

## Online Patient Support Groups during COVID-19

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### Abstract

There has been an exponential growth in the number of patients dealing with long-term disease who have access to and engage in online peer-to-peer support forums (also known as 'online patient support groups') as a result of the increased access to the Internet and the advancement in technology. Some study has demonstrated changes in the quality of life of patients who have participated in online patient support groups during the pandemic. There are wide variety of online patient support groups are available from before but engagement in this groups increases with the epidemic blow up. Some obstacles to enter online patient support groups include awareness, time limitations and the confrontation with derogatory implications of the illness. The goal of the article is to explore the experience of the patients, general public, and health practitioners of online patient support groups during COVID-19.

**Keywords:** Online patient support groups, Pandemic, Health information, WHO, Awareness.

### Introduction

There has been an exponential growth in the number of patients dealing with long-term disease who have access to and engage in online peer-to-peer support forums (also known as 'online patient support groups') as a result of the increased access to the Internet and the advancement in technology. Patients can connect with other patients through online patient support groups via written communication, either synchronous (e.g. chatting) or asynchronous (e.g. discussion room), and these groups can be proficiently moderated or moderated appropriately by peers [1]. There are two types of online communities: synchronous groups (simultaneously online with each member) and asynchronous groups (in which member can interface to the group various times). Although synchronous groups may be based on text alone, they are typically video conferences, using platforms that allow audio and video communication (e.g., Zoom, Vsee, Doxy.me). Typically, asynchronous parties use online forums (e.g., Google groups), while they can also use Instant Messaging Services (e.g. WhatsApp) which are based only on text messages [2]. Online patient support groups have several functions: educating patients/family, sharing disease experience, inspiring their participants, raising public consciousness, and raising funds. The research have indicated an increase in the quality of life of people with head and neck cancer who have engaged in support groups [3].

Coronavirus disease 2019 (COVID-19) was first described in China in December 2019 [4] and is an infectious disease caused by a novel virus called coronavirus extreme acute respiratory syndrome (SARS-CoV-2) [5]. In most patients, infection with COVID-19 ends up in moderate symptoms like fever and dry cough, however in some cases, particularly notably those with underlying health issues and immune deficiencies, COVID-19 will be a lot of extreme and may cause serious complications like acute metabolism distress syndrome or maybe death[6]. The science and patient support communities were able to identify the need to offer information on COVID-19 to patients [7]. When the pandemic erupted, the reaction to the

latest recommendations for security and social distancing soon changed. Visits to the doctor were made to the iPads. Some patient advocacy programs have done somewhat well in their attempts to offer support through online patient support groups [8]. The authorities in China, Singapore and Australia have reported that the emotional side effects of the pandemic have been shown and raised concern that the long-term effects of fear and hysteria could be more dangerous than the pandemic [9,10,11]. Pandemic has decreased the possibility of communicating emotionally with family and friends, leading to isolation. It can increase anxiety and depressive symptoms [12]. If these signs are left unattended, they can affect people in the long term. Psychological therapy should ensure that the overall well-being of the patient is adequately managed. Resource delivery, such as online patient support groups, is expected to help patients preserving and handling acute and acute psychological well-being [13].

### **Research Questions**

The research questions on which the review paper has been based are:

- Why Online Patient Support Groups were used during COVID - 19?
- What are the advantages of using Online Patient Support Groups during COVID - 19?
- What are the dis-advantages of using Online Patient Support Groups during COVID - 19?

### **Discussions**

#### **Different reasons to use Online Patient Support Groups during COVID - 19**

During the epidemic of COVID-19, China is aggressively offering numerous telemental health services. This programs are offered by government and university organizations which includes counseling, monitoring, instruction and psychoeducation across online channels (e.g., hotline, WeChat, and Tencent QQ). It is necessary to communicate all health needs when patients need to be alone. The Govt. and university organizations promotes the use of telehealth as a powerful means of meeting the physical and social needs of all patients, located in different geographical position [13].

The epidemic of COVID-19 and associated restrictive initiatives had a major effect on the use of online assistance. The potential reason for the rapid, significant and temporary rise in unplanned online help usage is that people have been greatly concerned and have encountered a high degree of anxiety, particularly within the first weeks of the crisis, prompting more people to access the service ) [14]. Online patient support groups became places of active public interaction during the COVID-19 epidemic, in which Chinese civilians demonstrated care and support, participated in accusations and opposition, and interacted with officials [15].

