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‘Nurturing Parents’ – mindfulness-based parent well-being group in pediatric Cystic Fibrosis.

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Abstract

Objectives: Parents of a child with Cystic Fibrosis (CF) are at increased risk of anxiety and depression. We examine the feasibility and acceptability of Nurturing Parents (NP) mindfulness-based parent well-being group in CF using a mixed methods design. NP is an 8 week group designed to help parents cultivate 1) resilience to stress, 2) kindness towards themselves, and 3) awareness of self when communicating. **Methods:** Mothers ($N = 12$) rated individual and group goals and completed measures of dispositional mindfulness, interpersonal mindfulness in parenting, anxiety, depression, and parenting stress, pre-NP and post-NP. Qualitative data from semi-structured interviews were analyzed using thematic analysis. **Results:** Participants who completed the NP group ($n = 9$; 75%) reported improvements post-NP in dispositional and interpersonal mindfulness and in at least one group goal. Clinically significant improvements were found for mothers reporting pre-NP anxiety ($n = 2$) or depression ($n = 2$) in the clinical range. Qualitative themes included: 1) gaining self-awareness and choice, 2) connection to others not defined by CF, and 3) validating self-care. **Conclusions:** Mothers reported psychological benefits of NP group and preferences that may promote retention. Findings may inform clinical practice. A future pilot trial of efficacy in CF may be feasible.

Keywords: mindfulness, parent, group, intervention, cystic fibrosis.

Implications for impact statement

‘Nurturing Parents’, a mindfulness-based parent well-being group, is a relatively inexpensive intervention that may offer psychological benefits to mothers of a child with CF. It was acceptable to mothers and feasible to deliver in the pediatric setting. The next stage is an initial ‘proof of concept’ study with clear strategies to boost uptake and minimize attrition, to test whether to proceed with a randomized design.

‘Nurturing Parents’ – mindfulness-based parent well-being group in paediatric Cystic Fibrosis.

Cystic Fibrosis (CF) is a common, life-threatening, hereditary condition (CF Trust, 2019), which creates complex parenting challenges due to demanding daily treatment regimens (Modi, et al., 2006). These include daily medications and physiotherapy, a high calorie diet, pancreatic enzymes at mealtimes, and regular exercise. CF is associated with parenting stress and risk of anxiety and depression (Cousino & Hazen, 2013, Quittner et al., 1998), which if left untreated can compromise CF health outcomes such as enzyme adherence (Barker & Quittner, 2016) and Health Related Quality of Life (Driscoll et al., 2009). Annual mental health screening is recommended to promote early detection of parental symptoms (Quittner et al., 2014) and in the UK parents can be referred to Adult IAPT (Increasing Access to Psychological Therapies) services for intervention. Whilst IAPT typically offers individual Cognitive Behaviour Therapy (CBT) or counseling, such approaches are delivered by adult mental health professionals without specialist knowledge of parenting or of pediatric health, so IAPT may not address the specific needs of parents of a child with CF.

Group-based mindfulness has shown similar effectiveness to individual CBT for adults with anxiety, depression, and stress, and may save limited resources in primary care (Sundquist et al., 2017). Kabat-Zinn (1994, p.4) describes mindfulness as the awareness that arises through “paying attention in a particular way; on purpose, in the present moment, and non-judgmentally”. Mindfulness skills are particularly relevant to conditions that are both hereditary and life limiting, where distress can involve rumination about difficult past experiences (e.g., the genetic aspect of CF) and fears for the future (e.g., lung transplant).

Mindfulness changes both intrapersonal (i.e., one’s relationship with thoughts and feelings) and interpersonal factors (i.e., responding with empathy and perspective taking, [Block-Lerner et al., 2007], anger management, and identifying and communicating emotions [Wachs & Cordova, 2007]). Both factors are relevant to parenting since individuals with

mindfulness skills are better at moderating their emotional reactivity (Coatsworth et al., 2010) and are more aware of habitual responses to their children (Bluth & Wahler, 2011). In a recent meta-analysis, Burgdorf et al. (2019) reported the effectiveness of mindfulness intervention for reducing parenting stress, based on studies of children with a mental health or neurodevelopmental difficulty. Mindfulness-based parenting interventions show potential for improving parental resilience in Type 1 Diabetes (van Gampelaere et al., 2019), and parental stress and burnout for a mixed sample of parents of children with chronic disease and/or functional disability (Anclair et al., 2018), but have not yet been evaluated for CF.

