

Chapter 21

Socialization or Social Isolation? Mental Health Community Support in the Digital Age

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ABSTRACT

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

INTRODUCTION

There are many people living and surviving in the community with mild to severe mental health problems who do not have easy access to professional health and social care services. Globally, we have started to see a demand for more choice in how healthcare provision is provided, however constant cuts to healthcare budgets in the Global North mean that options such as telehealthcare and online services are seen as a cheaper alternative, and are often billed as a more effective solution (Chambers *et al.*, 2016). This is despite much research showing that there is little to no benefit of this method of support, particularly that of peer to peer online support communities (Eysenbach *et al.*, 2004).

This chapter specifically examines the experience of online community support groups as reported by users. Twenty-five participants answered between one and six open questions posted on three different mental health forums. The research began out of concern that healthcare providers in the Global North are directing people with mental health problems to online self-care or peer to peer support services, which may not be suitable for all mental health patients. Despite a paucity of research showing completion rates of professional online therapeutic support interventions are rare (Simco *et al.*, 2014),

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those that do complete the set programmes have been found to benefit from the support (Learmonth *et al.*, 2008). However, statistics released in January 2017 by NHS Digital (the UK National Health Service) show that more people than ever are turning up at hospital emergency departments in the UK to receive support for mental health issues (NHS Digital, 2017). Since 2011, the numbers of people going to emergency hospital departments because of their mental ill health has increased by over 50%, and this is also the case for those under the age of 18 (NHS Digital, 2017). This shows that despite a growing number of professional and peer to peer online support services, there may still be a growing need for face-to-face intervention.

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

BACKGROUND

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

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

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

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