Online Peer Support for Parents of Children with Long-Term Conditions: A Randomised Pilot Trial

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Date: 15/06/2023

Overview

Part one entails a systematic review of 11 quantitative research studies that evaluated peer support for children and young people. The mental health outcomes of these interventions are reported, including on depression, anxiety and eating disorder outcomes. Patterns across and within studies are summarised.

Part two comprises the empirical project. A randomised pilot trial was conducted which aimed to assess the feasibility and acceptability of a randomised controlled trial (RCT) investigating the effect of signposting parents of children with long term conditions (LTCs) to online peer support. Preliminary differences on key outcomes of loneliness, social capital, anxiety, and depression were also explored.

Part three comprises a critical appraisal of the systematic review and empirical project. The following matters were reflected on: personal and professional experiences influencing my interest in the research topic, the wide scope of peer support, positive experiences of parenting a child with a LTC, macro-level factors that affect these parents' wellbeing, the level of involvement of experts by experience in the research, and reflections of the research process.

Impact Statement

Given the increase in prevalence of mental health difficulties for both young people and adults, alongside concerns about wait times for mental health support and NHS staff shortages in the UK, it is important to understand the effectiveness of alternative ways of providing efficient support. This thesis explores the potential outcomes of peer support interventions for two populations: children and young people, and parents of children with long-term conditions. The results found are of use to both clinical practice and as directions for future research.

The potential benefits of peer support have been previously explored, however, the effectiveness of peer support interventions on clinical mental health outcomes for young people 18 and under remains unclear. Therefore, part one entails a systematic review of the literature to explore this research question.. Although findings were mixed, some promising effects on mental health outcomes were found, most commonly when peer support was used as a preventative intervention with non-clinical samples. However, the lack of high-quality studies in the review meant that the evidence was inconclusive. This highlights the need for future research to use higher quality methodology when evaluating peer support interventions, in order to draw conclusions about the effectiveness of these interventions with both non-clinical and clinical samples.

Many parents of children with long-term conditions report psychosocial difficulties such as loneliness. When looking for support, parents are often signposted to online peer support services. However, there is limited and mixed evidence regarding the effects of using online peer support for this population. Part two, the empirical paper, found that signposting to online peer support was largely acceptable to parents of children with LTCs. Further, the results highlighted the potential benefits and harms of using online peer support. These results could inform the information that professionals share with parents when signposting to online peer support. The results also indicated that improvements in loneliness, depression and anxiety could be potential positive effects of engaging with online peer support for parents of children with LTCs, therefore a direction for future research is for these effects to be investigated through a fully powered definitive RCT. Finally, the results found that the current study methods were not fully feasible, therefore recommendations are made for adapted methods for a future RCT.

Both the systematic review and the empirical paper are being prepared for submission to a peer-reviewed journal, and the findings will be shared through other academic and non-academic routes that become available.

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Acknowledgments

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Part 1: Literature Review

Understanding the Mental Health Outcomes of Peer Support Interventions for Children and Young People: A Systematic Review

Abstract

Aims: With mental health difficulties increasing for children and young people worldwide, timely and effective support is essential. Peer support has been recognised as a potential way of providing support to children and young people, yet the effectiveness of these broad range of interventions remains unclear. Therefore this review aimed to examine the mental health outcomes of peer support interventions for children and young people.

Method: A systematic search of two databases, Medline and PsycINFO, was undertaken to identify relevant studies. Studies were included if they evaluated the effects of a peer support intervention on standardised measures of mental health symptoms.

Results: Eleven studies were included in the review after meeting inclusion criteria. The studies covered a range of peer support interventions, including peer-led interventions, group peer mentoring, a peer support group, and 1:1 peer coaching. Seven out of 10 studies that used inferential statistics found a significant and meaningful effect of the intervention on mental health symptoms; however, there was a lack of high-quality studies.

Conclusions: Although some promising findings were reported, the ability to draw conclusions was limited by the methodological quality of studies meaning there was high risk of bias. The review considers directions for future research, including the need for more high-quality studies, with a greater diversity of participants.

Introduction

In the United Kingdom (UK) in 2021, 17% of six to 19 year olds were identified as having a probable mental health condition, which equates to nearly one in six children and young people (Newlove-Delgado et al., 2021) and is a six percent increase in figures since 2017 (Vizard et al., 2018). Globally there is a similar picture, with research showing a deterioration in the mental health of children and young people worldwide since the COVID-19 pandemic, including increased anxiety, depression, and psychological distress (Kauhanen et al., 2022). With poor mental health strongly associated with poorer outcomes for young people, including substance abuse, lower educational achievements, violence, and poor sexual and reproductive health (Patel et al., 2007), timely support is essential.

Mental health services for children and young people are a focus of the UK's National Health Service (NHS) long term plan, which states that 345,000 more children and young people between the ages of 0-25 will be able to access mental health support through NHS services and Mental Health Support Teams based in their schools or colleges by 2023/2024 (National Health Service [NHS], 2019). However, with an average wait time of two months to begin mental health treatment in Children and Adolescent Mental Health Services (CAMHS) in the UK in 2019 (Crenna-Jennings & Hutchinson, 2020) and concern that NHS staff shortages could reach a gap of 250,000 staff by 2030 (Health Foundation, 2018), it is important to understand the effectiveness of alternative ways of providing efficient support.

NHS England's Five Year Forward View for Mental Health highlighted peer support as one way of providing support which is highly valued by young people (NHS, 2016), and the World Health Organisation's (2013) Mental Health Action Plan highlighted the need to use peer support to provide responsive community-based mental health care. Further, as negative attitudes towards seeking help from a professional can be a major barrier to asking for support (Rickwood et al., 2005), peer support may be a way to reach more young people in need. Additionally, from an economic perspective, there is evidence that peer support can be a cost-effective way of providing health care (Fisher et al., 2014).

What is Peer Support?

Peer support is a broad concept in which there is great heterogeneity. Dennis' (2003) concept analysis of peer support detailed that it can take multiple forms, such as one-to-one sessions, support groups and online groups. Dennis also stated that peer support interventions can take place within diverse settings, such as educational settings, homes, hospitals, clinics, community organisations, schools, prisons, or via telephone and computer. Additionally, peer support facilitators can take on a breadth of roles, such as counsellors, advocates, educators, and leaders, with varying degrees of structure (formalised interventions vs. informal support) (Dennis, 2003). Despite this breadth of the concept, Dennis found that peer support comprised three common attributes: emotional support, described as having someone who can listen to problems and show acceptance and care (Wills & Shinar, 2000); informational support, described as the provision of knowledge that can be used to solve problems (Wills & Shinar, 2000), and appraisal support, described as support that affirms the appropriateness of individuals' statements and behaviours (Kahn & Antonucci, 1980, as cited in Dennis, 2003). Dennis stated that these attributes may be present to different extents depending on the presenting difficulties and intended health outcomes of the peer support.

Due to the lack of definitional clarity of what constitutes a 'peer' in relation to peer support, Simoni et al. (2011) proposed that:

1) Peers should share key personal experiences, circumstances, or characteristics with the target group, which may include characteristics such as age and marginalised status.

2) The benefits of peer-led interventions should derive at least in part from the facilitators' status as peers, rather than solely due to the interventions themselves.

3) Although peers may have some training to deliver specific interventions, they should not have professional training or status. This differs from individuals with lived

experience that complete professional training and then work with their own communities, who might be described as ‘peer professionals’.

4) Peers should deliver intentional interventions which are based on protocols, rather than the support taking place in naturally occurring relationships such as between friends and family. The helping relationship with a peer should differ from these naturally occurring relationships, in that there is a different scope and reach and no anticipatory reciprocity.

Simoni et al. (2011) stated that by this definition, groups facilitated by professionals, even if they involve mutual support between peers, would not be considered a peer support intervention, whereas interventions that are peer-led, whether these are groups, mutual support or 1:1 support, would be considered peer support interventions. Demonstrating the heterogeneity of peer support interventions, Nesta and National Voices (2013) summarised over 1000 studies of peer support, finding that peer support can include providing emotional support, social support, befriending, education, activities, discussion, physical support, and/or peer-delivered services. Further, they found that peer support was facilitated in a wide variety of ways, such as by lay people, untrained or trained peers, peers with professionals, paid peers, and, conversely to Simoni et al.’s (2011) definition, solely professionals.

Theories of Peer Support

Several theories support the importance of shared experience between peers and explain how these experiences may promote health and wellbeing (Simoni et al., 2011). Fortuna et al. (2019) posited that the effects of peer support can be explained by several social and behavioural theories. First, by increases in social support (Sarason et al. 1983) as demonstrated in Kulik et al.’s (2014) evaluation of a peer support intervention, which found that adolescent females reported higher levels of social interaction and perceived social support from peers following the intervention. Second, through sharing experiential knowledge which leads to transformation (Borkman, 1999). For example, when facilitators of peer support share their first-hand experiences, which qualitative analysis has found to be a key theme in people's experience of peer support (Embuldeniya et al., 2013; Proudfoot et al., 2012). Third, by the helper-therapy principle, which posits that supporting others is therapeutic for the helper (Skovholt, 1974), and has been corroborated by qualitative analyses with facilitators of peer support (Proudfoot et al., 2012; Salzer & Shear, 2002). Fourth, that health behaviours may be adopted through observation and replication of peer support facilitators, as explained by social learning theory (Bandura, 2004). Fifth, by increases in autonomy, in line with self-determination theory (Ryan & Deci 2000). Fortuna et al. considered that when people's goals are mostly set by healthcare professionals, they may be less inclined to engage with these, whereas in peer support interventions where people are empowered to choose their own goals, they may be more likely to work towards them (Brehm & Brehm, 1981). Lastly, Fortuna et al. suggested that peer support is grounded in social comparison theory (Festinger, 1954). This is demonstrated in Legg et al.'s (2011) study which found that peer support programmes helped patients who felt high threat from their cancer diagnoses through increasing their exposure to potential positive upward comparison targets. Recipients of the peer support identified with their peer support facilitators, saw them as a positive role model for their own recovery, and felt good about themselves after this comparison. Finally, as well as outcomes being influenced from the shared experience between peers, some formalised peer support interventions may also affect outcomes through the teaching and/or administration of therapeutic methods, such as interventions that draw from cognitive theory (Beck et al.,1979) or coaching psychology (Law, 2013).

Dennis (2003) posited three mechanisms through which peer support can have a positive influence on health outcomes: through direct effects, buffering effects, or mediating effects. Examples of the direct effects of peer support could be a reduction in feelings of isolation and loneliness, or providing access to information that positively influences wellbeing (Dennis, 2003). An example of the buffering effects of peer support could be the broadening of coping responses (Dennis, 2003). Finally, examples of the mediating effects of peer support are that it can indirectly influence outcomes through observational learning through role modelling, and by providing opportunities for social comparison to promote motivation (Dennis, 2003).

Finally, Yalom and Lescsz (2005) suggested that progress in peer support groups can be conceptualised using the same therapeutic factors as in group psychotherapy, such as the installation of hope, universality, altruism, group cohesiveness, imitative behaviour, conveying information, and catharsis.

Uses of Peer Support for Adults and the Evidence Base

Simoni et al. (2011) summarised that peer support interventions are used in diverse settings globally, across different age groups, and can focus on a wide range of physical and mental health outcomes, such as cardiovascular disease (Carroll et al., 2007), breast cancer (Helgeson et al., 2001), and serious mental illness (Lawn et al., 2007). In the UK, peer support has been used in inpatient wards, service user groups and in the community for some time and has been more organised and structured since the 1980s (Beales & Wilson, 2015).

Concerning mental health outcomes, qualitative research suggests various benefits of peer support. These include finding a shared identity, increased confidence, and improved mental health (Faulkner & Basset, 2012), increased social networks (Walker & Bryant, 2013), and gaining practical, social, and emotional support (Gidugu et al., 2015). Several reviews of the effects of peer support on mental health outcomes for adults summarise the evidence base. Fuhr et al. (2014) conducted a systematic review and meta-analysis of randomised controlled trials (RCTs) comparing peer-led interventions to treatment-as-usual. For adults with serious mental illness such as psychosis, three high-quality superiority trials found significant effects that favoured peer-led interventions in increasing hope and quality of life, with a small standardised mean difference (SMD) of 0.24 for both outcomes.

However, no effect on clinical symptoms was observed. Further, they reported that two high-quality equivalence trials found peers to be equivalent to healthcare professionals in improving quality of life (SMD = -0.11) and symptoms of serious mental illness (SMD = -0.14). However, for the four superiority trials assessing peer-led interventions for depression, no significant effect on clinical symptoms was found. Similarly, Lloyd-Evans et al.'s (2014) review of RCTs for mutual support services, peer-delivered services and peer support services found that there was little evidence that peer support positively affected mental health symptoms. However, some evidence was found that peer support was associated with increases in empowerment, hope, and self-rated recovery at post-intervention or follow-up, though these were not consistent findings across or within the different types of peer support. Further, Pistrang et al.'s (2008) review of mutual help groups, a type of peer support group where members with similar difficulties provide reciprocal support (Chinman et al., 2002), found limited but promising evidence. Seven out of 12 studies found positive effects on mental health outcomes, including on chronic mental illness, depression, anxiety and bereavement, whilst the other five found no effect. Additionally, Chinman et al.'s (2014) review of peer support services found that across 20 studies, peers were consistently at least as effective as none peers when providing interventions, such as case management or education programmes. However, Chinman et al. (2014) found that the evidence on whether peer support services were *more* effective compared to traditional services in improving clinical outcomes was less consistent. For example, four studies found that peer support services reduced the use of inpatient services compared to traditional services, but this result was not seen in the other studies. Regarding negative effects of peer support, just one review (Chinman et al., 2014) reported a negative effect in one study (van Vugt et al., 2012). An association between the presence of an employed peer support worker in assertive community treatment teams and an increase in the number of days that patients spent in psychiatric wards was observed. However, the same study also found associations with improvements in mental and social functioning. Overall, the effectiveness outcomes of peer support for the mental health of adults are mixed, and the definition and type of peer support intervention studied is widely varied.

Uses of Peer Support for Children and Young People and the Evidence Base

As with adults, peer support for children is used in a multitude of settings and populations, such as in schools (King & Fazel, 2021) and online forums (Ali et al., 2015), with homeless young people (Fors & Jarvis, 1995), children with long-term health conditions (Berkanish et al., 2022) and children of parents with mental health difficulties (Parkinson et al., 2021). When investigating young people's perceptions of non-traditional mental healthcare services, such as online support groups and peer counsellors, Cohen et al. (2021) found high rates of usage and willingness to use these types of support. Further, qualitative research has demonstrated several potential benefits of peer support for children and young people, such as that it addresses barriers to seeking help (Kendal et al., 2017), allows children to express strong feelings (Tichon, 2015) and reduces feelings of isolation and self-blame (von Doussa et al., 2022).

Previous systematic reviews have explored and summarised the effects of peer support interventions for children and young people. However, the scope of these reviews was limited, looking specifically at the effects of online peer support for young people aged 12-25 (Ali et al., 2015), the mental health outcomes of peer-led interventions based in schools for children and young people aged 4-18 (King & Fazel, 2021), or technology-based peer support interventions for adolescents with long-term health conditions (Berkanish et al., 2022). The findings of these reviews were mixed. Overall, only two out of six of the RCTs in Ali et al.'s (2015) review were associated with significant positive outcomes; specifically, a reduction in anxiety (hedge's $g = -0.91$), and tobacco use. Peer support was not found to be effective in the remaining four RCTs. King and Fazel's (2021) review concluded that while peer-led interventions are widely used, there is little evidence on mental health outcomes. Eleven studies were included in the review, of which seven reported on effects for peer-facilitators. Only two of these found significant effects, which were improvements in social stress and self-esteem, and an increase in guilt. Of the five studies that reported on outcomes for peer-recipients, only two reported significant positive effects, which consisted of improvements in quality of life and self-confidence, whilst one study found that learning stress increased and overall scores on a mental health survey decreased (effect size = -4.12) (King & Fazel, 2021). Further, they noted that although the studies reported on outcomes related to emotional or wellbeing difficulties, none of the studies measured outcomes relating to psychiatric disorders, such as depression or anxiety disorders (King & Fazel, 2021). Berkanish et al.'s (2022) review evaluated 32 studies, most of which had a primary focus on feasibility outcomes, though several also evaluated psychosocial outcomes. Four studies reported statistically significant improvements on measures of social support, whilst two found no significant change. Further, three studies showed improvement in quality of life, whilst four showed no change.

The Department of Education funded a 2016 literature review into the available models of peer support that can improve children and young people's mental health in the UK, detailing their key features and evidence of their effectiveness (Coleman et al., 2017). They found that there was considerable diversity in the peer support schemes offered, in the form of school-based group support, training-based projects where young people were trained to act as 'champions', online projects, and community-based projects. They also detailed that evidence for effectiveness can be limited, often based on weak evaluation. Overall, they found that the peer support schemes had differing amounts of success, but they concluded that peer support can offer potential positive outcomes for the wellbeing of children and young people, such as improved self-esteem and increased happiness. Although promising, this review was limited in that it was not done systematically, focussed solely on the UK, and included some group-based support groups that were led by professionals rather than peers.

Promising effects were also found in a scoping review of the effect of peer support on young adults' (aged 18-25) mental health (Richard et al., 2022). They found an overall positive association of peer support with mental health, including significant associations with increased happiness ($\beta = 0.38$), self-esteem ($r = 0.40$), more effective coping ($\beta = 0.17$), and reductions in depression ($r = -0.12$ to -0.32), loneliness ($\beta = -0.49$), and anxiety ($r = -0.15$). These associations were present among university students, non-student young adults and minoritised ethnic and sexual groups. Benefits were seen for both individual and group peer support, as well as for those providing the support. However, of the seventeen studies that were evaluated, nine of these looked at perceived levels of support from peers in naturally occurring relationships, as opposed to intentional and protocol-based peer support interventions, which differs from Simoni et al.'s (2011) definition of peer support. Further, some interventions were again led by professionals rather than peer.

Further adding to the evidence base on peer support for children and young people, two reviews are currently in progress according to the PROSPERO prospective register of systematic reviews. Robinson et al. (2022) are conducting a realist synthesis of online peer support forums aimed at supporting mental health, for those aged 13 or over. De Beer et al. (2021) are conducting a review exploring formal peer support within children and young people's mental health services, for children with a diagnosed mental disorder, with the aim of gaining insight into the key features, mechanisms, barriers, and strengths of formal peer support services.

The Current Review

This review will differ from previous and planned reviews in that:

- It will focus on the outcomes for children and young people up to and including the age of 18, with or without a diagnosed mental or physical health condition, in any setting.
- It will evaluate any form of peer support modality, including 1:1 peer support, peer-delivered interventions, peer support groups, and online peer support forums. As per Simoni et al.'s (2011) definition, only peer support interventions that are intentional

and led by peers, rather than professionals alone, will be included. However, if interventions are co-facilitated by both a peer and a professional, they will be included, since young peer facilitators may be likely to have the support of a professional.

- It aims to understand the mental health outcomes of these peer support interventions, measured specifically using explicit standardised measures of mental health symptoms or disorders, rather than antecedents or mediators of mental health such as self-esteem, hope, or stress.
- It will focus on research published over the last decade, in order to understand up-to-date literature since a number of importance changes and policy decisions. For example, clarification of the definition of peer support for health contexts (Simoni et al., 2011), advancements in technologies which have enabled easier access to peer support, and changes in mental health strategy such as World Health Organisation's (2013) Mental Health Action Plan, and in the UK, the Department of Health and Social Care's (2011) 'No Health without Mental Health' strategy, and the NHS (2016) 'Five Year Forward View For Mental Health', which all recommended the use of peer support in responsive and personalised mental health care.

To this end, the proposed systematic review will address the following principal research question:

What are the mental health outcomes of peer support interventions for children and young people?

Method

A review of relevant literature was registered with PROSPERO (CRD42022357711)[1] and completed using a systematic review approach, in line with Cochrane guidance (Higgins et al., 2022). Retrieved records were stored and screened using Rayyan (Ouzzani et al., 2016), a software for managing systematic reviews.

Information Sources

Two electronic databases, PsycINFO and Medline, were systematically searched on September 6th 2022 for relevant articles. These databases were chosen due to their scope of literature regarding mental health. Forwards citation searches were then conducted on Web of Science. Backwards citation searches were also completed for all shortlisted papers. In addition, relevant previous systematic reviews found during the search were reviewed to locate any additional papers that were not captured by the initial search.

Search Strategy

Initial search terms were informed by terms used in previous systematic reviews involving children and young people (Ekeland et al., 2004) or looking at peer support (Ali et al., 2015; Fuhr et al., 2014) and refined through initial scoping searches. The final search terms were clustered into three key concepts: peer support, mental health, and children and young people. Search terms used for each database are shown in Appendix A. As COCHRANE guidance (Higgins et al., 2022) advises that date restrictions should be wider than the period of interest for the review, to account for inconsistent publication data in database records, the search was limited from 2011 to current. It was also restricted to only include peer reviewed journals on PsycINFO. No study design or language limits were imposed on the original search; however, only studies where the full article was available in

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[1] Since protocol registration, the age range of participants was narrowed from 0-25 years in order to focus on young people aged 0-18 years.

English were included. The search strategy was developed with input from a Psychology Librarian at University College London (UCL).

Eligibility Criteria

Studies were deemed eligible for the review if they met the following criteria:

- **Population:** the age range of the sample fell between 0 to 18 years. When the range was not reported, studies were included if the sample mean age was 18 or less, as long as it was not reported that the sample included adults. Where the age of the participants was not specified, studies relating to children and primary and secondary school students were included, while studies relating to young people, adults, parents, teachers or college or university students, were not included. Studies evaluating both children and young people and adults were included if the results for children and young people (0-18) were reported separately.
- **Intervention:** the study evaluated any form of peer support intervention that was facilitated by a peer or co-facilitated by a peer with a professional (e.g., 1:1 peer support, support groups, online peer support forums, peer-led interventions).
- **Comparison:** the study had any comparator or control, or none.
- **Outcomes:** the effectiveness of the peer support intervention was evaluated, where the peer support was either a stand-alone intervention, or part of a multi-component intervention where the peer support component could be evaluated separately, as in Ali et al.'s (2015) review. The study evaluated mental health outcomes measured using standardised assessment tools for measuring mental health symptoms or disorders, such as the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) or Strengths and Difficulties Questionnaire (Goodman, 1997)***.***
- The study collected quantitative data, within any type of study design.
- The paper was a research article and not an abstract, case report, book, protocol, magazine or newspaper article, dissertation, commentary paper or literature review.

- The study was published in a peer-reviewed journal.
- The full article was in English.
- The study was published from the year 2011 onwards.

Selection Process

To determine eligibility, all records were screened in two stages. First, the title and abstracts of all records were screened against the eligibility criteria. Second, all articles deemed to be potentially eligible in the first stage were retrieved so that they could be screened against the eligibility criteria using their full text. A second independent reviewer independently cross-checked 10% of the screening at both stages. Conflicts identified during screening were resolved through discussion and consensus within the pair. The number of studies meeting criteria at each stage of the review were depicted in a PRISMA flow diagram (Page et al., 2020) (Figure 1).

Data extraction

Two independent reviewers extracted the following study characteristics:

a) Study identification items: author(s), year of publication, country of study and study design.

b) Participant characteristics: sample size, target population, inclusion and exclusion criteria, age, gender and ethnicity or race.

c) Intervention characteristics: peer support format and description, including length and frequency, follow up, description of peer facilitator and their training, whether the peer support was moderated, and who by.

d) Comparator – presence or absence of a comparison and a description of the comparison intervention if applicable.

e) Outcomes – mental health outcome(s) measured and effects of the peer support intervention on these measures.

These data were tabulated and conflicts between reviewers were resolved by discussion within the pair.

Risk of Bias Assessment

Risk of bias in eligible studies was assessed using The Effective Public Health Practice Project (EPHPP) quality assessment tool for quantitative studies (Thomas et al., 2004) and the results of the studies were interpreted with consideration of this risk. Both reviewers assessed the studies independently and then discussed their ratings. Discrepancies between ratings were resolved by discussion within the pair. The EPHPP tool was chosen as it can be used to evaluate a variety of intervention study designs used in public health, including RCTs, pre-post, and case-control studies (Armijo-Olivo et al., 2012). It evaluates studies on six components: selection bias, study design, confounders, blinding, data collection method and withdrawals and dropouts, giving a score for each component: strong (1), moderate (2) and weak (3). The tool also allows global ratings of each paper, with strong (1) for papers with no weak rating, moderate (2) for papers with one weak rating, and weak (3) for papers with two or more weak ratings. Authors of all 11 papers were emailed to gather missing data needed to assess the quality of the study.

Strategy for Data Synthesis

A narrative synthesis was planned due to the expectation that there would be heterogeneity in the range of populations, study designs and types of peer support intervention, meaning that combining statistical effect sizes in a meta-analysis would not be meaningful (Sharpe, 1997). Narrative synthesis uses text to ‘tell the story’ of the results of included studies (Popay et al., 2006, p. 5). The findings from data extraction were analysed and summarised by the researcher, including the size and direction of effects organised by mental health outcome, common factors, and patterns across and within the studies, and with an assessment of the strength of the evidence.

Results

Study Selection

The search of databases identified 3048 relevant studies, with no additional papers sourced through citation searches, or reviewing relevant previous systematic reviews. One additional relevant study was found when searching for the full text of another research paper. Eleven research papers were deemed eligible to be included in the review, one of which reported on two studies (Vanderkruik et al., 2020a; Vanderkruik et al., 2020b), and two papers which reported on the same study, one with additional follow up data, and were therefore treated as one study (Noël et al., 2013; Noël et al., 2014). The process of selection of included studies can be seen in Figure 1.

Study characteristics

Table 1 provides an overview of the 11 studies that were deemed eligible for this review. Authors of all 11 papers were emailed to gather missing data that were needed to assess the quality of the studies. The authors of six of the papers responded with additional information, though only the author of one paper was able to provide all of the requested information. As seen in table 1, there was a range of study designs: RCTs (n = 2) (Eickman et al., 2018; Noël et al., 2014), quasi-experimental designs (n = 3) (Ciao et al., 2015**;** Haft, et al., 2019**;** Warner & Budd, 2018), pre-post designs (n = 3) (Eisenstein et al., 2019; Lewis at al., 2016; Vanderkruik et al., 2020a), pilot RCTs (Mulfinger et al., 2018; Vanderkruik, et al., 2020b) and a pilot pre-post design (Jennings & Jennings, 2013). Sample sizes ranged from 8 to 950 across all studies. The majority of studies were conducted in the United States of America (n = 7) (Ciao et al., 2015; Eickman et al., 2018; Haft et al., 2019; Jennings & Jennings, 2013; Noël et al., 2014; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b) and the remaining studies were conducted in the UK (n = 2) (Eisenstein et al., 2019; Warner & Budd, 2018), Australia (n = 1) (Lewis et al., 2016) and Germany (n = 1) (Mulfinger et al., 2018).

