



# Care4Parents: An Evaluation of an Online Mindful Parenting Program for Caregivers of Children with 22q11.2 Deletion Syndrome

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## Abstract

**Objectives** Parenting a child with special healthcare needs is associated with significant caregiver stress. Previous research has found that parenting stress and mental health impact outcomes for children with chronic illnesses. Despite this, the importance of managing parents' stress is often overlooked in the management of chronic health conditions, such as 22q11.2 deletion syndrome (22q11DS). The objective of this study was to investigate the acceptability of the mindful parenting program, Care4Parents.

**Methods** This study was designed as a non-randomised pilot study evaluating the acceptability of an online mindful parenting program Care4Parents, specifically designed for those parenting a child with special health care needs, including medical complexity. There were 20 participants recruited to take part, which involved attending eight online weekly group sessions for 2 h, with a follow-up after 2 months and practice exercises between sessions. Interviews were conducted with 12 participants after the completion of the program. Using attendance data and thematic analysis of semi-structured interviews, the study aimed to determine if the online program Care4Parents would be experienced by participants as acceptable.

**Results** Results indicate preliminary evidence of acceptability, with adequate retention and themes emerging from interviews highlighting the appropriateness of content, delivery, and perceived benefits, including personal growth, peer support, and enhanced coping. 'Barriers to engagement' was also a theme, and adjustments were discussed based on participant feedback to further enhance the program.

**Conclusions** The analysis of the data indicates that the program was deemed acceptable to participants, therefore warranting further research using quantitative measures to confirm findings and investigate effectiveness.

**Keywords** Mindful parenting · Velocardiofacial syndrome · Caregiver stress · Parenting · Special healthcare needs · Online intervention

Parents of children with special healthcare needs face profound and ongoing stress due to their child's condition. Compared to parents of typically developing controls, research has found that parents of children with chronic illnesses tend to report higher levels of parenting stress (Cousino & Hazen, 2013). Furthermore, amongst parents of children with chronic health conditions, higher levels of

parenting stress can predict poorer adherence to recommendations for the management of their child's condition, as well as increased child emotional and behavioural problems (Cousino & Hazen, 2013). Given parental stress can significantly influence outcomes for children with chronic health conditions, enhancing parents' capacity to cope and manage stress should be considered an integral part of childhood chronic health condition management. Despite this, parental distress is often overlooked, with the management of the child's symptoms of the primary health condition typically prioritised by health professionals and parents themselves.

One chronic health condition associated with significant caregiving burden is 22q11.2 deletion syndrome (22q11DS). Previously known as DiGeorge or velocardiofacial syndrome, 22q11DS is a genetic disorder caused by a deletion on the long arm of chromosome 22

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(McDonald-McGinn et al., 2015). The clinical manifestations are diverse due to variability in the expression of phenotype but commonly include cardiac anomalies, immune deficiency, craniofacial anomalies, hypocalcaemia, and developmental delays, including intellectual developmental disorder, all of which significantly impact daily activities and quality of life (Boot et al., 2023; McDonald-McGinn et al., 2015; Óskarsdóttir et al., 2023). Individuals with 22q11DS are also significantly more likely, compared to neurotypically developing children, to meet the diagnostic criteria for neurodevelopmental conditions such as autism and attention deficit hyperactivity disorder (ADHD) and mental health conditions such as anxiety disorders in childhood and psychotic disorders in adulthood (Hoeffding et al., 2017; Schneider et al., 2014).

Overall, while research shows that 22q11DS has a significant physical and psychological impact on those with this condition, there is hardly any research on the impact this condition has on parents and carers. The few studies that have been done show worrying results. Lived experience studies of parenting a child with 22q11DS have found that isolation and stigma are common experiences for parents, along with progressive loss of independence and disenfranchised grief (Goodwin et al., 2015, 2017a, 2017b). Parental stress levels are typically higher than for parents of typically developing children, and parenting a child with the syndrome impacts most aspects of the parents' lives (Briegel & Andriuschky, 2021; Briegel et al., 2008; Walkowiak & Domaradzki, 2023). Parents' stress and distress can be linked to the complexities of needs presented across different domains, including physical and psychological needs and manoeuvring health care, disability, and educational systems (Morishima et al., 2022). In another study, significant associations were found between parental mental health and the risk of psychopathology in children with 22q11DS (Sandini et al., 2020). This longitudinal study found that higher parental levels of anxiety and depression symptomology were associated with higher internalising and externalising symptoms for their children. Parental anxiety and depression at baseline predicted child psychopathology at follow-up; however, cross-sectional relationships of parental and child psychopathology were stronger than longitudinal ones. The authors suggested that this is indicative of bidirectional interactions between parent and child psychopathology, whereby child and parent mental health issues are likely to exacerbate one another. Although there were also significant associations between parental and child psychopathology amongst typically developing children, the associations were significantly stronger for individuals with 22q11DS. This finding provides a strong rationale for addressing parental wellbeing in the management of characteristics associated with 22q11DS to improve developmental, physical, and mental health outcomes for both parents and children.

Mindfulness-based interventions have been investigated as an approach to support parents of children with special health care needs to manage their distress and subsequently improve outcomes for children indirectly (e.g. Bazzano et al., 2015; Benn et al., 2012; Dykens et al., 2014; Lunskey et al., 2017; Lunskey et al., 2015; Neece, 2014; Roberts et al., 2020; Singh et al., 2016; Singh et al., 2021; Singh et al., 2006). Mindfulness has been defined as 'awareness that arises from paying attention on purpose, in the present moment, nonjudgmentally' (Kabat-Zinn & Kabat-Zinn, 2014). Mindful parenting extends this type of intentional present-moment awareness to the parent-child relationship (Duncan et al., 2009). Several papers have outlined models of mindful parenting and mechanisms by which mindfulness training has the potential to influence the quality of parent-child interactions to bring about change in mental health and child behaviour (e.g. Ahemaitijiang et al., 2021; Bögels et al., 2010, 2014; Dumas, 2005; Duncan et al., 2009; Kabat-Zinn & Kabat-Zinn, 1997, 2021). Mindfulness-based interventions include mindfulness-based stress reduction (MBSR), developed to assist people in coping with chronic illness (Kabat-Zinn, 1990), and mindfulness-based cognitive therapy (MBCT), developed for treating depression and reducing recurrent depressive episodes (Segal et al., 2002). Such generic programs can successfully be used by parents to improve mindfulness skills and reduce stress. However, drawing from both MBSR and MBCT, Bögels and Restifo (2014) developed a more specific curriculum adapting these approaches to the domain of parenting in an eight-week program designed to be delivered by mental health practitioners. Key adaptations in this program include mindfulness of everyday activities focusing on day-to-day parenting activities, the inclusion of short self-compassion exercises, exercises on limit setting and strategies for reconnecting after parent-child conflict. Evaluation of this program in mental health care settings has found low dropout rates, reductions in parental stress and improvements in parent and child internalising and externalising symptoms (Bögels et al., 2014). This program has since been evaluated in a range of different settings and found to have positive impacts on parents and their children (Meppelink et al., 2016; Potharst et al., 2021).

