE Research Methods. http://methods.sagepub.com/case/virtual-ethnography-vulnerable-participants-online-community-support-forums.

Chapter 1: Introduction

Mental health is a contested term globally. In this thesis, I will explore the term 'Mental Health' using a community psychology perspective, in a direct attempt to counter the longstanding ideals of the medicalisation of mental health. I do not reject medicalisation within this thesis, it is difficult to turn away from something that has supported me throughout the last twenty-five years, more that I believe medical intervention and cognitive behavioural therapy could be used less frequently if there was more support within a community. Communities are changing, and the reality of contemporary life is that many people in the UK use the internet, which has led to the use of online communities, such as forums, social media, vlogging and blogging. The exploration of the use of online communities to support people with mental ill health has been informed by general research on mental health within offline communities. This introduction outlines the perspectives I have drawn upon to shape my understanding of mental health, and how this epistemology feeds into the rest of the thesis.

1.1. The Framing of Mental Health within the Research

Despite a reliance on the psychiatric model of mental health (involving mainly medication and therapy), UK social policy focuses on enabling people to live and manage symptoms, as far as possible, within the community (Independent Mental Health Taskforce to the NHS in England, 2015). However, despite pledges from the UK Prime Minister Theresa May to put an extra £2 billion into mental healthcare every year, there is little confidence from service providers and commissioners that this funding will reach the individual (Gilburt, 2018; Care Quality Commission (CQC), 2017). There is an over-reliance on underfunded community support groups and third sector organisations such as the Citizens Advice to offer support (Citizen's Advice, 2015).

Mental health is complex to define, but is essentially a construct to pathologise abnormal or unusual behaviour (Kirk and Kutchins, 1997; Tudor, 1996). Foucault (1965) believed that the creation of madness was something that happened as a need for psychologists and psychiatrists to compartmentalise personal attributes or expressions (such as art, music and theatre) that others in society struggled to understand. He discovered how society became entrenched within the negativities of mental ill health, describing views of mental health as an 'abstract universality of disease' whereby

> 'the man of madness communicates with society only by the intermediary of an equally abstract reason, which is order, physical and moral constraint, the anonymous pressure of the group, the requirements for conformity' (Foucault, 1965: x).

Tudor (1996: 15) believed that the definition of mental health was made up of four areas: Fear of the unknown; historical and legislative responses to mental ill health; the medicalisation of madness and radical notions of mental health. Many other psychologists and sociologists also take the view that there are four themes that are predominant within the field of mental health, however they are generally looked at in terms of what is happening with the current discourse, rather than the historical discourse such as Tudor's (1996) definition encompasses. These four areas are usually a version of Gallagher's (1995) perspectives of: the medical model; the psychological model; the sociological model and the biological model.

The medical model is still the most used model in the Global North today, as most psychiatrists have medical training and believe that treating the physical body is the way to treat mental ill health (Gallagher, 1995). Psychiatric manuals, such as the Diagnostic and Statistical Manual (DSM) (APA, 2013), now in its fifth edition, having dictated mental health criteria since 1952, are still used by physicians for diagnostic purposes, despite not giving indications for treatment (Kirk and Kutchins, 1997). 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). The DSM also states that the person diagnosing the conditions must be a physician with relevant training as the recommendations for diagnosis in this manual are not enough to stand alone (APA, 2013). There are many issues within this diagnosis and statement, that I address within this thesis. Definitions for mental ill health that are accepted globally are lacking, and this makes it difficult to find one as a basis for my research. However, Pilgrim (2014:3) defines mental health as:

> 'Mental health is used positively to indicate a state of psychological wellbeing, negatively to indicate its opposite (as in 'mental health problems') or euphemistically to indicate facilities used by, or imposed upon, people with mental health problems (as in 'mental health services').'

I assert that this is a statement of how mental health can be viewed in society, particularly within the UK. The connotations that are associated with mental ill health will be explored further throughout this thesis, as the stereotypical image of someone with mental ill health is still portrayed negatively throughout society and the media including newspapers, online and television programmes (Whitley and Berry, 2013). These stereotypical images seep into

everyday life, affecting communities through creating a sense of 'them' (people with mental ill health) and 'us' (people without mental ill health).

Community Psychology aims to provide a platform for psychologists to 'critically reflect on the concept of community… to consider who is being 'othered' by being placed outside of 'community' through our talk, thought and action' (Coimbra et al, 2012: 135). The community being discussed within this thesis is somewhat different to the communities that are usually discussed within a social context (Resca and Tozzi, 2013). Most would imagine community to be a physical state, one in which we live, commute, see face-to-face. However, arguably, online communities have very similar traits to offline communities (Joinson, 2009). In order to understand how people with mental ill health behave, it is necessary to understand their interactions with others.

1.1.1. Mental Health Today

The mental wellbeing of people in high-income countries has been decreasing in recent years, alongside an increase in economic divisions between the richest and the poorest (World Health Organisation (WHO), 2015). Many believe that the rise in reported mental ill health is due to economic insecurity, social inequality and loneliness and those most affected are in the lowest economic strata (Davies, 2013; Muntaner et al., 2008; Lorant et al., 2003). Globally, one in ten people are estimated to have a mental health issue, yet up to two thirds of these do not access support services (WHO, 2015). Austerity measures and negative attitudes to mental health issues may lead to an increase in people isolated through lack of formal service support, so it is vital to understand the social factors that shape the way people may seek support in different formats (Heyes, 2018). It is estimated that 39% of health information seekers use social media, often joining a specific health related group (De Choudhury et al, 2014; Fox and Jones, 2009). Patel (2017) believes that peer- and lay person- led support should be embraced, but medical professionals may feel threatened by the potential loss of control this may encourage. There is a gap in evidence around the use of peer support for people with mental ill health, particularly within online support forums. This thesis goes some way towards providing evidence for why people are driven to use online support and what the benefits can be in terms of decreasing isolation and providing adequate support mechanisms.

Mental ill health is one of the leading causes of disability amongst women and by 2020 this is expected to become the main cause of years lost to disability' (Murray and Lopez, 1997). This costs society in terms of providing social support, but also highlights the extreme social inequalities of the effects of mental ill health on gender, although other social groups such as those from ethnic minorities and the lowest social classes are also adversely affected (Evans-Campbell et al., 2008; Bartley and Marmot; 2000). Studies on social integration have shown that it can have positive effects on people with both physical and mental health issues, and can even reduce mortality (Hobbs et al., 2016; Hartwell and Benson, 2007; Cohen et al., 2000). With more people being geographically isolated from friends and family support networks, social integration is becoming more reliant on social media connectivity (Boyle, 2016).

Community psychologists have recognised that there is a connection between environmental factors, acceptance of individualism (without judgement) and creating social change (Nelson and Prilleltensky, 2010), with a view to using 'collaborative research and action….to understand and to enhance the quality of life for individuals, communities and society' (Dalton et al., 2001: 5). The use of the internet in creating spaces for communities is a research area that is rapidly developing as an area that is used for social discussion of illness rather than the medicalisation of it (Giles and Newbold; 2013). Health communities in particular are increasing, and the anonymity of these sites means that all participants are equal and there are no judgements about class, race or gender (Giles and Newbold, 2013; Turkle, 1995). Through a lens of community psychology (CP) this thesis will research online mental health support forums to explore if the social change of internet communities enhances life for the individuals, communities and society.

Mental health services in the UK have been the focus of much scrutiny in the past few years. Since 2012, there have been proposals from the previous coalition and current Conservative UK Governments to improve access to mental health services, waiting times, parity between physical and mental healthcare. Since 2015 there has been an increase in local funding[1] (in 2016, this was by an average of 3.4%) (Healthcare Financial Management Association, 2016). Despite an increase in local funding, 50% of Clinical Commissioning Groups (CCGs) stated in

---

[1] Funding from the UK Government is given to councils throughout the UK to place funding where there is greatest need in that area. There is also funding from NHS England which is given to local Clinical Commissioning Groups (CCGs), which are to provide funding where the greatest healthcare needs are. However the councils and CCGs do not cover exactly the same areas and may have similar or vastly differing criteria. Local funding can therefore be one or the other of these methods, or a mixture of. All funding ultimately comes from the Government.

September 2017 that they are cutting mental health funding, and the Royal College of Psychiatrists (RCPsych, 2018) found that in real terms funding from the UK Government was less in 2016/17 than it was seven years earlier. These austerity measures mean that fewer people are getting the help that they need, leading to a need for alternative ways of finding support (RCPsych, 2018). If online peer communities are an effective method of support, this could provide an alternative to face-to-face underfunded mental healthcare services.

Reductions in funding to mental health support services and local authorities in the UK, meant that some voluntary agencies[2] were unable to continue to support people with mild to moderate mental health issues (Davidson et al., 2014). A lack of community support and an increase in isolation from society means that there has been an increase in suicides and mortality from loneliness (Thornicroft et al., 2011). Loneliness in high-income countries is now believed to be responsible for reduced life expectancy of between 15 and 20 years (Liu et al., 2017; Davies, 2013). The wellbeing of people with mental ill health is highly related to the experience of social isolation and the lack of social support (The Care Act, 2014; Steptoe et al. 2013; Corry 2008). Many patients (in general) are starting to take an active role in deciding on the best method of healthcare provision for themselves (Allen et al., 2016). Brown et al. (2016) found that the level of trust between providers and service users was of vital importance. Therefore, it is important that service users have a choice over their preferred method of care in order to get the best possible outcome for the individual (Allen et al., 2016).

In the age of the globalised digital world, communities are not always face-to-face. The rise of the use of the internet to find people with not only similar interests, but also similar health problems, has prompted a rise in research on health support forums[3]. Yet, there has been limited research around understanding what attracts people to these forums originally, and what they gain from them. In particular, there is a research gap around mental health support forums. In a time when there is arguably no future for the National Health Service in the UK (Triggle, 2017), it could be time to look to alternative support systems to save money and create communities where there may otherwise be none. This thesis acknowledges this gap in research and contributes to the knowledge of how people utilise mental health online communities.

---

[2] That relied on public funding

[3] Within the Global North, this research does not take into account literature or research from the Global South.

1.2. The Thesis
1.2.1. Research Questions

This doctoral study is in two phases. In the first phase I explore the use of anonymised support forums to understand what users gain from the online support communities. The second part of the research uses semi-structured interviews to investigate why people use online support and how they utilise online communities for mental health support. In order to explore specific notions of how users may benefit from online community support mechanisms, there are four over-arching research questions.

1) What is mental health to experts by experience?
2) How do people with mental ill health feel they are being viewed within their offline communities?
3) Why do people with mental ill health look for support online?
4) In what ways are online mental health communities supporting people with mental ill health?

Experts by experience is a term used when describing people with health issues who have become knowledgeable about their condition/s over time, or are well informed about their condition/s (McLaughlin, 2009). When considering what mental health means in the context of people who are deemed to have mental ill health, rather than placing my opinion on them, the research will draw upon the opinion of the participants (Noorani, 2013). This is then extended somewhat by research question two, which focuses on how people with mental ill health (the experts by experience) then believe that other people in their offline lives and wider society view them, drawing particularly upon works around community and stigma.

The findings of both phases should be utilised by mental health professionals in order to inform practice, and to inform online solutions going forward. This study contributes to an understanding of how and why people use online mental health support forums so that more suitable resources can be created to reduce the effects of mental illness and support those who are unable to find support elsewhere. The unique aspect of this thesis is the creation of models and theories of online support. Often personalisation of healthcare is deemed to be expensive, but through producing models of how online support works, we can start to create inexpensive mental healthcare that listens to the needs of the users rather than the people that set the budgets.

This research can make a unique contribution to the field of psychology, enabling social policy makers, NGO's and practitioners to examine the possibilities of online support in helping those experiencing mental health issues.

1.2.2. Methodology

Each phase of the research was completed using a different methodology. The methodology for phase one was virtual ethnography, asking questions to users of online communities over three forums, and the analysis was conducted using Braun and Clarke's (2006) Thematic Analysis approach. Phase two built upon the methodology of phase one, using a grounded theory approach to gathering and analysing one-to-one interviews. The rationale for using two methodologies was because there was a gap in the literature when researching online communities. Naslund et al. (2014) found that often researchers look at only one type of online community or do not try different methods to obtain differing views. Chapter Seven compares the similarities and differences, showing that there is more to gain from qualitative research in this area if different data collection methods are utilised.

1.2.3. Structure of the Thesis

This thesis has been developed over almost six years, and over this time, I have seen significant changes in the way that forums have been utilised, alongside a growth in the amount of research that has focused on online communities. This thesis truly is a journey of the last six years, and each chapter has been on this journey with me. Phase one of the research was completed almost three years before I completed the write up, and I have revisited it many times since. It has resulted in several publications, including one around the methodology and the difficulties of accessing online data. Instead of hiding what went wrong, I have outlined the pitfalls of the research. The things that went wrong have helped to shape me as a researcher, and there are lessons to be learnt here. I have read many PhDs during this process, and not one outlined what happens when research goes wrong. I hope that those reading this thesis can take heart from the fact that research is not perfect, and it is often through the failures that the most important lessons are learned.

Chapter 1: is an introduction to the positioning of the research, my interpretation of the available research around the current political context, and a vital outline of how mental health is framed within the thesis.

Chapter 2: is an exploration of the available literature through the theoretical perspectives that inform the epistemological understanding of the research, Community Psychology and Social Constructionism. The review established how difficulties identifying with any community (on or offline) can cause problems and lead to isolation and loneliness, what the effects of isolation can be on health, and why understanding online communities could be useful to understanding how those with mild to moderate mental ill health issues are functioning. The literature around mental ill health is vast, and the literature review within this thesis has had to focus on areas that are constantly changing and being updated. This chapter will discuss the current state of mental health service provision in the UK, including a brief review of the NHS five year forward view for mental health, and outlining how the NHS commission online services and policies affecting people with mental ill health. After I had completed the research for the first phase, my literature review was published in two different formats, one about virtual ethnography and mental health (SAGE, January 2017, and a video presentation published January 2018); and one focusing on the study as a whole (IGI Global book chapter, October 2017).

Chapter 3: reviews the academic literature around online health communities, particularly peer-to-peer anonymised forums, social media support and formal support offered by the NHS in the UK.

Chapter 4: focuses on the methods and methodology of both phases, including ethical considerations and participant recruitment. Phase one of the research was a virtual ethnography of three online community support forums, which was thematically analysed. Phase two was a grounded theory approach using semi-structured interviews. The idea of using two different methodologies was to gain a broad perspective on why people utilise online support forums, but more recently, researchers such as Hayes et al. (2016) have stated that this type of research is necessary to fill gaps in the literature around mental ill health and the use of online peer support.

Chapter 5: is the analysis of phase one of the research. In total 25 participants responses were analysed across three types of online support community. The findings were split into three main themes: The Effect of Online Support; Safety Within Shared Identities; and Network Sociality. The research found that online communities are useful for creating a sense of normalcy through identifying with others.

Chapter 6: is the analysis of phase two of the research. Four participants attended the interviews, a participation rate of 27% of those that initially wanted to take part. The nature of mental ill health is such that it can be difficult to attend something that is unknown, although the data gathered from the four participants was intended to show how individual experiences of mental ill health are, and by having few participants, it meant that I could explore their stories in more detail. There were three themes that were highlighted through the analysis: The effect of offline relationships; Views of experts by experience and how they may define themselves; and How (mis)understanding mental ill health in the workplace can affect employment and employability.

Chapter 7: is a combination of the data of phase one and phase two, identifying similarities and differences. This yielded three similarities: Social Connectedness; Fear of Judgement; and Information Seeking. And also two differences: Safe Spaces and Consumerism.

Chapter 8: is a discussion of the findings from Chapters Five, Six and Seven in relation to the literature from Chapters One, Two and Three. This culminates in a call for activism in two areas: getting GPs to recognise the benefits of prescribing online peer support communities, and the benefits of better discussions in the workplace. These are small changes that could make a big difference to those with mental ill health.

Chapter 9: is my conclusion of the research I have undertaken in this thesis. I discuss answers to the research questions posed in Chapter One, and finalise the thesis with recommendations for future research.

This research can make a unique contribution to the field of psychology; enabling social policy makers, NGO's and practitioners to examine the possibilities of online support in helping those experiencing mental health issues. The next chapter discusses existing literature around community psychology and mental health.

Chapter 2: A Literature Review of Current Mental Health Research through the Lens of a Community Psychology Framework

2.1. Introduction

My organising principle for this chapter is based on the premise that existing therapeutic and medical measures are not the answer to fixing mental health issues or to helping those with mental ill health lead fulfilling lives. This is not a traditional literature review, but an examination into how community psychology can make sense of the academic literature that currently exists around mental health. I focus primarily on mental health itself rather than online communities, which will be the focus of Chapter Three. Both of these chapters will lead to the summation that although there is some understanding of how people utilise online communities for help and support with their mental ill health, there are gaps in policy around utilising social media and online forums, and presently no published studies that have used two different methodologies to broaden the depth of knowledge in this area. This chapter presents a discussion about why the gaps exist and an argument is presented about what can be done to address this. This leads me to argue that mental health policy is not radical enough, and that social media and online forums need to be included in mental health policy and service provision. My thesis then goes on to show why this is important.

In Chapter One, I provided a brief consideration of the UK policy context for mental ill health, provided the rationale for the study and introduced the concepts of Community Psychology (CP) and online mental health support. This current chapter is about exploring the theoretical concepts of CP, and provides a critical discussion of relevant literature through this lens. In particular, I will discuss the themes of isolation, stigma and identity of people with mental ill health living within the community.

2.2. Mental Health and Community Psychology

The discourse around mental health is confusing (Pilgrim, 2012; Coppock and Hopton; 2000), and one social construction of having a mental health illness is one that is stigmatised as being crazy, mad, or schizo, with negative connotations running alongside this (Nelson and Prilleltensky, 2010). There are issues in the use of language regarding mental health and the terms used are contested. In this thesis, I will use the term mental ill health throughout, as this

is terminology used frequently in the literature I have drawn upon. This term allows for a framing of mental health as affecting the individual, their communities and society, rather than something that is an intrinsic part of their internal or biological being.

I am using a theoretical approach of CP, as community psychologists are concerned with an understanding of how the lives of people with disabilities can be improved through challenging, and trying to change, societal injustices (Walker et al., 2017; Nelson and Prilleltensky, 2010). Rappaport (1977) believed that CP was a fluid paradigm that could be developed alongside new and emerging societal processes, which I believe is relevant with the social media and online communities that have evolved. Rappaport's (1977) theoretical approaches are still relevant as much today as they were forty years ago. CP is not currently used to explore the use of online technology for supporting people with mental ill health, so this is an innovative approach. Health research usually focuses on the idea of the medical model, with little psychological research into the effects of online mental health support forums (Burr, 2015). My study is UK based, and I aim to draw on the findings to inform mental health service provision. A focus on online community support forums does require that I recognise that the Global South may not have access to, or use the internet as the Global North do, with some 3.8 billion people in the Global South without internet access (Broadband Commission for Sustainable Development, 2018). The nature of mental ill health is also considered differently in the Global South, so comparisons to literature that cover this geographical area are beyond the scope of this thesis.

2.3. Community Psychology as a Theoretical Framework

As a theoretical framework, I will be using Rappaport's (1977) three key areas of CP: How people connect to (and within) their environment; identifying social differences; and the importance of the 'focus on social change' (Nelson and Prilleltensky, 2010: 4). These will form the main headings of the sections within this chapter. Within each section I will discuss the issues surrounding mental ill health, through the use of Rappaport's (1977) recommendation that CP is 'concerned with human resource development, political activity and scientific inquiry, three elements that are often in conflict with one another' (Nelson and Prilleltensky, 2010: 4). I have used this as a framework as it is a flexible way to discuss CP that can incorporate all of the issues that I wish to raise, how people perceive mental health within their community, what is the scientific evidence or what does the recent literature say, and what

policies or political issues are helping or hindering. More specifically, I outline the ways in which existing literature defines the current issues around mental ill health, with a focus on the effects on the individual and the community. Wellbeing is highly relational to those we have contact with - our families, friends and communities (Weiner, 2008). In each section I then focus on the political agenda of the UK Government, and how I interpret their use of policy to control and guide collective values (Trickett, 1996), and ultimately, I focus on the evidence of, and the drive for, social change within the field of mental health (D'Andrade, 2008). Through structuring the chapter in this way, I outline the pertinent topics within the literature, analyse them through the political discourse and present academic evidence around why mental health research is both necessary and important.

2.4. How People Connect to (and Within) their Environment

In order to understand how people become who they are and how they identify, it is necessary to understand their interactions with others (Bloch, 2012). Community Psychology (CP) can be used as a reflexive tool for creating awareness and action around a social need (Kagan et al., 2011). This is about the notion that actions towards others is through what is often a political or media driven gaze (Whitley and Berry, 2012; Corrigan et al., 2005; Stout et al., 2004). Therefore, in order to further social justice and a create a fairer society, it is not the psychology of people we need to study, but the social constructionist psychology of how people are influenced by social normalities, and the ecology of how this has been allowed to happen in what are termed as civil societies (i.e. the UK) (Fisher et al., 2014).

Orford (2008) found that individuals construct their own identity within their communities, and that the treatment of the individual within the community can have a relational effect on how they perceive their place as part of that community, which could impact upon their wellbeing. If other people within the community treat that person with respect, then their identity is affirmed and there is a positive correlation of the individual within the community (Taylor, 1992). However, society in the Global North has constructed disability as a problematic issue, and one that generally affects people of the lower working classes (Nelson and Prilleltensky, 2010). This then creates anomie, whereby the individual does not feel connected to their community (Dorling et al., 2008), becoming 'the other' (Tajfel and Turner, 1979).

Rappaport (2000) collected narrative stories of people within his community. He found that through blaming victims (the person with a disability), groups of people within communities create the sense of 'them' and 'us' (Rappaport, 2000). The dominant group then start to believe that their oppressive actions are justified, creating a discourse of disability being unacceptable within that community. Instead of realising that societal attitudes of what is normal and not normal should be challenged, they try to fix or cure the individual medically, rather than trying to change attitudes to accept differences (Mackelprang and Salsgiver, 2015; Goodley and Lawthom, 2006).

This section discusses UK societal attitudes and approaches to disability and mental ill health as a disability, and how the social constructionism of those terms can lead to isolation and stigma. Current discourse can be related to political agenda, particularly from the closure of mental health institutions in the early 1990s, and the lack of service provision provided for those re-integrated into the community (Rochefort, 1993). The lessons learnt from this have led to further mistakes within health and social care provision, showing that there is a need for a considerable re-think of the way that services are commissioned and provided.

2.4.1. The Social Identity of People with Mental Ill Health

Social identity for people with mental ill health is embedded within the discourse of how disability is viewed within society (Dingle et al., 2012). Through Public Health campaigns in recent years, such as 'Time to Change', the discourse around mental ill health is beginning to change, but this may have 'the unintended consequence of minimising the effect that mental health disorders can have on people's lives' (The Lancet Psychiatry, 2018: online). This section will explore the medicalisation of mental ill health, isolation, stigma and labelling to portray an understanding of the complex current discourse of public understanding of mental ill health.

Bronfenbrenner's (1979) ecological theory framework is concerned with the evolution of a person through social interactions, the environment and experiences. Although Bronfenbrenner's (1979) work was based on the social interactions of children, it has also been applied to other areas within policy (Stanger, 2011). Therefore, the framework is useful to describe how society effects the individual within a community psychology context (Kagan et al., 2011). The framework is used to make sense of the individual – ultimately, what makes a person 'tick' and why do they respond to events in the way they do, by considering five levels

of interaction: micro, meso, exo, macro and chrono. Table 1 summarises the key points within each system level.

Micro	close tie relationships and those immediately around the individual such as work colleagues
Meso	The relationship between the microsystems in the individual's life. This can include social groups, healthcare and community services
Exo	Influences that the individual has no control over, such as the Government, the economy, educational system
Macro	Culture and social stratification or socio-economic status of the individual or their family.
Chrono	Cuts across all of the other systems as this is concerned with the changes throughout the lifespan.

Table 1 A summary of Bronfenbrenner's 1979 Ecological Systems framework.

The Ecological Systems framework enables researchers from all academic backgrounds to consider the influence of other people and social factors in how an individual's identity is formed. For those individuals with mental ill health, it can be important to understand these influences as often traumatic events in the past could help to understand the nature of the mental health issue.

It is not fully understood what causes mental illness, or indeed if mental illness really exists (Szasz, 1961). The DSM criteria are fluid, changing with what is sociably acceptable over time, for example, homosexuality was once in the manual as a mental illness (Spitzer, 1981). Frances (2013) and Szasz (1961) have argued 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 fact that a group of mainly male, mainly American psychiatrists decide on the characteristics of the DSM, who are not representative of the population, underscores the power dynamics, which have become so tightly bound up with mental illness diagnoses and definitions (Bentall, 2004; Kirk and Kutchins, 1997; Gallagher, 1995; Szasz, 1961).

Mental health issues tend to be predominantly diagnosed using the medical model of the American DSM[4] (APA, 1952) or the European ICD[5] developed by the WHO[6] (1948). However it is believed that although 1 in 4 people have experienced mental ill health at any one time, only a quarter of the people that have mental health problems in the UK are accessing services

---

[4] Diagnostic and Statistical Manual
[5] International Classification for diseases
[6] World Health Organisation

(Mind, 2015). Medical approaches to treating individuals with mental ill health issues can vary from involuntary incarceration, to providing signposting information about charitable services that can help with grief or suicidal thoughts, medication, or referral to counselling (Jacob, 2015). Evans-Lacko et al. (2013) argue that despite this range of possible medical actions, medications are generally relied upon in general practice and hospital care. They go on to note though, that despite a failure of this to happen in the past, 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).

General Practitioners within the National Health Service in the UK will often assign anti-depressants and counselling[7] (most commonly CBT) when a patient presents with any mental health issue, and patients learn that they must medicate themselves to feel 'normal' and to otherwise ignore their mental illness (Cox, 2015; Jacob, 2015). Their identity comes through their help-seeking engagement with health services and medicalisation of their condition (Haley et al., 1996), often self-regulating this new identity (Butler et al., 2006) as they also struggle to conceal their illness from friends and family, as the cost of disclosure is seen as too high to risk (Cox, 2015). The stigma of having mental ill health can prevent seeking support or accessing health and social care (Parcesepe and Cabassa, 2013), and lead to further mental health issues, social avoidance, isolation, and in extreme cases self-harm and suicide (Berger et al., 2018; Rozatkar, 2014; Gerlinger et al., 2013; Earnshaw et al., 2012).

Social isolation is one of the key risk factors in early mortality for people with mental ill health. Steptoe et al. (2013) found that isolation was a factor in mortality for adults above the age of 52. Although both factors were linked with mortality, it was found that isolation was more significant, and steps to reduce isolation must be taken to reduce this risk (Steptoe et al. 2013). Generally, those who have a good network of family and friends have a lower risk of mortality, and there is an embryonic body of work on these primary connections (family and friends). However, there is relatively little research focusing on secondary connections and it is often these relationships that are the most complex and multifaceted (Thoits, 2011a; 1986).

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

---

[7] IAPT (Improving Access to Psychological Therapies) will be discussed in section 2.4.2.

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 significantly 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). Being isolated from meaningful community engagement often leads to loneliness and further co-morbidity issues such as depression or substance misuse. It has been found that adults with chronic conditions and disabilities often benefit from peer support (Gilburt et al, 2008; DOH, 2001) but through fear or lack of knowledge of available resources, they can be unable to access this. Despite this lack of integration, the general public are becoming more understanding of people with mental health problems according to the 2012 survey of Attitudes To Mental Illness, with a reduction from 28% (1994) to 23% not wanting to live near people with a mental health problem (NHS Digital, 2011).

Judgement of people with mental ill health is based upon the idea that society has decided what is and is not acceptable behaviour (Bourdieu, 1984). Some academics argue that the role of the media has a controlling influence over how the general population view mental health, and can incite fear and hatred of the unknown (mental illness) (Whitley and Berry, 2012; Corrigan et al., 2005; Stout et al., 2004). Labelling of mental health can be problematic, as there is an unprecedented rise in medical mental health diagnoses in the UK (Chakrabarti, 2018). Many of these diagnostic labels can overlap with other diagnoses, and Chakrabarti (2018) found that many people diagnosed in 2004 would not receive the same diagnosis today. These labels can also have a significant effect on people's everyday lives. Labelling of mental health conditions can also have the effect of degrading the disorder. Walker (2007) states that people now use depression as a term that expresses life dissatisfaction, and this serves to degrade how disabling depression can be for those that have it. Erroneous labelling can mean that negative (or even positive) connotations become associated with a particular mental health disorder (Goffman, 1963), and this label can become the social representation (Moscovici, 1988) or 'common knowledge' of the disorder. However, recent research into the use of negative language around mental ill health in the UK media has shown that the way in which mental health is reported on is becoming more balanced (Time to Change, 2017). This is a significant move forward for challenging assumptions and stereotypes.

Stigma is a word that is often used in the media and in research when discussing mental ill health, and as such, has become a public health issue of concern worldwide (Corrigan, 2016,

Sartorius, 2007; WHO, 2015). The word stigma is used to describe a range of feelings around health issues such as 'the shame, social awkwardness, rejection, misunderstanding, and exclusion that people in these situations experience' (Link and Stuart, 2016: 3). Although it is used for a range of social issues and illnesses that are perceived as embarrassing, it is most synonymously used with mental ill health, and this can have a detrimental effect on health care seeking (Gronholm et al*.,* 2017; Link and Stuart, 2016; Clement et al*.,* 2015).

Erving Goffman's (1963) studies of social exclusion led to the first typologies of stigma. He attributed stigma to two main points. The first is the nature of the object: an obvious difference such as physical deformity; being of a different religion or social class; or dubious characteristics such as dishonesty. The second is visibility: such as skin colour, which may lead to the person being discredited; or if their political persuasion is not acceptable, this could be labelled discreditable. Goffman's (1963) observations on stigma lead the way for other theorists to deconstruct the issue and to find ways to limit stigmatisation.

Awareness raising initiatives, such as World Mental Health day and Time to Change's Stigma campaign (from 2009), have begun to change negative society-wide attitudes (Thornicroft et al*.,* 2014), however mental health service users in the UK still report high levels of societal discrimination. In Thornicroft et al.'s (2014) report, they found that 70% of people diagnosed with a mental health illness in 2011 felt that they needed to conceal it, and many people experienced discrimination in the workplace, with 17% stating that they had been discriminated against at work, and 46% were too worried about potential discrimination to apply for a job. Henderson et al. (2012) researched the sources of discrimination in England and found that the worst offenders in society for discrimination against those with mental ill health, were actually friends and family.

A study by the National Institute of Health Research (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 NIHR (Pinfold et al., 2015) 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). Those with complex mental health

issues may have alienated family and close friends that were unable to comprehend the nature of the illness. This supports the research by Henderson et al. (2012) and shows how easy it can be for people with mental ill health to push family and friends away after a diagnosis of mental ill health. This will then increase the likelihood of isolation and a reduction in life expectancy (Thornicroft et al., 2014).

Michel Foucault (1961) believed that modern day mental ill health has been created through the need for individuals to assert power over one another. Whether this is the need for physicians to maintain status through perceived knowledge, or over one's neighbour as they do not believe that their behaviour falls within what is acceptable boundaries, the description of someone else as mental, ill, or mad, creates power for the person not perceived so (Foucault, 1961). Societal interactions over the years have become what has exacerbated mental health, and have resulted in those who have been diagnosed with mental ill health being stripped of support through stigma and isolation (Adler et al., 2016; Link et al., 1999; Sartorius, 2007), or institutionalised and subject to a 'series of abasements, degradations, humiliations, and profanations of self' (Goffman, 1961: 14). Those who are diagnosed with mental ill health often have lower incomes, are more likely to be on benefits and are more likely to be homeless than those who do not have a diagnosis (Thornicroft et al., 2014; Sartorius, 2007; Thornicroft, 2007). This can then lead to a cycle of systemic failures, where those with mental ill health continue to deteriorate and remain isolated (Jodelet, 1991) rather than becoming engaged with a social support mechanism, such as those supported by research (Sartorius, 2007).

Community support mechanisms are of significant importance to the health and wellbeing of the individual and society. Sociologists such as Durkheim (1885) believed that the term community was too imprecise, favouring an individual approach to social structure. Community however, has continued to have a place within sociological and psychological research, and as Delanty (2010:x) states 'we need to work and embrace the idea of community rather than turn our back on it'. Definitions of community are contested, however they do tend to focus on community being a group of people with a common interest, geography or identity (MacQueen et al., 2001). This can be created through anything from living in the same area, to identifying with a similar medical diagnostic. Policy is often created around what is best for most of the people within a community, but this can have an impact on other communities. Just the concept of community immediately creates an 'in-group' and an 'out-group' and those who do not fit into an in-group can find themselves isolated (Tajfel and Turner, 1979; Goffman,

1963). Social needs also tend to be shaped by our immediate surroundings, which in turn leads to understanding and adopting acceptable behaviours. These behaviours can be different culturally, and ultimately lead to different rules within a social sphere (Bourdieu, 1990). The social groups are then associated with an individual's social identity, and if one wants to be part of the group they must continue to follow the social rules. If individuals within that group do not then abide by these rules, then their behaviour would be viewed as abnormal or deviant. This then gives rise to a notion of what is, and is not, 'normal' behaviour, but also if one were to behave differently due to an illness, how easy it would be to lose their group, and therefore, self- identity.

Social representations of people with mental ill health have been targeted in the UK in recent years by charity and third sector organisations such as 'Time to Change' (Evans-Lacko et al., 2014). The focus of these organisations has predominantly been to target the stigma, in the belief that society will stop 'othering' people with mental ill health, and realise that helping to promote good mental health would help to curb further isolation and reduce health and societal inequalities associated with this (Thornicroft et al., 2014). There is a continual growth in the numbers of people diagnosed with mental ill health, which may be explained by the increased ability of being able to record mental health data, the recognition of illness within the individual due to improved education, or the increase of societal and economic disadvantage (Nelson and Prilleltensky, 2010).

Psychiatric services within the Global North have a need to normalise what is seen as abnormal (Cohen, 2015), placing a distinctive 'otherness' on people with mental ill health, and placing them outside of a 'normal' community. This then creates a stigma around mental illness (Corrigan, 2015), making the individual feel as though they are different, ultimately distancing themselves from their community, and the community also feels as though they should distance themselves as the person no longer shares the same key attributes that solidifies the unity of the community (Riger and Lavrakas, 1981). A 'catch 22' situation that may well have been caused through the medicalisation of health and psychiatric hegemony (Cohen, 2015; Coimbra et al., 2012; Kirk and Kutchins; 2001). Nilsson and Nordentoft (2018) found a link between those with a low socio-economic status (and low family income), and those who self-harm, are violent and die by suicide. The stigma of mental health incorporates the idea that a person's identity includes poverty if they are diagnosed with mental ill health. This is damaging, and the labelling of mental health in this way also means that those with higher incomes may not

realise that they have mental ill health if they only associate it with lower socio-economic groups (Nilsson and Nordentoft, 2018).

Places that have elevated levels of social inequality are more likely to have higher levels of poor health throughout society as a whole, which suggests that health and wellbeing are intrinsically linked to the social environment (Blank and Lutz, 2017; Wilkinson and Pickett, 2009). Power, within health and wellbeing in society, can be created through the medical model, which aims to cure the individual and help them to recover to a state of normal happiness, usually through medication (Nelson and Prilleltensky, 2010). Happiness is a contested term, but some researchers believe that it cannot come from medication, but is intertwined with other people from our social environments – friends, family, work colleagues and so on (Weiner, 2008). Medical or other treatment of the individual may be futile, if it is the social environment that needs to be treated in order to create collective societal happiness (Collins et al., 2017; Ding et al., 2015; Berry and Welsh, 2010).

2.4.2. Social Policy in the United Kingdom

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 and policy making (WHO, 2005). Current 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 (The Care Act, 2014; The Mental Health Act, 2007; Mental Capacity Act, 2005). Contemporary discourse can be related to political agendas when the NHS and Community Care Act (1990) became policy under a UK Conservative government. Those who had previously been placed in mental health institutions were encouraged to live independently (Rochefort, 1993). The expectation was for them to become part of the existing community and be supported by health service provision within the local authority. However, there was a lack of forethought when commissioning service provision, and those with mental ill health were faced with inadequate housing, severe poverty and social isolation (Mechanic, 1995). The derogatory term 'care in the community' comes from this period in time (Herbert and Dunkel-Schetter, 1992). Issues such as a lack of resources, gaps between policy and practice, and unrealistic expectations of community support, caused tension within society, leading to a lack of integration (Mandelstam, 2009; Brown, 2006).

According to Bourdieu (1984), threats to society could be explained through understanding how existing communities felt integration would affect their capital values. People being resettled through the Community Care Act were given social housing and were on social welfare benefits (Groves, 1990). To live near people who rely on this kind of state hand-out could lower the value of other properties nearby (Groves, 1990). In a neo-liberal society, social class is attributed to economic capital (which can include house price) and social networks, to which the integration of people reliant on the state was seen to lower these economic values, fuelling tension between the two communities, and qualifies the common acronym NIMBY-not in my back yard (Groves, 1990). Goffman (1963: 5) also concluded that stigma was created for people to exercise their superiority, and make others inferior, to 'account for danger he represents, sometimes rationalising an animosity based on other differences, such as social class'. This can be damaging to the individual with a mental health problem as the stigma is not about them personally, but the perception that they are a societal burden (Evans- Lacko et al., 2013).

The former UK coalition Government (2010– 2015) used the term community to describe what is 'broken' in Britain and viewed it as a source of social issues (Hancock et al., 2012). While community is difficult to define, it consistently informs policy changes (Hancock et al., 2012). The former UK Prime Minister David Cameron asserted that a sense of community would be beneficial to society, stating that there is little 'social solidarity', rather a state of 'selfishness and individualism' (Cameron, 2009: online). The Mental Health Act (2007) and the Mental Capacity Act (2005) now focus more on the independence of the individual and have ascertained that it is better for most people to continue to be part of a community if they have help and support, providing that they have the mental capacity to cope. However, most people with mental ill health that live 'within the community' do not benefit from the resources available to them (Morris, 2012). Although there are many services offering mental health support, medication for mental ill health is the most common form of treatment in England (NHS Digital, 2016). In 2016, there were 64.7 million prescriptions for anti-depressant medication, an increase of over 108% since 2006 (Campbell, 2017). It is unknown exactly how many people are taking the medication, as this data is not recorded in the UK currently.

The second most common treatment in England is psychological therapy (NHS Digital, 2016). In 2015/16 1.4 million people in England were referred to counselling by their physician (Baker, 2018), however of these, only 537,000 had finished their course of treatment (deemed

to be two sessions or more). The average waiting time was just 29 days, although this varied greatly throughout England, with people in the Wirral (North West England) having an average wait of 139 days (Baker, 2018).

The Improving Access to Psychological Therapy (IAPT) programme currently running in the UK was set up in 2008 in order to enable service users with depressive and anxiety disorders to gain access to evidence based therapies, which is mainly through Cognitive Behavioural Therapy (CBT) (Department of Health (DoH), 2009). Thousands of new therapists would be employed throughout England so that the waiting times would be shorter and there would be access to group therapy sessions as well as one to one sessions. The National Institute for Clinical Excellence believe that CBT shows evidence enough for the IAPT programme to be successful, stating that they had reviewed evidence of clinical trials between 2004 and 2008 (McPherson et al., 2009). A second benefit of employing the IAPT programme was that there would be more accurate records of service users, the effectiveness of the therapies, and the costs involved. It can be argued that any data on mental health before this time cannot be compared to current statistics, and that the significant rise in mental health diagnosis is due to better measures rather than a lack of ingenuity when choosing how to run mental health programmes (Rizq, 2012; DoH, 2010).

The Five year forward view for mental healthcare report, commissioned by the UK Government (Independent Mental Health Taskforce, 2016), states that three quarters of people with a mental illness will receive no support in any given year, and it is not known what level of support people who do access services actually receive. The poor quality of data held at local authority and CCG level means that 67% of what is spent on mental health services is unknown, often cited as 'miscellaneous' (Mind, 2015).

The report highlighted that there are several populations within the UK that were the most vulnerable when it came to mental ill health (Independent Mental Health Taskforce, 2016):
- Post-natal women
- Those with physical illnesses such as heart disease and cancer often lead to premature death when comorbid with mental ill health
- Those without stable homes or employment, including zero hours contracts and short term poor quality tenancies.

- Veterans of the armed forces

- Older people

- Marginalised groups (BAME, LGBT, disabled)

- Prisoners

- Males aged 15-49 who have been in contact with mental health services within the last year (suicide risk)

Although suggestions are made throughout the review about how to develop mental healthcare going forward, I believe that the document still lacks original thinking, relying on putting extra funding into methods that have been used for many years. Statistics around the effectiveness of CBT and medication vary greatly, from being ineffective for some medically diagnosed disorders to being significantly effective for others (Lorenzo-Luaces et al., 2018; Hetrick et al., 2016).

In January 2018, Johnstone and Boyle (2018) published an alternative suggestion of how to view mental ill health – The Power Threat Meaning framework. They embrace principles of CP and believe that to solve the current mental health crisis, the medicalisation of mental health should be reduced, and that society is able to cope with supporting people in the community. The framework accepts that sometimes severe mental health issues need to be treated using the medical model until this point, there are other therapy-based alternatives (Johnstone and Boyle, 2018).

The creation of the Power Threat Meaning framework is the first time in modern history that the medical model has not been given power over people with mental ill health. The next section will explore the scientific research around community and how it supports the view that communities can be empowered to increase health and wellbeing within the individual, to the benefit of the community and society as a whole.

2.4.3. Theories of Community Support

Underlying theories about community and what benefits a sense of community may bring, are critical to this thesis. Solutions involving communities and peer support do not need to rely on being financed by the Government, and could offer some solutions and alternatives to healthcare led programmes. Burton and Kagan's (2015) research into connectedness and social isolation showed how fundamental community is to the health and wellbeing of the individual,

and by embracing social connectedness, it could save on public spending. They also discuss that although researchers in CP aim for transformative change, in reality the aspiration for change is more realistic when engaging in small-scale research (Burton and Kagan, 2015: 185). This section outlines some key perspectives in community theory, discussing them in terms of how Community Psychologists have embraced this 'aspiration' for transforming the lives of those with mental ill health.

McMillan and Chavis's (1986) Sense of Community theory aimed to identify what traits are needed to be able to identify within a group or community. The theory was intended to be flexible enough to be used in a broad range of applications, and can even be applied to online communities, despite being created several years before online communities became commonplace. It was hoped that the theory could be utilised within institutions, particularly mental health institutions, whereby fostering a sense of community could have a therapeutic effect on the inhabitants (McMillan and Chavis, 1986).

McMillan and Chavis (1986) found that there were four elements needed for there to be a sense of community: membership; influence; integration and the fulfilment of needs (reinforcement); and a shared emotional connection. Membership can be a thought of as a 'right to belong' (McMillan and Chavis, 1986:9) as one has invested themselves, either through deed (such as attending church) or through purchase (such as a house). This right to belong if fostered, is tantamount to being part of the 'ingroup'. However, these memberships can be tenuous depending on personal boundaries, particularly those linked to safety (Erikson, 1966). The shared emotional connection comes from positive associations including spiritual belonging, sense of locality (or gemeinschaft as Tonnies (1957) describes it), and shared values (Doolittle and MacDonald, 1978; Cohen, 1976). The group experience must be a positive one, and the more time people spend in a positively associated group, the more rewarded they are likely to feel and the stronger the bond of the group becomes.

Glynn (1981) also outlined key components of what it meant to be part of a community. The Measure of the Pyschological Sense of Community is made up of 202 behaviours and subconcepts, of which 120 items were developed to represent real and ideal characteristics. He found that the strongest predictors of sense of community were:
1) Expected length of community residency
2) Satisfaction with the community

3) Number of neighbours one could identify by first name

Relating the three predictors to an online community could be utilised as follows:
1) The length of time one has been a member of a particular community forum
2) How happy they are with the day to day interactions
3) Regular interaction with other long-term members

These indicators could be used to show how an online community can have the same psychological feeling of satisfaction and community as people feel in offline communities, despite the lack of physical interaction. Glynn (1981) also found a positive relationship between a sense of community and the ability to function competently within the community. Functioning competently within online interactions could be the ability to communicate coherently and spell properly in the language that the site operates in.

Riger and Lavrakas (1981) also believe that citizens need to operate on a similar level in order to create social bonds and 'behavioural rootedness', whether that is educational or perceived similarities such as social class, with age in particular playing a major role in determining status. However, Albrahnt and Cunningham (1979) found that the level of commitment by a community group member was important in gaining a sense of community. Those that were the most committed became part of the 'social fabric' of their neighbourhoods, and were ultimately satisfied with their community and the social relationships that it offered.

What is important when identifying how community support can help people with mental ill health, is that the social issues are what are considered rather than the 'illness' (Nelson et al., 2014). Positive relationships within communities can lead to happier and more secure individuals (Nelson et al., 2014; Glynn, 1981). Through emphasising peer support rather than giving power to health professionals or medicalisation, Community Psychologists believe that people with mental health can ascertain greater support systems within their current communities and that these could prove more beneficial than any other support mechanism (Walker et al., 2017; Davidson et al., 2014). What has not been identified by Community Psychologists, is if these communities can come in other forms, such as through social media or online forums.

2.5. Identifying Differences – How Mental Health Became the 'Other'

Social representations of mental health are often portrayed as negative in the Global North, and this impacts on how people with mental ill health relate to others within society (Al-Kouja and Corrigan, 2017). This is often due to stereotypical representations of people with mental ill health as different to what is perceived as normal within society which can affect the way that people with mental ill health view their own identity, and being identified as part of an out group may cause a decrease in self-confidence and understanding of where they fit within a community (Festinger, 1953). This lack of self-confidence could also lead to further mental health issues as a divide between how someone identifies themselves, and the general community becomes greater. This section explores identity through othering and social connections and then goes on to discuss how policies affect socialisation based on recommendations of how people with mental health should strive to behave.

2.5.1. Social comparison

Identity is a concept that has been researched in many disciplines. Social comparison theory (Festinger, 1953) found that people develop a sense of self through comparing themselves to others. Confidence is often derived through this identity and seeking out others who share the same behaviours (Festinger, 1953). Wood (1989) found that self-esteem can be affected by these comparisons with others. Downward social comparisons may validate behaviour and boost self-esteem, however if upwards comparisons are made, then self-esteem can become very low, leading to withdrawal from social relationships (Wood, 1989; Wills, 1981). Similarly, the Social Identity Approach (SIA) conceptualises how individuals see themselves through the group activities that they engage in (Tajfel and Turner, 1979). This sense of identity, which is usually formed over time and through many group associations, shapes how the individual behaves socially. However, if the individual does not identify with other group members, then they may find that they become part of the out-group, and this can lead to discrimination or prejudice by those in the in-group (Tajfel and Turner, 1979).

