



Understanding the Experiences of How Mindfulness is Used by People with Cystic Fibrosis: Barriers and Enablers

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Abstract

Objectives Mindfulness practices are increasingly being recognised as beneficial in supporting health, wellbeing, and psychological functioning. There is currently limited evidence of how mindfulness is used within a population of individuals with cystic fibrosis (CF). In order to effectively inform the development of future psychological mindfulness-based interventions for this population, it is imperative to first understand how individuals with CF are currently engaging with mindfulness.

Method Internet-mediated research (IMR) was used to explore attitudes, beliefs, and experiences regarding the use of mindfulness practices across a CF population. IMR allowed for a natural, unobtrusive method of data collection that involved the collection of publicly available posts from two global online CF forums.

Results A variety of formal and informal mindfulness practices were positively experienced by the CF community, with beneficial impacts upon emotional and psychological wellbeing, and physical health. The data highlighted a clear interest in proactive mindfulness practice, whilst also exploring some of the associated challenges with certain practices.

Conclusions Proactive psychological support that considers the use of mindfulness and self-care practices may form a particularly valuable tool in supporting the quality of life for present and future generations of people with CF. Increased awareness and education regarding the use of different formal and informal mindfulness practices in CF care would be beneficial in enabling people to make more informed choices.

Keywords Cystic fibrosis · Mindfulness · Mindfulness practices · Wellbeing · Quality of life

Cystic fibrosis (CF) is the most common life-limiting genetic disease affecting approximately 10,600 individuals within the UK, and 100,000 people worldwide (Cystic Fibrosis Trust, 2021). The condition is caused by mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene located on chromosome seven (Kerem et al., 1989). Symptomology for CF varies, but commonly affects the respiratory and digestive systems (Goetz & Ren, 2019; Kerem et al., 1990) with the challenges of symptom management and treatment adherence being prevalent for many (Keyte et al., 2017, 2019a, 2019b, 2020).

Treatments have traditionally aimed to reduce the severity of symptoms and slow disease progression in CF. Following

scientific advancements, genome-specific modulator therapies became available in 2019 via the National Health Service (NHS) England, with these treatments targeting the underlying cause of CF by treating and correcting specific genetic mutations (Cystic Fibrosis Trust, 2021). Currently, four modulator therapies (Kalydaco, Orkambi, Symkevi, and Kaftrio) are available for 90% of the UK CF population. Following the advances of CF care and CFTR modulator therapies, the demography of the CF population is changing, enabling most people with CF to now survive into adulthood (Keogh et al., 2020).

Individuals with CF today are reporting the changing effects of modulator drugs on physical health and quality of life (Heijerman et al., 2019; Middleton et al., 2019). Reformulations of identity and mental health require more attention, with research needing to investigate the psychological implications associated with life-changes pre- and post-modulator therapies, as some changes may need additional clinical support. Despite that the beneficial impact CFTR modulator therapy is having upon physical health, the

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psychological risk factors are becoming more prevalent with a clear need for increased support regarding mental health and wellbeing required (Keyte et al., 2022). Both adults and adolescents with CF report high rates of depression and anxiety (Quittner et al., 2014), with this being associated with poor quality of life, reduced physical functioning, lower lung function, and increased severity of chest symptoms (Yohannes et al., 2012). Additional research in CF illustrated that individuals who reported more severe negative emotional states (stress, anxiety, depression) endorsed greater self-criticism, whereas those who endorsed better quality of life tended to report greater self-compassion (Kausar et al., 2021). Therefore, it is important to explore potential strategies that address mental health-related challenges to better support the psychological wellbeing of the growing adult CF population.

A possible approach to maintain and improve quality of life for adults with CF may arise through the practice of mindfulness. Mindfulness is commonly described as an awareness that arises through paying attention to the present moment in a non-judgemental and accepting way (Kabat-Zinn, 1990). Mindfulness is also recognised as a fundamental element of self-compassion, involving individuals taking a balanced approach in acknowledging and understanding one's emotions without trying to suppress or deny them (Neff, 2003). Mindful self-compassion entails being mindfully aware of personal suffering to be able to extend compassion towards oneself, with the mindful self-compassion programme demonstrating effectiveness at enhancing self-compassion, mindfulness, and wellbeing (Neff & Germer, 2013). In mental health research, mindfulness practice is increasingly recognised as a beneficial construct that relates to reduced psychological symptoms and increased subjective wellbeing (Keng et al., 2011). People can engage with mindfulness through either *formal* or *informal* practices, or a combination of both. Formal practices can refer to the act of intentionally setting aside a time to partake in mindfulness, such as meditation or mindful writing. Informal practices, in contrast, focus on bringing mindful awareness to everyday activities and can be integrated into one's daily life and existing routines (Birtwell et al., 2019).

