



Online group support and wellbeing services for adults

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Abstract

Online support groups are internet-based networks that allow users to support each other by sharing information, advice and common experiences. In order to gain an understanding of best practice in this field, this research briefing reviews relevant research and latest practice. As such, it may be used to inform discussions about online group support alongside the findings of organisations offering such support like People Know How. The briefing looks at some technical aspects of support groups and their management, and how they may be used in different interventions. It begins with a brief history of internet-based groups and continues with an overview of some of the choices for implementing and managing online support. Then, it looks at its use in mental health interventions and discusses its use in some other areas of interest, concluding with a summary of observations.

Keywords

Online group support, group work, mental health, wellbeing, networking, social media

Key points

- The technology and practice of online peer support groups seems to be well established, however, as a field of scientific study it is relatively new.
- Initial indications are that online peer support is potentially an effective means of providing interventions that give rise to positive health outcomes.
- The main area of use and scientific interest is in its use for mental health interventions. It is this area of study that provides the best evidence for effectiveness.
- Studies provide some evidence of its effectiveness when used to support sufferers of chronic health conditions and their carers. People Know How may be able to identify groups within the population that may benefit from online group support.
- There is evidence that online group support is useful when people are experiencing major life-changes, such as becoming a new parent. People Know How provide support for people at times of transition through its Positive Transitions Service.

A brief history

As the internet continues to grow, it has become even easier to set up communication networks that bring together online communities with common interests (Barak, Boniel-Nissim and Suler 2008). Online groups take many forms and facilitate sharing of information, entertainment media, and mutual support (Shaw and Gant 2004). Historically, internet forums such as chat rooms and social networking services have been used as the format for discussion groups. Many discussion groups grew into peer-led support groups. Peer support functions as a self-help community formed on the basis of sharing their lived experience. Peer support is not necessarily internet-based, and not all online support groups are peer-based. However, online peer support groups have emerged as a frequently used intervention. They are often studied, and they form the basis of this review. As information technology has matured, social media platforms have grown larger (see, for instance, Google, Facebook, Twitter and Instagram). Furthermore, both Facebook Groups and Google Groups may be used for peer support but are only small parts of much larger packages of features. A discussion about these and other types of platform for online support follows.

Types of online group support

Online support groups can be based on a generic social media platform, of which Facebook Groups and Google Groups are good examples. It is known that moderated and unmoderated groups can lead to different user experiences. For instance, users are more likely to

post to a moderated group than an unmoderated one (Klemm 2012) and McAlaney et al. (2020) show that users prefer groups to be purpose-driven and not run as ordinary social networks.

Moderators tend to oversee groups to ensure safe and appropriate use, but peer supporters may themselves be trained to enable them to lead group discussions. There is evidence that groups led by trained peer supporters provide a better user experience when compared to support groups led by those with no training (Lekka, Efstathiou and Kalantzi-Azizi 2015). In the study, the trained peer supporters called on a wider range of support skills than the untrained; from using simple open-ended questions, to performing more complex problem solving. They also relied less on self-disclosure as a technique, which is a positive outcome.

In the future, Artificial Intelligence (AI) could also be used to assist moderators and may be able help them to identify users with more pressing needs (Milne, McCabe and Calvo 2019). In Milne et al.'s (2019) study, AI was used to categorize and prioritize message content and facilitated a significant reduction in response times to messages that were flagged by it as high priority.

Applicability: mental health interventions

Social media and peer support are identified as promising tools in helping people to manage, discuss, and learn about mental health issues. Naslund et al. (2016) identify advantages related to education, social connectedness, and empowerment. They present a

simple model, highlighting scenarios that can occur after having taking part in online peer support activities. From the peer interaction, users often feel empowered since they overcome the stigma of discussing mental health, and it provides a platform to challenge prevailing prejudices. In addition, users learn about their illness from those who have similar experiences and use this to make more informed choices about their future treatment. The authors identify some potential risks of online interaction, such as receiving incorrect advice, disapproval of posts and feelings of rejection, and negative attitudes of some users. Indeed, when dealing with health issues, in general, many issues may affect a user's experience. For instance, Newman et al. (2011) conclude that there is evidence that Facebook groups are not appropriate places for discussions about health, due to the conflict between self-image management and openness. They point to the fact that, in any number of groups, a person may present different images of the self (Lampinen, Tamminen and Oulasvirta 2009). So, in a group related to health, there may be a conflicting need to maintain a positive image and a desire to express the need for help. On social media, privacy can be managed by keeping groups separate and making use of security/visibility settings. However, this is often not the case (Young and Quan-Haase 2009). In the wider context of dealing with vulnerable users, we may consider privacy and security concerns relating to online support networks. A number of issues are identified by Lamnitchi and Kayes (Lamnitchi and Kayes 2017). They point out that social media users tend to present detailed profiles of themselves across multiple platforms, the presence of

