Perspectives of patients, family members, health professionals and the public on the impact of COVID-19 on mental health

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ABSTRACT

Background: The coronavirus (COVID-19) pandemic has seen a global surge in anxiety, depression, post-traumatic stress disorder (PTSD), and stress.

Aims: This study aimed to describe the perspectives of patients with COVID-19, their family, health professionals, and the general public on the impact of COVID-19 on mental health.

Methods: A secondary thematic analysis was conducted using data from the COVID-19 COS project. We extracted data on the perceived causes and impact of COVID-19 on mental health from an international survey and seven online consensus workshops.

Results: We identified four themes (with subthemes in parenthesis): anxiety amidst uncertainty (always on high alert, ebb and flow of recovery); anguish of a threatened future (intense frustration of a changed normality, facing loss of livelihood, trauma of ventilation, a troubling prognosis, confronting death); bearing responsibility for transmission (fear of spreading COVID-19 in public; overwhelming guilt of infecting a loved one); and suffering in isolation (severe solitude of quarantine, sick and alone, separation exacerbating grief).

Conclusion: We found that the unpredictability of COVID-19, the fear of long-term health consequences, burden of guilt, and suffering in isolation profoundly impacted mental health. Clinical and public health interventions are needed to manage the psychological consequences arising from this pandemic.

Key words: COVID-19, SARS-CoV-2, depression, anxiety, PTSD

INTRODUCTION

The coronavirus (COVID-19) pandemic has seen a global surge in rates of mental health problems including anxiety, depression, post-traumatic stress disorder (PTSD), and stress (Salari et al., 2020; Xiong et al., 2020). Spikes in suicides and substance abuse during this crisis are also evident (Czeisler et al., 2020). In their recent meta-analysis of 226,638 individuals across 60 studies, Castaldelli-Maia and colleagues (2021) reported that the global prevalence of depression and anxiety during the COVID-19 pandemic was 24.0% and 21.0% respectively. Prior to the COVID-19 pandemic, the prevalence of depression in Asia ranged from 1.3% to 3.4% versus 15.4% to 19.8% after the initiation of COVID-19. These increases in prevalence of depression were also seen in countries in Europe with a prevalence of 1.4-3.9% prior to the COVID-19 pandemic versus 26.0% during the COVID-19 pandemic and in other regions with a prevalence of 2.1-4.3% prior to the COVID-19 pandemic versus 29.2% during the pandemic (Castaldelli-Maia et al., 2021). Similarly, the prevalence of anxiety increased during the COVID-19 pandemic in Asian countries (2.1% to 4.1% versus 17.8%), among European countries (3.0-7.4% versus 19.2%) and in countries outside of Asia and Europe (2.8%-7.1% versus 28.6%) (Castaldelli-Maia et al., 2021). These increases in mental health problems may be directly attributable to COVID-19 infection as well as public health mitigation measures (Dubey et al., 2020; Killgore et al., 2020; Szcześniak et al., 2021). For patients with COVID-19, psychological consequences are also exacerbated by the fear of health complications, hospitalisation and treatment-related trauma (Dubey et al., 2020; Kong et al., 2020; Xiang et al., 2020).

The World Health Organization (WHO) defines mental health as "a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of

life, can work productively and fruitfully, and is able to make a contribution to her or his community" (WHO, 2004). Mental health, including anxiety, depression and PTSD have been specifically prioritised as important by patients with COVID-19, family members, the general public and health professionals (Evangelidis et al., 2020). Yet, addressing these mental health outcomes remains a major challenge (Torales et al., 2020; Xiang et al., 2020).

Insights into the causes and impacts of COVID-19 from the patient, family, public and health professionals' perspectives remain sparse. The aim of this study was to describe perspectives from people with suspected or confirmed COVID-19 and their family, health professionals and the general public on the impacts of COVID-19 on mental health.

METHODS

Context and study design

The COVID-19-Core Outcome Set (COS) project was launched in March 2020 to establish a core outcomes set for patients with suspected or confirmed COVID-19 across the full spectrum of disease and all healthcare settings (Evangelidis et al., 2020; Tong et al., 2020; Tong et al., 2020). The core outcomes for COVID-19 are mortality, respiratory failure, multiorgan failure, shortness of breath and recovery (Tong et al., 2020). Mental health outcomes of COVID-19 (e.g. depression, anxiety, loneliness, and PTSD) were also identified to be important by patients and their family, the general public and health professionals (Evangelidis et al., 2020; Tong et al., 2020). People aged 18 years and older with confirmed or suspected COVID-19, their family members, members of the public and health professionals (including clinicians, researchers and policy makers) were invited to participate