Groups can also act differently depending on the shared identity. For people with mental ill health, community acceptance is often problematic, and this can lead to them hiding their ill health, sometimes to detrimental effect (Knifton, 2013). As explored previously, in the UK there is stigma and shame associated with disclosing a mental health problem. This is due to

the way that mental health has been handled in the past. Often conditions were ill understood, and so people with learning difficulties, young single mothers and gay people were among those that were taken into mental institutions for being deviant from 'normal' society. Deviance has long since been a reason for stigma, and although these 'deviants' were no longer institutionalised, people with mental health problems can become part of societies 'out-group' (Goffman, 1963).

Mental health hospitals (asylums) were a way of creating social separation (Goffman, 1961) whereby normally functioning people created a safe and secure environment by extraditing anyone from their community who was considered abnormal. This created the idea of 'the other', if other people had mental health problems, and they are different to me, that means that I must be normal. Despite the statistic that 1 in 4 people will be diagnosed with a mental illness within their lifetime (McManus et al., 2016; WHO, 2001), there is still a misunderstanding of what it is to be normal and abnormal, and the stigma attached to mental health problems still means that society will try to justify a diagnosis and cure it, than try to live with or understand it (Szeto et al., 2012). People will also conceal their diagnosis from family and friends so that they don't need to feel the shame, however this then means that they may not get the help and support that they need to overcome the issue.

2.5.2. Community Integration Idealism and Reality

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 the NHS) (Whybrow and Heyes, 2016). Therefore, social connections are important in preventing further or future health issues, as are networks, which can lead to furthering ones social capital through new connections and communities (Putnam, 2000; Bourdieu, 1990; 1983).

The Mental Health Act (2007), the Mental Capacity Act (2005) and most recently the Care Act (2014), now focus more on the independence of the individual and have ascertained that it is better for most people to continue to be part of a community if they have help and support - if they have the mental capacity to cope. Stigma has often been blamed for societal attitudes around mental ill health and the negative treatment of people who may be afflicted with such illnesses, however UK policy and practice must take some of the blame. People with mental ill health often struggle to get disability benefits, and are made to feel as though their illness is not as significant as physical health (Jacob, 2015). It has also been of concern that prevalence of mental health is higher in those that suffer multiple disadvantages within society, for example those from BME groups or the lowest social classes, and stigma is often related to this (Knifton, 2013).

This downward mobility of people with mental ill health is particularly apparent within the prison population. Prison populations are noted for the amount of people who have a mental health diagnoses. In the US, the amount of people estimated to have a mental health issue is 'more than 56% of State prisoners, 45% of Federal prisoners and 64% of jail inmates' (Wright et al., 2014: 179). In the UK, the figure for prison population mental ill health was unknown (Wright et al., 2014) until a report by the National Audit Office was published in June 2017. It states that around 37% of the prison population of the UK suffer from mental ill health, and there were 40,161 incidents of self-harm, and 120 self-inflicted deaths in 2016 (out of an average prison population of 84,674), suggesting that the figure for hidden mental ill health is perhaps much higher (National Audit Office, 2017).

The negative connotations that are placed on people with mental ill health can be detrimental in society, and someone with a mental health issue and a prison record can find it much more difficult to re-integrate into society, with BAME groups suffering the most (see figure 1) (Lammy, 2017). Social representations of people with mental ill health are often not helped by the media (Whitley and Berry, 2012). Images in films such as Psycho (1960), Silence of the Lambs (1991) and Batman: The Dark Knight (2008) stigmatise people with mental ill health as violent and without emotion (Byrne, 2009). As part of a report about the depiction of mental health in films, Byrne (2009: 4) found that when defining film characters with mental illness, the top three answers were: 'violent (39%), weird (35%), and likely to kill violently (30%)'. Despite these negative portrayals, there are some films that are deemed to portray more realistic aspects of mental ill health, with the Royal College of Psychiatrists regularly blogging films

that fit this category (RCPsych, 2018a: online). However, these are usually films that are not mainstream, and a knowledge of where to access these films is necessary, making it somewhat unrealistic to expect most of the general public to gain knowledge about mental ill health through this medium.
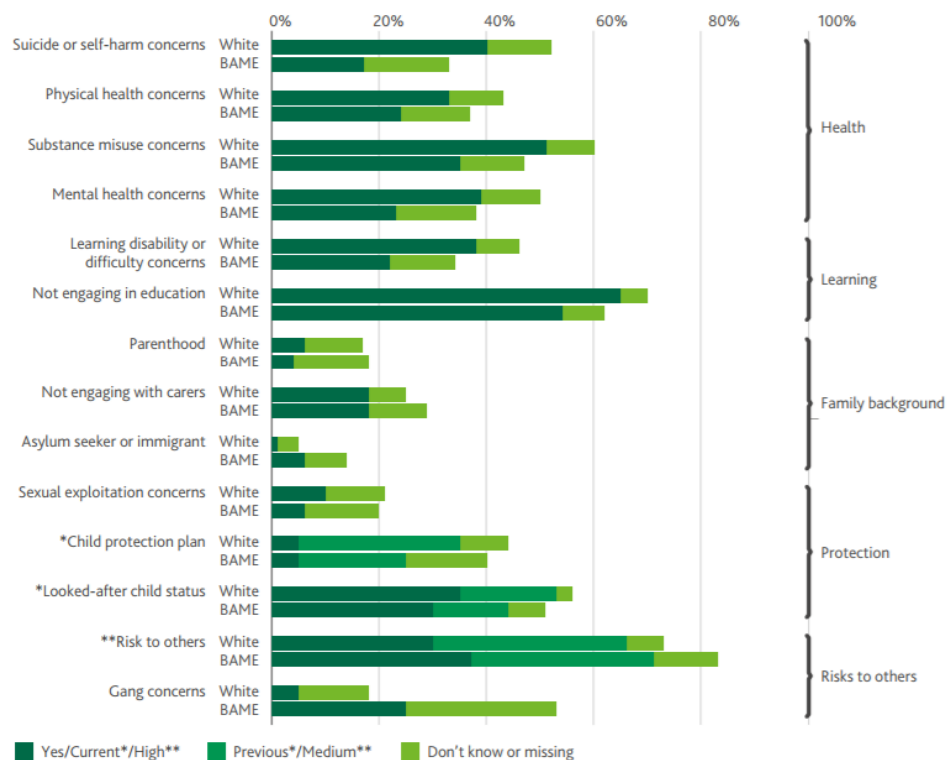
Figure 1 The distribution of key characteristics for all admissions to custody by ethnicity (Lammy, 2017).

The effects of this type of stereotypical understanding of mental ill health were seen in the early 1990's, when the NHS and Community Care Act (1990) was enacted. After the Act came into force, the Care in the Community initiative received unfavourable media coverage due to stories of mental health patients being responsible for killings, or for putting themselves at risk after leaving residential care and living in the community. Media attention has continued to contribute to the negative stereotypes of people suffering with mental health problems. The prejudice and discrimination that has grown from this coverage made it difficult for sufferers to become an accepted part of their local communities (Herbert and Dunkel-Schetter, 1992).

2.5.3. A Philosophy of Identity and Mental Health

In this section, I use philosophical debates to discuss how identity and mental ill health may have formed, and how historically community was used as an effective mechanism for support,

from as far back as the Stoic era. Community understanding was the key to how The Stoics (ca. 333 -262 BC) rationalised their issues. They used reason and knowledge to understand how they were affected by external events, and a method that they used frequently was that of confession, discussing complex issues with others in order to make sense of them. Knowledge and understanding was shared amongst communities which helped them to conclude that it was not events themselves that would influence human behaviours, but the perspective that we put on these events (Beck et al., 1979). Through communication, deliberation and rationalisation, the Stoics argued that human beings can control their emotions, and through collective action, issues could be resolved.

How personal experiences are interpreted, have long caused problems within communication, which can prove difficult for individuals trying to convey their experiences of having mental ill health. Phenomenological theorist Husserl (1936/ 1970) believed that stories should be told as the person telling them meant them, rather than as an interpretation from the person it is told to. However, in order to explain experiences, people generally communicate their understanding of a situation through using universally understood examples. This can be through sharing events, or using words that are simplified in order to make sense to others. It is difficult therefore, to fully understand other members of a community in a truly Husserlian way. Effectively, people would never understand one another and this would probably lead to disharmony and isolation.

The original aim of humanist psychology was to understand humans in their highest functioning form (Moss, 2015). However, by developing the idea of understanding the human form 'as it is', humanist psychology can help us to understand the way humans are in the everyday, rather than at a species perceived peak functionality (Moss, 2015). To excel as a human would be different for each person. If there is no ideal, then we should strive to be ourselves rather than strive to be something unachievable.

What it is actually like to have a mental health problem, could be deliberated through Gray's (2003:19) idea of ontology as the 'study of being'. The identification of mental health as part of who the person is, rather than as a disease that is inflicted upon them. Authors as diverse as Maslow (1966), and Csikszentmihalyi (1990) formulated this same challenge—to understand humans in terms of their highest potential and through the study of individuals who display the highest levels of human functioning. This would mean that functioning would be seen on an

personal level, which would require the personalisation of services for those who feel as though they cannot function at the highest level. Whereas I believe that personalisation of services could be beneficial to people with complex mental ill health, that is not within the scope of this thesis. Personalised services may also come at a higher cost to health services than community support, and this research aims to find inexpensive solutions that can be utilised by the many rather than the few.

2.6. Focus on Social Change

One positive response to mental health issues in the UK (and in many industrialised countries), has been an increase in various forms of mental health service user support groups; some formally supported, for instance by health care providers and others informally created, such as by individuals with mental ill health setting up their own support groups. The central aim of these groups is to bring service users together for mutual support and to reduce isolation (Mind, 2015). There is also a lack of insight into who accesses these support mechanisms. Although, there is a need to examine user-led social support, to understand who is benefitting from current provision (Kawachi and Berkman, 2001). Crabtree and Haslam's (2010) study on the positive and negative implications of user-group group identification showed that group support settings did create and reinforce a user community arena, which could outweigh the negativity of experiencing stigmatisation and social exclusion.

2.6.1. The Focus on Stigma

Public campaigns to reduce stigma have generally been successful, although to varying extents (Gronholm et al. 2017). Campaigns need to decide on whether to tackle mental health stigma as a whole or focus on a particular illness and also whether it is a national, or regional campaign (Gronholm et al. 2017). Gronholm et al. (2017) found that those that used education or contact were the most often used interventions, and they found that most of these were successful, although some were slower to show an effect than others. Through their review of worldwide interventions, Gronholm et al. (2017) stress that there is little evidence around the long-term effectiveness of any of the interventions as shown in figure 2.

Type of intervention or nonexperimental exposure	Knowledge and attitudes	Behaviour
Short term face to face contact	+ SR	− SR
Short term parasocial contact	+ SR	− SR
Long term face to face contact[a]	+ IS [37, 38]	− SR
Long-term parasocial contact (with or without other interventions)	+ IS (see section on "Anti-stigma interventions for the general public")	+ IS [39]
Education	+ SR	− SR
Protest	− SR	− SR
Structural approaches	− SR	− SR

Key: + positive evidence; − evidence lacking; SR evidence from one or more systematic reviews; IS evidence from one or more individual studies [study references in brackets]

[a]Long-term contact through knowing someone with a mental illness

Figure 2 Summary of evidence on interventions to reduce stigma (Gronholm et al., 2017).

In a systematic review on stigma and help-seeking, Clement et al., (2015) found that the most widely reported types of stigma (by people with mental ill health) were internal (self-stigma) and treatment stigma. This could suggest that stigma in general society is decreasing, and that people with mental ill health may be more concerned about how a diagnosis affects their identity, network sociality and life-balance.

As discussed previously, stigma is also perpetrated by the media. However, a recent annual report by Time to Change (2017) on media representations, found that 50% of UK print media articles about mental health were now anti-stigmatising, compared to 35% that were stigmatising throughout 2016. This shows that there is a positive shift in attitudes around mental health and could lead to a better general understanding of the effects of mental ill health. For people diagnosed with mental ill health, it may help to reduce negative stereotypes, helping to create more positive social identities leading to more socialisation and less isolation.

2.6.2. Radical Rethinking?

The financial cost of mental ill health is starting to become an issue within the Global North. 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 in rural locations or because of the negative stigma that even being seen to use orthodox services may have on family, friends and the self (Corrigan et al.*,* 2005; Link et al., 1999; Star, 1955). It is of great concern in the UK that through austerity measures and negative attitudes towards people with mental ill health, there may be an increase of people isolated through the lack of formal service support, so it is vital to understand the social factors that shape the way people may seek support in different and more cost effective formats.

Current mental health policies and therefore finances, have been dominated by the recommendations in the five-year forward plan in the UK. This was commissioned by the NHS, and compiled by a taskforce of mental health researchers, practitioners and specialists. This is frequently held as the 'gold standard' of what mental health practitioners in the UK are striving to achieve with mental ill health, as it introduced the idea that more money should be spent on mental health professionals to cut waiting lists, and that better care should be taken when recording information about people with mental ill health. The statistics and background research are an important starting point from which researchers in this field can refer to as the most recent and reputable academic work. However, the recommendations for the future of mental health services are somewhat limited, focussing on extending services that are already struggling to be effective. It is disappointing that the most prolific researchers in the UK in the field of mental health, have such limited visions of what needs to happen.

In contrast, the Power, Threat, Meaning Framework (Johnstone and Boyle, 2018) has caused controversy, meaning that one of the creators of the framework had to remove her profile from social media due to malicious and nasty comments, as figure 3 demonstrates.

adisorder4everyone!
@dropthedisorder

Follow

Outraged &upset to yet again hear about relentless trolling of @ClinpsychLucy Lucy,we all know u will carry on with all the crucial work u are doing with the #PTMFramework globally, offering much needed choice to people &we totally support your choice to stay off toxic twitter x

> **Lucy Johnstone #FBPE** @ClinpsychLucy
> I rest my case: clearly we can't have a civil debate re #ptmframework on Twitter. But the launch was free; all documents & resources are free; keen discussants can attend free or free places events (50 + so far); or like some, set up FB or Meetup groups. Taking a Twitter break 😊

8:44 AM - 14 Oct 2018

25 Retweets 66 Likes

💬 6   🔁 25   ♡ 66   ✉

Figure 3 Tweet showing the level of negative feedback received about the PTMF.

There is new hope for change with alternative thinking in the form of the Power, Threat, Meaning framework (PTMF) (Johnstone and Boyle, 2018). This framework does not re-hash existing service provision that does not seem to be working, but puts ownership on society to encourage positive change through collective action. Johnstone and Boyle (2018) are thinking differently about how society's view of mental health could be challenged. Although many people agree with the sentiments of the framework, others feel threatened and attack those responsibly for daring to think differently, which may hinder future radical suggestions for change. The use of social media to affect change is ever more important, and this gap in the literature around policy and mental health is a fundamental one. However, the PTM Framework does not necessarily offer such radical solutions. Albeit interesting that it suggests that change should occur, the PTM Framework does not offer too much in the way of real change, in the short term at least.

The PTM Framework originated from a paper written in 2013 that stated it was 'Time for a paradigm shift' (BPS, 2013:1). This paper outlined that the BPS Division of Clinical Psychology felt that the DSM and ICD were 'fundamentally flawed' (Johnstone and Boyle, 2018a:5) with 'significant limitations' (BPS, 2013:1). Although the BPS acknowledge that there are issues within the classification system, it continues to work within a medical framework, frequently using medicalised terminology. Central to their argument is that

alternative methods of diagnosis (or using a non-diagnostic system) and treatment should be aligned with ideas of personal agency (one has a story to tell, and that should be heard before being given treatment options). The framework also goes some way towards advocating the removal of the barrier between the power given to the medical model and people with mental ill health (Johnstone and Boyle, 2018a:5). By removing the diagnostic label, it is argued that power is given back to the individual due to the dominance of the medical model, although the options on offer are not very varied, encompassing IAPT and social prescribing that already occurs in the UK. Other mental health groups have also tried to offer (arguably more) radical solutions (such as Mad Pride, Refuse to Shock, Hearing Voices), but these have not become mainstream offers. Perhaps the slight changes proposed by the PTM Framework are the most radical that health and social care professionals, and policy makers, can comprehend at the current time.

Concepts of power and medicalisation relate back to the work of philosopher Michel Foucault, who himself remained worried about the pathologisation (and then rejection) of a certain way of being that is not seen as normal (Foucault, 1980). Similarly, it was noted in the PTM Framework that most people become diagnosed with mental health conditions after others notice their 'social rule transgressions and/or role 'failures' in everyday life' (Johnstone and Boyle, 2018:15). The understanding within the Framework, and formulated by Foucault, is that the negative association with mental health needs to be changed, along with the idea that people are abnormal if in mental distress. Therefore, the PTM Framework suggests that mental ill health should not be treated as a psychiatric diagnosis in the same way that Foucault (1980) believed that the medicalisation of mental health gives rise to hierarchy and power dynamics. What both the PTM Framework and Foucault argue is that the act of seeing a medical professional immediately gives rise to hierarchy and power dynamics in which the person is medicalised and psychiatrised, and even if the individual feels comfortable in the environment, they once again relinquish power through talking about their mental ill health in terms of a psychiatric abnormality. The PTM Framework however, suggests that instead of a diagnosis, mental health professionals ask the individual how **power** controls their lives, what **threat**(s) it has on their lives, and how they can make sense of this (**meaning**).

What the authors of the PTM Framework appear to have forgotten, is that the power dynamics that exist around mental ill health are still present through the process of help-seeking that still involves medically trained professionals. However, the PTM Framework then goes on to

suggest that changes to current treatment practices would take years to become embedded in modern discourse, and that the idea of giving power to the individual and their communities, may not necessarily be the way forward for all people with mental ill health anyway. Power could be given to individuals through choice, and medical intervention may eventually be bypassed altogether if we remove stigma and the psychiatric discourse (Johnstone and Boyle, 2018).

Mental health policy is currently being updated in the UK. When considering the functioning of the Mental Health Act 1983, the government notes with concern:

- rising rates of detention under the act
- the disproportionate number of people from black and minority ethnicities detained under the act
- stakeholder concerns that some processes relating to the act are out of step with a modern mental health system

Concerns include, but are not limited to, the following:

- the balance of safeguards available to patients, such as tribunals, second opinions, and requirements for consent
- the ability of the detained person to determine which family or carers have a say in their care, and of families to find appropriate information about their loved one
- that detention may in some cases be used to detain rather than treat
- questions about the effectiveness of community treatment orders, and the difficulties in getting discharged
- the time required to take decisions and arrange transfers for patients subject to criminal proceedings

(Gov.uk, 2018).

Currently, the distinction between someone with mental ill health having the capacity to function and the capacity to not function is a serious definition and one that can have many important effects (Jacob, 2015). Capacity in the UK can only be determined by a medical doctor, mental health professional, a nurse, or a police officer, and at least two of these professions must agree (Mental Capacity Act, 2005). If it is deemed that the individual does not have the capacity to make their own decisions and to function with basic daily tasks such as getting dressed or making food, then they would be sectioned (Mental Capacity Act, 2005). Being sectioned means that the individual is taken into care by the state (Government), usually

in a mental health institution. There are currently 211 mental health institutions in England, with 18,460 beds (NHS Digital, 2017). These are often over-capacity and in 2016, 6000 people who had been hospitalised were sent out of their local area (Marsh, 2017). Once again, this disproportionately affects people who are poor, as this group may not have the means to travel and are unable to benefit from the support of their loved ones (Nelson and Prilleltensky, 2010).

The rising rates of detention have been a cause of concern for some time, and as in David Lammy's report, there are a disproportionate amount of black and minority ethnic people who are affected by this, whether it is incarceration in mental health institutions or prisons (Lammy, 2017). There is evidence that institutional care should be phased out as even for the worst cases of mental ill health, there is no justification for incarceration. It is not beneficial to the service user and may actually cause harm rather than help. Once again, radical solutions rather than an adjustment of what is already happening, need to be considered when changing policy in this area. Community psychology advocates political activism, and the Mental Health Act may be a way to start significant changes.

2.6.3. Alternative Communities

> "Ideology offers a critique of existing society, a vision of a better one and a strategy for getting from here to there" (Fitzpatrick, 2011: 126)

Online spaces such as social media, blogs, support groups, information pages and so on, have become an intrinsic part of everyday life for some (Morrow et al., 2015). 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, 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).

A systematic review of research into online health communities in 2004, found that there was no evidence to support the social, psychological or informational benefits of online support, or online peer-to-peer support (Eysenbach et al., 2004). However, despite this, patient forums

have gained in popularity (Neal et al., 2007; Blank and Adams-Blodnieks, 2005). 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 and online forums are ideally situated to be able to educate people (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 (Guo and Cheng, 2016; Easterbrook and Vignoles, 2013; Hornsey and Jetten, 2004). 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 become further isolated (Daine *et al*, 2013). My research concentrates on user experiences of online mental health support communities, with an aim to suggest cost effective methods for mental health support in the future, and to take into consideration the negative effect of mass forums whereby voices may go unheard. Through researching multiple platforms and through multiple methodologies, I hope to add pertinent insights in the area of online support communities for mental ill health.

2.7. Summary

Mental health is a topic that is difficult to define, and recently the focus has been on the impact of stigma (Corrigan, 2015; Thornicroft, 2004). There is a paucity of knowledge about how community support groups are perceived by service users, whether they find them useful and in what ways they are helpful. Current UK provision emphasises self-help and mutual (offline) group support as positive for users, yet other alternatives to the traditional medical model, such as the Power Threat Meaning Framework are rejected due to their radical suggestions. Many people living and surviving in the community with mild to severe mental health problems do not have easy access to professional health and social care services, so radical solutions may be the answer to an over-burdened medical system. 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 tele-healthcare and online services are seen as a cheaper alternative and are often billed as a more effective solution (Chambers et al., 2016), but they are not taken seriously.

Health and wellbeing is embedded within societal attitudes and it is important to treat society as a whole to improve behaviours within communities and improve health at an individual level. Health researchers have focussed on interpersonal dynamics and social networks, which go some way towards highlighting the issues of social withdrawal and links to community theories (Pescosolido, 2010; Link et al, 1999). There are also a great deal of arguments around social inequalities linked to mental ill health and these should be taken into consideration when constructing arguments around the causation of mental ill health (McGrath et al., 2016; Pickett and Wilkinson, 2010; Wilkinson and Pickett, 2009; Wacquant, 2008; Marmot, 2004). Although, Yuill et al. (2010), further 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. In all cases, it is clear that mental ill

health in the main, (there may be exceptions) is not a cause or necessarily a symptom, but is a complex mixture of social and psychological issues that is uniquely experienced.

This chapter highlights the issues around current mental health policy and practice. Financial expenditure is high, and yet waiting lists for mental health professionals are increasing. Through three key organising principles of Community Psychology (Rappaport, 1977), I have undertaken a review of current understanding, policy and literature to build an argument for a more radical solution to the mental health crisis. I believe that one such solution lies within online community support, and my research within this thesis evidences why. The next chapter forms a bridge between Community Psychology theoretical perspectives and my research methodology. Chapter Three discusses available literature around online community support, where the gaps in the literature are, and how the NHS in the UK currently utilises online support for people with mental ill health.

Chapter 3: A Review of Online Support Literature

3.1. Introduction

This chapter reviews the literature around online peer-to-peer community support. Firstly, I define the term online community. Preece (2000: 10) defined online communities as 'people who interact socially as they strive to satisfy their own needs or perform special roles such as leading or moderating. A shared purpose such as interest, need, information exchange or service that provides a reason for the community'. This is through computer systems such as social media or web-based support forums that 'mediate social interaction and facilitate a sense of togetherness' (Al-Saggaf and Begg, 2004: 43). Online communities develop around a specific purpose, which is usually to bring people together to discuss specific health issues, meet new friends, or exchange information (Al-Saggaf and Begg, 2004). For the purpose of this thesis, any online community focusing on mental health is included in the definition, which encompasses social media[8], mass forum platforms[9], independent forums and those run by third sector organisations such as Mind[10]. The most important part of defining the support forums that are analysed through this research, is that the support comes from peer networks. Naslund et al. (2014:1) define peer-to-peer support as 'a system of mutual giving and receiving where individuals with severe mental illness can offer hope, companionship and encouragement to others facing similar challenges'.

Online spaces have become an intrinsic part of everyday life for some (Morrow et al., 2015). Online forums are commonplace amongst internet users worldwide, the number of worldwide users reached 3 billion in 2014, and is now approximately 3.5 billion in 2017, approximately 46% of the world's population (Internet Live Stats, 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).

---

[8] Facebook support forums are the most commonly used
[9] Such as Reddit
[10] Mind is a charity that provides information, funding for face-to-face support groups and runs online forums on specific mental health issues.

There are few statistics directly related to peer support online within the existing literature, however those that exist support the use of the forums for healthcare support (Fox et al., 2011). Although, DeAndrea and Anthony (2013) found that 60% of internet users reported that they had previously read information regarding the health issues of others online, and most of the participants stated that they would search online before seeking advice from a medical professional. Social media has been increasing in popularity for its mental health community support forums and is now an important means to connect and interact with others (Naslund et al., 2014). Dutton et al. (2013) emphasised how Facebook users are choosing to consume information through their online social networks rather than search through their internet browsers. People are no longer typing in terms related to mental health to find where to get support, but are relying on social media sites that they are already familiar with (Dutton et al., 2013). The idea that the users of online support forums are consumers is something that is repeated throughout the literature, which emphasises the choices that people have when looking for support with their mental ill health online (Giles, 2016; Fergie et al., 2015; Dutton et al., 2013; Broom, 2005).

I begin by exploring relevant literature on social interaction on the internet and the interplay between the internet and health seeking behaviours. A discussion of the literature around peer-to-peer forums and social media forums will then lead into a community psychology perspective of collective support behaviour, and how this may help to create our online identities. Formal professional support is offered online in the UK by the NHS, and I consider the evidence base (or lack of) for the services that it promotes, and how this model of health support works through the lens of social and community psychology.

In Chapter Two, I introduced the theoretical frameworks and literature around mental ill health, and in this chapter, I will further apply the frameworks and knowledge of Community Psychology (CP) to existing literature around online mental health support. I explore the evidence around online mental health service provision, starting with how and why people access online support for health conditions, how anonymous peer-to-peer forums differ from social media forums, the creation of the online self and whether it increases disclosure. I then consider, the role of the NHS in providing formal online mental health support.

3.2. Social Interaction on the Internet

Interest in researching internet communities has grown substantially in the past two decades (Buehler, 2017; Wright, 2016), although there is some argument between academics over whether using internet forums as a support network is beneficial. For example, Kraut et al.'s (1998) study claimed that the internet was responsible for an increase in loneliness and depression, and more recently, a report by Facebook (2017) found that social media can have a negative effect on wellbeing. Despite this, many researchers still believe that there are benefits to using online support (including social media) (Buehler, 2017; Wright, 2016; Pavalanthan and De Choudhury, 2015; Deters and Mehl, 2012; Ellison, 2007; Al-Saggaf and Begg, 2004). Pavalanthan and De Choudhury (2015) found that anonymity on community forums can disinhibit individuals, which can lead to disclosure about personal issues that they may not be able to disclose elsewhere. This type of self-disclosure has been shown to have positive effects on personal wellbeing, synonymous with reduced medical interventions and improved mental health (Pavalanthan and De Choudhury, 2015; Ellison, 2007).

Health policies in the UK have been changed to encourage the patient to be the expert rather than rely on medical advice from a general practitioner who may not hold specialist knowledge about their illness. 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). This may mean that some individuals feel that they are able to diagnose conditions in others. Giles (2011) found that users of online mental health community support forums tended to construct their own versions of mental health diagnoses, even creating diagnostic tools and diagnosing other community members. There are now many thousands of Mental Health community support groups online that are written in the English language, and they provide various methods of information and support such as offering advice with how to cope with specific health issues, or peer support groups (Wright, 2016). Misinformation can be an issue for online support forums, and this can lead to an increase in health information seeking from healthcare professionals offline (Neal et al., 2007).

There is, however, a sense of community created by a shared identity (Wright, 2016). In the case of mental health forums, people may be seeking information and advice from people who have had similar experiences (Tate and Zabinski, 2004). This help may boost self-esteem and the individual has found a community that they can identify with (King and Moreggi, 1998).

The 'field' of virtual community support groups may be a platform that can replicate face-to-face community support groups, and the security of the individuals' identity within this (Yalom and Leczcz, 2005; Tate and Zabinski, 2004; Wood, 1989). It is important to understand how individuals feel about their own mental health, and their choices and preferences in how they want help and support (The Care Act, 2014).

People with mental ill health are at risk of loneliness and isolation as a result of withdrawing from socialising offline, due to stigma, illness or lack of mobility (Al Kouja and Corrigan, 2017). However, healthcare professionals have recommend socialisation for people with mental ill health (Care Act, 2014). This can create conflict for those who cannot physically socialise due to their mental ill health, so there could be benefits by the support gained from peers in online communities. The benefit that people get through social interaction has been found to be replicated through online community interactions, or social prescribing (Park et al., 2018; Bartlett and Coulson, 2011; Hobye and Lowgren, 2011).

In Chapter Two, I argued that people with mental ill health are often stigmatised in Global Northern societies, and become isolated, subject to abuse, and fail to receive the healthcare support that they need (Al-Kouja and Corrigan, 2017). The stigma surrounding mental ill health is concerning, particularly as it has been found to have a detrimental effect on help seeking (Clement et al, 2015). This contradicts the research by Pavalanthan and De Choudhury (2015) where they found that disclosing information online was beneficial, and supports recent research by Facebook (2017) which states that the general trend of health help seeking is moving towards social media, whereby anonymity rarely exists and harm can occur as a result of time spent using social media. Most people will use their own names to join health forums, giving vast amounts of information about themselves in the process (Facebook, 2017). Park et al. (2018) reviewed recent studies of disclosure of mental health on social media, and found that there is an array of information that is then easily accessible about that person. Links between platforms can connect individuals to conversations about illegal drug use, smoking and drinking problems and predictions of future mental health episodes (Park et al., 2018; Dai and Hao, 2016; Conway and Connor, 2016; Tamersoy et al., 2015; De Choudhury et al., 2013). This amount of permanent information posted on the internet could be used to negatively affect the individual in the future, despite feelings of social camaraderie and support at the time (Passarelli, 2017).

3.2.1. Health Seeking Behaviours Online

People utilise health support groups for different reasons. Some wish to seek more information from reliable and trusted sources, and others may wish to interact with others who have a similar diagnosis. Giles and Newbold (2013) state that the act of finding information online can be empowering, almost a rebellion against the medical model. The problem of help seeking for people with mental ill health is that often there is not an agreed definition of what the illness looks like (Giles and Newbold, 2013; Csipke & Horene, 2007). There are many ways of experiencing the same mental health diagnosis, with different causes, symptoms and medications. It is difficult to measure what exactly creates a supportive online environment for health related issues:

> The lack of measureable evidence from controlled studies is in sharp contrast to the increasing body of anecdotal and descriptive information on the self-helping process in virtual communities, indicating that virtual communities are in fact the single most important aspect of the web with the biggest impact on health outcomes (Eysenbach et al., 2004:5).

Eysenbach et al. (2004) assert that the phenomenal rise of online communities is important, as they appear to be supporting and helping millions of people around the world. Biyani et al. (2014) found that people preferred asking others with a shared diagnosis about their experience, than just looking at websites for the information. Their research also found that people generally felt more supported through engaging with others with similar diagnosed conditions, which could help people who feel isolated offline (Biyani et al., 2014). In a study of internet health seeking behaviours (De Choudhury et al., 2014), the researchers found that many people choose to search for health information online due to the privacy (as opposed to asking friends and family), ease of use due to familiarity, or because they were unsatisfied with the diagnosis from the doctor. Research into web-based forums by Hou et al. (2015), found that the secure attachment that people experience within their online community can be as successful as face-to-face relationships with stable service providers, which shows that there may be a place for web-based social support.

A sense of community is 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 locates a community that they can identify with (Ren et al., 2012; King

and Moreggi, 1998). The 'field' of virtual community support groups may be a platform that can replicate face-to-face community support groups, and the security of the individuals' identity within this (Yalom and Leczcz, 2005; Tate and Zabinski, 2004; Wood, 1989).

Consumer choice means that people can search the various forums and decide which ones 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 (Guo and Cheng, 2016; Easterbrook and Vignoles, 2013; Hornsey and Jetten, 2004). Noelle-Neumann's (1974) Spiral of Silence theory states that people need to gauge public opinion in order to understand how they can interact on a similar level to avoid isolating themselves. Therefore, it is important that the forum chosen by the consumer is one whose participants share 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). There is little understanding of what drives people to seek information and support online in the first place. The participants in this study were already engaged with online mental health communities, and the analysis that follows is about how they make use of these online spaces (Park et al., 2018; Chen, 2014).

3.3. Changing Communities

Online mental health support has become an important social change within health seeking behaviour. It is important to consider what impact this change has on the mental health community, and how this change is being received and reacted to by health professions. Community Psychology (CP) is concerned with utilising successful societal practice, understanding how it works and replicating this to implement the practice elsewhere (Rappaport, 1977). The increased use of online support communities suggests that the communities are providing help and support that is lacking elsewhere, although there is a gap in evidence here that this thesis will address.

CP provides a platform for psychologists to 'critically reflect on the concept of community… to consider who is being 'othered' by being placed outside of 'community' through our talk, thought and action' (Coimbra et al, 2012: 135). Online communities are somewhat different to the communities that are usually discussed within a social context as they usually rely on the

non-verbal communication and the people who use them may not know each other outside of the communities (Resca and Tozzi, 2013). Most would imagine community to be a physical state, one in which we live, commute, see face-to-face. However, arguably, online communities have very similar traits to offline communities (Joinson, 2009) and in order to understand how people with mental ill health behave, it is necessary to understand their interactions with others.

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 offline. This means that if they are open and trusting in the offline environment, they will be the same online. Schiel (2005) states that a person who is not really known to us cannot be a friend and therefore must be the enemy. The person who we may talk to as a friend online cannot be relied on (nor can they not be relied on) making the link tenuous at best (Schiel, 2005). Using this logic, there can be no true friendships created online as we are unaware of the potentiality of the person. Although arguments could also be presented that we do not really know the people we spend time with offline either.

There can be a sense of community created by a shared identity. In the case of mental health forums, people may be seeking the information and advice of people who have had similar experiences (Tate and Zabinski, 2004). This help may boost self-esteem, and the individual has found a community that they can identify with (King and Moreggi, 1998). The 'field' of virtual community support groups may be a platform that can replicate face-to-face community support groups, and the security of the individuals' identity within this (Yalom and Leczcz, 2005; Tate and Zabinski, 2004; Wood, 1989; Bourdieu, 1985).

Communities change over time, and people can be a part of more than one. This makes the concept difficult to define or analyse. Bourdieu (1985) believes that a sense of community can be a useful phenomenon, often giving people a sense of identity through shared associations. The integration of different communities can be difficult, sometimes leading people with complex conditions to become isolated rather than risk being ostracised as a burden on society (Evans-Lacko et al., 2013). 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.

User-led initiatives, which can also be found 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 and Faxvaag, 2014; Tanis, 2008). These groups are usually created informally, for example, individuals with mental ill health issues setting up their own support groups, or backed by non-governmental organisations. The central aim of these is to bring users together for mutual support and reduce isolation (Mind, n.d; Barak et al. 2008), there is a need to examine the specific mechanisms that make up social support to understand who is benefitting from the current provisions (Eysenbach et al. 2004; Kawachi and Berkman, 2001). There are also many online mental health community support groups, although there has been less analysis of these. 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).

Online forums are usually available 24 hours a day, 7 days a week and are convenient for the user to access from an internet enabled device. An internet forum is a social space where people can pose a question or start a discussion (commonly called posting) and other people can respond if they wish. Some people may also choose to read and be a member of the forums without ever posting (commonly called lurkers) (Schneider et al., 2013). Users can go online at any time of the day or night and connect with others who have subscribed to that particular forum. Popular forums bring together people who may have previously been isolated from their communities. This may be due to being diagnosed with a health issue (there are many forums around different types of cancer for example), or many other reasons. The forums help to bring together people with a shared identity, which can help to reduce isolation and increase confidence through interaction with others that are 'like me'. There are many thousands of forums that focus on mental ill health, and using these could potentially lead the way to more easily accessible professional mental health care services in the future.

3.4. Characterising Online Groups

Computer based support groups are associated with a variety of platforms, including peer-to-peer information groups, Facebook groups set up by organisations or individuals, and Twitter hashtags (amongst others). The communities formed within these groups are either termed virtual or online communities, and are seen as providing social, emotional and informational

support (Neal et al., 2007; Eysenbach et al., 2004). Generally, online health communities are used for understanding more about a medical condition, particularly for those who have recently been diagnosed (Welbourne et al., 2013). What is not understood fully, is what individuals gain from being part of these groups and how beneficial they are in improving knowledge about the mental health condition. My research attempts to address this gap in the literature through asking these questions to users of these online communities.

Users of online communities can choose whether to be anonymous, or not, depending on the kinds of community forum they choose. The use of some social media sites such as Facebook, is done through the use of the person's real profile, giving information such as name, date of birth, where they live, work and family connections. The use of peer-to-peer forums or mass forums gives users the opportunity to create their own username. Some of these are completely anonymised, others are more easily recognisable, with less information given about the personal details of the user.

Although the study of online community support groups is somewhat different to that of 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. On and offline segregation should perhaps 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). Exploration of different fields may require different research methods, or the adaption of existing methods in order to revolutionize community psychology and social theory research (Kozinets, 2010). My research adopts this approach, ensuring that different research methods are used to gather information from participants in different research settings. This will be explored further in the next chapter.

Having considered offline community support groups in Chapter Two, the following two sections will examine academic literature around community interactions within anonymised peer-to-peer mental health forums, and social media forums.

3.4.1. Anonymous Peer-to-Peer Forums

Dickerson (1998) believed that self- or peer-support groups are not only useful in terms of empowering people with mental ill health, but also in creating social engagement. Barak et al. (2008) highlight how important this view is when considering interactions in online health communities. The difference between offline and online group support is obvious in that there is no physical interaction or comprehension of non-verbal communication, although this may be beneficial to members who feel self-conscious (Barak et al., 2008). This anonymity within virtual spaces can generate feelings of trust and security in a way that face-to-face groups cannot. This creates a disinhibition effect that may allow users to feel more secure in disclosing personal thoughts or feelings (Suler, 2004).

Online peer-to-peer community group composition and perceived level of expertise may draw members whose participation is temporary (Park et al., 2018). They may post to get their specific question answered, but then withdraw to lurking status (Litman, 2005) or entirely (Balestra et al., 2017). Peer-to-peer support networks are only successful whilst a core member group are actively posting and responding to posts (Park et al., 2015). Once these become inactive, then the lurking community[11] may also leave as the perceived experts are no longer in residence, and there is no reason to watch or read the conversations as written by perceived amateurs (Schneider et al., 2012; Janzik and Raasch, 2011). Schneider et al. (2012) also found that core members are driven by altruistic means. They are not searching for information themselves, but want to help others who need information or are seeking support (Schneider et al., 2012; Janzik & Raasch, 2011; Hall & Graham, 2004; Wasko & Faraj, 2000; von Krogh, 1998). Lurkers may however, have differing motivations. These motivations can vary depending on personality type (Schneider et al., 2012), the type of information needed, and the level of support required by an online community.

Preece (1999) suggests that those who have made a more concrete attachment to an online community, such as those with complex health needs, are more likely to remain active and loyal to the community. The social bonds created through conversations between members creates a familiarity that users feel comfortable with (Litman and Pezzo, 2007). In healthcare communities, particularly mental health, the sense of community goes beyond curiosity and

---

[11] Schneider et al. (2012) suggest that there is a high proportion of online community users that do not post, but lurk on the community site in order to gain information without contributing.

relies on a deeper social bond (Litman and Pezzo, 2005). Woong Yun and Park (2011) looked at the relationships of participants in 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 may be the same online.

Blanchard et al., (2011) argue that trust is 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). Trolling[12] 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 may increase negative online experiences for users (Phillips, 2015; Rafferty, 2011; Herring et al., 2002). The ease of use of the internet, along with relative anonymity, has meant that predators have found it cheap and easy to target victims (Reno, 1999).

Suler (2004) identifies six factors that create a perfect environment for online abuse: dissociative anonymity; invisibility; asynchronicity; solipsistic introjections; dissociative imagination; and minimisation of authority. The combination of being anonymous, not interacting in real time, and not being sanctioned for their actions means that predators can disassociate themselves from any wrongdoing. Whereas most trolling has little more consequence than bad feeling (Bishop, 2014), when trolling happens on support forums such as health related community support, where others have created strong social bonds, the effect can be detrimental.

3.4.2. Social Media Groups

Evidence around the use of social media for healthcare support is somewhat limited, and social media has been seen to have transformed the way that health communication is transmitted (Mano, 2014). It is believed that the availability of mass information that is created through

---

[12] Trolling is a means by which individuals attack others online through inflammatory comments.

multi-modal[13] platforms such as Facebook, Twitter and Instagram[14] has helped to create the phenomenon of e-health (Dutton et al., 2013; Ziebland and Wyke, 2012; boyd and Ellison, 2007). The use of social media for health seeking has most often been explored in the context of younger adults (18-30), as they are more likely to use the internet (Fergie et al., 2015; Yonker et al., 2014). Yonker et al. (2014) found that young adults generated a large amount of mental health related content on social media, so understanding what interactions occur are vital in understanding how to create future health interventions. A study by Fergie et al. (2015: 1327) found that young adults use multiple sources for fact finding about a particular health issue as part of 'being a responsible, informed individual'. Depending upon their needs at the time of searching, they may use social media to find out how other people deal with their health related concerns, and to help them 'feel less isolated and validate their experience' (Fergie et al., 2015: 1328).

Social media has been criticised for being the cause of some social isolation (Facebook, 2017), however, much research is to the contrary, with Facebook in particular being successful in enhancing positive social contact (Grieve et al., 2013; Leung, 2013). Goodings (2010) in a study of My Space (an online blogging platform), found that users created identities for themselves that were not entirely new, but a 'better' version of themselves. There is also no evidence to suggest that the virtual self was used to replace offline interaction, but rather that it served as a connection to others that have similar interests or experiences (Goodings, 2010).

For some of the participants in Fergie et al.*'s* (2015) study, time was a factor, and connecting to Facebook (for example) was something that most of the young people did on a regular basis, meaning that if they wanted information quickly, this resource was easily accessible and easy to navigate. The amount of information available to people through social media can help to give a holistic view of health issues and increase 'health empowerment' (Mano, 2014: 404). This behaviour can become embedded in daily activities, particularly if the person becomes a member of a group for a specific diagnosis. The posts will show up on a Facebook feed[15] and the user can click on them to read related content, or use the information contained within the

---

[13] These platforms can be accessed easily through computer access, mobile telephones, tablets or any other device that can access the internet, making them easy to connect to at any time of the day or night.

[14] There are many more social media sites than this. Facebook, Twitter and Instagram are the most used in the UK that are in the English language. There are other country and language specific social media platforms.

[15] A Facebook feed is the first page that a user sees with posts that are sorted by an algorithm. The more that users click on a friend's or page (such as a health related forum) post, they will be seen more often on the feed.

post to access recommended websites (for example) (Fergie et al.,2015). This kind of health related information seeking has been shown to be beneficial to those struggling to cope with disabilities, as they are able to find information online that is more easily accessible than the information that they may receive from their physician (Mano, 2014; Portnoy et al., 2008; Wagner et al., 2004).

Despite social media being part of an information seeking procedure by most of the participants in the study, it was still treated with caution. Some of the participants stated that they would not assume that the information on the internet, particularly from peers, was trustworthy (Fergie et al., 2015). Nonetheless, other participants were happy to assess trustworthy websites as ones that were designed professionally, and related directly to their own experiences. Users' impressions of websites and social media forums were important in forming opinions and were shown to influence the users experiences of help-seeking. Negativity in a title of Facebook pages (such as 'I hate my diabetes') were to be avoided if help-seeking was to remain a positive (Fergie et al.,2015: 1332) and empowering experience (Mano, 2014). Mano (2014) also found that individuals with serious health conditions were not likely to use the internet for accessing health information, and this could be problematic when trying to develop accessible professional services.

3.5. Formal Online Support

The internet is not accessible to the 54% of the world's population (Internetlivestats, 2017). 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. In the UK, internet access is available to 90% of the population, although regular use ranges from 99% of 16 – 34 year olds to only 44% of over 75 year olds (Office of National Statistics (ONS), 2018). The most popular activity of those that are able to use the internet worldwide is socialising (Silver and Johnson, 2018), which is an important observation when planning healthcare provision that encourages socialising.

The NHS in England and local authorities share the responsibility for mental health service provision (Smith et al., 2018). The NHS localises the funding by giving a budget to the Clinical Commissioning Groups (CCGs). The CCGs then decide what is the best method of funding mental health for their area. This means that the way mental healthcare is funded throughout

the country is different, leading to the idea of a 'postcode lottery[16]' (Asthana, 2012). CCGs also pay for the online provisions that NHS patients are offered. These are often commissioned due to what is seen as necessity, or as a response to non-academic research rather than a tried and tested method of support (NHS Choices, 2013).

3.5.1. NHS Funded Apps
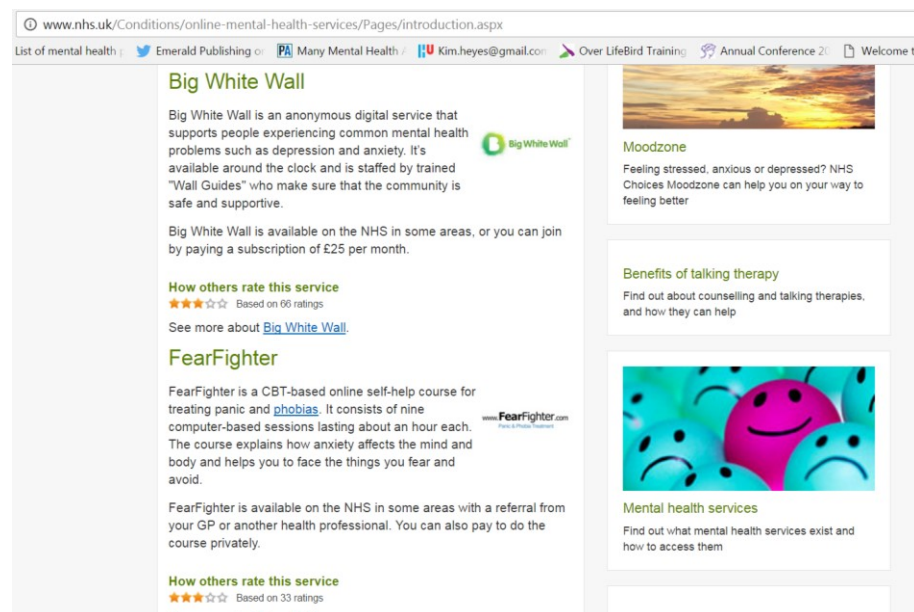
Figure 4 The top two online support apps on the NHS website. [Accessed June 3, 2017].