Several studies involving parents of children with developmental disabilities or delays have found evidence of reductions in parenting stress, negative mood states and anxiety after participating in mindfulness-based interventions either focussing on 'self' or 'self-as-parent' (e.g. Anclair et al., 2018; Bazzano et al., 2015; Benn et al., 2012; Chan & Neece, 2018; Dykens et al., 2014; Lo et al., 2017; Lunskey et al., 2017; Minor et al., 2006; Neece, 2014; Roberts et al., 2020; Singh et al., 2006). A few studies have specifically investigated generic mindfulness interventions focussed on 'self' for parents of children with chronic health conditions. For example, Minor et al. (2006) found that while caregivers

of chronically ill children (e.g. diabetes, asthma, epilepsy) showed elevated levels of stress and mood disturbance at baseline, these decreased significantly after participating in an eight-week generic MBSR program. Similarly, Anclair et al. (2018) found that parents of children with chronic disease or functional disability showed significant decreases in stress and burnout symptoms after participating in an eight-week structured mindfulness program based on MBSR and MBCT. Interestingly, 'spill over' effects were also found in a randomly controlled trial by Neece (2014), which found that after parents of children with developmental delays participated in an eight-week MBSR program, their children were reported to display less attention and behaviour problems compared with children of waitlist control parents. She has also found that parent and child-related changes are maintained at 6-month follow-ups after an MBSR intervention (Chan & Neece, 2018).

In a small study, focused specifically on mindful parenting, Heapy et al. (2022) reported improvements in parenting stress of parents of children with eczema or psoriasis. Additionally, some studies have also provided empirical support for mindful parenting interventions resulting in indirect changes in child behaviour such as significant decreases in aggression, noncompliance, and self-injury amongst children with autism (Singh et al., 2006); and decreased aggression as well as more appropriate social interactions with siblings amongst children with developmental disabilities (Singh et al., 2007).

Despite the growing body of evidence for the effectiveness of mindfulness interventions for parents of children with developmental delays and chronic health conditions, no studies to date have explored interventions specifically for parents of children with 22q11DS. Given parents of children with 22q11DS report experiences of isolation and stigma, a parenting program specifically targeting these parents would provide an opportunity for their caregiving stress to be addressed in an environment of shared understanding and experiences. Furthermore, there is limited evidence for mindful parenting interventions conducted with community samples or online. Given 22q11DS is relatively rare, occurring in around one in 2000 live births (Blagojevic et al., 2021), recruiting enough participants in one location to run a mindful parenting group for this population may not be realistic in the Australian context, given the large geographical distances and small population. Additionally, given the significant demands of caring for a child with 22q11DS, it may not be feasible for these parents to attend a group program away from home. This provides the rationale for exploring whether delivering a mindful parenting program online, tailored specifically to parents of children with 22q11DS, is something that would be feasible.

Feasibility studies are undertaken to explore the potential of an intervention trial, including if it is a study that can or

should be done and what methods are useful (Bowen et al., 2009; Eldridge et al., 2016). One way to answer these questions is through conducting a pilot study (randomised or non-randomised) where the intervention and study design is implemented on a small scale to see whether it can be done in practice and is suitable for efficacy testing (Eldridge et al., 2016). Another aspect of feasibility is the concept of *Acceptability* which refers to how the target population perceive the intervention, in particular if it is viewed as suitable, agreeable, and/or satisfactory (Bowen et al., 2009; Sekhon et al., 2017). More specifically, acceptability explores how the participants feel about the intervention, if they understand the purpose of the intervention, what they must give up engaging with the intervention, if they think it is effective and if they are confident in performing the behaviours required to participate in the intervention (Sekhon et al., 2017).

Despite research showing the importance of managing caregiver distress to improve outcomes for both caregivers and children with special healthcare needs, interventions for caregivers are overlooked, and more research into appropriate evidence-based interventions is needed. The present study was conducted as a non-randomised pilot study evaluating Care4Parents; an 8-week online mindful parenting program developed specifically for parents of children with 22q11DS modified and adapted from the evidence-based Mindful Parenting program designed by Bögels and Restifo (2014).

In line with guidelines by Bowen et al. (2009), we conducted a focused feasibility study that explored the acceptability of the online Care4Parents program as experienced by participants. It is hypothesised that the program will be deemed acceptable as evidenced by participant engagement in the program, affective attitude towards the program and perceived appropriateness and effectiveness. Engagement in the program will be demonstrated by enrolment and attendance data. Affective attitude towards the program and perceived appropriateness and effectiveness will be determined through qualitative interviews with those who participated in the program.

## Methods

### Participants

Participants were initially recruited via social media posts on the 22q Foundation Australia and New Zealand Facebook page. There were 45 people who expressed interested in participating in the Care4Parents program. Of those, 27 participated in an intake interview, 20 commenced the program across two groups and 12 participated in a follow-up interview. Participants needed to be over the age of 18 and have a child with a 22q11.2 deletion syndrome. Participants

were excluded if they had a major mental health disorder that would impact participation in a group of this nature. The inclusion criteria for participating in a follow-up interview was having participated in at least one of the Care4Parents sessions, with the rationale being that it would be important to not only interview participants who had completed the program but also those who dropped out.

Guidelines for qualitative research in feasibility studies suggest a small sample size between five and 20 participants may be reasonable; however, diversity within the sample may be more important than the number of interviews conducted (O’Cathain et al., 2015). Therefore, while all 20 participants were invited to participate in interviews, the target sample size was 10 to represent at least 50% of the total sample to capture diversity in demographics and engagement with the program.

Of the 20 participants who commenced the program, 15 were female (75%), and five were male (25%). Ages ranged from 28 to 52 years ( $M = 44$ ,  $SD = 6.81$ ). In terms of the highest level of education, one participant had completed a postgraduate degree, 12 participants had completed an undergraduate university degree, two had completed vocational qualifications e.g. Technical and Further Education (TAFE) course, and four had completed secondary education (Year 12 Higher School Certificate or equivalent). One participant did not disclose level of education.