in the survey and workshops. Participants were invited through multiple recruitment strategies including through the Steering Committee and investigator collegial networks and professional and consumer organisations using email, social media and a market research company. As depicted in Table 1, 9,289 stakeholders from 111 countries in the international survey (available in English, Chinese, Italian, Spanish and Portuguese) and 134 stakeholders from 21 countries in the consensus workshops contributed (Evangelidis et al., 2020). The countries included in both the survey and the workshops represents the range of countries that recruited participants came from. Of the 9,289 participants in the international survey, 5,927 responded in English, 1,480 responded in Chinese, 674 responded in Italian, 652 responded in Spanish and 556 responded in Portuguese. Further detail on the recruitment, methods, focus and results of the survey and workshops are provided in the previous papers (Evangelidis et al., 2020; Tong et al., 2020; Tong et al., 2020). The University of Sydney provided ethics approval (2020/151). Participants provided consent for their data to be used in the study.

We conducted a secondary analysis of the qualitative data from the COVID-19 COS project, which included open text comments from the international survey (open on March 31 2020 to April 16 2020 with 3,958 survey respondents providing at least one free text comment) and transcripts from seven online stakeholder consensus workshops conducted in April 2020 (workshops 1-4) and May 2020 (workshops 5-7) (Evangelidis et al., 2020; Tong et al., 2020). Secondary analysis of qualitative data involves the analysis of an existing dataset to maximise the use of the data collected from a different or similar research question and can produce new social and methodological understandings not included in the primary analyses (Irwin, 2013). In this study, the existing dataset was created to identify what outcomes people with COVID-19, their family, health professionals and members of the public believed

should be included in clinical trials assessing COVID-19. This study sought to maximise the use of this dataset by conducting a secondary analysis to produce new understandings on the perspectives of this group on the mental health impact of COVID-19. Quotations that have been reported in published work are referenced.

Data extraction and analysis

Participant quotations were extracted from the open text comments from the international survey and the transcripts of the seven online consensus workshops. The responses from the survey and the workshops were all translated into English and analysed by English-speaking authors. In addition, one native-speaking investigator reviewed the responses to ensure that the themes captured the data. EG manually analysed the data and recorded common patterns relating to the research question as initial codes. Regular meetings between EG, AT and AB were held to discuss the initial codes and a list of preliminary themes were developed. The transcripts were then reviewed line-by-line (EG) and coded in HyperRESEARCH version 4.5.1 (ResearchWare, Randolph, Massachusetts, USA). Themes were refined and finalised after discussions with other investigators (authors initials) to ensure they captured the full range and depth of data relating to the mental health impact of COVID-19.

RESULTS

Participant characteristics

Participant characteristics are provided in Table 1. Overall, 9,289 participants from 111 countries (776 people with COVID-19 or family members, 4,882 health professionals and

3631 members of the public) contributed to the international survey and 134 attendees (28 with suspected or confirmed COVID-19) from 21 countries (Australia, Austria, Belgium, Brazil, Canada, Chile, China [mainland China and Hong Kong SAR], France, Germany, Italy, Japan, Portugal, Republic of Ireland, Saudi Arabia, South Africa, South Korea, Spain, Switzerland, United States, United Kingdom) participated in the seven online stakeholder consensus workshops (Evangelidis et al., 2020; Tong et al., 2020).

Themes

We identified four themes (with subthemes in parenthesis): anxiety amidst uncertainty (always on high alert, ebb and flow of recovery), anguish of a threatened future (intense frustration of a changed normality, facing loss of livelihood, trauma of ventilation, a troubling prognosis, confronting death), bearing responsibility for transmission (fear of spreading COVID-19 in public, overwhelming guilt of infecting a loved one) and suffering in isolation (severe solitude of quarantine, sick and alone, separation exacerbating grief). Supporting quotations for each subtheme are provided in Table 2. A thematic schema demonstrating the relationships between the themes is provided in Figure 1. Concepts that were specific to patients, family members, the general public or health professionals are specified accordingly.

Anxiety amidst uncertainty

Always on high alert: Due to the uncertainty of COVID-19 symptoms and diagnosis, patients with COVID-19 and members of the public felt they were always "on high alert; constantly looking for information about symptoms and whether a symptom they are experiencing is a

sign of COVID -19.” Some felt apprehensive not knowing whether they had contracted the virus which was “one of the most challenging elements of this pandemic” and participants recognised that this “caused anxiety and makes breathing harder.”