The mental health webpages on the NHS website (figure 4), guide people towards using online therapies as they may have to wait several weeks for cognitive behavioural therapy funded through the NHS. As discussed in Chapter Two, waiting times can be up to an average of 139 days in some areas (Baker; 2018). The online mental health services introduction on the web page also states that online therapies could benefit those who suffer from agoraphobia and social anxiety, and gives the option for patients to pay for these therapies privately. The quote below was taken directly from the site and appears to state that the apps are approved by NICE (National Institute for Clinical Excellence), who represent the top standards for healthcare provision.

---

[16] A postcode lottery is an indication of how services are unequally funded around the country, leaving people in some areas worse off than others in terms of healthcare provision.

'NICE has approved the use of computerised cognitive behavioural therapy (CCBT) for the treatment of depression, generalised anxiety disorder and panic disorder.' (NHS Choices, n.d: online).

This statement is misleading as it may make people with mental health problems believe that the online services suggested are approved by NICE, when in fact they are the product of business meetings between the supplier and the NHS. What is not stated on the website is that the CCGs in each area are told that they must buy a certain number of licences for these websites each year, at a cost. If these are not used, the cost of each licence is wasted, and if they use more than this number, it costs considerably more (Martin et al., 2014).

According to the website, 'The following online mental health services have all been approved for use by the NHS' (NHS Choices, n.d.: online), and these are The Big White Wall, Fear Fighter, Ieso digital health, Silvercloud and Sleepio. Whilst these claim to be based on academic research, the only published research about the Big White Wall (BWW) states that it has limitations as it is 'not concerned with theory, and limits itself to one organisation as a case study' (Christie, 2013: 202). The research was also conducted by someone employed by the organisation, so the research findings which states 'Through the case study, BWW was shown to be addressing both the needs of its users and the challenges of operating in a digital environment.' (Christie, 2013: 202) cannot be taken as unbiased. It does claim to have helped 57% of the 35,000 users recover, although there is no information to back up this claim. And Ieso digital health was the product of just one randomised control trial of 297 people in 3 UK cities (Kessler, et al., 2009). It is concerning that the National Health Service is promoting such resources, although, if the results published on the individual service websites are true, they are proving to be more useful than offline mental health services (up to 57% recovery rate as opposed to a 44.8% recovery rate with IAPT (NHS Digital, 2015: online). If these figures are true, then much more should be done to promote these apps within GP surgeries to ensure that all people with mental ill health can access them. However, there also needs to be more research to ensure that these figures are accurate.

The NHS commission various online and telephone services and my study began with an interest in how people with mental health issues are being directed to these services, which may not be suitable for all mental health patients. Despite a paucity of research showing positive completion rates of online therapeutic support, these intervention programmes are rare

(Simco et al., 2014), those that do complete the programmes have been found to benefit from the support (Learmonth et al., 2008). Statistics released in January 2017 by NHS Digital show that more people than ever are turning up at hospital emergency departments in the UK (NHS Digital, 2017). Since 2011, the numbers of people going to emergency hospital departments about 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 online support services, there is still a need for some form of intervention and support. The increase in use of services such as accident and emergency[17] shows that people are struggling to find this support, although the way that both the public health agenda, and the wellness agenda in the UK[18] (pushed by IAPT– see Chapter Two) is currently posed, means that the individual is responsible for engaging in self-therapy. There is a need for further research into all types of online mental health support communities and offerings so that the needs of people are being addressed rather than untested interventions becoming more prevalent as a cheap alternative to offline methods.

3.6. Summary

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). Through exploring what is important to people who use online mental health community support, it must be acknowledged that this growing phenomenon is an important part of an individual's information gathering and a form of engaging in social interaction (Hou et al., 2015; Biyani et al., 2014; Giles and Newbold, 2013; Ren et al., 2012; Eysenbach, 2004; Tate and Zabinski, 2004).

The existing research contributes to an understanding of how and why people use online mental health support forums so that more suitable resources can be created to support those who are unable to find support elsewhere. Often personalisation of healthcare is deemed to be expensive, so through producing models of how online support works, we can start to create inexpensive mental healthcare that listens to the needs of the communities rather than the political agenda (Rappaport, 1977). My research addresses this gap by focussing on how people

---

[17] Accident and emergency (or A&E) is an emergency service offered at some hospitals in the UK. This is similar to the Emergency Room (ER) in the USA.

[18] This is also pushed by Matt Hancock, Health and Social Care Secretary for the UK Government in his speech on the 20th July 2018, where he stated that people should be given the tools to deal with their own mental health https://www.gov.uk/government/speeches/matt-hancock-my-priorities-for-the-health-and-social-care-system.

use these communities and what they gain from them. The next chapter explains the methodology of my study and why I used multiple methods to gain a breadth of knowledge over different online platforms.

Chapter 4: Methodology

4.1. Introduction

This doctoral study was undertaken in two parts: Phase One was a virtual ethnography, and Phase Two utilised one-to-one interviews. The literature reviewed in Chapters Two and Three highlighted a number of gaps in the research that required multiple platforms and multiple methods to be used to widen the knowledge of online community support for mental ill health. My epistemological stance stems from firstly post-positivism (Cupchik, 2001) and secondly a constructivist approach, embedded within the idea that knowledge is constructed from personal experience and a 'passion for justice and the ability to subject one's own assumptions to scrutiny' (Ryan, 2006:18). Ontologically, I remain constructivist in that I believe that people (participants) are both enacted, and the product of their interaction. Hence requiring a constructivist methodology that could capture the complexity for the unique sense making process. CP is concerned with change, which means that whilst it may draw on principles of feminism, critical theory, and perspectivist approaches, it's complexity drives community psychologists to use constructivist principles to produce new information and/ or scientific evidence (Tebes, 2017; Jason et al; 2016), alongside understanding the experiences of the group who are marginalised (for example, those with mental ill health) (Goodley and Lawthom, 2005).

Constuctivism is a way of understanding knowledge through building blocks of information produced by other researchers (Cupchik, 2001). This background information is then applied to new research as part of constructing new knowledge, building upon, or backing up existing knowledge (Williamson, 2013). There is value in trying to produce theoretical knowledge, however, constructivist and post-positive principles are more concerned with the advancement of knowledge. Using virtual ethnography in Phase One as a CP methodology, I recognised that there was a lack of theoretical excellence within the field of mental health. This lead to the idea of using grounded theory in Phase Two, which ultimately also failed to produce a robust theory (See Chapter Nine). This thesis, and particularly the methodology, is about my personal learning journey. I have used the knowledge gained from others in multi-disciplinary fields to construct knowledge within the field of community psychology (Williamson, 2013).

This chapter explains my rationale for using virtual ethnography (Bird and Baber, 2007), and for using one-to-one interviews. I will discuss how the research was conducted, the ethical issues, participant recruitment and methods of analysis.
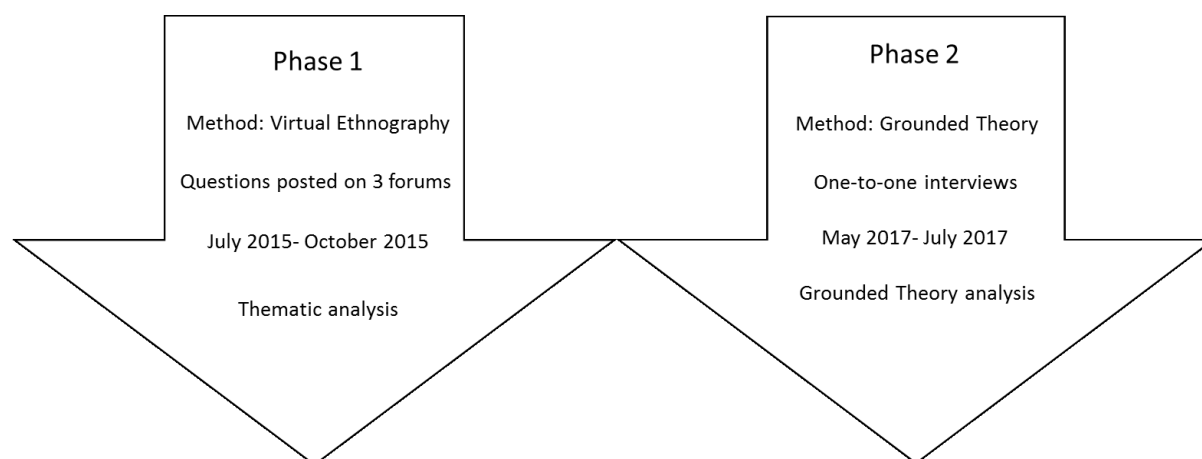
Figure 5 Outline of the two phases of the research

Figure 5 depicts an outline of the two phases along with the timeframes for data collection. The next section will explain about how Phase One was conducted, including the challenges that I overcame along the way. Phase Two methodology will be discussed at the conclusion of the Phase One methodology.

4.2. Participant Recruitment

The participants in both Phase One and Phase Two were recruited through purposive and snowball sampling. People with mental ill health are notoriously difficult to recruit for research purposes (Marpsat and Razafindratsima, 2010), which may be due to stigma (Barratt et al., 2015) or to being marginalised as a socially disadvantaged group (Bonevski et al., 2014; Sydor, 2013; Marmot et al., 2008). Recruitment issues were anticipated, and I set up a Facebook page called Community Mental Health Support, which had been gradually recruiting members (from August 2014). There has been a growing consensus among some academics that using Facebook for accessing this population is effective (Burgess et al., 2017; Baltar and Brunet, 2012). The Facebook page was used to re-post interesting research about mental health, although it also attracted people who were looking for help and support. Some of the people searching for support sent me messages through the messenger function on Facebook, asking for help and stating that they could not find anyone to help with their mental ill health. Pre-empting this, I had stated at the top of the page that I was not a mental health professional.

What I was not prepared for was the desperation of some people, and also the anger when they realised I was just another person who could not help them. This was somewhat upsetting at first, although it gave me the resolve to know that my research was definitely in a field where help is needed (See Reflections, section 4.5).

I gained ethical approval for both phases of the research from Manchester Metropolitan University on the 11th July 2015. In August 2015, I posted my call for participants for Phase One (figure 6). The call for participants for Phase Two was posted on the 5th December 2016 (figure 7), along with a video of myself talking about my research. Using a video was to help alleviate any fears that participants with mental ill health may have over meeting up with a stranger. By seeing what I look and sound like, I thought it would make the step between contacting me to be part of the research, to meeting me, easier (Baltar and Brunet, 2012).
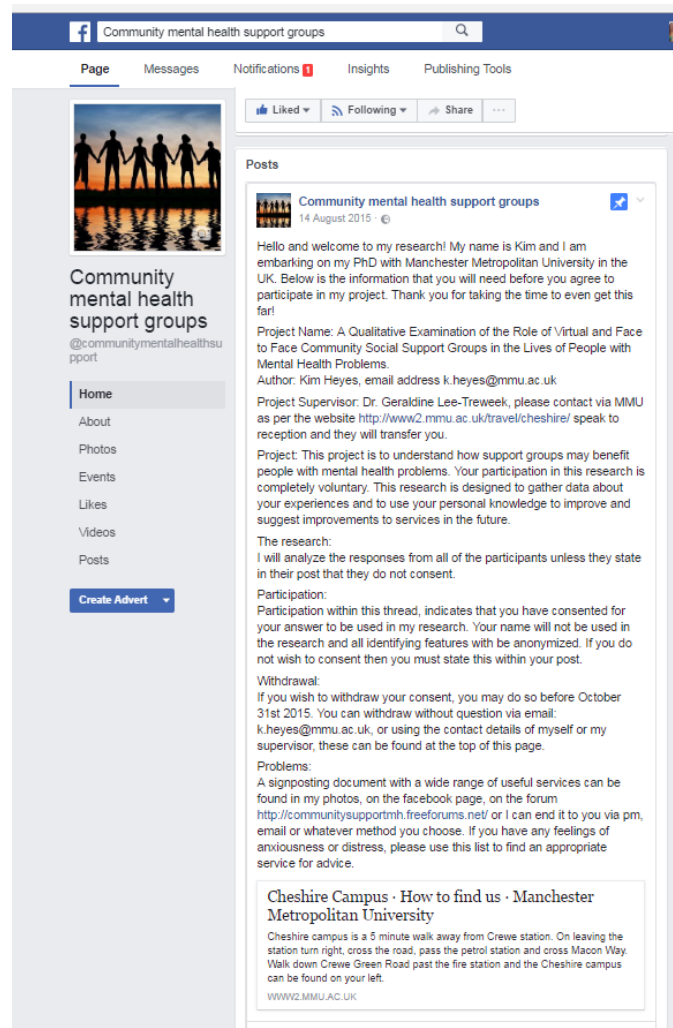
Figure 6 Facebook post used to recruit participants to Phase One.
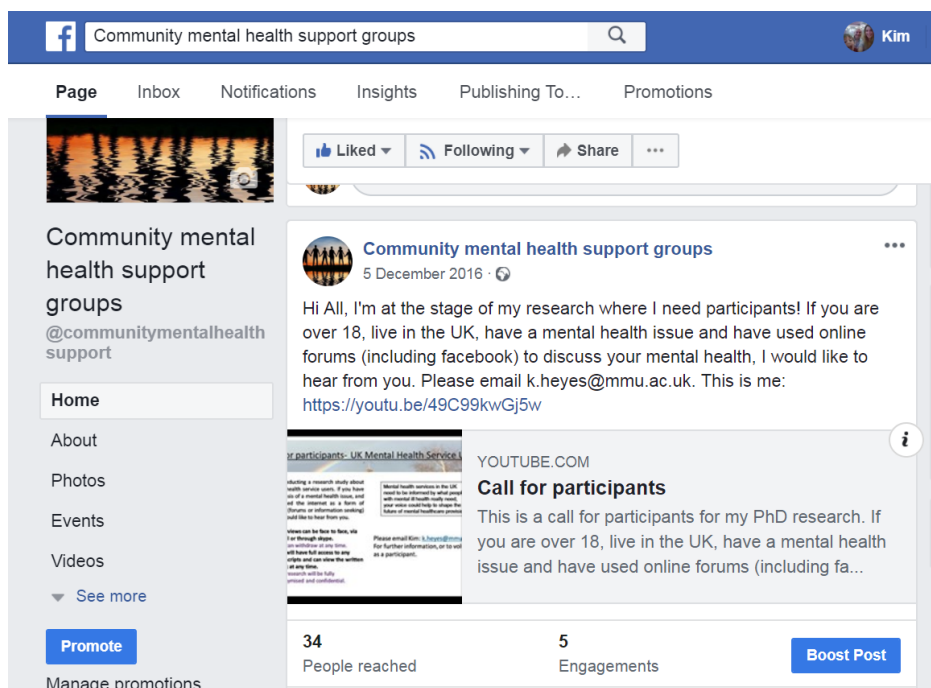
Figure 7 Facebook post used to recruit participants to Phase Two

I copied the posts onto my own Facebook page, asking friends and family to share the link. Snowball sampling in this way has been shown to be a cost-effective way of targeting a large population of people who are hard to reach (Baltar and Brunet, 2012; Marpsat and Razafindratsima, 2010). This led to a few people signing up to the forum, however, some of my friends and family also signed up to try and help. This meant that there were several people signed up to the forum who I could identify, either from the user name (which was not anonymised) or through comments they made. Other participants were not able to be used within the research as they stated they had not used a forum before, or gave other information that was not appropriate to the research. As Barratt et al. (2015: 6) found during their online research of drug users, the sampling of hard to reach participants is a balance between 'rigour and practicality'. Using both purposive and snowball sampling is a way of trying to gain this balance and attempting to make the sample more generalisable to other users. However, as this is a qualitative study, generalisability is not as important as the depth of information borne out of the resulting participation.

For Phase Two of the research, a call for participants was placed on the Facebook page in December 2016, with the aim of undertaking the interviews in January and February 2017. Batterham (2014) stated that although online recruitment is useful, there can be a variable range in up-take, and the demographics can be skewed towards women and younger people. However, I was interested in experiences and the most important part was that I had participants

that were willing to tell their story. Fourteen people contacted me, who were willing to be interviewed, and despite Batterham's (2014) research, half were male and half were female (I did not have other demographics at this point). Unfortunately, I suffered a significant bereavement in January, and was unable to carry out the interviews due to my own mental health issues. The decision was made to put the interviews on hold until such time as I was able to conduct them without issue. Some of the participants then decided not to participate, so a second call for participants was publicised in April 2017.This consisted of advertising on the Facebook page set up for this purpose, and by sharing the advert on social media. This sampling resulted in several people responding to the advert, with seven potential interviews booked in between April and the end of June (some were from the initial call). I did not accept any more interviewees at this stage, as grounded theory requires only enough interviews until there is no new data to be collected. I did not want to interview people unnecessarily, but could re-advertise if more participants were required. Using the same Facebook page as the advertisement for the first phase meant that people could participate in both phases if they wished. I did not ask the people in Phase Two if they had responded to Phase One as I did not want to impose on their right to anonymity,

Some interviews were not completed due to last minute cancellations. Four participants cancelled the day before, or even a few hours before the meeting was due to commence. However, the interviews that did take place were rich in data, ranging from 1 hour and 30 minutes long to over 2 hours and 30 minutes, which gave me a lot of information to analyse. After four interviews, I had not found any further categories, and my final participants decided that they no longer wished to contribute to the research. I felt that there were clear categories that had emerged from the data from the four participants. The research may have benefitted from more interviews, but I did not feel as though I would be able to adequately discuss their stories within the word count. Representing the participants was more important. Standard expectations of sample sizes for qualitative research is that interviews are conducted one after the other, until there are no new concepts emerging from the resulting data (Bernard, 2011; Bryant and Charmaz, 2007). Qualitative researchers have not been able to agree on the best sample size, although there are varying opinions on how to select the best sample size based on the nature of the research and the desire to generalise the results to the specific population in question (Trotter, 2012). Trotter (2012) suggests that 'pursuing in-depth descriptive studies of modal culture' requires a small sample, and Weller and Romney (1988) state that in order for qualitative research to be generalisable at all, we would need to understand the size of the

specific population that is being studied to be able to calculate the relevance of the sample size. The population of people that use online community support for mental ill health is unknown. Therefore, the data gathered from the participants in my research is an example of online mental health community support user experiences. When the results of Phase Two and Phase One are amalgamated, the total participants for this qualitative study is 29, gathered over two phases, using three online platforms and in-depth one-to-one interviews. This exceeds the recommendation by Charmaz (2006: 114) where she states that '25 are adequate for smaller projects'.

The one-to-one interviews were conducted in person, through email, and through a voice over IP (VOIP) online video connection (such as Skype). According to Swanson et al. (1999), with any participant, there should be a consideration around what is convenient, comfortable, private and safe for an interview setting. One participant decided to come to Manchester Metropolitan University in Cheshire to meet me, and agreed to be interviewed in a small room and with glass of water. Another participant did not want to meet, but was happy to answer questions over email. The other participants were happy with any method of meeting, and both resulted in a video call interview. The last one worked perfectly, however one interview kept 'dropping' (the call quality was poor due to the internet availability). Luckily, I was able to travel to meet him in person, and finish the interview off in a café that was comfortable, safe and convenient. It was also fairly empty, however the participant was happy that he was not going to be identified and was therefore still comfortable with talking about personal information.

4.3. Ethical Issues

Ethical permission was granted by Manchester Metropolitan University on the 11th July 2015, and ethical standards of the British Psychology Society (BPS) were adhered to throughout (BPS, 2017: 2014: 2009). The ethical permission covered both phases of the research. The research also adhered to the MMU Ethical Framework[19], the MMU Lone Worker Policy[20].

I have worked with people with severe mental health issues, living and working within the community for several years, I was a volunteer listener for the Samaritans[21] for two years, and

---

[19] http://www.mmu.ac.uk/policy/pdf/policy_ref_Academic_Ethical_Framework.pdf
[20] https://www.mmu.ac.uk/health-and-safety/manual/pdf/guidance-lone-working.pdf
[21] Samaritans are a charitable organisation, predominantly a telephone helpline that helps to support people when they are feeling suicidal, or in distress or despair.

I was a mental health professional for the online charity Mindfull[22] for a year. The training I received for these roles were concerned with safeguarding, personal boundaries, confidentiality, data protection and protecting the participant and myself. In case of distress, I produced a signposting sheet to enable the users to access help from third sector organisations immediately (Appendix A).

There are considerations around setting up an online forum for vulnerable people (Driscoll and Gregg, 2010; Buchanan, 2004). I set up the forum in a similar way to other forums that I had seen used frequently, in that there were several threads, sticky threads[23] with important information (such as a distress protocol or signposting document), and conversational threads that start with a main question (Androutsopoulos, 2008). I used my signposting and participant information documents as sticky threads, and pre-determined questions as a starter for the conversational threads. Other forums have moderators that ensure that the forums are used appropriately and they watch out for abusive behaviour, or signs of distress. As the researcher, I took on the role of the moderator. Even after there had been no more responses, I ensured that I regularly checked on the forum, as well as setting up email alerts if there was new activity. This continued until the forum closed in October 2015. If the participant wished, they could send an email address to me and the signposting document would be sent to them on a monthly basis. Although this was set out in a familiar format, the participant also had a choice of whether or not they wished to participate. The call for participants (Figure 6) clearly states that if a person wishes to participate, they are giving consent, however, they are free to withdraw their consent at any time by emailing either myself or my supervisor. This gave a choice to the participant, who was in full possession of the information before deciding whether or not to participate in the research (Sugiura et al., 2017). The ethics around enticing vulnerable participants to an external web page have therefore been mitigated through: transparency of the process and the aim, familiarisation; choice over whether or not to participate; being in full possession of the facts before participating; having the option and information to withdraw; an experienced moderator watching out for distress or despair and abusive behaviour; and the option of having a regular email with the signposting document automatically sent.

---

[22] Mindful was part of the Beat Bullying Charity. The charity went into administration in October 2014.

[23] Sticky threads are threads that stay at the top of the page to alert users to important information.

For those who consented by answering my questions on Reddit and the Mental Health Forum, there were contact details for my supervisor and the online link to the signposting document. They also had support from moderators active on the forums. Consent was gained from the Phase One participants in two ways. The participants who signed up and posted on my forum also needed to email a signed consent form (Appendix A) to me via email. For Reddit and the Mental Health Forum, I stated that replying to the post was therefore consent to participate in the research. I posted withdrawal information, who to contact for more information and mine and my supervisors email addresses.

Once the data was copied from the forums, I closed my forum to new participants (it was left accessible to existing participants for the signposting document and participant information sheet). The information on Reddit and the Mental Health Forum was not removed, however, all user names were anonymised on the forums. To further ensure data protection (Data Protection Act, 1998) I changed the names using an online name generator, which ensured there was no gender bias and meant that the pseudoanonymisation was not easy to decode.

Phase Two risks were mitigated through a risk assessment performed at the beginning of the research. In terms of managing physical risk to both the researcher and the participants, meetings for separate interviews were arranged at a mutually convenient location, or through alternative methods such as using online VOIP aided programmes. If meeting face to face was not in a public area (due to the nature of the discussions), then it was arranged that there would be regular phone calls to one of the supervisors for ensuring the researchers safety. The participants were encouraged to have the same arrangement.

Potentially the participants, as in any study, could become distressed and because the participants were people with a known vulnerability, extra care was taken. My supervisors all had considerable experience in interviewing adults with mental health problems and people with learning disabilities, and the advice of these supervisors was pivotal in guiding me through the fieldwork of this project. In addition, I am trained in adult safeguarding and used this knowledge, where necessary. However, it is current best practice in social work and social care, that adults who are deemed to have mental capacity are seen as able to make the choice – or not – to participate in activities of various sorts, including research (Lawthom, 2011). As long as care and precautions are taken, the benefits of the knowledge gained to help understand the

role and importance of social networking groups for people with mental health issues should mean that the project is worth the managed risks.

Consent for Phase Two participants was gained through them signing the consent form. They were reminded that they could withdraw their information at any time and that they could end the interview at any time. They all understood that they did not have to answer any questions that they felt uncomfortable with. The BPS (2009: 19) ethical guidelines for research state that to protect participants from harm the researcher should:

> 'Ask research participants from the first contact about individual factors that might reasonably lead to risk of harm, and inform research participants of any action they should take to minimise such risks.'

I employed this technique at the beginning of my one-to-one interviews. This made sure that I was prepared for any issues that may arise, and also alerted the participant to think about how discussing their mental ill health may make them feel. They were also told that they did not need to answer any questions if they did not want to, and that they were free to terminate the interview at any time. They could also withdraw their participation from the research at any time, contacting my supervisor if they felt uncomfortable contacting me directly. I emailed the participants with the transcript of their interviews shortly after they were conducted, and asked if there was anything that they wanted to add. None of the participants wanted to add anything further. I reminded them at this point of their right to withdraw and reminded them about the signposting sheet. None of the participants wished to add anything further at that point either, but I shared a brief conversation with each of them to ensure that there were no lasting negative effects from the interview discussions. It is not easy to understand if there has been a negative effect over email, however, due to the nature of the questions (around participating in online mental health support forums), I felt confident that all participants would be honest with me about the effects of their interviews. Stanko and Lee (2003) believe that there are risks to the participant and the researcher, both emotionally and psychologically. These risks could not necessarily be foreseen, but require the researcher to be able to draw on their skills and experiences to ensure minimal harm (Stanko and Lee, 2003). As a trained Samaritan, a trained mental health worker and qualified in child and adult safeguarding practices, I felt confident that I had the expertise to manage any situations that may have occurred. Fortunately, I did not need to draw upon this experience.

Immediately after the interviews, the audio file was transferred to a secure Manchester Metropolitan University laptop, which requires authorised sign in to access. The file was then deleted from the Dictaphone. Once typed up, all identifying information was removed from the interview transcripts and a pseudonym was used for each participant. The Data Protection Act (1998) was complied with at all times, and information pertaining to the participants was stored on a computer under password protection. All information about the participants and the transcripts will be deleted six months after the completion of this doctoral study.

As someone with mental health issues, I also had to manage the risks to my own health. My supervisors were available for me to talk to and debrief where I felt that this was necessary, but I also could utilise my own signposting document. Samaritans training also instilled in me that using colleagues to help you to debrief is an important part of being able to function effectively after being exposed to stories from vulnerable people, or those who have been abused.

There are ethical considerations to be had around the use of online community forums for research purposes. Online community forums for people with mental health issues are abundant (Carroll, 2014). They are also incredibly easy to access to those who are familiar with the internet, particularly if you use open access mass forums such as Reddit[24]. There are however, gatekeepers on some of the smaller forums. These gatekeepers seem to be a little 'fed up' of people researching their forums (as stated on some forums and as several told me in emails), and request that you fill out lengthy forms, proving who you are and what your intentions are (along with a copy of your ethical approval). Although this added time to the process, I personally felt that this was good practice as the moderators were trying to protect the vulnerable people within their forum. Ethical perspectives may differ at this point. Some academics (such as Salzmann-Erikson and Eriksson, 2012) believe that everything online is in the public domain, and if you do not need log in details then the information is eligible for research without seeking consent from the person who posted the words. Salzmann-Erikson and Eriksson's (2012) study used archival data from an online forum, arguing that the research was not considered to be on human subjects (as it was from the past), and is in the public domain, so does not need consent. However, there are many researchers who disagree with this perspective (such as Flicker et al., 2004; Hudson and Bruckman, 2004). Even once access

---

[24] Reddit is an American run forum that is accessed globally by thousands of people every day.

was granted, I started my questions with who I was and what I was going to do with the responses. This gives the users the option of participating or not, and helps to build trust between participant and researcher (Im et al., 2007; Ridings et al., 2002).

Another ethical issue was that I had access to a lot of information that my participants had posted in other forum areas, such as age, gender and so on. However ethically I did not feel that this was an appropriate way to collect data for this project and ignored any links from the participants through to other forum threads. It was difficult to ignore all of the other data that could have helped me to build a holistic profile of the participants, and I could understand the temptation of other researchers to utilize it. Salzmann-Erikson and Eriksson (2012) were able to justify their method, as to ask for participants may have greatly skewed their data, but in my research, it would have been a breach of trust to use this extra information.

4.4. Phase One
4.4.1. Virtual Ethnography

As has been explored in previous chapters, many researchers have found that online communities replicate those of offline communities (Yalom and Leczcz, 2005; Tate and Zabinski, 2004; King and Moreggi, 1998). From very early internet use in the late 1980's to early 1990's, academics have claimed that the nature of interactions in online virtual communities were suitable for ethnographic research (Rheingold, 1993). There have been a variety of methods used to observe these communities since the early 1990's, however in this study I have chosen a synthesis of Hauben and Hauben's (1996) study, where a bulletin board method is hosted on a web forum, and Baym's (1995) approach of evolving questions over time.

Hauben and Hauben (1996) observed online participants on a hobbiest site Usenet. They termed the users 'Netizens'[25] and became part of the group discussions. The participation of the researchers was seen as a facilitation of conversation about their research, and consequently, the research yielded plenty of data (Hauben and Hauben, 1996). Over time, the

---

[25] Netizens is a term that combines citizens with the use of the term 'internet'. So it means people who come together as a social group and interact as though they were conversing in the offline world, but within the confines of the world wide web.

names for areas on the internet have changed somewhat, sites such as Hauben and Hauben's (1996) are now called forums, and the bulletin boards are now threads.

In Phase One, to replicate this type of environment, I set up an online forum that was a similar layout to the types of forum the targeted groups already used. This was to ensure that the forum was not linked to any already established forum that may have put off potential participants. An easy to use site from freeforums.net was selected, it was free to develop, easy to set up and simple for participants to navigate. The aim was for the site to be easy to sign up to, allow for the researcher to create threads, but then disable this feature for anyone else, and to lock the Information, Consent form and Signposting threads and mark them as important and can be seen in Appendix A. The forum used was:http://communitysupportmh.freeforums.net/.

To sign up to the forum, the user was required to choose an anonymous user name and a password. This was to protect the user and afforded them some confidence in the fact that their names were already anonymised. Participants for this were recruited through mental health forums, Facebook, Twitter and Reddit[26]. The response to the sign up was slow, but over the period of one month, forty-three participants were recruited through this method.

The questions were open questions, designed to elicit response and discussion between forum members (Hauben and Hauben, 1996). The participants could answer just one question, or all five if they so wished. The forum remained open for 5 months so they could sign in to see the answers that other participants had given, and comment on these if wanted. The questions were also designed to explore the research questions and linked as below:

Q1. What have you gained from your involvement in internet support groups?

Q2. Have your relationships with members of the support group developed outside of the forum?

Q3. Do you feel able to be honest and open in online mental health support groups?

Q4. Are you able to share information about other service providers and have you used any services recommended by others?

Q5. Do you think the forum you use could do anything differently? If so, what? (Remember to discuss the support group forum, not this one).

---

[26] Facebook, Reddit and Twitter are social media sites where people interact with those that they follow, or to a question posed on a forum or group.

As per the participant observation virtual ethnography conducted by Poole et al. (2015), I announced that I was a PhD researcher and that I would also participate in the forum discussions elicited by the questions. Poole et al. (2015) felt that through participation in the forums being researched, that the data would be richer, mirroring that of non-virtual ethnographic research, and also reflecting the research conducted by Baym (1995). The research conducted by Poole et al. (2015) and Baym (1995) were the inspiration for looking at additional forums. This was because the participants on my forum tended to answer the questions and then not return to the site, meaning that the forum was not creating a dialogue. At this point, I had already contacted some established mental health forums as these were how Poole et al. (2015) and Baym (1995) had gathered their data, rather than set up their own forums like Hauben and Hauben (1996). This meant waiting for a response from the gatekeepers in order to access the forums and ask my questions.

Using ethnographic methods to research online forums is fraught with issues. Immersion of the researcher fully, as per Baym (1995) and Hauben and Hauben (1996) is time consuming and can scare away participants, so I opted for becoming a facilitator to the online forums, such as Hine (2008) suggests. This was an effective way of questioning the participants and probing them for further responses as an 'outsider'. I did not fully engage with virtual ethnography in the way I wanted, by setting up and running my own forum, so ultimately I ended up with a slightly piecemeal way of conducting my virtual ethnography. Despite the best of intentions, research methodology can go awry and as a result, I have learnt a lot from other researchers, and become more confident in my conduct of online research methods.[27]

During this time, in 2015, I met Amy Chandler, a researcher who had been using the mass forum Reddit for her research (she then published this work in 2016). She found that in order to maximise the participants to her work on self-harm, she utilised Reddit's pre-established mental health group (Chandler, 2016). She found that the mental health forums were well attended by users and therefore were more likely to get a response to posts (Chandler, 2016). I

---

[27] Qualitative research does not necessarily always go to plan, and I found that being flexible in the approach can lead to some surprising discoveries. I did not expect to conduct research using virtual ethnography, or that I would get the research methodology published by SAGE before my PhD was completed (Heyes, 2017) and then turned into a video (Heyes, 2018b), or that my whole Phase One research would be published as a book chapter in an aptly named book 'Novel Applications of Virtual Healthcare' (Heyes, 2018).

then posted the initial five questions on the General Mental Health and Anxiety[28] forums (40,000 users per day) and had 8 responses in 2 days. I realised that perhaps the way that my questions were phrased were not how the usual posts on a forum begin. Although I needed to keep the formal information about my research as a key part of my initial post, I felt that the questions could become more conversational (Burke et al., 2007), which would hopefully ensure that people would respond to my further prompting as a participant rather than answering the questions and not coming back (Kvale and Brinkman, 2009; Yeo et al*.,* 2014). A further question (Q6) was added to both Reddit forums in order to provoke discussion. A further 4 users participated in this discussion, and they each posted more than once, replicating conversation, which is what I hoped would happen.

Q6. Reddit: Has anyone used a support forum and found that the environment was not very supportive?

Consequently, the mental health forum I had used previously to recruit some participants, had granted permission to utilise the forum for research purposes, providing that the identity of the forum and the users were anonymised. This was a well-established mental health forum with around 350 daily users. As time was an issue, I posed one question (Q7) which I felt had yet been unanswered from the previous 6. This question had therefore evolved from both of the previous data collection methods. Ten participants entered into this discussion, with several posting more than once, creating a conversation.

Q7. Established MHF: Are forums and chatrooms really helpful for people with mental health issues or can it be isolating?

The questions were based on trying to understand the role that the online forums played in the lives of people with mental ill health. The first five questions sought to answer the research questions, with a focus on themes identified throughout Chapters Two and Three: self-assessment of the benefits of online support; the impact of the use of the forum in other areas of the participants life; the effectiveness of online support; referral and signposting; and expectations. Structured to provoke conversation as well as encourage responses that I felt were

---

[28] Reddit has many thousands of groups, within the mental health section it also has several. By choosing one that is related to general mental health and anxiety, I hoped to capture a large part of the population that use the forums.

missing from the previous data, I added two further questions that focused on user experience and stigma (see Table 2).

Forum Question	Key Theme	Research Question
Q1. What have you gained from your involvement in internet support groups?	Self-assessment of benefits	Why do people with mental ill health look for support online?
Q2. Have your relationships with members of the support group developed outside of the forum?	Impact in other areas of life (macro, meso, micro)	How do people with mental ill health feel they are being viewed within their communities?
Q3. Do you feel able to be honest and open in online mental health support groups?	Effectiveness of peer support	In what ways are online mental health communities supporting people with mental ill health?
Q4. Are you able to share information about other service providers and have you used any services recommended by others?	Referral and signposting	In what ways are online mental health communities supporting people with mental ill health?
Q5. Do you think the forum you use could do anything differently? If so, what? (Remember to discuss the support group forum, not this one).	Expectations	Why do people with mental ill health look for support online?
Q6. Reddit: Has anyone used a support forum and found that the environment was not very supportive?	User experience and stigma	What is mental health to experts by experience?
Q7. Established MHF: Are forums and chatrooms really helpful for people with mental health issues or can it be isolating?	User experience and stigma	What is mental health to experts by experience?

Table 2 Rationale for questions asked in Phase One

Figure 8 shows the timeline and numbers of participants of Phase One. Although it seemed to be a complex journey, it was a method that evolved as it needed to, in order to elicit the data required. Utilising the methods of previous researchers was helpful, and enabled me to gather data from several forums which enhanced the research. Each platform was different, and the user perspectives gathered over the three different forums means that the data has come from a variety of sources, affording a much wider overview of people's experiences than using just one source.
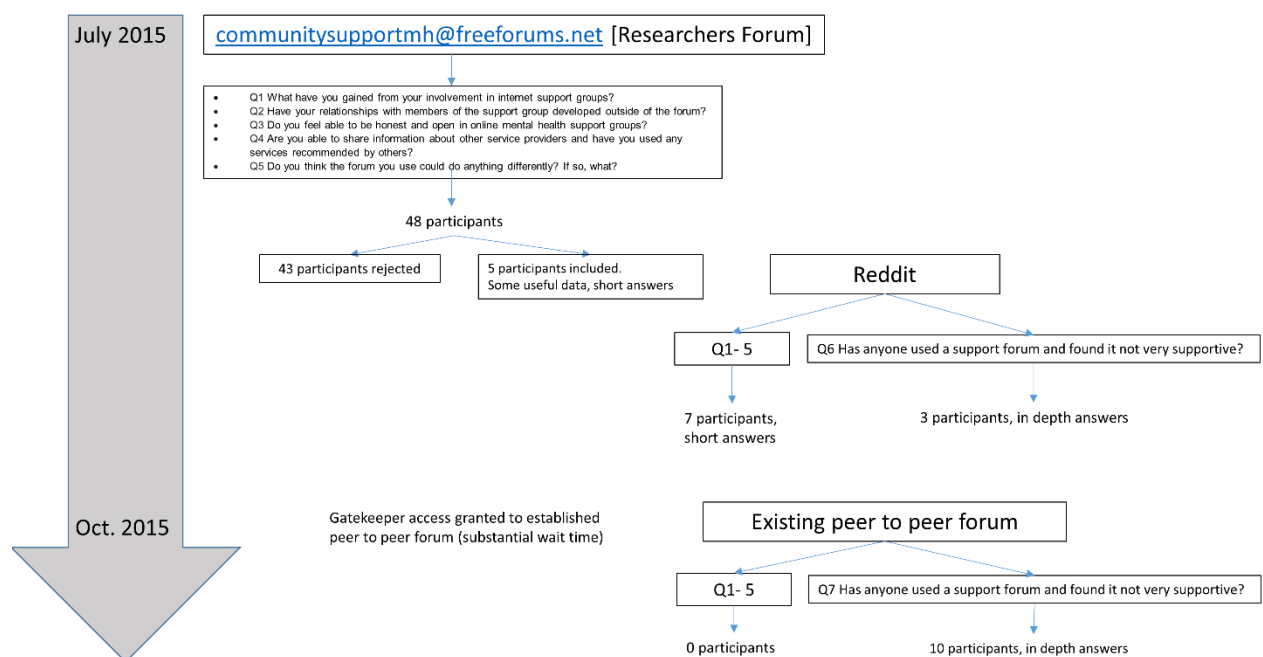
Figure 8 Timeline and participation of Phase One

4.4.2. Thematic Analysis of the Phase One Data.

Analysis of online research has been conducted in many ways. Giles et al.'s (2017) paper discussed the use of MOOD- Microanalysis in Online Data. They found that most of the approaches to analysis were conversation analysis, mainly within a sociological framework (Giles et al., 2017). Giles et al. (2017) also found that conversation analysis was the main choice for qualitative research analysis. This does depend on the particular form of online application that is being analysed, as some forms of social media such as Facebook threads or messenger 'chats' are presented as conversational (Giles et al., 2017). The forums that are being analysed

as part of this research could also be described in this way, although conversation does not really flow on the threads in which I asked questions. On the threads, I posed my five original questions, and many people answered the questions and then did not return to the thread. They also did not seem to read the answers of other people, or if they did, made no comment on them or attempt to converse with the other posters. The last two questions were slightly more conversational in that the posters seemed to have read each other's posts, indicated by opening sentences of 'Same as P22 pretty much, only I…' (MHF, P23) for example. These acknowledgements of the previous posters mean that there is more of a conversational style, however, there are still few posters that come back to comment further. Giles (2016:493) states that some research that has analysed these discursive forums have focused on the 'addressivity' of each poster, but that it can be difficult to follow some threads as not all post to the original post, nor do they necessarily take into account what others have posted. This can make conversations difficult to follow and therefore, it is difficult to determine how the posts link to one another. To this end, conversation analysis was not appropriate for this research, and thematic analysis (Braun and Clarke, 2006) was a better fit, as this would take each post on its own merits rather than as though it were an offline conversation (Giles, 2016).

Once the research was completed in October 2015, I gathered all the responses by question and started to look for themes. In thematic analysis, themes are generated from the data according to the researchers interpretation of meaning. To analyse the data from the 25 participants, I uploaded the data into NVivo 11 (Welsh, 2002; Seidel and Kelle, 1995), which is a tool for gathering and analysing qualitative data. Coding was performed in two stages, first from the different forums as this gave more context to the responses, and secondly by question (Tessier, 2012). Initial coding was informed by the literature review (DeCuir-Gunby et al., 2011), then recurrent codes began to form categories that could be gathered to create themes. Once this was completed for each of the three forums, the themes were organised into main themes and sub-themes, then the process was conducted again by question (this did not change for questions 6 and 7). The themes and sub-themes identified at this point were merged with corresponding themes from the first part of the analysis. The key theme related to the question and the research questions were also taken into account to be able to develop a cohesive picture of how users experience online mental health support forums.

4.5. From Phase One to Phase Two

Phase One of the project formed the foundations for the second phase. When I advertised for participants for the first phase, several people contacted me and wanted to talk about their mental health, rather than just answer the online questions. This made me think that although people are using online support, they may still not be getting the support that they require. The idea to interview people about why they use online forums therefore came about as a direct result of the first phase, and the interactions that I had with people because of this.

I wanted to explore the reasons for people using online forums, but felt that this was best investigated through personal interviews, rather than online. I was not confident that I could get the data that I needed by questioning people further through the online forums, and felt that there were several people that were using the forums who would like to speak with the researcher on a one to one basis too. Hence, the development from online mental health support forums to in-depth interviews to explore what drives people to use online support.

4.6. Phase Two

This phase of the research focuses on the interviews of people who have used online mental health support forums. By interviewing people that had previously used online forums for help, I hoped I could gain a better understanding of what was expected from forums and from mental health services, and what was and was not being received. Naslund et al.'s (2014) research showed that there was a gap when it came to multiple methods of asking people about their use of online forums and from Phase One, I felt that one-to-one interviews would add depth to the research.

4.6.1. Grounded Theory and the Analysis of the Interview Transcripts

Grounded theory focuses on the emerging concepts that come directly from the data, and online data offers new opportunities for exploring data in this way (Vaast and Urquhart, 2017; Urquhart, 2013). By meticulously coding the interviews immediately after their completion, it is possible to see where there are data gaps, and recruit further participants in order to explore these. The resulting concepts will create theories grounded within the data (Urquhart, 2013; Glasser and Strauss, 1967). During Phase One, it may have been better to adopt this format as the data leads the researcher rather than the other way round. Grounded theory has allowed for

a more rigorous research process, which only ended once there were no further emerging concepts. Research in the last few years has focused on identifying stigma and the effects on people with mental ill health, although the latest research by Clement et al. (2015) states that stigma is only fourth in the list of concerns for people with mental ill health.

Grounded theory is a way of gathering data and analysing it in order to generate new knowledge and new theories (Glaser and Strauss, 1967). The idea is that the data will identify or generate new theory, and that the theory is grounded in the data gathered. In strict Glasserian terms (Urquhart, 2013), the researcher should have no prior knowledge of the subject, as this may taint the interpretation of the data, however, this is deemed unrealistic in terms of modern research as most funding applications, or research for academic submission (such as this PhD), require substantial research before embarking on the data collection (Urquhart, 2013). Therefore, it is important that grounded theory becomes a flexible method of analysis that allows for the researcher to have knowledge about the subject, but trusts them to try and suspend all opinions in order to analyse the data in as raw a format as possible.

The analysis of the data starts in a similar way to that of thematic analysis (Braun and Clarke, 2006), although I took an abductive approach, being aware of the data as a whole and previous knowledge of the topic, but not letting it prejudice the results. Grounded Theory should be inductive however, there is no tabula rasa, therefore within my research, the analysis is abductive. It should be understood that the researcher has a background, but the literature does not colour the outcome of the coding process (Urquhart, 2013). Figure 9 summarises the research process of Phase Two using Urquhart (2013) and Charmaz (2006) for inspiration.

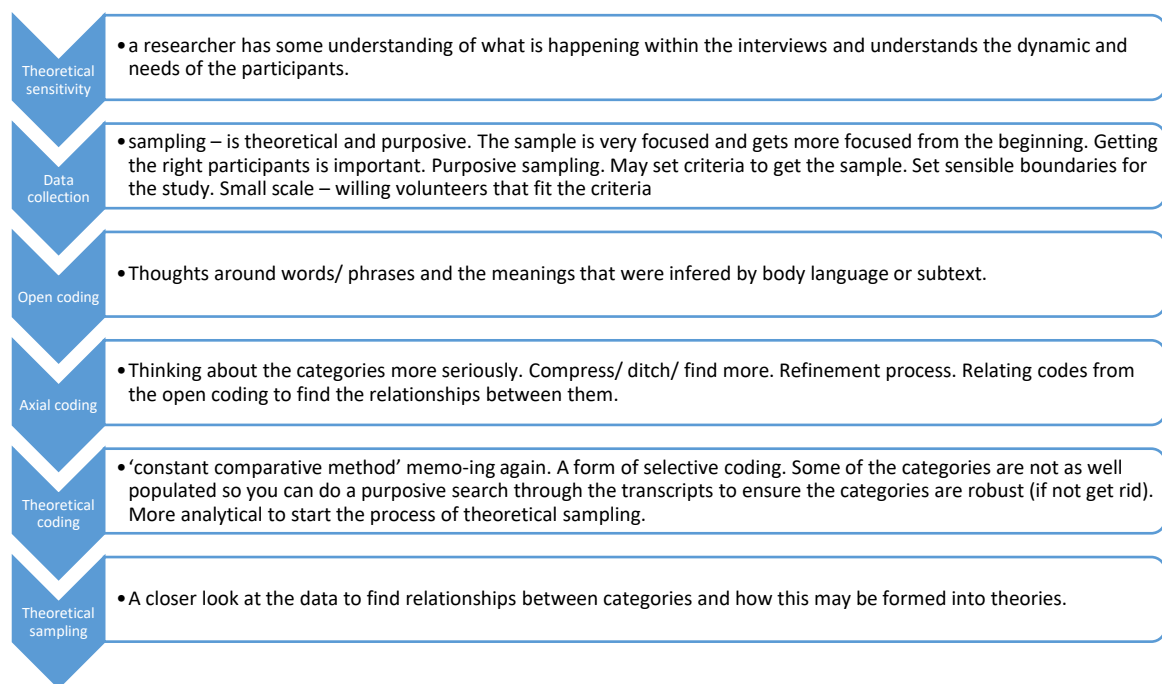| Theoretical sensitivity | • a researcher has some understanding of what is happening within the interviews and understands the dynamic and needs of the participants. |
Data collection	• sampling – is theoretical and purposive. The sample is very focused and gets more focused from the beginning. Getting the right participants is important. Purposive sampling. May set criteria to get the sample. Set sensible boundaries for the study. Small scale – willing volunteers that fit the criteria
Open coding	• Thoughts around words/ phrases and the meanings that were infered by body language or subtext.
Axial coding	• Thinking about the categories more seriously. Compress/ ditch/ find more. Refinement process. Relating codes from the open coding to find the relationships between them.
Theoretical coding	• 'constant comparative method' memo-ing again. A form of selective coding. Some of the categories are not as well populated so you can do a purposive search through the transcripts to ensure the categories are robust (if not get rid). More analytical to start the process of theoretical sampling.
Theoretical sampling	• A closer look at the data to find relationships between categories and how this may be formed into theories.