Online Patient support groups also offer peer support, and one such group on Facebook called the "Long Covid Support Group" has now more than 7000 members [16]. This group advocates for "proper rehabilitation, research and recognition." The "longcovid" hashtag is used on social media to express personal experiences. England had started an internet portal (online patient support group) during the pandemic, where individuals who have long-term symptoms of covid-19 (not only patients who have been taken to hospital) can interact with nurses, physiotherapists and mental health professionals. The portal will also provide users with access to a local clinical team that listens to enquiries and an online peer networking group, fitness tutorials and mental health support [17].

During this pandemic, global support networks and the development of online support communities could also help individuals to stay connected [18]. Mutual health associations have switched their sessions to streaming video channels. Often, community-based rehabilitation groups have joined hands to provide remote treatment group meetings for people with a range of recovery pathways (e.g., 12-step, secular, and medication-assisted). Online recovery support groups meeting involvement, like in-person groups meetings,

could help improve coping, self-efficacy, and inspiration by variations of fresh knowledge and insights, ready access to active support, and vicarious learning focused on peers. Online recovery support can also provide resources, but to a lesser degree than in-person groups, for integrated social network improvements [19].

A vast amount of potentially harmful disinformation has been created about the pandemic and much of it has been spread via social networks. This false news is made up of different components of an outbreak that is capable of impacting public safety and, once again, exasperates crisis management. The reports of the pandemic spread quicker than the virus, data can therefore be made available to the public and shown. Experts also proposed a variety of techniques for the use of online patient support groups to correct health misconceptions, including timely professional advice, day-to-day public health awareness, and a periodic contact correction campaign with the general public. This rectification policy would be successful if it were enforced easily and openly, although the facts could still be presented and shown to the public along with the appropriate document [20].

People who are not afflicted with a pandemic should get frequent care without the fear of being exposed to other patients in the hospital, particularly those at higher risk of being sick (e.g. old people and those with the chronic diseases)[21]. The use of online patient support groups as a telemedicine platform in epidemic situation has the potential to improve epidemiological research, illness detection and medical case management [22].

### **Benefits**

In reality, the body is not missing from online relationships. Therapists still see and feel their body, and the members of the party still feel theirs. What's lacking is body-to-body coordination or body language reading. The therapist can ask the patient to monitor their body sensations or, if appropriate, to move in space (e.g. to separate themselves from the screen or to catch up with it) according to complex situations and the needs of medical treatment [23].

Online patient support groups provides much-needed peer links, and doctors and trainees can facilitate those[24]. Online patient support groups for patients with chronic inflammatory skin disorders should be associated with the use of telemedicine, especially mobile telemedicine (such as WhatsApp), this leads to a more useful approach to increase commitment to care and improve the quality of life related to health, particularly in this extraordinary condition in which face-to-face visits are not feasible [25].

Immersive courses address obstacles to in-person distribution when delivering a variety of services (e.g., fitness, music). Interestingly, satisfaction was high even though a unidirectional experience was needed for privacy considerations. Future online patient support groups that allow users to communicate with physicians and each other will also alleviate depression and social alienation, essential priorities of care for patients and survivors before and after COVID-19 [26, 27].

During the lockdown, education on how to treat diabetes has also persisted. On April 28 and 29, MyWay Digital Wellness, a spun-out organization from the University of Dundee, UK, administered a free online course entitled "Understanding Type 2 Diabetes," drawing 2000 participants, ranging from individuals with diabetes and their caregivers to healthcare practitioners and members of the public. The course provided material on the causes of diabetes, how the likelihood of future complications could be minimized, and screening data. It also highlighted recordings of people with diabetes discussing their meetings, as well as the ability for participants to ask questions and share their meetings in a guided conversation [28].

Telehealth and online patient support groups tend to be on the right track to help physicians accelerate efforts to better manage chronic health problems in the community. When telehealth begins to gain motion

and people are searching for new opportunities to communicate with doctors and their own healthcare, online patient support groups appears to be a clear way to improve these ambitions [29].

The benefits of online patient support groups also include quick and continuous access, as well as their collaborative nature, which is vital for the rapid initiation of treatment and is compatible with the principle of fair access. However, the use of online patient support groups (OPSGs) depends on the consistency and speed of the internet, which has also become a problem, but according to many researchers, OPSGs have a major role to play in the swift decision-making of doctors and the prompt implementation of care and preventive steps [30].

### **Limitations**

Online patient support groups may not be ideal for people in acute distress and others who are easily deregulated. Affect regulation by body-to-body contact is also impossible online. Such clients typically need more time and energy that the organization cannot afford, particularly online, it is also difficult to reach out to them when crisis response is needed, since they are not physically available. Therefore, severely stressed clients with suicidal ideation should not be involved in online communities [2].