Ebb and flow of recovery: Patients and health professionals remarked that COVID-19 followed a dynamic and relapsing disease course, “recovery is not a single process, you don't recover or not, and you may recover different aspects at different times.” Some patients who had expected to recover within a two-week timeline felt despondent and anxious when they still felt unwell and experienced ongoing debilitating symptoms, “you're still here seven weeks later going, "Where do I fit in to all this?"”

Bearing responsibility for transmission

Fear of spreading COVID-19 in public: Being constantly preoccupied with potentially infecting others was deeply concerning for patients with COVID-19, “I wasn't worried about what was going to happen to me. I was worried about whether I'd given it to anybody when I went to the doctors.” The implications of having the virus and being contagious weighed heavily on the minds of patients with COVID-19 and posed “big implications on my life participation and my family.”

Overwhelming guilt of infecting a loved one: Participants experienced intense “guilt for spreading the disease to close and frail relatives, especially if they become hospitalised or die.” One participant described the “huge psychological, emotional impact” of passing the infection to their father who “ended up in ICU” and experienced life-threatening complications.

Anguish of a threatened future

Intense frustration of a changed normality: The possibility that life had changed permanently after diagnosis was a persistent worry among patients with COVID-19 who wanted to know when life would "get back to normal." People with suspected or confirmed COVID-19 and their families felt that the inability to partake in usual activities such as doing laundry or going for a run consequently "diminishes independence, erodes confidence and leads to depression [and] social isolation."

Facing loss of livelihood: The financial impacts of lockdown restrictions and widespread unemployment were emphasised by participants to be damaging to mental health. They were concerned that the socioeconomic impact of COVID-19 may contribute to an increase in "death due to suicide and economic distress." Health professionals observed that their patients with COVID-19 were terrified of potential financial instability from treatment with some "still requiring oxygen and hospitalisation" but nevertheless "they had to go back to work because they were day labourers and needed to make an income for their family" (Tong et al., 2020).

Trauma of ventilation: Treatment requiring ventilation was "very scary and uncomfortable" for patients with COVID-19 and "very distressing" for their family. The dread of needing ventilation was anxiety-provoking for patients and their family as "the word mechanical ventilation and ventilators ring a chilling bell in most patients and family members" (Tong et al., 2020). Patients who had undergone ventilation reported being left traumatised which some participants believed could contribute to patients and their families developing PTSD.

A troubling prognosis: Patients with COVID-19 and the general public were concerned of the risk of long-term health complications, "the most important thing to me would not be if I died with COVID, it's just if I got it and it destroyed say half my lung function" (Tong et al., 2020). Patients reported feeling "really scared" about "what my lungs are going to show because I've never had that kind of chest pain and shortness of breath before" (Tong et al., 2020).

Confronting death: For patients with COVID-19, facing "one's mortality or that of a loved one can lead to depression and anxiety." Other participants believed that the global media focus on deaths attributed to COVID-19 exacerbated this fear of death, "what a lot of people are worried about is death and I suppose it's because that is the big focus. Every day how many people died."

Suffering in isolation

Severe solitude of quarantine: Being quarantined or "enclosed" for extended periods of time, which for some people meant "literally no fresh air, no window, no sunlight," was considered to severely exacerbate "anxiety and depression levels." Isolation intensified fear of contracting COVID-19 among members of the general public when "they have to stay at home by themselves and fear for their lives (especially in the elderly) [which] has a huge psychological and emotional impact."

Sick and alone: Restricted contact with family during hospitalisation for COVID-19 was agonising for patients and participants felt the limited contact "could actually equate to you

actually being sicker and deteriorating a lot quickly into depression and anxiety" (Tong et al., 2020).

Separation exacerbating grief: Some participants were distraught witnessing families who were unable to say goodbye in-person and instead "had to stand outside and speak to their loved one on a walkie talkie" (Tong et al., 2020). They believed the inability to be "at the bedside of their dying family member" could have "long lasting effects" and prolong the grieving process for friends and family members.

DISCUSSION

This secondary analysis of an existing dataset provides important insight into how people with COVID-19, their family, the general public and health professionals perceive that COVID-19 in impacting mental health. The major themes identified highlight how COVID-19 is impacting mental health on different levels and through various mechanisms.

Participants were deeply worried about the uncertain trajectory and unpredictable impacts of COVID-19 on their daily lives, were fearful of serious long-term health consequences for patients, and suffered intense loneliness and isolation due to quarantine and social distancing measures. The possibility of being responsible for transmitting the virus to a family member or others in the community caused angst in patients with COVID-19 and some harboured guilt for infecting their family members. Patients who were quarantined endured distress as they were separated from their family support, and those who required medical intervention such as ventilation were traumatised about having to confront the imminent threat of death. Participants felt deeply concerned by the detrimental impact of COVID-19 on the economy,

work and their own and society's livelihood which was described as being exacerbated by the uncertainty of COVID-19 diagnosis, transmission and recovery and the harrowing mandatory quarantine and social isolation. Patients with COVID-19, their family, the general public and health professionals perceive that all these factors play a major role, individually and together, in worsening mental health outcomes.