Research demonstrates the positive benefits of mindfulness (e.g. mindful meditation, sitting and moving meditation, journaling, mindful colouring, and informal mindfulness practices) upon health, wellbeing, and psychological functioning in non-CF populations (Birtwell et al., 2019; Carmody & Baer, 2008; Dimidjian & Segal, 2015; Lutz et al., 2008; Mantzios et al., 2022; Smyth et al., 2018). Additionally, research in other chronic illnesses outside of CF demonstrates how and why mindfulness could be used to support people with CF as well. Kabat-Zinn (1982) highlighted the clinical use of mindfulness meditation for the self-regulation of chronic pain, suggesting the patients' abilities to observe

mental events, including pain, with an increased awareness and detachment, aiding the ability to cope successfully. Prior research discussed the prospect of mindfulness training for people with chronic health conditions in helping to reduce psychological distress and improve patients' quality of life, when used as part of a holistic approach to chronic disease management (Monshat & Castle, 2012). Research in patients with diabetes found that the combined pairing of a diabetes medical education with a mindfulness-based intervention improved physiological health and self-care behaviours, in comparison to the sole medical education of diabetes (Gregg et al., 2007). More recently, upon the completion of a mindfulness-based intervention, patients with diabetes showed significant improvements in diabetes-related distress, psychosocial self-efficacy, and glucose control, suggesting that mindfulness may offer an effective method for improving self-management and mental health (Whitebird et al., 2018). A systematic review indicated that mindfulness programmes such as Mindfulness-based Stress Reduction (Kabat-Zinn, 1990), Mindfulness-Based Cognitive Therapy (Segal et al., 2002), meditation with massage, and mindful awareness practices improved pain severity, anxiety, stress, depression, and quality of life for cancer-related pain (Ngamkham et al., 2019).

The distress and psychological burden caused by CF complexities have detrimental effects on emotional wellbeing and can further impact on other areas of life such as one's motivation to comply with treatment adherence (Kausar et al., 2022). Notwithstanding, the use of mindfulness has been proposed as an important resource for supporting physical and psychological wellbeing in the adult CF population (Mantzios & Egan, 2016), recognising the developments of mindful eating (Egan & Mantzios, 2016, 2021; Egan et al., 2021). Whilst the literature demonstrates how mindfulness practices can be used as an effective nonpharmacological treatment to aid the improvement of psychological health including stress, anxiety, and depression, as well as quality of life in chronic illness populations (with specific examples from cancer and diabetes research discussed), the development of effective mindfulness interventions in CF remains yet to be explored more fully.

Through encouraging and developing the practice of mindfulness into CF care, adults with CF could develop mindfulness skills to build resiliency and help better manage their emotional responses to stressful life situations. Currently, there are limited sources comprising of mindfulness education or training available directly for the CF community on a proactive basis beyond the information within the CF Trust and Beam CF webpages (Beam Feel Good, 2021; Cystic Fibrosis Trust, 2021). Mantzios and Giannou (2019) discussed the benefits of short, accessible, and easy-to-use mindfulness practices in enabling the initiation and intrinsic

motivation for people to commit to mindfulness practice, developing into an effortless mindful lifestyle.

Despite a growing interest in mindfulness over the last two decades, there is currently a limited understanding of how mindfulness is used within the CF population. With a projected 75% increase of the CF adult population by 2025 (Burgel et al., 2015), increased efforts are required to better support both physical and psychological wellbeing. In order to create localised and efficient mindfulness practices which aim to improve the quality of life for the adult CF population, it is imperative to first understand how people with CF are currently engaging with mindfulness as well as their attitudes, beliefs, and experiences. The aim of this study was to explore which mindfulness practices people are interested in, any health and wellbeing benefits, and any challenges or barriers that some mindfulness practices may present for individuals with CF, using an online forum investigation across the CF population.

Method

Procedure

Using internet-mediated research (IMR), qualitative data were gathered from sources of previously created information using a non-reactive method (Hewson, 2008). IMR allowed for a natural and unobtrusive method of data collection enabling individuals to engage in conversations based on their own choice of topics, in comparison to other qualitative methods where, for example, individuals' responses are formed by pre-conceived researcher questions (Wang et al., 2016). Data were collected through two open-access online global CF forums. At the point of data collection, one forum had 3200 members and the other had 21,428 members.

Data collection took place in June 2019, with posts from 2005 to 2019 collected. Both CF forums were opened as a webpage, and the following keywords were entered individually into the search functions: “mindfulness”, “meditation/e/ing”, “yoga”, and “cope”. Keywords were based on early discussions with clinical associates in the NHS, as well as a preliminary scoping exercise within the two forums, exploring discussions of how the term mindfulness was used within CF communities. The preliminary scoping exercise revealed mindfulness was often discussed alongside meditation and yoga, and in relation to coping with the complexities of CF. Furthermore, mindfulness, meditation, and yoga are considered non-stigmatising methods for supporting psychological wellbeing that share common underlying principles, situated within the field of mind–body interventions (Wahbeh et al., 2008). Thus, it would be useful to explore their use within the CF population.

A list of sub-threads and posts were produced within the websites following the keyword search. A collection of 10 posts surrounding each mention of the keyword were collected to produce a snippet of focussed text, if the keyword was used contextually. Often the entire sub-thread was read by the first author, but due to the large amount of data that was identified during data collection, a collection of 10 posts surrounding the keyword was deemed appropriate for further analysis. The collection of data using the 10 posts enabled a selection of multiple focussed and relevant conversations to analyse, as opposed to collection of the entire threads and sub-threads which often contained hundreds of posts with several different and unrelated conversations. The final datasets resulted in a total of 32,591 extracted words from 33 sub-threads within the first forum, and a total of 169,542 extracted words from 135 sub-threads within the second forum. Microsoft Word was used to collect the selected extracts from the two CF forums, using the copy and paste functions. Posts from individuals who did not have CF were disqualified from data collection. Where duplicate posts were present within the sub-threads, the original post was kept, and duplicate posts were removed.