Most of the participants identified problems due to a lack of technical infrastructure, especially problems with the speed and stability of the Internet link, on the part of either the patient or the therapist. In addition, some clients do not have the requisite equipment, such as a smartphone. As far as the mediated essence of contact is concerned, the most commonly mentioned difficulty involves the absence of non-verbal signs that practitioners typically use in face-to-face interactions, such as stance and hand gestures, but also overall demeanor, like smell. It is more difficult for practitioners to interact with their customers or express their desired message clearly [31].

For women who delivered during lockdown, reliance on support from online patient support groups was slightly lower, likely because their children were younger and they required more realistic support for the advancement of breastfeeding or other kinds of treatment. Women in this community have indicated more regular contact with health practitioners [32].

The general population, who have fewer pandemic details, has been mistaken for diagnosis and treatment-related misinformation. Examples of risks associated with inadequate health contact may be taken from Nigeria, where health authorities have reported several cases of chloroquine overdose after reports of its success in the treatment of pandemics has been released in the media [33]. The World Health Organisation (WHO), which has collaborated with a variety of social networking platforms (Online patient support groups), has agreed to address this disinformation and promote important announcements from health organizations [34].

### **Conclusions**

Advancement in technology has increased the number of users of online patient support groups. Patients discuss with their fellow patients, Physicians and Caregivers about the disease and experience via written communication, forums etc. The study found that after the Pandemic burst, some patient awareness services were conducted online by patient service organizations to provide educational, emotional and social support to patients and the general population about the disease. Govt. and many university organizations offered programs which includes self-monitoring, Counselling through the powerful means of telehealth Social networks provided a large amount of misleading knowledge about the COVID – 19. And the knowledge spread quicker than the virus. Accordingly, as recommended by the experts– Online patient support groups have been used to address health misconceptions and information through Guidance, Campaigns and the evidence are presented to the public with an appropriate document. Online patient support groups are not

suitable for people with chronic distress and pregnant women because, in this condition, physicians tend to monitor patients' health on a regular basis. Online patient support groups are readily available from any geographical area and have played a vital role in enhancing the patient's well-being since the pandemic.

### **Future scope of the study**

The future study should be focused on the characteristics and limitations of online patient support groups during the pandemic.

### **References**

1. N.S. Coulson, How do online patient support communities affect the experience of inflammatory bowel disease? An online survey. *JRSM short reports*, 4(8), 2013, 2042533313478004.
2. H. Weinberg, Online group psychotherapy: Challenges and possibilities during COVID-19—A practice review. *Group Dynamics: Theory, Research, and Practice*, 24(3), 2020, 201.
3. A. Hu, Reflections: the value of patient support groups. *Otolaryngology—Head and Neck Surgery*, 156(4), 2017, 587-588.
4. H. Lu, C.W. Stratton, & Y.W. Tang, Outbreak of pneumonia of unknown etiology in Wuhan, China: the mystery and the miracle. *Journal of medical virology*, 92(4), 2020, 401-402.
5. World Health Organization, Clinical management of severe acute respiratory infection when novel coronavirus (2019-nCoV) infection is suspected: interim guidance. In *Clinical management of severe acute respiratory infection when novel coronavirus (2019-nCoV) infection is suspected: Interim guidance*, 2020, (pp. 21-21).
6. H.A. Rothan, & S.N. Byrareddy, The epidemiology and pathogenesis of coronavirus disease (COVID-19) outbreak. *Journal of autoimmunity*, 109, 2020, 102433.
7. U. Košir, M. Loades, J. Wild, M. Wiedemann, A. Krajnc, S. Roškar, & L. Bowes, The impact of COVID-19 on the cancer care of adolescents and young adults and their well-being: Results from an online survey conducted in the early stages of the pandemic. *Cancer*, 126(19), 2020, 4414-4422.
8. P. Carragher, Virtual Support Groups Find Success Amid Pandemic. <https://moffitt.org>, 2020.
9. Australian Government Department of Health. Coronavirus <https://www.health.gov.au>, 2020.
10. National Health Commission of the People's Republic of China, Ministry of Civil Affairs of the People's Republic of China, Notice on Strengthening the Psychological Assistance and Social Work Services in the Response to the New Coronary Pneumonia Epidemic Disease. [www.nhc.gov.cn/jkj](http://www.nhc.gov.cn/jkj), 2020.
11. Lai L. (2020). Fear and panic can do more harm than the coronavirus, says PM Lee Hsien Loong. <https://www.straitstimes.com>.
12. E. M. Smith, Ethnic minorities: Life stress, social support, and mental health issues. *The Counseling Psychologist*, 13(4), 1985, 537-579.
13. X. Zhou, C.L. Snoswell, L.E. Harding, M. Bambling, S. Edirippulige, X. Bai, & A.C. Smith, The role of telehealth in reducing the mental health burden from COVID-19. *Telemedicine and e-Health*, 26(4), 2020 377-379.
14. M. Zaagsma, K.M. Volkers, E.A.K. Swart, A.P. Schippers, & G. Van Hove, The use of online support by people with intellectual disabilities living independently during COVID-19. *Journal of Intellectual Disability Research*, 64(10), 2020, 750-756.
15. X. Chen, Spaces of care and resistance in China: public engagement during the COVID-19 outbreak. *Eurasian Geography and Economics*, 61(4-5), 2020, 435-447.
16. E. Miyake, & S. Martin, Long Covid: quantitative and qualitative analyses of online Long Haulers' experiences, emotions and practices in the UK. *medRxiv*, 2020.
17. E. Mahase, Covid-19: What do we know about "long covid"? *bmj*, 370, 2020.
18. Ng, Q. X., Chee, K. T., M. L. Z. Q. De Deyn, & Z. Chua, Staying connected during the COVID-19 pandemic. *International Journal of Social Psychiatry*, 66(5), 2020 519-520.