Figure 1

PRISMA Flow Diagram (Page et al., 2020) Depicting the Different Stages of the Systematic Review Process

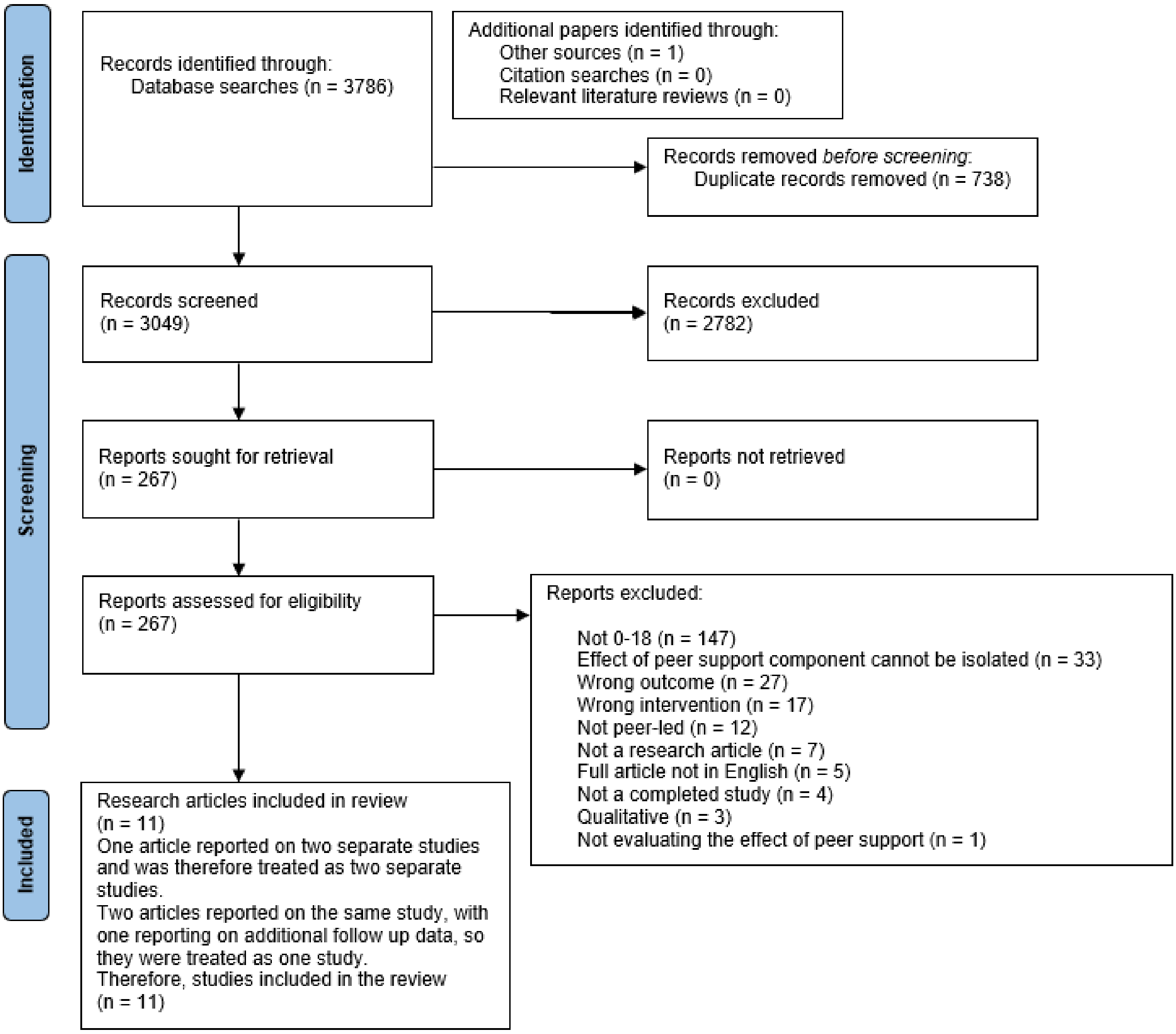

Table 1

Summary of Included Studies

Author	Country	Study design	Sample size	Peer-recipient description	Age (years)	Gender (% female)	Ethnicity or Race	Peer support intervention	Comparison (Y/N)	Description of comparison	Mental health outcome measures	Results
Ciao et al. (2015)	USA	Quasi-experimental	51	Ninth grade students	M (SD) = 13.98 (0.59)	100%	40% Caucasian, 32% Pacific Islander or Hawaiian, 18% Other/Mixed, 10% Asian	A peer-led dissonance-based group intervention for eating disorder prevention	Y	Waitlist	EDEQ (Fairburn & Beglin, 1994) EAT-26 (Garner & Garfinkel, 1979)	**EDEQ-total:** No significant time by group interaction was found for the active vs waitlist comparison ($p = .077$, $n^2 = 0.06$). However, across all participants after the intervention (active and waitlist combined), there was a significant effect of time ($p < .001$, $n^2 = 0.29$) with scores significantly reducing from pre- to post-intervention. This was maintained at follow up ($p < .05$) **EDEQ-restraint subscale:** No significant time by group interaction was found for the active vs waitlist comparison ($p = .315$, $n^2 = 0.02$). However, across all participants after the intervention (active and waitlist combined), there was a significant effect of time ($p = .031$, $n^2 = 0.13$). Scores significantly reduced from pre- to post-intervention and this was maintained at follow up ($p < .05$) **EAT-26:** A significant time by group interaction was found for the active vs waitlist comparison ($p < .01$, $n^2 = 0.13$), with scores dropping for the active condition and rising for the waitlist condition. Across all participants after the intervention (active and waitlist combined), there was a significant effect of time ($p < .01$, $n^2 = 0.26$), with scores significantly reducing from pre- to post-intervention ($p < .05$), but rebounding again at follow up. **EAT-Dietary subscale:** A significant time by group interaction was found for the active vs waitlist comparison ($p = .002$, $n^2 = 0.20$), with scores dropping more for the active condition than the waitlist condition.
Eickman et al. (2018)	USA	RCT	71	High school students	Not specified. Freshman to Senior year	81%	77–90% Caucasian	A peer-led dissonance-based intervention for eating disorder prevention	Y	Waitlist	EDEQ (Fairburn & Beglin, 1994) PANAS (Watson et al., 1988).	**EDEQ:** When baseline scores were controlled for, participants in both intervention schools, compared to participants in control schools, showed significant improvements post-intervention on the EDEQ Global score ($p < .001$ and $.01$), and the Eating Concern ($p = .004$ and $.04$), Shape Concern ($p < .001$ and $.01$), Weight Concern ($p < .001$ and $.004$) and Restraint ($p = .001$ and $.01$) subscales. Effect sizes ranged from medium to large ($d = 0.55 - 1.31$). **PANAS:** Participants in intervention school one, but not intervention school two, showed significantly healthier scores post-intervention compared to control school students on the

												PANAS (Positive affect: p = .002, d = 0.87, Negative affect: p < .001, d = 1.05).
Eisenstein et al., (2019)	UK	Pre-post	950 (84 peer facilitators 866 peer recipients)	Year 7 high school students	Not specified. Year 12 peer facilitators, year 7 peer-recipients	NR	42% of peer-recipients and 13% of peer-facilitators were of black and minority ethnic origins	A peer-led intervention supporting students to develop knowledge and skills to safeguard the mental health of themselves and their peers	N	n/a	M&MS (Deighton et al., 2013).	**Peer-recipients:** There was a significant decrease in scores on the M&MS emotional difficulties subscale post-intervention. However, the effect size was negligible (p = 0.005, d = 0.09). **Peer-facilitators:** There were no significant differences in peer educators' scores pre- and post-intervention. **Clinical change:** For both the peer-facilitators and the peer-recipients, 40% (16/40) of participants above threshold for behavioural difficulties and 38% (29/77) of participants above clinical threshold for emotional difficulties pre-intervention scored in the "normal" range post-intervention.
Haft et al. (2019)	USA	Quasi-experimental with two control groups	234	High school students with a diagnosis of a learning disability or ADHD or both	Range = 8 - 16	44%	42% 'non-white'	Group peer mentoring	Y	Participants with ADHD or a learning disability not in the mentoring intervention (Control-NM), and typically developing participants not in the mentoring intervention (Control-TD)	BASC-2 (Reynolds & Kamphaus, 2004)	**BASC-2 Depression:** A significant time by group interaction was found on depression scores when family affluence was controlled for (p < .005, partial n^2 = 0.12). Compared to both the control-NM group and control-TD group, there was a significant post-intervention effect on depression scores for the intervention group (d = -0.75, p < .005 and d = -0.38, p < .01 respectively). A significant main effect of time was found for the intervention group (p < .005, partial n^2 = .17), with depression scores significantly reducing from pre- to post-intervention. Overall, the intervention group showed significant improvements on depression scores, whilst the control-NM group showed significant worsening of depression scores over time. The control-TD group did not significantly change. The quality of the mentoring, as perceived by the mentee, significantly predicted change in depression (p = .049), though the explained proportion of variance of depression was low (4.2%). **BASC-2 Anxiety:** No significant interaction between time by group was found on anxiety scores when family affluence was controlled for (p = .602, partial n^2 = 0.01).
Jennings and Jennings (2013)	USA	Pilot pre-post	8	High school seniors	Range = 17 - 18	38%	NR but stated that participants were 100% European American	A peer-led mindfulness intervention	N	n/a	BAI (Beck, et al., 1993), IAS (Leary, 1983)	Descriptive statistics only. **BAI:** There was a 30% reduction in anxiety scores from pre- to post-intervention, with an 11% reduction in physiological anxiety and a 55% reduction in cognitive anxiety **IAS:** There was a 9% reduction in social anxiety scores from pre- to post-intervention

Lewis et al. (2016)	Australia	Pre-post	14	New members of a hospital-based peer support program with LTCs, including type 1 diabetes, liver cancer (in remission, Crohns disease, Turner’s Syndrome, juvenile idiopathic arthritis and severe burns	Range = 12 - 17	79%	NR but stated that there were no participants of Indigenous Australian origin.	A peer support group	N	n/a	K10 (Andrews & Slade, 2001)	Levels of psychological distress on the K10 did not significantly change during the intervention (p = 0.476).
Mulfinger et al. (2018)	Germany	Pilot RCT	98	Participants from four Child and Adolescent Psychiatry departments, who reported one or more current axis-I or axis-II disorder in the ICD-10 (WHO, 2016)	M (SD) = 15.8 (1.2)	69%	100% White Caucasian	A peer-led intervention supporting participants with mental illness disclosure decisions, to reduce the impact of stigma 'Honest, Open, Proud (HOP)'	Y	Treatment as usual	CES-D (Meyer & Hautzinger, 2001)	There was no significant effect found post-intervention (p = .50), however there was a significant large effect on depressive symptoms at 3-week follow up, with scores decreasing (d = 0.72, p < .001).
Noël et al. (2014)	USA	RCT	34	7th or 8th grade high school students who scored ≥10 on the CES-D, or reported moderate or severe anhedonia or depressed mood on the K-SADS	M (SD) = 13.75 (0.97)	100%	82% African American, 12% Non-Hispanic White, 6% Hispanic Latino	A peer-led intervention for depression prevention based on positive youth development and cognitive behavioural principles 'Talk and Time'	Y	Waitlist	adapted K-SADS (Kaufman et al., 1997).	Intervention group participants showed significantly greater reductions in depression scores post-intervention (p = .038) and at 6 month follow up (p = .005) than those in the control group, with a large estimated effect size of this difference at post-intervention (d = 0.86)

Vanderkruik et al (2020a)	USA	Pre-post	112	High school students	Range = 15 - 18	100%	83% White, 19% Asian/Asian American, 6% Hispanic/Latino, 4% African American/Black, 3% “other”, 16% identified with more than one race/ethnicity	A peer-led dissonance-based group intervention for eating disorder prevention	N	n/a	PANAS-R (Watson & Clark, 1992), PHQ-9 (Kroenke & Spitzer, 2002), GAD-7 (Spitzer et al., 2006).	**PANAS-R:** There was a significant decrease from baseline to post-intervention in reported negative affect (p < .001, d = 0.47) **GAD-7:** There was a significant decrease from baseline to post-intervention in reported anxiety (p < .001, d = 0.52). **PHQ-9:** Due to missing data, a weighted analysis was used for depression scores, which showed a significant effect of the intervention on reported depression scores (p <.001, d = 0.30), with the mean score decreasing from baseline to post-intervention.
Vanderkruik et al. (2020b)	USA	Pilot RCT	74	Female high school students	Range = 14 – 18	100%	77% White, 28% Asian/Asian American, 8% Hispanic/Latino, 1.4% African American/Black, 15% more than one race/ethnicity	A peer-led dissonance-based group intervention for eating disorder prevention	Y	Assessment only	PANAS-R (Watson & Clark, 1992), PHQ-9 (Kroenke & Spitzer, 2002), GAD-7 (Spitzer et al., 2006).	No significant effects of group allocation were found on changes in negative affect (p = .27), depression (p = .14) , or anxiety (p = .10).
Warner & Budd (2018)	UK	Quasi-experimental	56	Secondary school students	M (SD) = 17.28 (0.44)	47%	NR	1:1 peer coaching, based on IGROW model (Whitmore, 2010)	Y	Waitlist	Westside Test Anxiety Scale (Driscoll, 2007)	A significant main effect of condition (p = .016) was found, with a medium to large effect size (η = 0.112), where those in the intervention condition reported less test anxiety than those in the control condition.

Note. NR = not reported, EDEQ = Eating Disorder Examination Questionnaire, EAT-26 = Eating Attitudes Test – 26, PANAS = Positive and Negative Affect Schedule, M&MS = Me and My School Questionnaire, BASC-2 = The Behaviour Assessment System for Children 2nd Edition, BAI = Beck Anxiety Inventory, IAS = Interaction Anxiousness Scale, K10 = Kessler Psychological Distress Scale, CES-D = Center for Epidemiologic Studies Depression Scale, K-SADS = Kiddie Schedule for Affective Disorders and Schizophrenia, PANAS-R = Positive and Negative Affect Schedule – Revised, PHQ-9 = Patient Health Questionnaire-9, GAD-7 = Generalised Anxiety Disorder 7-item

🟩 = At least one statistically significant and meaningful improvement on measures
🟨 = Some clinically relevant change on measures
🟥 = No significant effect or clinically relevant improvement on measures

Mental Health Outcomes

The mental health outcomes reported on were depression symptoms (n = 5 studies), anxiety symptoms (n = 5 studies), eating disorder symptoms (n = 2 studies), emotional and behavioural difficulties (n = 1 study), psychological distress (n = 1 study) and negative affect (n = 3 studies). These were measured by a range of standardised questionnaires, including measures of depressive symptoms: the Centre for Epidemiologic Studies Depression Scale (CES-D) (Meyer, & Hautzinger, 2001), the Patient Health Questionnaire (PHQ-9), the adapted Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS) (Kaufman et al., 1997); and the depression scale of the Behaviour Assessment System for Children Second edition (BASC-2) (Reynolds & Kamphaus, 2004), which is a measure commonly used to evaluate behavioural and emotional difficulties in children. Anxiety symptoms were measured by: Beck's Anxiety Inventory (BAI) (Beck et al., 1993) and the GAD-7 (Spitzer, Kroenke, Williams, & Lowe, 2006)**,** which are self-report measures of anxiety and generalised anxiety; the Interaction Anxiousness Scale (IAS) (Leary, 1983), a self-report measure of dispositional social anxiety; the Westside Test Anxiety Scale (Driscoll, 2007), which measures anxiety impairment and cognitions which could impair test performance; and the anxiety scale of the BASC-2 (Reynolds & Kamphaus, 2004). Eating disorder symptoms were measured using the Eating Disorder Examination Questionnaire (EDEQ) (Fairburn & Beglin, 1994), which provides a measure of the severity and range of eating disorder features, and the Eating Attitudes Test (EAT-26) (Garner & Garfinkel, 1979), a self-report measure of eating disorder symptoms. Mental health outcomes that were not disorder-specific were measured using: the Me and My School Questionnaire (M&MS) (Deighton et al., 2013), a measure of emotional and behavioural difficulties; the Kessler Psychological Distress scale (K10) (Andrews & Slade, 2001), a measure of psychological distress; and the Positive Affect Negative Affect Scale (PANAS) (Watson, Clark, & Tellegen, 1988) and the revised scale (PANAS-R) (Watson & Clark, 1992), which are self-report measures that evaluate state positive and negative mood. All but one study used inferential statistics to analyse changes in these outcomes; Jennings and Jennings (2013) used only descriptive statistics.

Interventions

The majority of studies evaluated peer-led interventions (n = 6), which included four dissonance-based interventions, in which recipients complete exercises to create cognitive dissonance about target issues (Ciao et al., 2015; Eickman et al., 2018; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b), a mindfulness intervention (Jennings & Jennings, 2013), a mental health safeguarding intervention (Eisenstein et al., 2019), an intervention to support the disclosure of mental health conditions (Mulfinger et al., 2018) and a depression prevention intervention guided by cognitive behavioural therapy (CBT) and positive youth development (PYD) concepts (Noël et al., 2014). The remaining studies evaluated group peer mentoring (Haft et al., 2019), 1:1 peer coaching (Warner & Budd, 2018), and a peer support group (Lewis, et al., 2016). All studies evaluated peer support interventions that were face-to-face in modality. A summary of the interventions can be seen in Table 2, with further details in Appendix B.

Control Groups

Seven studies compared the intervention to a control group. Control groups consisted of a waitlist condition control (n = 4) (Ciao et al., 2015; Eickman et al., 2018; Noël et al., 2014; Warner & Budd, 2018), treatment as usual (n = 1) (Mulfinger et al., 2018), assessment only (n = 1) (Vanderkruik et al., 2020b), and one study included two control groups. This was a study of group peer mentoring for young people with attention deficit hyperactivity disorder (ADHD) or learning disabilities (LD), where the control groups were young people with ADHD or LD in schools without the mentoring intervention, and typically developing (TD) young people in schools without the mentoring intervention (Haft et al., 2019).

Peer-Recipients

A summary of the characteristics of the receivers of peer support ‘peer-recipients' and facilitators of the peer support ‘peer-facilitators’ can be seen in Table 2. Across studies where the age range of the peer-recipients was reported, the minimum age was 8 years and maximum age was 18 years. Across studies where only the mean age was reported, the lowest mean age was 13.98 (SD = 0.59), and the highest mean age was 17.23 (SD = 0.44). Across studies where only the school year was reported, peer-recipients ranged from being in year 7 to year 13 (or the USA equivalent). In all studies that did not report the age range, peer-recipients were either high school students or under child and adolescent psychiatry, therefore it was assumed that no peer-recipients over 18 were included.

One study recruited peer-recipients from child and adolescent psychiatry departments (Mulfinger et al., 2018), whilst another study recruited peer-recipients that were members of a hospital-based peer support programme for children with chronic illness (Lewis et al., 2016). In the remaining nine studies, peer-recipients were recruited from high schools. Only two studies had inclusion criteria regarding mental health for the peer-recipients, with one study including young people who reported one or more current axis-I or axis-II disorder in the ICD-10 (WHO, 2016) and at least a moderate level of self-reported distress relating to disclosure of their mental health condition (Mulfinger et al., 2018), and another study only included young people who scored 10 or above on the CES-D or reported moderate or severe anhedonia or depressed mood on the K-SADS (Noël et al., 2014). One study only included peer-recipients with a diagnosis of ADHD or a LD in the treatment condition (Haft et al., 2019).

Table 2

Summary of Peer Support Interventions and Descriptions of Peer-Recipients, Peer-Facilitators and Professional Involvement

Study	Intervention	Length	Frequency	Peer-recipient Description	Peer-facilitator Description	Peer-facilitator Training	Professional Involvement
Ciao et al. (2015)	A peer-led dissonance-based group intervention for eating disorder prevention	1 hour	Two sessions, two days apart	Female 9th grade students	11th or 12th grade students	12 hours training	Supervision was provided by a psychologist to individual peer-facilitators about their experience of running the group
Eickman et al. (2018)	A peer-led dissonance-based intervention for eating disorder prevention	0.5 - 1 hour	Weekly meetings for 8 months, plus activities for the whole school and in the community	High school students	High school students	Training given, length not reported	Teachers provided guidance to the students when picking weekly topics and activities, and documented meeting activities
Eisenstein et al. (2019)	A peer-led intervention supporting students to develop knowledge and skills to safeguard the mental health of themselves and their peers	40 minutes	Five sessions	Year 7 high school students	Year 12 students	Two days training	School staff supported the peer facilitators to deliver the sessions, however the level of involvement was not reported
Haft et al. (2019)	Group peer mentoring	NR	Once a week for 18 weeks	High school students with a diagnosis of LD/ADHD or both, age range 6-16	High school or college students, with a diagnosis of LD/ADHD, age range 16-32	Several hours training for peer mentors and each group of mentors had a designated leader who attended a 5-day training	None reported after training
Jennings and Jennings (2013)	A peer-led group mindfulness intervention	50 minutes	Four sessions within three weeks	High school seniors, age range 17-18	17-year-old high school students	Several hours training	None reported after training
Lewis et al. (2016)	A peer support group	2 hours	Once a week for eight weeks	New members of a hospital-based peer support program with a range of chronic illnesses, aged 12-17	An older member of the peer support programme, age not reported	One day training	Sessions were co-facilitated with a nurse
Mulfinger et al. (2018)	A peer-led intervention supporting participants with mental illness disclosure	2 hours	Once a week for three weeks	Participants from four Child and Adolescent Psychiatry departments	A young adult with lived experience of	Training given, length not reported	Sessions were co-facilitated with a young mental health professional

	decisions, to reduce the impact of stigma 'Honest, Open, Proud (HOP)'			with a current axis-I or axis-II disorder, with a mean age of 15.8	mental illness, age not reported		
Noël et al. (2014)	A peer-led group intervention for depression prevention based on CBT and PYD principles 'Talk and Time'	1.5 hours	Once a week for 12 weeks	7th or 8th grade female high school students reporting depressed mood. Mean age = 13.75 (SD = 0.97)	11th or 12th grade students, with a mean age of 16.15 (SD = 1.59)	Three days training, plus pre- session briefing and post session de-briefing	A teacher was required to be present during the group sessions but was given guidance on how to be present without being directly involved. A master's level social worker provided the briefing and debriefing and watched every session live via video conference to assess fidelity of the intervention, identify anyone at risk, and provide feedback
Vanderkruik et al (2020a)	A peer-led dissonance-based group intervention for eating disorder prevention	1 hour	Once a week for four weeks	Female high school students, age range 15-18	College age female students (age not reported, but in the USA this is usually 17+)	16 hours training + three booster sessions	Sessions were recorded and listened to by a supervisor and facilitators received ongoing support from a psychologist and a high school counsellor
Vanderkruik et al. (2020b)	A peer-led dissonance-based group intervention for eating disorder prevention	1 hour	Once a week for four weeks	Female high school students, age range 14-18	Undergraduate female students (age not reported, but in the USA this is usually 17+)	16 hours training + four booster sessions	Sessions were recorded and listened to by a supervisor and facilitators received ongoing support from a psychologist and a high school counsellor
Warner and Budd (2018)	1:1 peer coaching, based on IGROW model (Whitmore, 2010)	20 minutes	Once a week for 10 weeks	Secondary school students, with a mean age of 17.28	Secondary school students, with a mean age of 17.28	4 hours	Sessions were supervised by a teacher who was trained in coaching

Note. NR = Not Reported

Peer-Facilitators

As seen in table 2, the majority of studies had peer-facilitators that were some years older than the peer-recipients, but still shared a characteristic, such as being a student, or also having lived experience of an LD, ADHD, mental health or physical health condition (n=8) (Ciao et al., 2015; Eisenstein et al., 2019; Haft et al., 2019; Lewis et al., 2016; Mulfinger et al., 2017; Noël et al., 2014; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b). Whilst in two studies, peer-facilitators were students of the same age (Eickman et al., 2018; Jennings & Jennings, 2013), and in Warner and Budd's (2018) study, the peer-facilitators were also the peer-recipients as participants took it in turns to be the 'coach' and 'coachee' in pairs. All studies reported that training was given to the peer-facilitators. Where stated, the training ranged in time from 'several hours' to two days.

Professional Involvement

As seen in table 2, professionals were reported to be present during the intervention in five studies. There was a range of level of professional involvement, with some interventions being co-led by a peer-facilitator and a professional (n = 2) (Lewis et al., 2016; Mulfinger et al., 2018), the peer-facilitators being 'supported' by professionals to deliver sessions (n = 1) (Eisenstein et al., 2019), the professional supervising sessions (n = 1) (Warner & Budd, 2018), and the professional being present but not directly involved with the intervention, whilst another professional watched over video conference (n = 1) (Noël et al., 2014). In three further studies professionals were involved less directly, such as by supporting peer-facilitators to pick topics and activities (n = 1) (Eickman et al., 2018), by listening to recordings of sessions (n = 2) (Vanderkruik et al., 2020a; Vanderkruik et al., 2020b) or providing supervision about the experience of running the group (Ciao et al., 2015). The remaining two studies did not report the level of professional involvement during the intervention itself (Haft et al., 2019; Jennings & Jennings, 2013).

