Introduction and Aim

Peer-led support groups have been shown to be effective as a complement for traditional mental health services in some psychiatric disorders including depression, addiction and trauma. Individuals suffering from feeding and eating disorders, such as bulimia and anorexia nervosa, often face a stigma that prevents them from joining in-person peer support treatment groups. In some cases, they are also held back by seclusion, mobility challenges and physical illness. Instead of joining groups moderated by professionals, they often engage in online discussion forums and groups on social networking platforms, such as Reddit, Instagram and Tumblr. Social media use has previously been shown to be a risk factor for developing eating disorders. However, most of the studies done on online eating disorder communities focused on pro-eating disorder (pro-ED) communities that encourage harmful weight control behaviours. The aim of this literature review is to summarise existing literature on content and characteristics of recovery-oriented online communities focused on individuals receiving treatment or seeking to recover from eating disorders.

Methods and Materials

Relevant publications were selected from PubMed and Google Scholar database using search words "online eating disorder communities", "pro-recovery communities". Publications on communities focused on recovery were selected and summarised.

Results

Much of the data found on publicly available social media platforms and analysed in scientific papers can be categorised as personal information (e.g. personal experiences, symptoms related to eating disorders). A publication by Park et al. identified 14 topics as the most popularly discussed. The most common topics in online eating disorder recovery communities were self-confidence, motivation for recovery, health issues, feeling in control and seeking resources on eating disorders. Topics related to eating disorder diagnosis and seeking professional advice were popular but received many downvotes indicating that community members believe it is more appropriate to discuss various health care issues related to eating disorders with professionals rather than seeking information in online community. A study by Feldhege et al. revealed that members of a Reddit eating disorder recovery community had different participation styles, as some users tend to be more active in commenting and sharing content and received more mentions. In this light, certain community members emerged as opinion leaders that become more influential then others and shaped the way members regard health care information within community. Central members in pro-recovery communities tend to be less concerned about body image and exhibit more optimistic emotions while members who share more negative emotions and exhibit self-focused attention were less likely to be popular in online community. This is in line with previous studies analysing in-person community groups where individuals that exhibit more positive feelings were more likely to be more central in their social networks.

Discussion

Online platforms allow users to consume and produce information as well as facilitate the communication among people suffering from eating disorders and promote recovery related content. Research provides insights in their content, popular topics, network organisation and reasons for joining online eating disorder recovery communities. In these platforms, users engage and empathize more with content soliciting social and emotional support from health-related information. Most discussed topics include the importance of seeking professional help, regaining self-confidence and recovering from eating disorders. Most users see online communities as an outlet where they can share their experiences and difficulties in the process of recovery, however, some individuals also used online communities as an alternative to professional treatment. Key reasons for joining online communities were similar to reasons for engaging in-person peer-support groups and included social support. Studies indicate there is a strong segregation between pro-recovery and pro-ED communities, therefore, content, promoting healthy behavioural change shared in recovery oriented communities does not reach individuals with more disordered eating behaviours.

Conclusions

Online communities provide open, free and anonymous space for individuals recovering from eating disorder to discuss their symptoms without having to face stigma. However, due to their network organisation, lack of moderation and low efficacy online pro-recovery communities may exacerbate symptoms in later stages of recovery. While engaging in online eating disorder recovery communities may be helpful to some individuals as a supplement to traditional treatment, due to lack of moderation by a professional it should not be regarded as appropriate alternative to professional treatment. Insights in online eating disorder recovery communities highlight the importance of social support and may provide useful information for designing better intervention mechanisms in the future.

Keywords

Eating disorders, peer support, online communities

References


Electronic supplementary material

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