such information can allow individuals or organizations to exploit that information. In the case of a stalking, for example, vulnerabilities and location data may be identified and exploited. In the case of misuse by organisations, user data may give rise to the user becoming a target for spamming. The authors also point out that privacy controls can be used to restrict availability of data, but often, defaults settings are too open, allowing unrestricted access. Related to this issue and sharing of information, terms of service can be complex and the effects of a decision to accept them unclear, as most users do not read them.

In some cases, there may be conflicts between the problem being addressed and the solution. For instance, using social media to help with internet addiction can be a problem for some users. In their study of internet addictions, Van Rooij et al. (2017) suggest that it is useful to distinguish between problematic internet use and problematic game use. Similar distinction might be made when we consider the benefits of peer support groups, since they may include members with confounding issues. However, no research addressing this was identified in this literature search and review. There is, however, evidence of a link between psychosocial well-being and problematic internet use, in a wider sense (Kim, et al. 2016). Here, the authors find that people with problematic internet use frequently suffer from addictions and mood disorders and, specifically, are at higher risk of suicidal ideation and planning. One can see that in any support group dealing with depression, for instance, there may be users suffering from other problems such as gambling addiction, and vice versa. The authors suggest that

routine screening for suicidal ideas should be done upon clinical presentation of people with problematic internet use (presumably this is not already the case). This potentially highlights a need in the training of group moderators to include awareness of co-morbidity issues. As we see in wider case of problematic internet use, the association between co-morbidities may not generally be obvious. The effectiveness of considering co-morbidities in online interventions is discussed by Johansson et al. (2012), who recommend tailoring Cognitive Behavioural Therapy for depression, depending on the co-morbidities. We were unable to uncover significant research work on the more unusual co-morbidities which might be useful for moderators to be aware of. However, we would expect the more obvious associations between mood disorders, such as anxiety and depression, to be known by experienced peer supporters. As an observation arising from this, more information about unusual co-morbidities may need to be relayed in peer support training, since relying on lived experience might not be enough, at least in this case.

In many online support groups, anonymity is a good way of encouraging participation in discussion (Parkinson, et al. 2017), particularly when sensitive personal issues are being discussed. It also helps to overcome the perception of social stigma attached to mental health problems (DeAndrea 2015). However, the level of anonymity can have effects (Wodzicki, et al. 2011). Wodzicki et al. (2011) describe a group that includes pro-social and pro-self individuals, where a reduction in anonymity (in this case by adding a photograph) reduces participation by the pro-social group

and increases it in the pro-self group. It is the authors' opinion that the pro-self group become more aware that they are part of a group, so they contribute more. However, they speculate that for the pro-social group, seeing the other group members seems to affect them in a negative way such that they may be reacting to their appearance. This relates to the 'atmosphere' of a group, which is discussed in a paper based on the Elefriends project (Tucker and Goodings 2017). The authors discuss how the digital atmosphere is integral to how the user experience develops as the users seek out support and care using the tool. They point out that a digital atmosphere arises from the bodies (i.e. people), images (such as emojis) and the discourse. They discuss how the atmosphere may need to be managed. An example they use is the situation that arises when a peer is unexpectedly absent and a wave of anxiety, about the individual, spreads through the discourse. A moderator will need to try to limit its spread - that is to 'repair' the atmosphere. The authors also point out the limits of the peer supporters' ability to intervene and the need to limit support to an informal (non-professional) level.

Furthermore, an analysis of posts in an online depression peer support group to ascertain perceived benefits and drawbacks has been performed (Griffiths, Reynolds and Vassallo 2015). It shows that many users reported non-specific positive changes. They also report many specific positive changes, such as self-reported positive thinking, encouragement to act, mutual support and value of shared understanding. However, it is not clear whether the short-term benefits translate to long-term positive outcomes. The work of

Smith-Merry et al. (2019) examines how users of an online mental health support group 'move toward recovery', where a key aspect is the ongoing support. The study focusses on a group living in geographical or social isolation. The social connection, shared experience and mutual support derived from participation helped overcome isolation, stigmatisation and provided ongoing support. We consider that ongoing support may contribute to long-term positive outcomes, but more work seems to be required in this area.