Data Analyses

The data were analysed using thematic analysis following Braun and Clarke's (2006) model, which offered a systematic, yet flexible approach to identifying patterns of meaning and themes across the dataset. Thematic analysis embodied a contextualist method, recognising the ways that individuals make meaning of their experiences, in light of their broader social contexts (Braun & Clarke, 2006).

Following the steps of Braun and Clarke (2006), an initial process of immersion took place by re-reading and familiarisation of the data. Codes were initially generated by one researcher, and subsequently revised and evaluated by everyone on the research team, to determine the most relevant aspects of the data. Complete coding was conducted line by line and was used to identify and provide a label for all the data that was of interest or relevant to the research question, using a word or brief phrase. Data were coded in small chunks (e.g. a single line of data) and in larger chunks (e.g. more than a single line of data) dependent on the relevance of the data, in line with guidance by Braun and Clarke (2013). The process from codes to themes was an active process of examining the codes and searching for similarity or overlap between the codes, with a wider aim of creating potential patterns. At this point, candidate themes were formed which were revised and refined through the development of analysis in making sure the themes fit well with the coded data. Similarly, the researchers evaluated how each code fitted (or not) within the themes, reflecting on possible different meanings and perceptions of the data. These

collaborations helped to ensure the rigour and quality of the data generated. Themes were confirmed once agreement by the research team on their representation of data was reached. This process enabled alternative theories and perceptions to be challenged and integrated until a shared interpretation of the data between the researchers was reached to produce a clear understanding of the research aims. The process of theme formation ended with a set of four distinctive and coherent themes which told an overall story about the dataset (Table 1). Thematic analysis provided a detailed inductive construction of the data, providing valuable and data-driven information on the lived experiences of the CF community in relation to mindfulness practices.

Results

Four themes were constructed from the dataset providing an exploration into participants' attitudes, beliefs, and experiences with mindfulness (Table 1), providing insight into what interventions may be effective in CF care. The first theme explored the experiences of the different methods of formal and informal mindfulness practices used by the CF population, which led into the second theme illustrating the improved psychological wellbeing and physical health benefits following mindfulness practices. The third theme highlighted the beneficial impacts of the integration between mindfulness and self-compassion within the CF community. The final theme discussed the interest in mindfulness, limitations of mindfulness and increased need for proactive support measures for the CF community.

CF Community Use of Mindfulness Practices

This initial theme explores how the CF community engages with mindfulness, through formal and informal practices. Many people discussed using mindfulness practice as a means of coping with the complexities of daily life with CF, and with the hope of improving wellbeing. Engagement with mindfulness meditation, particularly moving meditation such as yoga, was often discussed. Several people outlined how meditative yoga enhanced one's ability to focus

on being present in the moment, taking notice of thoughts or feelings and attending to bodily sensations, all of which form some of the key concepts of mindfulness. Liam lived with CF-related chronic pain and used formal mindfulness practice, specifically meditative yoga as a form of pain management.

While I am meditating, I bring the temperature up in my heart and lungs. After some practice I am able to “send” messages to my lungs and abdomen. [Liam]

Liam demonstrated the benefits of successfully achieving a mind and body connection via meditation combined with Raja-Yoga, acknowledging how the body and mind can be influenced by one another to experience bodily sensations.

Whilst mindfulness was recognised as something that people naturally possess, Fran, Isobel, and others identified how the regular and formal practice of mindfulness meditation can facilitate the ability to observe negative feelings in the present moment.

On a daily basis I have found meditation helps me to recognise stress and worry. Without some practices which help me stay in the present more, I'd truly feel lost. [Fran]

The consensus was that focussing on the present moment or present day helped people to feel more clarity and control over of their lives. Through practising the human ability to be fully present, individuals were able to pay increased attention to their thoughts and feelings, signifying how mindfulness can help people to reshape their relationship with negative emotions, and overall mental health.

It wasn't until I started meditating that I got more of a handle on my fears. Not pushing them away, but allowing them to be there, observing them in a dispassionate way. [Isobel]

Some people experienced similar benefits following the use of mindful writing, often via journaling. Data illustrated the difficulty the CF community can experience when trying to verbally communicate with family, friends, and clinicians about their feelings or suffering related to CF. Discussions around the difficulty of open communication outlined that

Table 1 Development from codes to themes

Themes	CF community use of mindfulness practices	Physical and psychological health benefits of mindfulness	Benefits of mindful self-compassion	Future of mindfulness for people with CF
Codes	Meditation	Enhanced psychological wellbeing	Self-care	Interest in mindfulness practice
	Yoga	Physical health improvements	Self-compassion	Negative experiences with mindfulness practice
	Mindful writing/journaling	Using mindfulness to cope with psychosocial challenges	Common humanity	The future of mindfulness practice — increased need for proactive support
	Informal mindfulness			

individuals want to avoid feeling misunderstood, judged, or like a burden to others; thus, other methods such as mindful writing were pursued. Formal mindful writing allowed some people such as Jessica, to acknowledge her thoughts and emotions through writing, which she found especially useful shortly after her CF diagnosis.

