Designing remote care services for eating disorders: HCI considerations and provocations based upon service user experience and requirements.

HCI considerations for remote eating disorders support

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The use of remote support for eating disorder recovery has become increasingly important since COVID-19. It is important to explore the suitability of current platforms; to do this effectively, co-design with people with lived experience (PWLE) is essential. RHED-C (Remote Healthcare for Eating Disorders throughout COVID-19) is a 3-year project focused on future remote care solutions. As part of this larger project, we conducted a two-stage process exploring user experiences with remote care and key design considerations. The first, exploratory stage involved workshops and semi-structured interviews with 27 PWLE based within the UK. Reported barriers included complicated platform functionalities leading to sensory overload and a lack of perceived self-efficacy; poor or unstable internet access disrupting the therapeutic space; a focus upon the quantification of eating disorders (e.g., focus on BMI) that was perceived as triggering. Participants wanted more sharing of honest recovery stories to inspire, and help them to envisage recovery. At the second stage, a creative team comprising researchers, a service provider, and a creative arts professional with lived ED experience reflected upon these findings to identify provocations for future co-design of remote care based around: *i. The value of qualitative research methodologies and avoidance of quantification; ii. Need for design that minimizes physical representation and sensory overload; iii. Importance of honest, recovery-focused content that fosters realistic expectations; iv. promotion of digital accessibility and self-efficacy*. These provocations are discussed in this paper.

**CCS CONCEPTS • Human-centered computing • Human-centered computing~Accessibility • Applied computing~Life and medical sciences • Security and privacy~Human and societal aspects of security and privacy

Additional Keywords and Phrases: Eating Disorders, Remote Support, Co-design, Accessibility, Healthcare

1 INTRODUCTION

The COVID-19 pandemic drove a rapid transition to remote (i.e., online and digital) healthcare, including support for eating disorders (EDs) [1-4]. Subsequently, this increased recognition of the affordances that remote services can offer well beyond the pandemic - such as increased accessibility and capacity and therefore greater availability of services with potential to reach underrepresented groups (including individuals without diagnosis). Despite widespread adoption, little is understood about the ways in which platform design can help or hinder ED support. Research needs to identify how co-design can improve future care. Co-design of healthcare involves the target user groups as key stakeholders in shaping the design of an intervention, with the aim of ensuring greater accessibility for the needs of the specific group and improved health outcomes [5-8]. This paper discusses our recent research exploring the benefits and challenges faced by people with lived experience (PWLE) in accessing remote support since the beginning of the pandemic, including barriers to access. Based on critical reflection of these findings, 4 provocations are presented for future co-design of remote care services.

2 AIM

Remote Healthcare for Eating Disorders throughout COVID-19 (RHED-C) is a 3-year project working closely with ED organisations across the UK, creatives, designers, developers, and PWLE. RHED-C aims to: identify the key challenges and benefits of providing remote care during the pandemic; co-design improvements for future remote care.

3 APPROACH & RESULTS

This two-stage process comprised of: i. Exploratory research with PWLE to identify remote care experiences and needs, ii. Critical reflection and identification of design provocations by a creative team including researchers, an ED service provider and an arts professional with lived experience.

Phase 1 (2022): Group workshops and semi-structured one-to-one interviews with 27 PWLE within the UK, aged between 18-65 years (M=31.07yrs, SD=11.54yrs). 19 identified as female, 4 as male, 3 as non-binary and 1 participant chose not to disclose. In addition to oral discussion during the sessions, each participant was given the opportunity to share their experiences using Padlet (https://padlet.com/), a digital tool allowing them to record key reflections. Participants were also invited to list items on a 'wish list' for future support. This approach enabled participants to share rich data; and also provided the opportunity for them to return to the Padlet platform after the workshop/interview to add more information, if they wished. Additionally, Padlet allowed us to create visual tools (e.g., UK news timeline of COVID-19) which acted as engaging prompts and were used to record key memories or events.

Participants identified key issues including complicated platform functionalities leading to sensory overload and low perceived self-efficacy; poor internet access disrupting the therapeutic space; a focus upon quantification of EDs that was perceived as triggering and stigmatising (e.g., needing a BMI below a certain number to be eligible for support); and online content that encourages comparison with others. Participants also highlighted that they would like to see more honest recovery stories to inspire and aid recovery.

Phase 2 (2023): The key findings from phase 1 were shared with a creative team during an interactive session. The team comprised researchers, an ED service provider representative from the not-for-profit sector and a creative arts professional with lived ED experience. After critical discussion, 4 themes were generated: *i. The value of qualitative research methodologies (and avoidance of quantification) to maximise meaningful and ethical involvement of PWLE; ii. Need for design that minimises physical representation and sensory overload and maximises vocal representation of lived experience; iii. Importance of honest, recovery-focused content that fosters realistic expectations; iv. Issues around digital accessibility and self-efficacy.* In this section, we discuss each theme in more detail and raise provocations for future design.