Applicability: other applications and factors

Although online peer support seems to be most widely used for mental health interventions, it has also been studied as a means of supporting people with other health problems. For instance, it has been used to provide support for breast cancer sufferers (Batenburg and Das 2014). In this case it was most useful for participants who approach their emotions less actively. There was no evidence of benefit for those who already approached their emotions actively. A recent study of alopecia sufferers (Iliffe and Thompson 2019) found that participation in online group support allowed them to develop coping strategies and develop an understanding of the condition. It helped by allowing them to form new social connections, share experiences, obtain practical advice, and express emotions. Another example shows that online peer support is useful for youngsters suffering from Cystic Fibrosis and for their parents/carers (Kirk and Milnes 2016). An analysis of posts showed that five themes could be identified. Namely, those of managing

treatment, emotions, relationships, identity, and support from healthcare and service providers.

Not all peer support groups are set up to target health-related issues. Some address social issues. One example is support for students transitioning within the education system. Mattanah et al. (2010) find that peer support (in this particular case, not an online group) has a positive effect on social adjustment when students start university. Many students initially found the transition to university challenging. Those in the study that participated in peer support found that it helped to reduce feelings of loneliness. It also increased the feeling of being supported, since it allowed them to develop deeper, more meaningful relationships with a small group of people. Another type of group studied is that of caregivers. One study, by Friedman et al. (2018) shows that when caring for US military veterans, the care givers under the most strain and with least care resources make most use of online peer support (as measured by time spent online and the number of posts made). The results show that an increase in the number of care activities performed relates to an increase in the likelihood of visiting an online community. In addition, caring for a veteran with a psychological or neurological condition showed an increase in the likelihood of visiting. Caregivers of pre-9/11 veterans were more likely to access online support than caregivers of post-9/11 veterans. The authors consider the reason is most likely that the latter receive vastly improved formal support, in terms of healthcare and finance, compared to the former. Leaving the pre-9/11 group (potentially under greater strain) to resort to less formal means, such as peer support.

Moreover, in a study of young mothers, it was found that they preferred to use online peer support without professional guidance to online peer support with professional guidance (Sjöberg and Lindgren 2017). They also preferred it to face-to-face support with a professional. It was thought that this was because mothers were able to tailor participation to suit their needs, such as individual requirements, schedules, and additionally in the case of face-to-face support, avoiding logistical problems.

In the previously cited study by Griffiths et al. (2015), most of the subjects are aged between 12 and 25 years, which reminds us that we may need to consider outcomes for different age groups. For instance, Schneider et al. (2018) show that older users may need more reassurance of the effectiveness of new technologies, despite the fact that they benefit in the same way as younger users. One must also be mindful that some users may experience adverse effects from the interaction, although the following study indicates that they appear at comparatively low levels (Easton, et al. 2017). The adverse effects include negative experiences related to behavioural and emotional contagion, negative moderation, and social exclusion. Relating to this, the authors identify the difficult nature of moderation, i.e. striking the right balance when needing to direct discussion to avoid contagion (such as the wave of anxiety mentioned above) and to minimise the perception of negative moderation. No existing research relating to how this balance can be achieved with respect to moderator training was identified. To address the feeling of social exclusion, the authors suggest finding innovative ways to increase interaction

that includes those feeling excluded, but this is left as future work.

Conclusion

People Know How are developing a number of online group projects promoting health and wellbeing. This research briefing may be used to in conjunction with findings from delivering these projects in order to inform future work. This briefing focusses on online peer support and we find that this kind of peer support group is the most widely researched. Within the published research, most of the work relates to its use in mental health interventions. Results indicate that it has good potential in this field. There is also evidence that it is usefully applied in supporting sufferers of chronic physical conditions, although the body of evidence is much smaller. It also has applications in providing social support, as in the case of young mothers, and carers of injured veterans.

In order to obtain the best user experience, research shows that it is useful to provide training for peer supporters. This enables them to identify discourse that may indicate that a person is in danger. It also enables them to manage the digital atmosphere, to ensure that a negative atmosphere does not spread. In the long term, it may be possible to use artificial intelligence to assist moderators. It can identify discourse with certain characteristics facilitating a quicker response to those in most danger. We also think that it is useful to be aware that peer support appears to be used more often by those with most need, authors indicate that they are likely to have fewer options for support.

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