Journaling has had an immense positive impact in dealing with my emotions related to cf. I began writing like a mad woman after my diagnosis and it was the only place I had to release my thoughts and feelings. At the time I couldn't yet talk about cf with people and even now that I can I find there is nothing better than a journal to vent to because it's hard to get people to understand...without feeling judged. [Jessica]

Engagement with habitual mindful writing via journaling enabled Jessica to consciously attend to her challenging thoughts, feelings, and emotions in the present moment by allowing these thoughts to surface. Mindful writing was used as a coping mechanism by Jessica and others to deal with the emotional impact of CF, helping such individuals to achieve clarity over their emotions, improving their psychological wellbeing.

In addition to formal mindfulness practice, several individuals also described how informal mindfulness practices support positive wellbeing, with these involving individuals generalising their mindfulness skills into everyday life situations. For example, Dani and Krystal explored the positive connection between mindfulness and nature.

Even looking out the window at this huge tree we have in our yard, I start to feel peaceful again, and breathe easier. [Dani]

I look around and see all the beauty in nature, the simple things in life give me the most pleasure, the smell of roses, the sunseting. [Krystal]

Such narratives indicate the health and wellbeing benefits of observing and attending to one's surroundings. Being mindful in nature and feeling connected to nature positively benefit emotional wellbeing, often creating feelings of happiness. Through informal mindfulness practice, individuals were able to cultivate a mindful awareness that could be applied to improve everyday situations.

Several adults discussed their experiences of becoming more mindful over time. The data demonstrated that some adults with CF, such as Bailey and Isobel, did not believe they would reach adulthood due to a lower associated CF life expectancy during their infancy. These individuals admitted to over-identifying with thoughts about the future, particularly relating to missing out on life experiences and premature death. However, Bailey developed the ability to live in the present moment and to be happier and more satisfied in life. Nonetheless, the increased

emotional burden of not only living with a reduced life expectancy, but also exceeding the CF life expectancy was clearly depicted by Bailey, Isobel, and others.

I wasted a lot of my 20s being depressed about dying and missing out on life. And then, it didn't happen. I basically had a midlife crisis in my early 30s because I didn't know what to do with the fact that I was still here! These days I try to live one day at a time and just put one foot in front of the other, and I'm much happier for it. [Bailey]

Lots of people with CF, particularly over 30, have trouble. It's no wonder, right? We feel like we're supposed to be dead, and the side effects and symptoms are sometimes overwhelming. [Isobel]

Those who practised informal mindfulness and integrated a mindful awareness into their daily life demonstrated better emotional wellbeing and the ability to cope with the acceptance of associated complexities related to the reduced life expectancy for people with CF.

Overall, this theme explored the different ways that people with CF use mindfulness, with the positive impact of mindfulness upon emotional wellbeing being evident. The physical and psychological health benefits of mindfulness practices described in this theme are explored more fully in the second theme, relating to mental health.

Physical and Psychological Health Benefits of Mindfulness

This theme examines how mindfulness practices used by people with CF contribute to improved psychological wellbeing and physical health. The data indicated frequent discussions concerning increased levels of stress, anxiety, and depression within the CF community, particularly during the occurrence of health-related CF exacerbations. Whilst some individuals discussed coping with periods of decreased mental health via mindfulness-based interventions, others also discussed the use of combined mindfulness practice alongside drug treatment. Cai and Noah experienced anxiety and used mindfulness to successfully achieve deep relaxation and control.

I used to have panic attacks. Once I learned a few meditation and breathing tricks, I was able to get control over the attacks and only rarely have them now. [Noah]

For some, the benefits of mindfulness meditation were exceptional in minimising the onset of stress, anxiety, and depression to the point where some people described terminating drug treatments due to the positive effects of mindfulness practice on psychological wellbeing.

I get anxious and moody/agitated. I saw a therapist who taught me how to do deep relaxation/meditation and this helped a lot. I also went on zoloft and ativan, but after a few months I went off those because the deep relaxation, especially when I could feel the anxiety coming on, helped. It's amazing how quickly it can work. [Cai]

These individuals felt empowered to read and manage their own symptoms, highlighting the long-term benefits of mindfulness practices.

Whilst some people discussed the benefits of mindfulness relating to increased voluntary control over negative emotions and anxiety, others like Nial who practised mindfulness meditation and suffered from depression appeared to benefit from the increased ability to simply observe and detach from one's negative (and positive) experiences. Feelings of depression were commonly expressed within the data, with several people discussing the difficulties of coping with the inevitability of frequent and rapid health declines resulting from CF, as well as the awareness of a reduced life expectancy.

It's [meditation and yoga] done wonders for me and my depression. Meditation and yoga help me to put things in perspective; they help me to be 'the observer'; they help me to not feel so attached to the things that happen to me - both good and bad. [Nial]

Mindfulness practices such as meditation and yoga can help the CF community cope with depression by enhancing the skills of observation of thoughts and feelings and greater cognitive flexibility. Often, discussions concerning the overwhelming nature of CF resulted in personal descriptions related to increased (negative) instances of rumination and over-identification with one's thoughts and feelings, exacerbating feelings of depression. Mindfulness allowed the ability to detach from these unpleasant thoughts and feelings and to develop more adaptive responses to stressful or negative situations, resulting in increased mental clarity.

Several individuals initially used mindfulness practices to improve psychological wellbeing related to stress, anxiety or depression and subsequently felt a beneficial physical impact, particularly in lung function and breathing.