Figure 9 Techniques of grounded theory (Urquhart, 2013; Charmaz, 2006).

The first semi-structured interview took place in May 2017. I prepared questions based on the questions in Phase One and these were developed in conjunction with my research supervisors. A broad topic guide was developed (Appendix B) to elicit open discussion about the participants life and experiences, to find out what was behind the decision to use online support communities. Corbin and Strauss (1990) believed that the asking of questions, and the pursuit of their answers is the most important part of the research process. Charmaz (2006) also believes that interviews are integral, but believed that the purpose was not to interrogate, but to allow the exploration of the participant's story. By semi-structuring the interview, I felt that I could steer the questions to the point of focus, but allow enough flexibility for questions that may arise during the interview process. This was harder than I imagined, as the participants all had a story that they wanted to tell, and it was only once I had got through that story that I could then focus on the questions that I wanted answering.

As previously stated, the data was treated in accordance with the Data Protection Act (1998). Once it had been transcribed, I used NVivo to analyse the transcript, line by line. These initial codes created by the open coding were then gathered into categories. Through the stages of coding, it is important to justify why the category is relevant. With grounded theory, the aim is to get around six core categories, and that some of these can be turned into theory. The constructs of the coded categories (Glaser, 1978) were through the idea of related meanings,

and a robust category will have at least 6 codes, although the more codes the better. The coding stage takes a lot of time, but is necessary to prove that the categories, and therefore any theories derived from this, are robust. At this stage, I found that having transcribed the data, and gone through it several times to code and categorise, meant that I knew it very well. As I was going through the coding process, I kept a theoretical memoing 'diary', which was a separate document in which I stored any ideas of theories as the data emerged (Urquhart, 2013) (Appendix C).

Once the stages had been completed for the analysis of the first interview, the next interview was then arranged, conducted, transcribed, coded and categorised. After two and a half interviews, there was a pause of two weeks whilst the next interviews were arranged. The second half of one of the interviews was difficult to rearrange, so I analysed the part I had, to be as true to Grounded Theory as possible. After analysing the four interviews, I came up with three themes that I felt were pertinent to the research.

4.7. Reflections
4.7.1. Complications within the Research

The forum chosen was one in which all participants were fully aware that their responses would be used for research purposes. This may have meant that many people were reluctant to respond, which made it difficult to collect the data. There is a lot of information on the online forums that is free to access, such as personal stories of mental ill health. Ethically I did not feel that this was an appropriate way to collect data for this project. Instead, I decided that Hine, (2008:10) was correct when she stated that ethnographic researchers should not expect to become an accepted member of the group (unlike Hauben and Hauben, 1996; Baym, 1995), as their role is to be that of a 'tolerated and accepted observer', or facilitator as I decided to become. Alongside this learning, I found that using different questions during Phase One was useful, as they yielded more discussion than the answers to the previous five questions, where posters would answer the questions and then not return to the forum.

4.7.2. My Role in the Research

As someone with lived experience of mental ill health, I had thought about the kind of information that I was prepared to discuss about my own experiences of mental ill health. In order to facilitate discussion on the Reddit forum, I stated in my original post asking for

comments, that I had personal experience of mental ill health, and was happy to discuss this if anyone wanted to know more (via a personal message). What I was not prepared for was that no-one wanted to know my story. I had prepared myself to divulge my mental ill health, I was ready to answer questions and yet no-one wanted to ask. I was surprised that so many people wanted to talk about their mental health with a stranger, someone that they knew was a PhD student, but knew no more about than that. Once I had come to terms with this, I realised that this probably said more about the lack of availability for people to express their opinions within online forums, good or bad. Feedback is something that we are asked for regularly in the UK. How was the shampoo that you bought from Amazon last week, or how was the customer experience on the phone to your internet provider (for example)? I felt that I was almost providing a service rather than being an ethnographic researcher.

The method of virtual ethnography was difficult to engage with as I would have liked. I had not thought about what would happen if I did not get enough participants, and this became my biggest learning curve during my thesis. However, I managed to turn this into a positive, and through writing candidly about my experience as a junior researcher, I managed to publish twice on SAGE Research Methods online.

For the second phase of the research, the one-to-one interviews, I also prepared myself with an explanation of my mental ill health. Unfortunately, just as I was about to embark on my interviews in January 2017, my Grandfather passed away unexpectedly. I was very close to my grandfather, and years before, I had agreed to be executor of his will. I had no idea how much work was involved in executing a will, organising a funeral and keeping the rest of the family going. This was by far the worst year I had ever had in terms of my mental health, and I was also going through the closure of my university campus, potential loss of my job due to this, and my colleagues (friends) were also being made redundant. This was a difficult time not just for me, but everyone around me as well.

 I had to re-arrange my first lot of interviews, therefore, some of my participants were no longer available and I had to re-advertise. Even when I had confirmed interviews, people would drop out at the last minute and I ended up with just four participants. I had always intended to have a small number of one-to-one participants, but eventually, for the sake of my own mental health, I had to stick to four. On reflection, I gained so much from these participants, that it was too much to write about anyway! I also felt as though more participants would have

detracted from their stories, and it was the individualisation of mental health that I wanted to highlight within this phase.

Once again, none of my participants questioned my motives for the research, and none of them enquired about my own experience. I was quite happy at this point to not speak about my own mental health as on reflection, I was probably quite vulnerable. However, I did reflect on the stories of my participants as I transcribed them and went through to analyse them line-by-line. This helped me to think about my own mental health and how I managed it. My supervisors were also instrumental in supporting me through the research stage.

4.8. Summary

The methodology of the two phases are different, however, using thematic analysis in the first phase to analyse the virtual ethnography, informed the use of Grounded Theory in the second phase. It proved difficult to recruit participants through initial methods for Phase One. The Facebook page proved fruitful, however, mainly yielded participants from my friends and family. This meant that there were some people signed up to the forum for whom the data was invalid. Other participants were not able to be used within the research as they gave other information that was not appropriate to the research.

Phase Two also had issues, although these were mainly due to my personal life. It is difficult to admit when you have to take time out, and I am glad that I did not put undue pressure on myself to conduct my interviews in January whilst suffering with my own mental health. Ethically it would not have been right, although where to draw the line of what is too mentally unwell is a difficult one. I will reflect on this further in Chapter Nine. The results of the two phases will be discussed over the next three chapters, Chapter Five discusses the findings of Phase One of the research, Chapter Six discusses the findings from Phase Two, and Chapter Seven brings together the findings of the two phases, identifying similarities and differences between them.

Chapter 5: Phase One Findings

5.1. Introduction

The previous chapter outlined the methodology used in Phase One. This was virtual ethnography, whereby several questions were posed on three different online forums. This chapter discusses the findings of Phase One. I will discuss the views and experiences of the 25 participants from the three forums, through the three main themes, identified through the process of thematic analysis. These are: the Effect of Online Support; Safety Within Shared Identities; and Network Sociality.

5.2. The Effect of Online Support

As explored in Chapter Two, communities are complex, and are often created as a result of multiple social issues, exacerbated through continuing austerity in the UK (Collins et al., 2017; Ding et al., 2015; Berry and Welsh, 2010). In the UK, the medicalisation of mental health has meant that people with mental ill health are encouraged to supress their emotions through taking anti-depressants, and cope with their symptoms through distracting themselves with cognitive behavioural techniques (Cox, 2015; Jacobs, 2015). The participants of online support forums for mental ill health did not focus on the medicalisation of their health worries, searching instead for a supportive community that understood what they were going through.

The idea of community being similar online to offline is something that has not yet been fully explored within the psychology or sociology. It can be difficult to ascertain the best methods to explore how people use online communities or how they could engage those who are still isolated. Hayes et al. (2016) advocate using multiple methodologies to further understand what facilitates the support within online communities, a gap in research that my study works towards advancing knowledge in. I have drawn upon the works of Kendall (2002) to consider how individuals may use online and offline life in their daily interactions, and also Baym's (2000) work on how the offline world may have influence over the online world. This comparison and strive to understand how on and offline affect the support systems sought and received, is analysed further in Phase Two. The changes in technology and the continuing increase in the use of social media mean that the interwoven nature of online and offline is even more complex when vulnerabilities such as disability and mental ill health are taken into

consideration (Third, Forrest-Lawrence and Collier, 2014; Hine, 2008). This section discusses how the participants of Phase One feel that the online support community effects them.

Ziebland and Wyke (2012) found that online peer-to-peer support could be revolutionary, providing an outlet for those who are unable to seek support elsewhere. It can provide a space where people can speak[29] about sensitive issues that they may feel they are unable to discuss with people offline due to stigma, embarrassment, or because they are unable to socialise (Naslund et al., 2016; Berger et al, 2005; Dickerson et al, 2001). In their review of emergent trends in social media, Lankauskaitė and Liubinienė (2018: 52) ask whether 'loneliness and isolation are still relevant in the contemporary networked society?' suggesting that constant connectivity via the internet could alleviate loneliness and isolation, with positive benefits to the wellbeing of people with mental ill health. Chapter 2 explored how loneliness and being isolated from meaningful community engagement can be detrimental to health and wellbeing, reducing life expectancy by between 10 and 20 years (Thornicroft, 2014), so support from online communities 24 hours a day, 7 days a week may help to address this. The participants of the online mental health support forums in this study stated that they felt as though the support that they found through these forums was something that was not available to them elsewhere. Participants found support through the posts of other members 'lots of your words have helped me' (P8, Reddit), and a sense of normality through shared identity and education 'Mostly I learned that there are plenty of people like me, it's not unusual and can be improved upon' (P6, Researcher's Forum).

Much research has shown that community support and connections with social groups can be significantly beneficial to mental health and wellbeing (Schutt and Rogers, 2009; Weiner, 2008). Some of the participants said that identifying with people in a community support forum can be the key to their involvement in a forum, and were generally positive about their experiences when this was the case. Knowing that there were other people going through or having been through similar experiences seemed to give the participants a sense of relief in having found 'normality'. The ability to access a community where they had a shared identity with other members meant that they did not feel as though they were outsiders and could find support from people that they perceived had a shared identity (Wright, 2016).

---

[29] Speaking about is a metaphorical term, they users of the forums write their messages on threads (see Chapter Three). For the purposes of clarity I will state that the participants 'said' something, when they have written it.

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 (P3, Researchers Forum)

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. (P21, MHF)

The above examples show how the participants in my study felt that they have found a sense of identity that they could not display elsewhere – such as with families and friends offline. Having a sense of being like others and sharing issues was important to them. They felt accepted within this community and they no longer felt the need to hide their mental ill health in order to fit into offline society's idea of normal (Goffman, 1963). In the online support forums, the majority of the participants feel that they became part of an in-group (Yalom and Leczcz, 2005; Tate and Zabinski, 2004; Wood, 1989; Bourdieu, 1985; Tajfel and Turner, 1979), such belonging can boost self-esteem and reduce feelings of anxiety and isolation (King and Moreggi, 1998). Some participants felt that the other members had become friends who do not judge them on what they post in the forum. 'I have gained some really nice friends on here and they have not judged me for being different' (P19, MHF). Participants were wary of being judged, supporting previous research around stigma and mental ill health (Thornicroft et al., 2014; Corrigan et al, 2000), although stigma is not something that any of the participants discussed directly in this phase.

Being part of a supportive community meant that the members had access to emotional and practical support that they felt that they did not have access to outside of the forums. Many participants found that they could become educated about their mental health issue through the posts of other forum members: 'Whenever I feel anxious, it helps reading about it. Learning more about the illness and realising it's not just me' (P9, Reddit). Finding someone with similar symptoms helped them to feel more normal. Reading about how other people cope with symptoms can also be helpful, as they may be able to discover and try new coping mechanisms. Although Giles and Newbold's (2011) research on anorexia forums found that members of forums can try and diagnose each other, or state that there are methods that may cure mental health issues, both of which are potentially problematic. However, none of the participants raised such issues, the majority finding that hearing about how other people have overcome problems beneficial.

> Mostly I learned that there are plenty of people like me, it's not unusual… This is the most beneficial part of online support groups. Seeing others with similar problems to mine and how they deal with them. (P2, Researcher's Forum).

The experience of having mental ill health was explored by the participants as something that can be improved over time. Recovery was not discussed, but there were discussions around good health management, leading to becoming happier and less isolated. Peer support was a key aspect of this, and often it was through members of the forums divulging their own stories over a period of time that would give hope to others. Participant 4 felt that this type of insight into the mental ill health of their peers in the online community, was beneficial in decreasing loneliness and increasing happiness.

> I visited an online forum that was specifically for people who had the same condition as me. It was really helpful to my frame of mind at the time. To see that other people were going through the same as me and also to see people who were further down the line and updating on their progress. It made me feel much happier and less alone. (P4, Researcher's Forum)

This type of education about mental health conditions was also mentioned by other participants as an important part of the support that they felt from the community. They felt that learning from others with similar issues helped them to consider their own situation. This could be in terms of changing habits, accepting who they are, or understanding traits of the mental health issue that may be familiar to them.

> I have gained a lot of awareness and knowledge/ theory about what I'm supposedly dealing with. (P5, Researcher's Forum)

Information sharing is seen as helpful on the forums. Several participants stated that they had been given information about services, and several others stated that they would signpost to supportive services if they had a good experience of them. Other participants recognised that they were not able to share advice as they did not feel as though they were managing their mental health as well as they would like.

> I've seen providers for my severe anxiety but I know this illness is a disease of resistance. I have not progressed personally, so I don't share advice. (P15, Reddit)

The language that is used in these last two quotes is also indicative of negativity about mental health. For example, participant 5 uses the word 'supposedly' which could be taken as an indication of disdain for their medical diagnosis. Participant 15 expresses that the 'illness is a disease of resistance', again it appears that they are being quite negative, although this participant is using medical model terms (illness and disease) in a way that is quite embedded within mental health language (Haley et al., 1993). The language that people use to discuss their mental health online could be an indication of how they perceive themselves offline. Further research could also look at the language that people use when discussing their mental health in community support forums to identify people who are most at risk of loneliness and isolation.

Some participants stated that they preferred to offer their comments as helpful support, even if they had no professional (i.e. medical training or academic) insights to offer. This could be that by providing a support mechanism to others through offering encouragement, actually makes them feel better about themselves, rather than directly seeking help for their own issues. This aligns with research conducted by Naslund et al. (2014) where they found that users of You Tube would encourage each other through positive comments, or offering support. There were negative aspects to the videos uploaded on this form of media, but the community stepped in to protect the original poster when others would attack. Naslund et al. (2014: 5) explain these attributes as 'mirroring the democratic process of giving and receiving that defines informal peer support interactions'. In my research, when the participants offer their insights, I believe that they do not feel that they are burdening others with their own stories and benefit from the associated positive feelings of altruism (Schneider et al., 2013; Brown et al., 2006). 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:

> Writing about my own issues as a new post gives me anxiety (probably the vulnerability aspect). Commenting on other people's stuff, even if we have similar triggers, doesn't really make me anxious. Reading about them doesn't make me anxious at all. (P7, Reddit)

One member stated that although most people on support forums were helpful and supportive, comparisons between members can be negative, and this can trigger feelings related to the individual's mental health:

> I often think that although they can be extremely supportive in some instances members compare their situation with others which can negatively affect their own mood; creating a vicious cycle. (P6, Reddit)

This participant, and the one below, recognised that online support forums can have a negative as well as positive affect on their personal wellbeing. They utilise the forums when they need to, but tend to stay away when they are feeling well.

> I only tend to put in an appearance when I'm down, but I can ask anything on here. There's been times when I've found it very helpful, if I hadn't said it on here I wouldn't have said it at all. I do find if I stay around for prolonged periods it kind of keeps me down? So now I use it when I'm in car crash mode and then tend to stay away once I'm over the worst. (P24, MHF)

This could demonstrate an understanding of their condition and the triggers, although it is the opposite of what community support should be. It is clear from this research, and from other research in this area (Giles, 2016; Hayes et al., 2016; Naslund et al., 2014), that the effects of online community support can be immensely positive, but there can also be unintended consequences (Hayes et al., 2016; Giles and Newbold, 2013). Therefore, when accessing online community support, it is important that individual circumstances and personalisation must be taken into consideration. Those who find other people's posts triggering of their own mental health, or, feel that negative comments have an impact on their emotional wellbeing should use well moderated or professionally led community support forums to reduce the risks of this type of exposure.

5.3. Safety within Shared Identities

Communities are usually made up of people who can identify with other members of the group. This can be through a shared neighbourhood, or through a personal interest (Doolittle and MacDonald, 1978; Cohen, 1976). Online community support forums for specific health issues work in the same way. People seeking anonymous mental health community support forums, may read threads and posts made recently to decide whether or not the people on the forum are similar to themselves (Blanchard et al., 2011). Several of my participants stated that they may have 'lurked' on forums before posting, and being familiar with a forum made it easier to submit their first post (Schneider et al., 2012; Barak et al., 2008). Other participants stated that they found it easier to trust people on the internet than those offline, particularly on the basis of their shared identity (Tate and Zabinski, 2004; Suler, 2004). Many participants stated that

they wanted to be part of a forum that included people that they could relate to, which would include people that have had experiences similar to their own. This supports research conducted by Naslund et al. (2014: 4), where they found that social media peer support communities helped individuals to find 'normalcy', which made them feel happier and safer. This was experienced by several participants as shown in the three following quotes:

> I visited an online forum that was specifically for people who had the same condition as me…. it made me feel much happier and less alone (P1, Researcher's Forum)

> Mostly I learned that there are plenty of people like me, it's not unusual and it can be improved upon. This is the most beneficial part of online support groups. Seeing others with similar problems to mine and how they deal with them. (P14, Reddit)

> I've gained happiness in finally reading about other people like me, I've heard they exist, but until I discovered Reddit, I could never know for certain. (P8, Reddit).

A sense of safety is not just gained through a shared identity, but also through believing that other members of the community are truthful and honest (Daine et al., 2013; Suler, 2004). When asked directly if they were able to be open and honest in the support forums, most participants stated that yes, they could be open and honest. Participants 3 and 4 both stated that they felt they could be more honest online than offline.

> More honest than I can be face to face with people (P3, Researcher's Forum)

> Far more honest than I could be with friends and family (P4, Researcher's Forum)

Of the few participants that did not say whether they could be open and honest, none of them said that they could not be, but offered explanations of how they may use the forum instead. For example, one participant stated that if they read a post that explores the exact same diagnosis that they have, they will feel calmer, but they did not state if they would post honestly to that particular forum. Being able to be honest (or being perceived to be honest) means that a good culture is created within an online community (Coulson, 2013; Huang et al., 2011).

Even when praising 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 (Daine et al., 2013). One participant mentioned quietly evaluating forums, prior to being actively involved. 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 (Schneider et al., 2013; Bourdieu, 1990; Noelle-Neumann, 1977). This shows that idea of disclosing personal information for someone with mental health problems can still 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 (Al-Kouja and Corrigan, 2017; Evans-Lacko et al., 2013). Safety is therefore compromised and this could limit the amount of interaction in the forums that people are willing to participate in. For example, participant 13 stated that forums could quickly change and 'go bad' with changes in who was using them, arguments and disagreements, breaking out or trolling.

> …good ones [forums] can go bad quickly. [A forum] was originally brilliant, then it started to fill up with [..] assholes along with exploitative people… (P13, Reddit)

If users do not feel a sense of safety in online interactions, they are unlikely to feel supported in an online community support forum. Part of online forums is the fact that there are moderators or senior members who ensure that the site runs well, although occasionally they may fail. One participant described their experience of asking for help.

> **P10, Reddit**: the report button was very well hidden. You had to block someone to report them, and it was only when I did it (after someone told me how to report) that I got the option to report them. At first I thought that if I block they become invisible a la facebook and I lose the option of reporting.
>
> Then I just got a generic message that I should try someone else and that's when I decided that I had had it.
>
> The website has a policy. That doesn't mean it's followed.
>
> **Kim**: Don't the moderators do anything?
>
> **P10, Reddit**: I sure didn't notice anything.

It was clear that this experience had made the participant angry and frustrated stating they 'had had it' with the lack of response from the people who should be protecting the genuine people using the forum. Some of the other participants also gave examples of forums that had started well, but due to bad experiences were no longer to be trusted. One participant describing attacks on personal information as 'creepy'.

> [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.
>
> (P11, Reddit)

The bad experiences meant that the participants had lost their trust in the communities. When people lose trust in their communities, they can become withdrawn and isolated, increasing the chance of loneliness (Al-Kouja and Corrigan, 2017; Fergie et al., 2015). The experience of having their safety compromised reminded several participants of experiences of offline interactions. Some participants stated that they do not trust people outside of the internet either, with one participant admitting that they don't trust their spouse nor their friends 'to act in my best interest' (P9, Reddit). As discussed in Chapter Three, and confirmed by Brown *et al's*. (2016) study, trust can be an issue for members of online communities, but this does not necessarily deter them from online social engagement. Alternative methods of group participation may be sought in order for users to protect themselves. Some users of online forums may not identify their online participation as 'true' interaction, but more of a 'disembedded intersubjectivity that is somehow 'lifted out'' (Giddens, 1984, cited in Wittel, 2001: 51), a concept that separates on and offline, and may be a tactic used by some of the participants to feel safer. This was not something I found in my research, but is a concept that would be worth further research for those participants that do not seem to trust online communities after a bad experience.

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. Safety therefore comes from a sense of 'good' culture within an online mental health community: one that is supportive and offers help and advice. The safety of these interactions comes from anonymity (Daine et al., 2013), but also from a shared identity, honest and trust. If users do not feel a sense of safety in online interactions, they are unlikely to feel supported

in an online community support forum, becoming angry and frustrated, with a risk of becoming further isolated, as illustrated by my research.

5.4. Network Sociality

Network sociality is a phrase coined by Wittel (2001), who felt that community was something that was long standing and temporal, but the use of online resources had become the opposite. No longer were relationships community based and 'narrational', but they were more 'informational', based on an 'exchange of data and catching up' (Wittel, 2001: 51). My research has shown that there is some truth to this idea of being informational, and an exchange of data, with people using online communities to come and go as they please. Some of the participants stated that they used several forums at any one time, which emphasises Wittel's (2001) point that online communities are not communities as we understand them offline. This section looks at how the participants situate themselves within online support communities.

Trying to find a supportive community that is right for the individual can prove difficult for people with mental ill health, and there is evidence that some people may chose multiple forums affording them the opportunity to use each for something different (Hayes et al. 2016). The stigma of having a mental health problem in offline communities can be the cause of individuals seeking solace in the online world (Pavalanthan and De Choudhury, 2015; Link, et al., 1997). Therefore, participating online communities can still cause feelings of anxiety and uncertainty about how one's posts will be received and responded to by others.

> Asking for help was the hardest thing I had to do. (P2, Researcher's Forum)

> Sometimes I ask for help and if it's not immediately answered, I retreat. (P12, Reddit)

Asking for help was difficult for many of the participants, with some stating that they might retreat if their question is not answered immediately, and others were wary of the level of advice that might be given.

> Advice/ encouragement isn't always as valuable as is assumed by the person providing it. What's valuable is being validated, being heard loud and clear even if the listener can't personally identify. (P6, Reddit)

Some of the participants from the pre-established mental health forum expressed that they were constantly fearful of isolating themselves from the offline world, rather than worrying about not fitting in with the online world. Two of the participants both said that they found it difficult

to talk to people in the real world, particularly if they did not have experience of similar mental health issues. By seeking support online, they felt more comfortable and were more able to be open and honest about their feelings. This could be due to the shared values created through previous online interactions, or a shared mental health issue (and therefore a perceived shared understanding). The discomfort they feel talking to people offline could be due to the stigma of having a mental health issues, or due to self-stigma.

> I've been visiting forums and chatrooms since I overdosed last July and I'm not sure whether it's actually helping, don't get me wrong, it's great for distraction and keeping my mind busy, but I think it might be making me distance myself from actual human interaction. It can't be healthy having better conversations with people online than with the people I see and interact with. (P20, MHF)

> I find it is a good supplement, but not really a replacement for real live people to talk to and interact with. Whether it gets in the way, I'm not sure. I think you just need to limit the time you spend chatting on the internet to just a few hours a day, and leave enough time for real interaction and doing the other things one needs to do. (P17, MHF)

Many of the participants were unclear on the role of online relationships within the context of broader social experiences; they noted that the aim for online forums is to enhance interactions with others. Similarly, one participant noted 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.

> 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. (P19, MHF).

In line with Kendall's (2002) vision of the benefits of a 'blended world', many 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.

> For me, I can be the 'real me' on here. Although I do have friends and a loving family, I find it near impossible to let them know that I'm not good. (P17, MHF)

Getting the balance right between online and offline interaction was a common concern amongst the participants on all three forums. Kendall (2002) also states that most people do not use the internet *instead* of living offline, they utilise on and offline interactions depending on how they are feeling at any given time. Two of the participants felt that offline and online were separate to one another, both of which provide a place in which to air feelings and ideas.

> …cant mix with real people outside,…. this forum is great and a life saver for me (P18, MHF)
> I find them helpful as I can't do real interaction with people except my parents who work (P25, MHF)

These posts emphasise interaction online and offline as separate arenas, the online space providing unique opportunities for mental health discussion. This relates to the idea of Giddens' (1984, cited in Wittel, 2001) 'disembedded intersubjectivity', that the on and offline are kept as separate entities (by some). Being online allows a sense of 'playing at' interaction and experience, where 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 (Calleja, 2010; Hine, 2004). 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). This idea of escapism or playing at being online supports Wittel's (2001) suggestion that online communities are not really communities, but somewhere functional for people to gain whatever it is that they need. Lawlor and Kirakowski (2014) argue that online support groups can promote excessive dependency, especially if the user is trying to escape other factors offline, such as stigma. How people utilise online support communities may therefore be important, as using them for avoidance rather than support may be harmful in the long term (Lawlor and Kirakowski, 2014).

Online support communities reflected offline communities in ways other than just support through an online medium. For example, some participants expressed that they had on occasion had disagreements with other forum members. In these cases they typically went on to describe how they no longer trusted anyone online or offline, although one participant described their experience as unfortunate rather than confidence destroying. A few of the participants stated that their relationships with people from the forum had gravitated to an offline group, one felt as though they could only really develop their personal friendships offline, and one participant stated that they had kept in contact with a couple of people that they had met in an online forum. Of those that did not want to meet their online friends in person, one participant was concerned

that people would have 'ulterior motives', and others believed that having anonymity was important, stating that they would be more truthful if anonymity was kept, any meeting compromising confidentiality.

Social constructions that surround mental ill health make it easy for vulnerable people to become invisible in society due to isolation (Steptoe et al., 2013; Corry, 2008), 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. My research found that there were social 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. 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 (2008; 2004) 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, and Wittel's (2001) Network Sociality may be more positive and community oriented than he portrayed it to be in his article.

5.5. Summary

Participants of the research generally felt that community support groups were positive, helping to create a sense of identity and normalcy for the user. Online support provides information and education about mental ill health that is often not provided as a result of participation in the medical model or other offline healthcare services. A few participants had negative experiences, reporting that they had lost trust in the communities. Those with trust issues keep using forums though, but are more cautious about giving away too much personal information. Online forums could be seen more as a network sociality than a community. Wittel (2001: 51) describes a 'disembedded intersubjectivity' (Giddens, 1984), where users gain information, 'exchange data and catch up', rather than replicate the social connections of an offline community. My research sought to explore and clarify what was important about the interactions within virtual mental health support groups and to provide an insight into these

communities. It is important to consider that a network sociality is exactly what is needed for users of mental health online. Creating valid, temporary communities, that help the user identify with others who have mental ill health. New users join frequently, offering new insights, information and education. This in turn helps to prevent isolation and loneliness, and increase socialisation, albeit briefly in some cases. Education around mental health helps to fill in information not provided by the GPs or other health professionals, enabling people to feel more confident about how they discuss their mental ill health to people on and offline. The next chapter discusses the findings of four semi-structured interviews. The insights into the on and off line lives of people who use online community support forums for their mental ill health, helps to give depth to the findings in Chapter Five, by taking into account the micro, meso and macro reasons for seeking alternative support methods.

Chapter 6: Phase Two Findings

6.1. Introduction

The previous chapter outlined the findings of Phase One that were identified through a thematic analysis. In Phase Two, four participants were interviewed and these interviews were analysed using grounded theory (Vaast and Urquhart, 2017; Urquhart, 2013). The use of significant individual narrative throughout this chapter, shows that although there may be some common themes, each experience is individual. Three main themes were identified through the analysis process: The effect of offline relationships; Views of experts by experience and how they may define themselves; and How (mis)understanding mental ill health in the workplace can affect employment and employability. As is required in ground theory, I had to ignore the knowledge that I already had on the topic of mental health and online forums, and whilst coding, I tried to ensure that my own bias around the information that I *thought* I was going to hear did not affect the results. I am confident that I have allowed the participants voices to drive this chapter, and I did not imagine that social media was going to have been such a large part of the journey for the participants. This chapter explores the three themes using direct quotes from the participants along with my interpretation of their answers, using existing literature for further credibility of my argument.

Table 3 introduces the participants in this chapter. Names have been pseudo-anonymised for confidentiality, and the participants are more complex than the information given in the below table, however, this serves as an introduction to the individuals with some pertinent information for readers of this chapter.

Name	Age	Family	Job	Diagnosis
Sally	48	Lives with husband and two teenage daughters. Both daughters have physical disabilities and mental ill health.	Left role as SENCO Manager at a school due to mental health, is now working part-time in a temporary SEN support role at a different school	Depression. Was signed off work and offered counselling and medication. Medication was refused and counselling stopped after one session. First episode was at the age of 17.
Toby	39	Divorced, has two sons under the age of 10 who he sees regularly. In a relationship.	Left role at the local council due to mental ill health. Now working part-time in a temporary role as a college lecturer.	No definite diagnosis. Has had problems with alcohol and drugs in the past. Stated that he had a breakdown. Has taken medication, and had counselling through AA only. Started at the age of 18.
Roberta	21	Lives with mum. Strenous relationship with dad and brother, whom she does not live with. In a relationship.	Just graduated from university, now working part-time in a fast food restaurant.	Depression and anxiety. Diagnosis occurred at 14. She takes medication and has had counselling.
Angel	22	Lives with mum. Father died recently.	Just graduated from university, awaiting the start of a Masters course.	Depression. Was given medication for IBS when she went to the GP about this. Has had counselling for PTSD.

Table 3 Introduction to the participants of Phase Two.

6.2. Support Seeking Journey

Three of the participants decided to out their mental health issues via social media and as a result have been able to orchestrate their support networks in a way that suits them. One participant preferred the use of anonymous peer-to-peer support as a pre-cursor to offline support. This participant found transition from an adolescent service to an adult service difficult and has still not found a support network to replace her original support forum. This highlights issues with transition that mirrors issues of transition between services in the offline world.

The participants were able to talk about their mental health support seeking journeys, and as a result of this there are many reasons why they decided to go online to look for help and support. Although the participants had stated that Facebook can be a supportive environment, it is also one of the main reasons that people sought support in the first place. Research conducted by Facebook (2017) stated that social media use for people outing their mental ill health can be problematic. There are notifications on Facebook that can signpost people to support networks,

and many public and private[30] forums including those specialising in peer-to-peer mental health community support, are available on the platform.

> I had seen a link to it on Facebook – once I signed up, I was hooked. Roberta
> (Line 154).

Toby stated that it was Mental Health Awareness[31] day that was the catalyst he needed to think about how to talk about his own mental health issues. His situation illustrates how the awareness day can impact on one's life, hence the aim to educate the population can lead to help-seeking behaviours.

> It was national mental health awareness week, or awareness day, and my friend
> put a post about the problems that she's had with her mental health, and the
> various different issues that she's struggling with in terms of manic depression,
> and suicidal thoughts, and I thought that was amazingly brave, what she did.
> Toby (Lines 253-256)

Sally felt as though she was unable to be sociable through a period in her life where she felt exhausted with her own mental health, work and the health of her children. Her need to still feel as though she was having contact with her support network of friends and family was an important driver for her to post about her mental ill health online (Carr and Hayes, 2015). She stated that being able to physically go and see family and friends was too difficult, particularly when struggling with a disabled child.

> There were days that it was the only contact that I would have with people,
> through Facebook or messenger. And even when it wasn't messenger, just kind
> of being aware that the rest of the world was just ticking on and that people were
> still going out shopping, and people were still cooking rubbish food for their
> tea, and that kind of banal stuff was just there. It was grounding somehow. Just
> that the rest of the world is still going on, and that life is still happening. Sally
> (Lines 484-489).

---

[30] Need to contact a gatekeeper for access
[31] Mental Health awareness day in the UK is in March. On this day there are promotional activities to raise awareness about mental ill health.

This comment from Sally shows that she feels isolated, and that she is trying to reconnect to friends and family through their posts on Facebook, so that she feels as though she is part of their lives. This could mean that she feels engaged for a period, but ultimately may leave her feeling increasingly isolated.

Angel told me of two main drivers to seeking support, and these enabled her to post about her mental ill health online. The first was that she felt she needed some support to help her get through a lengthy transition time between seeing her GP and getting offline support (CBT), and the second was that she wanted people to know that serious events had happened in her life. Angel said that she felt as though she was always expected to be happy and bubbly, but she felt unable to keep up this persona. Not wanting anyone to be offended by this, she decided to post what she was feeling, so that when they saw her in real life, they would understand why she was not as bubbly as normal. Through alerting a network of people on social media, Angel told me that it gave people the choice of whether or not to raise the issue, and to be aware of the difficulties that she is going through without being intrusive.

> Naturally one of my pet peeves is attention seeking people and people that seem to want the limelight, but I feel that sometimes you have to be, because that's the only way I've been able to get help and support and understanding from people. It's not necessarily that people need to come up to me to discuss my mental health all the time every day, but for people to know that my father's deceased or that I'd been assaulted, or various anxiety or depressive episodes have happened recently, that's just enough for me to feel a little bit safer in the knowledge that people understand that behind the layer of my upbeat and happy, sort of positive demeanour, there are some issues that I'm still battling, still improving on each day. Angel (Lines 132 -139).

One of Angel's worries was that she would be seen as attention seeking by posting about her father and her abusive relationship. She repeated several times that she did not like attention seekers and that she did not want people to see her this way. Supportive messages can also be sent as a result of posts such as these, and that can also help the poster feel as though they are not isolated. Sally, Toby and Angel all described how supported they felt with the comments they received after their initial post.

Throughout the interviews, the four participants clearly expressed positive motivations for finding a supportive community online. However, they raised some issues that they sought to avoid when looking for information and support online. These were judgement and accessibility.

Sally, Toby and Angel told me that they were afraid of being judged online as well as offline due to their perceived views of stigma around mental health. Even though both Sally and Toby had used online forums or social media for support for their mental health, they were still intolerant of other people who did the same. Toby expressed these feelings by discussing how he dealt with a friend's constant posting about her mental ill health and Sally expresses her irritation at having to deal with other people's problems when she is trying to get support with her own.

> most of her posts are about her battles, her daily battles, and she's really open about it. And actually, I don't mind, but sometimes even I go, well you don't need to share everything. Toby (Lines 270-272).

> But then, they seem to be quite whingy and, do you know what I mean? It gets quite depressing doesn't it? Lots of people who have got this and they've got that, and that 'where's this problem going'? and that. So I didn't, kind of, want to throw myself into depression groups for the same, because I didn't think I could deal with that on that basis. Sally (Lines 224 -227).

Although Sally and Toby both expressed judgemental opinions about other people, they are expressing a societal view that people with disabilities are 'quite whingy'. However, they both also realise that they need to re-train themselves to think differently.

> But then I have to check myself and go, well what's wrong with her sharing everything? You know, Facebook, whilst it is a public forum, is your own space, in your own private journey. People can chose to read it or not to read it. They can choose to engage with it or not engage with it. Toby (Lines 313-317)

> Even now. My eldest has chronic pain condition. And there are days when I want to say to her – 'for goodness sake, sort it out'. And then I kind of give

107

myself a mental slap and move on, but yeah, I am [judgemental]. And I try really
hard not to be. Even knowing what I know, and even living with her and seeing
what she goes through day in, day out, I still slide too easily into the 'well you
don't look ill'. And if I, if that's me, then how can I expect other people to not
fit that role? Sally (Lines 418-422)

As discussed in Chapters Two and Five, negative societal representations around mental ill
health issues can be due to stigma, and stigma is linked to lower self-esteem and increased
isolation (Lawlor and Kirakowski, 2014; Thornicroft et al., 2014). Trying to change attitudes
towards mental health has been taking time to achieve (Evans-Lacko et al., 2013), and as is
clear from Sally and Toby's comments, it needs to be a conscious decision to change how
thoughts are processed around this topic, even for those with lived experience (Pescosolido,
2010; Link et al, 1999).

6.3. The effect of offline relationships

All of the participants explored their mental health experiences in the interviews by telling me
how they viewed their own lives, with a focus on relationships with other people offline. They
often made sense of their mental health through their interactions with other people, including
their parents, significant others, children, colleagues, friends, kin and acquaintances. Familial
relationships were important to the participants, but personal circumstances dictated how these
affected the individual. This section will explore each of the participant's micro-level
relationships and the impact that these relationships have on their mental ill health.

The participants all commented that their family members were important in their lives, and
felt that they did not want to be a burden to them or let them down. Many researchers have
shown that relationships with close-ties are important for self-esteem and for positive mental
health (Bloch, 2012; Thoits, 1986), but complex interactions with families mean that this is not
always the case, and close-ties often get pushed away after a mental health diagnosis
(Henderson et al., 2012). Sally felt as though she knew that her mum and dad were there if she
needed them, but she enjoyed spending time with them and did not want to change that by
telling them about her mental health. Angel spoke of her mum as her best friend, but having
suffered a stroke when Angel was 18, she said that she did not want to burden her mum further
with her mental health initially. Roberta said that she was close to her mum, and yet she stated

that she still feels a sense of letting her down if she confides in her. She does find that she will eventually confide in her mum, and that she is the one person that will support her regardless of her perceived faults:

> I've never had someone – beside my mum - accept my anxiety so completely and yet still believe I can do anything. Roberta (Lines 123-124).

Toby's relationship with his parents was strong when he lived with them, and he felt as though his mental health issues started when he left them to go to university.

> It's been a recurring problem I would say. From about the age of 18 onwards really. I guess from the moment really that I kind of went off and was on my own as an adult and when pressures become your own pressures with nobody else really to help. Toby (Lines 2-5).

The relationships that participants had with their parents were all positive, yet they had all decided to withhold the full extent of their mental health issues from them. As Sally said, this could be that they did not want their relationships to change, despite the fact that they also knew that they would be supportive. Relationships can often change between family and friends through the onset of a disability due to stigma or pity (Thoits, 2011).

Support from family members was important in order for some of the participants to be able to function normally during difficult periods within their mental ill health. This type of support can vary depending on the need and the source of help (Santini et al., 2015), although most studies state that high levels of perceived emotional support mean lower levels of depression (Hayes et al, 2016; Huang et al., 2011). The relationships that the participants had with family members were more complex that just providing emotional support. For example, Angel's mother relied on her for physical support after a stroke, Sally's two children needed her for support during their own disability issues, Roberta had to negotiate her mother and father's negative relationship with one another, and Toby had become distanced from his immediate family. This meant that the participants were not just receiving or expecting support from close-ties, but they also had multiple roles to navigate within their relationships.

Sally had been married for around 20 years, and her relationship with her husband formed a large part of her own sense making around her mental health.

> When I look back now and I think, God, how does he [husband] not walk away because I've been just vile and he's just carried on. Sally (Lines 33-34).

Sally's husband had been supportive, not through talking about the issues that Sally was facing, but through carrying on as normal. Sally stated that he does not really talk about emotions and feelings, and when she asks him about how he feels about her mental health state, he replies in a matter of fact way, reassuring her that he will continue to support her.

> And he's just like 'yeah, well I love you, what else would I do?' Sally (Lines 37-38)

Sally told me that her children both have physical and mental disabilities which she has felt exacerbated her own mental health. She thought that as they got older they would be more independent, which would mean that her role as a mother would get easier.

> I've had to be there for them in a way that I didn't think I would have to be now that they are both teenagers. Sally (Lines 30-31).

She said that the stress of having to cope with their needs meant that she has put her own social needs on hold.

> But I have let those relationships fizzle. And, just, you know, going out on a Friday night, well that's massive. It just doesn't happen, you know. 'Do you want to come to the pub for a beer?' Well you know, yeah, I'd love to , however I've got a child whose in tears on her knees, and I can't leave her, for me. And so yeah, I think, yeah. My relationships have fallen by the wayside I think. Sally (Lines 199-203).

When asked about who she felt her main support networks were, she stated 'fundamentally family, but, I think the wider community have been there too' (Line 216). Although it appears that she is crediting her family for being her main support network, this quote comes as part of a much longer narrative that suggests Facebook posts from friends are just as supportive to her on a day-to-day basis. She seems to be distancing herself from being a burden to her family (Henderson et al. 2015; Thornicroft et al., 2014), but also finding that her emotional needs are not being fulfilled in her immediate environment, hence seeking further support online.

Sally states that the needs of her children are always prioritised above hers. An example of this was that Sally was texting on her phone as she entered the interview room. She stated that she

had told her daughter that she was in a meeting. An hour into the interview her phone started to buzz (indicating text messages were being received).

> **Kim:** Are you getting texts?
> **Sally:** Yeah! (laughs) It's a positive one! So, it's the first one today that's been positive.
> **Kim**: Do you feel like you have to be attached to your phone all the time because of your daughter's mental health?
> **Sally**: There are days when it's nonstop. She knows when the days are that I will have my phone with me. And she uses that. I know she uses that. And I don't know whether I'm helping her by being on the other end of the phone or if I'm not.

Sally discussed the issues around supporting her daughter, but stated that was struggling with how to do this effectively. She said that she felt as though she had to be around when her daughter was at home (before and after school) as there were days when she needed significant help to shower, dress and generally be mobile. The pressure of the constant need on her to provide that support meant that Sally felt that she was not able to focus on her own needs. Her role as a mother meant that her family's needs came first, but this meant that she started to feel negatively about the situation.

> And in my head at that point, work was hard, but it was hard, it wasn't anything unmanageable. But with the issues I'd got at home, the two together were unmanageable. And obviously, home is far more important than work, so although I kind of said, and I know I used the word shit – home's shit, work's shit, and I can't carry on like this. Sally (Lines 74-78).

This kind of 'double negative' when seeking support means that Sally feels as though she is providing the support to her close ties, but not receiving the support she needs in return. Her attitude towards her life means that she may withdraw emotionally, finding it difficult to connect and share her own feelings (Santini et al., 2015). This creates an environment whereby she feels that it is not worth expressing how she feels as the situation is not likely to change anyway. This can lead to social isolation and withdrawal from society (Henderson et al, 2015; Hawkley and Cacioppo, 2010; Uchino, 2006).

Sally said that she felt as though her family relied upon her to be strong and to be able to manage the care of two teenage children with physical and mental ill health. The support from her husband meant that she was able to continue with this role as his efforts to take on the

majority of the household chores, meant that she did not feel like she was failing, but that she was over-whelmed. She said that she felt as though she could not manage to help her children enough for them all to lead a 'normal' life, which meant that she sometimes viewed her children's health as a burden, and felt guilty that she could not alleviate their pain. As a mother, she felt as though mental health is seen by society as a weakness, and that she does not want to be seen to be letting down her family, ultimately putting unrealistic expectations on herself. She realised that she needed to ask for help when she felt that she could no longer keep up these appearances.

> I was low, I was catching everything [illness]. Looking back, I must have been vile to live with. I'd got no patience. I was (pause) away with the fairies really. Just, kind of, no focus, no ….. I couldn't stick at anything. The house was a mess and I couldn't quite, I didn't get, it didn't impact at all. There was no 'this is a mess and I need to do something about it'. It was just, yeah, there was just, no kind of, yeah, I just stopped being I think. If that makes sense? Sally (Lines 18-23).

The stigma of mental health, and not coping as a mother can be damaging, especially when considering the historical context of mothers and mental ill health (Tasca et al., 2012). The stigma of this continues within society, meaning that often women do not seek the help and support they need through fear of having their children removed and taken into care, an issue that is stigmatising in historical, and contemporary society. It is clear that there are many complex issues affecting Sally's mental ill health within her relationships, and it is difficult to provide the support that she needs through her micro-level relationships alone.

6.4. Views of experts by experience and how they may define mental ill health

The participants all had an idea of what their mental ill health was called, what triggered it and how it should be dealt with. This section looks at the perceptions of mental ill health from the participants' perspective. Each of the participants have their own stories of diagnosis. All of them had been diagnosed with a mental health issue, although they all had different impressions of how this had been handled by healthcare services. The manifestation of mental health issues was something that each person found difficult in coming to terms with. Although it was difficult to acknowledge, a diagnosis also became a relief to have a reason for their behaviours. Research has found that most psychotic mental health problems begin between the ages of 14 and 17, with mood disorders being identified as having some very early onset, but are significantly more difficult to pinpoint (Kessler et al., 2009). de Lijster et al. (2017) found that

the average age of onset for common mood disorders was 21 years old, however, there are many caveats to this. Of all of the participants, only one felt that their illness had begun before the age of 14, but all felt that their mental health problems had started by the age of 18.

