Mental Health and Social Inc

Foregrounding the perspectives of mental health service users during the COVID-19 pandemic.

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Structured Abstract

Purpose

This viewpoint highlights the critical importance of perspectives of mental health service-users during the COVID-19 pandemic.

Design

This viewpoint is based on a review of recent research and literature and draws on consultations with experts by experience, including the lead author.

Findings

We argue that expertise-by-experience is critical to policy, service development and research; but there is a risk it will be neglected at a time of rapid and reactive clinical development.

Research Limitations / Implications

Understanding and responding to the nuances of individual need can only be achieved through coproducing service strategy design, delivery and research with mental health service users. The consultation outlined in this viewpoint gives some indication of the type of valuable insights that can be gained through seeking and listening to the perspectives of experts by experience.

Originality

Our discussions revealed that experience of managing severe and complex mental health conditions can actually be advantageous when facing a crisis such as COVID-19.

Main Text

The potentially devastating impact on public mental health of the COVID-19 pandemic and associated quarantine measures is widely recognised (Brooks et al, 2020) and the economic impact of the pandemic poses additional risks to health. However, very little is known about the impact of pandemics on those who live with pre-existing mental health conditions and rely on mental health services. It is highly likely that anxiety about the virus, confusing and changing health messages, and social distancing measures will exacerbate existing mental health difficulties, at a time when access to mental health support may be more limited, and largely delivered remotely for the first time. Understanding the perspectives and needs of mental health service users during the COVID-19 pandemic, and how services can respond optimally within the limitations set by the virus, will be critical to minimising negative outcomes for patients. The personal cost to patients of service provision that does not meet dominant needs is high and could include increased and additional symptoms of mental illness, acute crisis, risky behaviour, domestic violence, and suicide. Unmet mental health needs and confusion about where to seek emergency mental health support is likely to burden the wider healthcare system at a time when it is critical to minimise the burden on these services.

The lead author, who lives with bipolar 1 disorder, consulted with six fellow long-term mental health service-users (five women, one man) from across the UK to share experiences of the COVID-19 crisis and the mental health service response. These discussions identified that, within one month of COVID-19 related social distancing measures being implemented in the UK, people who rely on mental health services are already confronting many practical and psychological difficulties. People discussed becoming more isolated during quarantine, with enforced separation from family members and friends, as well as reduced access to mental health professionals. This isolation has resulted in feelings of extreme loneliness and, in one instance, suicidal ideation. For others, isolation has prevented participation in community-based activities that are important for regulating mood and maintaining connections. For one person who can find social interaction difficult, the separation enforced by quarantine was initially a relief; however, she was aware that loneliness was likely to lead to severely depressed mood if quarantine persists. Several people observed that heightened anxiety had resulted in sleep disturbance, which exacerbated comorbidities.

There is a growing recognition that the perspectives of experts by experience are essential to effective strategic decision making in healthcare service delivery and research (NICE, 2011, Beresford, 2007). However, the perspectives of those with lived experience of mental ill-health have so far been largely absent during the COVID-19 pandemic.4 Coproduction of mental health service development based on reciprocal relationships that honour the expertise of patients as well as service providers, clinicians and researchers, leads to improved services and outcomes. However, during crisis situations, including the COVID-19 pandemic, the need for rapid and responsive decision making and service development may result in neglect of the perspectives of experts by experience.

It is important to understand how the changes to mental health service delivery (e.g. remote provision such as consultations being offered by telephone or video call to minimise the risk of viral spread) impact people who use mental health services. Our discussions indicted that, the shift to remote service provision was mostly proving unproblematic and, for some, had actually resulted in more frequent interactions with psychiatrists. However, concerns were raised about accessing remote services if people experience deterioration in their mental health. For example, one person stressed that when unwell she loses much of her ability to articulate distress verbally, at which juncture a telephone consultation would no longer be useful to manage her condition. Further, a number of people have found it hard to access essential services requiring in-person contact, such as blood monitoring. Three people voiced intense concern about what services they would be able to safely access in the event of becoming seriously unwell and requiring acute or inpatient care. Limited communication from mental health services was also identified as contributing to increased anxiety; for instance, care professionals not explaining the rationale for advising that service users ensure they have a longer-term supply of medications.

Extreme precarity in the outside world, and the amplification of this via media, has been recognised as exacerbating the psychological impact of quarantine (Holmes et al, and was remarked on in our discussions as a factor that has recently intensified difficulties with maintaining internal mental stability. However, for some, the sense that everyone is ‘in it

together' was positive, and for one person, the quarantine was not experienced as any more stressful than other life events. Indeed, all commented that skills and resilience they have developed to enable them to live with serious mental health conditions had been helpful in coping with the COVID-19 pandemic. These coping mechanisms include having a structured routine, maintaining social contact, keeping a steady focus on the present, knowing how to monitor wellbeing and manage micro triggers, and understanding personal limitations. Interestingly, people also reflected on having already learnt to adapt to social isolation and reduced agency due to mental illness or service interventions (e.g. inpatient treatment), which appears to have helped people acclimatise to the current situation.

It is vitally important that we understand how to effectively support people with pre-existing mental health conditions during the COVID-19 pandemic and beyond. Understanding and responding to the nuances of individual need can only be achieved through coproducing service strategy design, delivery and research. The consultation outlined in this viewpoint gives some indication of the type of valuable insights that can be gained through seeking and listening to the perspectives of experts by experience. However, more substantial coproduction and systematic research will be needed to fully realise the potential benefits of this approach (New Economics Foundation, 2013). We know that genuine coproduction is rarely achieved even in more typical circumstances. Therefore, in these extraordinary times of global public health crisis, and rapidly changing service delivery, if we are to succeed in realising the benefits of participation and coproduction, a clear commitment, supported by appropriate resource allocation, will be required. Further, it is likely that methodological innovation will be needed to facilitate effective coproduction while respecting the need for social distancing.

Importantly, our discussions revealed that experience of managing severe and complex mental health conditions can actually be advantageous when facing a crisis such as COVID-19. It is likely that understanding the resilience of people who have long-term mental health conditions may be relevant to supporting wider society to cope effectively in situations of adversity and times of reduced liberty.

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