I have noticed that the [yoga] positions are great for postural drainage and I've noticed a positive difference in the way I have been breathing. I am looking forward to my doctors appointment, I'm hoping that I'll see my FEV1 [lung function] stable or have even an improvement in my lung function. [Valerie]

For Valerie and others, moving mindfulness practices such as yoga helped to loosen the thick mucus in their lungs so it could be removed easier via coughing, allowing them

to breathe more easily. It was apparent how mindfulness practice facilitated hopefulness in individuals for a future with improved physical health (particularly lung function capacity) and quality of life.

With CF impacting the respiratory system, many people discussed breathing problems they have encountered, and the associated anxiety felt. Consequently, several people mentioned how they favoured the concept of breath awareness and breath control within mindfulness practices, discussing the long-term physical health benefits of deep breathing where the effects were also apparent outside of the practice. Paula, who also practised yoga and meditation, discussed the importance of feeling in control over her breath.

What I really love about yoga is how it focuses on breathwork. The most important thing is making sure you focus and have control over your breath; you push yourself but only as long as you have breath control. This is SUCH a valuable thing to learn for someone with CF. Learning to control your breath and calm yourself via mediation is SO helpful when you are really sick. [Paula]

Through yoga and meditation, people were able to enhance the skill of focussed attention and learn how to control their breath, reducing stress and increasing calmness during exacerbations. With many people discussing the problematic and anxiety-inducing nature of not feeling in control over their breath, the value of mindfulness practices which support breath control demonstrated increases in both physical and psychological wellbeing.

Whilst many were aware of their reduced psychological wellbeing, they often felt that their physical symptoms were taken more seriously by both clinicians and the general population. Ella and others discussed the lack of psychological support available.

The statistics are undeniable that we show depression and anxiety at a much higher rate than the general population. I know I would have benefited from seeing my mental health issues as legit symptoms right alongside my cough and greasy poop. I'm almost 30 with CF, and it wasn't until about 2-3 years ago that someone actually asked me about my feelings as they relate to CF. [Ella]

The data demonstrated an increased need for clinicians and the general population to perceive both mental health and physical health as important, illustrating the need for proactive psychological support for people with CF.

Overall, this theme demonstrates both psychological and physical health benefits of mindfulness practice. Mindfulness practices were perceived as separate from medical treatments such as physiotherapy, which enhanced feelings of normality, increasing the likelihood of continued

engagement. The increased need for proactive mental health measures including the teachings of mindfulness is apparent. It is plausible that improved mental health could be facilitated through self-care practices, with the importance of mindful self-compassion being discussed in the next theme.

Benefits of Mindful Self-Compassion

This theme explores the integration of mindfulness and self-compassion within the CF community. Data demonstrated that many people become particularly stressed during periods of health fluctuations, with individuals describing engagement in self-care practices as a means of coping. For Elisha, self-care derived from an array of activities that made her feel recharged and happy.

Mostly things I've always enjoyed that I've learned can be my own version of self-care. Listening to music, reading a favourite book, sketching, [additional redacted activities], talking to a friend, when I'm stressed saying no thanks sometimes to an invite so I can stay in and recharge. Self-care doesn't have to mean bubble baths, candles, and face masks I've learned; more about finding the thing that makes you feel recharged and happy. [Elisha]

Elisha described a range of activities that many other participants also discussed, with Elisha highlighting how her ability of saying "no" to other people was a version of self-care, demonstrating the notion of mindful self-compassion, which enables such individuals to respond to challenges in their life with self-kindness and understanding.

Similarly, others explained the importance of ensuring self-care in relation to employment. Many described how employment impacted negatively upon both physical health and psychological wellbeing, especially when self-care practices and self-compassionate behaviour were not considered. Discussions often related to excess tiredness, frequent health declines, and an inability to balance employment with CF needs. Savannah recognised how the demands of her job were impacting negatively on her health following increased exacerbations, resulting in the difficult decision to leave her full-time role in social work to prioritise her health care needs.

I had a very hard time deciding to stop working, partially because I loved [redacted information about job role] and didn't know what I'd do without it, but also because I felt like I was being a wimp and wasn't sick enough. Well, I easily qualified for Social Security as well as disability from my employer, and it was SUCH a relief to just listen to my body and take care of myself instead of forcing myself to work and wearing myself out. [Savannah]

For many people, including Savannah, the decision to stop working proved a very emotionally challenging time. However, Savannah demonstrated the benefits of mindful self-compassion through her ability to respond to her feelings of inadequacy and confusion around leaving work, with both care and understanding. Often the CF community recognised an increased need for self-care due to their physical and psychological health declines associated with their employment, but rarely left their employment or implemented self-care practices to look after their health. This recognition, but lack of implementation of prioritising self-care, highlights a need for the development of more ways for the CF community to effectively practice mindful self-compassion.

Some people discussed how self-care practices were used to aid challenging aspects of life with CF, including treatment adherence and exercise. Upon having successfully completed the required treatment or exercise, rewarding oneself with a "treat" proved beneficial in increasing the likelihood of further compliance with the task as highlighted by Bonnie, Wynter, and Cameron.

If you made a list of your treatments on a calendar. When you finish 4 weeks of treatments in a row, you get to reward yourself with your treat. Repeat every month. (Or if this is too long, try a smaller treat every 2 weeks.) [Bonnie]

I would reward myself after a treatment was done as well. (Favorite cup of tea with honey etc.) [Wynter]
Exercising with a friend also really helps as it keeps you accountable and then treat yourselves by going out for a bite to eat afterwards. [Cameron]

For several people, treatment compliance and completing exercise and/or physiotherapy often felt like a burden which interfered with one's personal, social, or work life, reducing their motivation to continue such tasks on a daily basis. However, when people implemented self-care practices and approached treatments, exercise and physiotherapy with mindful self-compassion behaviours and attitudes, adherence, and motivation for the task improved.