Participants’ children with 22q11.2DS ranged in age from 2 to 22 years ( $M = 11$ ,  $SD = 6.53$ ). The age of the child at which diagnosis was received varied widely from birth to adolescence, with the average age of receiving a diagnosis being 49.5 ( $SD = 47.08$ ) months. Of the 12 participants who completed interviews, nine were female (75%) and three were male (25%). Interviews ranged in length from 9 min 35 s to 41 min 1 s ( $M = 20:30$ ,  $SD = 9:33$ ).

## Procedures

The content of the Care4Parents program was developed from Bögels and Restifo’s (2014) evidence-based eight-week mindful parenting program. During the development phase, one of the authors (SD) consulted with the Mindful Parenting program developer (Susan Bögels) on the proposed content, which was used with permission. Two authors (SD and LC) have completed a Mindful Parenting teacher training. SD is a mindfulness trainer MBSR/MBCT. Adaptations were made to increase suitability for carers of children with special healthcare needs, specifically focusing on 22q11DS, the area of expertise of authors LC and SD. This included delivering the program online to make it more accessible, adapting examples and exercises to make them more relevant to the lived experiences of parenting a child with 22q11DS, such as including more psychoeducation on stress, the circle of security, and including a component on *live loss*, a term

used to describe the lifelong feeling of loss and grief someone experiences when they or a loved one are confronted with chronic illness or disability (Keirse, 2020).

The content was developed into a trainer’s manual, which the facilitators used to lead sessions, and a participant workbook. The participant workbook summarises key content from each session and includes additional reading and instructions for the home practice exercises for each week. A summary of the topics covered each week and practice exercises are presented in Table 1. Each session was 2 h in length.

Demographic information and attendance data were pre-collected by the program facilitators. Participants who provided consent to be contacted were invited to participate in an interview and provided with an information statement and consent form via email. Interviews were conducted via phone or Zoom video call between four and nine months after participating in the Care4Parents program. Interview transcripts were partially provided by Zoom software and corrected manually via audio file cross-reference. Transcribed interviews were assigned a pseudonym and de-identified to protect confidentiality. Participants were provided a copy of their interview transcript to check for accuracy and confidentiality if they opted in for this. The interviews and transcriptions were completed by student researchers, protecting the privacy and confidentiality of participants from the researchers who developed and delivered the program.

## Measures

A semi-structured interview schedule was designed to be conducted flexibly and responsively. This was determined to be the most appropriate method of data collection for gaining insight into individual participants’ experiences and perceptions of the intervention to answer research questions related to acceptability. Questions in the interview schedule covered topics such as what participants liked about the program, their perception of different components, how they felt about the structure and delivery of the program, barriers to participation, if they found the program beneficial and how, and if they noticed any changes since completing the program. The interviews were completed by author SS.

## Data Analyses

Thematic analysis was used to interpret qualitative data as per the methods described by Braun and Clarke (2021). Familiarity with the transcripts was obtained by initially concurrently listening to the audio files and reading the transcripts, checking for accuracy. Transcripts were then imported into NVivo (version 12) computer software and active reading of each transcript was completed, making annotations and notes on potential emerging themes and

**Table 1** Care4Parents program session summary

Session	Topics covered	Practice exercises
1. From Automatic Pilot to Parenting with Attention	Parenting with extra challenges Psychoeducation on stress Beginner's mind	Looking at your child with a beginner's mind Mindful eating Mindfulness in daily routine
2. Taking Care of Yourself at Difficult Moments	Observing the body during (parenting) stress Body scan Window of tolerance The seven qualities of mindfulness	Mindfulness in daily routine with child Body scan Lying yoga Awareness of the breath Diary of pleasant experiences
3. Responsive vs Reactive Parenting	Holding and avoiding Staying with parenting stress	Diary of stressful experiences Sitting meditation with awareness of body and breath 3-min breathing space
4. Curiosity and the Circle of Security	The circle of security The body and connection with our child	3-min breathing space with child Reflection on attachments with child and own parents Sitting meditation with attention to breath, sounds, thoughts Standing yoga
5. Parenting Patterns and Schemas	Origins of patterns in parenting Schema modes	Noticing schema modes 3-min breathing space with daily stressor Walking mediation Sitting meditation with attention to breath and emotions
6. When Your Child Gets a Diagnosis; Dealing with Expectations	Live loss Compassion for yourself as a parent	Awareness of loss-focused and recovery-focused moments Sitting in choiceless awareness Self-compassion meditation
7. Setting Limits from Love	Setting boundaries	Setting boundaries Meditation of choice
8. A Lifetime Parent with Falling and Standing Up	Suggestions for staying mindful Energy givers and takers Personal meditation plan	Implementation of 8-week personal meditation plan

codes. The next phase involved applying codes to the data and labelling features of the data that are of interest and relevant to the research question. Codes were then refined and grouped into overarching themes and subthemes. These themes and subthemes were then reviewed, refined, and defined with an additional researcher (LC) through robust discussion until agreement was reached. For credibility and trustworthiness, in addition to following the methodological steps described by (Braun & Clarke, 2006, 2021), developments, comments and reflections at each step were recorded in memos in NVivo as a project journal that could be reviewed by other members of the research team.

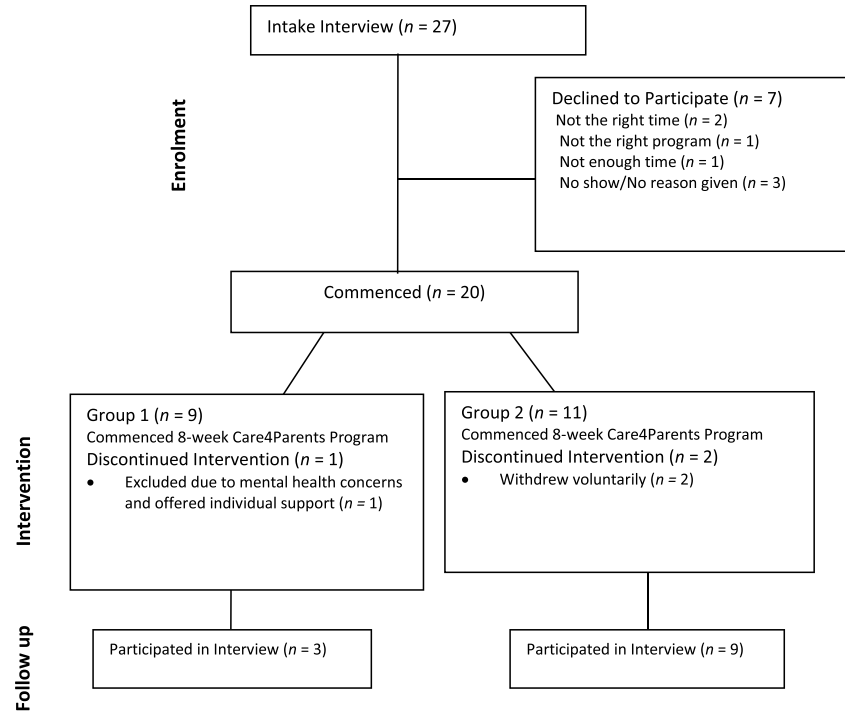
Both inductive and deductive approaches to coding were used. For example, the coding of data related to how participants responded to the content and delivery of the program was more deductive, driven by the overarching research question, specific interview questions asked, and theoretical definitions of acceptability. However, the coding of data related to the perceived benefits of participating was more inductive, with codes and themes emerging from the data rather than preconceived questions or theories.