Sally put forward her own theories of why people may find mental ill health difficult to comprehend, posing the point that mental ill health is invisible, and although you may feel unwell, other people cannot see physical symptoms and therefore the illness does not exist.

> The whole 'invisible illness thing'. You don't look sick, there's nothing wrong with you. You're standing, you're walking. And that's it isn't it? People drag themselves through with mental health. Sally (Lines 273-275).

> People are frightened, in that, if it's your body, it's out there, but in your head, it's you. Sally (Lines 293-294).

She also felt as though other people with mental ill health could understand each other, or were more readily able to understand what it is like to live with a mental health issue. Those outside of this group were less likely to be able to understand, and she uses the historical context of how people were treated to emphasise that it is those people (without lived experience) that perpetuate the stigma. This supports the theories of community discussed in chapter 2 (Glynn, 1991; McMillian and Chavis, 1989; Doolittle and MacDonald, 1979) and the theory of the ingroup and outgroup (Tajfel and Turner, 1979).

> If people aren't quite the same as us, we don't quite get it. Sally (Line 316)

> I think historically, that the ones with the weird brains, that were stoned or kicked out of the village, we've still got an element of that haven't we? Sally (Lines 314-315)

Sally talks about the health of her children in terms of physical and mental disabilities. Her attitude towards the her child's disability was one of despair, and she stated that there's 'nothing we can do anything about' which alludes to the state of the healthcare system and how they are failing to help her children to function normally, which ultimately impacts on the whole family, and also how society views them (the children). As she described their treatment by healthcare services, she was dismissive, and felt that they treated her children as objects to be cast aside. 'Child's health is nothing we can do anything about, so let's just throw that over there'. Sally (Lines 135-136). Having been through what she said was a stressful time trying to navigate the

healthcare system with her children, she now felt as though the generic options that her children had been offered were not enough to help her children feel as though they could function as normally as a person without a disability. She also felt as though this was a burden that was constant, as their health would sometimes be worse and as a family they would have to renegotiate their relationships and how to navigate societal issues such as school, going shopping and so on.

> I know my kids health issues are not going to go away, they will change and we will all learn to cope with it. Sally (Lines 133-134).

Accessibility of information was a barrier for Sally, Roberta and Angel. Sally had found coming to terms with her mental ill health difficult, and wanted to be able to access online information without having to trawl through pages of self-help information leaflets. Sally stated that peer-to-peer community support groups often ensure that their members have access to professional documentation so it can be wordy and complex to understand. Most of the participants felt that social media is much easier to use as the format is familiar and most of the peer support forums have active users 24 hours a day. Ease of access to information and support was necessary for the participants, and if they felt that it was difficult, then this became a barrier (Hayes et al., 2016; Naslund et al., 2014).

> it's easy isn't it to have the name of a website thrown at you, but what can they do? Nobody's ever said to me, try this they can talk to you about this, try this, they can talk to you about that. The ones that we looked at were very much about kind of self-help sheets, and I don't want to read, you know? I don't know what would have been useful, but looking at pages and pages of writing, which is what we kind of came across when we first started looking, even though it was teen friendly, it still seemed very wordy. Sally (Lines 375-381)

Angel felt that it was more difficult to access offline services, and this could be facilitating the rise in online support seeking.

> Mental health has had a stigma attached to it, obviously in this country and all over the world, there's varying degrees of how much people understand or don't understand mental health. So, yeah I think it is quite challenging for people to access the services. Angel (Lines 276-279).

As I discussed in Chapter 3, there can be an issue for people in accessing online forums that are genuine and not exploitative (Daine et al., 2013). Roberta had found a forum that she gained

a significant amount of support from, but could not find a suitable alternative when she exceeded the upper age limit of 19 years. One issue for her was that a lot of forums that she was interested in required payment to access. This was not an issue that anyone else brought up.

> I've looked more into online forums over the years, trying to find a slightly more grown-up forum to speak with people in. Most, however, you do have to pay for. Therefore, I rarely use any anymore. Roberta (Lines 159-160)

Regardless of whether or not there were free of charge forums available, the perception for Roberta was that there was nothing online that suited her needs. Similarly to the participants in Phase One who had lost trust in online forums, the lack of finding a community that is right for her could increase her risk of isolation and exacerbate her mental ill health (Hayes et al., 2016; Giles and Newbold, 2013).

> I genuinely think I might have ended my life if it wasn't for [a forum]. Roberta (Lines 164-165)

Roberta was honest about the fact that she felt she may have killed herself if she had not found the right support network, so it is clear that there can be detrimental effects of not getting the support networks right for people seeking online support for their mental ill health.

Sally found the GP helpful, and credits her with recognising that she was depressed. When Sally went to the GP, she was feeling low, but had not realised that she had been quite run down with coughs and colds and so on for quite some time. When she discussed her poor ongoing physical health, the GP recognised that there may be an underlying mental health issue that was causing the other health issues. This diagnosis was a turning point in Sally's life and she felt as though it was helpful in understanding her own needs, and for her family to also understand in order to support her.

Angel also felt that her diagnosis from the GP was positive, although she was more confident in her ability to speak about her mental health at the point in which she sought help. This was in her final year of university, just before her exams. She believed that talking about her mental health through social media helped her to be honest and open with the GP. However, the GP did not seem to respond to Angel's mental health needs, but medicated the physical needs

instead. However, Angel walked away from the GP feeling satisfied with the outcome. Even when I asked further questions around this, she felt as though the GP knew best and felt positive about the results of the medication that she had been given, even though it was not directly linked to her mental health, but was a holistic approach to her overall wellbeing.

> **Kim** (Line 190): When you went to see the GP, what experience did you have there?
>
> **Angel** (Lines 191 – 201): It was a largely positive one. In a way I'd geared myself up for being open and frank by posting on social media, that discussing my mental health is not an alien concept to me, it's something I do quite regularly, quite frequently, quite often, so going to the GP, I wasn't shy to state the issues I'd been through and that I needed support to be able to get through the exam period, because I was still on the waiting list for PTSD treatment, although I'd never actually got it, because I'd been on the waiting list so long, and now I've moved back home for the summer. It was definitely challenging being on a waiting list but I definitely thought that medication would potentially help. When I explained all of the issues I had been through, I was diagnosed with irritable bowel syndrome and it seemed to quite clearly relate to my interactions with this individual and so I was prescribed a few pills of mebeverin which just regulates the bowel movements and the intestines, so that they can relax a little more, and that really did help around the exams period.

However, Toby and Roberta felt as though their GPs did not listen to them or adequately address their needs. Roberta in particular felt as though they were not taking her seriously, although all of the participants felt as though the treatment given was not enough (in terms of access to good quality counselling).

The amount that the participants relied on their diagnosis, whether it was by a GP (2 participants – Sally and Roberta) or originally a self-diagnosis (2 participants - Toby and Angel) was important in how they then proceeded in their daily lives. For example, Sally did not question the diagnosis, although she was shocked by it. She did however realise that the GP was not a mental health specialist, and was frustrated at the limited options and lack of a clear pathway to recovery.

> I came away from the GP that first day with a little slip of paper, with a phone number on to ring and the GP said 'it's all self-referral now, you have to go away and do it. That was one of the hardest phone calls I have ever made. Sally (Lines 322-324)

> When the Dr said to me, well you've got two options, one is medication and you can do counselling. I was like, why is that only 2 options? And she did

clarify that I could still go down the medication route at some point down the line. A girl I used to work with went to the Drs the day before me, and her GP just gave her medication. No mention of counselling. So two of us went, two consecutive days, two different Drs, similar needs, she was given medication and is still on that medication and things don't feel much different for her. Sally (Lines 284-289).

The lack of options was clear in all of the participants' cases. Three of the participants had taken the option of anti-depressants, but only for a short while, preferring not to show weakness for 'relying on medication' (Angel, line 180). Often the option of medication was to help alleviate anxiety whilst awaiting further treatment, usually CBT. For some there was a defined waiting period of 11 weeks, and for others, there was no timeline, but they had not received any treatment or told any further information about expectation of treatment even 4 months later. Toby did not feel as though the GP would help at all, and gave very little credit to their involvement in his recovery. He realised that his issues were social and felt that he needed to resolve the issues himself. He spent a lot of his young adult life suffering from mental ill health, which led to risky behaviours and ultimately the loss of his marriage and his job. Although he sought help for his health issues, he was only offered anti-depressants, which he took for a short while, but felt as though it was a 'fog' that he didn't want to be in. Toby lives a long way from his immediate family with little contact, but has supportive friends that he believes helped him through the darker times. This mistrust of the GPs can mean that people do not seek treatment, or only seek treatment when they feel at their lowest (mood and health) (Croker et al., 2013). This means that there is not an accurate estimate of how many people actually have a mental health issue, and it is not accurately understood how they may manage (or not) their mental health on a daily basis.

Roberta had been through a transition from adolescent to adult mental health, and at the same time moved from a major city in the North East, to a small university in the North West. She initially received counselling support through Childline, but once she had been diagnosed with anxiety and depression at university, she was able to start taking medication.

Still, as an adult – I feel like I'm fortunate to have medication, it does help immensely – but sometimes I feel like I'm just another name on a waiting list. That they'll get around to me at some point. For someone like me who struggles with self-worth, it's an odd procedure. Roberta (Lines 128-129).

Sally and Roberta had also been offered counselling appointments through the NHS, although Roberta had not yet received any, despite being on a waiting list for 3 years.

> I've been told many times to access Talking Therapies, I've had assessment appointments and then been on waiting lists. So far, I've not had an actual CBT appointment. Roberta (Lines 143 -144).

Sally had found the process of self-referral for counselling very difficult, as part of her anxiety was using the phone but she was expected to make the initial call to the counselling office.

> To be contacted by somebody, I think would have been better, than for me to actually make that call. Because it would have been very easy for me to have just left the bit of paper on the mantelpiece and not done anything with it. Erm, and then for that to be followed up quickly. Sally (Lines 325 – 329).

Similarly, Roberta had issues with phone calls which shows how difficult it can be for people with mental ill health to access therapy.

> I've been encouraged to access Talking Therapies many times over the past few years but have put off doing so due to anxiety about talking to strangers on the phone. Roberta (Lines 23-24).

Both Angel and Roberta felt that they had to fight for their treatment, albeit that they did seek help at various points through their illnesses. Angel was not offered any support from health practitioners when her mother had a stroke, despite the fact that she was her main carer until she went to university. An opportunity was also missed by at least one of her school teachers, as they had realised that she was struggling (which they admitted to her afterwards) throughout her A Level exams[32]. She asked for help at University, which was offered in the form of counselling, however due to an administrative mistake she was then discharged and had to go back onto a waiting list. Angel's father died during the Christmas period of 2016, and once again, this would have been a good time for Angel to access services for bereavement and therefore, her mental health, however, nothing was offered. She is currently still on a waiting list for CBT.

---

[32] A Levels are taken at age 18 in the UK and are the common form of entry into University.

Sally found that the CBT offered to her did not meet her expectations, and she felt as though she was left to work out how to help herself. She felt that she was lucky enough to have the support of her family around her to help her do this, but feels as though she may need to go back for anti-depressants if she feels as though she is 'going downhill' again.

> I don't really know what I expected from it [CBT]. I kind of expected a bit more challenge maybe or something. Do you know what I mean? I expected it to kind of look at some of what the issues were and, kind of, for me to have to think about that. Sally (Lines 125-127).

Roberta has had a similar experience in that finding adequate services for her needs has been difficult. She first accessed support through Childline's[33] online service at the age of 14. This was a great source of support for Roberta, however, she soon outgrew the maturity level of the people on the forums, so wanted to transfer to a similar site for adults. However, she struggled to find anything that she felt met her needs. She eventually went to the GP for support but was unsure of accessing treatment this way as she did not think that the answer was to take anti-depressants or go through CBT. This made her anxiety worse:

> My current GP dismisses so much that I say because she doesn't want to change the medication I'm on. In the past 6 months, I've experience much more physical symptoms and they frighten me but because they're generalised symptoms, my GP acts as though it's normal for me to be paralysed with fear, for my arms and hands to get pins and needles so sharp I can't just get on with things. Roberta (Lines 180-183).

Information seeking behaviour was a personal journey for each of the participants. All of the participants started with anonymous peer-to-peer support forums. Three of the participants became regular users, and one used the support forums as and when it was required, often depending on his own mood at the time. However, at the time of the interviews, none of the participants used peer-to-peer support forums anymore, but had all moved over to exclusively use social media. The move to social media, in the case of three participants, coincided with their decision to 'come out' (Corrigan, 2015) with their mental health issue to their social networks.

---

[33] A charity phone and online service that helps children who are experiencing difficulties or abuse.

The use of peer-to-peer support communities was generally a positive experience, although Roberta struggled to find an alternative to the forum that she had been part of when she became an adult. Two of the participants, Roberta and Angel found that they felt acceptance within in a community, and relief that there were others who felt the same as them. They also found that the anonymity of the online support groups meant that they found it easier to talk about their issues.

> I've always found it easier to tell strangers about experiences I've gone through, and in doing so – it helped me process it and talk about it till I was strong enough to tell the people close to me. Roberta (Lines 164-168).

Here, Roberta talks about how much the forum helped at a low point in her life. She felt unable to access support offline and credits the online support community with saving her life as she had considered suicide. Even though Roberta was close to her mother, she still felt isolated by the abusive relationship she was in, and felt that it was easier to find support in a group that was not going to judge her decision making. However, she felt as though the online group was there to support her until she felt strong enough to speak to her support network in the offline world. There is a distinct separation between these areas when using anonymous peer-to-peer support forums.

Sally used peer-to-peer support forums to help initially with the health of her children. She found that she would read the posts of other people to gain as much information as she could, preferring to lurk rather than actively participate in the discussions. She did not want to join in with the people who she felt were victims (being negative and 'whingy' (line 224) about their situations), preferring to try and stay positive. Although she was happy to share information about her experiences if she felt that it was helpful to other members. The altruistic support that she was able to offer others helped her to stay positive, and even though she felt that she was not personally getting support from the group, the information that she found was enough for her to continue to be part of the group for a while.

> that's been really useful, because I've, well we've both been able to comment and support other people in kind of little ways. You know, I've found this product, or this product works for me or have you tried this to help with that pain, or have you tried that? So those kind of things are very kind of concrete, I think. There's no soul searching associated with that, that's just things that we have found. Sally (Lines 231 -235).

Sally and Toby were the two participants that were noticeably more inward looking in the way that they spoke about their mental ill health. They joined communities initially because they wanted support and did not want to give anything in return and they both appear to give back to their online communities reluctantly. Toby feels as though he can participate as himself through social media, but is reluctant to encourage others to do the same (Lines 270-272 on page 99).

Three of the participants Sally, Toby and Angel, had a preference for using social media platforms and they had all decided to use Facebook to tell everyone about their mental health issue. The 'coming out' of their mental ill health to their friends and family networks was an important moment for all three of these participants, although Sally and Toby used it more to orchestrate their new support networks.

> So I just shared mine, my story I suppose online, and said this is how I've been and this is how I've been dealing with it, these are the people I would like to thank for being there to support me, and it was actually just really cathartic, putting it out there. And actually people did get in touch with me. A few people commented on it. It was more interesting and more kind of supportive from the people that took the time to private message me and say, it was really brave of you to share that, you are doing really well, and because I'd mentioned the boys, people said just hold on to those feelings, you know, and remember the good things about yourself, because it can be difficult to remember those things. Toby (Lines 259-266).

Toby felt that there was a hierarchy in the way that people responded to his post. Those people that posted a comment directly under his were dismissed. This could be that he assumed that they were just commenting to show other people that they had commented (as names are shown to everyone that looks at the post). Those that sent a private message were seen to be taking the time to contact him directly, which was seen as more personal. Those that sent personal messages and mentioned his children were seen as the most important part of his social network, and throughout the interview, Toby often spoke about people who took the time for him and his children as the most important to him, even if he saw them physically very rarely.

All four participants felt as though the GP was not adequately trained to deal with mental ill health. They also felt that there was a lack of personalisation, a lack of choice, they had to fight for their treatment, and they had to treat themselves as the treatment provided was not adequate for their needs. Toby and Roberta felt as though the GP(s) did not listen to them or sufficiently

address their needs. Roberta in particular felt as though they were not taking her seriously, although all of the participants felt as though the treatment given was not enough, or right for them.

6.5. How (mis)understanding mental ill health in the workplace can affect employment and employability.

Three of the participants, Sally, Toby and Roberta, had their own story about their experience of their mental health at work, before and after disclosure. Sally worked in a school as a Special Educational Needs co-ordinator (SENco), and was a senior member of staff. Having many years of experience, her position was somewhat integral to how she perceived herself and her social status. When I asked Sally to introduce herself, it was the first part of the introduction, even before talking about family members.

> **Kim** (Line 1): Tell me a little bit about yourself and how you see your mental health
> **Sally** (Lines 2-4): Now there's a big question. So, I have been a professional, worked in Education. Mum of two, full time worker until very recently, happily married for too many years to mention now!

Sally did not want to admit that she was not coping at work, and had struggled in her role for quite some time before deciding that the only way to cope with it was to hand in her notice.

> Erm, having spoken to my immediate line manager and my ultimate boss, I told them both very clearly when I handed my notice in, that it was because I'd felt, kind of 'wobbly'. And this was quite a while before I saw the GP actually so it was quite interesting that I'd kind of recognised it enough to kind of have that conversation with them, but not to really and truly admit it to myself. Sally (Lines 61-65)

Toby's experience was similar in that he said his position and salary afforded him a status that he said he had believed previously was aspirational. However, he too realised that this was exacerbating his mental health problem, so he decided that he would be better off earning less, but being happier.

> I quit my job, I handed my notice in on my house, I gave my car back to Mini and got all of my finances into a nice little bundle. And I moved into a tiny flat, got a shitty car, and I quit. Toby (Lines 237-239).

The decision for both Sally and Toby to go from a well-paid job to relative uncertainty about their next steps is complex. The psychological trauma that came with going in to work each day, outweighed the option of telling people that they had a lower status job for quite some time, until it became too much to cope with. Walker and Fincham's (2011) analysis of work and mental health, highlights how people's identity is often embedded within their jobs. If their work identity is lost, being part of a community (work) ingroup is also lost along with the inherent support that comes with this, to the detriment of the wellbeing of the individual (Strangleman, 2007).

Sally handed in her notice and was told that she must work for a further 4 months, which she was prepared to do. What she was not prepared for was the way that she would be treated.

> So there was very, well, there was no support from work, and in fact it was the other way, there was lots more pressure put on. Erm, lots of being put in positions where, well I don't like the word but, bullied. I was being bullied, but I was also expected to bully people who I was line managing. Sally (Lines 65-67).

In fact, the increased pressure that Sally was put under was the trigger for her to go and see the GP, resulting in her being signed off work for the remainder of her notice period. Toby's mental health manifested itself in a different way, he was given too much freedom within his position, and no one noticed that he was struggling. Toby stated that there were times that he turned up drunk or that he didn't turn up at all, and still no one realised that there was a problem. Alcohol misuse is common with male workers in particular (Smith and Randall, 2012) however, Toby had a lengthy relationship with alcohol and substances previously, hence alcohol was his 'go to' stress reliever when times were tough.

> I was working in the public sector, in council offices, with multiple people who I was reporting to, very senior position, erm expected to just be able to get on and do it. But I got on and did it in my own way. My own way would be mostly drunk and mostly hungover and mostly absent. And just do enough to get by, and go to enough meetings to say the right words, but I was never really there. Toby (Lines 69-70).

Both Toby and Sally's experiences are summarised through Fincham et al.'s (2011) research on experiences in the workplace. Fincham et al. (2011:45) found that 'cultures of work' impacted on the positive or negative experiences. For both Sally and Toby, Fincham et al.'s

(2011) theme of money explains the motivations behind struggling on at work, despite the fact that they both knew that the environment was detrimental to their health.

Roberta worked part-time for a fast food restaurant chain, and her approach to work was very different to Toby and Sally. She was still eager to enter employment after university. Her anxiety had always previously stopped her from getting paid employment. However, even though she had disclosed her mental ill health, and asked the manager to alert the members of staff on her first shift, Roberta found that her anxiety had not been taken seriously, something that she feels is also an issue in other areas of her life.

> I work at [place of work] – before medication, hell would have frozen over before I even considered it – and I told them on my application and in my interview that I'm medicated for an anxiety disorder. Yet when I started work, nobody knew or took it into consideration. And the amount of "I'd never have thought, you're so confident" responses was/is irritating beyond belief. Roberta (Lines 197 -200)

Disclosing mental ill health in the workplace can exacerbate the issue (Business in the Community, 2017), and here it is clear that even in large corporations, the message is still not filtering down to all levels of employees, and stigma around mental ill health could still be a problem in work culture. A report by Business in the Community (2017) found that only 13% of individuals felt that they were able to disclose their mental ill health in the workplace, which could link back to Fincham et al.'s (2011) study whereby one motivation is money. The fear of losing a job, or being put on sick pay could be a significant driver of the lack of disclosure.

Roberta felt as though she had accomplished something by being able to hold down a job, although her anxiety was still quite high. For her, the task of being able to apply for, go for an interview and then start the role was more difficult than the work itself. The satisfaction and boost in self-esteem that come from working could help Roberta's mental health improve in the long term, however, if she has a negative experience it could make her anxiety worse and lead to her being unemployed once more.

Sally's initial disclosure post was confidence building for her, and she found that once she had put her mental health into words, that others started to talk about their issues too. The way she portrayed the reaction of others was almost with a sense of pride, as though she was pleased to

be the catalyst of people starting to talk about their mental health, and as she was the first they would come to her for advice.

> why am I only knowing this now? I've worked with you for 10 years and I only know now that you've been through this at some point in your life, why don't we talk about this? Sally (Lines 239 – 240).

Sally did not like the stigma attached to when she had to 'go off sick' (Line 302) from work, and she was pleased that she could gained back some credibility as people realised that she was really unwell rather than the perceived pretence that comes from taking time off work with stress.

Angel used her 'outing' as a statement rather than to create a social network. She then reacted to the responses as a way of helping others rather than keeping the focus on her needs. Although she continues to write her statements on social media about her mental health issues, it has become a cathartic diarised account of her 'battles' (line 139). She continues to get responses, but tends to feel as though she has a responsibility towards helping other people get through their problems.

> But I feel that if I share my story, that's one story out there, I don't have to then talk about other people, it won't build up for me because I'm also going through my thing, so if I alleviate that burden for myself then I can be more receptive, and more help and more sensitive to other people's issues and it also kind of shows that although I'm helping others, I'm also going through something, so it can definitely help to form a sense of solidarity between everyone that's going through various issues. Angel (Lines 116 -121).

She may feel as though she is dealing with her problems as she has openly published them to the world. However, it seems as though once she has written about it, she moves on and puts her efforts into supporting others rather than accepting any support herself.

Toby was the only person that had experienced any negativity at all on social media.

> And there was some negative response to it, you know, some people say good on you for sharing it, and some people say 'mate, why are you doing this on here, it's not the forum' type of thing. Toby (Lines 258-260).

But this did not deter him from expressing his feelings, commenting that most people were positive, and the most important people took the time to message him privately to show their

support. It is concerning that people felt as though they could be annoyed at the contents of such a personal post. This may show that levels of tolerance on social media could be waning, and that support should not be expected because others may have been seen to be getting support previously. He was the only participant to experience this negativity, however, it had clearly had an impact on him.

As discussed in Chapter Two, identity is a key concept that is fundamental to the wellbeing of people with mental health problems. Social comparison theory found that people develop a sense of self through comparing themselves to others with confidence being derived through this identity and seeking out others who share the same behaviours (Festinger, 1954). Wood (1989) found that self-esteem can be affected by these comparisons with others. Downward social comparisons may validate behaviour and boost self-esteem, however if upwards comparisons are made, then self-esteem can become very low, leading to withdrawal from social relationships (Wood, 1989; Wills, 1981). Sally and Toby in particular make references to upwards and downwards comparisons, without being aware that this shapes who they are, or why they feel as though their identity is linked to the type of job they do or the amount of money they earn.

Work environments are one area that has recently come into focus as an area that needs significant support when dealing with mental health (Farmer and Stevenson, 2017). An EU level estimate of cost of lost productivity to mental ill health, and associated health costs, is currently 617 billion Euros a year (Matrix, 2013). The UK alone estimating costs in the region of £105 billion a year (Independent Mental Health Taskforce, 2015).

To both Sally and Toby, having a job that is seen as 'good' by society is important to their sense of who they are. Although Toby is no longer earning as much money as he used to, his job as a lecturer at a college affords him the status that he needs to feel as though he is important. Sally is similar, in so far as she realised her job as a manager of Special Educational Needs at a primary school was of good standing within society. Far from being conceited however, Sally and Toby have created a schema of self-salience that enables them to validate themselves as good and worthy in society (Thoits and Virshup, 1993). Without the job status, their mental health may suffer more, as they would be unable to find what value they add to society or their communities (Walker and Fincham, 2011).

Roberta and Angel rationalised that their expectations seemed to come from low self-esteem in adolescence. Roberta and Angel seem to validate their self-esteem through relationships with a significant other, however both have been victims of intimate partner violence (IPV), which ultimately lowers their self-esteem and confidence. There is plenty of research to denote that low self-esteem leads to feelings of depression and anxiety (Henderson et al., 2017; Corrigan, 2015; Thoits, 2011; Crabtree and Haslam, 2010), and this can lead to low power within relationships which elevates the risk of internalising mental ill health.

However, work may also been seen as part of the solution to combating mental illness. A longitudinal study found that although being employed was synonymous with generally better health than being unemployed, those who had the highest psychosocial issues (high stress, low autonomy over work tasks for example) were only marginally better, but showed a greater level of mental health declination over time (Butterworth et al., 2011). Roberta felt as though she had accomplished something by being able to hold down a job, although her anxiety was still quite high. For her, the task of being able to apply for, go for an interview and then start the role was more difficult than the work itself. The satisfaction and boost in self-esteem that come from working could help Roberta's mental health improve in the long term (Waldenstrom et al., 2008), however, if she has a negative experience it could make her anxiety worse and lead to her being unemployed once more. LaMontagne et al. (2010; 2007) reviewed the cost benefits of putting in a management system for ill health, and found that interventions were worthwhile in all organisations surveyed, with lost workdays due to illness reduced, and the negative effects of stress were also reduced.

Each of the participants had a different relationship to work, which highlights difficulties when writing policies to support people with mental ill health in the workplace (Business in the Community, 2017). However, the commonality within this area was that the participants all had negative issues with people they worked with. Whether this was the failure to acknowledge the mental ill health, or to actively ignore it, each participant stated that the way that their colleagues and seniors reacted to their mental health had a lasting impact on their emotional wellbeing and ability to continue working.

6.6. Summary

All of the participants discussed their lives in terms of what their relationships with family and friends were, their diagnosis of mental ill health and how this impacted on them in a work or college environment. Despite the commonality of the discussions, it was clear throughout the analysis of the interviews that the individual experiences were unique. Discussing mental health with friends and family was a barrier to all of the participants, centring around not wanting to worry them, and realising that even if they do disclose their mental health, they wouldn't know how to cope with it anyway. The participants that did disclose, did not fully disclose all of their thoughts due to the fear that a lack of understanding on the part of the family member would make them overly-worried.

The GP's place in the diagnosis and support of the participants was more to do with the systematic issues within the NHS, such as a lack of funds for services, and training issues for GPs. Some of the participants felt that the GP listened and understood, however the majority felt as though their needs were left unmet. The participants were not able to gain sufficient support from their places of work, and in some cases, once mental ill health had been disclosed, the working environments became more difficult, leading to resignation. For one participant, finding that disclosing her mental ill health at an interview was taken positively, she felt that the working environment would be suitably inclusive. However, even where employers are supportive of workers with mental ill health, it is clear that managers often do not know how to disseminate information. Experiences of mental ill health appear to be quite negative overall for these participants. Small changes to the way that the medical system in the UK operates, could have made a big difference to the people in this research. For example, support with accessing appropriate online forums whilst waiting for counselling would be something that is easily achievable and has no cost to the NHS (unless using NHS funded applications). Future policy and research recommendations will be made in Chapter Nine. The next chapter considers the answers from the participants in both Phase One and Phase Two, identifying similarities and differences from the two datasets.

Chapter 7: The Two Phases, Similarities and Differences.

7.1. Introduction

In this chapter, I consider my analysis of the two sets of findings (Phases One and Two). Phase One was a virtual ethnographic study of three online community support forums and Phase Two was a grounded theory study of semi- structured interviews. My study is innovative in considering why people use online forums for mental health support using multiple methodologies and multiple types of online platforms to find out more about how people use online community support to discuss their mental health. Mertens and Hesse-Biber (2012: 75) also advocate a 'more in-depth nuanced understanding of research findings through a layered analysis, and clarifying disparate results by placing them in dialogue with one another'. In Chapter Five, I considered the findings from Phase One and the key themes were: The Effect of Online Support; Safety Within Shared Identities; and Network Sociality. In Chapter Six I discussed the findings from Phase Two and the key themes were: The effect of offline relationships; Views of experts by experience and how they may define themselves; and How (mis)understanding mental ill health in the workplace can affect employment and employability.

The overall aim of my study was to explore whether online communities were useful as a tool for supporting people with mental ill health. An issue with previous research is that there has been a significant amount of research undertaken with college (university[34]) students (Bouiliane et al., 2015). My study was specifically open to anyone over the age of 18, and does not focus on the age of the participant, but rather their experience. Fifty-four percent of adults (over 16) use the internet for seeking health related information in the UK (ONS, 2018), highlighting the importance of including all age groups. Rains and Brunner (2015), and Hayes et al. (2016) evidenced that there is not enough diversity in the forums that are being researched, with most researchers focusing on just one platform. This chapter will discuss how I went about exploring multiple platforms, how this relates to existing literature, and why the findings are important.

---

[34] In the US and Canada, where a lot of the research is conducted, college usually starts at the age of 18 and is for under-graduate degree level education. In some other countries including the UK, this level of education is called University.

In Phase One, the aim was to find out why people used online communities for support with their mental ill health, and was it useful to them. The overall findings suggested that most people that use anonymous online forums felt that it was a safe space where they could find out information from people like them, without involving offline friends and family. The sharing of information was not about types of medication per se, but more about coping mechanisms and what episodes of mental ill health actually look and feel like. The negatives to this were that there could be individuals wanting to cause problems through salacious comments (trolling), or people looking to cause trouble (such as hackers), which could ruin these safe spaces. Once safe spaces became unsafe, those who went online looking for support could end up more isolated than they were before joining an online community.

In Phase Two, the aim was to find out more about the micro, meso and macro drivers of why people went online to find support for their mental ill health. What was significant in this phase was that most of the participants used social media communities in which to 'come out' (Corrigan, 2015) with mental ill health. Instead of going online to avoid telling close-ties, they utilised online as the communicative tool to share their mental ill health with friends and family. The consequences of announcing their mental ill health so publicly meant that they could never escape the label of ill health, even offline, feeling that every time they spoke to people, they were being judged about how well they were coping.

The next section of this chapter explores the key commonalities and differences within the research phases. This begins with the significance of relationships with others. Relationships with friends and family (close-ties) and non-close ties (such as acquaintances, or Facebook friends), were central to the participants sense of self-perception, which links to the literature on what constitutes a community. Another common issue was that people were concerned about revealing their mental ill health in case these perceptions changed, and they were subjected to judgemental attitudes. The final commonality discussed in this chapter is how online communities are utilised for information seeking. There were two significant areas where the findings differed. The first is the idea of online communities as safe spaces, where there are differences between anonymous forums and the lack of anonymity through social media. The second is the consumerism of online communities, which may have an impact on how health professionals utilise and recommend online support communities (see Table 4).

Similarities	Differences
Social connectedness	Safe spaces
Fear of judgement	Consumerism
Information seeking	

Table 4 Similarities and Differences: Themes from the two research phases.

7.2. Social Connectedness

Relationships with friends and family were discussed in both phases of the research. It was clear that close and non-close ties all had a role to play in how the participants decided to connect with others online. Similarities in both phases were that some participants stated that they used online groups so as to not burden friends and family, whereas others did not want to talk to anyone offline as they felt that they would not understand, or they were not able to talk to anyone through fear or anxiety. Anonymised support forums and social media forums were used to write about how mental ill health affects the individual. My study found that this can be cathartic for most participants, as they experience a sense of relief from sharing their experiences. They may however, have different rationales for how they choose to disclose their mental ill health. Tamir and Mitchell's (2012) study found that disclosure fulfils fundamental needs for social connectedness and belonging, and is intrinsically rewarding, which my findings substantiate.

It is estimated that 39% of health information seekers use social media (De Choudhury et al., 2014), often joining a specific health-related group. The openness and honesty of posting about such sensitive issues online, can help to create a sense of closeness between individuals, even if they are geographically far away (Rozzell et al., 2014). In 2008, one in five social media users reported that posting about emotional issues on social media enhanced connections with friends and family (Ellison, 2007). Disclosure goals may include re-connecting with friends and family after a period of isolation, and social media may be an easy way of doing this (Bazarova and Choi, 2014). Similarly, my study found that posting on social media can help to rebuild personal connections, particularly when the individual has previously isolated themselves. In addition to this, I also found that many people use anonymous forums for the

opposite reason. Most of the participants did not want to tell close-ties how they are feeling. By finding a community support group online, they were able to be open and honest in a way that they were unable to be offline.

My study has shown how these relationships are an important part of how individuals with mental health perceived themselves, but also about how they were worried that coming out would somehow change the way that close family and friends perceived them. Relationships with friends and family in particular had a profound effect on how the participants in Phase Two felt about themselves in relation to their mental ill health, and through coming out on social media, they felt better connected to their close-ties and more able to speak with them about their feelings offline. However, a negative side to disclosing mental ill health on social media is that the information is available for everyone to see, which meant that when meeting close and non-close ties offline, the individual felt that they were unable to escape the identity of 'a person with mental ill health'. Similarly, there was a risk with anonymised forums also. If the person is unable to connect with, or does not feel that they have gained anything from their contact with online community support, then it is likely that they will not feel supported, and a detrimental experience could lead to further isolation and an increase in their mental ill health.

Overall, participants found that writing about their mental ill health online was a good experience and they felt supported by their peers or by their friends and family. Those who used social media felt that they may not be able to escape the label of having mental ill health after their disclosure. Those who used anonymised forums were able to keep their online and offline relationship separate, stating that they could be more honest and open than they would usually be face-to-face. Most of the participants had felt acceptance within in a community, and relief that there were others who felt the same as them.

7.3. Fear of Judgement – The Perfect Facebook Life

The influence of stigma was discussed in both phases when talking about the misunderstanding of mental ill health within society as a whole. During both phases, participants stated that the risk of upsetting other people offline through 'coming out' or disclosure drove them to seek support online. A finding of the research was that some participants believed that people offline did not understand mental health, which made it difficult for them (the participant) to function as they were constantly trying to live up to the unrealistic expectations of others. This

corroborates the research around mental ill health in the community, and studies have shown that those trying to be 'normal' in comparison to one's community whilst struggling with their mental ill health can be difficult and may lead to people withdrawing from society altogether (Cox, 2015; Jacob, 2015). One's identity is often intrinsically linked to their community and the accepted behaviours within it, hence the need for people with mental ill health who perceive that stigma is a barrier, needing to find a new one (Cohen, 2015; Corrigan, 2015; 2005).

The participants of my research touched upon this as an explanation for why others may not feel able to discuss or identify their own mental ill health on or offline. A barrier to disclosure on social media is that often people use their profiles to showcase family photos and what may be perceived as perfect lives. This could be construed as a place for only happy people, and may deter those seeking support for fear of negative judgement. One participant describes this as a 'wonderful Facebook life' (Sally, line 475, Phase Two). Phase One participants generally avoid this by staying anonymous, however, a few of the participants stated that they had met up with people that they had met online. This reflects findings by Gowen et al. (2012), who conducted a survey of young adults, finding that those identifying with mental ill health were more likely to build new friendships online. Spinzy et al. (2012) also found that adults with mental ill health were more likely to overcome barriers such as low income, fewer offline connections and being less likely to have internet access, than adults without mental ill health. This, along with my research suggests that online connections work well for people with mental ill health, and to be able to socialise with online connections offline as well, shows that using online communities works to reduce loneliness and isolation. This is important for policy makers and healthcare practitioners to take into account when considering the best methods for people accessing mental health support.

7.4. Information Seeking

People use the internet for information seeking, placing value on the type of information that they could gain through online communities, because the information from offline health practitioners was not enough. Policy makers and practitioners should take note that information found online is not just about the medical model, but is about understanding mental health from experts by experience. Participants of my research wanted to find out what happens to other people, what coping mechanisms they might use, and understand how they feel about their identity in terms of their mental ill health. Most participants said that the information given by

the GP was not enough, and that counselling was inadequate, or the waiting times were too long, but they were able to satisfy their need for information through specialist forums.

This aligns with a study by Shepherd et al. (2015), where they found that many people who went online to find support via Twitter, expressed their concern at the lack of understanding from a GP and their over-reliance on medication and CBT. This study also found that through seeking support online, users shared information about other forms of therapy that worked for them, but did so by explaining how it worked for them, understanding that it may not work for everyone (Shepherd et al., 2015). This shows that the knowledge gained from having mental ill health and discussing their issues in online support groups could offer a beneficial alternative to the medical model, much more in line with the idea of the Power, Threat, Meaning framework (see Chapter Two).

There is a fear that peer-to-peer support communities are potentially exposed to misleading information, however, Naslund et al. (2016) felt that after their research, the risks were outweighed by the benefits of being part of an online support community. Giles and Newbold (2013) found that there could be negative outcomes from erroneous information sharing, particularly on forums where people were encouraging one another to self-harm. This issue was raised in both phases of my research, as sometimes reading through other people's posts could trigger a negative response in the reader. Whereas there may be a negative side to online peer-to-peer support, my research ultimately supports the view of Naslund et al. (2016), that there are more benefits to using online support than risks.

People online provide necessary support to others who felt that they could not find support elsewhere. Naslund et al.'s (2014: 115) research into peer-to-peer support using social media, found that people with mental ill health usually go online to find support at time of 'significant personal challenges', so is likely to be at a 'critical point in their illness experience'. Therefore, connecting successfully with a group can be significant to the wellbeing of the individual. My research found that accessibility can be important for a person to connect with a group online. Ease of access, such as not having to sign in immediately to view the content, or going onto social media sites that are already set up to remember log in details, mean that users are more likely to go to these to seek support. A finding of the research was that social media is much easier to use as the format is familiar and most of the peer support forums have active users 24 hours a day. Ease of access to information and support was necessary for the participants, and

if they felt that it was difficult (as they did with offline information), then this would be a barrier.

The theme of peer support versus medicalisation seems to be commensurate with the idea of the expert patient (Fox et al., 2005). Phase One participants seemed to find that it was more helpful to gather information and seek support from other people who had a similar condition to themselves, whereas Phase Two participants seemed to discuss their health in terms of the medical model. Being informed by peers helped the participants to feel better educated about their mental ill health, and afforded them the opportunity to become part of a supportive community, reducing isolation and loneliness. The medical model appeared to be ineffective for those who tried it, and they ended up seeking online support, which they found more beneficial. Evans-Lacko et al. (2018) found that people do not always recognise the symptoms of mental ill health, and therefore may not seek medical support for the correct issues. Through participating in online communities, my study shows that people begin to understand their mental ill health through the experience of others, and they are therefore able to recognise some of the symptoms that they may have through the words of other people within the community.

Information seeking about mental health was a personal journey for each of the participants. All of the participants started with anonymous peer-to-peer support forums. Three of the participants became regular users, and one used the support forums as and when it was required, often depending on his own mood at the time. However, at the time of the interviews, none of the participants from Phase Two used peer-to-peer support forums anymore, but had all moved over to exclusively use social media. The move to social media, in the case of three participants, coincided with their decision to 'come out' (Corrigan, 2015) with their mental health issue to their social networks. My research therefore shows that using anonymised peer-to-peer support forums could be a stepping stone to feeling confident enough to share health information with friends and family.

7.5. Safe Spaces - 'People Like Us'

Communities can be influenced by social and political agendas, which can lead to 'othering' (Dorling et al., 2008; Tajfel and Turner, 1979). The creation of mental health as something that happens to 'other people' means that it becomes difficult to talk about issues that a person may be facing in relation to their mental health (Corrigan, 2015) as was the case in my study. As previously stated, this creates isolation and separation, and further contributes to the stigma

around mental ill health (Corrigan, 2015). This chapter has so far discussed how in the offline world people can struggle to disclose mental ill health and find adequate support. Even online, there may be negatives, although generally, the participants of my research found that people accessing online mental health support communities tended to have similar mental health issues or similar interests. Finding a community where the participants felt 'normal' was important to them, and they reported that this increased their self-confidence, and made them feel less isolated.

Some participants chose to use anonymous forums as they did not trust friends and family, or could not tell their friends and family in case it caused them hurt or anguish. My study found that this was because they sought out a community that did not obviously include people that they already knew, but people that they felt they could identify with – 'people like me' (P7, Reddit). Other research around online forums has also found that communicating with a group of people that are perceived to be similar can increase self-esteem, particularly for people with mental ill health who struggle to interpret normal social cues (Highton-Williamson et al., 2015). Communicating with people online can overcome feelings of anxiety or fears of social interaction, particularly when anonymised (Naslund et al., 2016; Schrank et al., 2010). Hou et al. (2015) found that anonymous social interactions online can create secure attachments, showing that there is a possibility that online interactions can be just as important as offline interactions. My research found that people felt that they were more honest and open online which helped to alleviate some of the anxiety felt about not being able to open up to anyone offline. This is important to consider, as other research has shown that many people may not go to their GP about a mental health condition due to fear (Henderson et al., 2017).

The benefits of opening up to an online community, particularly on social media is that it may encourage others to disclose their mental ill health, and to share their feelings. This creates a supportive environment, and one in which discussing mental ill health becomes normalised. This in turn may help with discussions offline. Several participants commented that they felt as though online peer-to-peer support forums had been a significant factor in how supported they felt with their mental ill health. This is commensurate with a study by Ma and Sayama (2015) where they found a positive correlation between using online support communities and recovery outcomes from mental disorders. The participants in my study felt that being able to express yourself without interruption was therapeutic, and the comments received as a result of their post were significant in helping to manage their self-esteem.

7.6. Consumerism

Silver and Johnson (2018) state that the internet is not only a great resource for unprecedented consumer choice, but it is also a place where people can research products before they buy. Similarly, users of online support forums have a vast array of choice (Carroll, 2014), and this makes them consumers of peer communities. Centola and Van der Riijt (2015) found that when choosing a social network online, people tend to only seek and read information that is already part of their belief system. This means that people may only read what they think is true from their general or social knowledge, but are unwilling to adopt new ideas. As discussed in Chapter Three, users of online support communities do not trust just any forum, but prefer to participate where other users are perceived to be similar to themselves (Fergie et al., 2015). Finding information online can be empowering for individuals, particularly if they are trying to avoid the stigma and labels of the medical model (Giles and Newbold, 2013). The idea that users of online community support are consumers, is repeated throughout the research literature, emphasising the choices that people have when seeking support for mental ill health online (Fergie et al., 2015; Giles, 2015; Dutton et al., 2013; Broom, 2005). My research found that around half of the participants that used anonymised forums discussed using multiple forums, often utilising a specific forum for a particular need. The consumer nature can mean that users expect too much from the forums. For example, some participants wanted to find a support forum that could fix their mental ill health, rather than support them to manage it themselves. There are also concerns around what happens when a user reaches an age where they are no longer allowed to be part of a community (from child to adult at 18 for example), meaning that those who have found a community that is supportive can be forced to start their process again. This transition may also occur when forums close down, leaving vulnerable people more isolated. This is a finding that needs further research.

My research participants offered advice for improvements to the information provided by support forums. One participant stated that sometimes the posts were too many or too long, and they did not want to read through lots of information, but would prefer a 'thought of the day' (Sally, Line 384) short, daily post. Participants felt that particularly at the beginning of a diagnosis, everything was hard work, and they did not want to work hard to find out more information. Some participants also felt as though there was not much help in choosing where to find information online in the first place, so used search engines to find a suitable community. GPs did not give information about NHS funded online support communities, and

all of the participants of Phase Two were unaware that these even existed. Health practitioners and policy makers should therefore take this into consideration when funding resources, as if solutions are being subsidised but unused, it is a waste of public spending.

7.7. Summary

Research over two phases and two types of community support forums, including multiple platforms has never been undertaken before, to my knowledge. My study has been able to add insights into previous research in either anonymised peer-to-peer support communities, or on social media sites (or social networking sites (SNS)). The sample sizes for each phase were relatively small, albeit within recommended guidelines of qualitative research (Charmaz, 2006), so the research findings should be understood as an interpretation of how some people use online community support for their mental ill health, rather than as a representation of all people who may use them. Nevertheless, the findings have been expressed in terms of how policy could be addressed in order to improve access to support, and have framed suggestions for healthcare providers to signpost individuals to online spaces where they may get immediate information, rather than wait for support through the traditional (and insufficient) medical model.

The key findings were:

- Social connectedness can happen within online communities, particularly when the user feels that the people in the group have a similar identity.

- People need to feel connected to others, without fear of judgement. This can be achieved in anonymous spaces, but not so much on social media.

- People need more information than is currently given by a GP when there is a new or changed diagnosis of mental ill health. This can be found through anonymous forums and can be a stepping stone to mental health disclosure offline or through social media.

- Users are consumers, and this means that the nature of online forums will change over time. Changes or closure of forums, mean that people could be left further isolated. However, there could also be improvements that would make it easier for people to transfer, and for this, further research is needed.

There are benefits to being able to choose which method of community support forums are used, but from my findings, I would recommend that policy makers and health practitioners signpost people to anonymised forums in the first instance, to help them make sense of their diagnosis using their peers as experts by experience. The majority of people find these forums useful in understanding how mental health may manifest, how it may affect offline relationships, and what coping mechanisms people may use. Having a new identity as someone with mental ill health can be difficult to come to terms with, and having a community of people who can normalise this, can help to navigate the journey, potentially becoming a stepping-stone to opening up to friends and family. The next chapter takes this a step further, discussing mental health literacy, how lay people approach community support and systems resilience.

Chapter 8: Discussion

There is no speaking about 'what happened' wholly apart from narrative and, in this sense, again, there may be no speaking about the 'real world' apart from narrative either. Indeed, what I want to suggest here is that, by and large – and I emphasize 'by and large' – this real world we inhabit is in fact a *storied* world. (Freeman, 2017: xxxvi).