Nurturing Parents (NP) is a mindfulness-based, well-being group for parents that was developed at The Centre for Mindfulness Research and Practice (Bangor University, Wales) and teaches parents to use mindfulness skills in parenting practices (Jones et al., 2018). NP group is adapted from standard 8-week Mindfulness Based Stress Reduction (MBSR), which has an established evidence base for stress, anxiety and depression (Khoury et al., 2015). As standard MBSR is demanding, adaptations such as shorter practices and reflecting on parenting values (reported fully in Eames et al., 2015) were made to increase relevance to parenting and feasibility for parents in challenging situations, such as parents of children with autism and related difficulties (Jones et al., 2018) and socio-economically disadvantaged mothers (Eames et al., 2015). Parents reported high satisfaction with course duration, demand on time, group format, support during and between classes, as well as increased mindfulness and self-compassion and reduced general stress (Jones et al., 2018), and reduced parental stress and depression (Eames et al., 2015) from pre- to post-NP group intervention.

In a brief audit, parents in our CF service expressed interest in accessing self-care skills to promote resilience to CF. NP group had been delivered locally, via government funding, to parents of children with additional needs at children’s centers and college campuses. Positive feedback indicated the intervention could be acceptable for our service.

Mixed method design can provide a fuller understanding of intervention outcomes and ensure strategies are relevant to the lived experience of a target population (de Visser et al., 2015). We used an embedded experimental design and collected qualitative data post group to understand intervention outcomes (Creswell & Plano Clark, 2007). Two recent studies have used mixed methods to examine the feasibility of mindfulness intervention for caregivers of children with ADHD (Zhang et al., 2017) and young people recovering from depression (Racey et al., 2018), but this is a novel methodology for mindfulness intervention in pediatric CF. Using the ORBIT framework for behavioral treatment development (Czajkowski, et al., 2015), the goal was to determine whether NP group would be suitable for a new population and setting, in a phase Ib study with a small sample of highly selected participants. The principal aim was to assess the feasibility and acceptability of NP group in CF and establish readiness for ‘proof of concept’ Phase II preliminary testing (Czajkowski, et al., 2015), by evaluating: 1) recruitment and adherence potential, 2) acceptability of the intervention, and 3) the potential value of NP group for improving anxiety, depression and parenting stress. We hypothesized that NP group would be feasible in our service and acceptable to parents and lead to reliable and clinically significant improvements on outcome measures. A secondary aim was to understand parents’ subjective experiences of change in relation to the three goals of NP group and explore the fit of NP group to our population in an embedded qualitative study.

Method

Participants

Parents of children aged 0-18 years receiving CF care through a pediatric specialist CF center in the UK were eligible for inclusion. Exclusion criteria were: not speaking English, any significant diagnosed neurological or psychiatric disorder, or current mental health intervention (as reported at annual review).

Procedure

Local NHS Research & Development approval was obtained for a service development project. Rockinghorse Children’s Charity provided funding for an accredited mindfulness trainer (TG) with experience of delivering NP groups. Parents were given written information in clinic and by post and invited to an orientation session that included time for private and group questions. Parents were screened by SH (CF psychologist) for suitability (i.e. no recent major life event) during a telephone call and provided written consent. Measures were completed at baseline, post group and at four-month follow up.

Feasibility and acceptability criteria

Our operational criteria were that parents of $\geq 50\%$ of children with CF should express interest in taking part with recruitment and retention rates $\geq 75\%$ (feasibility), plus an improvement in at least one NP group goal post-group and evidence of parents’ satisfaction with NP group within the qualitative data (acceptability).