Some discussed the benefits of understanding that CF-related challenges were not only experienced by themselves, but that others with CF also encounter the same or similar difficulties too. The use of CF online forums was often discussed as beneficial in regard to allowing the CF community to share and read direct experiences from others, avoiding the risk of cross infection through physical socialisation.

Sometimes when I read what other people are going through (being in a similar situation, I mean) it helps me relate and reflect, knowing I'm not the only person going through this. [Darius]

We need to remind ourselves that everyone has problems, some worse than CF. Thankfully, I think CF

gives us an advantage in the way we see the world and more of an appreciation for life, many times. Everything you're feeling is so normal. [Salina]

The concept of common humanity (an element of self-compassion) was apparent through individual's ability to understand that suffering and challenging life experiences are part of the shared human experience. This appreciation reduced feelings of isolation and allowed individuals to recognise that suffering is something which many others with CF also go through, with common humanity further evoking positive feelings of gratitude and appreciation for life.

Overall, this theme highlights the importance and benefit of mindful self-compassion where being both mindful and self-compassionate lead to greater physical and psychological wellbeing of the CF community. Combining the understanding and skills of mindfulness and self-compassion, one is able to acquire a powerful tool for emotional resilience. This theme demonstrates the increased need for the development of opportunities which allow the CF community to effectively prioritise self-care and practice mindful self-compassion. The following theme will further consider how mindfulness can be used to benefit people with CF.

Future of Mindfulness for People with CF

This final theme explores how mindfulness practice can fit the needs of a growing adult CF population. Individuals discussed their interest in mindfulness practice, negative experiences with mindfulness, as well as the increased need for proactive support measures. Despite the largely positive physical and psychological health outcomes of mindfulness practices discussed, on some occasions, mindfulness practices were negative due to the difficulties associated with breath, focus, and physical positioning. Whilst many discussed the benefits of mindfulness practices upon breathing, Paisley and April described the challenges of attempting to focus and control one's breath during meditation and yoga.

When I've gotten all zoned out, the instructor starts talking about breath as a way to relax and it of course, has the opposite effect. I instead notice all the catches and cracks and pain associated with breathing (not to mention the coughing) and it stresses me out. Because of this, I practice this stuff alone at home and when I do seek out a video or something to guide me I kinda ignore the breath stuff. [Paisley]

I've been into the idea of meditation for a while, I've tried a few exercises but most seem to require "just focusing on your breathing" and I dunno about you all, but that's like the least relaxing possible thing for me to focus on. I just hear all the crackles and feel how labouring it is and stuff. [April]

Several discussed the general difficulties of breathing due to CF, however for some, these breathing challenges became exacerbated during mindfulness practice which brought a preoccupied awareness to breath, particularly in meditation and yoga. The inability to focus and control one's breath during mindfulness practice reduced the relaxation effects and instead increased both feelings of stress and anxiety.

Others discussed the challenges associated with successfully forming exercise positions, predominately concerning yoga. Several discussed how they really enjoyed the practices of yoga. However, CF symptoms unfortunately interfered with the ability to continue with yoga as demonstrated by Noah, Becky, and Kendra. Yoga became increasingly difficult during instances of ill-health, particularly when one's port was accessed (when taking intravenous antibiotics).

I do yoga, and I noticed some positions felt uncomfortable, accessed or not, and so I've tended to shy away from those or alter them just slightly. [Noah]

I tried yoga, but had to stop when I started coughing up blood during some of the positions. Up until then, I enjoyed it so much. [Becky]

So I'm having issues with coughing up blood anytime I get my heart rate up. It's annoying and some of the most basic exercises set it off. I can't lay on my back at all and doing yoga even makes it happen...even the most low key poses...I really want to work out and get stronger but the bleeding is preventing me from doing that. [Kendra]

Whilst Noah discussed the need to alter his yoga positions due to his CF, unfortunately for Becky, the discomfort felt whilst completing yoga ended with termination of the practice. The inability to successfully create the positions led to feelings of frustration as these individuals demonstrated a genuine desire and determination to practice yoga. Whilst for some people, as demonstrated in prior themes, yoga proved particularly beneficial during ill-health. This highlights the need for increased education around alternative mindfulness practices to be offered on a proactive basis for those who demonstrate interest in mindfulness, particularly less physically demanding mindfulness practices which could be continued during periods of ill-health, such as mindfulness meditation.

Despite the negative experiences with mindfulness practice, several people within the CF community, including both Paisley and April, expressed an interest to continue exploring and partaking in future mindfulness practices. April and Paisley sought guidance and advice within the online CF forums to explore alternative methods of mindfulness, which did not focus as heavily on breathwork. These discussions around the suitability of mindfulness highlight the interest of the CF community, regarding involvement in mindfulness practices. There were several mindfulness

alternatives to breathwork proposed within the data including mobile phone application-based methods and the benefits of sound-based meditation and yoga where sound is used as an anchor rather than breath.