Risk of Bias in Studies

Risk of bias in the selected studies was assessed using the EPHPP quality assessment tool for quantitative studies (Thomas et al., 2004). As seen in table 3, apart from one study which was assessed as ‘moderate’ (Lewis et al., 2016), all other studies were given a global rating of ‘weak’ due to having two or more components rated as ‘weak’. Regarding selection bias, no studies were rated ‘strong’, affected by the lack of random sampling. One paper (Lewis et al., 2016) was rated ‘moderate’ as it used purposive sampling and 100% of selected individuals agreed to participate in the study, whereas all other studies were rated ‘weak’ as participants self-referred or were referred from a source in a non-systematic manner. Four studies were rated ‘strong’ for study design due to being RCTs and controlled clinical trials (Eickman et al., 2018; Noël et al., 2014), or pilot RCTs (Mulfinger et al., 2018; Vanderkruik et al., 2020b). Four studies were rated ‘moderate’ for using pre-post designs (Eisenstein et al., 2019; Lewis et al., 2016; Vanderkruik et al., 2020a), or a pilot pre-post design (Jennings & Jennings, 2013). The remaining three studies (Ciao et al., 2015; Haft et al., 2019; Warner & Budd, 2018) were rated ‘weak’ due to using quasi-experimental designs. Of the seven studies that used a control group, three of these were rated as ‘strong’ as they were assessed as having controlled for at least 80% of relevant confounders (Haft et al., 2019; Mulfinger et al., 2018; Noël et al., 2014). Three studies were rated ‘moderate’ as they were assessed as having controlled for 60-79% of relevant confounders (Ciao et al., 2015; Eickman et al., 2018; Warner & Budd, 2018), whilst one study (Vanderkruik et al., 2020b) was deemed ‘weak’ as it was judged that less than 60% of relevant confounders were controlled for. To note, where potential confounders were not reported, such as the ethnicity of participants or whether they were accessing other mental health interventions, it was judged that these were not controlled for. All studies were assessed as ‘weak’ for blinding, as it was assumed that all participants were aware of the research question, and as all studies used self-report questionnaires, it was also assumed that the outcome assessors were aware of their own intervention status. For data collection methods, all studies were rated as ‘strong’ due to using reliable and valid measures. For studies that reported withdrawal and dropout data, six of these were rated as ‘strong’ due to having a follow up rate of at least 80% (Ciao et al., 2015; Eickman et al., 2018; Noël et al., 2014; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b; Warner & Budd, 2018), whilst the remaining three were rated as ‘moderate’ due to follow up rates being between 60 - 79% (Jennings & Jennings, 2013; Lewis et al., 2016; Mulfinger et al., 2018). Finally, regarding intervention integrity, six studies (out of the eight studies where this was reported) reported that the consistency or fidelity of the intervention was measured in some way (Ciao et al., 2015; Eickman et al., 2018; Mulfinger et al., 2018; Noël et al., 2014; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b). Further, to control for unintended interventions, Haft et al.’s (2019) study did not include participants that were receiving counselling and Noël et al. (2014) reported that none of the participants had been previously exposed to a depression intervention, whilst one study controlled for mental health treatment centre in the analysis (Mulfinger et al., 2018). However, all other studies either did not measure, or did not report whether participants were also receiving any other mental health interventions, therefore the influence of unintended interventions on reported effects cannot be ruled out.

Table 3

Effective Public Health Practice Project Quality Assessment Ratings

Study	Selection Bias	Study Design	Confounders	Blinding	Data Collection Methods	Withdrawals and Dropout	**Global Rating**
Ciao et al. (2015)	Weak	Weak	Moderate	Weak	Strong	Strong	**Weak**
Eickman et al. (2018)	Weak	Strong	Moderate	Weak	Strong	Strong	**Weak**
Eisenstein et al. (2019)	Weak	Moderate	n/a	Weak	Strong	NR	**Weak**
Haft et al. (2019)	Weak	Weak	Strong	Weak	Strong	NR	**Weak**
Jennings and Jennings (2013)	Weak	Moderate	n/a	Weak	Strong	Moderate	**Weak**
Lewis et al. (2016)	Moderate	Moderate	n/a	Weak	Strong	Moderate	**Moderate**
Mulfinger et al. (2018)	Weak	Strong	Strong	Weak	Strong	Moderate	**Weak**
Noël et al. (2014)	Weak	Strong	Strong	Weak	Strong	Strong	**Weak**
Vanderkruik et al (2020a)	Weak	Moderate	n/a	Weak	Strong	Strong	**Weak**
Vanderkruik et al. (2020b)	Weak	Strong	Weak	Weak	Strong	Strong	**Weak**
Warner and Budd (2018)	Weak	Weak	Moderate	Weak	Strong	Strong	**Weak**

Intervention Efficacy and Strengths and Limitations of the Evidence

As anticipated, there were high levels of heterogeneity across the studies; therefore it was not appropriate to conduct a meta-analysis. A narrative synthesis was conducted as planned. The results are presented by mental health outcome, with consideration of statistical significance, effect size, direction of effect, and where reported, clinically significant change.

Depression Outcomes

As seen in table 1, five studies measured depression outcomes. Haft et al.'s (2019) evaluation of group peer mentoring for high school students with a diagnosis of LD and/or ADHD in the USA found that, there was a significant time by group interaction on depression scores, when family affluence controlled for ($p < .005$, partial $n^2 = 0.12$). Compared to the non-mentored control group (Control-NM) and the typically developing control group (Control-TD), there was a significant effect of condition on depression scores post-intervention for the group that received peer mentoring ($d = -0.75$, $p < .005$ and $d = -0.38$, $p < .01$ respectively). Further, a significant main effect of time was found for the intervention group ($p < .005$, partial $n^2 = 0.17$), with depression scores significantly reducing from pre- to post-intervention. Overall, the intervention group showed significant improvements on depression scores over time, whilst the control-NM group showed significant worsening of depression scores, and the Control-TD group showed no significant change. Additionally, the quality of the mentorship, as perceived by the mentee, significantly predicted change in depression ($p = .049$), although the explained proportion of variance of depression was low (4.2%). Further, Vanderkruik et al.’s (2020a) evaluation of a peer-led dissonance-based group intervention for eating disorder prevention for high school students in the USA found a significant effect of the intervention on depression scores ($p <.001$, $d = 0.30$), with the mean scores reducing from baseline to post-intervention.

Noël et al.’s (2014) study evaluated a peer-led group intervention for depression prevention based on CBT and PYD principles 'Talk and Time' for school students who reported low mood in the USA. They found that participants in the intervention group experienced greater reductions in depression scores than waitlist participants post-intervention ($p = .038$) and at six-month follow-up ($p = .005$), with a large estimated effect size of the mean score difference ($d = 0.86$) at post-intervention. Additionally, a pilot RCT in Germany evaluated a peer-led group intervention ‘HOP’ which supported children and young people with mental illness disclosure decisions (Mulfinger et al., 2018). They found that the intervention had no significant effect immediately post intervention ($p = .50$) but a significant decrease in depressive symptoms at three-week follow up ($p < .001$), with a medium effect size ($d = 0.72$) suggesting that the peer support intervention may take time to have a positive effect on depression symptoms.

Vanderkruik et al.’s (2020b) pilot RCT comparing a peer-led dissonance-based intervention for eating disorder prevention to a control group for high school students in the USA found no significant effect of group allocation on depression (p = .14). However, the sample size was smaller than initially intended, resulting in an underpowered study and limiting the possibility of a significant effect being found (Vanderkruik et al., 2020b).

With respect to strength of methodology, four out of five studies had moderate or strong study designs (Mulfinger et al., 2018; Noël et al., 2014; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b) and three out of the four studies with a control group controlled for at least 80% of possible confounding variables, reducing the impact of confounding variables. Further, of the four studies that reported dropout and withdrawal data, all of them retained at least 78% of participants (Mulfinger et al., 2018; Noël et al.,2014; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b), potentially indicating acceptability of the intervention. Additionally, all but one study (Haft et al., 2019) reported that they measured the consistency of the intervention, improving intervention fidelity. However, as all five studies were rated as ‘weak’ in overall methodological quality, results should be interpreted with caution. Haft et al. (2019) used a quasi-experimental design, limiting the ability to infer causality, and increasing selection bias. Further increasing the risk of selection bias, in all studies, participants were referred to the study from a source in a non-systematic manner or by self-referral. Further, although three of the studies controlled for or measured whether participants were receiving another mental health intervention (Haft et al., 2019; Mulfinger et al., 2018; Noël et al., 2014), this was not reported in the other two studies, meaning the effectiveness of the intervention may have been contaminated. These limitations mean that clear conclusions about the effect of peer support interventions on depression outcomes cannot be drawn.

Eating Disorder Outcomes

Ciao et al.’s (2015) evaluation of a peer-led dissonance-based intervention for eating disorder prevention in the USA found no significant time by group interaction for the active vs waitlist comparison on the EDEQ-total score (Fairburn & Beglin, 1994) (p = .077, n^2 = 0.06)**.**

However, across all participants after the intervention (active and waitlist combined), there was a significant effect of time ($p < .001$, $n^2 = 0.29$) with scores significantly reducing from baseline to post-intervention, which was maintained at follow up ($p < .05$). A similar pattern was found for the EDEQ restraint subscale, where they found no significant time by group interaction for the active vs waitlist comparison ($p = .315$, $n^2 = 0.02$). However, across all participants after the intervention, there was a significant effect of time ($p = .031$, $n^2 = 0.13$) with scores significantly reducing from baseline to post-intervention. Promisingly, this was maintained at follow up ($p < .05$). For outcomes measured using the EAT-26 (Garner & Garfinkel, 1979), there was a significant time by group interaction for the active vs waitlist comparison ($p < .012$, $\mathrm{n}^2 = 0.13$), with scores dropping for the active condition and rising for the waitlist condition. Across all participants after the intervention, there was a significant effect of time ($p < .001$, $n^2 = 0.26$), with scores significantly reducing from baseline to post-intervention ($p <. 05$); however, this rebounded again at follow up. When looking specifically at the EAT-Dietary subscale, there was a significant time by group interaction for the active vs waitlist comparison ($p < .01$, $n^2 = 0.20$), with scores dropping by significantly more for the active condition compared to the waitlist condition. Although promising, the discrepancies between the effects on measures assessing similar constructs indicate that the results should be interpreted with caution, as stated by Ciao et al. (2015). Though it is possible that the final sample size (n = 50) was too small to capture some differences between groups.

Further, Eickman et al.'s (2018) evaluation of a peer-led dissonance-based group intervention for eating disorder prevention in schools in the USA found that when baseline scores were controlled for, students in both schools that implemented the intervention, compared to students in control schools, showed significant improvements at post-intervention on the EDEQ Global score (p values < 0.001 and 0.01), and the Eating Concern (p values = .004 and .04), Shape Concern (p values < .001 and .01), Weight Concern (p values < .001 and .004) and Restraint (p values = .001 and .01) subscales, with effect sizes ranging from medium to large ($d = 0.55 - 1.31$).

In terms of strengths, both studies controlled for over 60% of confounding variables. Further, they retained at least 80% of participants, indicating potential acceptability of the peer support interventions. Further, intervention fidelity was recorded in both interventions. However, the studies were limited in that they both were rated ‘weak’ in terms of methodological quality. Although Eickman et al. (2018) used a randomised design, Ciao et al. (2015) used a quasi-experimental design, limiting the ability to infer causality, and increasing selection bias. Again, both studies were further open to selection bias due to participants either self-referring or being referred from a source in a non-systematic manner. Neither study reported whether participants were receiving another mental health intervention, meaning the effectiveness of the intervention could have been contaminated. Additionally, participants in these studies were predominantly female, limiting the ability to make conclusions about the effectiveness of peer support interventions on eating disorder symptoms for males. Therefore, these methodological limitations impact the ability to draw firm conclusions.

Anxiety Outcomes

Vanderkruik et al.’s (2020a) evaluation of a peer-led dissonance-based intervention for eating disorder prevention for high school students in the USA found a significant decrease from baseline to post-intervention in reports of anxiety, with a medium effect size ($p < .001$, $d = 0.52$). Similarly, Warner and Budd’s (2018) evaluation of 1:1 peer coaching for high school students in the UK found a significant main effect of condition ($p = .016$), with a medium to large effect size ($\eta = 0.112$), where those in the intervention condition reported lower test anxiety than those in the control condition.

However, in Haft et al.’s (2019) evaluation of group peer mentoring for high school students with a diagnosis of LD and/or ADHD in the USA, no significant interaction was found between time and group on anxiety scores when family affluence was controlled for ($p = .602$). Similarly, Vanderkruik et al.’s (2020b) pilot RCT evaluating a peer-led dissonance-based intervention for eating disorder prevention for high school students in the USA found no significant effect of group allocation on change in anxiety (*p* = .10), though as previously noted, this study was underpowered. Jennings and Jennings (2013) evaluation of a peer-led group mindfulness intervention for high school seniors in the USA did not use inferential statistics and the sample size was very small (N = 8), therefore statistical significance and effect size cannot be reported, and generalisations cannot be made. Descriptively they found a 30% reduction in anxiety scores on the BAI from pre- to post-intervention, with an 11% reduction in physiological anxiety and a 55% reduction in cognitive anxiety. On the IAS, there was a 9% reduction in the ratings of social anxiety from pre- to post-intervention. Although improvements were seen, the paper did not report whether these changes were clinically significant for any individuals.

Regarding methodological strengths, for the three studies that reported withdrawal and dropout data, all retained at least 80% of participants (Vanderkruik et al., 2020a; Vanderkruik et al., 2020b; Warner & Budd, 2018) indicating potential acceptability of the peer support interventions. Intervention consistency was recorded in two studies (Vanderkruik et al., 2020a; Vanderkruik et al., 2020b), improving the likelihood of intervention fidelity. However, again, all studies were limited in that they were all rated ‘weak’ in terms of methodological quality. Only one study implemented a randomised design, and this was underpowered (Vanderkruik et al., 2020b), whilst two studies employed quasi-experimental designs (Haft et al., 2019; Warner & Budd, 2018) limiting the ability to infer causality and increasing selection bias. Vanderkruik et al.’s (2020a) evaluation was also limited by the study design, with the lack of a control group threatening the internal validity of the study. Again increasing selection bias, in all studies, all participants were either self-referred by themselves or parents or referred from a source in a non-systematic manner. Three of the studies did not report on whether participants were receiving any other mental health interventions (Vanderkruik et al., 2020a; Vanderkruik et al., 2020b; Warner & Budd, 2018). In the studies with control groups, there was variation in the amount that confounders were controlled for in the design or analysis, with Haft et al. (2019) controlling for an estimation of over 80% of relevant confounders, whilst it was assessed that less than 60% were controlled in Vanderkruik et al.'s (2020b) study and between 60-79% for Warner and Budd's (2018) study, meaning there may have been differences between groups that affected the results. Therefore, the ability to draw conclusions about the effectiveness of peer support interventions on anxiety outcomes is limited by the strength of the research methodology.

Emotional and Behavioural, Psychological Distress, and Affect Outcomes

Five studies evaluated mental health outcomes that were not disorder-specific, including emotional and behavioural difficulties, psychological distress, and affect, and the results were varied. Eisenstein et al.'s (2019) evaluation of a peer-led intervention that supported students to develop the knowledge and skills to safeguard the mental health of themselves and their peers found a significant decrease on the M&MS emotional difficulties subscale post-intervention; however, there was a negligible effect size (p = .005, d = 0.09). Further, they found no significant effect on behavioural difficulties (p = .10). They also evaluated outcomes for the peer-facilitators but found no significant effects of the intervention on emotional and behavioural outcomes (p = .24 and .65). When looking at individual clinical change for both peer-facilitators and peer-recipients, of the participants who were above clinical threshold at baseline, 40% of participants with behavioural difficulties and 38% of participants with emotional difficulties scored in the “normal” range after the intervention. However, given this was a pre-post design, conclusions about causality are not possible (Eisenstein et al., 2019). Regarding other limitations of the study, Eisenstein et al. (2019) reported that the implementation of the intervention varied across schools, and that the levels of reported difficulties were low, therefore the amount of change detected could have been limited by floor effects. The authors reported that the lack of effect was not surprising, as the intervention was not intended as a ‘therapeutic intervention’, but rather to improve needed knowledge and skills to safeguard participants' and their peers' mental health.

Evaluating affect, Eickman et al.'s (2018) RCT of a peer-led dissonance-based group intervention for eating disorder prevention in schools in the USA found that students in one out of two schools that implemented the intervention had statistically healthier scores than students in the control school on the PANAS (Negative affect: $p < .001$, $d = 1.05$, Positive affect: $p = .002$, $d = 0.87$). However, the other school did not find significantly different scores. They reported that this difference may be due to differences in statistical power, with the second school having a smaller number of students enrolled in the intervention, as well as differences in how the schools delivered the interventions, such as the first school offering more 'school-wide' activities as well as weekly meetings. Vanderkruik et al.'s (2020a) evaluation of a peer-led dissonance-based intervention for eating disorder prevention for high school students in the USA found a significant decrease from pre- to post-intervention in reported negative affect ($p < .001$, $d = 0.47$), though causality cannot be inferred due to the pre-post study design (Vanderkruik et al., 2020a). Further, Vanderkruik et al.'s (2020b) pilot RCT evaluating the same intervention for high school students in the USA found no significant effect of group allocation on change in negative affect ($p = .27$), though as previously noted, this trial was underpowered. Finally, Lewis et al.'s (2016) pre-post evaluation of a peer support group for new members of a hospital-based peer support intervention for children and adolescents with chronic illnesses found no significant effect of the intervention on levels of psychological distress ($p = .476$). However, although the study was rated 'moderate' in terms of methodological quality, the sample size was small (N = 14) which reduces the power of the study to find significant effects.

Regarding strengths, three studies retained at least 80% of participants (Eickman et al., 2018; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b), whilst Lewis et al. (2016) retained 64%, indicating some potential acceptability of the peer support interventions. Further, intervention fidelity was recorded in three interventions (Eickman et al., 2018; Vanderkruik et al., 2020a; Vanderkruik et al., 2020b). However, none of the studies reported whether participants were receiving another mental health intervention, meaning the effectiveness of the intervention could have been contaminated. The only study to use purposive sampling (Lewis et al., 2016) did not find a significant effect of the peer support intervention. The other four studies recruited participants by self-referral or participants being referred from a source in a non-systematic manner, increasing the likelihood of selection bias. Again, the paucity of high-quality methodology of studies increases the risk of bias, therefore clear conclusions cannot be drawn.

Patterns Across Studies

Intervention Factors

There was no observable relationship between the type of peer support intervention and its effectiveness of mental health outcomes, with a range of peer-led interventions, group peer mentoring, and 1:1 peer coaching all finding significant results. Similarly, the length and frequency of the intervention did not appear to determine effectiveness, with interventions with positive effects on outcomes varying from two sessions to 18 sessions, and 20-minute sessions to two-hour sessions.

Peer-Recipient Factors

Of the 10 studies that reported the gender of peer-recipients, 67% of the participants were female, limiting the generalisability of results to males or non-binary participants. There was no observable pattern across studies in terms of the effectiveness of the interventions and gender; however, one study did observe gender differences in the change in anxiety levels. Although not statistically significant, test anxiety reduced more post-intervention for females than males (Warner & Budd, 2018). There was ethnic and racial diversity of participant samples in some studies (Ciao et al., 2015; Eisenstein et al., 2019; Haft et al., 2019; Noël et al., 2014). However, four studies' sample participants were over 70% White (Eickman et al., 2018; Mulfinger et al., 2018; Vanderkruik et al., 2020a, Vanderkruik et al., 2020b), whilst three studies did not report these data (Jennings & Jennings, 2013; Lewis et al., 2016; Warner & Budd, 2018), though Lewis et al. (2016) did state that were no participants of Indigenous Australian origin. Although there was no observable pattern between effectiveness of interventions and participant ethnicity or race, this limits generalisability of findings. Further, although there did not appear to be any observable pattern between the age of peer-recipients and effectiveness of interventions, of the studies that reported age range, only one study included participants of primary school age (Haft et al., 2019). Of the studies that reported mean age, the lowest mean age was 13.98 (Ciao et al., 2015), meaning results cannot be generalised to children of younger ages. As all but two studies (Lewis et al., 2016; Mulfinger et al., 2018) took place in schools or college, it is difficult to generalise findings to other settings. Additionally all studies took place in high-income countries, limiting the generalisability of findings to other populations.

Facilitator Factors

In terms of characteristics of the peer-facilitators, there were no clear patterns about whether the 'nearness' of the peer (e.g. closeness in key characteristics such as age) makes a difference to the effectiveness of the peer support intervention; however there was a limited number of studies that used peers of the same age (n = 2) (Jennings & Jennings, 2013; Warner & Budd, 2018) and a limited description of peer-facilitators in other studies. There did not appear to be a pattern between the level of training of peer-recipients and effectiveness of the intervention.

Similarly, there did not appear to be an observable pattern between the level of professional involvement and the mental health outcomes of the intervention, as both interventions that were solely peer-led and interventions that were led by both professionals and peers found significant results. Of the two studies that found no significant results, one was solely peer-led (Vanderkruik et al., 2020b) and the other was led by a peer and a professional (Lewis et al., 2016). However, it is difficult to draw conclusions as in some studies there was limited information on how much involvement the professionals had in the intervention (Eisenstein et al., 2019).

Discussion

Overview

This review examined the mental health outcomes of studies of peer support interventions for children and young people. It also aimed to assess the methodological quality of studies, in order to understand the strength of the evidence. Through systematic searching, eleven studies were screened as eligible and included in the review.

Summary of Main Results

Overall, as seen in table 1, seven out of 10 studies that used inferential statistics found a significant and meaningful effect of the intervention on at least one mental health outcome, with effect sizes ranging from small to large where reported, whilst one study with a negligible effect size found clinically relevant improvements (Eisenstein et al. 2019). For depression outcomes, four out of five studies found significant effects of the peer support intervention at either post-intervention or follow up, with effect sizes ranging from small to large. The effects of peer support interventions on anxiety outcomes were varied, with two of four studies that used inferential statistics finding a significant effect, with medium and medium-to-large effect sizes; the other two found no significant effect. One study measuring anxiety did not use inferential statistics (Jennings & Jennings, 2013), therefore generalisations could not be made. Both studies measuring eating disorder outcomes found a significant effect of the peer support intervention on some eating disorder symptoms, with effect sizes ranging from small to large. Whilst, for studies measuring mental health outcomes that were not disorder specific, the results were more varied. Although negative effects of the peer support intervention on mental health symptoms were not reported in any study, one study did find a small negative effect on school ‘climate’, defined as the perceived quality of relationships and support (Eisenstein et al., 2019). Overall, despite some significant results being reported, the methodological limitations of all of the reviewed evidence mean that it is difficult to draw conclusions about the effectiveness of peer support interventions on mental health outcomes.

Quality and Applicability of the Evidence

Regarding methodological strengths, all studies used outcome measures that were shown to be reliable and valid, most evaluations used study designs that were ‘moderate’ or strong’, and the majority of studies reported the peer support intervention in some detail, allowing understanding of what was being evaluated. Further, most studies were conducted in real-life settings, increasing ecological validity. However, overall, the strength of the evidence is hindered by the methodological quality of the studies. As noted, all but one study were rated as ‘weak’ on the quality assessment tool global rating, indicating a high risk of bias. Although three out of the four studies that implemented randomised controlled designs found significant effects on mental health outcomes (Eickman et al., 21018; Mulfinger et al., 2018; Noel et al., 2014), these studies were assessed as having a high risk of bias. Further, the lack of randomised controlled designs in the remaining studies threatens internal validity, limiting the ability to infer causality of findings. Additionally, across all studies, the mental health outcomes were measured using self-report questionnaires, meaning there is a possibility of social desirability bias, as well as the majority of studies having a high risk of selection bias due to sampling methods. It is therefore difficult to draw strong conclusions, an issue that has been noted in previous reviews of peer support interventions in both children (Ali et al., 2015) and adults (Fuhr et al., 2014).

The lack of diversity of gender, ethnicity, race and age of participants, as well as most interventions taking place in schools, and in high-income countries, impedes the external validity of findings. The lack of younger participants may be due to the nature of peer support meaning children are usually older in order to be able to facilitate and/or lead the interventions. However, as the majority of studies used peer-facilitators that were some years older, research could use younger populations with older peer-facilitators, as long as they still share some key characteristics. Further, all the included studies evaluated face-to-face interventions. Although Ali et al.'s (2015) review explored the effectiveness of online peer support interventions, when looking at the studies that used standardised measures of mental health, the participants were university age students or had mean ages of over 18; therefore the effectiveness of online peer support interventions on mental health outcomes for this younger population remains unknown. Additionally, the lack of follow-up in most studies means that it is not known whether the effectiveness of the interventions remained over time.

Strengths and Limitations of this Review

To the author's knowledge, this is the first systematic review looking at peer support interventions for children and young people aged 18 and under, that was not limited by modality or setting. The focus on understanding the interventions' effects on mental health outcomes measured by standardised measures, is useful for understanding how peer support interventions may be beneficial for reducing clinical symptoms, particularly given the wait times for CAMHS in the UK (Crenna-Jennings & Hutchinson, 2020).

There are some limitations of this review which hinder the strength of evidence. Studies were identified through searches on two main databases; therefore, the search strategy may have missed some eligible studies. To try to address this, the references of selected papers, previous reviews and other relevant reviews were searched, as well as forward citation searches being conducted on a third database. However, no additional studies were found from this. Moreover, all included studies took place in Western, high-income, countries. This may have been in part due to limitations with the search strategy, given that it was not possible to use search terms in different languages, or to include papers that were not fully translated into English.

Further, although it was important to understand mental health outcomes specifically, this meant that other benefits of peer support interventions were not reported on. Many of the peer support interventions reviewed also aimed to improve mediators and risk factors of mental health outcomes. These included: self-esteem, which has been found to be both negatively correlated with and a predictor of symptoms of anxiety and depression in adolescents (Henriksen et al., 2017); loneliness, which has been associated with depression and anxiety in children both prospectively and cross-sectionally (Hards et al., 2022) and body dissatisfaction; which has been shown to be prospectively associated with onset of eating disorders in adolescents (Prnjak et al., 2021). The effectiveness of peer support interventions on such factors were not covered in the scope of this review, but similar to the findings of previous similar reviews (Coleman et al., 2017; Richard et al., 2022), some studies did report significant effects on self-esteem (Eickman et al., 2018; Vanderkruik et al., 2020a) and loneliness (Vanderkurik et al., 2020b).

Finally, the EPHPP quality assessment tool for quantitative studies (Thomas et al., 2004) was used to assess methodological quality and risk of bias for each study. Although this tool assesses for many areas of bias, it does not consider sample size. As there was great heterogeneity in sample size, with some studies having very small samples, it may have been helpful for this to have been considered in the overall risk of bias rating. Additionally, all studies were rated as ‘weak’ for blinding using the tool, reducing their global methodological quality rating. As full blinding is notoriously difficult in trials of psychological intervention (Mataix-Cols & Andersson, 2021), there could be an argument not to include this rating in the global ratings.

Conclusions

This systematic review synthesised the recent evidence on the effectiveness of peer support interventions on mental health outcomes for children and young people aged 18 and under. Overall, although findings were mixed, there were some promising effects of peer support interventions on mental health outcomes, including on symptoms of depression, anxiety and eating disorders. However, due to a lack of high-quality studies, it is difficult to draw clear conclusions.