Standardized outcome measures

PHQ-9 (Lowe et al., 2004) and GAD-7 (Spitzer et al., 2006) are screening measures for depression and anxiety respectively. PHQ 9 scores of 5, 10, 15, and 20 represent cut-points for mild, moderate, moderately severe and severe depression and GAD-7 scores of 5, 10, and 15 represent cut-points for mild, moderate, and severe anxiety. Each has good psychometric properties (PHQ-9, internal consistency, Cronbach’s $\alpha = 0.86-0.89$, test-retest reliability, $r = .84$; GAD-7, internal consistency, Cronbach’s $\alpha = 0.92$, test-retest reliability, $r = .83$; Kroenke et al., 2010) and is recommended in CF annual parental mental health screening (Quittner et al., 2014). Parental Stress Scale (PSS, Berry & Jones, 1995) is a brief 18-item measure of the levels of parental stress for parents of children under 18 years. PSS has good psychometric properties (internal consistency, Cronbach’s $\alpha = 0.83$). Items are rated on a 5 point likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*) and some are

reverse scored. Possible scores range from 18-90, with higher scores indicating more stress. There is no clinical threshold, but normative data are available for non-clinical ($M = 37.1$, $SD = 8.1$) and clinical samples (children with developmental disability, $M = 40.1$, $SD = 9.3$). As CF is a life limiting condition we added *near* to item 8: “Having child(ren) gives me a more certain and optimistic view for the near future”.

Process variables

Five Facets Mindfulness Questionnaire (FFMQ, Baer et al., 2006) has 39-items that measure dispositional mindfulness (the general tendency to be mindful in day-to-day life) on five underlying constructs: observing, describing, acting with awareness, non-reactivity, and accepting without judgment. FFMQ includes item such as; “I find myself doing things without paying attention”. Items are rated on a 5-point likert scale from 1 (*never or very rarely true*) to 5 (*very often or always true*) and some are reverse scored. Facet scores range from 8-40, except for non-reactivity, which ranges from 7-35. Higher scores indicate more mindfulness. FFMQ has good psychometric properties (internal consistency Cronbach’s $\alpha = 0.72-0.92$). The Interpersonal Mindfulness in Parenting Scale (IM-P, Duncan, 2007) is a 10-item measure of mindful parenting including items such as “I often react too quickly to what my child says or does”. Items are rated on a 5-point likert scale from 1 (*never true*) to 5 (*always true*) and some are reverse scored. Scores range from 10-50 with higher scores indicating more mindful parenting. IM-P has adequate psychometric properties (internal consistency Cronbach’s $\alpha = 0.62$; Coatsworth et al., 2010).

Individual learning plan (ILP)

Developed for NP group in CF, ILP was completed pre/post group. Parents rated the three NP group goals and described and rated their own personal goals on a 4 point scale (from 1, *I can’t do this*, to 4, *I can do this well*). Parents rated their confidence in learning mindfulness skills on a 4 point scale (from 1, *not at all confident*, to 4, *very confident*).

Intervention

NP group was held at a children’s hospital in the South of England between October 2018 and May 2019 and delivered as eight weekly, two hour, sessions with a 15 minute break, by TG, co-facilitated by SH. Before delivery, TG attended three full day CF clinics to familiarize herself with CF and its challenges. TG shadowed the multi-disciplinary team and spoke with families. The CF team were offered a two-hour mindfulness session to experience a range of NP mindfulness practices and the format of NP group, and then gave feedback on the suitability of the NP group manual for CF. No adaptations were suggested.

NP has three group goals: to help parents cultivate 1) resilience to stress through mindfulness practice, 2) kindness towards themselves through mindfulness practice, and 3) awareness of themselves when communicating. NP mindfulness practices are shorter than those taught for MBSR (5-20 minutes rather than 30-45 minutes) so that mindfulness is achievable in everyday life (see supplemental materials). NP promotes parents learning self-care in order to care for their families and emphasizes parenting values and mindful communication and listening. Mothers were given home practice tasks and access to mindfulness audiofiles (via a website) and were invited to practice each week at home. Mothers could contact TG between sessions for support if needed by telephone or email. For some, NP group was the first time meeting other parents of a child with CF and for all but one the first experience of mindfulness practice. TG and SH assessed mothers’ welfare each week by email, telephone or in person. A follow up session was offered at 4 months.