Another app I use which doesn't focus on breathing is Pzizz. "Relax melodies" has binaural beats, relaxation exercises and a bunch of sounds (rain, ocean etc). Headspace is a mindfulness app that always has good reviews but I haven't tried it. Lastly "the honest guys" on YouTube. [Gared]

Advances in the availability of mindfulness practice were discussed with an appreciation of how YouTube and mobile phone applications have greatly increased accessibility. The need for psychological support relating to mindfulness practices embedded within CF care, which include methods beyond breath-focussed methods, was clear. Maya further demonstrated an interest in incorporating mindfulness into her daily life.

I am trying to be proactive with my health & join groups for support etc. I have recently joined one in-person group in my hometown for people with chronic illness who wish to incorporate Mindfulness into their daily lives, also follow some CF blogs & have now joined a couple of forums like this one, which seems great! [Maya]

This theme highlights the clear and continued interest in mindfulness practice by the CF community, providing insight into which psychological interventions could be embedded within the future of CF care. Overall, these data illustrate the increased need for proactive psychological support (incorporating the teachings of mindfulness and self-care) for the CF community with individuals reporting that the impact CF has upon their mental health is equal in severity to their physical health.

Discussion

The researchers explored the CF communities' attitudes, beliefs, and experiences with different methods of formal and informal mindfulness practices, coupled with a variety of consequential health and wellbeing benefits. Furthermore, the researchers examined the integration between mindfulness and self-compassion through self-care practice. This leads to a consideration of the challenges associated with mindfulness and how future practices can be adapted to suit the needs of an adult CF population. The findings of this research highlight the benefits and practicality of mindfulness practices and self-care techniques for individuals with CF, signifying how mindful awareness can help people to

reshape their relationship with negative emotions and overall mental health.

Data suggested that individuals with CF proactively engage with a variety of mindfulness practices, including both formal and informal methods, often as a means of coping with the complexities of life with CF, and with the hope of achieving better health and wellbeing. During an era of CFTR modulator therapies where disease characteristics are changing, adults with CF are currently experiencing an increased emotional burden of not only living with a reduced life expectancy, but also exceeding the CF life expectancy, as highlighted in this study and recent prior research (Kauser et al., 2022; Keyte et al., 2022). With the understanding that this will most likely become a shared reality for many adults with CF, an increased need for additional psychological support and education is required for the growing population of older patients with CF. Following the largely positive health and wellbeing experiences of mindfulness within this study, we believe that encouraging the CF population to use self-care techniques and acquire mindfulness skills would be beneficial in better supporting their emotional wellbeing, acceptance of coming to terms with a new reality, and impacts upon identity.

Generally, people described some of the key concepts of mindfulness particularly involving observation, recognition, and present-moment awareness, which corroborate the well-known depiction of mindfulness (Kabat-Zinn, 1990). Experiences of mindfulness practices that predominantly involved meditation, yoga, journaling/writing, and informal practices related to improved emotional and psychological wellbeing, and physical health, which was also in line with previous literature (Birtwell et al., 2019; Carmody & Baer, 2008; Dimidjian & Segal, 2015; Smyth et al., 2018).

There is a clear gain to be had in CF healthcare by acknowledging and incorporating the use of mindfulness practices, which may be particularly attractive to individuals concerned with the stigmatisation of conventional treatments for mental health. Consistent with the literature, it was evident that many people with CF experience heightened levels of negative emotions and decreased psychological wellbeing (Quittner et al., 2014). This illustrates the increased need for preventative mental health measures incorporating the teachings of mindfulness practices and self-care techniques. Present findings suggested people were less likely to view mindfulness practices as part of their medical regimen and more so as a socially acceptable behaviour, allowing people with CF to have a normal identity. This is particularly important with previous research demonstrating that some individuals with CF struggling with their mental health may not feel comfortable in seeking the required support, so instead they may engage in health risk behaviours in a desire for normalcy (Keyte et al., 2020). Therefore, increased involvement with mindfulness practices that people from the general

public also engage in may improve the prospect of people with CF seeking proactive support to improve their mental health and overall quality of life.

The current findings illustrated the benefits of mindful self-compassion in relation to health and wellbeing, supporting prior literature which demonstrated that quality of life and self-compassion were positively correlated in people with CF (Kauser et al., 2021). In the present results, when individuals described being able to acknowledge and turn towards their feelings and need to “recharge”, the first element of mindful self-compassion, i.e. a mindfulness awareness, was apparent. When these individuals responded to their challenges with kindness and understanding, often through self-care behaviours, the second element of mindful self-compassion, i.e. self-compassion, was apparent. This corroborates prior literature that explored the concept of mindful self-compassion, highlighting that a mindful awareness is initially required to understand when one is suffering, in order to then extend compassion towards the self (Neff & Germer, 2013). Within the present data, despite a recognition of the importance and necessity, there was still a clear lack of implementation in prioritising self-care, highlighting an imperative need for increased methods to enable people with CF to effectively practise mindful self-compassion.