Implications for Future Research and Clinical Practice

Several considerations for future research are highlighted by this review. As the reviewed evidence for the effectiveness of peer support interventions for this population is inconclusive, further research studies with stronger methodology are needed. Evaluating peer support interventions using fully powered RCTs that use random sampling and follow the CONSORT statement (Altman et al., 2001), could help to reduce the risk of bias and increase internal validity of studies, enabling clearer conclusions to be drawn. The majority of studies in this review used peer support as a preventative intervention in schools for depression and eating disorder symptoms, in line with the WHO’s (2013) wider mental health strategy to use peer support in community settings. However, higher-quality research is needed in order to better understand the effectiveness of peer support as a preventative intervention before being able to make clear clinical recommendations. One study (Mulfinger et al., 2018) saw a reduction in depressive symptoms for a clinical population of young people. However, the risk of bias and limited number of studies with clinical populations, highlights the need for further high-quality research with clinical populations. RCTs that use an active therapeutic intervention as a control could provide insight into whether peer support interventions could be offered as stand-alone treatments for clinical populations, or whether they are better offered to young people who are waiting for further therapeutic support. Further, as only three studies included follow up (Ciao et al., 2015; Mulfinger et al., 2018; Noël et al., 2014), conclusions about the long-term effectiveness of peer support interventions are limited; therefore future research should include longer follow-ups. Doing so may also allow for the effect of improvements on predictors of mental health outcomes to be seen. Given one study found a negative impact of the peer support intervention on the perceived quality of relationships and support in the school (Eisenstein et al., 2019), and other potential harms of peer support interventions, such as conflict, criticism, contagion stress, lack of stability and guilt have been highlighted (Dennis, 2003; King & Fazel, 2021), adverse effects should be monitored in future research and practice.

Regarding the peer-led interventions that were evaluated, it remains unclear whether the significant effects of the interventions were largely as a result of the peer-to-peer interaction, or because of the intervention itself, as no studies compared the peer-led interventions with the same intervention led by a professional. This could be a helpful focus for future research. Further, studies of this type may be useful for exploring what types of interventions, in what contexts, can be effectively delivered by peers compared to professionals, as studies in adult populations have indicated that particular peer-led interventions may not be well received by participants or may be hard for peers to deliver (Letourneau et al., 2011). Additionally, the level of involvement of professionals in the peer support interventions should be clearly detailed in future research, in order to understand whether interventions with less professional involvement than other traditional therapeutic interventions can still be effective, an important consideration given the predicted NHS staff shortages (Health Foundation, 2018).

Surprisingly, all the peer support interventions evaluated were conducted face-to-face. However, a recent study published after the search date of this review, looked at the effectiveness of a moderated online platform ‘Kooth’, which offers access to both professional and peer support (Stevens et al., 2022). It found that even for participants that only used the peer support space, there were significant improvements in psychological distress, suicidal ideation, self-esteem, and loneliness in young people with a mean age of 16.7**.** As many younger children now use technology and social media (Ofcom, 2022), and given the context of increases in remote interventions during the COVID-19 pandemic, further research should continue to evaluate mental health outcomes of online peer support interventions for children and young people under 18.

As generalisability was limited, further research is needed into the effectiveness of peer support interventions for children and young people in low-income countries. As well as further research with greater diversity of participants, including gender, age, ethnicity and race, and mental health difficulties, and greater diversity in the settings that the peer support interventions are offered in. Finally, future research could compare whether the ‘nearness’ of the peer facilitator, in terms of the amount of characteristics that they share with peer-recipients, has an impact on effectiveness.

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Part 2: Empirical Paper

Online Peer Support for Parents of Children with Long-Term Conditions: A Randomised Pilot Trial

Abstract

Aims: As mental health services for families in the UK are stretched, other avenues of support for parents of children with long term conditions are often needed. A randomised pilot trial was conducted with the aim of evaluating the feasibility and acceptability of a future RCT investigating the effect of signposting parents of children with long term conditions to online peer support.

Methods: Parents of children with long-term conditions were randomly allocated to either an intervention or waitlist condition and completed outcome measures at baseline and three-month follow up. The intervention involved participants being signposted to relevant online peer support. Recruitment routes and numbers, retention rates, and levels of measure completion were assessed to determine feasibility. Acceptability was assessed by evaluating engagement with the intervention, qualitative feedback, and data from an adapted Experience of Service questionnaire. Outcome measures were used to evaluate preliminary effects of the intervention on the key outcome of loneliness, and secondary outcomes of social capital, anxiety, and depression.

Results: Although recruitment numbers met study targets, the sample lacked diversity, and retention rates were low, limiting feasibility. Data indicated that the majority of intervention participants found trial methods and online peer support largely acceptable. Potential positive and negative experiences of using online peer support were identified. Small improvements were seen in the intervention group on loneliness, anxiety and depression measures, though results were mixed, and comparisons between groups were limited by the unequal retention.

Conclusion: Although the trial methods and the intervention were deemed to be largely acceptable, current trial methods were not fully feasible. Consequently, further research and changes to trial methods are indicated.

Introduction

Psychosocial Difficulties for Parents[2] of Children with Long-term Conditions

Long-term conditions (LTCs) in children have been defined as conditions, diseases or illnesses that last for more than six months, including chronic physical health conditions, disabilities, and mental and behavioural disorders (Australian Institute of Health and Welfare, 2020). There are 1.7 million children in the UK living with long-term physical illnesses (National Institute for Health and Care Excellence, 2022). Further, nine percent of children in the UK had a reported disability in 2021, including social and behavioural impairments, learning impairments and mental health difficulties (Department for Work and Pensions, 2022). Although parenting any child comes with both joys and challenges, research has indicated that parents of children with LTCs may be at risk of higher levels of psychosocial distress, such as depression and anxiety (Brehaut et al., 2009; Jones & Reilly, 2016; Scherer et al., 2019) and loneliness (Florian & Krulik, 1991; Nowland et al., 2021).

There are important distinctions for parents of children with LTCs that can contribute to, and increase, this risk (Resch et al., 2010), such as greater levels of material hardship (Parish et al., 2008; Scherer et al., 2019) and challenges associated to care-giving responsibilities, including having difficult childcare tasks and increased demands on time (Plant & Sanders, 2007; Raina et al., 2004), which can impact a parent’s abilities to work (Scherer et al., 2019). Qualitative research has also suggested that the wellbeing of parents of children with LTCs can be hindered by a perceived a gap between the parent’s needs, their families’ needs, and the support available to address these needs (Resch et al., 2010), in addition to a lack of occupational balance and environmental support (McGuire et al., 2004). Further, qualitative research has suggested that loneliness in this population is experienced due to a lack of support and psychosocial resources, support available not

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[2] Throughout this report, the term 'parent' is used. This term is intended to include a breadth of roles, including any adult caregivers or guardians who are parenting children.

meeting parents' needs, changes in partner relationships, feeling burdened by the needs of their child, and experiencing a sense of helplessness (Nowland et al., 2021).

Loneliness

Loneliness is defined as an unpleasant and distressing subjective experience that happens when a person's social network is lacking in either quantity or quality compared to their needs (Perlman et al., 1984). Nowland et al.'s (2021) scoping review of loneliness in parents found that many parents of children with LTCs reported experiencing loneliness, with the percentages ranging from 19.1% to 70% across studies. In one of these studies, 75% of parents of children with a rare disease reported having no contact with other parents of children with similar diseases and 42% reported not having access to any disease specific support groups (Pelentsov et al., 2016). Further, the prevalence of loneliness increased in the UK during the COVID-19 pandemic (Li & Wang, 2020). As the Disabled Children's Partnership's (2020) survey found that parents of LTCs reported feeling abandoned by society, and some had to continue to 'shield' when social restrictions were eased, it is possible that parents of children with LTCs experienced heightened loneliness during this period.

Loneliness is associated with other adversities, such as depression and anxiety (Hawkley & Cacioppo, 2010; Wang et al., 2018), and has been shown to have negative consequences for both parents and children. Associations have been found between loneliness and parental stress (Au et al., 2008; Berry & Jones, 1995) and maternal loneliness and dissatisfaction with life and the couple relationship (Luoma et al., 2019). In a prospective study, maternal loneliness was found to predict chronic depression (Luoma et al., 2015). Between parent and child, a longitudinal study found paternal loneliness to predict sons' loneliness, with daughters' loneliness being predicted by maternal loneliness; however, this effect was not true across genders (Salo et al., 2020). Maternal loneliness was also found to predict fear of negative evaluation and social competence in adolescents (Zafar &

Kausar, 2015). Therefore interventions that reduce loneliness could impact outcomes for the whole family.

Social Capital

Significant inverse associations have been found between loneliness and social capital in a range of populations, including students and older adults (Bai et al., 2021; Thomas et al., 2020). Social capital is understood as the building of relationships and the benefits that come with them (Williams, 2006). As well as ‘real-world’ contexts, research has examined the relationship between the virtual world and social capital. For example, a positive relationship was seen between Facebook use and the creation and maintenance of social capital in a cross-sectional study (Ellison et al., 2007). Additionally, Drentea and Moren-Cross’ (2005) discourse analysis of an online messaging board for mothers suggested that the board provided instrumental support, emotional support, and community building, all of which contribute to the building of social capital. Further, research has suggested that social capital gained from online interactions can impact offline interactions, and vice versa. Kent et al.’s (2019) field study found a positive association between offline social capital and online discussions for students, and de Zúñiga et al.’s (2017) longitudinal study found that social media social capital predicted offline social capital. As interviews with parents of children with LTCs have identified that many experience social isolation (Heiman, 2002), interventions which increase social capital are indicated, which may also lead to a reduction in loneliness.

Interventions for Loneliness

Hawkley & Cacioppo’s (2010) review of existing interventions for loneliness identified that they typically include providing social support, increasing opportunities for social interaction, enhancing social skills, or addressing maladaptive social cognitions; with interventions targeting opportunities for social interaction being particularly successful. Further, a recent systematic review and meta-analysis found that psychological interventions for loneliness, including cognitive behavioural therapy, interpersonal therapy, and peer support interventions based on the social identity approach, can be effective across the lifespan (Hickin et al., 2021). Looking at parental loneliness in particular, Nowland et al.'s (2021) scoping review found no intervention studies that were designed to *specifically* reduce loneliness. Of the studies that had loneliness as an outcome measure, interventions that showed promise of improving loneliness included e-meeting forums with health-care professionals and peers (Nyström & Öhrling, 2006), home visiting peer support (Chan et al., 2005), interpersonal skills training (Richey et al., 1991), child development parenting programmes (Skar et al., 2015), and short-term cognitive therapy (Sorenson, 2003). Nowland et al. (2021) concluded that these studies highlight some key mechanisms of reducing loneliness which should be considered when designing future interventions, including the use of peer support to build social connections. However, none of these studies were specifically for parents of children with LTCs, indicating a need for further research. One possible intervention for this group may be peer support.

Peer Support and the Evidence Base

Peer support interventions are broad and heterogenous, but generally include accessing emotional support, receiving informational support, and support which affirms one's thoughts and feelings (Dennis, 2003), from peers who share key personal characteristics (Simoni et al., 2011). Peer support interventions are used in a diverse range of settings globally (Simoni et al., 2011), and many take the form of support groups and online peer support (Dennis, 2003), where there is often a focus on increasing peer-to-peer interaction and social support. Several reviews of the effect of peer support interventions on psychosocial outcomes have been conducted. They show mixed effectiveness, with some promising results seen for quality of life, hope, depression, and anxiety (Chinman et al., 2014; Fuhr et al., 2014; Lloyd-Evans et al., 2014; Pistrang et al., 2008). Additionally, a more recent randomised controlled trial (RCT) of a peer support intervention for older Chinese adults found a positive effect on loneliness (Lai et al., 2020). Further, qualitative research has indicated that peer support can increase social networks (Walker & Bryant, 2013) and be beneficial for building social capital (Thomson et al., 2015). Peer support interventions may be of particular value in areas of unmet need given that they are relatively cost-effective (Fisher et al., 2014). With mental health services for families in the UK struggling to meet demand (NHS England & Department of Health [DOH], 2018), parents of children with LTCs are often signposted to peer support services for support.

For parents of children with LTCs specifically, there is promising but uncertain evidence about the effects of peer support interventions on psychosocial outcomes. Wong & Shorey's (2022) qualitative systematic review of experiences of peer support for parents of children with neurodevelopmental disorders found that the emotional support gained through peer support allowed parents to build connections with other parents with similar experiences and to feel understood, and that the holistic support received improved parent's mental health, quality of life and coping skills, and reduced stress levels. Further, Shilling et al.'s (2013) review of face-to-face peer support found that in qualitative research, parents reported being able to learn from each other, give each other support, experience personal growth and less depression and guilt, and find a "shared social identity with other parents", which reduced their sense of isolation and loneliness (p. 605). However, the synthesis of quantitative data showed that although there were some positive effects seen for levels of anxiety, concern, confidence and coping, the evidence was inconsistent for all psychological outcomes (Shilling et al., 2013). Further, Sartore et al.'s (2021) systematic review and meta-analysis of peer support interventions for parents of children with 'complex needs' found no clear evidence of peer support interventions for any psychosocial outcome. However, the certainty of evidence in this review was deemed to be low due to the risk of bias, inconsistent findings, and imprecise estimated effects. The qualitative data again suggested that parents valued the interventions. Loneliness was not reported on as an outcome in any of the reviews.

Although no studies reported harmful effects in these reviews (Sartore et al. 2021; Shilling et al., 2013; Wong & Shorey, 2022), due to the uncertainty of evidence overall, it was recommended that adverse events should continue to be monitored (Shilling et al., 2013). Further, Shilling et al.'s (2013) analysis of qualitative research suggested that not all parents found peer support helpful, particularly when parents did not feel there was a shared social identity, when they did not seek support due to worries about comparisons between children, and when time was a concern for parents, meaning they had to prioritise their child over time for themselves. Wong and Shorey (2022) also identified barriers to seeking peer support including unmet expectations, inaccessibility, limited time, and the potential benefits of peer support not being clear. This highlights the importance of better understanding and communication about the benefits and limitations of peer support.

Online Peer Support

During the COVID-19 pandemic many in person peer support groups were forced to close, with signposting options for parents with LTCs being mostly limited to online peer support groups and forums. The majority of research into peer support for parents of children with LTCs has focussed on in-person peer support, although exploring the use of technology to facilitate peer support has been advised (Wong & Shorey, 2022). The limited existing research into the effectiveness of online peer support on psychosocial outcomes for parents of children with LTCs is again mixed. Niela-Vilén et al.'s (2014) integrative review of online peer support for parents found that it connected parents and provided encouragement and emotional and mutual support. For parents of children with LTCs in particular, they found that parents reported improvements in coping and that they felt assured by other parents. Some effects on mothers' depression and fathers' anxiety and depression were seen, however, the evidence was limited. Further, several negative aspects of online peer support were reported, such as a lack of replies, misinformation, and postings that were off-topic in online peer support forums. Two RCTs of online peer support for parents of children with LTCs that were published after Niela-Vilén's (2014) review showed no significant effects on parental stress (Aiello & Ferrari, 2015; Boogerd et al., 2017). However, other recent studies have found significant preliminary effects on parents' perceived emotional and informational support (Martin et al. 2017) and perceived competence in managing the care of their child's LTC at home (Swallow et al., 2014).

Aims and Research Objectives

There is an increased demand for mental health support for children, families, and adults in the UK that local mental health services in many areas are struggling to meet (National Audit Office, 2023; NHS England & DoH, 2018). This often leads to long wait-times (Baker, 2020; Crenna-Jennings & Hutchinson, 2020) and high eligibility thresholds (Care Quality Commission, 2018). Given this, other avenues of support for parents of children with LTCs are needed. The evidence above suggests that online peer support could be one possible option. However, as there is mixed evidence on the effects of online peer support for parents of children with LTCs, it is important to better understand the acceptability, and potential harms and benefits of signposting parents to these supports. In addition, as there is limited evidence on interventions that alleviate loneliness for this population, there is a need to understand whether online peer support could be a beneficial intervention. Further, as loneliness is associated with social capital and mental health difficulties such as anxiety and depression, understanding whether online peer support could improve these outcomes is also important. Pilot trials are routinely used in many areas and are often an important pre-requisite to full scale RCTs designed to provide evidence of the clinical efficacy of an intervention (Thabane et al., 2010). Reasons for performing pilot studies include assessing the feasibility of study processes, understanding the resources needed, and estimating the treatment effect and variance of an intervention, as well as its safety (Thabane et al., 2010). A randomised pilot trial was therefore conducted to understand whether a larger scale RCT researching the effect of online peer support on the above outcomes would be feasible and acceptable, and to understand preliminary effectiveness.

Therefore the primary objectives of this randomised pilot trial were:

1. To assess the feasibility of participant recruitment, retention rates, and the measures used in the trial.
2. To investigate the acceptability of the randomised pilot trial methods.
3. To investigate the acceptability of signposting to online peer support as an intervention, including negative effects, and levels of engagement.

A secondary objective was to measure preliminary group differences on the key primary outcome of loneliness, and secondary outcomes of online/offline social capital, anxiety, and depression

Method

Trial Design

The study followed a randomised pilot trial, as described in the CONSORT 2010 statement extension for randomised pilot and feasibility trials (Eldridge et al., 2016)[3]. The CONSORT 2010 checklist of information to include when reporting a pilot or feasibility trial is included in Appendix C. The trial involved a parallel design, using a waitlist control condition with 1:1 allocation ratio. There were two timepoints: baseline (T1) and three months post-intervention (T2).

Participants

Parents of children with LTCs, who self-identified by following the link on an advert for the study, were recruited between July 2022 and January 2023. The study was advertised through contacting charities and organisations related to LTCs and parenting, contacting schools and nurseries, putting posters in community spaces, sharing the advert on online social media platforms, and through word of mouth. Participants were eligible if they were over 18, and sufficiently fluent in English to be able to engage in the study and

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[3] The study was initially planned to be a full-scale RCT, which was prospectively registered with clinicaltrials.gov.uk on 9th May 2022 (protocol ID: 22125/001). Due to various reasons including the time pressures of a doctoral thesis and challenges with recruitment, it was decided that the study would instead be a pilot trial to inform a future RCT. Reflections on this are covered in the Critical Appraisal (pp 137-138).

online peer support, which they confirmed by consenting to the study. There were no exclusion criteria regarding the LTC of the child, or the upper age limit of the parent. As an incentive for taking part in the study, participants were offered an entry into a prize draw, to win one of 10 prizes of £20 vouchers, or a £20 donation to a charity of their choice. All data were collected online on the Qualtrics platform.

Sample Size

As this was a pilot trial, a formal sample size power calculation was not required. Given the potential increased demand on this participant population (Plant & Sanders, 2007; Raina et al., 2004) and previous research into online peer support showing high rates of attrition (45.3% at follow-up) (Griffiths et al., 2012), a sample size of 60 was proposed, in order to allow for 50% attrition and still retain 15 participants per arm. .

Consultation with Experts

Great Ormond Street Hospital (GOSH) Patient and Public Information forum and GOSH clinical research team were consulted when designing the proposed trial. During these consultations, online peer support signposting options and charities to contact for recruiting participants were recommended. Feedback from the consultations also included ensuring that, where possible, the study signposted to condition-specific online peer support, and a mixture of both groups and forums, to reflect real world signposting. It was also recommended that all of the forums signposted to were moderated to reduce potential risks to participants, and that the study captured any negative experiences of using online peer support.

Procedure

Rolling recruitment occurred from July 2022 to January 2023. After following the link on the advert for the study, participants were taken to a Qualtrics site with a participant invitation letter detailing information about the study, and a consent form, as seen in Appendix D and E. Participants were then asked to complete demographic information and baseline measures on the Qualtrics survey and were randomised to either the intervention or waitlist condition. Randomisation was automatic, through a random allocator built into Qualtrics.

Once participants had completed the baseline survey at T1, those in the intervention group were emailed a list of online peer support options and informed that it was up to them whether and how much they engaged with these. They were asked to keep a weekly engagement log, emailed to them as a word document, as seen in Appendix F. Participants were sent two reminder emails to complete these logs, one month and two months after completing T1 measures and being sent the online peer support. The online peer support options signposted to were associated with registered charities. They were chosen dependent on the LTC of the child and geographical location of the family. Possible signposting options were found from consultations with experts, and through searching online. First, by searching on the website of ‘Contact’, a charity that supports families of disabled children, which has a directory of LTCs and associated support [https://contact.org.uk/conditions]. Second, by Google searches of local and national charities related to the LTC. If it was not clear whether the online peer support was moderated, charities were contacted to verify this before participants were signposted to them. A list of the online peer support options signposted to can be seen in Appendix G, with an example email sent out to participants in Appendix H. Those in the waitlist condition were informed that they would be contacted again in three months.

Three months after completing T1 or receiving the online peer support, all participants were emailed a further Qualtrics link and asked to complete the measures again (T2). Those in the intervention group were also asked questions about the acceptability of the intervention and trial. After completion of the T2 survey, those in the waitlist group were signposted to peer support. Participants were debriefed by being shown a brief statement regarding the purpose of the study and services where they could seek support if needed, as well as being reminded of the contact details of the researchers. If participants did not fill out the T2 survey after the first reminder, they were emailed two more reminders. Those that did not fill out the T2 survey following this were assumed to have dropped out of the study.

Changes to Protocol After Pilot Trial Commencement

The recruitment routes of contacting schools and nurseries to advertise the study were added after trial commencement, to attempt to increase recruitment numbers. Further, due to high rates of attrition at T2, in December 2022, it was decided that participants would be given the option to answer the survey over telephone or video call if they preferred. This was offered by adding an option for participants to provide their telephone number in the T1 survey and informing existing participants of this option in the reminder emails. Intervention participants were also encouraged to fill out the T2 survey even if they had not completed the weekly engagement log.

Measures

Demographic and Descriptive Information

Participants were asked their age and gender, the number of children they had, and their children’s age. They were also asked which area they lived in and the name of the LTC(s) their chid(ren) had, and to indicate if they had more than one child with an LTC, in order to inform appropriate signposting. After December 2022, participants were also given the option of providing their telephone number. Use of social media was also asked about, as it was considered that this could be a potential covariate in a future definitive RCT. Previous research measuring social media use has asked participants to state which social media sites and applications they use frequently, and the frequency of usage on a typical day (Tibber et al., 2020). Informed by this, at T1 and T2, participants were asked:

i. Which social media sites or apps do you use most regularly? (please list up to three)
ii. On average in the past week, approximately how long have you spent on social media per day? (less than 10 minutes, 10-30 minutes, 1-2 hours, 2-3 hours or more than 3 hours)

Feasibility Measures

Feasibility of the trial was evaluated by observing:

1. Recruitment and Enrolment: How many organisations of those contacted agreed to advertise the study, how many participants it was possible to recruit in the time frame (July 2022 – January 2023), the characteristics of these participants, and the proportion of participants that completed all of T1.
2. Retention: The proportion of participants that completed T2 (retention rate) and differences between those who initiated T2 and those who dropped out.
3. Measures: Completion rates and missing data for each key outcome measure, and the proportion of intervention participants that completed and returned the engagement log.

Acceptability Measures

To measure the acceptability of the intervention and trial, an adapted version of the Experience of Service Questionnaire (ESQ; Attride-Stirling, 2003) for parents/carers was used, which can be seen in Appendix I. The measure consisted of eight statements. Participants were asked to think about their experience of taking part in the study and choose which response option best described their experience. An example statement was *'I was treated well by the people in the online peer support groups/forums'*. The response options were: 'certainly true', 'partly true', 'not true' and 'don't know'. The measure also asked four open ended questions:

1. What was good about the online peer support?
2. Was there anything you didn't like or anything that needs improving about the online peer support?
3. Was there anything you didn't like or anything that needs improving about the study?
4. Is there anything else you want to tell us about the online peer support or this study?

Engagement with Online Peer Support

Engagement with the online peer support was also used as an indicator of acceptability and feasibility of the intervention. To measure any pre-existing engagement in online peer support, at T1 participants were asked to detail up to three online peer support groups and forums that they used most regularly, and how often they use these (daily, weekly, monthly, less than monthly, never). To measure engagement with online peer support during the study, participants were asked to keep a weekly log while they were in the intervention phase. The log was informed by previous research that measured engagement with online peer support (Friedman et al., 2015).The engagement log asked:

i. Did you use an online peer support group/forum and if so, which?
ii. Approximately how much time over the week did you spend using the peer support group/forum? The following response options were given: less than 10 minutes; 10 to 30 minutes; 30 minutes to an hour; more than an hour.
iii. Did you actively participate in the group/forums by posting or speaking? (Yes/No).

At T2, participants were asked similar questions in the online survey, in order to capture a measure of engagement even if participants had not completed the weekly engagement log. The questions asked:

i. Since you joined this study, which, if any, dedicated online peer support groups/forums have you used?
ii. On average, approximately how much time per week did you spend using the online peer support groups/forums? The following response options were given: less than 10 minutes; 10 to 30 minutes; 30 minutes to an hour; more than an hour.
iii. How much did you actively participate in the groups/forum by posting or speaking? They were asked to rate this on a scale of 0-10, where 0 was that they did not say or post anything, and 10 is where they spoke, posted, or replied to a post every time they accessed the online peer support.

Negative Experiences

It is recommended to always consider negative effects of internet-based interventions (Rozental et al., 2015), and this was further advised during the consultations with experts. Therefore, at all time points, participants were asked if they had ever experienced any negative experiences of using online peer support (yes/no), and if yes, to detail these. Examples were given of experiencing disagreements, misinformation, and increased worry. These negative experiences were considered as an indication of acceptability of online peer support.

Key Outcome Measures

Primary Outcome: Loneliness

Loneliness was measured using the 20-item revised UCLA Loneliness Scale (R-UCLA**:** Russell et al., 1980), as commonly used in studies researching loneliness (Nowland et al., 2021). The R-UCLA consists of 20 statements. For each item, participants are asked to indicate how often each of the statements is a description of them, marked on a four-point Likert scale, ranging from one (never) to four (often). An example statement is *''There is no one I can turn to'.* Some items are reverse scored, such as *'I feel in tune with the people around me'*. The total scores range from 20 to 80, with higher scores indicating higher levels of perceived loneliness. A commonly used categorisation is: 20–34 denoting a low degree of loneliness, 35–49 denoting a moderate degree of loneliness, 50–64 denoting a moderately high degree of loneliness, and 65–80 denoting a high degree of loneliness (Deckx, et al., 2014). The R-UCLA has high internal consistency (coefficient alpha of .94) and has been found to have good reliability and validity in a number of contexts (Russell et al., 1980; McWhirter, 1990; Pretorius, 1993).