## Results

### Enrolment and Attendance

From those who participated in the intake interview, there was favourable uptake, with 74% going on to commence the Care4Parents program. Reasons given for not commencing included not being the right program at the right time due to dealing with other issues ( $n=2$ ), not having time ( $n=1$ ) and not being suitable ( $n=1$ ). Others did not give any reason for not commencing and did not notify facilitators ( $n=3$ ). Of the 20 participants who commenced the program, two discontinued after session five. One participant was advised not to continue the group program due to their mental health at the time and was offered individual therapy instead. Therefore, 17 completed the program (85%). A flowchart summarising recruitment and retention is shown in Fig. 1. Of the eight weekly sessions, participants attended between three and eight sessions ( $M=6.42$ ,  $SD=1.57$ ). More than half (60%) attended at least seven out of eight sessions. All attended the follow-up session 2 months later.

**Fig. 1** Flowchart of participants' enrolment and retention



**Acceptability: Qualitative Thematic Analysis**

The data obtained from the interviews were organised into two overarching themes with subthemes to best capture the acceptability of the Care4Parents program as experienced by participants. These themes and subthemes are summarised in Table 2. Quotes reported to support the themes are reported verbatim, with any identifying information altered or removed and names replaced with pseudonyms.

**Perceived Benefits**

**Personal Growth** Participants described participating in the program as enlightening, encouraging self-reflection and increasing hope and empathy. For example, Peter stated,

**Table 2** Themes and sub-themes for qualitative thematic analysis to evaluate program acceptability and feasibility

Organising theme	Sub-theme	Meaning
Perceived Benefits	Personal growth	Participant references of changes in mindset and/or habits experienced as life-changing or transformative
	Peer support	Sense of validation, comfort and community connecting with other people dealing with the same challenges
	Relationships	Participants who were joined by their partner, reported additional benefits in their relationship with their partner in their coparenting journey
	Enhanced coping	Participant descriptions of applications of mindfulness skills and changes in how they respond to parenting stress with more awareness and less reactivity
	Self-compassion	Having more compassion for one's own feelings and challenges
	Self-care	Recognising the importance of prioritising self-care
Engagement with Intervention	Appropriateness of content	Participant understanding of the content of the program and perception of relevance of the program overall and the individual components
	Barriers to engagement	Participant reasons for missing sessions and difficulties with homework tasks, including how participants adapted tasks to fit their capacity
	Program delivery	Participant feedback regarding how the program content was delivered and suggestions for improvement

Lifelong knowledge I think I've come out of it with, and I just feel a better person for it. Like I feel like I walk a little taller if that makes sense?

For some, although the process was experienced as worthwhile, it could be confronting at times. Such as Jenny, who stated,

I got quite a lot out of it. I was gonna say I enjoyed it, there were times where it didn't feel enjoyable because it was, you know, confronting or made me think or made me question things. So it was, it wasn't always enjoyable, but it felt like personal growth, and it felt like a good thing to be doing.

There was also recognition from participants that small changes can be life-changing but need to become routine. Ingrid described,

I had tapped into mindfulness before, but it was such a great reminder that mindfulness is available to us all the time... Bringing those little snippets of mindfulness, so awareness to my everyday situations, was really life-changing and I need to go back and read the manual and do all those things again, because when I was doing it, I felt wonderful... if something's going to be life-changing, you have to build it into your routine, you have to go build it into your little daily habits otherwise it just walks by the wayside.

**Peer Support** Although peer support was not a target of the intervention, this was one of the most reported themes, with all participants reporting liking or benefiting from this aspect. Participants described valuing hearing from other parents with similar lived experiences of the challenges of parenting a child with 22q11DS and felt they could share things that they might not otherwise share with their existing support networks. For example, Ingrid responded,

Sometimes I can be more honest with strangers cause I'm likely maybe not going to see them again or you don't want to burden family and friends with your really raw, honest thoughts and experiences. Yeah. So, I actually liked that, that I'm building a rapport with someone, although initially uncomfortable, you felt like part of a community by the end of it. And really it, it was so great to be able to relate to people that are going through different things, and to not feel alone.

Some parents had never met or had the opportunity to connect with other families of children with the same diagnosis. For some parents, they found it inspiring and encouraging to hear from others who were perhaps further ahead

in receiving a diagnosis and their parenting journey. For example, Demi commented,

It was good to know others, how they are travelling along, and what little changes did they make in their lives, so that I could learn from them... It was a very good learning experience to be interacting with other parents who are uh, having a similar kind of journey in their parenting.

Conversely, for other parents, connecting with other parents meant they were able to acknowledge their progress and achievements, such as Taylah, who reflected,

I also learned that I had come a long way because my child's a lot older than some of the others that were starting out, and I realised how far I'd actually come.

Although social connection was one of the strongest themes emerging as a perceived benefit, some participants would have liked more opportunities to connect socially in the program. For example, Jenny commented,

I think it would have been good, helpful to have more opportunities to just chat with other parents and maybe that's different for parents who potentially are already really well connected in a network... But I think it lost a lot of that and it meant like, you know, I've come away not having ongoing connection with anyone.

Ingrid suggested that having an online platform or group would be helpful to keep in touch with the other parents in the program, strengthen connections and encourage each other to keep up with practices learnt in the program:

But some sort of after support program, or Facebook group, or something that you can keep in touch with these people without it being too intrusive... I don't know how long it would last, but just something that people can check-in with and say, how's everyone going? Um, what strategies did we use this week um, which have helped you... There were other people, I guess that I felt more of a connection with so if you had a little community from that course, I think that might be helpful to actually keep up the activities.