19. B.G. Bergman, J.F. Kelly, M. Fava, & A.E. Evins, Online recovery support meetings can help mitigate the public health consequences of COVID-19 for individuals with substance use disorder, 2020.
20. H. Sahni, & H. Sharma, Role of social media during the COVID-19 pandemic: Beneficial, destructive, or reconstructive?. *International Journal of Academic Medicine*, 6(2), 2020, 70.
21. A.C. Smith, E. Thomas, C.L. Snoswell, H. Haydon, A. Mehrotra, J. Clemensen, & L.J. Caffery, Telehealth for global emergencies: Implications for coronavirus disease 2019 (COVID-19). *Journal of telemedicine and telecare*, 26(5), 2020, 309-313.
22. E. Monaghesh, & A. Hajizadeh, The role of telehealth during COVID-19 outbreak: a systematic review based on current evidence. *BMC Public Health*, 20(1), 2020, 1-9.
23. P. Ogden, & B. Goldstein, Sensorimotor psychotherapy from a distance. *Theory and practice of online therapy: Internet-delivered interventions for individuals, families, groups, and organizations*, 2020, 47-65.
24. M. Stout, The role of virtual support groups for patients with hidradenitissuppurativa during the COVID-19 pandemic. *International journal of women's dermatology*, 6(3), 2020, 154.
25. C. L. A. U. D. I. O. Marasca, A. N. G. E. L. O. Ruggiero, G. Fontanella, M. Ferrillo, G. Fabbrocini, & A. Villani, Telemedicine and support groups could be used to improve adherence to treatment and health-related quality of life in patients affected by inflammatory skin conditions during the COVID-19 pandemic. *Clinical and experimental dermatology*, 45(6), 2020, 749-749.
26. A.M. Young, F.D. Ashbury, L. Schapira, F. Scotté, C.I. Ripamonti, & I.N. Olver Uncertainty upon uncertainty: supportive care for cancer and COVID-19, 2020.
27. A. Chan, F. Ashbury, M.I. Fitch, B. Koczwara, R.J. Chan, & MASCC Survivorship Study Group, Cancer survivorship care during COVID-19—perspectives and recommendations from the MASCC survivorship study group, 2020.
28. Y. Zhai, & X. Du, Addressing collegiate mental health amid COVID-19 pandemic. *Psychiatry research*, 288, 2020, 113003.
29. B.J. Sanborn, Telemedicine and social media interest advance population health. <https://www.healthcarefinancenews.com>, 2020.
30. M.S. Taheri, F. Falahati, A. Radpour, V. Karimi, A. Sedaghat, & M.A. Karimi, Role of social media and telemedicine in diagnosis & management of COVID-19; An experience of the Iranian Society of Radiology. *Archives of Iranian medicine*, 23(4), 2020, 285.
31. M. Feijt, Y. de Kort, I. Bongers, J. Bierbooms, J. Westerink, & W. IJsselsteijn, Mental health care goes online: Practitioners' experiences of providing mental health care during the COVID-19 pandemic. *Cyberpsychology, Behavior, and Social Networking*, 23(12), 2020, 860-864.
32. N. Hull, R.L. Kam, & K.D. Gribble, Providing breastfeeding support during the COVID-19 pandemic: Concerns of mothers who contacted the Australian Breastfeeding Association. *medRxiv*, 2020.
33. S. Busari, & B. Adebayo, Nigeria records chloroquine poisoning after Trump endorses it for coronavirus treatment. CNN Available online at: <https://www.cnn.com/2020/03/23/africa/chloroquine-trump-nigeria-intl/index.html>, 2020.
34. N. Statt, Major tech platforms say they're 'jointly combating fraud and misinformation' about COVID-19. *The Verge*, 2020.