Whilst it is important to explore the positive benefits of mindfulness practices, it is equally imperative to consider the negative experiences and challenges to collectively consider the future of mindfulness practice for people with CF. There is a generic overlap between themes in regard to the suffering that people with CF share, with the data suggesting three main difficulties associated with mindfulness-based practices that include breathwork, focus, and physical positioning, which interfered with acquiring the desired positive health benefits. Whilst some people discussed their challenges with mindfulness, many of these same individuals also used the forums to then seek advice from the CF community to find mindfulness practices more suitable to their specific needs. The demonstrable interest in mindfulness practice was clear, yet it was also evident that the CF community did not feel educated about the different mindfulness practice options available, particularly for those who struggled with breath-focussed mindfulness practices. Given the importance and commonness of breathing behaviour in meditation, in particular its role in generating concentration (Lutz et al., 2008), clinicians should offer mindfulness practices with a variety of different anchors beyond breath. Focus on the breath may be overcome through different practices, an alternative example being sound, which was experienced well by the CF community within the present analysis but requires further exploration. Overall, increased awareness and education regarding mindfulness practices would be extremely beneficial in enabling people to make more informed choices regarding the suitability of proactive

mindfulness and self-care practices for themselves. These may include, but are not limited to, the consideration of formal mindfulness practices, informal mindfulness practices, breath-based practices, sound-based practices, mindful writing, moving meditations, and sitting meditations.

Furthermore, the findings from the current study offer practical contributions to the CF and mindfulness literature, providing preliminary insights into how a personal practice or the design of a pilot study could be structured to better meet the needs of a CF population when exploring mindfulness practices. There are valuable findings around how particular objects of attention of mindfulness, such as the breath, can take on additional meaning for this population given the respiratory difficulties experienced by people with CF. CF is a chronic respiratory condition, largely characterised by shortness of breath and coughing (National Health Service, 2022); thus, the discrepancy between attentional anchors (i.e. breath) in mindfulness practice was a considerably important finding, especially when considering the most taught meditative anchor includes the observation of ones’ breath (Shonin et al., 2014). This is an important insight that researchers and practitioners should be more aware of. The findings demonstrate how core mindfulness practices of body and mind can take on second-order meanings for populations like those in CF, based on how these individuals see their bodies and breath. This noteworthy discussion point requires further research to unpack the barriers and enablers of different mindfulness practices, paying particular attention to meditative practice, based on the conflicting perspectives identified within the present study on how breath practices, yoga practices, focusing on breathing, and using the breath as an anchor can be helpful or harmful. Following the latest developments of modulator therapies such as Kaftrio, we recognise how this may further change the dynamic between body and breath considering the improvements in physical health for some people with CF, which requires additional research to explore the enablement of practising different mindfulness practices, and their effectiveness. This is increasingly important in a currently changing landscape for people with CF, due to the availability of new CFTR treatments and the consequential implications for mental health and wellbeing including a changing identity, survivor guilt, and anxiety for a future that they feel under-prepared for, further highlighting how mindfulness practices might be useful for this population (Keyte et al., 2022).

Limitations and Future Research

There are two limitations to this study. The first limitation refers to the lack of background information we have regarding the data. Whilst IMR data proves valuable in obtaining a natural and unobtrusive method of data collection (Wang et al., 2016), we had to take the data at face value due to an

inability to follow up answers with the individual, unlike in qualitative interview research where researchers can use probing questions. Thus, we were unaware of individuals' motivations, previous experience with mindfulness, or self-care practices beyond the information provided. It may be interesting for future studies to explore a wider variety of keywords related to mindfulness, with a particular focus on some of the mindfulness-related activities that were not detailed within this study such as mindful colouring books and more informal practices such as washing dishes. It could be beneficial to use interviews or focus groups to achieve a greater understanding into how these practices can be used to enhance CF quality of life. The second limitation is that data collection was conducted prior to the availability of the latest CFTR modulator drug, Kaftrio; therefore, experiences may differ today for people with CF. Whilst the findings are still applicable considering the growing adult CF population, a re-examination of forum data post the availability of Kaftrio could explore any potential differences in experiences with mindfulness.

Overall, this research provides an understanding of how mindfulness can be used to improve the quality of life for people with CF, paying particular attention to the direct experiences of the CF community to propose the integration of mindfulness into CF care. Mindfulness enables individuals with CF to develop skills that help to approach and reshape their relationship with negative emotions, build resiliency, and improve wellbeing. Due to its accessibility, cost-effectiveness, and versatility (Mantzios & Giannou, 2019), mindfulness proves to be an exceptional tool which HCPs should encourage amongst their CF patients on a proactive basis. With CFTR modulators continuously improving health and life expectancy of the growing adult CF population, this is even more imperative today.

Author Contribution SK, MM, RK, and HE designed the study. SK executed the study and conducted data analyses. SK, HE, MM, and RK interpreted the data. SK wrote the initial manuscript. MM, RK, and HE critically reviewed and edited the manuscript. All authors approved the final version of the manuscript. All authors gave their final approval of the manuscript.

Availability of Data Due to ethical concerns, supporting data cannot be made openly available.

Declarations

Ethics Approval Ethical approval was obtained by the University's Faculty Ethics Committee (3275 /R(A) /2019 /May /BLSS FAEC), and with the 1964 Helsinki Declaration and its later amendments. This manuscript does not contain any studies with animals.

Informed Consent Consent was not gained for this study as publicly available, open-access data were used. Both CF forums used for data collection contain open-access data where individuals viewing posts do not require a password or an account; therefore, the data were consid-

ered public. Consent was not gained from the individuals across either of the sites due to the understanding that public open-access data were used for data collection in line with the guidelines by the British Psychological Society (2021). Identifying information was removed and data were redacted in places to protect privacy and to reduce the risk of potential harm (British Psychological Society, 2021).

Conflict of Interest The authors declare no competing interests.

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