**Relationships** Several participants described the benefits of both parents participating. Parents who participated as a couple appreciated that being exposed to the same concepts and content from a neutral third party opened new conversations about parenting and allowed co-parents to prompt and remind each other during moments of parenting stress to respond more effectively. For example, Peter stated,

It gave us the opportunity to talk about things that we probably had never really addressed which was...good for us...doing it as a couple was fantastic for us, which I really enjoyed.

Participating together also seemed to strengthen or grow relationships. Ingrid reported,

It was wonderful for me to see my husband realise that change is possible, and even just little, little changes make a big difference... I have more respect and admiration for my husband for putting his hand up to do it, and actually doing it, and actually enjoying it...seeing his willingness to embrace things to take our family forward was, yeah, I have newfound respect for my husband.

It was apparent to participants that fewer fathers were participating, and it was suggested by Georgia that it would be beneficial for more men to participate:

Maybe it'd be good to have more men. And I think in particular men...you know they find it harder to take direction on this stuff, on parenting.

**Enhanced Coping** Parents who participated in the program reported improvements in coping skills and learning to be more patient and accepting. Participants described an increased sense of calm and less reactivity in response to parenting stress. For example, Hayley stated,

I've calmed down a lot. I'm able to accept the unavoidable and just carry on as best we can.

Georgia highlighted greater awareness contributing to enhanced coping:

It's made me aware of my parenting style and my triggers, and what I can do to get a better outcome, keep my kids happier, and not just continue with this cycle of escalation... I think I'm a calmer parent. I don't get so worked up about the kids' behaviour so much. So that's a good thing... I just feel a bit more in control, I guess, and that's, that's great.

**Self-Compassion** Participants described greater acknowledgement and compassion for their own difficult emotions and experiences because of participating in the program. For example, Cory commented,

[I am] more compassionate about the challenges that we're going through as parents... more compassionate for my own feelings that come up now in my own

behaviours and actions, and in a way, those actions are actually changing as a result.

Additionally, participants described that the program reinforced the importance of taking time to prioritise self-care, an act of self-compassion, which may otherwise often be overlooked when parenting a child with special healthcare needs. For example, Eva reflected,

I think it just reinforced how important it was for me to have time to myself and take care for myself, and because up until not that long ago I always felt guilty about taking time for myself, and you know, and prioritizing that over spending time with the kids... I know how important now it is to, you know, look after my own mental health, in order to function as a person and as a mum.

Similarly, Taylah commented,

I think what resonated with me was taking care of myself first so I can take care of others. That's something that we all forget to do, and especially parenting a child with a special need.

One participant, Ingrid, even emphasised that self-care can be lifesaving in the context of managing the stressors associated with parenting children with special healthcare needs:

A reminder that self-care is essential, absolutely essential... [it] can potentially save your life. If you're living in such a stress situation and you're not doing anything to care for yourself, you can go to dark places.

## Engagement with Intervention

**Appropriateness of Content** Parents appreciated that the program overall was tailored to the challenges associated with parenting a child with additional needs. For example, Brittany commented,

I think the thing that was the best part of it for me was that coming into it, it was all tailored specifically for people like myself who had a child with a disability, and the therapists who ran the program were very understanding or knowledgeable about the struggles and the differences that families who have a child with disability face, you know, in relation to mainstream families... the advice and the suggestions were, were quite appropriate.



Conversely, parents also commented on the broader relevance and appropriateness for any parent, such as Ingrid:

I think every parent should do it. I don't think it's just for people that have kids with special needs.

Two participants with older children noted that they found some of the content more relevant for those with younger children. Such as Hayley,

Some of it was based upon the younger kids. Which is fine. I didn't dismiss it, but it wasn't relevant to me.

Taylah expressed it would have been more useful when her child was younger:

I probably needed something like this, maybe about ten years ago, when I really was going through something that I couldn't deal with... but I feel that there's many benefits from people starting out all with younger kids. So that's the only thing I'd say. I wish that was around a long time ago for me.

Only one participant referenced confusion in regard to some of the content. Cory stated,

For me there was a couple of times I sort of felt a little bit, what would you say, a little bit confused by the content, but I think that was only, that was... because of my own level of education, I think. So, it wasn't really what the program... it's just how I felt about things were a little bit confusing to me.

Some participants reported that at first, they didn't realise that the program was more focused on controlling and reflecting on their own responses, rather than parenting strategies. And although this may have been unexpected or uncomfortable initially, it was ultimately experienced as valuable. For example, Georgia commented,

When you go into it you think are they going to give me strategies about how to get my child to behave, or whatever. But it's all about controlling your own responses. Yeah. And I think if you, you said that to us up front that would turn a lot of people off so that was really good, how it was done that it was just, you know, you go through and then you come to this self-realisation yourself.

Frank commented,

I found it daunting to begin with because I didn't fully understand that it was more for the parents rather than the child. But once I realized that I was quite comfortable with it, and um, enjoyed the new things that we had to do.

Participants were asked in the interview if there were specific components of the program that did or did not resonate with them and why. Feedback related to this as well as the number of participants who stated each topic resonated most and least is presented in Table 3. Participants were also asked about topics they felt would have been helpful to include or would like to see included in a follow-up program. Suggestions included dealing with guilt or failure associated with a sense of not living up to expectations, strategies for grief management and caring for more than one child with additional needs.

**Barriers to Engagement** Many parents described struggling with the time commitment required to fully engage with the course content and homework exercises. For example, Jenny stated:

It was beneficial, but I don't think I got the optimum value out of that, because I wasn't able to commit or engage with it as fully as the course was designed to be engaged with.

It was also more challenging for parents with multiple children with special needs and single parents. Brittany reflected,

I think sometimes it was hard for me to find the two hours because I was really tired, I'd walk straight in from work and um, you know. Then, being separate from my family because I've got two kids with special needs, not one. That was a bit of a strain.

One single parent who commenced the program, Alice, did not complete the course because of difficulties attending:

I started off strong, and then it just got too tricky to organize the evenings. But it was really good, and I can see a huge benefit in it. So yeah, but it, being a single parent, seven o'clock on an evening is just too hard. Too hard... So, I'd love to participate again. But at a different time.

Reasons given for missing sessions included child or parent illness, holidays, special events, competing work commitments, feeling overwhelmed and prioritising spending time with children over participating.