Secondary Outcome: Social Capital

Williams' (2006) Internet Social Capital scale (ISCS) was used to measure changes in social capital, online and offline. The measure consists of two parallel scales, with one for measuring offline social capital, and one for online social capital. Each scale consists of 20 items marked on a five-point Likert scale, ranging from one (strongly disagree) to five (strongly agree), with some items reverse scored. Higher scores indicate greater social capital. Each scale is composed of two subscales representing ‘bridging’ and ‘bonding’ social capital. ‘Bridging’ is said to occur ‘when individuals from different backgrounds form connections between social networks’ (Williams, 2006, p. 597). An example item is *‘Interacting with people online/offline makes me feel like part of a larger community’.* ‘Bonding’ is said to occur ‘when strongly tied individuals […] provide emotional or substantive support for one another’ (Williams, 2006, p. 597). An example question being *‘When I feel lonely, there are several people online/offline I can talk to.’* The measure has been shown to have strong internal consistency of the two factors (bridging and bonding) (Williams, 2006). The online scales and bridging subscales have been found to be adequately reliable (Johnston et al., 2013; Kaye et al, 2017).

Secondary Outcome: Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS**;** Zigmond & Snaith, 1983) was used to measure anxiety and depression. The HADS has seven statements relating to anxiety and seven relating to depression and asks participants to select the response which is closest to how they have been feeling in the last week. An example statement is *‘Worrying thoughts go through my mind’.* Each response is scored from 0-3, with scores ranging from 0-21 for both anxiety and depression. Higher scores indicate higher severity of symptoms, and clinical cut-offs are available for both anxiety and depression (0-7: normal, 8-10: borderline, 11-21: abnormal). The scale has been found to be reliable and have good concurrent validity (Bjelland et al., 2002).

Planned Analyses

Qualitative Data

Qualitative data regarding acceptability was analysed using content analysis, as recommended for use in pilot studies by Sidani and Braden (2011), where data were sufficient enough to identify themes. Otherwise, data were reported descriptively. Themes were identified through familiarisation with the data, breaking data down into smaller meaning units, labelling each unit with a code, and categorising codes into themes and sub-themes which were then quantified (Bengtsson, 2016). Themes were generated inductively and using latent analysis, which involves interpreting text to find underlying meanings, as opposed to only focussing on visible communication (Downe-Wamboldt, 1992). When analysing feedback about negative experiences of online peer support, feedback from participants at T1 and T2 were combined to allow for a richer analysis, and triangulated from two open-ended questions, ‘If yes, please detail the negative experiences e.g., experiencing disagreements, misinformation or increased worry’, which was asked to all participants, and ‘Was there anything you didn’t like or anything that needs improving about the online peer support?’, which was asked to intervention participants at T2. Where there was more than one source of data available for a participant, if the same themes were mentioned at both time points or question, this was only counted once.

Preliminary Analysis of Quantitative Data

Data were analysed using JASP (2022) (Version 0.16.2). Missing data for demographic and characteristic variables were reported and not included in descriptive statistics such as percentages. Sum scores for the key outcome measures scales and subscales were calculated. Completion rates and number of missing items for each measure were reported, as seen in table 5. To address missing data for single items on outcome measures, the mean score of the participant’s observed responses to the subscale at that time point were imputed. Where a full scale was not completed by a participant, their data were excluded from the analysis of this outcome.

Baseline demographics, key outcomes, recruitment numbers, retention rates and measures of feasibility were reported descriptively. Chi-squared tests, and independent *t*-tests, were conducted to compare those who initiated T2 to those who dropped out on key variables and outcomes. Quantitative data from the ESQ were reported by observing the percentage responses to each item. Descriptive statistics were used to show any preliminary group differences on the key outcomes of loneliness, social capital, anxiety and depression, and a series of mixed ANOVAs were run with one between-subjects factor (group, at two levels: intervention vs waitlist) and one within-subjects factor (timepoint, at two levels: T1 and T2).

Data were examined to ensure test assumptions were not violated. Alternative tests, such as Welch's test, were used where assumptions were violated. Where outliers were identified, the mixed-ANOVAs were run with and without these to see if they influenced significance, and both tests were reported. The standard alpha of 0.05 was used for determining if the chi-squared tests, *t*-tests, and mixed-ANOVAs suggested that the results were significant. The mean difference and Cohen's *d* effect size with 95% confidence intervals of outcomes were also reported.

Reliable change analysis was conducted for the HADS total score, by calculating a reliable change index (Jacobson & Truax, 1991). Clinically significant change was also analysed for loneliness and anxiety and depression, using suggested categorisations for the R-UCLA and the HADS subscales. For the R-UCLA, clinically significant improvement was defined as a change from a higher to a lower categorisation, and clinically significant deterioration defined as moving from a lower to higher categorisation. For the HADS subscales, clinically significant improvement and deterioration were determined using the clinical cut off score of 8 (Stern, 2014).

Ethical Considerations

Ethical approval for the study was granted from University College London (UCL) Research Ethics Committee (Project ID: 22125/001), as seen in Appendix J. All participants provided informed consent. Although we hoped that participants might benefit from the online peer support, there were ethical considerations. These included the potential impact on participants of accessing online peer support, being asked to share their negative experiences of online peer support, and being asked to complete outcome measures about potentially emotive topics. To manage these risks, it was ensured that the online peer support options were associated with registered charities, free, and moderated. Further, participants were informed that it was up to them how much they engaged with the online peer support, and information on the potential risks of the study (e.g. questionnaires about emotive subjects) was made explicit prior to consent. Participants were advised that they had the right to withdraw at any time without explanation. Participants were also informed that they could request to withdraw their data, provided they request to do so within two weeks of T2. Details of services that can offer support were shown to participants at each time point. Feedback on the potential risk of harm from engaging with online peer support and the trial was sought as part of the research.

Results

1. Feasibility of Participant Recruitment, Retention Rates, and Measures Used

Recruitment

Recruitment Routes

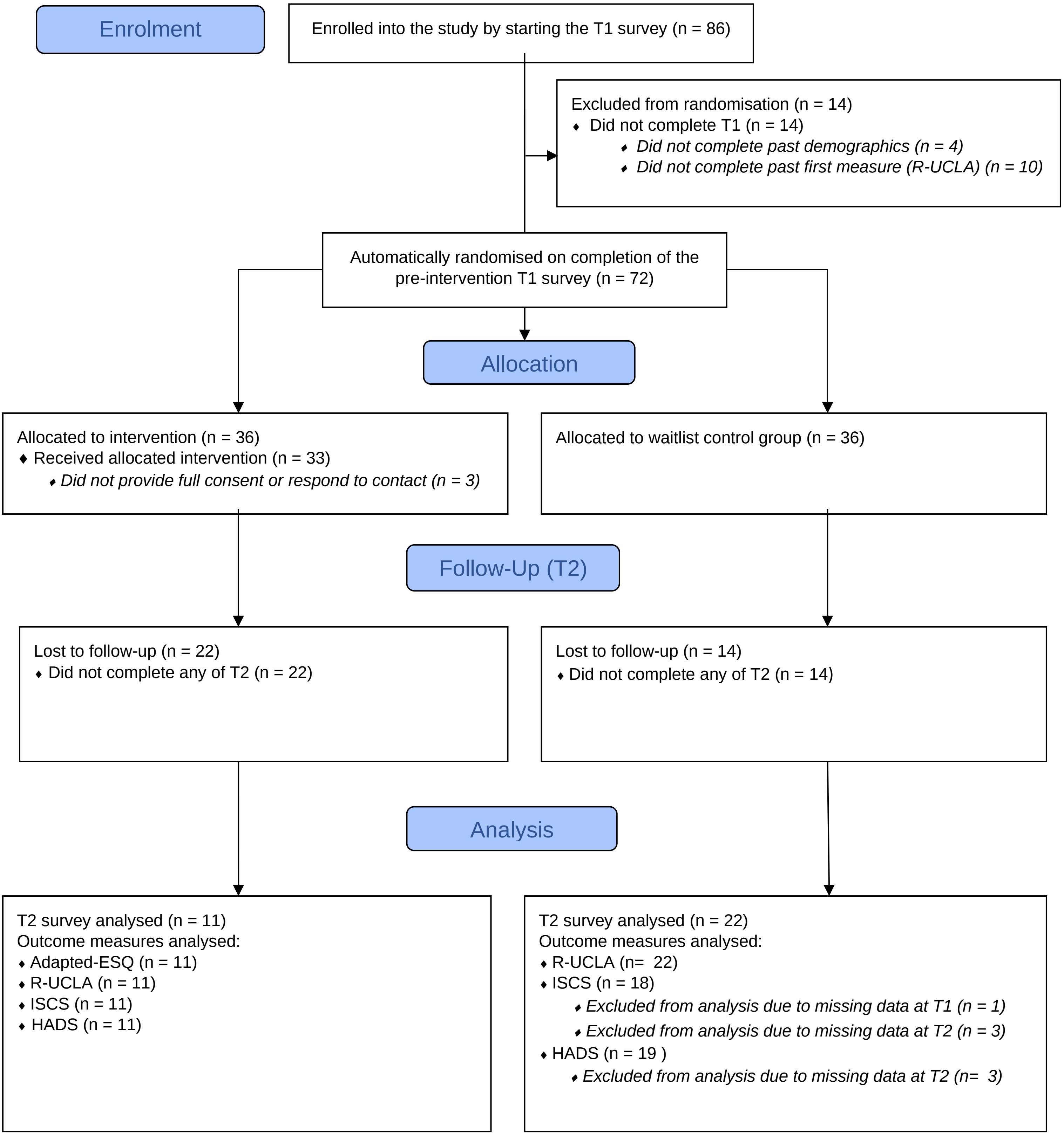
To recruit participants, 77 charities associated with LTCs, families, or parenting were contacted to ask if they could advertise or share the study. These were identified through consultation with experts, Contact's directory of LTCs and associated support, and internet searches. Of these 77 charities, 19% (15/77) advertised the study at least once, through sharing on their social media sites, bulletins or newsletters, or advertising on their website, 64% (49/77) did not respond, and 17% (13/77) said they were not able to help. A further 122 organisations related to LTCs, families, or parenting, such as parent carer forums, were also contacted. Of these, 13% (15/122) shared the advert, whilst 87% (97/122) did not respond. Thirty-two schools and nurseries were also contacted. Only one school (3%) agreed to share the advert with parents at a parents evening, though one education professional agreed to share the advert with special educational needs co-ordinators of other schools. Other routes for advertising the study included placing the advert in community spaces such as libraries and sharing on social media and through word of mouth. It was not known how many participants entered through each route of recruitment.

Recruitment Rates

The trial was open for recruitment between July 2022 – January 2023. The proposed sample size was reached by November 2022, however due to high attrition already being observed, the decision was made to continue recruitment for a further two months to maximise recruitment numbers whilst allowing time for analysis within the constraints of a doctoral thesis. A CONSORT diagram shows the flow of participants through the study in Figure 1. A total of 83 participants consented to take part in the study and completed the demographics section of the survey. Four participants dropped out after this section by not completing the rest of the survey or responding to contact to clarify if they wanted to continue. Ninety five percent (79/83) of participants completed up to and including the first outcome measure, the R-UCLA. Ten more participants dropped out after this section, leaving 83% (69/83) of participants that reached the end of the T1 survey. These were then automatically randomised to one of two conditions on Qualtrics: the intervention group (N = 33) or waitlist control group (N = 36). One of the participants in the waitlist group reached the end of the T1 survey but missed out one of the measures (the ISCS), therefore they were not included in analyses for this measure. Three more participants were automatically randomised by Qualtrics but had not ticked all consent boxes and did not respond when contacted to ascertain full consent; therefore, it was assumed that they did not consent to taking part, their data was excluded and deleted, and they did not receive the intervention. Recruitment numbers were deemed feasible as they were above the proposed sample size of 60 participants.

Figure 1

CONSORT Diagram



Characteristics of Recruited Participants

As seen in table 1, participants were predominantly female (98%) and had a mean age of 42.63 (SD = 9.20) years, with a range of 20 - 69 years. Participants had an average of two children and a large range of LTCs were reported. Most commonly reported was having a child with a rare condition, such as a rare chromosomal disorder (55%, 46/83). Followed by having an autistic child (31%, 26/83), a child with Down's Syndrome (14%, 12/83), a learning disability (11%, 9/83), Cerebral Palsy (10%, 8/83) and ADHD (8%, 7/83), as seen in Figure 2, and appendix K. The ages of the children with LTCs were not analysed, due to a lack of clarity regarding which child had an LTC. The majority of participants were already using online peer support, with only 12% (10/82) having never used online peer support before.

Based on commonly used categorisations of loneliness on the R-UCLA (Deckx et al., 2014), on average, participants reported a 'moderate' degree of loneliness (mean = 48.76). Individually, 30% (24/79) of participants fell within this 'moderate' category, whilst 18% (14/79) of participants reported a 'low' degree of loneliness, 42% (33/79) of participants reported a 'moderately high' degree, and 10% (8/79) of participants reported a 'high' degree. Based on categories of severity on the HADS (Zigmond & Snaith, 1983), on average, participants reported 'abnormal' levels of anxiety (mean = 11.30). Individually, 55% (38/69) of participants fell within this 'abnormal' category, whilst 26% (18/69) of participants reported 'borderline' levels of anxiety, and 19% (13/69) of participants scored within the 'normal' range. For depression, on average, participants reported 'borderline' levels (mean = 8.67). Individually, 32% (22/69) of participants fell within this 'borderline' level, 32% (22/69) of participants reported 'abnormal' levels of depression, and 36% (25/69) of participants scored within the 'normal' range. All outcome data were shown to be normally distributed using a Shapiro-Wilk test (p < .05).

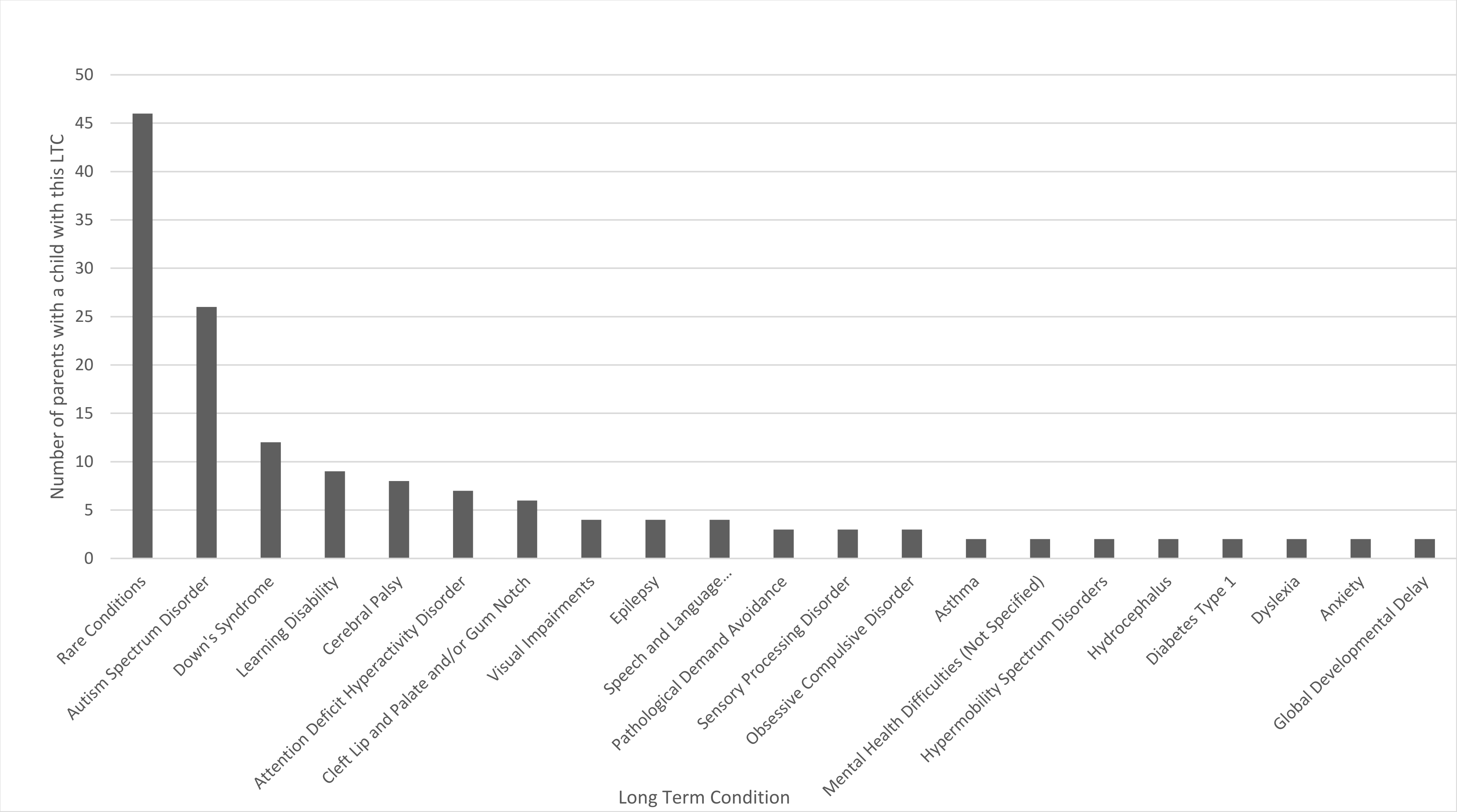
Table 1

Characteristics of Recruited Participants

Variable		%	N	Mean	SD	Range	Missing
Age (years)				42.63	9.20	20 - 69	
Gender (% female)		98%	81				
Number of children				2.13	0.12	1 - 6	1
Daily Social Media Use	<10 mins	2%	2				0
	10-30 mins	22%	18				
	1-2 hrs	46%	38				
	2-3 hrs	17%	14				
	3+ hrs	13%	11				
Online Peer Support Use	Daily	35%	29				1
	Weekly	33%	27				
	Less than monthly	20%	16				
	Never	12%	10				
Negative experiences	Yes	35%	28				2
	No	64%	52				
	Not applicable	1%	1				
R-UCLA				48.76	12.56	24 - 76	4
ISCS-offline				69.42	14.54	36 - 97	15
ISCS-online				64.72	17.46	26 - 98	15
ISCS-total				134.13	26.24	63 - 186	15
HADS-anxiety				11.30	4.44	1 - 20	14
HADS-depression				8.67	4.25	0 - 18	14
HADS-total				19.97	7.66	2 - 35	14

Figure 2

Number of Recruited Parents That Reported Having At Least One Child with Each LTC (where N ≥ 2)



Characteristics of Randomised Participants

Characteristics of participants that were randomised to a condition, are seen in table 2. Regarding pre-existing use of online peer support, participants in the waitlist condition reported using it less than participants in the intervention condition, with 61% (22/36) using it daily or weekly, compared to 78% (25/32) in the intervention condition. Despite the high pre-existing use of online peer support, 100% (33/33) of intervention participants were signposted to online peer support options that they did not report already using.

Table 2

Characteristics of the 69 randomised participants, split by group

Variable		Intervention Group (N = 33)						Waitlist Group (N = 36)					
		%	N	Mean	SD	Range	Missing	%	N	Mean	SD	Range	Missing
Age (years)				43.06	6.85	32 - 63	0			43.14	9.86	20 - 69	0
Gender (% female)		100%	33				0	94%	34				0
Number of children				1.94	0.66	1 - 3	0			2.39	1.32	1 - 6	0
Daily Social Media Use	<10 min	0%	0				0	6%	2				0
	10-30 min	21%	7					25%	9				
	1-2 hrs	48%	16					39%	14				
	2-3 hrs	18%	6					17%	6				
	3+ hrs	12%	4					14%	5				
Online Peer Support Use	Daily	50%	16				1	25%	9				0
	Weekly	28%	9					36%	13				
	< Monthly	13%	4					28%	10				
	Never	9%	3					11%	4				
Negative Exp	Yes	45%	15				1	25%	9				0
	No	55%	18					75%	27				
R-UCLA				49.52	12.74		0			49.42	12.97		0
ISCS-off				68.96	15.25		0			69.85	14.05		1
ISCS-on				64.52	17.86		0			64.91	17.33		1
ISCS-total				133.48	25.89		0			134.76	26.94		1
HADS-anx				10.67	5.04		0			11.89	3.79		0
HADS-dep				8.70	4.52		0			8.64	4.05		0
HADS-total				19.36	8.75		0			20.53	6.58		0

Note. Negative exp = negative experiences, ISCS-off = ISCS offline subscale, ISCS-on = ISCS online subscale, HADS-anx = HADS anxiety subscale, HADS-dep = HADS depression subscale

Retention Rates

Of the 69 participants that were randomised to a condition, 48% (33/69) of participants initiated T2. However, three of these 33 did not progress beyond the first outcome measure of the T2 survey, such that 43% (30/69) of randomised participants *completed* T2. Retention rates were therefore slightly lower than the expected 50%, estimated from retention rates seen in previous research into online peer support (Griffiths et al., 2012) and potential increased demands on this population (Plant & Sanders, 2007; Raina et al., 2004). Further, significantly more waitlist participants were retained (61%, 22/36) than intervention participants (33%, 11/33) (p = .021). Independent samples t-tests found that there were no other significant differences between participants that were retained (N = 33) and those who dropped out (N = 36), in age or on any key outcome measure (ps > .05), as seen in table 3.

Table 3

Statistical Analyses of Differences Between Retained Participants and Dropouts

Variable	Statistical Analysis
Condition	X^2 (1, 69) = 5.32, p = .021
R-UCLA	t(67) = 0.17, p = .862
ISCS-offline	t(66) = 0.20, p = .839
ISCS-online	t(66) = -1.20, p = .235
ISCS-total	t(66) = -0.68, p = .500
HADS-anxiety	t(67) = 0.33, p = .746
HADS-depression	t(67) = -0.23, p = .822
HAD-total	t(67) = 0.06, p = .949
Age	t(56.237) = 0.50, p = .626[a]

[a]Welch's test

Feasibility of Measures

Completion rates and number of missing data items for each outcome measure can be seen in table 4. For the outcome measures that were completed, there was a small number of missing items across both time points (N = 7), and just one participant that reached the end of T1 missed out a full measure (ISCS).

The majority of participants that initiated T2 did so after more than one email reminder, with 27% (9/33) responding after two email reminders, and 30% (10/33) responding after three email reminders, whilst 42% (14/33) responded after just one email. Time taken to complete the surveys ranged from 7 minutes to 19 hours at T1, and 5 minutes to 49 hours at T2, indicating that some participants returned to complete the surveys on a different day.

Only one of the intervention participants that completed T2 returned the weekly engagement log. In contrast, 100% (10/10) of intervention participants that reported using online peer support filled out the retrospective questions about engagement on the online survey. No participants chose to complete the measures over the phone or video call after this was added as an option.

Table 4

Completion Rates and Missing Items of Data for each Outcome Measure

Variable	Timepoint	R-UCLA	ISCS-offline	ISCS-online	HADS
Completion Rates (%, N)	T1	95%, 79/83	82%, 68/83	82%, 68/83	83%, 69/83
	T2	100%, 33/33	91%, 30/33	91%, 30/33	91%, 30/33
Missing items of data (N)	T1	2	2	1	0
	T2	1	1	0	0

2. Acceptability of the Randomised Pilot Trial Methods

All 11 intervention participants filled out the adapted-ESQ. One participant who reported not using the online peer support responded ‘don’t know’ for each question and was therefore not included in the percentages about experiences of online peer support. Quantitative results can be seen in table 5.

Regarding acceptability of trial methods, the majority of participants (82%, 9/11) reported that it was ‘certainly true’ or ‘partly true’ that they had been given enough information about the online peer support groups and forums, with two answering ‘don’t know’, indicating that this part of the trial was largely acceptable to most intervention participants. Further, the majority of participants that completed T2 were in the waitlist condition, potentially indicating that being randomised to this condition was acceptable to them.

Participants were also asked the following two open-ended questions regarding the acceptability of the randomised trial in the adapted-ESQ: '*Was there anything you didn't like or anything that needs improving about the study?'* and *'Is there anything else you want to tell us about the online peer support or this study*?' Six participants answered at least one of these questions. Three participants (50%) stated '*no',* that there was not anything they did not like or that needed improving. Two participants (33%) reported aspects of the study that they did not like; one (17%) reported that the demand to keep the weekly engagement log was too much, and one (17%) stated that there was a lack of open-ended questions, that they were unclear about the aim of the study and that the study did not provide anything new as they were already very familiar with online peer support groups. One participant (17%) suggested using an online form with reminder alerts, though it was unclear whether this suggestion was for the online survey or the weekly engagement log.

Table 5

Responses to the Adapted-ESQ Multiple Choice Questions

Question	Percentage of participants [N, (%)]			
	Certainly True	Partly True	Not True	Don't know
I feel that the people who I spoke to in the online peer support groups/forums listened to me	4/10 (40%)	6/10 (60%)	0/10 (0%)	0/10 (0%)
It was easy to talk to the people in the online peer support groups/forums	6/10 (60%)	2/10 (20%)	2/10 20%	0/10 (0%)
I was treated well by the people in the online peer support groups/forums	7/10 (70%)	2/10 (20%)	1/10 (10%)	0/10 (0%)
My views and worries were taken seriously in the online peer support groups/forums	6/10 (60%)	4/10 (40%)	0/10 (0%)	0/10 (0%)
I have been given enough information about the online peer support groups/forums	6/11 (55%)	3/11 (27%)	0/11 (0%)	2/11 (18%)
I feel that the people in the online peer support groups/forums were able to support me with problems	5/10 (50%)	4/10 (40%)	0/10 (0%)	1/10 (10%)
The online peer support groups/forums were easy to use	5/10 (50%)	5/10 (50%)	0/10 (0%)	0/10 (0%)
If a friend needed similar support, I would recommend the online peer support	7/10 (70%)	2/10 (20%)	1/10 (10%)	0/10 (0%)

3. Acceptability of Signposting to Online Peer Support as an Intervention

Engagement

At T2, 91% (10/11) of the intervention participants reported having used online peer support during the three-month period since their point of recruitment; however, only 60% (6/10) of these reported using one or more of the online peer support options that they were signposted to as part of the study. The other 40% (4/10) of these participants used other online peer support groups and forums that were not signposted to, such as social media groups not associated with charities. Further, of the six participants that did report using the signposted support, 67% (4/6) also used other online peer support groups and forums that were not signposted to. For the waitlist participants, 71% (15/21) reported having used online peer support during the three-month period, while one person did not answer this question. Levels of engagement and self-rated participation with online peer support for both groups can be seen in Table 6. Overall, there were higher levels of engagement for those in the intervention group, with 70% (7/10) using online peer support for at least 30 minutes per week, compared to 24% (5/21) of the waitlist group. The mean self-rated level of participation was also slightly higher for participants in the intervention group than the waitlist group (mean = 5.09 and 4.10 respectively).