8.1. Introduction

In this doctoral thesis, I argue that online community support for mental ill health can be beneficial. This was established through a research project that has used two different methodologies and multiple online platforms to understand what people gain from online mental health support communities. The study contributes to a qualitative understanding of research around online support communities. What the research shows is an in depth understanding of personal experiences in relation to how they make sense of their mental ill health, particularly non-medicalised understandings of how mental health can be present in everyday life. Online support forums help to 'fill in' the missing information that only people with experience of mental ill health can discuss and make sense of as a group.

In the previous three chapters, I have analysed the data gathered through the two methods, comparing the similarities and differences in Chapter Seven. The themes from Phase One were the Effect of Online Support; Safety Within Shared Identities; and Network Sociality. The themes in Phase Two were: The effect of offline relationships; Views of experts by experience and how they may define themselves; and How (mis)understanding mental ill health in the workplace can affect employment and employability. Both of these phases focused on relationships with others, identity and trust. Chapter Seven found similarities of three areas: Social Connectedness; Fear of Judgement; and Information seeking; and two areas with significant differences: Safe Spaces and Consumerism. In this chapter, I will draw upon the literature reviewed in Chapters Two and Three to discuss the implications of my research. This begins with a review of lay approaches to community mental health, followed by a discussion of mental health literacy, and concluding with a look at how systems resilience may help to improve health outcomes going forwards.

8.2. Mental Health Literacy

Jorm et al. (1997) surveyed over 2000 people, using vignettes to see if lay people could identify depression or schizophrenia. Their conclusion was that to be able to support people with mental ill health better within the (offline) community, mental health literacy should be improved (Jorm et al., 1997). More recently, Choudhry et al. (2016) conducted a meta-synthesis on published research about lay persons perceptions of mental ill health. They found that overall, mood disorders such as depression were seen to be minor problems, and people tended to under-estimate the impact that this could have on an individual. The majority of lay people within the studies felt that unless symptoms were very severe, medical intervention should not be sought, but social support within the community was a much better alternative (Choudhry et al., 2016). Generally, it was clear from the meta-analysis that mental health literacy in the main had not improved much in 20 years. In contrast, although with a much smaller sample, what I have found through this study is that lay people have found a way to educate themselves about mental ill health. Some people with mental ill health have sought like-minded individuals through online support forums, naturally forming a community of interest. These communities are sometimes utilised long-term, but are mostly used short-term for people to gain support, education about mental ill health and to increase socialisation.

A study by Shepherd et al. (2015) found that many people who went online to find support via Twitter, expressed their concern at the lack of understanding from a GP and their over-reliance on medication and CBT. This study also found that through seeking support online, users shared information about other forms of therapy that worked for them, but did so by explaining how it worked for them, understanding that it may not work for everyone (Shepherd et al., 2015). This shows that the knowledge gained from having mental ill health and discussing their issues in online support groups could offer a beneficial alternative to the medical model, much more in line with the idea of the Power, Threat, Meaning framework (as discussed in Chapter Two).

There is a reluctance within health professions to embrace peer-led interventions for several reasons, including a perceived lack of evidence, and not wanting to relinquish power from the medical model (Patel, 2017). Firstly, Davidson et al. (2012) felt that face-to-face peer support services for mental ill health were being encouraged as an alternative to more expensive interventions that may involve mental health professionals on a one-to-one basis, although

there was no robust evidence to support the efficacy of such roles. The lack of evidence meant that professionals were unlikely to take the method seriously when deciding possible healthcare solutions for patients. However, Farkas et al. (2018) believe that interventions have been improved since 2012, and peer support is no longer seen as the poor relation when it comes to health interventions. There are several RCTs that have been actioned in the past few years, showing the effectiveness of peer support in reducing self-stigma (Rusinova et al., 2014); a decrease in symptoms (Cook et al., 2012) and decreasing loneliness (Boevink et al., 2016). Peer support within online forums adds an extra level of uncertainty, and as of yet there are no RCTs that can support the effectiveness of online peer support communities on mental ill health. My research goes some way towards exploring the reasons why people choose online support and that they can be successful, however, due to the small sample size this cannot be generalizable in the way that an RCT with a larger sample size could be (there are qualitative and quantitative arguments to be had here that are not within the scope of this thesis).

Secondly, medical professionals are wary of the alternatives to the medical model and are keen to cling to the power that medicalisation over health issues has given to them over the last few centuries (Patel, 2017). To have the medical label removed and enable peer support or alternative support mechanisms such as self-help and online support, could mean that medicine becomes all but obsolete for people with mild to moderate mental health conditions (Allen et al, 2016). Peer support is not only beneficial as it is less costly, but it can also overcome structural issues as there does not have to be specific medical premises to attend, and access to services can be at the convenience of the person, within spaces that are easy to access in the case of physical disability, language barriers and so on. Online peer support could be even easier to access, although there are questions around ease of use and access to the internet that would need to be overcome in some cases. A solution to this could be that GPs are trained in directing people towards these alternatives, at least in the interim whilst waiting for IAPT interventions. This could potentially shorten the amount of time that people would need to access these services and ensures that the treatment would be personalised to the individual based on their needs and wants as stated in the Care Act (2014).

Phase One participants felt as though they were not given enough information about their mental ill health, and turned to online communities to help them to fill in missing information. GP's cannot fill in this information for patients, however, they could direct them to online communities, offline social groups or other sources of communities of people with mental ill

health, based on what the individual feels they can participate in. My research found that online communities may be a stepping stone for people to understand more about their mental health, before they move on to social media, or to disclosing to offline friends and family, although this needs further research.

Although all four participants in Phase Two, live in very different geographic areas in the UK, they all felt as though the GP was not adequately trained to deal with mental ill health. They also felt that there was a lack of personalisation, a lack of choice, they had to fight for their treatment, and they had to treat themselves as the treatment provided was not adequate for their needs. Some of the participants felt as though the GP(s) did not listen to them or sufficiently address their needs. This is a common complaint in the UK and there are calls for mental health to be taught to all general practitioners (Pereles et al., 2017; Ver Haak, 1988). One participant in particular felt as though they were not taking her seriously, although all of the participants felt as though the treatment given was not enough, or right for them. Through minimal training, healthcare professionals could give many more options to people with mental ill health, personalising their care and directing them to immediate support whilst waiting for NHS alternatives.

Despite the lack of lay mental health literacy (Choudhry et al., 2016), communities of interest have found a way to overcome their own lack of knowledge. Supportive communities online, through social media or anonymised forums, provide education that helps people with mental ill health fill in missing information around how health related issues can affect them in everyday life. This shows that alternative methods of accessing information and peer support can be beneficial. This will be explored further in the next section.

8.3. Online Peer-to-Peer Approaches to Community Mental Health

This section discusses the role of online communities in helping to support people with mental ill health. There have been arguments for and against the utilisation of social media, although the evidence suggests that access to online support communities is more beneficial than it is detrimental in the present study. The space online seems infinite, with new communities and social media sites appearing constantly. Despite this space being seemingly unlimited, it has boundaries. For example, although the World Wide Web is a global space, some of it is controlled heavily by the government (such as China or Cuba) (Economy, 2018; Marsh, 2018),

and much of it is in native languages, meaning that it is inaccessible to people who are not proficient in those languages (Chair and De Lannoy, 2018). Therefore, even the spaces accessed by people living in the UK are limited to participants and website hosting within countries that speak English (either as a first or subsequent language). This impacts on accessibility, but also limits the diversity of the communities.

Internet communities are utilised to bring people together who have common interests or medical diagnoses. Studies from as far back as 1998 (Kraut et al., 1998) have claimed that the internet was responsible for an increase in loneliness and depression, and more recently, reports by the McDaid et al. (2017) and Facebook (2017) found that social media can have a negative effect on wellbeing. As discussed in Chapter Two, the political and media propaganda, can influence the way that people feel about options offered to them such as support online, particularly around mental health and the stigma that is created through this media gaze (Whitley and Berry, 2012; Corrigan et al., 2003). Despite this, many researchers still believe that there are benefits to using online support (including social media) [Buehler, 2017; Pavalanthan and De Choudhury, 2015; Deters and Mehl, 2012; Ellison, 2007).

As my study showed, people online provide necessary support to others who may feel that they could not find it elsewhere. Naslund et al.'s (2016: 115) research into peer-to-peer support using social media, found that people with mental ill health usually go online to find support at time of 'significant personal challenges', so is likely to be at a 'critical point in their illness experience'. As found within my research, connecting successfully with a group can be significant to the wellbeing of the individual. As discussed in Chapter Five, if the person is unable to connect or feel that they have gained anything from their contact with online community support, then it is likely that they will have a detrimental experience and this could lead to further mental health problems. However, several participants commented that they felt as though online peer-to-peer support forums had been a significant factor in how supported they felt with their mental ill health. Ma and Sayama (2015) also found a positive correlation between using online support communities and recovery outcomes from mental disorders.

As discussed in Chapter Two, McMillan and Chavis's (1986) research into community support, found that the therapeutic effects of a sense of community are of vital importance. Phase One of my research echoed this, and found that there are several factors needed for the most beneficial outcome of therapeutic support within an online community setting for people with

mental ill health. These were the Effect of Online Support, Safety within Shared Identities and Network Sociality. If one of these factors is negative or missing, it can create mistrust of the community for the user of the forum, and can lead to further isolation and loneliness. There are now many thousands of Mental Health community support groups online, and they provide various methods of information and support such as offering advice of how to cope with specific health issues, or peer support groups (Wright and Bell, 2003). Preece (2000: 10) defined online communities as 'people who interact socially as they strive to satisfy their own needs or perform special roles such as leading or moderating. A shared purpose such as interest, need, information exchange or service that provides a reason for the community'. Online communities develop around a specific purpose, which is usually to bring people together to discuss specific health issues, meet new friends, or exchange information.

It is difficult to measure what exactly creates a supportive online environment, and often as forums change, they can alienate those who feel that they no longer identify with the other members. Users of forums such as PalTalk[35] have seen the forum change over time from an anonymous written forum to one that uses voice in 30 second blocks, to having live video streaming for premium subscribers. There are reportedly now over 100 million subscribers to PalTalk, making it one of the biggest online forums in the world, showing that people are clearly drawn to what it offers. Participants in my study felt that it was easier to trust people online, particularly based on their perceived shared identity as it is believed that they will not be judged by their peers as they would be by friends and family offline.

The social media phenomenon has been criticised for being the cause of some social isolation, however, much research is to the contrary, with Facebook in particular being successful in enhancing positive social contact (Grieve et al., 2013; Leung, 2013). A study of My Space (an online blogging platform), found that users created identities for themselves that were not entirely new, but a 'better' version of themselves (Lewis, 2010). There was no evidence to suggest that the virtual self was used to replace offline interaction, but rather that it served as a connection to others that have similar interests or experiences. PalTalk may offer a community that provides an alternative to talking about personal issues whilst taking away the feeling of isolation.

---

[35] PalTalk is a controversial forum that encourages participants to write abuse to one another.

Trolling has also been mentioned within media coverage of the PalTalk suicides[36], suggesting that the people who use the forum are causing trouble. Most forum trolling in the past has had little more consequence than bad feeling, although when trolling happens on support forums where others have created strong social bonds, the effect can be detrimental (Bishop, 2014). I found that where there are people using these sites that are not there to join in as part of the community, this can start the destruction of the community, and can further increase social isolation. There were some participants in Phase One of my research that felt as though they needed some social interaction, but did not feel able to seek this offline or on social media. Several of the participants stated that they thought it may not be healthy to only have online conversations. Phase Two participants also had a mixed view on whether or not it was healthy to have social contact only online, however all of the participants found that it was useful in conjunction with offline interaction, whether that was helping them to find the right words to use to describe their emotions to close friends and family by discussing it online first, or disclosing via social media to get a conversation going, as the quotes below show.

Users of anonymous online forums may also have a certain goal that is their motivation for posting a disclosure, sometimes seeking out an audience of people that they do not know in order to do so (Bazarova and Choi, 2014). The larger the audience, the more likely someone will respond (Norris et al., 2006). Phase One participants did not state that this was their goal, but preferred to talk about their forum use as a choice of 'fit' rather than their end goal. This fit was discussed as finding where they belonged, a supportive environment that was right for them at the time that they were looking for the support.

The negative connotations associated with online forums may come from a lack of understanding. The participants who were negative about people usually had a reason to be wary. If forums 'go bad' (P9) and they felt that they had to leave it and find another community. The participants stated that this can cause ill feeling and resentment. As discussed in Chapter Three, putting trust into a community can be a complex process, often starting with lurking in order to gauge public opinion (Litman, 2005), to ensure that they are going to fit in as part of the 'ingroup' (Schneider et al., 2012; Tajfel and Turner, 1979). If they do not think that they will fit in, then they will try to find one that fits their needs. The consumer nature of this choice means that some people may take advantage of those that are vulnerable by trolling or attacking

---

[36] There have been 3 live suicides via the video aspect of PalTalk. For further information see: https://www.thetimes.co.uk/article/builder-broadcasts-suicide-to-verbal-abuse-chatroom-paltalk-9dsgpqx52.

sites to gain personal information (Phillips, 2015; Rafferty, 2011; Herring et al., 2002). Through being pro-active, having secure, well-moderated forums, such attacks could become scarce. Further research in this area would help policy makers and the general public feel more secure when accessing mental health forums.

8.4. Community Psychology and Transformative Policy.

The unknown aspect of utilising online community support means that there has been negative media coverage (Facebook, 2017; Whitley and Berry, 2012). Policy makers need to start embracing online support mechanisms as a cost effective way of helping people who need support with their mental ill health. Workplaces also need to start engaging with best practice around supporting people with mental health issues, as this has been shown to enhance wellbeing and production, and cut down on lost work days.

The phenomenal rise in social media use from 35% in 2008, to 72% in 2013 (Pew Research Internet Project, 2014) is credited by the participants in Phase Two for creating a platform where people feel able to be open and honest about issues, such as mental health, that were previously hidden due to stigma (Bouiliane, 2015). Benefits of opening up to an online community, particularly on social media is that it may encourage others to disclose their mental ill health, and to share their feelings. This creates a supportive environment, and one in which discussing mental ill health becomes normalised. This in turn may help with discussions offline. In Phase One, the theme of online peer support provided reasons why users of anonymised forums felt that online communities were more supportive than offline support groups. This was due to feeling less inhibited by the space so they were able to discuss their mental health in anonymity. The participants of my research also stated that they felt as though they had found people 'like me' (P7), and that it was more comfortable for them to talk about their mental health with people that understood. Latest UK figures show that 1 in 6 adults has a current mental health problem (McManus et al., 2016). Although more money is promised to help resolve the current mental health 'crisis' (NHS Digital, 2017), there do not seem to be any radical solutions being offered. The five-year forward plan set out an agenda to put in place more IAPT therapists, however, there is still a long waiting list to see a mental health specialist despite this move (Independent Mental Health Taskforce, 2016). The participants of Phase Two also did not mention IAPT, even though this would have been available to them. They still had

to negotiate lengthy waiting lists to see a therapist and were offered medication for depression. 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 formal service support, so it is vital to understand the social factors that shape the way people may seek support in different formats.

Participants in my study mainly stated that they were using an anonymous forum as they did not trust friends and family, or could not tell their friends and family in case it caused them hurt or anguish. This meant that some of them sought out a community that did not obviously include people that they already knew. Identifying with a group of similar people can build self-esteem (McKenna and Bargh, 1998), particularly for people with mental ill health who struggle to interpret normal social cues (Highton-Williamson et al., 2015), and communicating with these people online can overcome feelings of anxiety or fears of social interaction, particularly when anonymised (Naslund et al., 2016; Schrank et al., 2010). Hou et al. (2015) found that anonymous social interactions online can create secure attachments, showing that there is a possibility that online interactions can be just as important as offline interactions. Comments from participants in Phase One backed up these findings, meaning that there could be ways of utilising support groups such as these for future mental health support (Naslund et al., 2016).

8.4.1. Are There Dangers to Using Social Media?

There are many arguments around the medicalisation of mental health, with current political discourse torn between self-help and a reliance on medication and IAPT in the UK. I argue here that my research shows that there could be a benefit in training medical and healthcare professionals to signpost to various services, including online support communities, in an effort to increase personalisation of services and ensure that there is instant access to peer support rather than putting people on lengthy waiting lists. Phase Two participants did not discuss the consumer nature of online communities, but through their discussions, brought up mainly Facebook as their social network of choice. This was somewhat different to my expectations (having asked for participants who have used online support forums), however, the majority described in detail how using Facebook for their mental ill health disclosure helped them. 'Facebook, whilst it is a public forum, is your own space, in your own private journey' (Toby, line 273). This quote may appear contradictory considering that most Facebook users have an average of 338 friends (Pew Internet Research Project, 2014), although much research has

found that the majority of Facebook friends are known as non-close, or weak ties. This means that they can be acquaintances, or people from the past that are no longer in the same geographical area for example (Ellison et al., 2011). Most significantly, research into social networking sites (SNS) such as Facebook, show that these weak ties can be beneficial to those with health worries (Rozzell et al., 2014; Wright et al., 2011; Wright and Miller, 2010). Those using non-anonymous platforms do not necessarily want to build new connections, but want to preserve or develop existing social friendships that had previously been created offline (Ellison, 2011; Ellison et al., 2007). SNSs afford users the ability to nurture friendship whilst also allowing them to become mobilized (Tang and Lee, 2013; Gil de Zuniga et al., 2012). This means that friends no longer have to be offline or in the same geographical location in order to been seen as present in our social support system (Bazarova and Choi, 2014).

Friends and family proved to be a large part of the support networks that the individuals had, particularly those who were in contact via social media. It did not matter if they were close geographically, as long as they responded positively when the individual posted about their mental health. The response did not have to be on social media either, in the case of one participant, a friend from several hundred miles away phoned him as soon as he could after reading his 'coming out' post, and came to stay for two days to help. Without social media, that interaction may never have occurred.

Consequently, some participants felt that people posted too much personal information, stating that there are posts that some people should not share on a public forum. One participant felt that people like this are leaving themselves open to abuse from exploitative people. Participants shared concern that the negative judgement of people posting about their mental ill health online could be damaging to the individual. Angel was worried about the stigma of mental ill health, fearing that her posts may mean that people would judge her negatively. Despite this fear, she felt that by challenging this type of stigma and discrimination that she would post anyway. Naslund et al. (2016) believe that by challenging stigma in this way it can provide hope to other people who are seeking help and support with mental ill health.

Some participants who used social media sites to out their mental health problems found that they were still intolerant of others who did the same. In Hayes et al.'s (2016: 7) study, attention seeking individuals in online support forums were named 'chronic bitches'. These types of support seekers were often too emotionally needy, and as a result ended up with fewer 'friends'

in their social network support system. General status updates that are woeful or cryptic may mean that the person is seen as "whingy" and friends may not see a cry for help, potentially leaving the poster isolated and vulnerable. Phase One participants also found that this was an issue on some sites, but they would quickly move to another forum if they felt that it was a problem.

The participants in Hayes et al.'s study (2016: 7) stated similar intolerances, saying that they were 'sick of GoFundMe requests' and that it became embarrassing if someone asked for support but there were no responses. My research showed that there could be an apathy around over-sharing, and that somehow there may be an unspoken level of acceptable sharing within non-anonymous forums. This kind of post may also affect other people in the community, to the point where they feel that they must stay away in order to protect their mental ill health, the antithesis of what the support community is trying to achieve. Another negative issue was that some participants felt that expectations of them as part of a supportive community, were difficult to uphold. One participant struggled with a friend that often posted about her mental health via Facebook. On Facebook, it is advertised how many 'friends' a user has on their personal page. This particular person kept their friendship group (and therefore support community) to just a few people. Because of this, the participant felt as though it was his duty to offer supportive comments, even when he felt as though it was quite labour intensive.

The influence of other people is discussed in both phases when talking about the misunderstanding of mental ill health within society as a whole. During both phases, participants stated that the risk of upsetting other people through 'coming out' or disclosure drove them to seek support online. Some participants felt that people offline did not understand mental health, which made it difficult for them (the participant) to function as they were constantly trying to live up to the expectations of others. The stigma of mental health could be one explanation for this, as the idea of being 'abnormal' places barriers between 'normal' society and those with mental ill health (Cohen, 2015; Corrigan, 2015). The participants touched upon this as an explanation for why others may not feel able to discuss or identify their own mental ill health. A barrier to disclosure could be that those with mental ill health may feel as though social media is for displaying happy photos and perfect lives. The pressure of having to keep up the pretence of a perfect life could prevent people from seeking help and support in this environment for fear of negative judgement.

Community psychology is not only concerned with the community itself and the social and political issues that affect the way that people are treated within those communities, but it is important to utilise community psychology to influence change and ultimately influence policy. There are two particular issues brought up by my research, that I believe are opportunities for activism. One is to get GPs to recognise the use of community peer support online, and to start suggesting the anonymous forums for people who come to speak to them about mental ill health, and the second is for workplaces to recognise the benefits of talking openly about mental ill health. There are other issues such as the wider problem of increasing mental health literacy, which I believe can be achieved through educational programmes in schools.

Community psychology is not only concerned with the community itself and the social and political issues that affect the way that people are treated within those communities, but it is important to utilise community psychology to influence change and ultimately influence policy (Milburn, 2016). There are two particular issues brought up by my research, that I believe are opportunities for activism. The first is to train GPs to recognise the use of community peer support online, and to start suggesting the anonymous forums for people who come to speak to them about mental ill health, and the second is for workplaces to recognise the benefits of talking openly about mental ill health. There are other issues such as the wider problem of increasing mental health literacy, which I believe can be achieved through educational programmes in schools.

Community Psychology as a discipline tends towards a clinical psychology perspective in the UK currently. This research goes 'back to basics' in terms of utilising Rappaport's (1977) framework. The idea that CP is a holistic approach to health is important for the discipline to remember. By utilising a multi-disciplinary approach, encompassing the social, the political and psychological evidence, Community Psychologists can affect change. One issue with online research is that it is difficult to understand the effect of the social and political if there is a lack of research that focuses on health and wellbeing community support systems. What I would like Community Psychologists to take from this research, is that communities online should be understood as communities in their own right, with nuances and actions that occur

as a result of these complex relationships. I will discuss the issues I have identified in more detail in the following pages.

8.4.2.1. Social Prescription for Anonymous Online Peer Support Forums

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.

The Department of Health (DOH, 2001) found that adults with chronic conditions and disabilities often benefit from peer support (something it promotes through its 'expert patient' peer scheme). It has been found that adults with chronic conditions and disabilities often benefit from peer support (Gilburt et al, 2008; DOH, 2001) but through fear or lack of knowledge of available resources, they can be unable to access this. Isolation from meaningful community engagement often leads to loneliness and further co-morbidity issues such as depression or substance misuse.

People with mental ill health are at risk of loneliness and isolation as a result of withdrawing from the social world, due to stigma, illness or lack of mobility, however the recommended cure for people with mental ill health is socialisation. Societal attitudes towards mental ill health are currently a matter of political and health narratives in the UK. Understanding the effects of community on an individual is vital to enact social change and attitudes towards mental health. Communities can be influenced by social and political agendas, which can lead to 'othering' (Dorling et al., 2008; Tajfel and Turner, 1978). The creation of mental health as something that happens to 'other people' means that it becomes difficult to talk about issues that a person may be facing in relation to their mental health (Corrigan, 2015). This creates isolation and separation, and further contributes to the stigma around mental ill health (Corrigan, 2015). The influence of people in the offline world can mean that even people with close social ties can struggle to disclose mental ill health and find adequate support. Even

online, people may have a negative influence, although my research found that generally people frequenting online mental health support communities tend to be like-minded and help others to feel normal. This can increase self-confidence, and reduce loneliness and isolation.

It is still unclear how much of the UK population have access to, and are able to, take advantage of the help available online. For those who are signposted to online mental health services and information (often via the NHS) who are not able to fully utilise this (through illiteracy or lack of support), there are considerable ongoing issues that remain unaddressed by the UK Government and local health and social care provisions. This could ultimately lead to an increase in isolation, morbidity and suicide in those with mental health problems, rather than a solution. However, the benefit to those people who can access online services could greatly outweigh any negatives.

8.4.2.2. Problems at Work

Work environments are one area that has recently come into focus as an area that needs significant support when dealing with mental health (Stevenson and Farmer, 2017). An EU level estimate of cost of lost productivity to mental ill health, and associated health costs, is currently 617 billion Euros a year (Matrix, 2013). The UK alone estimating costs in the region of £105 billion a year (DoH, 2016). In fact, the increased pressure that some participants faced, were the catalyst to go and see the GP, resulting in her being signed off work for the remainder of her notice period. Another participant's mental health manifested itself in a different way, he was given too much freedom within his position, and no one noticed that he was struggling. He stated that there were times that he turned up drunk or that he did not turn up at all, and still no one realised that there was a problem. Alcohol misuse is common with male workers in particular (Jensen et al., 2010; Head et al., 2004).

Despite workplace policies being updated in Education and Local Authorities in particular in the UK (Time to Change, 2017), the understanding of how to handle staff mental ill health is still something that many managers do not know how to handle. A recent survey by the Health and Safety Executives (HSE) found that the three worst sectors for stress, depression or anxiety, were: Human health and social work activities; Public administration and defence; and Education. And in the 2012 Labour Force Survey (Figure 10), the most cited causes for stress,

depression or anxiety were work pressures, including too much responsibility, and lack of managerial support (HSE, 2017).

Industries with higher than average rates of stress, depression or anxiety, averaged 2014/15-2016/17
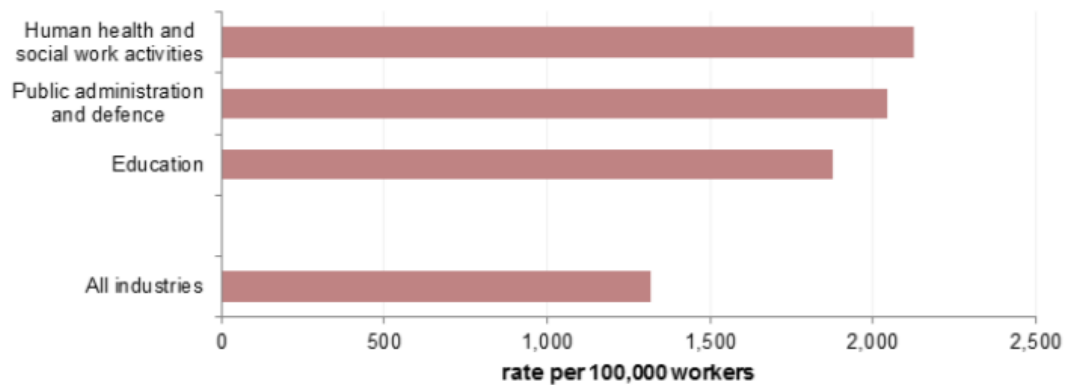
Figure 10 Labour Force Survey (HSE, 2017).

Two participants in Phase Two are prime examples of those in the high rates of stress categories, however, they were both forced to feel that there only option was to leave their employment. Brown et al. (2016) found that the level of trust when discussing mental ill health is of vital importance, if trust is lost, it can exacerbate mental health issues, and in the case of the workplace, can lead to hostility and even the loss of income for the person with a mental health issue. However if trust is fostered, then the result is likely to be positive, and the person is more likely to feel valued and able to come back to work sooner or feel more comfortable in their work environment. Therefore, it is important that employees and employers can discuss a variety of methods in order to get the best possible outcome for the individual (Allen et al., 2016).

However, work may also been seen as part of the solution to combating mental illness. A longitudinal study found that although being employed was synonymous with generally better health than being unemployed, those who had the highest psychosocial issues (high stress, low autonomy over work tasks for example) were only marginally better, but showed a greater level of mental health declination over time (Butterworth et al., 2011). LaMontagne et al. (2007) reviewed the cost benefits of putting in a management system for ill health, and found that interventions were worthwhile in all organisations surveyed, with lost workdays due to illness reduced, and the negative effects of stress were also reduced.

A recent UK Government report found that well paid senior manager and directors were less likely to have severe mental ill health, or to die by suicide (Stevenson and Farmer, 2017). The most at risk people are those on temporary or zero hours contracts with no stability of household income, who are generally those on relatively low pay (Eurostat, 2017). Within the EU as a whole, the numbers of people on temporary (or fixed term contracts) varies greatly, with the average being 14.2%, but ranging from 71% in Slovenia to 1.4% in Romania (Eurostat, 2017).

Therefore, the focus in social change needs to revolve around a shift in attitudes in providing long term employment, rather than fixed term contracts. This should be prioritised politically, helping those who have lower incomes feel more secure about employment. This is not possible in all organisations, however where it is being used as an mechanism for cheap labour, measures should be put into place to prevent this. In terms of my research, political priorities should focus on supporting people in the workplace when they have disclosed mental ill health. Managers should be supported by providing them with training on best practice of dealing with workers with mental ill health. Research has shown that if the correct action is taken, that there are fewer lost work days, and staff are more productive overall.

8.5. Summary

Communities are important for creating a sense of belonging, identity and increasing socialisation. My research supports existing literature that states online communities work in the same way. Policy makers and health professionals should embrace online community support as a simple, easily accessible and cheap solution to finding mental health support for some people, at least whilst on the waiting list for existing medical model solutions such as IAPT.

Insight into the lack of mental health literacy shows how important human resource development in community psychology is to eliminate the idea of the other and provide a space for talking about mental ill health in the same way that the participants of Phase Two appear to be able to, in an open, honest and non-judgemental way (Choudhry et al., 2016). However, both types of supportive community appear to be beneficial if compared to no community at all, or to an offline community that the individual with mental health fears will be negative (Thornicroft, 2015).

This research has shown that online support could be effective as peers can fill in missing information that cannot be provided through medical consultation. An understanding of how mental ill health can affect a person on a day-to-day basis is an important step in coming to terms with mental ill health, and could be a stepping stone to further disclosure, including to friends and family members. The next chapter concludes with how the research contributes to existing knowledge, and what implications this should have for the future of mental healthcare.

Chapter 9: A Conclusion

9.1. Introduction

My original contribution to knowledge is that peer-to-peer online communities enable people to construct their own mental health narrative by combining the lived experience of others with their own experience. By doing so, people can escape the social labelling (Link et al., 1999), the stigma (Gronholm et al. 2017), and recreate a sense of self out of, or detached from, the medical and social discourses (Cox, 2015; Jacob, 2015). This informs the gaps in the health pathways as people's needs or impediments to health and/or accessing health services. From a community psychology perspective, sociality and socialisation are needs that contribute to a sense of self through belonging and affiliation. This study highlights how online forums can restore sociality and how online social processes and online communities help people to clarify their own mental health narrative. As such, online forums and communities contribute to and are a new aspect of the health pathway. Hence, from an ethical perspective, this study emphasised the empowerment and equity that online forums can help achieve, overcoming difficulties such as isolation, lack of support and rurality.

While conflicting evidence is published around online communities (in particular social media), this study favours the benefits and the positive impact of these forums. My research shows that online anonymised communities and social media communities can be effective in their support of people with mental ill health. The research questions forming this thesis are significant in terms of understanding how people view their mental ill health, and how this can help them to make the most of online communities to support them. Mental ill health is currently a term that UK policy makers and professionals alike are trying to understand, in order to improve the current mental health 'crisis'. This crisis is so termed as currently 1 in 4 people are expected to have mental ill health throughout their lifetime, and 1 in 6 people in the UK are currently receiving some form of medical support for their mental ill health (McManus et al., 2016). This is an expensive issue, which until recent years has been vastly underfunded. My research was borne out of the need to find inexpensive alternatives to the medical model. A large percentage of the UK now has internet access, with 54% of those accessing social media platforms on a daily basis. New communities have been emerging on social media and on forums that are specifically aimed at peer-to-peer support for people with ill health, whether it is cancer, fibromyalgia or mental health. These are accessed by thousands of people,

anonymously and non-anonymously. Although there has been research around these peer-to-peer forums, there was a need to research multiple platforms and use multiple methodologies to enhance understanding about the needs of people that are part of these communities, and could they be used as a successful and cheap alternative to medical interventions. To demonstrate how I concluded that online peer-to-peer communities are effective, I will address the research questions set out at the beginning of the thesis and the recommendations that I have for future research. The research questions were:

1. What is mental health to experts by experience?
2. How do people with mental ill health feel they are being viewed within their communities?
3. Why do people with mental ill health look for support online?
4. In what ways are online mental health communities supporting people with mental ill health?

9.2. What is Mental Health to Experts by Experience?

The study found that people struggled to understand the medical model of mental ill health. This could be to do with the lack of time or understanding by the GP who is usually the first point of contact for people with mental ill health. The solutions offered by GPs are usually only medication or cognitive behavioural therapy. Alongside this, in the UK, people diagnosed with illnesses are encouraged to become patient experts (Allen et al., 2016) which allows them to find out more about their condition and request appropriate treatment. Service users need to feel confident when discussing their condition with medical doctors, making them feel empowered when it comes to decision making (Allen et al., 2016). When it comes to mental health diagnosis, my research found that there is a lack of information about how mental health affects the individual in terms of their everyday lives, relationships with friends and family and the impact it has on their ability to work.

Mental ill health is synonymous with isolation, a lack of supportive networks and loneliness (The Care Act, 2014; Steptoe et al., 2013; Corry, 2008). My study found that people do not necessarily understand the impact that their mental ill health has had on them until they have already isolated themselves from their community. Through searching for information online, many people find that they identify with others that offer information on peer-to-peer support

forums. Identity is a key concept that is fundamental to the wellbeing of people with mental health problems. People develop a sense of self by comparing themselves to others with confidence being derived through this identity and seeking out others who share the same behaviours (Festinger, 1954).

9.3. How do People with Mental Ill Health Feel they are Being Viewed Within their Communities?

People with mental ill health still feel that there is a problem with social stigma. Experiences in the workplace are particularly bad. The findings during Phase Two, found that people in professional occupations that have disclosed mental health disorders to their employers generally feel as though they then become bullied by their manager. This is often through nasty comments aimed at them in meetings, or through an increased workload which leads to time off sick, or resignation. Despite policies being updated in these particular areas in the UK, the understanding of how to handle staff mental ill health upon disclosure is still something that many managers do not know how to handle (Time to Change, 2017). My research found that even where workplaces put measures in place, people are still unclear about their roles. There is more research happening in this area which will be helpful to managers when talking to people who disclose mental ill health, and also identifying problems as they manifest instead of waiting until symptoms have become severe.

Almost all participants in both phases felt that their relationships with friends and family had deteriorated due to their mental ill health. This was partly due to the withdrawal of themselves from society, but also because the person with mental ill health felt that their friends and family would not be able to understand, or would take it personally. Those who posted about their mental ill health on social media found that friends and family seemed to be very supportive.

9.4. Why do People with Mental Ill Health Look for Support Online?

People in my study stated that they went online to seek information about mental health that could help them to understand how they were feeling. They also went online to talk to people like them, in order to become part of a community where they felt normal. Those that chose to 'come out' on social media found that it was easier to write their feelings in a post, than to tell friends and family individually, and likewise, those on the anonymised forums felt that talking

to like-minded people about their mental health made it easier to talk to people about their ill health offline. Online community support groups work in a variety of ways, bringing people together who have mental ill health. People want to use anonymised support forums for information gathering, to find people that appear to be like them, and to feel less isolated. People use non-anonymised platforms, such as social media, to alert friends and family to their mental ill health and gain support without having to physically socialise.

9.5. In What Ways are Online Mental Health Communities Supporting People with Mental Ill Health?

Social representations of mental health are embedded within communities, and this impacts on how people with mental ill health relate to others within society. The wide use of online communities and social media means that there is now another way to find people who have similar interests and experiences, and create communities virtually to enhance social connections and reduce loneliness. Comparable to the findings of McMillan and Chavis (1986), I found that the therapeutic effects of a sense of community are of vital importance and a careful balance of several factors is needed in order to secure this in an online community setting for people with mental ill health. If there is one of these factors missing, it can create mistrust and even lead to further isolation.

By assessing the impact of online support networks and concepts of society through the lens of community social spaces on 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 (Steptoe et al., 2013; Corry, 2008). The notion of offline community spaces means that people can be reluctant to look at alternatives, such as online sources. 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.

Both phases of the study highlighted that some people would rather use online community spaces to speak about and make sense of their mental ill health. Sometimes this is before they go on to speak to friends and family, and others prefer to never speak to people about their mental ill health offline. As with any community, online communities are diverse, and it was clear that each person used online support in different ways. Through using two research methods, my research gave a broader perspective than research that uses only one method. This was recently highlighted by Hayes et al. (2016) and Naslund et al. (2014) as a gap in the literature.

9.6 Limitations of the Research

Small scale qualitative research is difficult to generalise to the whole population; however, the personal nature of mental ill health needs to be understood on an individual level before research can be produced on a more industrial scale. My research highlights that there is a need to look further at multiple platforms and to use multiple methodologies to gain an in-depth knowledge of why people use online support communities, and what are the key aspects that help people within these. There is a growing importance of online communities as a means of connecting and interacting (Naslund et al., 2014), although researchers often struggle to identify the best way to research this. Researchers such as Markham (2004) believe that there are unique opportunities to research online communities, and that through not having visual cues, we may learn something new about how humans interact. It certainly seems that participants within online forums were more forthcoming when they were anonymous in Phase One, than those in Phase Two, where a large percentage of those who had committed to be interviewed pulled out at the last minute. Obviously it can never be known how many anonymous people were going to answer the questions and then decided not to, but there were more participants in Phase One regardless. The on and offline 'worlds' 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), rather than expecting people to meet face-to-face. These different fields then require different research methods, or the adaption of existing methods in order to revolutionize community psychology and social theory research (Kozinets, 2010).

This leads on to the idea that virtual ethnography may not be the best way of researching online communities, especially when time is short. I do not believe that becoming immersed in the community support forums would have elicited any more, or any richer information. This was

because the people who wanted to put forward their answers to my questions had nothing to gain from participating in the research unless they had an opinion to put across. This reflects Hine's (2010: 10) idea of being a 'Tolerated observer' - a presence that is apparent to the participant, but does not hinder the information given. Hine (2008) also stated that the researcher should not expect to become a member of the group, as that is somehow cheating the participants into believing that you are one of them in a space where they have learnt to trust people and feel as though they are normal. Ethical perspectives may differ at this point. Some believe that everything online is in the public domain, and if you do not need log in details then the information is eligible for research without seeking consent from the person who posted the words. Salzmann-Erikson and Eriksson's (2012) study used archival data from an online forum, arguing that the research was not considered to be on human subjects (as it was from the past), and is in the public domain, so does not need consent. However, there are many researchers who disagree with this perspective (Flicker et al., 2004; Hudson and Bruckman, 2004).

The benefits of virtual ethnography are that it offers many new opportunities for insight into online consumerism, online support networks, health seeking behaviour and the effects of social media on health.

9.6.1. Reflections on the methodology

A PhD is about developing as a researcher and gaining knowledge to apply in academic life beyond the thesis. I used virtual ethnography as I wanted to use innovative and forward thinking methodology to conduct online research in the future. I had never used virtual ethnography before, and my learning journey has been detailed in this thesis as one of trials and tribulations that were overcome. I wrote a paper for SAGE Research Methods on the process (Heyes, 2017), focusing on helping future PhD students navigate the pitfalls of trying to engage in virtual ethnography. Of great comfort is that many other researchers have also told me that their research did not go smoothly either, and I believe it is right to help others to learn, so that they may recognise that research is not easy, but is achievable.

During my transfer viva from MPhil to PhD, I was fortunate enough to have Professor Cathy Urquhart as one of my examiners. She suggested that I try to use grounded theory for my next phase. I had considered using grounded theory for my first phase, but did not feel as though I

understood it enough. Cathy assured me that I would be able to conduct my research using this methodology, and that she had helped many nervous PhD students through the process. She also assured me that low level theories do not have to be ground breaking, and that if the research does not result in theory, then this does not matter either, it is the process and the potential to create theory that is important (although not really to purist Glasserians!).

I invoked the principles of grounded theory throughout phase two. Each interview was transcribed immediately, and I used Nvivo to go through and make notes, that then became codes, that then became suggested themes. After each interview, my themes would alter slightly, however, I found three strong themes from the beginning. The decision to stop after four interviews was partially time driven, but was mainly because of the amount of data collected. The participants had all been keen to tell their stories, and if I continued to collect more stories, then I did not think that I would be adequately reflecting their voices.

I did not feel as though I could clearly define a low level theory from the research and analysis that I had conducted. I had achieved my personal learning goal, in that I felt I understood how to conduct grounded theory as a method and as an analysis tool. Appendix C shows some of the notes that I made in order to try and 'force' a low level theory, however, I felt that as much as I tried, there was no theory that I was happy with, or that reflected what all of my participants in both phases had said. In Appendix C, figure 12 (which also appears in publication in Appendix G), I made a rudimentary attempt at a low level theory for Phase One. I would like to test this out further, utilising other platforms such as social media (non-anonymised forums), again using virtual ethnography. It is a very simplified version that does not take into account network sociality, or non-anonymous forums, hence it was not included in the final thesis. After deciding not to develop a low level theory, it was suggested by my supervisors that I took out mention of grounded theory and continued with phase two as a thematic analysis. I rejected this idea as I wanted my PhD to reflect my journey, and my journey was that I conducted a phase using grounded theory, and then I recognised that I could not produce a theory from the research. Rather than pretend I did not have this experience, I felt it was important to show it, and I have learnt a great deal in the process.

9.7. Recommendations for Future Research

During the Autumn budget on the 29th October 2018, the UK Government announced that there would be an extra £2 billion a year to spend on mental health. However, there have been concerns raised that it is not just money that is needed, but there is a fundamental shortage of skilled staff within the NHS that can deliver mental health services, which will continue to get worse as Brexit[37] happens in March 2019. **My recommendations for future research therefore do not cost money**, although there is an assumption that people are already conducting research in the area of online communities, social media and mental health, based on the amount of journal articles published within the last year, and mental health funding that has been distributed.

- Social media is not just used by young people, and policy makers should acknowledge that the effects of social media are also felt by people over the age of 24. Research should be conducted using a wide range of ages, not just the most prevalent current users. This bias towards researching only younger people could be a form of indirect discrimination and could leave a large population of people invisible.

- Forums (particularly on social media) need to have an authentication process, then people can choose whether they want to access forums moderated by professionals or peers. This can be built in to the model of the social media platform, and there is current research on the use of algorithms that detect mental distress (Card, 2018). These indicators may however change frequently, so research should be conducted regularly to address this, and become a built in part of the duty of care that social media platforms have to their users.

- The NHS should refrain from advocating unregulated apps and forums, and instead recommend properly researched forums and apps. These then need to become widely available through GP surgeries.

- The needs of minority groups should be taken into account by policy makers and practitioners. For example, it should be considered how minority groups are defined, how individuals want to be defined (if indeed they do), and that they have access to mental health professionals that they can identify with where necessary. Mental health

---

[37] Brexit is the colloquial term used for 'Great Britain's (actually the UK, but I do not think UKexit rolls off the tongue in the same way) 'choice' to leave the European Union. I hope in years to come that this will be an amusing term that came from a decision overturned based on its sheer madness.

professionals recruited from more diverse backgrounds is a necessity (Jeste et al., 2009). Research should be conducted around why there are not more BAME mental health professionals and the identified barriers should be actively removed.

9.8. Summary

Using two phases and two methodologies to understand how online communities can help to support people with mental ill health, has contributed to the current research. The significant original contribution of this research was that it went beyond understanding the social and medical issues associated with mental ill health, finding that people need to 'fill in missing information' as a medical diagnosis and lay mental health literacy is not enough (Choudhry, 2016). Online peer-to-peer support communities are useful to help with filling in the missing information, as people tend to share their thoughts and feelings which helps others to realise how their own mental health is affecting them. This also helps individuals to make sense of their feelings and find support within a community of like-minded people. This is turn helps to reduce loneliness and isolation, which will help to decrease mortality.

These research findings have already had interest through my article on The Conversation about social media (Heyes, 2018: Appendix D). This article has also been printed in The Times, Malta, and translated into Spanish, picked up by a Spanish newspaper and widely read (See Appendix E). I also guest lectured on The Student Room forum where there have been over 350,000 hits to their mental health forum since May 2018. Insights from people with mental ill health who participated in the discussion, corroborated the findings from my research[38] (see Appendix F). However, the findings of the study could have further reaching implications, as using online peer-to-peer communities could provide affordable alternatives to medication and lengthy counselling waiting lists. A larger study (a randomised control trial or RCT) needs to take place involving people that utilise online peer-to-peer support communities, comparing them to people that are put on medication or a waiting list, to measure the outcomes in a way that in generalizable to the population as a whole. This could then be replicated in other countries around the world, and when considered alongside in-depth qualitative research, could help to identify the best methods of using technology, to help people struggling with their mental ill health.

---

[38] The discussion is closed, but can still be found on The Student Room www.thestudentroom.co.uk.

References

Adler, N.E., Cutler, D.M. Fielding, J.E., Galea, S., Glymor, M.M., Koh, H.K. and Satcher, D. (2016). *Addressing Social Determinants of Health and Health Disparities*. Discussion Paper, Vital Directions for Health and Health Care Series. National Academy of Medicine, Washington, DC. https://nam.edu/wp-content/uploads/2016/09/addressing- social-determinants-of-health-and-health-disparities.pdf.

Ahlbrant, R. S., and Cunningham, J. V. (1979). *A new public policy for neighbourhood preservation.* New York: Praeger.

Al-Khouja, M. and Corrigan, P. (2017). Self-Stigma, Identity, and Co-Occurring Disorders. *The Israel journal of psychiatry and related sciences*. 54. 56-60.

Allen, D., Braithwaite, J., Sandall, J., and Waring, J. (2016). Towards a sociology of healthcare safety and quality. *Sociology of Health and Illness.* 38:2, 181-197

Al-Saggaf, Y. and Begg, M. M. (2004). Online communities versus offline communities in the Arab/Muslim world. *Journal of Information, Communication and Ethics in Society*. 2:1, 41-54

American Psychiatric Association (APA). (2013). *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-5.* Washington, DC: American Psychiatric Publishing.

American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders.* Washington, DC: American Psychiatric Publishing.

Androutsopoulos, J. (2008). Potentials and limitations of discourse-centred online ethnography. *Language@ internet*. 5:8.

Argyle, M. (1969). *Social Interaction.* London: Methuen.

Asthana, S. (2012). *Variations in access to social care for vulnerable older people in England: Is there a rural dimension?* Commission for Rural Communities. [online] [accessed 4.4.2018] http://webarchive.nationalarchives.gov.uk/20130702113826/http://www.defra.gov.uk/crc/files/Asthana-Variations-in-Social-Care-Final.pdf.

Baker, C. (2018). Mental health statistics for England: prevalence, services and funding. Briefing paper no. 6988. London: House of Commons Library.

Balestra, M., Zalmanson, L., Cheshire, C., Arazy, O. and Nov. O. (2017). It was fun, but did it last? the dynamic interplay between fun motives and contributors activity in peer-production. *Human-Computer Interaction*. 1:1.