**Table 3** Participant feedback on specific topics covered in the program

Topic	Resonated most	Resonated least
Session 1: Beginners Mind	<p>2 participants endorsed</p> <p><i>The exercises around looking at your child with a beginner's mind, and just being in the moment and just appreciating what's happening in the here and now was a powerful thing that I realised, you know, how little I have been doing in day-to-day life. So that was a very good thing. —Jenny</i></p> <p><i>You're sort of dropping the past and you're just completely in the present... it's a wonderful experience. It's like you're looking, you're looking at someone as if they're a newborn child. You know when you pick up a newborn, there is no baggage, you know, there's no history. They've done nothing, and you just get the sense that they're perfect you know, and to be able to replicate that with my kids, because we've got kind of stressful history... when [my child] senses that I'm just looking at [them], and I'm only seeing the good, I'm only seeing what begs to see in that present moment without judgement, it's very powerful for a child that has felt judged all [their] life because [they are] so impulsive and yeah, lacks that social, those social skills and whamot. —Ingrid</i></p>	0 participants endorsed
Session 1: Parenting on automatic pilot	<p>3 participants endorsed</p> <p><i>...you start yelling at them, they're yelling back at you that kind of thing. Um, that's something that, yes, we were falling into the trap of, yelling back at our children. And yeah, I'm really mindful of that now, so that's really helped us a lot... and [facilitator] was always talking about changing the dance, and so I always remember that, you know, change the dance. Don't, don't get involved in this kind of cycle of you know who did what right and where they went wrong or whatever. Yeah, that was quite powerful for us. —Georgia</i></p> <p><i>Because it's the story of everybody's life. We're all so busy, we all of a sudden, we get through the day, but we don't know what we did that day. We don't know how we got to where we got to um, but we just did it. —Hayley</i></p>	0 participants endorsed
Session 2: Window of Tolerance	<p>1 participant endorsed</p> <p><i>The window of tolerance, um, that resonated um, quite significantly with me because I actually experience it often on an almost daily basis. So, having that understanding I now know when I need to calm down or remove myself from the situation. —Frank</i></p>	0 participants endorsed

**Table 3** (continued)

Topic	Resonated most	Resonated least
Session 3: Responsive vs Reactive Parenting	<p>3 participants endorsed  <i>The bits around... in those kind of moments of tension and stress where your child's having a really difficult time and therefore, you're having a really difficult time and how to kind of break that down or step out of that mode to not just both inflame the situation, you know, and how to prepare for some of those moments were probably some of the most practical bits.</i> —Jenny</p> <p><i>As in, you know, just don't go quickly to react. Um. And I think that's really helpful for, for all parents, not just parents with, you know, special needs kids, to just control, check your own emotions first about well, how you're reacting to this. Yeah, that, that was very powerful for me.</i> —Georgia</p>	<p>0 participants endorsed</p>
Session 4: Circle of Security	<p>1 participant endorsed  <i>I was able to understand... the circle of security, more than I had before. I looked at that before um, with another psychologist, but I hadn't been able to make it fit, I didn't really understand it, I didn't appreciate it. But the way this was presented I was able to grasp at it better.</i> —Brittany</p>	<p>2 participants endorsed  <i>I mean the circle of security I had done that in earlier work with child psychologists, other work we've done.</i> —Cory  <i>I think the thing was that I'd looked into a lot of things around parenting trying to find some help for me anyway. So, the circle of security wasn't new.</i> —Georgia</p>
Session 5: Parenting patterns and schemas	<p>3 participants endorsed  <i>The component where we talk about, we talked about our own history, of growing up with different parents, and how that plays into our current um, behaviours as parents. So yeah, it's definitely improved our um, acceptance of each other and also in terms of the kids. Yeah, just more acceptance of their behaviour and, and how we respond to it.</i> —Cory</p> <p><i>Because understanding that the, the way I was brought up is probably the way I'm trying to bring up my children.</i> — Frank</p>	<p>1 participant endorsed  <i>.. Some of the things about, you know, how you were parented... though, that's really relevant... it didn't help me in any way. If anything, it just kind of was like, well, why can't I be as good as a parent as my parents were?</i> —Georgia</p>
Session 6: Live Loss	<p>2 participants endorsed  <i>I found it most relatable in that, you know, that was an area that we probably didn't spend much time thinking about until the course, and it just helped to understand those areas and the emotions associated with them, and sort of moving towards acceptance was a really helpful, helpful part of that.</i> —Cory</p> <p><i>I found that was really helpful, because I think in my mind, I was trying to get over the grief and move on but in actual fact there's grief at every stage... there's new grief that comes up all the time. And then that's okay, that's just part of the process, and acknowledging that was really helpful, because I find it does affect my mental health where I'm constantly grieving these little losses, for my [child].</i> — Ingrid</p>	<p>2 participants endorsed  <i>I guess the grief and loss were not as applicable to me... I've had grief and loss but at the same time, I think the other ones... I had more in common with and more experience with.</i> —Eva</p>

Table 3 (continued)

Topic	Resonated most	Resonated least
Session 6: Self-Compassion	4 participants endorsed <i>I acknowledged the fact that I should be kind to myself... self-compassion was another thing which I thought was very, very, very much resonating to what was happening to me at that time. —Demi</i> <i>I think what resonated with me was taking care of myself first so I can take care of others. That's something that we all forget to do, and especially a child with a special need. —Taylah</i>	0 participants endorsed
Session 7: Setting boundaries	0 participants endorsed	1 participant endorsed

Some participants described certain ways they had either adapted or selectively engaged with exercises to suit their lifestyle, capacity, and preferences. For example, Eva stated,

Probably with the body scan, and the breathing one, they're the two main ones that I do... because they're quick and I can generally do them like, say here at work, or you know, any time really. Whereas I find it very difficult to listen to people in my ears, so you know, people talking continuously. And if, if someone's, if I don't like the sound of someone's voice, then I just tune out, I can't do it. So yeah, there's a few little issues there that um, that I just managed to tweak a little bit, I guess.

Ingrid described finding it helpful to implement brief exercises in her daily routine:

Little snippets of self-care, which were manageable um, instead of putting pressure on myself to, I don't know, meditate for half an hour a day, that I just put these little prompts in my day. So, for example, I still do it when I get to work after I drop the kids off, it's just a moment in my car to have a mindful minute and just to, to breathe, and not to think about anything else.

Peter described his personal adaptation of meditation practice he continues to implement daily:

Even now I find that I still keep meditating, but I've kind of had my own spin on it if you like, just being aware of, of how I'm feeling so I just play a little bit of light music. Just, just calming music, and that helps me yeah. Just, just probably do that three, four times a day for a minute or two, when I'm driving and yeah, just that sort of thing.

**Program Delivery** Participants reported that they found the course well structured. They liked how each session started and ended with a meditation, and each week explored a different topic that could be experimented with over the next week and had the program workbook to look back on. For example, Jenny commented,

Having the resources, the written material was really good. I like reading things and thinking through things rather than just sort of hearing things orally on the spot. So being able to, you know, hear something, and then reread it or have further resources and things like that. Um, and having a sort of structure where you're experimenting with different, I

guess, themes or topics or exercises at different times to expose you to different things and see what kind of fits for you was good.