Quantitative analysis

Descriptive statistics are used to report feasibility data and the means and SD for outcome measures (Table 1). Reliable Change Index (RCI) (Jacobson & Truax, 1991) was used to determine reliable change ($RCI \geq 1.96$) on each outcome measure for each parent. RCI can be used to determine whether the change in an individual’s score is reliable or due to the

degree of error of the measuring tool, and whether change in scores at the end of treatment (in comparison to baseline) is clinically significant (Morley & Dowzer, 2014). Using Jacobson’s method (1991), we calculated RCI by dividing the difference between the pretreatment and post-treatment scores by the standard error of the difference between the scores ($RCI = (x_1 - x_2) / SE_{DIFF}$). Where $(SE_{DIFF}) = \sqrt{2(SE_M)^2}$, and $(SE_M) = SD \sqrt{(1-r_{xx})}$ (where r_{xx} is test-retest reliability). When a reliable change score is ≥ 1.96 it is unlikely that the post-test score does not reflect reliable change. Clinically significant change was determined by an RCI score ≥ 1.96 plus moving across a clinical cut-point for GAD-7 and PHQ-9. For PSS there is no clinical cut-point but norms are available for clinical and non-clinical populations hence to determine clinically significant change we used criterion c), in which the level of functioning should place the client closer to the mean of the functional group than the mean of the dysfunctional group (Jacobson & Truax, 1991).

Embedded qualitative study

Whilst Reliable Change Index (RCI) (Jacobson & Truax, 1991) can be used to quantify the extent of change on a particular outcome following intervention, and determine if change is clinically significant, RCI cannot provide detailed insight into whether change is experienced as important or meaningful (Staunton et al., 2019). Qualitative methods provide rich information about the subjective experience of change and are appropriate for evaluating clinical approaches with new pediatric populations (Fiese & Bickman, 1998). Qualitative data were collected via semi-structured (telephone or face-to-face) exit interviews about parents’ experience of NP group within four weeks of the final session. Telephone and face-to-face interviews have been used to investigate implementation of parenting interventions (Shapiro et al., 2011). The interview schedule was designed to elicit parents’ experience of ‘how’ and ‘why’ change may have occurred in relation to the three group goals and how this may have been meaningful for families in the context of CF, and to establish the fit of NP group in CF

in terms of acceptability and feasibility. All nine who completed the NP group agreed to an interview. Written and verbal consent was obtained and parents were told they could stop at any stage and decline questions they did not wish to answer. Mothers were given opportunities to ask questions and reminded that information provided would be confidential. Interviews were conducted by SH and a psychology student (SK-H) and recorded digitally.

We approached this evaluation with specific aims from the contextualist perspective of ‘critical realism’ (Willig, 1999). In our attempt to understand the reality of mothers’ subjective experience we acknowledged that they would make meaning of, and report, their experiences within broader social contexts. Practical steps were taken to facilitate honest and open accounts and interpret mothers’ descriptions within the wider contexts of 1) the project setting and baseline questionnaire data, and 2) family culture and approach to coping with CF. In doing this we attempted to look at what was said but also move beyond this by interpreting text within a historical, cultural, and social context (Harper, 2011). Specifically, mothers knew that NP group had been arranged by SH (known to families for 4 years) and funded by the hospital charity, which would be interested in mothers’ feedback. Mothers were reminded before interview that they were invited to provide fully honest feedback and that neither the CF team members nor hospital charity had special affiliation with NP intervention. We emphasized the need for service user input into shaping pediatric CF services across the UK and trialing new ideas. We invited feedback on both positive and negative aspects of the experience of NP group to fully understand the suitability of this intervention for this particular population. Interviews were transcribed verbatim by SH ($n=5$) and a psychology student (LG) ($n=4$). Transcripts were read and re-read to familiarize with the data set. Qualitative data were analyzed by SH and LG using an inductive Thematic Analysis (TA; Braun & Clarke, 2006). TA is a method of identifying, analyzing, and reporting themes in qualitative data that is not aligned with a particular theoretical framework

and fits well with a critical realism approach. In the first stage SH analyzed five transcripts until no new codes were attainable and an initial coding scheme had been established. LG used this coding scheme to code the same five transcripts to reduce analysis bias. Discrepancies in coding and definitions of codes were resolved through discussion and codes were organized into themes based on initial interpretations. A refined coding scheme was then applied by LG to the remaining four transcripts and new codes and themes were incorporated. The final coding scheme, based on all interviews, was then re-applied to all interviews by SH to ensure inductive thematic saturation (Saunders et al., 2018). This enabled evaluation of themes within each transcript and across the dataset.