Baltar, F. and Brunet, I. (2012). Social research 2.0. Virtual snowball sampling method using Facebook. Internet Research. 22, 57–74. doi:10.1108/10662241211199960.

Bamberg, M. (2006). Biographic-narrative research, quo vadis? A critical review of 'big stories' from the perspective of 'small stories' in Milnes, K., Horrocks, C., Kelly, N., Roberts, B. and Robinson D. (Eds.)(2006). *Narrative, Memory and Knowledge*. Huddersfield, UK: University of Huddersfield Press.

Barak, A., Boniel-Nissim, M., Suler, J. (2008). Fostering empowerment in online support groups.

Computers in Human Behavior. 24:5, 1867 – 1883.

Barratt, M. J., Ferris, J. A., and Lenton, S. (2015). Hidden populations, online purposive sampling, and external validity: Taking off the blindfold. *Field Methods*. 27(1), 3-21.

Bartlett, Y.K. and Coulson, N.S. (2011). An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication. *Patient Education and Counseling.* 83:1, 113 – 119.

Bartley, M., and Marmot, M. (2000). Social class and power relations at the workplace. *Occupational Medicine: State of the Art Reviews*. 15, 73–78.

Batterham, P.J. (2014). Recruitment of mental health survey participants using Internet advertising: content, characteristics and cost effectiveness. *Int. J. Methods Psychiatr. Res.* 23, 184-191

Baym, N., (1995). *The emergence of community in computer-mediated communication* in Jones, S. (ed) (1995). *Cybersociety* .Thousand Oaks, CA: Sage.

Bazarova, N. N. (2012). Public intimacy: Disclosure interpretation and social judgments on Facebook. *Journal of Communication*. 62, 815-832.

Bazarova, N. N., and Choi, Y. H. (2014). Self-disclosure in social media: Extending the functional approach to disclosure motivations and characteristics on social network sites. *Journal of Communication*. 64, 635–657. doi:10.1111/jcom.12106.

Beck A.T., Rush A.J., Shaw B.F. and Emery, G. (1979). *Cognitive Therapy of Depression*. New York: Guilford Press.

Bell, V. (2007). Online information, extreme communities, and Internet therapy: Is the Internet good for our mental health? *Journal of Mental Health.* 16, 445-457.

Beresford, P., Perring, R., Nettle, M. and Wallcraft, J. (2015). *From mental illness to a social model of madness and distress*. [Online] [Accessed on 12th January 2017] http://www.shapingourlives.org.uk/wp-content/uploads/2016/05/FROM-MENTAL-ILLNESS-PDF-2.pdf.

Berger, T., Krieger, T., Sude, K., Meyer, B. and Maercker, A. (2018). Evaluating an e-mental health program ("deprexis") as adjunctive treatment tool in psychotherapy for depression: Results of a pragmatic randomized control trial. *Journal of Affective Disorders.* 227, 455-462.

Berry, H., and Welsh, J. (2010). Social capital and health in Australia: An overview from the household, income and labour dynamics in Australia survey. *Social Science and Medicine*. 70, 588–596. doi:10.1016/j.socscimed.2009.10.012.

Bernard, H.R. (2011). *Research Methods in Anthropology: Qualitative and Quantitative Approaches, Fifth edition*. New York: Rowman Altamira.

Bentall, R. (2004). *Madness Explained: Psychosis and Human Nature.* Penguin

Bird, E., and Baber, J. (2007). Constructing a virtual ethnography. In Angrosino, M.V. (ed) (2007). *Doing cultural anthropology: Projects for ethnographic data collection.* Illinois: Waveland Press.

Bishop, J. (2014). Representations of 'trolls' in mass media communication: a review of media-texts

and moral panics relating to 'internet trolling'. *Int. J. Web Based Communities*. 10:1.

Biyani, P., Caragea, C. Mitra, P. and Yen, J. (2014). *Identifying emotional and informational support in online health communities*. In Proceedings of COLING 2014, the 25th International Conference on Computational Linguistics: Technical Papers, pages 827–836, Dublin, Ireland. Dublin City University and Association for Computational Linguistics.

Blanchard, J.J., Kring, A.M., Horan, W.P. and Gur, R. (2011). Toward the Next Generation of Negative Symptom Assessments: The Collaboration to Advance Negative Symptom Assessment in Schizophrenia. *Schizophrenia Bulletin*. 37:2, 291–299. https://doi.org/10.1093/schbul/sbq104.

Blank, G., and Lutz, C. (2017). Representativeness of Social Media in Great Britain: Investigating Facebook, LinkedIn, Twitter, Pinterest, Google+, and Instagram. *American Behavioral Scientist*. 61:7, 741–756. https://doi.org/10.1177/0002764217717559.

Blank, T.O., and Adams-Blodnieks, M. (2005). The who and the what of usage of two cancer online communities. *Computers in Human Behaviour.* 23, 1249-1257.

Bloch, M. (2012). *Anthropology and the cognitive challenge*. Cambridge: Cambridge University Press.

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J. Brozek, I. and Hughes, C. (2014). Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC medical research methodology.* 14:42. doi: 10.1186/1471-2288-14-42.

Bourdieu, P. (1990). *The logic of practice.* Cambridge: Polity Press.

Bourdieu, P. (1985). The genesis of the concepts of Habitus and of Field. *Sociocriticism*. 2, 11-24.

Bourdieu P. (1984). *Distinction: A Social Critique of the Judgement of Taste*. Harvard: University Press.

Bourdieu, P. (1983). The field of cultural production, or: the economic world reversed. *Poetics*. 12, 311-356.

Boyatzis, R.E. (1998). *Transforming Qualitative Information.* London, Sage.

boyd, D., and Ellison, N. (2008). Social Network Sites: Definition, History, and Scholarship. *Journal of Computer-Mediated Communication*. 13, 210-230. http://dx.doi.org/10.1111/j.1083-6101.2007.00393.x.

Braithwaite, J., Sandall, J., and Waring, J. (2016). Towards a sociology of healthcare safety and quality. *Sociology of Health and Illness.* 38:2, 181-197.

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design.* Harvard: University Press.

Bouilianne, S. (2015). Social Media Use and Participation: A Meta-Analysis of Current Research. *Information, Communication and Society*. 18:5, 524–38. doi:10.1080/13691 18X.2015.1008542.

Boyle, B. (2016). Can Concepts Associated with Physical Environments Be Applied to Social Media Sites? An Empirical Study Using Theories from Place Attachment, Social Behavior, and Social

Integration. *CUNY Academic Works.* https://academicworks.cuny.edu/gc_etds/1386.

Broom, A. (2005). Virtually he@lthy: The impact of Internet use on disease experience and the doctor-patient relationship. *Qualitative Health Research.* 15, 325-345.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology.' *Qualitative Research in Psychology* 3:32, 77–101.

British Psychological Society (2017). *Ethics Guidelines for Internet-mediated Research.* Leicester: British Psychological Society.

British Psychological Society. (2014). *Code of Human Research Ethics*. Leicester: British Psychological Society.

British Psychological Society. (2009). *Code of Ethics and Conduct*. Guidance published by the Ethics Committee of the British Psychological Society. Leicester: British Psychological Society.

Broadband Commission for Sustainable Development. (2018). *Monitoring and Evaluation*. [online] [Accessed 16.08.2018]. https://www.broadbandcommission.org/about/Pages/default.aspx.

Brown, P.R. and Calnan, M. W. (2016). Chains of (dis)trust: exploring the underpinnings of knowledge-sharing and quality care across mental health services. In Allen, D., Burr, V. (1995) *An Introduction to Social Constructionism.* London:Routledge.

Brown, A. D. (2006). A narrative approach to collective identities. *Journal of management studies*. 43:4, 731-753. https://doi.org/10.1111/j.1467-6486.2006.00609.x.

Bryant, A., and Charmaz, K. (2007). Grounded theory in historical perspective: An epistemological account. In A. Bryant and K. Charmaz (Eds.) (2007). *The Sage handbook of grounded theory*. London: Sage.

Buchanan, E. A. (Ed.). (2004). *Readings in virtual research ethics: Issues and controversies*. IGI global.

Buehler, E. M. (2017). "You Shouldn't Use Facebook for That": Navigating Norm Violations While Seeking Emotional Support on Facebook. *Social Media and Society*. https://doi.org/10.1177/2056305117733225.

Burgess, J. D., Kimble, R. M., Watt, K., and Cameron, C. M. (2017). The Adoption of Social Media to Recruit Participants for the Cool Runnings Randomized Controlled Trial in Australia. *JMIR research protocols*. 6:10. doi:10.2196/resprot.8189.

Burke, M., Joyce, E., Kim, T., Anand, V., and Kraut, R. (2007). *Introductions and Requests: Rhetorical Strategies That Elicit Response in Online Communities.* Third International Conference on Communities and Technologies.

Burr, V. (2015) *Social Constructionism 3ʳᵈ ed.* London: Routledge.

Business in the Community. (2017). *Mental Health at Work Report- 2017*. [online] [accessed 23.08.18.] https://wellbeing.bitc.org.uk/all-resources/research-articles/mental-health-work-report-2017.

Butler, B., Sproull, L., Kiesler, S. and Kraut. R. (2007). Community effort in online groups: Who does the work and why? In Weisband, S.and Atwater, L.(eds.) (2007). *Leadership at a Distance*. Mahwah, NJ: Lawrence Erlbaum Associates. 171–194.

Burton, M. and Kagan, C. (2015). Theory and practice for a critical community psychology in the UK. *Psicología, Conocimiento y Sociedad*. 5:2, 182-205.

Butterworth, P., Leach, L.S., Strazdins, L., Oleson, S.C., Rodgers, B. and Broom, D.H. (2011). The psychosocial quality of work determines whether employment has benefits for mental health: results from a longitudinal national household panel survey. *Occup Environ Med.* 68, 806-812.

Byrne, P. (2009). *Film Report Screening Madness: A century of negative movie stereotypes of mental illness*. London: Time to Change. https://www.time-to-change.org.uk/sites/default/files/film-report-screening-madness-time-to-change.pdf.

Calleja, G. (2010) 'Digital games and Escapism.' *Games and Culture*. 5:4, 335–353.

Care Act (2014) *The Care Act* [online] [Accessed 21st March 2016] http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm.

Cambell, D. (2017). *NHS prescribed record number of antidepressants last year.* [online] [Accessed 29.06.2017] https://www.theguardian.com/society/2017/jun/29/nhs-prescribed-record-number-of-antidepressants-last-year.

Cameron, D. (2010). *'Big Society Speech' 19 July 2010*. London: Number 10. [Online] [Accessed 29.4.2012] http://www.number10.gov.uk/news/big-society-speech/.

Care Quality Commission (CQC). (2017). *The state of health care and adult social care in England 2016/17*. [online] [accessed 26.4.2018] https://www.gov.uk/government/publications.

Card, C. (2018) *How Facebook AI Helps Suicide Prevention*. [Online] [Accessed 28.02.2019] https://newsroom.fb.com/news/2018/09/inside-feed-suicide-prevention-and-ai/

Carr, C. T. and Hayes, R. A. (2015). Social media: Defining, developing, and divining. *Atlantic Journal of Communication*. 23, 46–65. doi:10.1080/15456870.2015.972282.

Carroll, J. M. (2014). *The neighborhood in the Internet: Design research projects in community*. London: Routledge.

Centola, D. and van de Rijt, A. (2015). Choosing your network: Social preferences in an online health community. *Social Science and Medicine*. 125, 19-31. https://doi.org/10.1016/j.socscimed.2014.05.019.

Chair, C. and De Lannoy, A. (2018). *Youth, Deprivation and the Internet* Policy paper no. 4, Series 5: After Access – Assessing digital inequality in Africa. https://researchictafrica.net/after-access-survey-papers/2018/After_Access:_ youth_and_digital_inequality_in_Africa.pdf.

Chakrabarti, B. (2018). Diagnostic labels for mental health conditions are not always useful. *The Conversation.* https://theconversation.com/diagnostic-labels-for-mental-health-conditions-are-not-always-useful-102943.

Chambers, R., Schmid, M., and Birch-Jones, J. (2016). *Digital Healthcare: the essential guide*.

Oxford: Otmoor Publishing.

Chandler, A. (2016). *Self-Injury, Medicine and Society: Authentic Bodies*. London: Palgrave Macmillan.

Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London: Sage.

Chen, A. T. (2014). What's in a Virtual Hug? - A Transdisciplinary Review of Methods in Online Health Discussion Forum Research. *Library and Information Science Research*. 36:2, 120-130.

Choudhry, F. R., Mani, V., Ming, L. C., and Khan, T. M. (2016). Beliefs and perception about mental health issues: a meta-synthesis. *Neuropsychiatric disease and treatment*. 12, 2807-2818. doi:10.2147/NDT.S111543.

Christie, S. (2013). "Big White Wall: transforming mental health services through digital technologies". *Mental Health and Social Inclusion*. 17:4, 202-205. https://doi.org/10.1108/MHSI-07-2013-0024.

Citizens Advice. (2015). *Prescribing advice – a pathway to health and saving money.* [online] [accessed 17.06.2015] https://www.citizensadvice.org.uk/global/migrated_ documents/corporate/aftf-prescribing-advice-apathway-to-health-and-saving-money-feb2015.pdf.

Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., Morgan, C., Rüsch, N., Brown, J.S.L. and Thornicroft, G. (2015). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*, 45:1, 11–27.

Cohen, B.M.Z. (2015). *Mental Health User Narratives: New perspectives on Illness and Recovery*, *revised edition*. Houndmills, Basingstoke: Palgrave Macmillan.

Cohen, E. (1976). The structural transformation of the kibbutz. In G. K. Zollschan and W. Hirsch (Eds.) (1976). *Social change.* New York: Wiley.

Cohen, S., Gottlieb, B., and Underwood, L. (2000). Social relationships and health. In S. Cohen, L. Underwood, and B. Gottlieb (Eds.) (2000). Measuring and intervening in social support (pp. 3–25). New York: Oxford University Press.

Coimbra, J. L., Duckett, P., Fryer, D., Makkawi, I. Menezes, I., Seedat, M. and Walker, C. (2012). Rethinking community psychology: Critical insights. *The Australian Community Psychologist*. 24, 135-142.

Collins, C.R., Neal, Z.P. and Neal, J.W. (2017). Transforming social cohesion into informal social control: Deconstructing collective efficacy and the moderating role of neighborhood racial homogeneity. *Journal of Urban Affairs*. 39:3, 307-322. doi: 10.1080/07352166.2016.1245079.

Conway, M., and O'Connor, D. (2016). Social Media, Big Data, and Mental Health: Current Advances and Ethical Implications. *Current opinion in psychology*. 9, 77-82.

Coppock, V. and Hopton, J. (2000). *Critical perspectives on mental health*. London:Routledge

Corbin, J.M. and Strauss, A. (1990). Grounded theory research: procedures, canons, and evaluative

criteria. *Qualitative Sociology.* 13, 3–21.

Corrigan, P.W. (2016). Lessons learned from unintended consequences about erasing the stigma of mental illness. *World Psychiatry*. 15, 67-73.

Corrigan, P.W. (2015). Challenging the stigma of mental illness: different agendas, different goals. *Psychiatr Serv.* 66:12, 1347–9.

Corrigan, P. W. (2007). How clinical diagnosis might exacerbate the stigma of mental illness. *Social Work.* 52:1, 31–39.

Corrigan, P. W. (2004). How stigma interferes with mental health care. In *American Psychologist,* 50:7, 614–625.

Corrigan, P.W., Kerr, A. and Knudsen, L. (2005). The stigma of mental illness: Explanatory models and methods for change. *Applied and Preventative Psychology.* 11:3, 179-190.

Corrigan, P. W., Larson, J. E., Rüsch, N. (2009). Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry.* 8, 75-81.

Corrigan, P. W., Markowitz, F.E., Watson, A. C. (2004). Structural levels of mental illness stigma and discrimination. *Schizophrenia Bulletin*. 30, 481–491.

Corrigan, P., Markowitz, F., Watson, A., Rowan, D., Kubiak, M. A. (2003). An attribution model of public discrimination towards persons with mental illness. *Journal of Health Behavior*. 44:2, 162–179.

Corrigan, P. W, River, L. P., Lundin, R. K., Wasowski, K. U., Campion, J., Mathisen, J. (2000). Stigmatizing attributions about mental illness. *Journal of Community Psychology*. 28:1, 91–102.

Corrigan, P. W., Tsang, H. W., Shi, K., Lam, C. S., and Larson, J. (2010). Chinese and American employers' perspectives regarding hiring people with behaviorally driven health conditions: The role of stigma. *Social science and medicine*. 71:12, 2162-2169.

Corry, P. (2008). *Stigma shout: service user and carer experiences of stigma and discrimination.* London: Time to Change.

Coulson, N.S. (2013). How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. *J R Soc Med Sh Rep.* 4, 1-8.

Coulthard, K., Patel, D., Brizzolara, C., Morriss, R. and Watson, S. (2013). A feasibility study of expert patient and community mental health team led bipolar psychoeducation groups: Implementing an evidence based practice. *BMC Psychiatry*. 13:1, 301.

Cox, M. (2015). *Schizophrenia: The complete Beginners Guide – Understanding Symptoms, Diagnosis and Schizophrenia Therapy!* Online: Create Space Independent Publishing Platform.

Crabtree, J.W, and Haslam, S.A. (2010). Mental Health Support Groups, Stigma, Self-Esteem: Positive and Negative Implications of Group Identification. *Journal of Social Issues.* 66:3, 553-569.

Creswell, J. K. (2003). *Research design. Qualitative, quantitative and mixed methods approaches 2nd ed.* Thousand Oaks: Sage Publications.

Creswell, J. K. (2007). *Qualitative inquiry and research design. Choosing among five approaches 2nd ed*. Thousand Oaks: Sage Publications.

Croker, J.E., Swancutt, D.R. and Roberts, M.J. Abel, G.A., Roland, M. and Campbell, J.L. (2013). Factors affecting patients' trust and confidence in GPs: evidence from the English national GP patient survey. *BMJ Open.* doi:10.1136/ bmjopen-2013-002762.

Cruwys, T., Dingle, G. A., Haslam, C., Haslam, A. S., Jetten, J. and Morton, T. A. (2013) Social group memberships protect against future depression, alleviate depression symptoms and prevent depression relapse. *Social Science and Medicine*. 98, 179–186.

Csikszentmihalyi, M. (1990). *Flow: The psychology of optimal experience*. New York, NY: HarperCollins.

Csipke, E. and Horne, O. (2007). Pro-eating disorder websites: Users' opinions. *European Eating Disorders Review.* 15, 196-206. https://dx.doi.org/10.1002/erv.789.

Cuijpers, P. (2003). Examining the Effects of Prevention Programs on the Incidence of New Cases of Mental Disorders: The Lack of Statistical Power. *American Journal of Psychiatry.* 160:8, 1385 – 1391.

Cupchik, G. (2001, February). Constructivist realism: An ontology that encompasses positivist and constructivist approaches to the social sciences. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* (Vol. 2, No. 1).

Dai, H., Lee, B. R., and Hao, J. (2017). Predicting Asthma Prevalence by Linking Social Media Data and Traditional Surveys. *The ANNALS of the American Academy of Political and Social Science*. 669:1, 75–92. https://doi.org/10.1177/0002716216678399.

Dai, H. and Hao, J. (2016). Mining social media data for opinion polarities about electronic cigarettes. *Tobacco Control.* doi:10.1136/tobaccocontrol-2015-052818.

Daine, K., Hawton, K., Singaravelu, V., Stewart, A., Simkin, S. and Montgomery, P. (2013). The power of the web: A systematic review of studies of the influence of the Internet on self-harm and suicide in young people. *PLoS ONE.* 8:10.

Dalton, J., Elias, M., and Wandersman, A. (2001). *Community Psychology: Linking individuals and communities*. Belmont, CA: Wadsworth/Thomson Learning.

D'Andrade, R. (2008). *A study of personal and cultural values*. New York: Palgrave.

Das, A. and Faxvaag, A. (2014). What Influences Patient Participation in an Online Forum for Weight Loss Surgery? A Qualitative Case Study. *Interact J Med Res*. 3:1. doi: 10.2196/ijmr.2847.

Data Protection Act. (1998). *Data Protection Act 1998.* [online] [Accessed 26 Feb. 2015]. http://www.legislation.gov.uk/ukpga/1998/29/section/1.

Davidson, L., Bellamy, C., Guy, K. and Miller, R. (2012). Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry*. 11:2, 123–128.

Davies, S. (2013). *Annual Report of the Chief Medical Officer 2013. Public Mental Health Priorities: Investing in the Evidence*. [online] [Accessed 17.05.2017]

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/413196/CMO_web_doc.pdf.

Davidson, L., Ridgway, P., O'Connell, M. and Kirk, T. A. (2014). Transforming Mental Health Care Through the Participation of the Recovery Community. In Nelson, G., Kloos, B. and Ornelas, J. (2014). *Community psychology and community mental health: towards transformative change*. Oxford: University Press.

DeAndrea, D. C., and Anthony, J. C. (2013). Online peer support for mental health problems in the United States: 2004-2010. *Psychological medicine*. 43:11, 2277-88.

De Choudhury, M., Gamon, M., Counts, S., and Horvitz, E. (2013). *Predicting Depression via Social Media.* In Proceedings of the 7th International AAAI Conference on Weblogs and Social Media (Boston, MA, Jul. 8 – Jul. 10, 2013). ICWSM 2013.

De Choudhury, M., Morris, M. R., and White, R. W. (2014). *Seeking and Sharing Health Information Online: Comparing Search Engines and Social Media.* Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (Toronto, Canada Apr. 26 – May 01, 2014). 1365-1376.

DeCuir-Gunby, J. T., Marshall, P. L., and McCulloch, A. W. (2011). Developing and using a codebook for the analysis of interview data: An example from a professional development research project. *Field methods*. 23:2, 136-155.

De Fina, A. and Georgakopoulou, A. (2008). Introduction: narrative analysis in the shift from texts to practices. *Text Talk*. 28, 275-281.

Delanty, G. (2010). *Community.* London: Routledge.

de Lijster, J.M., Dierckx, B., Utens, E.M. Verhulst, F.C., Zieldorff, C., Dieleman, G.C. and Legerstee, J.S. (2017). The age of onset of anxiety disorders: a meta-analysis. *Can J Psychiatry*. 62:4, 237–246.

Department of Health (DoH). (2010). Commissioning talking therapies for 2011/ 12. Issue 2, IAPT. [online] [Accessed 16.6.2018] https://www.gov.uk/government/publications/talking-therapies-a-4-year-plan-of-action.

Department of Health (DoH). (2009). In D. Richards and M. Whyte (Eds.), *National Programme Educator Materials for support the delivery of training for psychological wellbeing practitioners delivering low intensity interventions (2nd ed.).* London: Department of Health.

Department of Health (DoH). (2001). *The Expert Patient: A New Approach to Chronic Disease Management*. London: Department of Health.

Deters, F. g [sic], and Mehl, M. R. (2013). Does Posting Facebook Status Updates Increase or Decrease Loneliness? An Online Social Networking Experiment. *Social Psychological and Personality Science*. 4:5, 579–586. https://doi.org/10.1177/1948550612469233.

Dickerson, F.B., Sommerville, J., Origoni, A.E., Ringel, N.B. and Parente, F. (2001). Outpatients with schizophrenia and bipolar I disorder: do they differ in their cognitive and social functioning? *Psychiatry Research*. 102, 21–27.

Ding, N., Berry, H., O'Brien, L. (2015). One-year reciprocal relationship between community

participation and mental wellbeing in Australia: A panel analysis. *Social Science and Medicine.* 128, 264-254.

Dingle, G. A., Brander, C., Ballantyne, J., and Baker, F. A. (2013). 'To be heard': The social and mental health benefits of choir singing for disadvantaged adults. *Psychology of Music*. 41:4, 405–421. https://doi.org/10.1177/0305735611430081.

Doolittle, R.J. and MacDonald, D. (1978). Communication and a sense of community in a metropolitan neighbourhood: A factor analytic examination. *Communication Quarterly.* 26, 2-7.

Dorling, D., Vickers, D., Thomas, B., Pritchard, J. and Ballas, D. (2008). *Changing UK: The Way We Live Now.* A report commissioned by the BBC. [Online] [Accessed on 10th October, 2012] http://www.sasi.group.shef.ac.uk/research/changinguk/Changing_UK_report_sheffield_webv1.pdf.

Driscoll, C., & Gregg, M. (2010). My profile: The ethics of virtual ethnography. *Emotion, Space and Society*. 3:1, 15-20.

Durkheim, E. (1885). *The Rules of Sociological Method and Selected Texts on Sociology and its Method.* New York: The MacMillan Press.

Dutton, W., Grant, B., and Groselj, D. (2013). *Cultures of the internet: The internet in Britain*. Oxford University: Oxford Internet Institute.

Earnshaw, V.A., Quinn, D.M., Park, C.L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illn.* 8:2, 79–88. doi:10.1177/1742395311429393.

Easterbrook, M. and Vignoles, V. (2013). What does it mean to belong? Interpersonal bonds and intragroup similarities as predictors of felt belonging in different types of groups. *European Journal of Social Psychology*. 43:6, 455-462.

Economy, E.C. (2018). The great firewall of China: XI Jinping's internet shutdown. *The Guardian.* [online] [Accessed 3.7.2018] https://www.theguardian.com/news/2018/jun/29/the-great-firewall-of-china-xi-jinpings-internet-shutdown.

Ellison, N.B. (2007). Social network sites: definition, history, and scholarship. *Journal of Computer-Mediated Communication.* 13, 210–230.

Ellison, N., Mason, O. and Scior, K. (2015). Renaming schizophrenia to reduce stigma: Comparison with the case of bipolar disorder. *Br. J. Psychiatry*. 206, 341–342.

Ellison, N.B., Steinfield, C. and Lampe, C. (2007). The benefits of Facebook "friends": social capital and college students' use of online social network sites. *Journal of Computer-Mediated Communication*. 12, 1143–1168.

Erikson, K. (1966). *Wayward puritans.* New York: Wiley.

Eurostat. (2017). *Temporary employment in the EU.* Online: European Commission. [online] [Accessed 3.7.2018] https://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20170502-1.

Evans-Campbell, T. (2008). Historical trauma in American Indian/Native Alaskan

communities: A multilevel framework for exploring impacts on individuals, families, and com-munities. *Journal of Interpersonal Violence.* 23:3, 316–338.

Evans-Lacko, S., Henderson, C., and Thornicroft, G. (2013). Public knowledge, attitudes and behaviour regarding people with mental illness in England 2009-2012. *The British Journal of Psychiatry.* 202, 51-57.

Evans-Lacko, S., Stolzenburg, S., Gronholm, P.C., Ribeiro, W., York-Smith, M. and Schomerus, G. (2018). Psychometric validation of the self-identification of having a mental illness (SELF-I) scale and the relationship with stigma and help-seeking among young people. *Soc Psychiatry Psychiatr Epidemiol*. https://doi.org/10.1007/s00127-018-1602-2.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. and Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ* 328.

Facebook. (2017). Getting Our Community Help in Real Time. [Online] [Accessed 28/1/2018] https://newsroom.fb.com/news/2017/11/getting-our-community-help-in-real-time/.

Farmer, P. and Stevenson, D. (2017). *Thriving at Work: The Independent Review of Mental Health and Employers*. [online] [Accessed 12.11.2017] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/658145/thriving-at-work-stevenson-farmer-review.pdf.

Fergie, G., Hilton, S. and Hunt, K. (2015). Young adults' experiences of seeking online information about diabetes and mental health in the age of social media. *Health Expectations*. 19, 1324-1335.

Festinger, L. (1953). Group attraction and membership. In J. G. Miller (ed.) (1953). *Experiments in social process.* New York: McGraw-Hill.

Flicker, S., Haans, D., and Skinner, H. (2004). Ethical dilemmas in research on Internet communities. *Qualitative Health Research.* 14, 124–134.

Fincham, B., Walker, C. and Easlick, H. (2011). Mental Health and Work-Experiences of Work. In Walker, C. and Fincham, B. (2011). *Work and the Mental Health Crisis in Britain*. Chichester, East Sussex: John Wiley and Sons. eISBN-13: 9781119974239

Fisher, J.C., Lawthom, R. and Kagan, C. (2014). Revolting talks of migrant workers and community organisers – a UK Community Psychology perspective. *Australian Community Psychologist.*

Fitzpatrick, T. (2011). *Welfare Theory: An Introduction to the Theoretical Debates in Social Policy 2nd ed*. Basingstoke: Palgrave Macmillan.

Foucault, M. (1965). *Madness and Civilization.* New York: Random House, Inc.

Foucault, M. (1961). *Histoire de la folie à l'âge classique*. Reedited Paris, Gallimard. / [1964]. *Madness and civilization. A History of insanity in the age of reason*. New York: Vintage Book

Fox, S. (2011). *Health.* PEW Internet Research. [online] [Accessed 3/11/2017] http://pewinternet.org/~/media//Files/Reports/2011/PIP_Social_Life_of_Health_Info.pdf.

Fox, S. and Jones, S. (2009). *The social life of health information.* PEW Internet Research. [online]

[Accessed 3/11/2017] http://www.pewinternet.org/2009/06/11/the-social-life-of-health-information/.

Fox, N., Ward, K. and O'Rourke, A. (2005). The expert patient. *Social Science and Medicine*. 60, 1299–1309.

Frances, A. (2013). *Saving normal: An insider's revolt against out-of-control psychiatric diagnosis, DSM-5, big pharma and the medicalization of ordinary life. Psychotherapy in Australia*. 19:3, 14-18.

Freeman, M. (2017). Narrative at the Limits: (Or What is 'Life' Really Like?) in Schiff, B. McKim, A.E. and Patron, S. (eds) (2017). *Life and Narrative: The Risks and Responsibilities of Storying Experience.* New York: Oxford University Press.

Gallagher III, B.J. (1995). *The Sociology of Mental Illness 3rd edition*. New Jersey: Prentice Hall.

Gerlinger, G., Hauser, M., De Hert, M., Lacluyse, K., Wampers, M., and Correll, C. U. (2013). Personal stigma in schizophrenia spectrum disorders: a systematic review of prevalence rates, correlates, impact and interventions. *World psychiatry : official journal of the World Psychiatric Association (WPA)*, *12*(2), 155-64.

Giddens, A. (1984). *The Constitution of Society.* Cambridge: Polity.

Gilburt, H. (2018). *Mental health funding in the 2018 Autumn Budget: the devil will be in the detail* [online] [Accessed 28.11.2018] https://www.kingsfund.org.uk/blog/2018/10/mental-health-funding-2018-autumn-budget.

Gil de Zúñiga, H., Jung, N. and Valenzuela, S. (2012). Social Media Use for News and Individuals' Social Capital, Civic Engagement and Political Participation. *Journal of Computer-Mediated Communication*. 17:3, 319–336. https://doi.org/10.1111/j.1083-6101.2012.01574.x.

Giles, D. (2016). Observing real-world groups in the virtual field: The analysis of online discussion. *British Journal of Social Psychology.* 55, 484-498.

Giles, D. and Newbold, J. (2013). 'Is this normal?' The role of category predicates in constructing mental illness online. *Journal of Computer-Mediated Communication.* 18, 476-490.

Giles, D. C., and Newbold, J. (2011). Self- and Other-Diagnosis in User-Led Mental Health Online Communities. *Qualitative Health Research*. 21:3, 419- 428. https://doi.org/10.1177/1049732310381388.

Giles, D.C., Stommel, W., and Paulus, T. (2017). The Microanalysis of Online Data: The next stage (introduction to special section). *Journal of Pragmatics*. 115, 37-41.

Glaser, B. G. (1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. California: The Sociology Press.

Glasser, B. and Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.

Glynn, T. J. (1981). Psychological sense of community: Measurement and application. *Human Relations*, 34. 780-818.

Goffman, E. (1963). *Stigma: notes on the management of spoiled identity.* New York: Simon and Schuster Inc.

Goffman, E. (1961). *Asylums.* London: Penguin.

Goodings, L. (2010) *Social Network Sites: A Constructionist Approach to Self, Identity and Community in MySpace.* Loughborough University. https://dspace.lboro.ac.uk/dspace-jspui/bitstream/2134/6337/2/Thesis-2010-Lewis.pdf.

Goodley, D. and Lawthom, R. (2005). *Disability and Psychology.* Palgrave Macmillan.

Gowen, K., Deschaine, M., Gruttadara, D. and Markey, D. (2012). Young adults with mental health conditions and social networking websites: Seeking tools to build community. *Psychiatric Rehabilitation Journal.* 35:3, 245-250. http://dx.doi.org/10.2975/35.3.2012.245.250.

Gov.UK. (2018). *Independent Review of the Mental Health Act*. [online] [accessed 23.05.2018]. https://www.gov.uk/government/groups/independent-review-of-the-mental-health-act.

Gray, D.E. (2013). *Doing Research in the Real World*. London: SAGE.

Grieve, R., Indian, M., Witteveen, K., Tolan, G.A. and Marrington, J. (2013). Face-to-face or Facebook: Can social connectedness be derived online? *Computers in Human Behavior*. 29:3, 604-609.

Gronholm, P. C., Henderson, C., Deb, T., and Thornicroft, G. (2017). Interventions to reduce discrimination and stigma: the state of the art. *Social psychiatry and psychiatric epidemiology*. 52:3, 249-258.

Groves, T. (1990). The future of community care. *BMJ.* 300, 923–924.

Guo, T.-C., and Cheng, Z.-C. (2016). Sense of belonging based on novel posting: Individuals processes of social and psychological integration into virtual groups. *Online Information Review*, 40:2, 204–217. doi:10.1108/OIR-06-2015-0198.

Haley, W. E., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A., Collins, R. P. and Isobe, T. L. (1996). Appraisal, coping, and social support as mediators of well-being in Black and White family caregivers of patients with Alzheimer's disease. *Journal of Consulting and Clinical Psychology*. 64, 121-129.

Hall, H., and Graham, D. (2004). Creation and recreation: Motivating collaboration to generate knowledge capital in online communities. *International Journal of Information Management*. 24:3, 235–246.

Hancock, L., Mooney, G. and Neal, S. (2012). Crisis social policy and the resilience of the concept of community. *Critical Social Policy.* 32:3, 343 – 364.

Hartwell, S.W. and Benson, P.R. (2007). *Social Integration: A Conceptual overview and two case studies. In Mental Health, Social Mirror*. Boston: Springer.

Hauben, M., and Hauben, R. (1996). *Netizens: On the history and impact of Usenet and the Internet.* Los Alamitos, CA: IEEE Computer Press.

Hawkley, L. C., and Cacioppo, J. T. (2010). Loneliness matters: A theoretical and empirical review of consequences and mechanisms. *Annals of Behavioral Medicine*. 40, 218–227. doi:10.1007/s12160-010-9210-8.

Hayes, R.A., Carr, C.T. and Wohn, D.Y. (2016). It's the Audience: Differences in Social Support Across Social Media. *Social Media and Society.* 1-12. doi: 10.1177/2056305116678894.

Healthcare Financial Management Association. (2016). *Mental health funding concern (England).* [online] [Accessed 17.10.2016] https://www.hfma.org.uk/.

Heidegger, M. (1962). *Being and time.* New York, NY: Harper and Row. (Original work published 1927).

Henderson, C., Corker, E., Lewis-Holmes, E., Hamilton, S., Flach, C., Rose, D. Williams, P., Pinfold, V. and Thornicroft, G. (2012). England's Time to Change anti-stigma campaign: one-year outcomes of service user-rated experiences of discrimination. *Psychiatr Serv.* 63, 451–57.

Henderson, C., Farrelly, S., Moran, P., Borschmann, R., Thornicroft, G., Birchwood, M. and Crimson, T. (2015). Joint crisis planning in mental health care: The challenge of implementation in randomized trials and in routine care. *World Psychiatry.* 14:3, 281-283.

Henderson, C., Robinson, E., Evans-Lacko, S., and Thornicroft, G. J. (2017). Relationships between anti-stigma programme awareness, disclosure comfort and intended help-seeking regarding a mental health problem. *Br J Pschiatry.* 211:5, 316-322. doi: 10.1192/bjp.bp.116.195867.

Herbert, T. B., and Dunkel-Schetter, C. (1992). Negative social reactions to victims: An overview of responses and their determinants. In L. Montada, S.-H. Filipp, and M. J. Lerner (Eds.) (1992). *Life crises and experiences of loss in adulthood.* Hillsdale, NJ, US: Lawrence Erlbaum Associates, Inc.

Herring, S.C. (2002). Gender violence: Recognizing and resisting abuse in online environments. *Asian Women.* 14, 187–212.

Hetrick, S.E., Cox, G.R., Witt, K.G., Bir, J.J. and Merry, S.N. (2016). Cognitive behavioural therapy (CBT), third-wave CBT and interpersonal therapy (IPT) based interventions for preventing depression in children and adolescents. *Cochrane Database of Systematic Reviews.* 8. doi: 10.1002/14651858.CD003380.pub4.

Highton-Williamson, E., Priebe, S., and Giacco, D. (2015). Online social networking in people with psychosis: A systematic review. *International Journal of Social Psychiatry.* 61:1, 92–101. https://doi.org/10.1177/0020764014556392.

Hine, C. (2008). *Virtual Ethnography: Modes, Varieties and Affordances* in Fielding, N. G., Lee. R.M. and Blank, G. (2008). The SAGE Handbook of Online Research Methods: Online Research Methods and Social Theory. Oxford: SAGE.

Hine, C. (2004). Social research methods and the internet: a thematic review. *Sociological Research Online.* 9:2.

Hine, C. (2000). *Virtual Ethnography.* Thousand Oaks, CA: Sage.

Hobbs, W.R., Burke, M., Christakis, N.A. and Fowler, J.H. (2016). *Online social integration is associated with reduced mortality risk.* Proceedings of the National Academy of Sciences of the United States of America. 113, 12980–12984. doi:10.1073/pnas.1605554113.

Hobye, M. and Löwgren, J. (2011). Touching a Stranger: Designing for Engaging Experience in

Embodied Interaction. *International Journal of Design*. 5, 31-48.

Holt-Lunstad, J., Smith, T. B., Baker, M., Harris, T. and Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: A Meta-Analytic review. *Perspectives on Psychological Science*. 10:2, 227–237.

Hornsey, M. J., and Jetten, J. (2004). The Individual Within the Group: Balancing the Need to Belong With the Need to Be Different. *Personality and Social Psychology Review*, 8:3, 248–264. https://doi.org/10.1207/s15327957pspr0803_2.

Hou, H-T., Wang, S-M., Lin, P.C. and Chang, K-E. (2015). Exploring the learner's knowledge construction and cognitive patterns of different asynchronous platforms: comparison of an online discussion forum and Facebook. *Innovations in Education and Teaching International*. 52:6, 610-620. doi: 10.1080/14703297.2013.847381.

Huang, M., Cai, F., Tsang, A. S. L. and Zhou, N. (2011). Making your online voice loud: the critical role of WOM information. *European Journal of Marketing*. 45:7/8, 1277-1297.

Hudson, J. M., and Bruckman, A. (2004). "Go Away": Participant objections to being studied and the ethics of chatroom research. *The Information Society*. 20, 127-139.

Husserl, E. (1977). *Phenomenological psychology* (J.Scanlon, Trans.). The Hague, Netherlands: Martinus Nijhof. (Original work published 1925).

Hyvarinen, M. (2017). *Foreword.* in Schiff, B. McKim, A.E. and Patron, S. (eds) (2017). *Life and Narrative: The Risks and Responsibilities of Storying Experience.* New York: Oxford University Press.

Im, E., Chee, W., Tsai, H., Bender, M., and Lim, H. J. (2007). Internet communities for recruitment of cancer patients into an internet survey: A discussion paper. *International Journal of Nursing Studies*. 44, 1261–1269.

Independent Mental Health Taskforce to the NHS in England. (2015). *The Five Year Forward View for Mental Health*. https://www.england.nhs.uk/mentalhealth/ wp content/uploads/sites/29/2015/09/fyfv-mental-hlthtaskforce.pdf.

InternetLiveStats. (2017) *Internet usage and social media statistics*. [Online] [Accessed on 11th January 2017] http://www.internetlivestats.com/.

Jacob, K. (2015). Recovery model of mental illness: A complementary approach to psychiatric care. *Indian Journal of Psychological Medicine*. 37:2, 117. https://doi.org/10.4103/0253-7176.155605.

Janzik, L., and Raasch, C. (2011). Online communities in mature markets: Why join, why innovate, shy share? *International Journal of Innovation Management*. 15:4, 797–836.

Jeste, D. V., Twamley, E. W., Cardenas, V., Lebowitz, B., & Reynolds III, C. F. (2009). A call for training the trainers: focus on mentoring to enhance diversity in mental health research. *American Journal of Public Health.* 99:S1, S31-S37.

Jodelet, D. (1991). *Madness and social representations.* Hemel Hempstead: Harvester Wheatsheaf.

Johnstone, L. and Boyle, M. with Cromby, J., Dillon, J., Harper, D., Kinderman, P., Longden, E.,

Pilgrim, D. and Read, J. (2018). *The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis*. Leicester: British Psychological Society.

Joinson, A. N. (2009). *Privacy Concerns, Trust in Government and Attitudes to Identity Cards in the United Kingdom.* 42nd Hawaii International Conference on System Sciences, Big Island, HI, 2009, 1-10. doi: 10.1109/HICSS.2009.352.

Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., and Pollitt, P. (1997). Mental Health Literacy: A survey of the public's ability to recognise mental health disorders and their beliefs about the effectiveness of treatment. *Medical Journal of Australia*. 166, 182–186.

Kagan, C.M. and Burton, M.H. (2016). Theory and practice for a critical community psychology in the UK. *Psicología, Conocimiento y Sociedad.* 5:2, 182-205.

Kagan, C., Burton, M., Duckett, P., Lawthom, R. and Siddiquee, A. (2011). *Critical Community Psychology.* Chichester, West Sussex: Wiley-Blackwell.

Kawachi, I. and Berkman, L.F. (2001). Social Ties and Mental Health. *Journal of Urban Health: Bulletin of the New York Academy of Medicine.* 78:3, 458-466.

Kendall, L. (2002). *Hanging Out in the Virtual Pub: Masculinities and Relationships.* Berkeley: University of California Press

Kessler, D., Lewis, G., Kaur, S., Wiles, N., King, M., Weich, S. Sharp, D.J., Araya, R., Hollinghurst, S. and Peters, T.J. (2009). Therapist-delivered internet psychotherapy for depression in primary care: a randomised controlled trial. *Lancet*. 374, 628– 34.

King, S. A.; Moreggi, D. (1998). Internet therapy and self-help groups—the pros and cons. in Gackenbach, J (Ed), (1998). *Psychology and the Internet: Intrapersonal, interpersonal, and transpersonal implications.* San Diego, CA, US: Academic Press.

Kirk, S. and Kutchins, H., (1997). *Making us crazy*. London: Constable.

Knifton, L. (2013). Understanding and addressing the stigma of mental illness with ethnic minority communities. *Health Sociology Review.* 21:3, 287-298.

Kozinets, R.V., (2010). *Netnography: Doing ethnographic research online*. Sage Publications, Thousand Oaks.

Kraut, R., Patterson, M., Lundmark, V., Kiesler, S., Mukophadhyay, T., and Scherlis, W. (1998). Internet paradox: A social technology that reduces social involvement and psychological well-being? *American Psychologist.* 53:9, 1017-1031. http://dx.doi.org/10.1037/0003-066X.53.9.1017.

Kvale, S. and Brinkman, S. (2009). *Interviews – Learning the Craft of Quantitative Research Interviewing.* London: SAGE.

Lammy, D. (2017). The Lammy Review: An independent review into the treatment of, and outcomes for, Black, Asian and Minority Ethnic individuals in the Criminal Justice System. [online] [Accessed 12.02.2018]

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/643

001/lammy-review-final-report.pdf.

LaMontagne, A.D., Sanderson, K. and Cocker, F., (2010). Estimating the economic benefits of eliminating job strain as a risk factor for depression. *VicHealth.*

LaMontagne, A. D., Keegel, T. and Vallance, D. A. (2007). Protecting and promoting mental health in the workplace: Developing a systems approach to job stress. *Health Promotion Journal of Australia*. 18, 221-228.

Lankauskaitė, V. and Liubinienė, V. (2018). A shift from 'me' to 'we' in social media. *Digital Age in Semiotics and Communication.* 1:1, 51-61.

Lawlor, A. and Kirakowski, J. (2014). When the lie is the truth: Grounded theory analysis of an online support group for factitious disorder *Psychiatry Research.* 218, 209-218. 10.1016/j.psychres.2014.03.034.

Lawthom, R. (2011). Developing learning communities: Using communities of practice within community psychology. *International Journal of Inclusive Education*. 15:1, 153-164.

Learmonth, D., Trosh, J., Rai, S., Sewell, J. and Cavanagh, K. (2008). The role of computer-aided psychotherapy within an NHS CBT specialist service. *Counselling and Psychotherapy Research*. 8:2, 117-123. doi: http://dx.doi.org/10.1080/14733140801976290.

Leung, L. (2013). Generational differences in content generation in social media: The roles of the gratifications sought and of narcissism. *Computers in Human Behavior*. 29:3, 997-1006.

Link, B.G. and Stuart, H. (2016). *On Revisiting Some Origins of the Stigma Concept as It Applies to Mental Illness.* In Gaebel, W., Rössler, W. and Sartorious, N. (2016). *The Stigma of Mental Illness - End of the Story?* Switzerland: Springer.

Link, B.G., Struening, E.L., Rahav, M., Phelan, J., Nuttbrock, L., (1997) On Stigma and It's Consequences: Evidence from a Longitudinal Study of Men with Dual Diagnoses of Mental Illness and Substance Abuse. *Journal of Health and Social Behaviour.* 38, 177-190.

Link, B.G., Phelan, J.C., Bresnahan, M., Stueve, A. and Pescosolido, B.A. (1999). Public Conceptions of Mental Illness: Labels, Causes, Dangerousness, and Social Distance *Am J Public Health.* 89:9, 1328-1333.

Litman, J. A. (2005). Curiosity and the pleasures of learning: Wanting and liking new information. *Cognition and Emotion.* 19:6, 793–814.

Liu, N. H., Daumit, G. L., Dua, T., Aquila, R., Charlson, F., Cuijpers, P., Druss, B., Dudek, K., Freeman, M., Fujii, C., Gaebel, W., Hegerl, U., Levav, I., Munk Laursen, T., Ma, H., Maj, M., Elena Medina-Mora, M., Nordentoft, M., Prabhakaran, D., Pratt, K., Prince, M., Rangaswamy, T., Shiers, D., Susser, E., Thornicroft, G., Wahlbeck, K., Fekadu Wassie, A., Whiteford, H., … Saxena, S. (2017). Excess mortality in persons with severe mental disorders: a multilevel intervention framework and priorities for clinical practice, policy and research agendas. *World psychiatry*: *official journal of the World Psychiatric Association (WPA).* 16:1, 30-40.