However, it was also suggested that having two weeks between sessions may have given participants more opportunity to implement exercises and explore concepts between sessions. Jenny stated,

If it had been, you know, maybe two weeks between sessions there would have been more opportunity to explore some of those things. Yeah, I can see you'd lose some intensity and for some people who've got the time on their hands and are committed you just kind of want to keep that momentum going. Um, but for me, I think I would have got more out of it if it had been paced a bit more so that I could have engaged with the different topics more along the way.

Ingrid also indicated a preference for fortnightly delivery:

Probably at the time, I would have preferred fortnightly. But then I can appreciate that that would not have worked for everybody, because people like momentum.

Participants generally found the length of sessions to be acceptable, but many struggled with fatigue and competing family demands in the evenings. For example, Cory commented,

Sometimes it was a difficult time of the day with, you know, with putting kids to bed at that time, and things like that, and just saving enough energy, I guess, to pay attention at the end of the day. Um, so probably that was, I guess, partly a challenge. But yeah, we managed to overcome that.

Although some participants said they would have preferred to participate in a program face-to-face, the online delivery was still found to be acceptable. For example, Frank stated,

It would be nice if you could meet face to face. But then, Zoom is the next best thing, and I don't think it can get any better than that. I didn't have any complaints or feel that this could be better.

Others noted that the online delivery increased accessibility, enabling them to participate. For example Jenny, who stated,

Doing it remotely enabled participation in that if I had to travel somewhere, it wouldn't have happened. Um, even though I know you get other things out of being together in person in a room, but it was ultimately, ultimately more accessible being remote... being able to meet people, you know across Australia and so on probably speaks to its accessibility.

Some participants liked that there wasn't too much pressure about completing the homework exercises; however, others felt that people should have been held more accountable for engaging with homework tasks. For example, Georgia stated,

The homework was really important, and I know that you know we're all adults there, and you know we've invested our time so sure we should do it, but I think they needed to place more emphasis that you know every week like, hey, guys, and like hold us accountable. Because you know I mean I didn't do it all, but I was probably even one of the better ones. Some of them just did stuff all, and I know we're all busy and got kids with extra needs and whatever. But it doesn't matter like if you're going to do this program, get the most out of it, you've really gotta invest the time. So, I know that's painful for the facilitators... but I think they need to build something else in there about trying to get everyone to do it, I don't know how they'd do that.

Conversely, Jenny stated,

While the time commitment involved, if you were doing all of the exercises and activities and homework diligently would have been a lot and was beyond what I was able to commit... you weren't kind of thrown out of the group for not doing it, or you know, not getting into trouble or feeling like, made to feel like a failure or anything for not having been able to fully commit.

## Discussion

This study aimed to determine if the online Care4Parents program would be experienced as acceptable to parents of children with 22q11DS. Uptake, attendance, and low attrition attest to the general feasibility of the program. Acceptability is indicated by participants' affective attitudes towards the program expressed in interviews, perceived appropriateness of content and perceived effectiveness expressed through reported benefits. Thematic analysis of qualitative interviews identified that participants perceived the program

to be beneficial to them in many ways, including experiences of personal growth, peer support, enhanced coping and enhanced self-compassion. However, feedback related to barriers to engagement, the content of the program and how it was delivered also gives insight into adjustments that could be made to the program in the future to enhance acceptability further.

## Perceived Benefits

Perceived benefits identified by participants in this study are consistent with previous research on mindful parenting programs for parents of children with additional support needs. For example, in Bazzano et al. (2015) study investigating an MBSR program adapted for parents and caregivers of individuals with developmental disabilities, results indicated significant improvements in measures of mindfulness, self-compassion and personal growth after the program. Similarly, Benn et al. (2012) found that after mindfulness training parents and educators of children with developmental challenges and special learning needs showed significant increases in mindfulness, self-compassion and personal growth compared to waitlist controls at program completion, which was also sustained at 2-month follow-up. In both studies, increases in mindfulness were associated with reductions in stress. The perceived benefits subthemes in our study of enhanced coping, self-compassion and personal growth mirror these earlier findings that have been identified on quantitative measures in larger trials.

The other subtheme identified as a perceived benefit by participants in this study was peer support. Although this wasn't necessarily targeted by the content of the program or mindfulness training, participants benefited a lot from this aspect. In the study by Goodwin and colleagues on the positive and negative lived experience of parenting a child with 22q11DS, parents described psychological distress driven by stigma and social isolation (Goodwin et al., 2017a, 2017b). This suggests why the peer support element was so important to participants in our study. Furthermore, Goodwin et al. (2017b) identified that psychological growth was a positive aspect and potentially a protective factor for parents of adults with 22q11DS. Given personal growth and peer support were perceived as benefits of participating in the Care4Parents program, it is possible that participation in the program could enable or be a trigger for psychological growth and may ameliorate some of the negative aspects that come with parenting a child with 22q11DS, such as isolation and stigma, which contribute to psychological distress. Many participants wanted more opportunities for social connection with each other. One participant suggested having an online platform to connect outside of the weekly sessions, such as a WhatsApp or Facebook group. While the current study did set up a Facebook group, it was rarely utilised. perhaps as

the participants expected the trainers to post as opposed to the participants taking ownership of the group. This could be considered as an optional add-on for participants to enhance peer support and reduce social isolation, without taking time and focus away from delivering the program content. Finally, those who participated as a couple felt this was beneficial and that it strengthened their relationship with one another.

## Engagement with Intervention

### Program Content

In terms of the program content, participants appeared to find the content relevant and acceptable overall. Results indicate individual differences regarding what topics resonated most and least with participants. Some participants revealed in the interviews they had already been exposed to certain themes through engagement with previous interventions, and therefore, these topics did not resonate as strongly for them. Differences in personal and family histories also impacted the relevance of some topics. For example, while parenting patterns and schemas resonated strongly with three participants, one participant did not resonate with this topic as they felt they were unable to identify negative patterns in how they were parented. Conversely, they felt disappointed they were not living up to how well they were parented. Additionally, while the concept of live loss resonated strongly for some, others did not resonate with this concept, or it was something they felt they had already reconciled. The only topic that no participants identified as resonating most with was setting boundaries. However, this does not necessarily mean it should be excluded, as only one participant identified not finding it relevant, but perhaps it could be expanded upon or tailored to make it resonate more with parents of children with 22q11DS.