Table 6

Engagement with Online Peer Support at T2

Variable		Intervention group (N = 11)	Waitlist group (N = 22)
Average Online Peer Support Use Per Week [Valid %, (N)]	Less than 10 minutes	2/10 (20%)	9/21 (43%)
	10 – 30 minutes	1/10 (10%)	7/21 (33%)
	30 minutes – 1 hour	3/10 (30%)	3/21 (14%)
	More than 1 hour	4/10 (40%)	2/21 (10%)
	Missing	1	1
Rated Level of Participation (0-10)	Mean (SD)	5.09 (3.18)	4.10 (3.45)
	Missing	0	1

Experiences of Using Online Peer Support

As seen in table 5, data from the adapted-ESQ showed that all the participants that had used online peer support reported that it was ‘certainly true’ or ‘partly true’ that their peers in the online peer support listened to them, that their views and worries were taken seriously, and that the online peer support was easy to use. Further, the majority reported that it was ‘certainly true’ or ‘partly true’ that it was easy to talk to people (80%, 8/10), that they were treated well (90%, 9/10), that people were able to support them with their problems (90%, 9/10), and that they would recommend the online peer support to a friend (90%, 9/10). However, two participants (20%) reported that it was not easy to talk to people, and one participant (10%) reported that they were not treated well and would not recommend the online peer support.

Two themes were identified from the qualitative feedback to the question ‘*What was good about the online peer support?’* as seen in Table 7. Meeting others with similar experiences was the most commonly reported (N = 8), with two of these participants reporting that meeting others with similar experiences meant it was easier to discuss things and to understand each other. Two participants reported benefiting from the shared knowledge on the online peer support. Other individual feedback included: the platform being easy to interact with (N = 1), having a wider reach of people than in the real world (N = 1), and finding peer support groups in their first language (N = 1).

Table 7

Participant’s Qualitative Feedback: Positive Experiences of Using Online Peer Support (N = 10)

Themes	Participants reporting %	(N)	Quotes (Participant Number)
Meeting others with similar experiences	80%	8/10	*It's easy to find someone with experience of the issues you face.* (IN7) *Knowing that the people in the group were in a similar situation to me.* (IN18)
Shared knowledge	20%	2/10	*Always a knowledgeable voice with experience to help you think through a situation.* (IN5)

In response to the question asking if participants had ever had any negative experiences of using online peer support, at T1, 34% (28/82) of participants reported having had negative experiences. Of the randomised participants, 48% (15/31) of intervention participants and 25% (9/36) of waitlist participants reported having had negative experiences. At T2, 56% (18/32) reported having had negative experiences when using online peer support. By condition group, 64% (7/11) of intervention participants and 52% (11/21) of waitlist participants reported having had negative experiences when using online peer support. However, only 9% (1/11) of participants in the intervention group that had not previously reported negative experiences when using online peer support, reported that they had experienced negative experiences at T2.

As seen in table 8, three themes of negative experiences were identified from two open-ended questions about negative experiences of online peer support and what participants did not like or thought needed improving about the online peer support. These themes were: Interpersonal difficulties between peers (N = 25), difficulties related to the content of the discussions (N = 18), and technological problems (N = 2). The most commonly reported sub-themes of interpersonal difficulties were: disagreements and differing opinions with peers (N = 15), judgement and criticism (N = 9), and aggression and bullying (N = 7). Some participants also reported ableism (N = 2) and lack of support from peers (N = 3). Other individual feedback included: misunderstandings due to the written nature of communication (N = 1), unwanted attention from peers (N = 1) and comparisons of children being made (N = 1). Regarding difficulties related to the content of discussions, the sub-theme most commonly reported was that participants experienced a lot of negativity in the discussions, which lead to an impact on their own wellbeing, such as feelings of worry and stress (N = 11). The sub-theme of misinformation was also commonly reported (N = 10), including one participant reporting receiving information that contradicted medical advice. A further sub-theme identified was that the online peer support had poor, or a lack of moderation, which was reported by two participants. Other individual feedback included forums having banned topics, such as COVID-19, meaning support was restricted (N = 1) and off-topic inappropriate postings (N = 1). Finally, the theme of technological difficulties was reported by two participants, sharing that the online peer support forums that they used had a poor interface. An example analysis schedule can be seen in Appendix L. Although the majority of participants did not report any negative experiences when using online peer support, these results show that signposting parents of children with LTCs to online peer support may expose them to these negative experiences.

Table 8

Participant's Qualitative Feedback: Negative Experiences of Using Online Peer Support (N = 35)

Themes and Sub-themes	Participants Reporting %	 (N)	Quotes (Participant Number)
Interpersonal difficulties between peers			
Disagreements and differing opinions	43%	15/35	*Differences of opinion on approaches that work.* (IN30) *Disagreements about diet…* (W26)
Judgement and criticism	26%	9/35	*People can be critical which is hard when you are trying your best.* (IN22) *Judgemental attitudes…* (IN36)
Aggression and bullying	20%	7/35	*Aggressive people.* (W3) *Name calling.* (W9)
Lack of support from peers	9%	3/35	*Not such support to posts.* (W7)
Ableism	6%	2/35	*Ableism.* (W9)
Difficulties related to the content of discussions			
Negativity of content leading to an impact on wellbeing	31%	11/35	*A lot of negativity and moaning, found it very unhelpful for my wellbeing.* (IN10) *Hearing worrying things.* (U9)
Misinformation	29%	10/35	*Advice which contradicts medical professionals* (IN36) *Misinformation.* (IN21)
A lack of, or poor, moderation	6%	2/35	*Some groups don't have very good moderation, so you have to work out if a group is for you or not.* (IN7)
Technological problems			
Poor interface	6%	2/35	*Message boards like […] were a little trickier to navigate* (IN5)

Note: An ellipsis shows where text has been omitted.
N = number of participants who detailed negative experiences of online peer support who reported this theme at either time point

Preliminary Group Differences on Key Outcomes

An outline of the key outcomes for participants that completed measures at T1 and T2, can be seen in tables 9 and 10. Figure 3 shows the change in outcomes for each group. When looking at reliable and clinically significant improvement, just over half of intervention participants (55%, 6/11) made an improvement on at least one outcome; however, reliable or clinically significant improvement was also seen in 45% (10/22) of waitlist participants. When looking at reliable and clinically significant deterioration, 27% (3/11) of intervention participants and 27% (6/22) of waitlist participants deteriorated on at least one outcome.

Primary Outcome: Loneliness

An improvement in R-UCLA score was seen for the intervention group (mean difference = -2.51, 95% CI [-8.60, 3.58]), with a small effect size, that was not seen for the waitlist group (mean difference = 0.82, 95% CI [-3.49, 5.13]). A mixed ANOVA showed that there was no significant time by group interaction effect on the R-UCLA score (*F(*1, 31) = 1.58, *p* = .218). When looking at clinically significant change, 45% (5/11) of the intervention group showed clinically significant improvement, compared to 23% (5/22) of waitlist participants.

Social Capital

For the ISCS offline subscale, a small decrease in offline social capital was seen for both the intervention (mean difference = -0.27, 95% CI [-10.32, 9.78]) and waitlist group (mean difference = -1.93, 95% CI [-9.78, 5.93]), though this decrease was smaller for the intervention group, and effect sizes were negligible for both. For the ISCS online subscale, the waitlist group showed a small increase in online social capital (mean difference = 0.67, 95% CI [-6.29, 7.63]), whereas the intervention group showed a decrease in online social capital (mean difference = -3.36, 95% CI [-12.27, 5.54]), though effect sizes were negligible for both. A mixed ANOVA showed no significant time by group interaction effect on the ISCS-offline (*F(*1, 27) = 0.14, *p* = .715) or ISCS-online (*F(*1, 27) = 1.03, *p* = .319).

Table 9.

Primary and Secondary Outcomes for Retained Participants: Descriptive Statistics, Pre-Post Mean Difference Effect Sizes, and Mixed-ANOVAs

Variable		Intervention group (N = 11)				Waitlist group (N = 22)				Mixed-ANOVA: Time*Condition	
		Mean	SD	Missing	Within group pre-post Cohen's *d* (95% CI)	Mean	SD	Missing	Within group pre-post Cohen's *d* (95% CI)	F value	*P* value
R-UCLA	T1	43.46	12.37	0	-0.21 (-0.71, 0.29)	52.09	12.40	0	0.07 (-0.29, 0.42)	1.58	0.218
	T2	40.85	11.77	0		52.91	11.78	0			
ISCS-offline	T1	74.64	16.18	0	-0.02 (-0.63, 0.59)	66.17	14.98	1	-0.12 (-0.60, 0.36)	0.14	0.715
	T2	74.36	15.64	0		64.24	17.41	3			
ISCS-online	T1	75.09	13.74	0	-0.19 (-0.67, 0.30)	64.83	18.86	1	0.04 (-0.34, 0.42)	1.03	0.319
	T2	71.73	13.68	0		65.50	21.66	3			
ISCS-total	T1	149.73	25.35	0		131.00	30.35	1			
	T2	146.09	25.97	0		129.74	32.86	3			
HADS-dep	T1	7.91	3.86	0	-0.26 (-0.86, 0.34)	9.21	4.10	0	-0.14 (-0.59, 0.32)	0.21	0.653
	T2	6.72	4.88	0		8.58	5.09	3			
HADS-anx	T1	10.00	5.62	0	-0.36 (-0.87, 0.15)	11.84	3.75	0	-0.17 (-0.56, 0.21)	0.71	0.407
	T2	8.36	4.86	0		11.05	4.44	3			
HADS-total	T1	17.91	8.75	0		21.05	6.36	0			
	T2	15.09	9.03	0		19.63	8.86	3			

Note. HADS-dep = HADS depression subscale, HADS-anx = HADS anxiety subscale

Table 10.

Reliable and Clinically Significant Change

Variable	Intervention Group (N = 11)		Waitlist group (N = 22)	
	CSC	RC	CSC	RC
R-UCLA	45% (5/11)		23% (5/22)	
	18% (2/11)		23% (5/22)	
HADS-depression	9% (1/11)		11% (2/19)	
	0% (0/11)		0% (0/19)	
HADS-anxiety	9% (1/11)		21% (4/19)	
	9% (1/11)		0% (0/19)	
HADS-total		27% (3/11)		16% (3/19)
		0% (0/11)		11% (2/19)

Note. CSC = clinically significant change, RC = reliable change
🟩 = improvement, 🟥 = deterioration

Anxiety and Depression

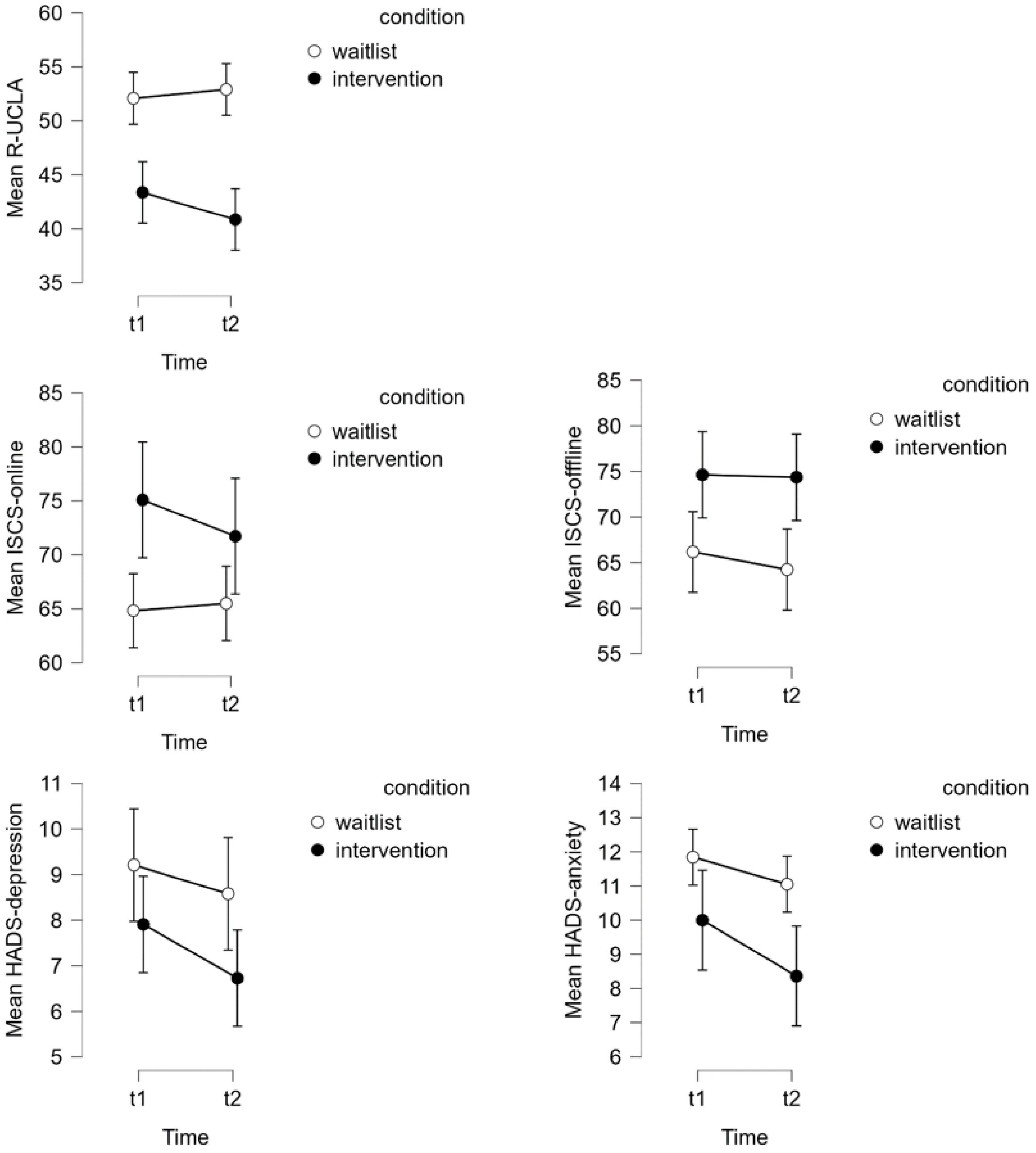
For the HADS depression subscale, a slight improvement was seen in both groups, with a greater reduction in depression score and a larger effect size for the intervention group (mean difference = -1.18, 95% CI [-3.92, 1.55]) than the waitlist group (-0.63, 95% CI [-2.71, 1.45]). A mixed ANOVA showed that there was no significant time by group interaction effect (*F(*1, 28) = 0.21 *p* = .653). Two outliers were identified at T1, however, removing these did not make a difference to the significance of the analysis (*F*(1,26) = 0.32, *p* = .576). When looking at clinically significant change, there was a slightly higher rate of improvement in the waitlist group (11%, 2/19) than the intervention group (9%, 1/11).

For the HADS anxiety subscale, an improvement was again seen in both groups, with a greater reduction in anxiety score, and a larger effect size, for the intervention group (mean difference = -1.64, 95% CI [-3.91, 0.64]) than the waitlist group (mean difference = -0.79, 95% CI [-2.52, 0.94]). A mixed ANOVA showed that there was no significant time by group interaction effect (*F(*1, 28) = 0.71 *p* = .407). One outlier was identified at T2, however, removing this did not make a difference to the significance of the analysis (*F*(1,27) = 0.53, *p* = .473). When looking at clinically significant change, there was a higher rate of improvement in the waitlist group (21%, 4/19) than the intervention group (9%, 1/11).

When looking at the total HADS scores, there were higher rates of reliable improvement in the intervention group (27%, 3/11) than the waitlist group (16%, 3/19).

Figure 3.

Change in Key Outcomes



Discussion

Summary of Findings

This study describes a randomised pilot trial assessing the feasibility and acceptability of an RCT to investigate the effect of signposting parents of children with LTCs to online peer support, particularly on the key primary outcome of loneliness. Overall, the results suggested that some aspects of the trial are feasible and acceptable; however, changes to the protocol are indicated. The main findings of each research objective are discussed further, followed by the limitations of the study and implications for future research, including a future definitive RCT.

1. Feasibility of Participant Recruitment, Retention Rates, and the Measures Used

Although it is not known how many participants entered the study through each route of recruitment, advertising the study through charities and organisations was found to be more feasible than through schools and nurseries, due to the percentage of institutions that agreed to advertise the study. However, this percentage was still low, indicating that other recruitment routes may be needed for a future RCT. Further, although these recruitment routes gained a diverse sample in terms of ages of parents and nature of LTCs, there was a lack of diversity of gender and pre-existing use of online peer support, with the majority of participants already frequently using online peer support, which affects generalisability of the findings.

Recruitment numbers were found to be feasible, as they were above the proposed sample size of 60 participants for the pilot trial. However, there were issues with low retention. The retention rate was lower than estimated from previous research into online peer support (Griffiths et al., 2012), impacting feasibility. However, differences between the current study and Griffiths et al.’s (2012) study limit the ability to make direct comparisons of retention rates; the studies had different populations, different interventions (purpose-built online peer support vs. signposting to existing online support), and different levels of contact between participants and the research team. Nevertheless, attrition rates of over 20% have been suggested to pose serious threats to validity (Straus et al., 2018), although it is acknowledged that expected loss to follow-up can depend on various factors, such as the topic examined and length of follow up (Schulz & Grimes, 2002). Further impacting feasibility, significantly more waitlist participants were retained than intervention participants, although Christensen et al.'s (2009) review of online interventions for depression and anxiety found that this pattern of retention is often seen in online interventions.

Regarding feasibility of measures, as a minority of participants started but did not complete the survey at both time points, and time taken to complete measures varied vastly, it is possible that the length of the surveys may have been a barrier to completion for some participants. Additionally, multiple reminder emails were found to be needed to increase the number of participants completing the T2 survey. However, as the majority of participants that initiated the surveys did complete them, with little missing data, this suggests that the measures were mostly feasible. The results also showed that the retrospective engagement questions on the survey were more feasible than the separate weekly engagement log, which only one participant returned. Reasons for the lack of use of the weekly log are not known for all participants, however, one participant reported that the demand of the weekly log was too much. It is possible that this may have been a reason for other participants too, given that research highlights the high levels of demand on this population (Plant & Sanders, 2007; Raina et al., 2004).

2. Acceptability of the Randomised Pilot Methods

Data from the adapted-ESQ indicated that the trial methods were largely acceptable for most intervention participants. However, this should be interpreted with caution due to the small sample size of intervention participants that completed T2, and no data being available for participants that did not complete the T2 survey. Some recommendations for changes to the methods were suggested, such as having more open-ended questions in the surveys and the use of automated online reminders.

Attrition rate is sometimes used as an indicator of acceptability; however, attrition has been attributed to many factors; both personal characteristics and study characteristics (Christensen et al., 2009; Sidani & Braden, 2011). As participants were informed that they could withdraw at any time without reason, data were not gained on the reasons for withdrawal. Therefore it is not possible to know whether the high attrition is an indicator of the acceptability of study methods or intervention, or due to other factors, such as those reported in Christensen et al.'s (2009) review of online interventions. These included lack of motivation, technical problems, lack of face-to-face contact, or time constraints, which may be particularly relevant to this population, given the additional demands that they can face (Plant & Sanders, 2007; Raina et al., 2004). Waitlist participants did not receive the adapted-ESQ at T2, so their experience of the trial methods is not known. There were higher retention rates for participants in this waitlist condition. Again, the reasons for this are not known, but one reason for this might be that waiting for the signposting information was an incentive to stay in the trial.

3. Acceptability of Signposting to Online Peer Support as an Intervention

Data from the adapted-ESQ indicated that online peer support is a largely acceptable intervention. However, as there was high attrition of intervention participants, it is possible that there was bias towards participants that found online peer support more useful. Further, although engagement in online peer support was high, only 60% of intervention participants used the online peer support which they had been signposted as part of the trial, with many participants using online peer support options that were not associated with charities and therefore not signposted to. This could indicate that these options could be integrated as part of the intervention in a future RCT. However, given that the importance of moderation was highlighted in the qualitative feedback, it would be important to ensure that these signposting options still have adequate moderation. On the other hand, these results could indicate that signposting is less helpful and not always needed in real-world settings if parents are already accessing sources of online peer support. This is in line with feedback given by one participant who reported already being very familiar with online peer support options.

From the qualitative feedback on online peer support, participants reported positive experiences of meeting others with similar experiences and benefiting from shared knowledge, further indicating acceptability of online peer support. These findings are similar to themes identified in previous reviews of peer support for parents of children with LTCs. Previous similar themes identified include building connections with others with similar experiences (Wong & Shorey, 2022) and being able to learn from each other, give each other support, and find a “shared social identity with other parents”, which reduced their sense of isolation and loneliness (Shilling et al., 2013, p. 605). However, it is not possible to attribute these positive experiences solely to the use of the online peer support options signposted to in the intervention, given that the majority of participants also reported using other sources of online peer support. This impacts the feasibility of trial methods, indicating that adapted methods would be needed for a future RCT in order to capture the acceptability of the intervention being investigated.

The adapted-ESQ data also showed that there was a minority of participants who found the intervention less acceptable. Further, participants’ qualitative feedback identified a number of negative experiences that can be had when using online peer support: interpersonal difficulties with peers, difficulties related to the content of the discussions, and technological problems. Again, these findings are similar to those found in a previous review of online peer support for parents, which identified negative experiences of misinformation, a lack of replies, and off-topic postings (Niela-Vilén et al., 2014). Data about negative experiences were grouped from participants from both conditions at both T1 and T2, meaning that these negative experiences were not solely attributable to the intervention, again limiting feasibility of current trial methods. However, both datasets showed the same themes. Further, as the majority of intervention participants also used online peer support options that were not signposted to, it is not known whether these experiences are universal across online peer support, or whether there is a difference for participants that only use online peer support that is associated to charities and is moderated. As only one intervention participant reported being newly exposed to negative experiences of online peer support during the trial, this indicates that the majority of participants had already been exposed to negative experiences when using online peer support prior to the trial. Given that the majority of participants still engaged with online peer support during the study despite having had these prior negative experiences, this could suggest that the benefits outweigh the negatives of online peer support, further indicating acceptability. Overall, whilst the data provides more information about both the potential benefits and harms of online peer support, signposting to online peer support appears to be a largely acceptable intervention. Given that an identified barrier to accessing peer support is a lack of clarity about its benefits (Wong & Shorey, 2022), a role of professionals could be to inform parents of the potential benefits. However, informing parents of the potential harms is also important, particularly given the finding that there is potential for misinformation which can contradict medical advice, which has also been seen in other research evaluating information provided on online forums (Mertan et al., 2021).

Preliminary Group Differences on Outcomes

No statistically significant differences were found, although this was expected given that this was a small, non-powered pilot study. When looking at mean differences from T1 to T2, small effects were seen in improving loneliness in the intervention group that were not seen for the waitlist group. Further, there was a higher rate of clinically significant improvement on the R-UCLA. When looking at the mean differences on the HADS, small effects were seen for improvements on the anxiety and depression subscales for the intervention group that were negligible in size for the waitlist group. Further, there was a higher rate of reliable change on the total HADS score for the intervention group, although the number was still small. However, there was a slightly higher rate of clinically significant improvement for participants in the waitlist group on both of the HADS subscales. No improvements in social capital were seen for the intervention group, with an improvement seen in the online subscale for the waitlist group; however this was negligible in size.

These results should be interpreted with caution and may not be generalisable to a future RCT given the differences in retention and small sample sizes in each group which limit the ability to compare differences between groups, the high pre-existing use of online peer support in both groups which is likely to have comminated any differences between groups, and given that it was a non-powered pilot study. As measuring these outcomes appeared to be feasible, a future fully powered RCT should be used to investigate these possible group differences and establish the effectiveness of signposting to online peer support.

Limitations

There were several limitations to the study. First, the trial was initially planned and initiated as a definitive RCT. However, challenges with recruitment being slower than expected meant that a fully powered RCT was not feasible within the time constraints of a doctoral thesis. The study was therefore converted to a pilot study with primary outcomes of acceptability and feasibility. As the study had already commenced, major changes to the trial design were not possible, leading to some limitations which may have been avoided if the study was originally designed as a pilot trial. For example, the recruitment route of participants was not asked about in the T1 survey, meaning data were not obtained about the most feasible routes of recruitment. This meant that the most feasible recruitment routes could not be prioritised in the pilot study and that understanding of the feasibility of recruitment routes is limited for a future trial. Further, limited demographic questions were asked at T1; further questions could have enabled a better understanding of the diversity of the recruited sample. Additionally, qualitative research can be a useful and common contribution to understanding the feasibility of RCTs (O'Cathain,et al., 2015). Although this study gathered some qualitative data, there was limited information gathered about trial methods. Having a larger qualitative aspect to the study with more specific questions about trial methods, including about participant's experiences of randomisation and the measures used, may have allowed for better understanding of acceptability and feasibility of the methodology.

Second, the sample lacked diversity in terms of gender and pre-existing use of online peer support. This limits the generalisability of the results, particularly as research has evidenced gender differences in the experiences of parenting a child with an LTC (Dervishaliaj, 2013; Woodman, 2014). The high pre-existing use of online peer support may have been an unintended consequence of how the study was advertised: mainly through charities and organisations that offer support to parents. This may have biased the sample towards parents who were already accessing forms of support through these organisations and therefore may be already aware of the online peer support available, and who may have had higher levels of distress leading them to be accessing these organisations in the first place. Further, the high use of online peer support that was not associated with charities both before and during the trial, is likely to have influenced outcomes. This also meant that it was not possible to know if the reported positive and negative experiences and effects on outcomes were attributable to the intervention, impacting internal validity.

Third, there were some limitations of the survey and measures used. Despite social capital being widely researched, there is no consensus on its measurement (Jeong et al., 2021). Although the ISCS is commonly used in research, Appel et al. (2014) found that it lacks validity; therefore alternative measures should be considered. Further, the wording of the demographic questions asked to participants meant that for participants with more than one child, it was not possible to identify which child(ren) had an LTC, and what age they were. This should be rectified in a future RCT, so that the age of child and type of LTC can be investigated as potential moderating variables, as these factors have been found to impact parental experiences (Neely-Barnes & Dia, 2008; Woodman, 2014). Further, parents were not asked about other potential confounding variables, such as whether they were accessing other forms of support for their mental health.

Additionally, although informative, the low and unequal levels of retention are a limitation of this study. This impacts the feasibility of the trial and the ability to compare preliminary differences between conditions, and threatens validity (Schulz & Grimes, 2002). Therefore strategies to improve retention need to be implemented in a future RCT.