3.1 The value of qualitative research methodologies and avoidance of quantification

Interviews and workshops allowed a space for, in the words of one participant, PWLE to 'feel heard'. This approach shifted focus towards qualitative data and away from an over-reliance on quantifying information (e.g., focusing on weight lost/gained during the pandemic). Participants reported feeling that their ED is 'quantified' by society and healthcare and that this is triggering and stigmatising (e.g., needing a BMI below a certain number to be 'ill enough' for support). Participants regarded our qualitative approach as more inclusive and holistic, considering the fuller lived experience.

The creative team reflected upon how quantifiable (or quantitative) data is often prized or prioritised due to the ability to measure, compare and test. However, qualitative approaches allow for meaningful interpretation of how PWLE access services through the capture of data that is complex, multi-dimensional, and allows for a diverse range of voices.

Provocations: Should we embrace qualitative approaches and encourage a move away from quantification? What are the challenges to this approach - for service users, providers and designers?

3.2 Need for design that minimises physical representation and sensory overload

Participants discussed the negative impact of public preoccupation with physical appearance and dieting. For many participants this was exacerbated by COVID-19, with an emphasis on fitness and losing weight during lockdown that one participant described as 'inescapable'. Participants talked about triggering 'before and after' photos on social media which exacerbated ED symptoms, and, for some, fostered feelings of competitiveness and comparison to others. Participants also talked about online mental health resources focusing on medicalized, clinical settings. One participant reported that seeing ED support represented in this way heightened their anxiety and dissuaded them from seeking help.

In responding to participant's concerns, the creative team considered interface design that moves away from visual representations of people and toward the sharing of stories (e.g., through non-pictorial/symbolic design and/or audio recordings from PWLE). Several participants reported listening to podcasts during lockdown and reflected on the audio-only space allowing them to gain information without the anxieties associated with visual representations.

Avoiding sensory overload through simple design was discussed as a potential approach for reducing anxiety, including for users with additional mental health comorbidities (e.g., several participants reported diagnoses of autism and/or OCD). Sensory overload can fuel underlying stress and anxieties; in addition to negatively impacting intervention efficacy. Providing information in a simple, easy to digest and accessible way is essential.

Provocations: Should we encourage simplicity to minimise sensory overload with an emphasis on voices not bodies? What approaches could achieve this? What are the challenges of minimising 'noise' in design?

3.3 Importance of honest, recovery-focused content that fosters realistic expectations

Most participants said that they would like more opportunities to access stories of recovery from PWLE, with some regularly using social media to access this type of content. However, participants identified risks of accessing stories via social media (e.g., difficult to avoid triggering content, platform algorithms presenting an echo chamber of ED content). Despite this, some felt that this was the *only* way of gathering stories about recovery from 'real people.'

The power of authentic recovery stories as core content for a digital platform was discussed by the creative team. Recovery is difficult and non-linear. Access to honest recovery stories was discussed as critical, both for PWLE and those supporting them – with particular importance on representing recovery as complex and not a simple linear, upward trajectory. Relapse happens, and this should be acknowledged, to aid support and reduce feelings of failure should it occur.

Provocations: Should focus be on stories of recovery authored by PWLE, which reflect honest representations of recovery as a non-linear journey? What are the challenges and opportunities for presenting stories in this way?

3.4 Digital accessibility

Two key accessibility/usability issues were identified by participants. The first related to the home as therapeutic space. Poor home internet connection can cause issues if users find they are unable to connect to a support session when needed, or if the connection drops during a session. Additionally, sharing a house with others can make it difficult for users to access support confidentially. Secondly, participants discussed a need for easy-to-use platforms. Desired features included accessible microphone and camera on/off options, and chat and emoji options. Interestingly, these features are available on the platforms participants reported accessing (e.g., Zoom and Microsoft Teams) but many did not feel confident using them. Digital efficacy is key to improving accessibility and the therapeutic experience.

The creative team were keen to explore how digital inaccessibility or exclusion could be mitigated, by addressing both connectivity and self-efficacy. Discussions included what platforms could do to mitigate lost connection (e.g., using what can be accessed without online connectivity and/or platforms which remember user progress if connection is lost) and improved platform training and support.

Provocations: How can poor internet access be addressed? What support contingencies could be arranged should internet connection be lost? To what extent can guidance and training around existing platforms help?

4 CONCLUSION

PWLE engaged with our research to share incredibly valuable experiences. They have highlighted key barriers to effective remote support. In this paper, we have highlighted key provocations for discussion based upon 4 key needs for future remote care; with the aim of using the generated ideas and suggestions to guide co-design of future remote care.

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