There were some differences in perspectives by participant group, health status, age and location. Patients with COVID-19 were anguished by the possibility of long-term health complications, dynamic and relapsing recovery trajectories and were immensely worried about transmission of the virus to others. Members of the general public felt intensely anxious about contracting the virus, which they expressed was intensified by being isolated for extended periods. Patients and health professionals were troubled by the possible psychological impact on hospitalised patients with COVID-19 and their family in the face of restrictions that limited families from visiting sick relatives. Participants with comorbidities described their intense fear of contracting COVID-19 and developing severe health consequences due to their existing medical conditions. Hospitalised patients with COVID-19 that required ventilation described feeling terrified when they were forced to confront their own mortality. Younger patients feared the risk of inadvertently transmitting the infection to vulnerable relatives and, if transmission occurred, felt immense guilt. Further, health professionals in low-resource settings were concerned about the repercussion on mental health of patients who lost their jobs because of hospitalisation and treatment for COVID-19, which severely impaired patients' psychological well-being and livelihood.

According to a recent meta-analysis of 226,638 individuals across 60 studies, the global prevalence of depression and anxiety is increasing (Castaldelli-Maia et al., 2021). Compared

to before the COVID-19 pandemic, rates of both anxiety and depression have increased in Asia, in countries in Europe and in other regions (Castaldelli-Maia et al., 2021). Our findings provide some explanations for increased stress, anxiety and depressive symptoms due to the COVID-19 pandemic (Castaldelli-Maia et al., 2021; Torales et al., 2020; Xiang et al., 2020). Quarantine, isolation and hospitalisation for COVID-19 have previously been found to cause acute panic, anxiety, depression and PTSD (Dubey et al., 2020; Kong et al., 2020). However, our findings highlight additional reasons for the increase in mental health issues with COVID-19. Patients with COVID-19 and the general public lamented being unable to return to their usual activities. They were also distressed by the ongoing symptoms, ill-health, and unpredictability of their prognosis. The uncertain and extended recovery trajectories for COVID-19 can be detrimental to the mental health for many patients with COVID-19. This is particularly relevant given the emerging evidence of prolonged illness and persistent symptoms in patients with COVID-19 (Tenforde et al., 2020).

There are some similarities in the effects on mental health reported during other pandemics including the Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS) pandemics. The SARS and MERS outbreaks instigated fear, anxiety and panic in the general public and were associated with increased levels of PTSD, stress and psychological distress (Kim et al., 2019; Lee et al., 2007; Mukhtar, 2020; Xiang et al., 2020). Patients who were hospitalised for MERS also reported PTSD and people in Taiwan and Canada who were isolated for SARS reported increased levels of depressive symptoms and occurrence of PTSD (Batawi et al., 2019; Hawryluck et al., 2004; Ko et al., 2006). However, we identified the following additional mental health challenges of COVID-19: the anguish of the ups and downs of recovery, the loss of normality due to long-term illness and symptoms preventing patients from returning to routine activities such as exercise and work, and the

distinct mental health hardships of unprecedented community lockdown and quarantine including increased feelings of anxiety and depression from being isolated for extended periods. This analysis drew on existing data from a multinational dataset and we developed detailed insights into the perceived impacts of COVID-19 on mental health among a diverse population. We acknowledge the potential limitations in secondary analysis of qualitative data. The data analysed were not collected to specifically address the impact of COVID-19 on mental health which may have resulted in aspects of this topic being unreported such as the mental health impact on health care workers. Furthermore, while participants worldwide were invited to contribute to the survey and workshops, they were predominantly from high-income and English-speaking countries (Evangelidis et al., 2020; Tong et al., 2020).

Our findings highlight that the impact of the COVID-19 pandemic on mental health can be severe, complex and may be compounded by the uncertainty of COVID-19 infection, transmission and recovery and the potential long-term mental health effects of mitigation strategies such as mandatory quarantine and social distancing. Addressing mental health issues during the pandemic thus requires a multifaceted approach. We propose four key strategies based on recommendations from the United Nations (UN, 2020), our findings and the existing literature, to: 1) adopt a communication strategy that addresses COVID-19 information overload, informational uncertainty and misinformation; 2) upscale and expand digital-technology and telehealth interventions to increase access to mental health care; 3) increase funding for mental health care and training of community and frontline health workers in psychological first aid; and 4) increase research to evaluate the effectiveness of interventions that address the mental health impact of COVID-19.