Two participants expressed the opinion that some of the program was more tailored to parents of younger children. However, given the actual content is broadly applicable to the experience of parenting, it is possible that participants perceived this from some of the examples given (e.g. taking a child to get a blood test, child having a tantrum in a supermarket). Parents of older adolescents or young adults may have felt left out when other parents in the group were discussing their preadolescent children. This highlights that without prior experience with mindfulness, participants might be quite literal in their interpretations rather than understanding the broader applicability and generalising to their own experiences. In the future, facilitators should consider making sure metaphors and examples used when delivering the program are applicable and including scenarios relevant for a range of different child ages. To make the program further relevant to the individuals participating, facilitators could consider exploring what individual's

greatest parenting challenges are and how their children react in certain situations. Examples used could then be tailored to these experiences.

### Barriers to Engagement

Regarding barriers to engagement, participants who were interviewed in this study described difficulties with being available for both the weekly sessions and the practice tasks between sessions. This is unsurprising given the significant demands associated with parenting a child with 22q11DS and a barrier common to any mindfulness training. Participants referenced greater use of shorter practices or adapted practices to fit into their daily routines. When Lunsky et al. (2015) piloted a mindfulness-based group program for parents of adults and adolescents with developmental disabilities, they similarly identified that parents found brief and informal practices most practical, and completing assigned tasks between sessions was difficult. In response to this, home practice expectations were modified, including providing audio recordings shorter in length for formal practices and placing more emphasis on informal practices that could be incorporated into life circumstances. The shorter audio recordings and some of the exercises encouraging practising mindfulness in daily life, such as the habit releaser exercise, were drawn from Williams and Penman's (2011) 'Mindfulness: Finding Peace in a Frantic World' (as cited in Lunsky et al., 2015; Williams & Penman, 2011). Parents who participated in this modified version of the program reported significantly lower levels of stress following the intervention, suggesting that participating in a mindfulness group program can lead to stress reduction even without committing to practising longer formal meditations regularly. However, participants in the study by Lunsky et al. (2015) did not demonstrate significant changes in measures of mindfulness despite the significant reductions in stress. This could indicate that longer formal meditation practices are required for significant measurable increases in trait mindfulness. Alternatively, it may reflect that the measures used were not sensitive enough to change or administered too soon for changes in mindfulness to develop. Indeed, Benn et al. (2012) found that increases in mindfulness observed on self-report measures immediately following mindfulness training grew larger upon follow-up assessment two months after the intervention.

Although it may be reasonable to include longer formal meditations within the sessions to expose parents to these practices in the Care4Parents program, expecting them to be able to do these practices regularly in their own time may not be realistic. To reduce barriers to engagement and enhance feasibility, the Care4Parents program could benefit from similar adaptations as made by Lunsky et al. (2015), focusing more on embracing mindfulness in daily life and

providing shorter options for guided mindfulness practices. Parents may be put off by expectations to complete 'homework' when they are already overloaded, so emphasising bringing mindfulness into daily parent-child interactions may enhance parents' self-efficacy regarding committing to the requirements of the program. However, options should also be provided for those parents interested in engaging with regular formal mindfulness practices, as this may enhance benefits for those who have the capacity to do so. Finally, many more mothers than fathers participated; while this is not uncommon in this type of research, it is important to look at how more fathers can be recruited, and factors that may encourage or discourage them from participating.

### Program Delivery

In terms of how the program was delivered to participants, feedback from interviews highlights several factors that should be considered for anyone planning to run a mindfulness program for parents of children with special healthcare needs. Firstly, online delivery is feasible and acceptable and enables parents to attend who otherwise might not be able to participate in an in-person group intervention due to caregiving demands and other barriers. Other research has found that outcomes are similar when the same mindfulness-based group intervention is delivered to parents in-person and online (Boekhorst et al., 2021; Lunsky et al., 2021), so as well as being feasible and acceptable, it may be similarly effective. Secondly, as parents have differing busy schedules, and parenting a child with 22q11DS can be associated with unpredictable demands, it may be worthwhile to consider running two groups concurrently, with the option to attend a daytime or evening session. The benefit of running two groups concurrently would be that if something unavoidable or unexpected comes up (e.g. medical appointment, child's needs require attending to), parents may be able to attend the other class rather than missing the content from that session. Increasing flexibility may increase feasibility and acceptability. Third, some participants stated they would have preferred fortnightly as opposed to weekly sessions, allowing them more time to experiment with concepts and exercises between sessions. Future research could compare acceptability and effectiveness of weekly versus fortnightly delivery.

### Limitations and Future Research

A strength of this study is that interviewing participants about their experiences engaging with the Care4Parents program allowed for the collection of rich and meaningful data. The information gained through this qualitative approach will be more useful in informing future design and delivery of the Care4Parents program than if rating scales had been

used in an attempt to assess feasibility and acceptability. However, reliance on qualitative data collected from participant interviews also has limitations. The reported benefits of participating are subjective, and there are possible biases in coding and interpretation (Anderson, 2010). Future research should investigate whether perceived benefits are supported by changes in quantitative measures, reflecting effectiveness. In addition, the use of semi-structured interviews, in which the interviewer follows a flexible interview guide rather than adhering to a set of specific interview questions, does have some limitations; for instance, the specific questions that are asked may vary across each interview, which may limit the consistency of information provided across interviews and limit the ability to make comparisons across participants. The format also allows for the use of leading, suggestive, direct, repeated questions, etc., which may influence the direction of the interview, thus reducing the overall reliability and validity of the extracted information (Newton, 2010). To improve the quality of the data collection, the interviewer was trained to stick closely to the scripted questions and to use prompts only when necessary. In addition, the interviewer was a registered psychologist with extensive experience in interviewing and building rapport while keeping the aims of the interview in mind. All verbatim scripts were reviewed by LC. Another limitation is that interviews were conducted between four and nine months after completing the program, and therefore, participants may not have been able to accurately recall their experiences of participating in detail. However, it did provide an opportunity to see if participants were still applying principles of mindfulness learned in the program and if they perceived any benefits to be lasting over this period. Finally, as previously mentioned, most participants were female. Therefore, results may be more reflective of how female parents perceived the program, and caution is warranted in generalising these findings to parents of all genders.

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**Data Availability** Data is available from the authors upon request.

## Declarations

**Ethics Statement** This research was approved by the Human Research Ethics Committee (HREC) at the University of Newcastle (H-2022–0038) and was carried out in accordance with the National Statement on Ethical Conduct in Human Research, Australia (<https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023>).

**Informed Consent Statement** Informed consent from each parent who participated in the study was obtained electronically and verbally at the start of each interview as per the HREC approval.

**Conflict of Interest** All authors declare no competing interests.

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