Results

Recruitment and adherence potential

Two families (5.8%) who did not speak English were excluded, thus parents of 32 children were eligible. Parents of 17 children (53.1%) were interested in taking part. Parents of 15 children either gave no reason for not taking part ($n = 5$, 15.6%), were not interested in mindfulness ($n = 4$, 12.5%), or were interested in mindfulness but unable to consider group participation due to working full time ($n = 4$, 12.5%) or living too far away to attend weekly sessions ($n = 2$, 6.2%). Of the 17 interested parents, 12 (70.58%) consented to participate (all were mothers); reasons for non-participation were lack of childcare ($n = 3$), being the only father and his wife already taking part ($n = 1$), and a late change to work hours ($n = 1$).

The final sample ($n = 12$) was aged between 35 and 56 ($M = 43.5$ years) and white. Most were employed ($n = 11$, part time $n = 7$) and had one ($n = 11$) or two ($n = 1$) children with CF. One had previously completed MBSR. Children were aged between 5 and 12 years.

Of these 12 mothers, three stopped, for reasons that included “*too busy before Christmas*” and finding mindfulness “*unhelpful as I have chronic pain*”. These mothers attended up to three sessions but had not attended the orientation. One had high anxiety and

depression scores at baseline. Of the nine mothers who remained in the group (a retention rate of 75%) all attended the orientation session and eight attended at least six group sessions. Three children received inpatient care and one underwent a significant medical intervention during the course. One mother could attend only four sessions, for personal reasons, but continued home practice. Three (33.33%) came to the follow up session; six could not attend due to sickness or work commitments.

Potential barriers to engagement described by four mothers following orientation included worry that others might “*overshare negative stories*” which would undermine the purpose of seeking self-care skills to improve their own well-being. In response, group guidelines were co-developed in session one to improve retention and establish the role of the group, and these four mothers all completed the group. Guidelines emphasized learning mindfulness in a safe and supportive group space to develop self-care skills rather than sharing personal experiences of CF. Mothers were invited to socialize in the break or chat with the facilitators about course content. Some children had a gastrostomy or intravenous port, or had needed more frequent hospitalization than others. In order to prepare mothers for others’ experiences we normalized the idea that CF care varies for each child and is planned according to individual need. Mothers were encouraged to cultivate a supportive space by remaining mindful of communication others may find difficult (e.g. procedural distress). Guidelines were re-visited each week to remind mothers and minimize deviation.

Acceptability of NP group and taking part in a mindfulness research

Descriptively, all nine mothers reported improvements in at least one group goal (resilience $n = 7$, kindness $n = 7$, communication $n = 8$) on their ILP, and greater dispositional mindfulness and interpersonal mindfulness in parenting (higher FFMQ and IM-P scores) immediately post group. Eight reported improvements in individual goals on their ILP and felt more confident learning mindfulness and applying techniques to everyday situations. One

stopped mindfulness home practice but focused on group practice and kindness at home. In the final session group reflection, all mothers orally reported regularly using mindfulness ($n = 8$) or kindness to self ($n = 1$) at home, perceived improvements in self-care, and intention to continue with mindfulness practice post group. All nine mothers who completed NP group completed questionnaires. Measures were acceptable but some found FFMQ long and repetitive. Of the three who stopped NP group, two did not fully complete measures.

Outcome measures: Anxiety, depression, and parenting stress ($n = 9$)

Means and SD are reported in Table 1. Four mothers reported no clinical symptoms of anxiety, depression, or parenting stress at baseline but reported other benefits of NP group qualitatively. Five (55.5%) mothers reported anxiety in the clinical range at baseline (mild $n=3$, moderate $n=2$). Clinically significant improvement was found for two (22.2%) mothers who both moved from the moderate to mild category post group. Two mothers in the mild range moved below the clinical threshold, but change was not reliable ($RCI \leq 1.96$), whereas the other mother experienced greater anxiety and depression post group due to her child requiring significant medical interventions, while reporting other benefits of NP group. She was offered additional support. Two (22.2%) mothers with anxiety also had baseline scores in the clinical range for mild and moderate depression. Both showed clinically significant improvements and moved below clinical cut-points post group. One of these mothers reported high parenting stress (PSS score=50) at baseline and showed a clinically significant improvement post group (PSS score=34), which is comparable with non-clinical normative data.