The provision of current, clear and accurate information about COVID-19 in public health communication may help to minimise undue anxiety caused by COVID-19 information overload, uncertainty and misinformation (Brooks et al., 2020; Salari et al., 2020; UN, 2020; Vraga & Jacobsen, 2020). Government and public health officials as well as media outlets should adopt a clear, consistent and focussed communication strategy that avoids information overload by reporting essential information first and tailoring messages for select target audiences, ensures communication is transparent, and disseminates accessible, up-to-date and accurate information (Vraga & Jacobsen, 2020).

Recent evidence from systematic and rapid reviews suggest that digital interventions, including telehealth, are effective in reducing the COVID-19 related mental health burden by reducing symptoms of loneliness, anxiety and depression and have potential to benefit patients with COVID-19, their family and the general public (Brooks et al., 2020; Courtet et al., 2020; Galea et al., 2020; Gupta & Dhamija, 2020; Merchant & Lurie, 2020; Razai et al., 2020; Wind et al., 2020; Zhou et al., 2020). For example, online-psychological interventions such as cognitive behavioural therapy may be effective in addressing a wide range of mental health conditions associated with medical pandemics (Reay et al., 2020). Telephone hotlines staffed by psychiatric nurses or other qualified hospital staff may also be useful, particularly during pandemics, to identify the unique mental health needs of patients and their family (Reay et al, 2020). Decision-makers should consider the involvement of patients with COVID-19 and their family in the design, implementation and monitoring of such interventions to ensure their mental health concerns are addressed.

Consistent with UN policy, we also advocate for increased overall investment in mental health such that mental health care is included in national health care benefit packages and

insurance schemes (UN, 2020). This could increase the capacity of the health sector to manage the mental health problems exacerbated by COVID-19 (and other pandemics) (UN, 2020). Psychological first aid involves providing humane, supportive and practical help to others suffering serious crisis events in a way that respects their dignity, culture and abilities (Shah et al., 2020). Training in psychological first aid for community and frontline health workers is one way to increase capacity and has been encouraged in the literature and endorsed by WHO and the UN to tackle the growing global mental health crisis from COVID-19. (Shah et al., 2020; UN, 2020; WHO, 2011).

Further research is needed to generate robust evidence about mental health interventions for patients with COVID-19, family members, and also at the community level. A recent systematic review found that various interventions have been developed and trialled around the world to address mental health issues associated with COVID-19 and other medical pandemics (Soklaridis et al., 2020). Interventions included resilience training and support for health professionals, progressive muscle relaxation for inpatients with COVID-19 to reduce anxiety and improve sleep, online nurse consultations for isolated patients to reduce levels of anxiety and depression and mobile-based musical therapy for hospital staff working in a coronavirus unit (Giordano et al., 2020; Liu et al., 2020; Maunder et al., 2010; Zhou et al., 2020). However, rigorous evaluations on their effectiveness and feasibility in other contexts remain sparse. This secondary analysis also suggested that certain mental health issues may be more pertinent to different severities of COVID-19 infection. Additional insights into the unique mental health challenges that may be associated with different manifestations of COVID-19 should also be researched to help tailor interventions appropriately.

Patients with COVID-19, their family, the general public and health professionals perceive that the COVID-19 pandemic has had profound consequences on the mental health of

patients and the broader population. Participants described various mechanisms of how the pandemic is impacting mental health. These are the anxiety of an uncertain disease course, the guilt of infecting others, the fear of long-term health consequences, intense loneliness of quarantine, and grief of the loss of the normality of life. Although each of these factors play a significant role in influencing mental health outcomes for patients and the broader population, the mechanisms of this differ and their relative importance is not deduced from this dataset. Every country will experience the mental health impacts of COVID-19 in their own way and the relative importance of these factors will differ. It is the responsibility of public health officials and policymakers to ensure the unique mental health experiences of their population are addressed accordingly. Further investigations may be warranted to identify the relative importance of these factors to assist in effective resource allocation and targeted interventions. Thus, this issue requires a multifaceted approach, involving clinical, public health and policy interventions to address the unique mental health challenges of the COVID-19 pandemic. Patients with COVID-19, their family, the general public and health professionals should be closely involved in the design, implementation and monitoring of these interventions to ensure they protect and promote people's human rights and reflect the needs of the relevant end-users (UN, 2020).

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