Lorant, V., Deliège, D., Eaton, W., Robert, A., Philippot, P. Ansseau, M. (2003). Socioeconomic

Inequalities in Depression: A Meta-Analysis, *American Journal of Epidemiology*. 157: 2, 98–112. https://doi.org/10.1093/aje/kwf182.

Lorenzo-Luaces, L., Zimmerman, M., and Cuijpers, P. (2018). Are studies of psychotherapies for depression more or less generalizable than studies of antidepressants? *Journal of Affective Disorders*. 234, 8-13. DOI: 10.1016/j.jad.2018.02.066.

Ma, X., and Sayama, H. (2015). Mental disorder recovery correlated with centralities and interactions on an online social network. *PeerJ.* 3. doi:10.7717/peerj.1163.

Mackelprang, R. O., Salsgiver, R. W. (2015). *Disability: A Diversity Model Approach in Human Service Practice 3rd Edition.* Chicago: Lyceum Books.

Maclure, M. (1998). Refutation in epidemiology: why else not?, in Rothman, K.J. (ed) (1998) *Causal Inference* Chestnut Hill, Pa: Epidemiology Resources.

MacQueen, K. M., McLellan, E., Metzger, D. S., Kegeles, S., Strauss, R. P., Scotti, R., Blanchard, L. and Trotter, R. T. (2001). What is community? An evidence-based definition for participatory public health. *American journal of public health*. 91:12, 1929-38.

Mandelstam. M. (2009). *Safeguarding vulnerable adults and the law*. Philadelphia: Jessica Kingsley Publishers

Mano, R.S. (2014). Computers in human behavior social media and online health services: a health empowerment perspective to online health information. *Comput. Human Behav*. 39, 404-412.

Markham, A. (2004). Internet as research context. In Searle, C., Gobo, G., Gubrium, J. and Silverman, D. (eds) (2004). *Qualitative Research Practice.* London: Sage.

March, S. (2017). Almost 6,000 mental health patients sent out of area last year. The Guardian. [online] [Accessed 27.06.2017]. health https://www.theguardian.com/society/2017/jun/27/almost-6000-mental-health-patients-sent-out-of-area-for-care-last-year-nhs-treatment-england.

Marmot, M. (2004). *Status Syndrome*. London: Bloomsbury.

Marmot, M., Friel, S., Bell, R., Houweling, T.A.J. and Taylor, S. (2008). Closing the gap in a generation: health equity through action on the social determinants of health. *Lancet.* 372, 1661-1669. 10.1016/S0140-6736(08)61690-6.

Marpsat, M. and Razafindratsima, N. (2010). Survey methods for hard-to-reach populations: Introduction to the special issue. *Methodological Innovations Online*. 5:2, 3–16.

Marsh, S. (2018). Communist-run Cuba starts rolling out internet on mobile phones. *Reuters.* [online] [Accessed 10.10.2018] https://uk.reuters.com/article/uk-cuba-internet/communist-run-cuba-starts-rolling-out-internet-on-mobile-phones-idUKKBN1K62UD.

Martin, J.L., Simons. L., Craven, M.P. and Betton, V. (2014). Towards a framework for the appraisal of digital products for mental health. *International Journal of Integrated Care*. 14:8. doi: http://doi.org/10.5334/ijic.1814.

Maslow, A. H. (1966). *The psychology of science: A reconnaissance*. New York, NY: Harper and Row.

Matrix. (2013). *Economic analysis of workplace mental health promotion and mental disorder prevention programmes and of their potential contribution to EU health, social and economic policy objectives.* Executive Agency for Health and Consumers, Specific Request EAHC/2011/Health/19 for the Implementation of Framework Contract EAHC/2010/Health/01 Lot 2, 2013. [online] [Accessed 4.6.16]

http://ec.europa.eu/health/mental_health/docs/matrix_economic_analysis_mh_promotion_en.pdf.

McDaid, D. Park, A. and Knapp, M. (2018). *Commissioning cost-effective services for promotion of mental health and wellbeing and prevention of mental ill health.* [online] [Accessed 21.2.2018] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/640714/Commissioning_effective_mental_health_prevention_report.pdf.

McLaughlin, H. (2009). What's in a name:'client','patient','customer','consumer','expert by experience','service user'—what's next?. *The British Journal of Social Work*. 39:6, 1101-1117.

McGrath, L., Walker, C., and Jones, C. (2016). Psychologists Against Austerity: mobilising psychology for social change. *Critical and Radical Social Work.* 4:3, 409-413.

McKenna, K. Y. A. and Bargh, J. A. (1998). Coming out in the age of the Internet: Identity "demarginalization" through virtual group participation. *Journal of Personality and Social Psychology*. 75:3, 681-694. http://dx.doi.org/10.1037/0022-3514.75.3.681.

McManus, S., Bebbington, P., Jenkins, R. and Brugha, T. (eds.). (2016). *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014.* Leeds: NHS Digital.

McMillan, D. W. and Chavis, D. M. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*. 14:1, 6–23.

McPherson, S., Evans, C. and Richardson, P. (2009). The NICE Depression Guidelines and the recovery model: is there an evidence base for IAPT? *Journal of Mental Health*. 18:5, 405-414.

Mechanic, D. (1995). Sociological Dimensions of Illness Behavior. *SocialScience and Medicine.* 41, 1207–16.

Mental Health Act. (2007). *Mental Health Act* [online] [Accessed 24.11.2014]
http://www.legislation.gov.uk/ukpga/2007/12/pdfs/ukpga_20070012_en.pdf.

Mental Capacity Act. (2005). *Mental Capacity Act.* [online] [Accessed 24.11.2014]
http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf.

Mertens, D. M., Hesse-Biber, S. (2012). Triangulation and mixed methods research: Provocative positions. *Journal of Mixed Methods Research*. 6:2, 75-79.

Milburn, N. G. (2016). Commentary on the future of community psychology: Perspective of a research community psychologist. *American journal of community psychology*. 58:3-4, 245-250.

Mind. (2015). *Mental health facts and statistics.* [online] [Accessed 1.1.2016]
https://www.mind.org.uk/information-support/types-of-mental-health-problems/statistics-and-facts-about-mental-health/how-common-are-mental-health-problems/#.XAGDCCXFKpo.

Mind. (n.d.). Peer support: helping each other. [online] [Accessed 21.09.2014]

http://www.mind.org.uk/information-support/guides-to-support-and-services/peer-support/about-peer-support/?o=10153.

Morris, J. (2012). *One town for my body, another for my mind*. York: JRF.

Morrow, O., Hawkins, R. and Kern, L. (2015). Feminist research in online spaces, Gender, Place and Culture. 22:4, 526-543. doi: 10.1080/0966369X.2013.879108.

Moscovici, S. (1988). Notes towards a description of social representations. *European Journal of Social Psychology*. 18, 211–250.

Moss, D. (2015). The Roots and Genealogy of Humanistic Psychology. In K.J. Schneider, J.F. Pierson and J.F.T. Bugental. (eds.) (2015). *The Handbook of Humanistic Psychology: Theory, Research, and Practice, 2nd ed.* London: SAGE.

Muntaner, C., and Chung, H. (2008). Macrosocial Determinants, Epidemiology, and Health Policy: Should Politics and Economics Be Banned from Social Determinants of Health Research? *Journal of Public Health Policy.* 29:3, 299-306.

Murray, C.J.L. and Lopez, A.D. (1997). The utility of DALYs for public health policy and research: a reply. *Bull World Health Organ.* 75, 377–381.

Naslund, J.A., Aschbrenner, K.A. and Bartels, S.J. (2016). How people with serious mental illness use smartphones, mobile apps, and social media. *Psychiatric Rehabilitation Journal.* http://dx.doi.org/10.1037/prj0000207.

Naslund, J. A., Grande, S. W., Aschbrenner, K. A., and Elwyn, G. (2014). Naturally occurring peer support through social media: The experiences of individuals with severe mental illness using you tube. *PLoS ONE*. 9:10. https://doi.org/10.1371/journal.pone.0110171.

Neal, L., Oakley, K., Lindgaard, G., Kaufman, D., Leimeister, J.M., and Selker, T. (2007). Online Health Communities. *Extended Abstracts on Human Factors in Computing Systems.* 2129-2132.

Nelson, G., Kloos, B. and Ornelas, J. (2014). *Community psychology and community mental health: towards transformative change*. Oxford: University Press.

NHS Digital. (2017). *Hospital accident and emergency activity, 2015-16*. [Online] [Accessed on 11th January 2017] http://www.content.digital.nhs.uk/catalogue/PUB23070.

NHS Choices online. (2013). *Online Mental Health Services*. [Online] [Accessed 3.6.2017] http://www.nhs.uk/conditions/online-mental-health-services/pages/introduction.aspx.

Nelson, G. and Prilleltensky, I. (2010). *Community Psychology 2nd Edition.* Palgrave MacMillan

NHS Digital. (2016). *Survey of Mental Health and Wellbeing.* [online] [Accessed 15.5.2016] http://webarchive.nationalarchives.gov.uk/20180328140249/http://digital.nhs.uk/catalogue/PUB21748

NHS Digital. (2015). *Psychological therapy: big differences in recovery rates across England.* [online] [Accessed 17.2.2016]. http://content.digital.nhs.uk/article/6829/Psychological-therapy-big-differences-in-recovery-rates-across-England.

NHS Digital. (2011). *Attitudes to Mental Illness – 2011, Survey Report.* [online] [Accessed 14.04.2013] https://digital.nhs.uk/data-and-information/publications/statistical/attitudes-to-mental-

illness/attitudes-to-mental-illness-2011-survey-report.

National Health Service and Community Care Act. (1990). *National Health Service and Community Care Act.* [online] [Accessed 10.10.2012] https://www.legislation.gov.uk/ukpga/1990/19/contents.

National Audit Office. (2017). *Mental Health in Prisons.* London: Her Majesty's Prison and Probation Service, NHS England and Public Health England.

Nilsson, S.F. and Nordentoft, M. (2018). How family income is associated with suicidal and violent behaviour in young adults. *Lancet Public Health.* 3:10. doi:https://doi.org/10.1016/S2468-2667(18)30181-6.

Noelle-Neumann, E. (1974). The Spiral of Silence: A Theory of Public Opinion. *Journal of Communication.*

Noorani, T. (2013). Service user involvement, authority and the 'expert-by-experience'in mental health. *Journal of Political Power.* 6:1, 49-68.

Norris, M. L., Boydell, K. M., Pinhas, L., and Katzman, D. K. (2006). Ana and the Internet: A review of pro-anorexia websites. *International Journal of Eating Disorders.* 39:6, 443–447. doi:10.1002/eat.20305.

Office for National Statistics (ONS). (2018). *Internet access- households and individuals, Great Britain, 2018.* [online] [Accessed 7/8/2018]. https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2018.

Orford, J. (2008). *Community Psychology: Challenges, Controversies and Emerging Consensus.* Wiley Online Books https://onlinelibrary.wiley.com/doi/book/10.1002/9780470773154.

Ostrum, L., Wilhelmsen, C., Kaplan, B. (1993). Assessing Safety Culture. *Nuclear Safety.* 34:2, 163-172.

Parcesepe, A. M., and Cabassa, L. J. (2013). Public stigma of mental illness in the United States: a systematic literature review. *Administration and policy in mental health.* 40:5, 384-99.

Park, A., Conway, M. and Chen, A.T. (2018). Examining thematic similarity, difference and membership in three online mental health communities from Reddit: A text mining and visualization approach. *Computers in Human Behaviour.* 78, 98-112. https://doi.org/10.1016/j.chb.2017.09.001.

Passarelli, N. (2017). Be careful with social media – employers are watching. *Financial Times.* [online] [Accessed 2.5.2018] http://on.ft.com/2tafipa.

Patel, V. (2017). Treating depression where there are no mental health professionals. *Bulletin of the World Health Organization.* 95, 172–173.

Patton, M.Q. (1990). *Qualitative evaluation and research methods.* Thousand Oaks, CA: Sage.

Pavalanathan, U., and De Choudhury, M. (2015). *Identity Management and Mental health Discourse on Social Media.* In Proceedings of WWW'15 Companion: 24th International World Wide Web Conference, Web Science Track. (Florence, Italy, May 18-22, 2015).

Pereles, L., Jackson, R., Rosenal, T. and Nixon, L. (2017). *Listening with a narrative ear.* [online]

[Accessed 19 Jul. 2017] http://www.cfp.ca/content/63/1/E44.

Pescosolido, B., Martin, J., Long, J., Medina, T., Phelan, J. and Link, B. (2010). 'A disease like any other'? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence.' *The American journal of psychiatry.* 167:11, 1321–30.

Pew Research Internet Project. (2014). *Social media networking fact sheet.* Pew Research Center. [online] [Accessed 7.7.2017] http://www.pewinternet.org/fact-sheets/social-networking-fact-sheet/.

Phillips, W. (2015). *This is Why We Can't Have Nice Things: Mapping the Relationship between Online Trolling and Mainstream Culture*. Massachusetts: MIT Press.

Pinfold, V., Sweet, D., Porter, I., Quinn, C., Byng, R., Griffiths, C., Billsborough, J., Gragn Enki, D., Chandler, R., Webber, M., Larsen, J., Carpenter, J. and Huxley, P. (2015). Improving community health networks for people with severe mental illness: a case study investigation. *Health Serv Deliv Res.* 3:5.

Pickett, K. E., and Wilkinson, R. G. (2010). Inequality: An underacknowledged source of mental illness and distress. *British Journal of Psychiatry.* 197:6, 426–428.

Pilgrim, D. (2014). *Key Concepts in Mental Health 3rd Edition.* London: SAGE.

Poole, R., Smith, D., and Simpson, S. (2015). How patients contribute to an online psychoeducation forum for bipolar disorder: A virtual participant observation study. *JMIR mental health*. 2:3.

Portnoy, D.B., Scott-Sheldon, L.A.J., Johnson, B.T. and Carey, M.P. (2008). Computer-delivered interventions for health promotion and behavioral risk reduction: A meta-analysis of 75 randomized controlled trials, 1988–2007. *Preventive Medicine.* 47:1, 3-16.

Putnam, R. D. (2000). *Bowling alone: The collapse and revival of American community*. New York: Simon and Schuster.

Preece, J. (2000). *Online Communities: Designing Usability and Supporting Socialbilty (1st ed.)*. New York, NY, USA: John Wiley and Sons, Inc.

Rains, S. A. and Brunner, S. R. (2015). What can we learn about social network sites by studying Facebook? A call and recommendations for research on social network sites. *New Media and Society*. 17, 114–131. doi:10.1177/1461444814546481.

Rafaeli, S., Ravid, G. and Soroka, V. (2004). *De-lurking in virtual communities: A social communication network approach to measuring the effects of social and cultural capital.* In Paper presented at the 37th annual Hawaii international conference on system sciences.

Rafferty, R. (2011). Motivations Behind Cyber Bullying and Online Aggression: Cyber Sanctions, Dominance, and Trolling Online. [online] [Accessed 27.12.2017] https://etd.ohiolink.edu/.

Rappaport, J. (2000). Community narratives: Tales of terror and joy. *American Journal of Community Psychology.* 35, 231-238.

Rappaport, J. (1977). Community Psychology: Values, Research and Action. USA: Holt, Rinehart and Winston.

RCPsych. (2018). *Mental health services have less money to spend on patient care in real terms than*

they did in 2012, official figures analysed by the Royal College of Psychiatrists show. [online] [accessed 24.02.2018] https://www.rcpsych.ac.uk/members/devolved-nations/rcpsych-in-wales/latest-news/press-releases.

RCPsych. (2018a). Cultural blog [online] [accessed 3.8.2018]. https://www.rcpsych.ac.uk/news-and-features/blogs/detail/cultural-blog/.

Reddit. (2015). *Reddit Forums* [online] [accessed 16th September 2016] https://www.reddit.com/.

Ren, Y., Harper, F. M., Drenner, S., Terveen, L., Kiesler, S., Riedl, J., and Kraut, R. E. (2012). Building member attachment in online communities: Applying theories of group identity and interpersonal bonds. *MIS Quarterly: Management Information Systems*. 36:3, 841-864.

Reno, J. (1999). *Report on cyber stalking: A new challenge for law enforcement and industry*. [online] [Accessed 18.2.2016] http://www.usdoj.gov/criminal/cybercrime/cyberstalking.htm.

Resca A., Tozzi M.L. (2013). Offline and Online Communities: Great Differences and Some Similarities. In: Baskerville R., De Marco M., Spagnoletti P. (eds) (2013). *Designing Organizational Systems. Lecture Notes in Information Systems and Organisation, vol 1*. Berlin, Heidelberg: Springer.

Rheingold, H. (1994). *The virtual community: Finding connection in a computerized world.* London: Secker and Warburg.

Richardson, L-J. (2015). Micro-blogging and Online Community. *Internet Archaeology.* 39. http://dx.doi.org/10.11141/ia.39.2.

Ridings, C. M., Gefen, D., and Arinze, B. (2002). Some antecedents and effects of trust in virtual communities. *Journal of Strategic Information Systems*. 11, 271–295.

Riger, S., and Lavrakas, P. J. (1981). Community ties: Patterns of attachment and social interaction in urban neighbourhoods. *American Journal of Community Psychology.* 9, 55-66.

Rizq, R. (2012). The perversion of care: Psychological therapies in a time of IAPT, *Psychodynamic Practice.* 18:1, 7-24. DOI: 10.1080/14753634.2012.640161.

Rochefort, D.A. (1993). *From poor houses to homelessness: Policy analysis and mental health care.* Westport, CT: Auburn House.

Rozatkar, A.R. (2014). Stigma of suicide. *J Neurosci Rural Pract.* 5, 206-7.

Rozzell, B., Piercy, C., Carr, C. T., King, S., Lane, B., Tornes, M., Johnson, A.J. and Wright, K. B. (2014). Notification pending: Online social support from close and nonclose relational ties via Facebook. *Computers in Human Behavior*. 38, 272–280. doi:10.1016/j. chb.2014.06.006.

Sahoo, J.R. (2017). Marginalisation, Communication and Media Life: An Explorative Study of Santal Community in India. *Global Media Journal.* [online] [Accessed on 13.09.17] http://www.globalmediajournal.com/open-access/marginalisation-communication-and-media-life-an-explorative-study-ofsantal-community-in-india.php?aid=85881.

Salzmann-Erikson, M. and Eriksson, H. (2012). LiLEDDA: A six-step forum-based netnographic research method for nursing science. *Aporia*. 4:4, 6-18.

Santini, Z.I., Koyanagi, A.Tyrovolas, S., Mason, C. and Haro, J.M. (2015). The association between

social relationships and depression: a systematic review. *J. Affect. Disord*. 175, 53-65.

Sartorious, N. (2007). Stigma and mental health. *Lancet.* 370:9590, 810-811.

Schiel, T. (2005). Modernity, Ambivalence and the Gardening State. *Thesis Eleven.* 83, 78 -89.

Schomerus, G., Angemeyer, M.C., Baumeister, S.E., Stolzenberg, S., Link, B.G. and Phelan, J.C. (2016). An online intervention using information on the mental health-mental illness continuum to reduce stigma. *European Psychiatry*. 32, 21–27.

Schneider, A., von Krogh, G., and Jager, P. (2013). "What's coming next?" Epistemic curiosity and lurking behaviour in online communities. *Computers in Human Behaviour.* 29:1, 293-303.

Schrank, B., Woppmann, A., Sibitz, I., and Lauber, C. (2010). Development and validation of an integrative scale to assess hope. *Health expectations : an international journal of public participation in health care and health policy*. 14:4, 417-28.

Schutt, R. K., and Rogers, E. S. (2009). Empowerment and peer support: Structure and a process of self-help in a consumer-run center for individuals with mental illness. *Journal of Community Psychology*. 37:6, 697-710. http://dx.doi.org/10.1002/jcop.20325.

Seale, C., Anderson, E. and Kinnersley, P. (2006). Treatment advice in primary care: a comparative study of nurse practitioners and general practitioners. *Journal of Advanced Nursing.* 54:5, 534–541.

Seidel, J. and Kelle, U. (1995). Different functions of coding in the analysis of textual data. In: Kelle U, (ed.) (1995). *Computer-aided qualitative data analysis: theory, methods, and practice*. Thousand Oaks, CA: Sage Publications.

Shepherd, A., Sanders, C., Doyle, M. and Shaw, J. (2015). Using social media for support and feedback by mental health service users: thematic analysis of a twitter conversation. *BMC Psychiatry.* doi 10.1186/s12888-015-0408-y.

Silver, L. and Johnson, C. (2018). Internet use is growing across much of sub-Saharan Africa, but most are still offline. Pew Research Center. [online] [accessed 20.10.2018] http://www.pewglobal.org/2018/10/09/internet-use-is-growing-across-much-of-sub-saharan-africa-but-most-are-still-offline/.

Simco, R., McCusker, J. and Sewitch, M. (2014). Adherence to self-care interventions for depression or anxiety: A systematic review. *Health Education Journal*. 73:6, 714–730.

Smith, A., Heyes, K., Fox, C., Harrison, J., Kiss, Z., and Bradbury, A. (2018). The effectiveness of probation supervision towards reducing reoffending: A Rapid Evidence Assessment. *Probation Journal.* https://doi.org/10.1177/0264550518796275.

Smith, J. P., and Randall, C. L. (2012). Anxiety and alcohol use disorders: comorbidity and treatment considerations. *Alcohol research: current reviews*. 34:4, 414-31.

Star, S. (1955). *The public's ideas about mental illness.* Paper presented at: Annual Meeting of the National Association for Mental Health; November 5, 1955; Indianapolis, Ind.

Spinzy, Y., Nitzan, U., Becker, G., Bloch, Y. and Fennig, S. (2012). Does the Internet offer social opportunities for individuals with schizophrenia? a cross-sectional pilot study. *Psychiatry Research*.

198, 319–320.

Spitzer, R.L. (1981). The diagnostic status of homosexuality in DSM-III: a reformulation of the issues. *Am J Psychiatry*. 138:2, 210–215. doi:10.1176/ajp.138.2.210. PMID 7457641.

Stanger, N. (2011). Moving "eco" back into socio-ecological models: A proposal to reorient ecological literacy into human developmental models and school systems. *Human Ecology Form*. 18:2, 167-173.

Stanko, E, A. and Lee, R, M. (2003). Introduction: Methodological reflections on researching violence. In Lee, R, M. and Stanko E, A. (eds.) (2003). *Researching Violence*. London: Routledge.

Steffens, N. K., Haslam, S. A., Schuh, S. C., Jetten, J. and van Dick, R. (2016). A Meta-Analytic review of social identification and health in organizational contexts. *Personality and Social Psychology Review.* doi: https://doi.org/10.1177/1088868316656701.

Steptoe, A., Shankar, A., Demakakos, P., and Wardle, J. (2013). Social isolation, loneliness, and all-cause mortality in older men and women. *PNAS.* 110:15, 5797 – 5801.

Stout, P.A., Villegas, J. and Jennings, N.A. (2004). Images of mental illness in the media: identifying gaps in the research. *Schizophrenia Bulletin*. 30:3, 543-561.

Strangleman, T. (2007). The nostalgia for permanence at work? The end of work and its commentators. *The Sociological Review*. 55:1, 81-103.

Sugiura, L., Wiles, R., & Pope, C. (2017). Ethical challenges in online research: Public/private perceptions. *Research Ethics*. 13:3-4, 184-199.

Suler, J. (2004). The online disinhibition effect. *Cyberpsychology and Behavior.* 7, 321-326.

Swanson, K.M. (1999). What's known about caring in nursing science: A literary meta-analysis. In: Hinshaw, A.S., Feetham, S. and Shaver, J. (eds.). (1999). *Handbook of clinical nursing research*. Thousand Oaks, CA: Sage.

Sydor, A. (2013). Conducting research into hidden or hard-to-reach populations. *Nurse Res*. 20:3, 33-37. 10.7748/nr2013.01.20.3.33.c9495.

Szasz, T.S. (1961). The uses of naming and the origin of the myth of mental illness. *American Psychologist.* 16, 59 – 65.

Szeto, A.C.H., Luong, D. and Dobson, K.S. (2013). Does labelling matter? An examination of attitudes and perceptions of labels for mental disorders. *Soc Psychiatry Psychiatr Epidemiol.* 48: 659-671. https://doi.org/10.1007/s00127-012-0532-7.

Tajfel, H., and Turner, J. C. (1979). An integrative theory of intergroup conflict. *The social psychology of intergroup relations?* 33, 47.

Tamersoy, A., De Choudhury, M., and Chau, P. (2015). *Characterizing Smoking and Drinking Abstinence from Social Media.* In Proceedings of 26th ACM Conference on Hypertext and Social Media (Middle East Technical University, North Cyprus Campus, September 1-4, 2015).

Tamir, D. I., and Mitchell, J. P. (2012). *Disclosing information about the self is intrinsically rewarding*. Proceedings of the National Academy of Sciences of the United States of America.

109:21, 8038-8043.

Tanis, M. (2008). Health-related on-line forums: What's the big attraction? *J Health Commun.* 13:7, 698–714.

Tang, G., and Lee, F.L.F. (2013). Facebook Use and Political Participation: The Impact of Exposure to Shared Political Information, Connections With Public Political Actors, and Network Structural Heterogeneity. *Social Science Computer Review*. 31:6, 763–773. https://doi.org/10.1177/0894439313490625.

Tasca, C., Rapetti, M., Carta, M. G., and Fadda, B. (2012). Women and hysteria in the history of mental health. *Clinical practice and epidemiology in mental health: CP and EMH*. 8, 110-9.

Tate, D.F. and Zabinski, M.F. (2004). Computer and Internet applications for psychological treatment: Update for clinicians. *Journal of Clinical Psychology.* 60:2, 209-220.

Taylor, C. (1992). The Politics of Recognition. In A. Gutmann (Ed.). (1992). *Multiculturalism and the Politics of Recognition.* Princeton: Princeton University Press.

The Lancet Psychiatry. (2018). *The medication debate: time to change the record* [online] [Accessed October 2018] https://www.thelancet.com/pdfs/journals/lanpsy/PIIS2215-0366(18)30359-6.pdf.

Third, A., Forrest-Lawrence, P. and Collier, A. (2014). Addressing the cyber-safety challenge [online] [Accessed 12.09.2015] https://www.telstra.com.au/content/dam/tcom/about-us/community-environment/pdf/cyber-safety-challenge-risk-resillience.pdf.

Tessier, S. (2012). From field notes, to transcripts, to tape recordings: Evolution or combination? *International Journal of Qualitative Methods*. 11:4, 446-460.

Time to Change. (2017). *For the first time, print media reporting of mental health is significantly more balanced and responsible with more coverage than ever before – latest study shows.* [online] [Accessed 13.11.2017] https://www.time-to-change.org.uk/news/first-time-print-media-reporting-mental-health-significantly-more-balanced-and-responsible-more.

Thoits, P.A. (2011). Resisting the stigma of mental illness. *Soc Psychol Q.* 74, 6–28. https://doi.org/10.1177/0190272511398019.

Thoits, P.A. (2011a). Mechanisms Linking Social Ties and Support to Physical and Mental Health. *Journal of Health and Social Behavior.* 52.

Thoits, P. A. (1986). Social Support as Coping Assistance. *Journal of Consulting and Clinical Psychology*. 54, 416–23.

Thoits, P. A., and Virshup, L. K. (1997). Me's and we's: Forms and functions of social identities. In R. D. Ashmore and L. J. Jussim (Eds.). (1997). R*utgers series on self and social identity, Vol. 1. Self and identity: Fundamental issues*. New York, NY, US: Oxford University Press.

Thornicroft, C., Wyllie, A., Thornicroft, G. and Mehta, N. (2014). Impact of the "Like Minds, Like Mine" anti-stigma and discrimination campaign in New Zealand on anticipated and experienced discrimination. *Aust N Z J Psychiatry*. 48, 360–70.

Thornicroft, G. (2011). Physical health disparities and mental illness: The scandal of premature

mortality. *British Journal of Psychiatry*. 199, 441-442.

Tonnies, F. (1957). *Community and society (C. P. Loomis, Ed. and Trans.)*. New York: Harper Torchbook.

Trickett, E.J. (1996). A future for community psychology: The contexts of diversity and the diversity of contexts. *American Journal of Community Psychology.* 24, 209-229.

Triggle, N. (2017). *NHS future precarious, says regulator.* [Online] [Accessed 24.2.2018] http://www.bbc.co.uk/news/health-41559669.

Trotter R.T., II. (2012). Qualitative research sample design and sample size: resolving and unresolved issues and inferential imperatives. *Preventive Medicine.* 55:5, 398–400.

Tudor, K. (1996). *Mental Health Promotion: Paradigms and practice.* London: Routledge.

Turkle. S. (1995). *Life on the Screen: Identity in the Age of the Internet.* New York: Simon and Schuster Trade.

Uchino, B. N. (2006). Social support and health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine*. 29, 377– 387. doi:10.1007/s10865-006-9056-5.

Urquhart, C. (2013). *Grounded Theory for Qualitative Research: A Practical Guide*. California, United States: Sage

Urry, J. (2002). Mobility and Proximity. *Sociology*. 36:2, 255–74.

Vaast, E. and Urquhart, C. (2017). Building Grounded Theory with Social Media Data. R. Mir, S. Jain. In: *Routledge Companion to Qualitative Research in Organization Studies*. London: Routledge.

von Krogh, G. (1998). Care in knowledge creation. *California Management Review.* 40:3, 133–153.

Verhaak, P. F. (1988). Detection of psychologic complaints by general practitioners. *Medical Care.* 26:10, 1009-1020. http://dx.doi.org/10.1097/00005650-198810000-00009.

Wacquant, L. (2008). *Urban outcasts: A comparative sociology of advanced marginality*. Cambridge: Polity Press

Wagner, T.H., Baker, L.C., Bundorf, M.K. and Snger, S. (2004). Use of the internet for health information by the chronically ill. *Preventing Chronic Disease*. 1:4.

Waldenström, K., Ahlberg, G., Bergman, P., Forsell, Y., Stoetzer, U., Waldenström, M. and Lundberg, I. (2008).   Externally assessed psychosocial work characteristics and diagnoses of anxiety and depression. *Occupational and Environmental Medicine*. 65, 90-96.

Walker, C. (2007). *Depression and globalization: The politics of mental health in the 21st century.* Berlin: Springer Science and Business Media.

Walker, C., Hart, A. and Hanna, P. (2017). *Building a New Community Psychology of Mental Health: Spaces, Places, People and Activities.* New York: Palgrave.

Walker, C. and Fincham, B. (2011). *Work and the Mental Health Crisis in Britain*. Chichester, East Sussex: John Wiley and Sons. eISBN-13: 9781119974239.

Wenger, E. (1998). *Communities of Practice.* Cambridge, UK: Cambrige University Press.

Wasko, M. M., and Faraj, S. (2005). Why should I share? Examining social capital and knowledge contribution in electronic networks of practice. *MIS Quarterly*. 29:1, 35–57.

Weiner, E. (2008). *The geography of bliss.* New York: Twelve.

Wenger, E. (1998). *Communities of Practice*. Cambridge, UK: Cambrige University Press.

Welbourne, J.L., Blanchard, A.L. and Wadsworth, M.B. (2013). Motivation in virtual health communities and their relationship to community, connectedness and stress. *Computers in Human Behavior.* 29, 129 -139.

Weller, S.C. and Romney, A.K., (1988). Systematic data collection. *Qual. Res. Meth*. 10.

Welsh, E. (2002). Dealing with Data: Using NVivo in the Qualitative Data Analysis Process. *Forum for Qualitative Research.* 3:2.

Wilkinson, R. G., and Pickett, K. (2009). T*he spirit level: Why greater equality makes societies stronger.* New York: Bloomsbury Press.

Wittel, A. (2001). Toward a network sociality. *Theory Culture Society*. 18:6, 51–76.

Whitley, R. and Berry, S. (2013). Analyzing media representations of mental illness: Lessons learnt from a national project. *Journal of Mental Health.* 22:3, 246-253. doi:10.3109/09638237.2012.745188.

Wills, T. A. (1981). Downward comparison principles in social psychology. *Psychological Bulletin*. 90, 245-271.

WHO. (2015). *Global health workforce, finances remain low for mental health*. World Health Organization. [Online] [Accessed on 11th January 2017] http://www.who.int/mediacentre/news/notes/2015/finances-mental-health/en/.

WHO. (2005). *Promoting mental health.* [Online] [Accessed on 8.8.2016] http://www.who.int/mental_health/evidence/MH_Promotion_Book.pdf. WHO (1948) International Classification of Diseases (ICD) 6th Edition. Geneva: WHO.

Wood, J.V. (1989). Theory and research concerning social comparisons of personal attributes. *Psychological Bulletin.* 106, 231-248.

WHO. (2001). *The World health report: 2001: Mental health: new understanding, new hope.* Geneva: WHO.

Whybrow, P. and Heyes, K. (2016). *Caring for Carers 15th June.* Cost of Living blog [Online] http://www.cost-ofliving.net/caring-for-carers/.

Woong, Y. G. and Park, S.-Y. (2011). Selective posting: Willingness to post a message online. *Journal of Computer-Mediated Communication*. 16:2, 201–227.

Wright, K. B. (2016). Communication in Health-Related Online Social Support Groups/ Communities: A Review of Research on Predictors of Participation, Applications of Social Support Theory, and Health Outcomes. *Review of Communication Research*. 4, 65-87. doi:10.12840/issn.2255-4165.2016.04.01.010

Wright, N., Jordan, M. and Kane, E. (2014). Mental health/illness and prisons as place: Frontline

clinicians' perspectives of mental health work in a penal setting. *Health and Place*. 29, 179–185.

Wright, K. B., and Miller, C. H. (2010). A measure of weak-tie/strong-tie support network preference. *Communication Monographs*. 77:4, 500–517. http:// dx.doi.org/10.1080/03637751.2010.502538.

Yalom, I. and Leszcz, M., (2005). *Theory and Practice of Group Psychotherapy, Fifth Edition* New York: Basic Books.

Yeo, A., Legard, R., Keegan, J., Ward, K., McNaughton Nicholls, C. and Lewis, J. (2014). *In-Depth Interviews.* In Ritchie, J., Lewis, J., McNaughton Nicholls, C. and Ormston, R. eds. (2014). *A Guide for Social Science Students and Researchers* London: SAGE.

Yonker, L.M., Zan, S., Scirica, C.V., Jethwani, K. and Kinane, T.B. (2014). "Friending" teens: systematic review of social media in adolescent and young adult health care. *J. Med. Internet Res*. 17.

Yuill, C., Crinson, I., and Duncan, E., (2010) *Key concepts in health studies* London: Sage Publications Ltd.

Zhu, Q. (2011). *Self-disclosure in online support groups for people living with depression*. Singapore: National University of Singapore. 105.

Ziebland, S. and Wyke, S. (2012). Health and illness in a connected world: how might sharing experiences on the internet affect people's health? *Milbank Quarterly*. 90, 219–249.

Appendices

Appendix A. Signposting document, participant information and consent form

HEALTH AND WELLBEING SERVICES

August 2015   Issue 2

Should you feel that you need to speak to someone about your emotional wellbeing, please see the suggestions below.

CHECK YOUR MOOD

www.nhs.uk/conditions/stress-anxiety-depression

This is a great website with lots of advice for improving health and wellbeing. There is also an online mood checker and audio guides to common mental health issues.

Another useful website is:

moodgym.anu.edu.au

the MoodGYM
TRAINING PROGRAM / Mark III

This website aims to provide the user with the tools to cope with mental illness.

Rethink Mental Illness

Support and advice for people living with mental illness.
Phone: 0300 5000 927 (Mon-Fri, 10am-2pm)
Website: www.rethink.org

Depression Alliance

Charity for sufferers of depression. Has a network of self-help groups.
Website: www.depressionalliance.org

Samaritans

Confidential support for people experiencing feelings of distress or despair.
Phone: 08457 90 90 90 (24-hour helpline)
Website: www.samaritans.org.uk

Sane

Charity offering support and carrying out research into mental illness.
Phone: 0845 767 8000 (daily, 6pm-11pm)
SANEmail email: sanemail@org.uk
Website: www.sane.org.uk

Mind

Promotes the views and needs of people with mental health problems.
Phone: 0300 123 3393 (Mon-Fri, 9am-6pm)
Website: www.mind.org.uk

The Mental Health Foundation

Provides information and support for anyone with mental health problems or learning disabilities.
Website: www.mentalhealth.org.uk

Participant Information Form

PhD title: Narrative accounts of how people with mental health issues construct support mechanisms.

The project consists of research conducted by Kim Heyes, a PhD student at the MMU Cheshire campus. As someone with mental health issues, I feel that the way mental health support services are conducted in the UK, are not necessarily what service users need. There is now a push towards using online support services, and I am interested in why people with mental health issues have used online support services or forums.

Through conducting one to one interviews, I aim to show how different everyone's experiences are. Mental health service provision is not as diverse as physical health provision, and I believe that should change. The first interview will be approximately one hour long. I will arrange a safe location, near to your home if that is easiest, or at a Manchester Metropolitan University campus. A time and date will be agreed between us. I will record the interview on a dictaphone, and will transcribe (type up) our conversation soon after. The recording will then be deleted and I will save the written work on a password protected computer. A second interview will take place for you to comment further on your experience, and you may add or delete anything from the previous discussion.

During the interview, I may utilise anxiety reducing techniques, such as drawing, whilst talking. This will be discussed with you beforehand to ensure that the most appropriate technique is used for you.

Before conducting the research, I will ask you to sign a consent form (Please see the next page). This allows me to use the data in my research, including any publications that may arise from the final PhD. If you wish to remain anonymous, then your confidentiality will be of utmost importance to me, and I will ensure that any identifying information is taken out of any written work.

If you have any further questions, please feel free to email me – k.heyes@mmu.ac.uk

Consent Form

Project Name: Narrative accounts of how people with mental health issues construct support mechanisms.

Department: Department of Interdisciplinary Studies

Author: Kim Heyes, email address k.heyes@mmu.ac.uk

Project Supervisor: Dr. Geraldine Lee-Treweek, contact number: 0161 247 5419

Project: This project is to understand why people with mental health issues have used online support services. Your participation in this research is completely voluntary. This research is designed to gather data about your experiences and to use your personal knowledge to improve and suggest improvements to services in the future.

Ethical guidelines: During this study, your anonymity and confidentiality will be upheld as per the ethical standards of the British Psychological Society (BPS) and Manchester Metropolitan University (MMU). Information gathered will be anonymized, this means that no one will recognize you through the information that you give. All names will be changed within 48 hours of data collection and data storage will be locked in a filing cabinet, or stored on a pc with passwords as per requirements of the Data Protection Act (1998). The ethical standards set by the BPS and MMU are designed to protect participants and ensure researchers adhere to guidelines.

The research: Will be recorded on a dictaphone, and may include the researcher taking notes. If you wish to see anything that I have written about you, you are welcome to access this at any time. I will not discuss any other participant with you, or let you have access to the notes I have on them, nor will I share any information about you to anyone else participating in the research.

Use of information: The information that is gained from this research will be used in my doctoral work and related projects only. This means that my written qualification and papers may be published in academic journals, all adhering to the confidentiality and anonymization as stated above.

Withdrawal: You do not have to participate, although I hope you will see the benefits of conducting this type of research. You may also decide to participate and then change your mind at a later date. This is perfectly understandable, and if that is your choice, all of the data relating to you will then be removed and deleted. You can withdraw without question through email, phone or in person.

If you are not clear about anything at any stage of the research, please contact me and I will be happy to answer any questions. If there are any concerns or complaints, please contact Dr. Geraldine Lee-Treweek at Manchester Metropolitan University.

If you are satisfied with the information given and would like to participate in the research, please sign below.

I understand what the research is for, my part in the research and that I am able to withdraw at any time.

Signature: _____

Full Name: _____

Date: _____

Questions for interviews:
Main themes from phase 1: Safety, support and Network Sociality
I want to know about people's experiences of mental health services.
If they could tackle stigma surrounding mental health, how would they do it?
I also want to understand how their mental health experience has shaped where they are today, how they think about themselves and what issues that have found with health service providers. Some leading questions may be asked in order to probe certain points.

Personal
Tell me a little about yourself and how this links with participating in this interview
Tell me about your mental health problem in your own words
When do you think it started? How and when did you recognise it?
Was there a reason for the start of it (in your opinion)?
Did you realise at the time?
Did anyone around you realise? What kind of help did you seek – if any
How long was it until you sought help?
Did you tell anyone outside of health service providers? How did you tell others about your difficulties and why?

What is the impact that this has had on you (work/ friends/ family)?

What about work?

Barriers
Do you feel that there are barriers attached to your mental health condition?
Have you had experiences that have led you to think this way?
What are the main factors? Is it community based or political?
Prompt – i.e. stigma
Do you think you are dis-proportionately affected by stigma for any reason? (ie. Sexual orientation/ religion etc)
What advice would you give to the Government in order to combat this (*whatever they state as the main barrier)*?

Experiences of health services
What experience have you had of health services?
Have you had a professional diagnosis?
What happened after this point? Were you given any further support?
How did you feel at that point?
Were all of your questions answered?
Was there any explanation or guidance given?
Were you referred to anywhere else? (Also known as signposted).

Online Forums
When did you first use an online forum/ social media?
Can you tell me about what made you think of using the forum?
What was your experience of going online in order to find a forum?
What do you feel you gain/ed from being part of it?

What do you think health care professionals could put in place to make mental health treatment and assessments better?
If you could change anything about how mental health is dealt with in the UK, what would it be?

Theory creation:

Basic coding: 6 c's Causes, Contexts, contingencies, consequences, covariances and conditions.

Moment capture: The enormity of a situation (as deemed by the person with mental ill health) is either made positive or negative by the support provided immediately afterwards. If participant goes online and manages to offload, she turns it into a positive experience, if participant looks forward to going out, but is unable to because of family issues, the continuation of work and little rest or play ultimately turns into a negative experience.

This is the same with work issues, if help is given at a point of enormity, the chances are that the experience is positive. If there is a lack of understanding, or punishment, the outcome will be negative.

Code: Safe spaces + Category: Support = Positive outcome

Code: Safe spaces − Category: Support = negative outcome
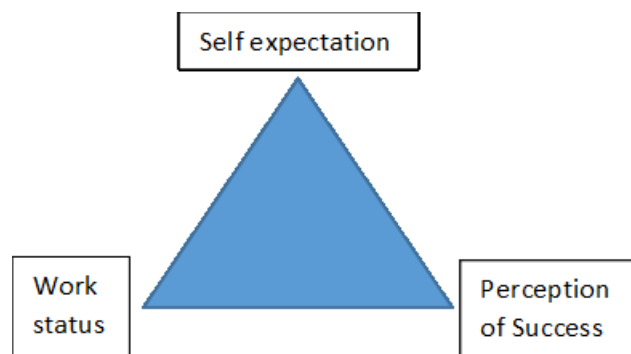
Figure 11 Causal inference of the impact of work, self-expectation and the perception of success
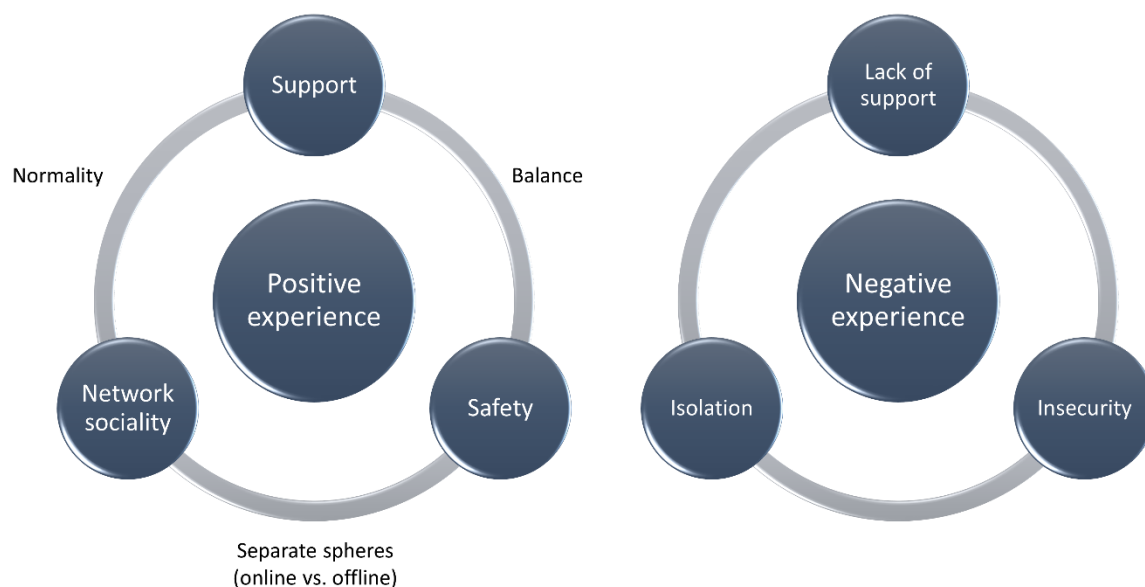
Figure 12 Causal inference of themes on experience of online support

Appendix D. The Conversation Article

THE CONVERSATION
Academic rigour, journalistic flair

Search analysis, research, academics…

Arts + Culture   Business + Economy   Cities   Education   Environment + Energy   **Health + Medicine**   Politics + Society   Science + Technology   Brexit

Mental health: the dangers of the social media diagnosis

February 28, 2018 1.31pm GMT

Shutterstock/AntonioGuillem

Email
Twitter   60
Facebook   258
LinkedIn
Print

Even Facebook agrees that social media can be <u>bad for your mental health</u>. And research by the Department of Education has found that the mental well-being of teenage girls in the UK <u>is worsening</u>, with the impact of social media cited as the cause.

Yet <u>my research</u> reveals that more people are turning to these platforms for help with their

Author

Kim Heyes
Research Associate, Manchester Metropolitan University

Disclosure statement

Appendix E. Article Impact (End of Oct. 2018)

Heyes, K. (2018). Socialisation or Social Isolation? Mental Health Community Support in the digital age. In El Morr, C (ed) (2018) *Novel Applications of Virtual Communities in Healthcare Settings* PA, USA: IGI Global https://www.igi-global.com/chapter/socialization-or-social-isolation/190033.

Heyes, K. (2017). *Using virtual ethnography to research vulnerable participants online: A case study of mental health online community support forums.* Online: SAGE Research Methods. http://methods.sagepub.com/case/virtual-ethnography-vulnerable-participants-online-community-support-forums.

Appendix I. Kim Heyes Academic C.V.