Four-month follow-up

The three mothers who attended follow up had maintained higher FFMQ and IM-P scores. All had reported baseline anxiety and two had maintained improvements at four months. One had also maintained improvements for depression and parenting stress.

Qualitative results

Resilience to stress through mindfulness practice

Gaining self-awareness and choice. Mindfulness increased self-awareness and sense of choice: *“how you can practice mindfulness and the explanations for how our brains are the way they are and that we can do something about it”*. It changed how mothers approached stressful situations: *“I had a recent hospital stay...and to pause and think before reacting”* and helped them stay present and accept what they cannot control: *“made me more reflective that all I can do is control the now and... deal with and appreciate that... and getting too worked up about the little things with CF might not help”*.

A connection to other parents not defined by CF. There was a sense of unspoken understanding and empathy because all mothers had a child with CF. Most described feeling connected as central to their experience of learning mindfulness skills in a group: *“I loved doing it and in a group...with these other parents who totally understood everything about CF”*. However, mothers also described the value of protected group time to connect with their self rather than CF: *“The most interesting thing was we very rarely touched on CF we were just mothers and people rather than a parent with a CF child”*.

Using strategies to manage group challenges. Mothers developed strategies to cope with hearing about others’ experiences and maintain a sense of safety and well-being in the group. These included resisting comparisons and staying present: *“you’ve got to make sure you don’t feel too, oh like, my child might experience that in the future”* and staying focused on your own experience *“So not reading too much into other people’s experiences”*.

Kindness to self through mindfulness practice

Validating self-care. NP group offered a space that encouraged mothers to prioritize their own needs: *“by teaching me to take more time for self-care and to be kinder to myself”*. Cultivating kindness, a key tenet of NP group, validated being kind: *“It was a really good*

reminder about being kind to myself ... if I feel kinder to myself, I can be kinder to other people” and time being, not doing: *“take five minutes for yourself and a having bit of space”*.

Using kindness to help practice mindfulness. One mother chose to stop home practice at session 4. She continued mindfulness practice in the group, which led to positive outcomes, but home practice increased awareness of coping by being busy and led to negative feelings. Learning self-kindness helped her resolve this: *“it’s been making me feel a bit bad about myself... but actually I’ve come to the conclusion that that’s me...that’s okay”*.

Awareness of self when communicating

Mindfulness skills led to less reactivity in CF-related interactions and communication:

“Things I can’t control... being calmer, it’s easy to get wound up, but taking a step back”, less stress: *“it does help in terms of like thinking before reacting. We’ve had a tricky time and makes me feel less stressed if she’s unwell”,* more kindness and open communication: *“being kinder and checking in with the burden of it for her and slowing down to empathise more”*.

Fit of NP group in CF: Acceptability and feasibility

Acceptability. Mindfulness was described as *“refreshing”,* with *“no judgment”,* and *“acceptable and very real, not mumbo jumbo”*. Mothers welcomed the shift in focus from CF to self-care. It created a safer group space: *“Not much was directly related to CF. This was quite nice as talking about it too much may have made the space quite negative”,* with a strong sense of non-judgmental support: *“I found it really helpful, apart from the fact we are going through the same experiences, there was no judgment in the group”*. Group guidelines helped alleviate anxiety about the group format, establish important boundaries and enable positive outcomes: *“I was really nervous of what might be shared and how is that going to be managed? We established the rules early on and that’s what made things work really, well”*. Group guidelines were also acceptable to mothers who had not expressed concerns: *“it was*

quite interesting how it was set up in terms of we’re not here to talk about CF, but the odd bit came out. I thought actually it’s probably just safer for us to not get into too much detail”.

Feasibility. Home practice was manageable for some, but others struggled, which evoked emotional reactions. One felt under pressure: *“Feeling like you should do it and then you don’t, wasting time getting caught up in that”*. This seemed more apparent for mothers reporting higher parenting stress pre intervention. Brief practices were preferred by all mothers and helped promote mindfulness of everyday events: *“easy to become mindful at small points during the day”* and *“more mindful of everyday things”*. Longer practices were difficult to assimilate into treatment regimens and many requested an app for ease of use.