Finally, progression criteria are a suggested strategy to help researchers to interpret whether and how to advance with a future definitive RCT from an external pilot (Mellor et al., 2023). Although previous research was used to estimate factors such as acceptable retention rates, pre-set progression criteria were not used, which may have increased the risk of bias when assessing feasibility. However, there are challenges of using pre-set progression criteria, as research has found that there is a lack of guidance on how to devise the criteria and assess whether these have been sufficiently met (Hallingberg et al., 2018) and that it is often unclear how progression criteria are determined and assessed in published pilot trials (Mellor et al., 2023).

Implications for Future Research

The results and limitations of this pilot trial indicate that the trial is not fully feasible with the current methods; therefore changes to trial methods are indicated before progression to a future RCT. First, in order to recruit a more diverse sample and ensure results are generalisable, additional recruitment routes are needed. For example, recruiting participants through the NHS may enable the study to be advertised to parents of children who are newly diagnosed and not yet accessing support, including online peer support. This may also allow professionals to directly discuss the study with parents, including male parents, and may help to increase recruitment numbers.

The results also indicate that changes are needed to improve retention of participants, particularly those in the intervention group. Although reasons for attrition were not known, several strategies to improve retention could be considered. Incentivising participants with money to complete the surveys, rather than for signing up, could be considered as this has been shown to improve response rate (Brueton et al., 2014) and increase retention (Alexander et al., 2008), although this may reduce ecological validity. Further, as there is evidence that unconditional incentives improve response rate more than conditional incentives in online surveys (David & Ware, 2014), this should be piloted and could be offered in addition rather than in replacement. Additionally, although no participants chose to complete questionnaires over telephone or video call, this was a late amendment to the protocol; offering this as an option from the beginning of a future trial might also aid retention. Further, given the increased demands and lack of time that this population can face (Plant & Sanders, 2007; Raina et al., 2004; Wong & Shorey, 2022) and the hypothesis that the length of the survey may have been a barrier for some participants, retention might be improved by making the surveys easier to complete, such as by shortening them. Modifying the outcome measures are further indicated given the reported limitations of the social capital measure used. Jeong et al.'s (2021) research comparing social capital scales in online brand community contexts recommends Lin & Lu's (2011) social capital scale. This scale is shorter, with just 12 items, but only focuses on online social capital. A future RCT could consider whether using an adapted version of this shorter scale may be more feasible in this context. There are also several shorter versions of the R-UCLA (e.g. ULS-4; Russell et al., 1980; ULS-8; Hays & DiMatteo, 1987), which could be considered. Further, as the engagement log was found to not be a feasible way to measure engagement, using just the retrospective measures of engagement may make participation in the study for intervention participants less demanding.

In order to better understand the effects of signposting to online peer support, a future RCT would benefit from asking specifically about positive and negative experiences of the moderated online peer support signposted to as part of the trial. Further, in order to reduce contamination of results, an exclusion criterion of pre-existing use of online peer support could be considered. However, this may reduce recruitment numbers and ecological validity. Other changes to the survey are also indicated. Questions about the age and LTC of each child should be clearer; this could be achieved by having separate text boxes for each child. Additionally, asking participants how they found out about the study could allow for prioritisation of the most feasible recruitment routes. Consideration should also be given to the participant suggestions of having more open-ended questions in the surveys and using automated online reminders. Further, potential confounders such as pre-existing mental health support could be asked about.

Due to the limited sample of intervention participants, it is recommended that future research continues to explore the acceptability of signposting to online peer support as an intervention, and of trial methods. This could be done through qualitative research, as well as continuing to seek participant feedback in a future RCT. Consideration should also be given as to whether to include online peer support options that are not associated to charities as signposting options, as long as these still have adequate moderation.

Conclusions

Overall, the results indicated that the trial methods and intervention were largely acceptable, although this was mostly based on data from a small sample of intervention participants, and the current trial methods were found to not be fully feasible. Therefore, further research and changes to trial methods are indicated. It may be helpful to further pilot amended trial methods before running a full-scale RCT. Further, qualitative research with parents of children with LTCs could build understanding of the acceptability of signposting to online peer support, including the potential benefits and harms, as well as shed light on any potential barriers to engaging in online trials.

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Part 3: Critical Appraisal

Introduction

This report will outline my reflections on the experience of conducting research into peer support, both in my empirical paper and my systematic review. First, I will reflect on personal and professional experiences that influenced my initial interest in this area of research. Second, I will discuss the wide scope of peer support and the limitations of this research. Next, I will consider the areas that the scope of my empirical paper did not cover, including positive experiences of parenting a child with a long-term condition (LTC), and the macro-level factors that impact parents. Following this, I will consider the involvement of experts by experience in the empirical project. Finally, I will reflect on my experience of the research process.

My Personal and Professional Experiences and the Research Topic

My initial interest in peer support began when I was working as a psychological wellbeing practitioner in an Improving Access to Psychological Therapies service, completing training to support people with LTCs. One component of this training involved finding out about local peer support groups that patients could be signposted to and visiting one of these. I was invited to sit in on a peer support group for adults with heart conditions at a local hospital. The group ran weekly and was attended by a diverse group of adults of all ages who shared experiences and knowledge with each other over tea and biscuits. I remember feeling struck by the sense of community there was in the group, seeing how people could discuss difficult topics and offer each other support, and I left with a new appreciation of the importance of having others with shared experiences to talk to. This gave me confidence when signposting patients to this group and others like it.

When the time came to choose a thesis topic, we were in the middle of a COVID-19 lockdown. Starting clinical training during this time and attending all of our lectures remotely had been particularly challenging. Never having met my cohort in person, I struggled with not having a sense of community and not being able to seek support from my peers on the course during what was an intense period. However, through the work I was doing on placement and speaking with friends, I was also very aware of the impact that the lockdown was having on other people in different situations to me, particularly people who had LTCs, or had children to care for. I heard stories of people feeling isolated, as well as anxious and low, and loneliness was being highlighted as a common issue during the lockdowns (Mental Health Foundation, 2020). Consequently, there were initiatives to try to tackle this; the National Health Service (NHS) created a website for how to cope with loneliness during coronavirus (https://www.nhs.uk/every-mind-matters/coronavirus/coping-with-loneliness-during-coronavirus/), and communities were coming together to finding alternative ways of connecting and supporting those in need. I also heard hopeful stories of individuals volunteering in befriending schemes to telephone people who lived alone or signing up to be 'volunteer responders' to support neighbours in need. These experiences sparked my interest in the concept of loneliness, and what kind of interventions could help to reduce it. Therefore, when the time came to choose a research topic, and I was made aware of a potential research idea investigating peer support groups and their impact on loneliness, it felt like an area of research that was both timely and fitted with my previous experiences and interests.

The Wide Scope of Peer Support and the Limitations of this Research

Having attended the aforementioned peer support group, my initial idea of peer support consisted of a group of people with shared experiences meeting together to discuss their experiences and to support each other. However, when planning my systematic review of peer support interventions for children and young people, I became aware of the vast range of interventions that can be classed as peer support (Dennis, 2003; Simoni et al., 2011). These included online peer support groups, formalised peer-led interventions and peer workers being employed in NHS services. I was pleased to learn about the multitude of ways peers could be valuable in supporting others and wanted to include this wide range in my review in order to understand the effectiveness of these interventions. However, in order to ensure the review was feasible, I made the decision to only focus on the impact of these interventions on mental health outcomes specifically. Although this was important for better understanding the clinical outcomes of peer support, I was aware that this meant that I may be missing out on other reported benefits of peer support for children and young people, such as reductions in isolation (von Doussa et al., 2022) and loneliness (Vanderkruik et al., 2020), which is what had first drawn me to wanting to research peer support. Further, the review focussed on peer support as a stand-alone intervention, or a component intervention that could be separately evaluated, in order to try to capture outcomes that could be attributable to the peer support. However, in reality, many peer support interventions are offered and evaluated in conjunction with other interventions, such as professional input (e.g. Chory et al., 2022), or parallel interventions for other family members (e.g. Fawzi et al., 2012; Abel et al., 2020). Further, much of this work happens in the community rather than in experimental research, meaning that their evaluations might be published in reports or articles (e.g. Day et al., 2020), rather than research papers, which were not within the scope of my review. Therefore, a more comprehensive review of peer support interventions for children and young people might consider a broader scope of outcomes and research sources, for which more time, and a larger research team would likely be necessary.

Additionally, although the context of COVID-19 was one of the factors that interested me in this research topic, it is also a context that brought challenges and limitations to the research. Given the COVID-19 lockdown restrictions, in-person peer support groups were not running, and at the time of the designing the study it was unknown how long COVID-19 restrictions would be in place for. Therefore, it was decided to focus solely on online peer support. This felt valuable to research given the context that we were in, however, during the timeframe of my research, covid restrictions were eased and many in-person peer support groups resumed. On reflection, this may have had consequences on the success of the research. Although some families were likely still needing to ‘shield’ and rely on online peer support, others may have been keen to return to in-person support, given the documented ‘zoom-fatigue’ (Wiederhold, 2020) that came from spending so much time online. It is possible that this was a factor that contributed to the recruitment and retention of participants, given that this was online research on a solely online intervention, at a time when people might have been wanting to spend less time online. It also impacted the ecological validity of the findings, as in real-life settings, families were now likely being signposted to peer support options that were both online and offline, meaning parents would be able to decide for themselves which better suited their needs. Now that COVID-19 restrictions are no longer in place in the UK, it may be beneficial for a future randomised controlled trial (RCT) to include signposting to both online and offline peer support options.

Positive Experiences of Caring for a Child with a Long-Term Condition

The scope of my empirical paper focussed on the challenges that can come with caring for a child with an LTC. Although this was necessary in order to understand whether online peer support can reduce negative experiences such as loneliness, anxiety, and depression, it did not leave room to consider the positive experiences of caring for children with an LTC. This is important as research has found that although there can be many challenges, there are also many reported joys. Ferguson’s (2002) literature review summarised numerous reported benefits for families associated with raising a child with LTCs, including family harmony, adaptability, spiritual growth, shared parenting roles, communication, and shared values. Further, Green et al.’s (2016) meta-analysis of qualitative research reported additional positive outcomes of parenting a child with LTCs of learning valuable skills, increased confidence, and feeling transformed into stronger and better people. As mentioned in the discussion of the empirical paper, further qualitative research could continue to explore the use and acceptability of online peer support for this population. This could enable a broader range of parents’ experiences to be heard and explore whether positive experiences of parenting children with LTCs are shared in peer support spaces, and the impact of this.

Macro-level Factors

Alongside my interest in peer support, through clinical training I have become aware of and interested in ideas from community psychology, in which a central idea is that people’s functioning, including distress, can be understood by their social contexts, from the micro-level to the macro-level (Orford, 2008). My research into peer support focussed on social factors to wellbeing at a micro-level, thinking about the individual parent and their relationships and interactions with peers. The impact of macro-level factors, such as current healthcare policies and the economic climate, were not a focus of this research. Despite this, the process of conducting this research increased my awareness of the impact of these macro-level factors on parents. Much of the previous research into the wellbeing of parents of children with LTCs that I read during the research process highlighted these macro-level factors. For example, Parish et al. (2008) reported that families with a child with a disability in the US experienced significantly more material hardship, and several studies highlighted the common experience of inadequate services and available support not meeting parents’ needs (Alaee et al., 2015; Burnes et al., 2008). Further, the impact of macro-level factors became more evident when I started recruitment for the empirical project and began to advertise the study. Although I received messages of support regarding the research, with many parents and organisations highlighting the value of peer support, I also received several emails from parents contacting me to share their experiences of the failings and harm caused by current health and social care services and policies where they lived. Further, when searching for online peer support options, I found that not all peer support options were free, with smaller charities often having to charge a fee for individuals to become a member and access their support. Although these were usually low-cost, they may still have been unaffordable to families with lower economic status, highlighting how economic inequality might impact wellbeing through the inability to access support options. This emphasised to me that although micro-level interventions such as peer support can be vital for parents and may contribute to improved wellbeing, parents may be turning to these supports because of the negative impact of macro-level factors on the wellbeing of them and their children. This is a theme that has been highlighted in qualitative research; that parents often report delays in diagnosis and a lack of information, support, and services, meaning they are forced to spend energy and time searching for the information and support that they need (Green et al., 2016). These experiences during the research process highlighted to me that as well as focussing on micro-level interventions, there needs to also be a focus on transformative change at a macro-level, such as policy change, adequate funding, and services being easier to access. I also wondered whether some of these reported impacts of macro-level factors could have been captured in the research if I had included a larger qualitative aspect to the study. For example, one participant suggested having more open comment boxes, or further data could have been gained from interviewing participants. Giving participants the opportunity to share the reasons why they use online peer support, or to consider what factors affect their experience of loneliness or their mental health, might have given them a space to highlight some of these macro-level factors.

Engagement with Experts by Experience

When I began this research, I was fairly new to independent research, and although I was aware of the importance of involving experts by experience in research, I was not aware of the different ways that this could be done. Adapted versions of Arnstein’s (1969) ladder of citizen participation are often used to describe the different levels to which experts by experience can be involved in research. Although I discussed the research with the Patient and Public Involvement forum at Great Ormond Street Hospital, this was done at a ‘consultation’ level; where we invited experts by experience’s opinions and views on the research idea and proposed design, which then informed how the study was further designed and implemented. The consultation provided valuable insight into how I might design and conduct the study, as well as reassuring me that there was support for the research topic. However, higher levels of participation, where research is co-produced through partnership and shared power and decision making (Arnstein, 1969) may have enhanced the research and research process**.** Co-production in research is a collaborative approach which involves putting into practice principles of empowerment (Durose et al. 2012) and sharing power when developing, implementing, interpreting, and disseminating research (Redman et al., 2021). It gives communities more control over the research process, offers opportunities to reflect and learn from their experiences, and is viewed as a way of making research more relevant and impactful (Durose et al., 2012). Co-production has become widely recognised as a valuable approach, and it is a requirement in statutory guidance for NHS trusts and integrated care boards (NHS England, 2022). My limited knowledge and the time scale, pressures and budget of doing a doctoral thesis meant that the research was not co-produced, which is a limitation. In hindsight, this research could have been co-produced by involving experts by experience earlier in the research process, thinking together about the research questions and aims, and co-producing later stages of the research by having an expert by experience as part of the research team. In future, I hope to conduct research which is co-produced with experts by experience.

Reflections on the Research Process

At the time of designing the research project, I was more confident in quantitative research methods, having only conducted quantitative research previously. RCTs were familiar to me, and I was excited at the prospect of running one as a thesis project. However, I was unaware of some of the challenges that would come with this. A particular challenge was the difficulty in recruiting the large sample that would have been needed to power the study. When recruitment first began, it was hoped that the study would be a full-scale RCT. However, recruitment was much slower than anticipated, with only nine participants signing up to the study in the first month, despite great effort to advertise the study. The initial hope was to recruit 180 participants over a six-month period, in the hope that we would retain at least 90 participants. It became clear that this was not likely with the current recruitment method, therefore other options were considered, including amending my ethical approval to allow me to contact schools and nurseries to advertise the study. However, this did not speed up recruitment as much as was necessary, and it was clear that a full-scale RCT would not be feasible within the time constraints of a doctoral thesis. Consequently, the decision was made to instead conduct a pilot trial, focussing on acceptability and feasibility of the study and intervention. Although I felt some disappointment that the RCT would not be possible, I was relieved that meaningful research could still come out of all of the work that had been put in so far. I was much less familiar with what a pilot study was and spent time familiarising myself by reading Eldridge et al.'s (2016) definition of feasibility and pilot studies and the CONSORT 2010 statement extension for randomised pilot and feasibility trials (Eldridge et al., 2016) and using these to guide the next stages of the study, including analysis and write up. However, as recruitment had already started, it was not possible to make major changes to the design of the study. In hindsight, if the trial had been planned as a pilot study from the start, there are some things I might have done differently. For example, as mentioned above, having a larger qualitative aspect to the study might have allowed for greater understanding of the acceptability of the trial and intervention. Additionally, it would have been helpful to ask more demographic questions, such as parents' ethnicity or race and an indicator of socio-economic status, in order to understand who might not be represented in the sample through the current recruitment procedures. Further, I would have made changes to how I asked about negative experiences of online peer support. This question was initially planned to be analysed quantitatively, by reporting the number of participants that had been exposed to negative effects of online peer support before and after the trial. When the focus of the trial changed to acceptability and feasibility, it was realised that this could provide valuable data about the acceptability of the intervention. However, as mentioned in the empirical paper, the way that the question was phrased meant that it was not possible to differentiate which negative experiences were attributable to the intervention itself. Further, there was a heavier weighting towards negative experiences than positive experiences, as the question about negative experiences was asked to all participants at both time points, whereas the question about positive experiences was a part of the adapted-ESQ (Attride-Stirling, 2003) and therefore only asked to intervention participants post-intervention. Having clearer questions about positive and negative experiences at both time points may have allowed for richer analysis.

Evaluating these questions as an indicator of acceptability of the intervention required me to use qualitative research methods. Although these were unfamiliar to me when I was initially designing the research, since then I had completed a thematic analysis as part of my work in a placement and had come to value the richness that can come from enabling individuals to share their meanings and experiences. Although the qualitative aspect to this study was limited, it provided me with a richer understanding of parent's experiences of using online peer support. A future RCT could continue to use mixed methods, to enable participant's voices and experiences to be heard.

Concluding remarks

Conducting this research has been a valuable learning experience for me, which it has been helpful for me to reflect on. The experience has also helped me to grow professionally; giving me confidence and appreciation in new research methods, as well as reminding me to consider macro-level factors, as well as micro-level factors, on people's wellbeing. I hope that these experiences will help me to continue to grow both in my clinical practice and future research.

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Appendix A

List of Search Terms Used on PsycINFO and MEDLINE

Search Terms for PsycINFO

1) Peer support terms	**Subject headings:** peer tutoring/ or peer counseling/ **Key words:** ((mutual support group or user group or support group) or peer adj2 (support? or group? or intervention?) or (peer adj2 (volunteer? or worker? counsel* or expert? or advisor? or consultant? or leader? or educator? or tutor? or instructor? or facilitator? or therap* or aide? or staff or helper? Or mentor*)) or (lay led or lay run) or lay person? Or expert patient? Or expert by experience or user led or peer led or peer to peer or non professional).ab,ti.
2) Mental health terms	**Subject headings:** mental disorders/ or affective disorders/ or anxiety disorders/ or autism spectrum disorders/ or bipolar disorder/ or borderline states/ or chronic mental illness/ or dissociative disorders/ or eating disorders/ or gender dysphoria/ or mental disorders due to general medical conditions/ or neurocognitive disorders/ or neurodevelopmental disorders/ or neurosis/ or personality disorders/ or psychosis/ or serious mental illness/ or sleep wake disorders/ or somatoform disorders/ or "stress and trauma related disorders"/ or "substance related and addictive disorders"/ or thought disturbances/ or attention deficit disorder/ or attention deficit disorder with hyperactivity/ or behavior disorders/ or chronic illness/ or communication disorders/ or emotional adjustment/ or emotional disturbances/ or homeless mentally ill/ or intellectual development disorder/ or learning disorders/ or perceptual disturbances/ or physical disorders/ or psychiatric patients/ or psychiatric symptoms/ or psychopathology/ or "recovery (disorders)"/ or

	"relapse (disorders)"/ or "remission (disorders)"/ or special needs/ or suicide/ or treatment resistant disorders/ or mental health/ **Key words:** (mental disorder? or mental health or psychiat* disorder? or anxiety or anxious or affective disorder? or depress* or autis* or ASD* or bipolar or borderline or mental illness or dissociat* or eating disorder? or gender dysphoria or neurocognitive disorder? or neurodevelopmental disorder? or neuroses' or personality disorder? or psychos?s or sleep disorder? or somatoform disorder? or somatic symptom disorder? or psychosomatic disorder? or stress or traum* or PTSD or substance abuse or addict* or thought disturbance* or attention deficit disorder or ADHD or behavio?r disorder? or chronic illness* or long term condition? or disabilit* or communication disorder? or emotional adjustment? or emotional disturbance? or homeless* or intellectual development disorder* or intellectual disabilit* or learning disabilit* or perceptual disturbance? or physical disorder? or psychiatr* patient? or psychiatr* symptom? Or psychopathology or recovery or remission or special need? or suicid* or self harm or treatment resistant).ab,ti
3) Children and young people terms	**Key words:** (Child* or Teen* or Youth* or Adolescen* or Boy? or Girl? or Student* or (Young adj2 Person*) or (Young adj2 People*) or (Young adj2 survivor*) or (Young adj2 Adult*)).ab,ti
4	1 and 2 and 3
5	limit 4 to (peer reviewed journal and yr="2011 -Current")

Search Terms for MEDLINE

1) Peer support terms	**Key words:** (mutual support group or user group or support group or lay led or lay run or lay person? Or expert patient? Or expert by experience or user led or peer led or peer to peer or non professional or (peer adj2 (support? Or group? Or intervention? Or volunteer? Or worker? Counsel* or expert? Or advisor? Or consultant? Or leader? Or educator? Or tutor? Or instructor? Or facilitator? Or therap* or aide? Or staff or helper? Or mentor*))).ab,ti.
2) Mental health terms	**Subject headings:** mental disorders/ or anxiety disorders/ or “bipolar and related disorders”/ or “disruptive, impulse control, and conduct disorders”/ or dissociative disorders/ or “feeding and eating disorders”/ or mood disorders/ or motor disorders/ or neurocognitive disorders/ or neurodevelopmental disorders/ or neurotic disorders/ or personality disorders/ or “schizophrenia spectrum and other psychotic disorders”/or sleep wake disorders/ or somatoform disorders/ or substance-related disorders/ or “trauma and stressor related disorders”/ or mental health/ **Key words:** (mental disorder? or mental health or psychiat* disorder? or anxiety or anxious or affective disorder? or depress* or autis* or ASD* or bipolar or borderline or mental illness or dissociat* or eating disorder? or gender dysphoria or neurocognitive disorder? or neurodevelopmental disorder? or neuros?s or personality disorder? or psychos?s or sleep disorder? or somatoform disorder? or somatic symptom disorder? or psychosomatic disorder? or stress or traum* or PTSD or substance abuse or addict* or thought disturbance* or attention deficit disorder or ADHD or behavio?r disorder? or chronic illness* or long term condition? or disabilit* or communication disorder? or emotional adjustment? or

	emotional disturbance? or homeless* or intellectual development disorder* or intellectual disabilit* or learning disabilit* or perceptual disturbance? or physical disorder? or psychiatr* patient? or psychiatr* symptom? Or psychopathology or recovery or remission or special need? or suicid* or self harm or treatment resistant).ab,ti
3) Children and young people terms	**Subject headings:** adolescent/ or child/ young adult **Key words:** (Child* or Teen* or Youth* or Adolescen* or Boy? Or Girl? Or Student* or (Young adj2 Person*) or (Young adj2 People*) or (Young adj2 survivor*) or (Young adj2 Adult*)).ab,ti
4	1 and 2 and 3
5	limit 4 to (yr=”2011 -Current”)

Appendix B

Further Details of Peer Support Interventions

Study	Intervention	Intervention Described	Length	Frequency
Ciao et al. (2015)	A peer-led dissonance-based group intervention (DBI) for eating disorder prevention	Three to four peer-facilitators led sessions in classes with six to 12 peer-recipients. The content of sessions was detailed in Becker et al.'s (2006) study evaluating the same intervention in a university, as below. A further section on cultural and ethnic beauty ideas was included due to the diversity of students in the high school where the study took place. Session one included: - analysing the 'thin-ideal' - watching a video about digital enhancement in the media - looking at 'before and after' images that have been professionally edited - listing the negatives of pursuing the 'thin-ideal' - group discussion about the costs and the attainability of the 'thin-ideal' - homework: looking at themselves in the mirror and observing positive physical, emotional and mental attributes about themselves Session two included: - sharing their positive attributions from the homework tasks - role play exercise: facilitators role played various identities pursuing the thin ideal, peer-recipients tried to persuade the facilitators to stop this pursuit - counter arguments to pursuing the 'thin-deal' were discussed and practised - peer-recipients created a list of top ten strategies to counter the 'thin-ideal' - homework: to complete a self-affirmation exercise	1 hour	Two sessions, two days apart
Eickman et al. (2018)	A peer-led dissonance-based intervention for eating disorder prevention 'RebeL'	Peer-facilitators were guided by their teachers when selecting the activities and discussion from the modules, to pick topics based on the needs of the school. Instructions were given to schools to cover at least six modules over the year: 1) 'Body Image': Students were supported to evaluate their beliefs about their body image and learn ways of promoting body positivity. Example activities included: Discussing what the body is capable of vs. its form in order to show gratitude to their bodies, and discussing the consequences of negative body talk. 2) 'Eating Disorders': Students discussed the signs and symptoms of eating disorders, and how to support a peer to get professional help. Example activities included: Discussing myths and stereotypes about people with eating disorders and creating a "public service announcement" to share with peers. 3) 'Mindful Eating and Exercise': The consequences of dieting were considered, and the principles of mindful exercise and eating were taught. Example activities included: Discussing the efficacy and negative effects of dieting and encouraging listening to the body for cues about hunger and satiety. 4) 'Self-Worth and Self Esteem': Students were supported in identifying strengths about themselves and others. Example activities included: writing and sharing characteristics that they loved about themselves, and giving compliments on cards to their family members and peers 5) 'Weight Bias, Bullying, and Appreciation of Others': Students were provided with education about bullying and weight	0.5-1 hour	Weekly meetings for 8 months, plus activities for the whole school or in the community

		bias and activities focused on developing respect for other people. Example activities included: discussing ways that the school environment could be more inclusive and putting positive messages about inclusion around the school and community. 6) ‘Media Messages and Media Literacy’: This session focused on media literacy. Example activities included: Education on different types of media, levels of exposure to the media, and the impact of this, and encouraging ‘positive posts’. Additional Modules were also provided for the school to cover based on the needs of students.		
Eisenstein et al. (2019)	A peer-led intervention supporting students to develop knowledge and skills to safeguard the mental health of themselves and their peers 'Peer Education Project (PEP)’	Mental Health Foundation (2017) developed PEP in co-production with students in year seven and year 12, the target year groups. The five sessions followed a syllabus of session topics: ‘Mental Health Awareness, Myths, Facts and Stigma’, ‘Staying Well, Getting Help’, and ‘Helping Others’. In pairs, the peer facilitators delivered the sessions. They were instructed to use a guide which outlined the session content, guidance on how to deliver the content, and session plans. The Year seven students received workbooks with worksheets that supported the session plans and that included information about mental health.	40 minutes	Five sessions
Haft et al. (2019)	Group peer mentoring	The group of mentors met with the group of mentee and used art activities with social-emotional learning objectives to discuss challenges and strengths associated with having a learning disability or ADHD, and to develop relationships. Example art projects were: - to make a box of their ‘ideal learning environment’, in order to explore the contexts in which they learn best or can become distracted - a ‘superhero project’, in order to support with identification and celebration of their strengths - a ‘utility belt project’, in order to recognise and encourage accommodations - a ‘parachute project’ in order to support a growth mindset and encourage positive ideas of themselves	Not reported	Once a week for 18 weeks
Jennings and Jennings (2013)	A peer-led group mindfulness intervention	A series of mindfulness group sessions were led by a peer-facilitator. Each session covered two experiential exercise which were chosen from a mindfulness training manual: 1) A breathing exercise and a guided meditation designed to allow peer recipients to practice staying focused and keeping calm and relaxed despite changes that can occur. 2) A breathing exercise and exercise where peer-recipients selected an object to focus on. This session was held outside. 3) A breathing exercise and a guided ‘safe place’ meditation. 3) Two guided meditation exercises, the first with the goal of focussing on the present and trusting a team in order to reach a goal, and the second focussing on ‘accepting’ a disruption.	50 minutes	Four sessions within a three-week period
Lewis et al. (2016)	A peer support group ‘Chronic Illness Peer Support (ChiPS)’	Groups were co-facilitated by a peer and a nurse. The groups were guided by a ChIPS Program Manual (Olsson et al. 1998, as cited in Lewis et al. 2016). The groups included: an ice-breaker activity relevant to the week’s topic, a discussion of a topic relevant to their lives, and a closing game that provided a fun way to end the session without any overt relevance to the topic of the weekly discussion. The discussion topics were:[a]	2 hours	Once a week for eight weeks