Suggestions for future groups. Mothers were curious about applying mindfulness to CF specific events such as procedures and clinic visits: *“something that would be relevant, to being mindful about procedures because my child does get worried”*. A separate space or support group to share CF experiences was suggested both by mothers who would have welcomed this and those who preferred to only learn self-care: *“If you have two things alongside it could be a more holistic group of people for the mindfulness.”*

Discussion

We aimed to establish the feasibility and acceptability of NP group intervention in pediatric CF and determine readiness for ‘proof of concept’ Phase II preliminary testing (Czajkowski, et al., 2015). We hypothesized that NP group would be feasible and acceptable to parents and would lead to reliable and clinically significant improvement on outcome measures. Findings indicate that NP group intervention is acceptable to mothers and may be feasible in future research if steps are taken to overcome barriers to recruitment and adherence. Whereas 53.1% of parents were initially interested in the intervention, only 70.58% of these parents were subsequently recruited due to practical barriers and this did not meet our feasibility criteria for $\geq 75\%$ recruitment. A further 18.7% who were interested in

mindfulness could not attend weekly face-to-face NP group sessions for practical reasons. This highlights the need for future work to explore strategies to increase accessibility and maximize recruitment potential. However, among those recruited there was 75% retention, and all who completed reported being satisfied with the intervention in the qualitative data, and showed pre-post changes on mindfulness measures and group and/or individual goals, which suggests that NP was acceptable to mothers.

NP group showed potential to improve mothers’ mental health in CF. Where anxiety was within the clinical range at baseline ($n = 5$), four mothers moved below a clinical cut-point on GAD-7 and for two of these the change was clinically significant. Both mothers who were also within the clinical range for depression at baseline moved across a clinical threshold post group. Interestingly mothers within both clinical and normal ranges for GAD-7 and PHQ-9 at baseline experienced pre-post changes in mindfulness and provided qualitative reports of associated psychological benefits, such as improved communication with their child and less reactivity. This suggests that NP group could be suitable for both prevention and intervention. Anxiety and depression are important outcomes in parental adjustment to pediatric CF and our data support previous work that NP group may have potential as an effective intervention for parental depression (Eames et al., 2015). Parenting stress is a key outcome in mindfulness parenting intervention research (Burgdorf, Szabó & Abbot, 2019) and mothers in our sample reported similar levels to a clinical sample (Berry & Jones, 1995). However, only one mother showed a clinically significant improvement in her PSS score post NP group. Others reported, qualitatively, an increased resilience to stress by learning to accept what they could not control in CF, rather than less stress. The PSS is a generic measure of the levels of parenting stress and may not have been sensitive to change in our sample. In CF, parenting stress is likely due to the burden of CF treatments, which would not

change due to mindfulness intervention, compared with other populations in which parenting stress may be due to child behavioral/emotional difficulty and amenable to intervention.

A secondary aim was to understand parents’ experiences of the process of change in relation to the three goals of NP group and explore the fit of NP group intervention to the needs of our population in an embedded qualitative study. Mixed methods offered valuable insight into mother preferences for specific aspects of NP group and how meaningful change occurred. Qualitative findings suggest that the group-based format is of particular value for future groups because families do not typically meet ‘face to face’, due to infection risks. Mothers experienced the process of change through learning mindfulness skills (self-awareness and kindness to self) while feeling highly connected to others with shared experience of CF in a safe way. NP group embodies key tenets of mindfulness (non-judgmental, present moment awareness) with a focus on mindfulness in communication and interactions, and kindness towards the self and others. As such the intervention itself may have taught the skills necessary to resolve the challenges of group participation when a child has a life-limiting hereditary condition, and to access the benefits of group support. The clear group guidelines and focus on self-care likely contributed to the positive outcomes mothers reported and should be emphasized in future groups. Furthermore, the shorter practices should be retained as mothers could assimilate brief practices into CF care.

Estimated effect sizes ranged from small to medium, so the data support the move into phase II testing to assess whether NP group in CF produces clinically significant improvement in anxiety and depression (Czajkowski, et al., 2015). However, steps to promote recruitment and retention are needed. Further work should include sequential testing, starting with an initial ‘proof of concept’ study with clear strategies to boost uptake and minimize attrition, before deciding whether to proceed with a randomized design.