		Week 1: 'Getting to know you' – sports/hobbies/etc. Week 2: 'Frenemies' – friends and bullying Week 3: 'Back to school (& work)' Week 4: 'L.I.F.E style' – the impact of chronic illness on a young person's life (including the prospect of death) Week 5: 'It's not easy being teen' – challenges that all young people experience to some degree Week 6: 'Family ties' – the impact of chronic illness on the young person's parents, siblings, and extended family Week 7: 'Me, myself, and I' – developing a positive self-image Week 8: 'Review of the previous seven weeks'		
Mulfinger et al. (2018)	A peer-led group intervention supporting participants with mental illness disclosure decisions, in order to reduce the impact of stigma 'Honest, Open, Proud (HOP)'	For this study the HOP intervention was adapted from Corrigan & Lundin's (2001) 'Coming Out Proud' intervention. A young mental health professional and young adult peer co-facilitated the intervention. The aim was for the intervention to empower people to make their own decision about disclosing mental illness (MI). The intervention covered five themes and the themes were discussed using vignettes and first-person stories, role plays and worksheets. 1) 'Beliefs': peer-recipients read stories of other adolescents in workbooks and discussed attitudes to having MI and ways to challenge self-stigma 2) 'Pros and Cons of Disclosure': The short and long-term benefits and risks of disclosing or not, different levels of disclosure, and disclosing on social media were discussed 3) 'The right person': This session focused on choosing the right person to disclose to, as well as anticipating other's responses 4) 'Telling one's story': Peer-recipients read other's accounts and practised how they might tell their own story if they decided to disclose, and discussed how to find supportive peers 5) 'The role of solidarity and peer support': The session focussed on summarising what lessons had been learnt during the intervention, and what next steps could be taken.	2 hours	Once a week for three weeks
Noël et al. (2014)	A peer-led group intervention for depression prevention based on positive youth development and cognitive behavioural principles 'Talk and Time'	Sessions included interactive classroom activities, outdoor activities and small group discussion. Handouts were given at the end of sessions with key learning points and homework tasks related to the content of the session. Each session had three parts: - 'What': the group discussed an event and their related feelings and behaviours - 'So What': the group discussed the purpose of the event and opportunities for learning - 'Now What': skills that could be applied The main components of the intervention included: 1) Identifying negative thought patterns and challenging these 2) Understanding moods and how to control them 3) Identifying and participating in new positive behaviours 4) Understanding how to respond to peer pressure 5) Exploring the impact of media images of women 6) Networking and developing social skills 7) Problem- solving	1.5 hours	Once a week for 12 weeks

		8) Psycho-education about thoughts, feelings and behaviours		
Vanderkruik et al. (2020a)	A peer-led dissonance-based intervention for preventing eating disorders ‘The Body Project’	Sessions were delivered by two peer facilitators to groups of 8-10 peer recipients. The sessions were based on the original version of HOP (Stice et al., 2001) and included a series of verbal, behavioural, and written exercises which gave opportunities to evaluate the ‘thin-ideal’ The four sessions included: 1) Discussion led by the peer-recipients on the origin of the ‘thin-ideal’ and how it perpetuates and impacts people, and how corporations profit from the ‘thin-ideal’. An example homework task was writing to a fictional younger girl about the potential negative consequences of pursuing the ‘thin ideal’. 2) Discussion and reflection on the homework tasks, a role play where peer-recipients persuaded facilitators not to pursue the thin ideal. An example homework task was to come up with verbal challenges to pressures to be thin in their lives. 3) Discussion and reflection on the homework tasks, peer-recipients then came up with ‘quick comebacks’ to statements their peers might say about the thin-ideal. An example homework task was to do one idea to resist the ‘thin-ideal’. 4) Discussion and reflection on the homework tasks and how they could keep challenging themselves, discussion about the subtle ways the ‘thin-ideal’ can be perpetuated and how to manage challenges that might come with resisting the pressure to conform, as well as how to use positive body-talk. An example homework task was to do another self-affirmation exercise.	1 hour	Once a week for four weeks
Vanderkruik et al. (2020b)	A peer-led dissonance-based intervention for preventing eating disorders ‘The Body Project’	As above	1 hour	Once a week for four weeks
Warner and Budd (2018)	1:1 peer coaching	Every student took part in five sessions as the coachee and five sessions as the coach. The intervention was based on IGROW model (Whitmore, 2010) and sessions followed the following structure: - The coachee stated what issue they wanted to explore - The coachee identified a goal related to the issue - The reality of the issue was explored - Different options of how to take action were explored - Steps and actions to take were identified - The coachee made a ‘coaching promise’ where they made a commitment about what action they would talk before the next session	20 minutes	Once a week for 10 weeks

[a] Information gathered from research paper author

Appendix C

CONSORT 2010 Checklist of Information to Include When Reporting a Pilot or Feasibility Trial (Eldridge et al., 2016)

Section/Topic	Item No	Checklist item	Reported on page no.
Title and abstract			
	1a	Identification as a pilot or feasibility randomised trial in the title	69
	1b	Structured summary of pilot trial design, methods, results, and conclusions	70
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial	71-77
	2b	Specific objectives or research questions for pilot trial	78
Methods			
Trial design	3a	Description of pilot trial design (such as parallel, factorial) including allocation ratio	78
	3b	Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons	81
Participants	4a	Eligibility criteria for participants	78
	4b	Settings and locations where the data were collected	80-81
	4c	How participants were identified and consented	78, 80
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	80
Outcomes	6a	Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed	80-86
	6b	Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons	
	6c	If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial	
Sample size	7a	Rationale for numbers in the pilot trial	79
	7b	When applicable, explanation of any interim analyses and stopping guidelines	
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	80
	8b	Type of randomisation(s); details of any restriction (such as blocking and block size)	

Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	80
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	
	11b	If relevant, description of the similarity of interventions	
Statistical methods	12	Methods used to address each pilot trial objective whether qualitative or quantitative	86-88
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective	91
	13b	For each group, losses and exclusions after randomisation, together with reasons	91
Recruitment	14a	Dates defining the periods of recruitment and follow-up	89
	14b	Why the pilot trial ended or was stopped	89
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	95
Numbers analysed	16	For each objective, number of participants (denominator) included in each analysis. If relevant, these numbers should be by randomised group	89-106
Outcomes and estimation	17	For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates. If relevant, these results should be by randomised group	103-106
Ancillary analyses	18	Results of any other analyses performed that could be used to inform the future definitive trial	
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	101-105
	19a	If relevant, other important unintended consequences	
Discussion			
Limitations	20	Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility	112-114
Generalisability	21	Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies	107, 112

Interpretation	22	Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence	107-112
	22a	Implications for progression from pilot to future definitive trial, including any proposed amendments	114-116
Other information			
Registration	23	Registration number for pilot trial and name of trial registry	RCT registration - 78
Protocol	24	Where the pilot trial protocol can be accessed, if available	
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	
	26	Ethical approval or approval by research review committee, confirmed with reference number	88

Appendix D

Participant Invitation Sheet

PARTICIPANT INVITATION SHEET

UCL Research Ethics Committee Approval ID Number 22125/001

Is signposting to peer support helpful in decreasing loneliness in parents of children with long-term conditions and disabilities?

UCL Division of Psychology and Language Sciences

Researchers: Katrina Walsh (katrina.walsh.17@ucl.ac.uk), Dr Sophie Bennett (sophie.bennett.10@ucl.ac.uk), Dr Marc Tibber (m.tibber@ucl.ac.uk)

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully

Who am I?

I am a postgraduate student in the Department of Psychology at the University College London and am studying for a Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

What is the purpose of the research?

I am conducting research about the usefulness of online peer support groups and forums for parents of children with long-term conditions or disabilities. We are particularly interested in the potential impact of such groups on people’s experiences of loneliness and social capital, i.e. the building and benefits of relationships.

Why have I been chosen?

I am hoping to recruit parents of children with long-term conditions or disabilities. I am looking to involve parents who are 18 years of age or over, and are sufficiently fluent in English to be able to engage in online peer support groups and forums. Participation in the study is entirely voluntary and you can withdraw at any time without providing a reason for doing so or any negative consequences.

What will happen if I take part?

All participants will first be asked to complete a survey online. You will be first be asked for your email address. You will then be asked your age, gender, the number of children you have, their age, the conditions or disabilities of your children, and the area in which you live. You do not have to provide all the demographics if you do not wish to. You will be asked to complete three short questionnaires about loneliness, social capital, and your mental health. You will also be asked about your current use of social media and online peer support groups and forums. We estimate the survey will take up to 20 minutes.

You will then be randomly allocated to either the ‘intervention’ or the ‘waitlist’ group. If you are in the intervention group, you will be sent information about relevant online peer support groups and forums and asked to keep a weekly log of how much you engage with them. We estimate the log will take less than 5 minutes per week to complete.

You will be contacted again in 3 months, at which point you will be asked to complete the online questionnaires again. If you are in the waitlist group, you will then be signposted to relevant online peer support groups and forums and asked to keep an engagement log.

All participants will be contacted again at 6 months to complete the online questionnaires again for a third time. You may be contacted again 6 months after this to complete the online questionnaires again as a follow-up. You can complete the questions on any device (laptop, phone etc.).

Do I have to take part?

It is up to you to decide whether or not to take part. You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. You are free to withdraw from the research study at any time without explanation, disadvantage or consequence.

You may also request to withdraw your data, provided this request is make within 2 weeks of when you have completed the questionnaires for the second time at the 3-month time point. After this the data analysis will begin and withdrawal of your data will therefore not be possible.

Are there any disadvantages or risks to taking part?

The questionnaires you will be asked to complete do ask questions about emotive topics such as your experiences of loneliness and your mental health. The questions you will be asked are not designed to cause distress.

The online peer support groups and forums you might be signposted to have been collated in discussion with a Patient and Public involvement group at Great Ormond Street Hospital and are associated with national charities. It is up to you how much you engage with the peer support groups and forums.

If you experience any distress from taking part in the study, you are free to stop at any point without providing a reason for doing so. Support organisations will be provided in the debrief form at the end of the survey. These organisations are also provided at the end of this participant information sheet. You may wish to save these now in the event that you withdraw from the survey before the end. Additionally, all members of the research team are qualified Clinical Psychologists and Clinical Psychologists in training.

If you have any concerns or complaints during the study, you can contact my supervisors Dr Sophie Bennett on sophie.bennett.10@ucl.ac.uk, or Dr Marc Tibber on m.tibber@ucl.ac.uk. Should you feel your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk

What are the possible benefits of taking part?

All participants will have received signposting to relevant online peer support groups and forums by 3 months into the study.

We hope that your data will provide valuable information into the usefulness of online peer support groups.

All participants that sign up to the study will be entered into a prize draw to win one of 10 prizes of a choice of a £20 Amazon voucher or a £20 donation to a charity.

Will my taking part in this project be kept confidential?

All the information that we collect during the course of the research will be kept strictly confidential. Your email address will only be used to contact you to ask you to complete the questionnaires at the stated times (3 months, 6 months and possibly 12-month follow up), and to remind you to keep the engagement log. Your email address and unique ID will kept on a password-protected file on a secure UCL database. All other data you provide, including the answers to the questionnaires will be kept on a separate password-protected file, only linked to your unique ID code, meaning this data will be pseudonymised. The data will be analysed at group level; therefore your individual responses will not be identifiable. The data file containing your email address and unique ID will be deleted after the last data collection point. Only the research team will have access to any identifiable or pseudonymised data. Once analysed, data will be used for the write-up of the research and disseminated as appropriate. You will not be identified in any ensuing reports or publications. Anonymised data will be stored indefinitely on a secure UCL database and may be used for future research, it will not be identifiable to you in any way.

What will happen to the results of the research?

The findings will be disseminated as appropriate to a range of audiences (e.g. academics, clinicians, the public), through journal articles, presentations, talks and other relevant articles, as appropriate. You will not be identified in any ensuing reports or publications.

Privacy Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice: https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies

The categories of personal data used will be as follows:

Email Address
The area in which you live
The number of children you have, their age, and your child(ren)'s condition or disability
Measures regarding your experiences of loneliness
Measures regarding your social capital
Measures regarding your mental health

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Who is organising and funding the research?

UCL

Who can I contact if I have questions about the study?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me: katrina.walsh.17@ucl.ac.uk (Katrina Walsh).

You can also contact my supervisors:

Dr Sophie Bennett Email: sophie.bennett.10@ucl.ac.uk
Dr Marc Tibber. Email: m.tibber@ucl.ac.uk

If you or your child feel you are in crisis, please call 999 or attend your local A&E.

If you live in England, you can call a local NHS urgent mental health helpline for support during a mental health crisis. Anyone can call these helplines, at any time. The NHS website has more information on urgent mental health helplines, including how to find your local helpline: https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline'

Otherwise, other forms of support include:

- You can find your local NHS Psychological Therapy Service (IAPT) here: https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/
- The Samaritans: 116 123. A free 24/7 helpline for anybody experiencing distress.
- If you're experiencing a mental health problem or supporting someone else, you can call SANEline on 07984967708, leave a message, and a volunteer will call you back, You can also email: support@sane.org.uk
- You can call Campaign Against Living Miserably (CALM) on 0800 58 58 58 (5pm–midnight every day) if you are struggling and need to talk. Or if you prefer not to speak on the phone, you could try the CALM webchat service.
- If you're under 35 and struggling with suicidal feelings or concerned about a young person who might be struggling, you can call Papyrus HOPELINEUK on 0800 068 4141 (weekdays 10am-10pm, weekends 2pm-10pm and bank holidays 2pm–10pm), email pat@papyrus-uk.org or text 07786 209 697.
- If you identify as gay, lesbian, bisexual or transgender, you can call Switchboard on 0300 330 0630 (10am–10pm every day), email chris@switchboard.lgbt or use their webchat service. Phone operators all identify as LGBT+
- Your General Practitioner (GP) can signpost you to additional services if you experience emotional distress.

Thank you for reading this information sheet and for considering taking part in this research study. If you decide to take part, please save this information sheet for your records.

Appendix E

Consent Form

Please complete this form after you have read the Information Sheet.

Title of Study: Is signposting to peer support helpful in decreasing loneliness in parents of children with long-term conditions and disabilities?

Department: UCL Division of Psychology and Language Sciences
Name and Contact Details of the Researcher(s): Katrina Walsh (katrina.walsh.17@ucl.ac.uk), Dr Marc Tibber (m.tibber@ucl.ac.uk)
Name and Contact Details of the Principal Researcher: Dr Sophie Bennett (sophie.bennett.10@ucl.ac.uk)
Name and Contact Details of the UCL Data Protection Officer: Alexandra Potts (data-protection@ucl.ac.uk)
This study has been approved by the UCL Research Ethics Committee: Project ID number: 22125/001

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet you have seen, please ask the researcher before you decide whether to join in. Please save a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without it impacting any benefits I am entitled to.	
3.	I understand that I will be able to withdraw my data up to 2 weeks after when I have completed the questionnaires for the second time at the 3-month time point	
4.	I consent to participate in the study. I understand that my personal information including my age, gender, information about the condition or disability of my child(ren), and measures regarding loneliness, social capital and mental health will be used for the purposes explained to me. I understand that according to data protection legislation, ‘public task’ will be the lawful basis for processing, and ‘research purposes’ will be the lawful basis for processing special category data.	

5.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I understand that my email address and unique ID will be kept on a password-protected file on a secure UCL database and all other data I provide will be stored pseudonymously and securely on a separate password-protected file. It will not be possible to identify me in any publications.	
6.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the possible benefits of participating.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I agree that my anonymised research data may be used by others for future research. No one will be able to identify you if these data are shared.	
11.	I understand that the information I have submitted will be published as a report and the findings will be disseminated as appropriate to a range of audiences (e.g. academics, clinicians, the public), through journal articles, presentations, talks and other relevant articles, as appropriate	
12.	I hereby confirm that I am a parent of a child with a long-term condition, illness or disability.	
13.	I hereby confirm that I am 18 years of age or over.	
14.	I hereby confirm that I am sufficiently fluent in English to be able to engage with online peer support.	
15.	I am aware of who I should contact if I wish to lodge a complaint.	
16.	I voluntarily agree to take part in this study.	
17.	I would be happy for the data I provide to be archived at UCL Research Data Repository I understand that other authenticated researchers will have access to my anonymised data.	
18.	I consent to being contacted by the research team for future studies related to this research	

Appendix F

Online Peer Support Engagement Log

Week number	**Did you use an online peer support group/forum and if so, which?**	**Approximately how much time over the week did you spend using the peer support group/forum?** **a) less than 10 minutes** **b) 10 to 30 minutes** **c) 30 minutes to an hour** **d) more than an hour**	**Did you actively participate in the group/forums by posting or speaking (Yes/No)**
Example: *Week commencing 04.07.22*	*Yes – Diabetes UK parent forum*	*C*	*Yes*
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			

Appendix G

Online Peer Support Options Signposted To

- ADHD embrace's closed Facebook group forum for parents and carers of young people with ADHD and all its comorbidities
- Carers UK's forum, an online community to talk to other carers
- Children's Heart Association's closed Facebook group for families of children with heart disorders
- CLAPA closed Facebook support group for parents and carers of children with a cleft lip and/or palate
- Contact's closed Facebook group for parents or carers of children with any health condition, disability, or form of additional need
- Diabetes UK's parent support forum, an area for parents of children with diabetes to discuss, help and advise each other
- Down's Syndrome Association's closed Facebook groups for parents and carers of children, young people and adults who have Down's syndrome
- Ehlers-Danlos Support UK's local online support groups and closed local Facebook groups for families and friends of, and people with Ehlers-Danlos syndrome
- Epilepsy Action's local virtual support groups for parents and carers of children with epilepsy
- Heartline's closed Facebook group for parents of children with heart disorders
- HME - The New Generation's closed Facebook group for people affected by Hereditary Multiple Exostoses
- Look UK's online parent support groups for parents of visually impaired children
- Mencap's online HealthUnlocked community for parents, siblings, or friends of a person with a learning disability
- National Autistic Society's community forum and local closed Facebook groups for autistic people and their families
- Parenting Mental Health's closed Facebook group for parents of children with mental health difficulties
- Positive About Down's closed Facebook groups for parents and carers of children who have Down syndrome
- Royal National Institute of Blind People's closed Facebook groups for parents and carers of children and young people affected by sight loss
- Scope's online community forum for parents and carers of people with disabilities, health conditions and developmental disorders
- Shine's virtual support groups, peer support networks and closed zoom sessions for parents and carers of people with Spina Bifida and/or Hydrocephalus, Spina Bifida Occulta, Normal Pressure Hydrocephalus, Idiopathic Intracranial Hypertension, or Encephalocele

- Somerville Heart Foundation’s closed Facebook group for families of people born with Congenital Heart Disease
- STARS’ HealthUnlocked forum for individuals and their families coping with blackouts, unexplained losses of consciousness, and syncope. Including syncope disorders, reflex anoxic seizures, and postural tachycardia syndrome
- Steps’ closed Facebook group for families and individuals who are affected by lower limb conditions such as clubfoot and hip dysplasia, perthes, fibular hemimelia, tibial hemimelia, congenital vertical talus, metatarsus adductus and other lower limb deficiencies
- SWAN UK’s online forums and virtual coffee mornings for families with children with undiagnosed genetic conditions
- Tiny Tickers’ virtual support groups for parents and parents-to-be of babies with congenital heart disease
- Twins Trust’s closed Facebook groups for parents of twins with additional support needs
- Unique’s closed local Facebook groups and ‘Chromosome network’ cafés for families affected by rare chromosome and gene disorders
- Young Epilepsy’s online forum for young people with epilepsy and their parents

Appendix H

Example Email Sent to Participants with Signposting Information

Subject: Online Peer Support research

Hello,

Thank you so much for taking the time to participate in this research looking at the usefulness of online peer support.

Please see below some online peer support options. It is up to you how much you engage with these.

Please also see attached your engagement log, we ask that you try to record your engagement with any online peer support groups or forums each week. We estimate that the log will take less than 5 minutes per week to complete. If you miss a week or two, feel free to fill it out retrospectively as best as you can remember.

In 3 months, I will contact you again to repeat the questionnaires again, and to return the engagement log. If you would prefer to complete these questionnaires over the phone, please send me your phone number and we can arrange a time to do so, alternatively we can arrange a Teams or Zoom call.

With best wishes,
Katrina Walsh
Trainee Clinical Psychologist
University College London (UCL)

Online Peer Support Options

- **Unique** provides support to families affected by rare chromosome and gene disorders. It has private local Facebook groups and a ‘Chromosome network café’. To access this, you can become a member for free: https://rarechromo.org/join-us/

- **Scope** has an online community forum, for parents and carers of people with disabilities, health conditions and developmental disorders: https://forum.scope.org.uk/categories/carers-of-disabled-children-and-adults?_ga=2.45730340.1025353656.1639756005-2073081146.1639756005

- **Contact** has a closed Facebook group for parents or carers of children with any health condition, disability, or form of additional need: https://www.facebook.com/groups/ContactFamiliesGroup

Appendix I

Adapted Experience of Service Questionnaire for parents/carers (Attride-Stirling, 2003)

Closed questions, with response options of ‘Certainly True’, ‘Partly True’, ‘Not True’ and ‘Don’t know’:

1. I feel that the people who I spoke to in the online peer support groups/forums listened to me
2. It was easy to talk to the people in the online peer support groups/forums
3. I was treated well by the people in the online peer support groups/forums
4. My views and worries were taken seriously in the online peer support groups/forums
5. I have been given enough information about the online peer support groups/forums
6. I feel that the people in the online peer support groups/forums were able to support me with problems
7. The online peer support groups/forums were easy to use
8. If a friend needed similar support, I would recommend the online peer support

Open ended questions:

1. What was good about the online peer support?
2. Was there anything you didn’t like or anything that needs improving about the online peer support?
3. Was there anything you didn’t like or anything that needs improving about the study?
4. Is there anything else you want to tell us about the online peer support or this study

Appendix J

Confirmation of Ethical Approval from UCL Research Ethics Committee

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

23rd March 2022

Dr Sophie Bennett
Department of Population, Policy & Practice
UCL GOS Institute of Child Health

Cc:
Katrina Walsh, UCL Division of Psychology and Language Sciences
Dr Marc Tibber UCL Division of Psychology and Language Sciences

Dear Dr Bennett

Notification of Ethics Approval with Provisos
Project ID/Title: 22125/001: Is signposting to peer support helpful in decreasing loneliness in parents of children with long-term conditions and disabilities?

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **31st August 2023.**

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form' https://www.ucl.ac.uk/research-ethics/responsibilities-after-approval

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Appendix K

Descriptive Statistics Showing the Number and Percentage of Recruited Parents With At Least One Child with Each Reported Long-term Condition

LTC	Number of Parents	Percentage of Parents (%)
Rare Conditions e.g. Rare Genetic Conditions	46	55
Autism Spectrum Disorder	26	31
Down's Syndrome	12	14
Learning Disability	9	11
Cerebral Palsy	8	10
Attention Deficit Hyperactivity Disorder	7	8
Cleft Lip and Palate and/or Gum Notch	6	7
Epilepsy	4	5
Speech and language disorders/difficulties	4	5
Visual Impairments	4	5
Obsessive Compulsive Disorder	3	4
Pathological Demand Avoidance	3	4
Sensory Processing Disorder	3	4
Anxiety	2	2
Asthma	2	2
Diabetes Type 1	2	2
Dyslexia	2	2
Global developmental delay	2	2
Hydrocephalus	2	2
Hypermobility Spectrum Disorders	2	2
Mental Health Difficulties (not specified)	2	2
Heart Condition (not specified)	2	2
Anorexia	1	1
Attachment Disorder	1	1
Crohn's Disease	1	1
Cystic Fibrosis	1	1
Deafness	1	1
Developmental Dysplasia of the Hip	1	1
Dyscalculia	1	1
Feeding Tube	1	1
Fibromyalgia	1	1
Food Allergies (not specified)	1	1
Gastroesophageal Reflux Disease	1	1
Glycogen Storage Disease	1	1
Graves' Disease	1	1
Immunocompromised	1	1
Kidney Failure	1	1
Learning Delay	1	1
Low Muscle Tone	1	1
Chronic Fatigue Syndrome	1	1
Non-Verbal	1	1
Physical Disability	1	1
Postural Tachycardia Syndrome	1	1
Raynaud's Disease	1	1
Squint	1	1
Tourette's Syndrome	1	1

Appendix L

Example Analysis Schedule

Meaning Unit	Code	Sub-Theme	Theme
People can be critical which is hard when you are trying your best. It's hard not to take it personally.	Criticism	Judgement and Criticism	Interpersonal difficulties between peers
Increased worry due to information that was shared with me.	Increased worry	Negativity of content leading to an impact on wellbeing	Difficulties related to the content of discussions