Our data highlight options to overcome potential barriers to engagement and further explore feasibility. For instance, it is unfortunate that we could only offer a single time during the working day for our NP group, as this clearly restricted recruitment potential because parents in full-time employment could not easily participate. Future groups should offer a choice of times and dates, including evenings and weekends, and consider the provision of childcare. This could increase accessibility and accommodate the needs of parents who work full time, particularly fathers and younger mothers who were not represented in this sample.

Offering a choice of face-to-face or online format might also improve uptake and the option of ‘virtual’ attendance or catch up for face-to-face sessions missed could ensure parents receive the full intervention dose. On average mothers who completed the group missed no more than two sessions and the familiar pediatric setting facilitated attendance as mothers could attend when their child was an in-patient. Online groups are particularly relevant and topical for parents of children who are clinically vulnerable to respiratory infection risks from CF-organisms and, more recently, COVID-19. NP group could easily be adapted for online delivery, with break-out opportunities for small group work, and would normalize the concept of online well-being groups for parents of children who cannot meet. However, the ‘in person’ group created a valuable sense of connection that may prove harder to achieve online. Weekly attendance was an additional commitment for parents already burdened with CF treatment regimens. Our group started in late October and seasonal patterns in CF symptoms and the Holiday Season may have affected recruitment, adherence to weekly sessions and home practice, and perceived levels of stress.

Our findings highlight the importance of an orientation to mindfulness session and screening for group suitability. Mindfulness requires noticing internal experiences, which may be too unsettling in some cases, such as following a significant life event or chronic pain. During screening facilitators should fully assess individual motivation for attendance

and perceived response to meeting other parents with a child with CF. At orientation, future groups could acknowledge the potential burden of participating in a group and, in addition to group guidelines, provide targeted techniques to help parents cope.

Mothers reported benefits of weekly in-group practice even without home practice. An emphasis on ownership and choice in selecting intervention aspects to suit one’s preferences might further increase uptake and retention. This may be especially important for parents with anxiety, depression, and greater treatment burdens and can be partly guided by the specific needs of each cohort. Facilitators could further emphasize the invitational nature of home practice and encourage parents to set their own weekly home practice goals. A larger choice of brief practices accessed via an app may also increase uptake. The need for longer-term support to maintain skills was also raised and has been implemented at our center in both face-to-face and online format, with good uptake.

Limitations include the single center design with only nine mothers completing the group, which may limit generalizability. Unfortunately mothers who did not complete could not be interviewed and provided only brief information about reasons for stopping. Naturally, the lack of a control group and limited follow up mean interpretations must be made with caution; nevertheless this study meets the conditions of a phase Ib design (Czajkowski, et al., 2015) and the sample size is comparable with other published mixed-methods feasibility research (Zhang et al., 2017). Future work should also aim to increase sample diversity. Nonetheless, we believe our findings offer sufficient promise to proceed with further testing of NP group on parental mental health in CF, across multiple sites and with different trainers, and can inform hypotheses for future research. At a clinical level, group interventions in the pediatric setting may be less stigmatizing than a referral to an external adult mental health service, so parents may seek earlier help. Attention to mothers’ preferences may also assist with retention. Findings suggest a future pilot trial of efficacy in CF may be feasible.

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Table 1 *Descriptive Statistics and Estimated Effect Sizes for Outcome Measures and Clinically Significant Change*

Measure	N	Pre mean (SD)	Post mean (SD)	95% CI Mean		FU mean (SD) (n=3)	Effect Size		% Clinically significant change post group	% Clinically significant change at FU
				diff			Cohen’s <i>d</i>	Hedges <i>g</i>		
				Low	High					
GAD 7	9	6.11 (4.19)	4.55 (3.74)	-1.97	5.09	7.66 (6.65)	0.39	0.37	22.2% (n = 2)	22.2% (n = 2)
PHQ 9	9	4.55 (3.97)	3.22 (2.38)	-1.44	4.10	3.00 (3.60)	0.41	0.39	22.2% (n = 2)	11.1 % (n =1)
PSS	9	42.33 (9.01)	40.66 (6.12)	-3.44	6.78	39.00 (5.56)	0.22	0.21	11.1 % (n =1)	11.1 % (n =1)

Note. SD = standard deviation, PSS = Parenting Stress Scale, FU = Follow up,

Effect sizes (Cohen’s *d*) fall between small to medium according to Cohen’s criteria (Cohen, 1988).