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Experiences of Parents of Children With Cerebral Palsy Participating in an Online Parenting Course Grounded in Acceptance and Commitment Therapy

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ABSTRACT

Background: To understand the experiences of parents of children with cerebral palsy (CP) participating in an online parenting course grounded in acceptance and commitment therapy (PACT) from an implementation perspective.

Method: Fifty-five parents from 50 families of children with CP (GMFCS I = 21, II = 15, III = 8, IV = 8, V = 3) participated in this mixed methods study. Families were drawn from 67 families participating in an RCT of PACT. Parents participated in a qualitative interview and gave additional feedback on 10-point Likert scales and open-ended questions via the course platform. The implementation analysis consisted of a thematic analysis as well as descriptive statistics, *t*-tests and ANOVAs to examine the impact of child age and motor functioning as potential barriers.

Results: Parents reported that they liked both the ACT content and the online format, and the modules were rated highly in the course feedback (7–9 on 10-point Likert scales). Parents reported positive changes for both them and their child. Parents of younger (2–5 years) children rated the videos from Module One Living a Meaningful Life more highly than parents of older (6–10 years) children. There were no other effects of child age or motor functioning.

Conclusion: Overall, parental response to PACT was positive, and child age and motor functioning level were not barriers. The online format of the programme and ACT content were well suited to the needs of this population. In particular, the ACT components of values and mindfulness were found to be particularly relevant. Implementation should focus on understanding that ACT can be psychologically challenging, ensuring that parents who need individualised support for intervention adaptation receive it, providing good support to address technological difficulties and building effective reminders into the intervention protocol.

Trial Registration: Australian New Zealand Clinical Trials Registry: ACTRN12616000351415

Abbreviations: ACT, acceptance and commitment therapy; CBT, cognitive behavioural therapy; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System.

Summary

- Acceptance and commitment therapy (ACT) is acceptable to parents.
- Increased awareness of discrepancy between values and current behaviour can be distressing.
- Online intervention is both acceptable to parents.
- Parents who need extra support need to be identified.
- Online interventions need to be trauma-sensitive.

Cerebral palsy (CP) is an umbrella term encompassing a group of physical disabilities affecting the development of movement and posture, with common comorbidities in speech (58%), intellect (42%), vision (39%), hearing (8%), and epilepsy (22%) (Novak et al. 2009). The diagnosis of CP may have a profound impact on the entire family resulting in complex care responsibilities, financial burden, limitations to parental occupation, public scrutiny, relationship stress between family members, parental grief, and social isolation (Bourke-Taylor et al. 2010; Pretorious and Steadman 2017; Ribeiro et al. 2016; Whittingham et al. 2011). Parental psychological flexibility—the ability to flexibly attend to one's child and notice what works with awareness of the present moment and psychological contact with long-term valued ends (Hayes 2004)—is associated with reduced parental stress, grief symptoms, and experience of parenting burden in families of children with CP (Whittingham et al. 2013b) as well as increased parental responsiveness in families of infants born preterm (Evans et al. 2012).

Psychological flexibility can be bolstered with a form of cognitive behavioural therapy (CBT) called acceptance and commitment therapy (ACT) (Hayes 2004). ACT has a growing evidence base (A-Tjak et al. 2014; Fang and Ding 2020), including for families of children with neurodevelopmental disabilities (Brown and Whittingham 2015; Brown et al. 2015; Brown et al. 2013; Corti et al. 2018; Hahs et al. 2019).

To date, there have been two RCTs of ACT with families of children with CP. The first found that ACT delivered in groups and combined with the behavioural parenting intervention Stepping Stones Triple P was associated with improvements in child behaviour, parenting style, child quality of life and parental adjustment compared to a wait-list control condition (Whittingham et al. 2016; Whittingham et al. 2014; Whittingham et al. 2013a). The second RCT with families of children with CP was the trial of an online parenting course grounded in ACT, Parenting Acceptance and Commitment Therapy (PACT). PACT showed an intervention effect for parent–child emotional availability, specifically for parental non-intrusiveness and child involvement (removed for de-identification). Importantly, this reflects aspects of emotional availability that are known to be at risk in families of children with neurodevelopmental disabilities, with children with disabilities initiating less and their parents becoming more intrusive to compensate (Barfoot et al. 2017; Biringen et al. 2005). Intervention effects were also shown for parental mindfulness and parent-reported child quality of life and on Likert scales measuring parental comfort with CP diagnosis, likelihood of seeking support, likelihood of maintaining social connections and meaningful living (Whittingham et al. 2022).

As an online intervention, PACT has the potential to address equity-of-access and crisis-resilience issues within the Australian health system by enabling access in regional and rural areas. That said, online interventions have their own barriers. A full understanding of the contextual factors (facilitators and barriers) affecting implementation can support the development and use of implementation strategies and enhance intervention utility (Safaeinili et al. 2019). This includes exploring intervention acceptability and appropriateness for the target end user. Acceptability and appropriateness are multifaceted concepts including user experiences and perceptions of the intervention, affective attitudes towards the intervention, perceived opportunity costs of the intervention, willingness to engage with the intervention, goodness of fit of the intervention with values and the burden of the intervention (Sekhon et al. 2017).

1 | Aim

This mixed methods implementation study builds upon the recently published RCT of PACT for families of children with CP (Whittingham et al. 2022). The aim of this study is to better understand the acceptability and appropriateness of PACT for parents of children with CP as well as to identify contextual factors acting as facilitators and barriers to implementation within the RCT (Safaeinili et al. 2019), both in terms of the use of ACT concepts and strategies and PACT as an online intervention. In addition, child age and child motor functioning will be tested as potential barriers in a quantitative analysis to identify whether PACT is only appropriate for specific sub-groups.

2 | Method

2.1 | Design

The current study was a mixed methods design, utilising qualitative (telephone interviews and written feedback given directly in the PACT course) as well as quantitative data (parental ratings of aspects of PACT content using Likert scales). Although participants were drawn from an RCT of PACT (removed for de-identification), this study includes participants allocated to both the PACT and the wait-list control groups. All participants received PACT after the duration of the RCT, and hence, parents allocated to the wait-list control condition had the same opportunities to give feedback on the PACT intervention as participants allocated to the PACT condition.

2.2 | Participants

A total of 67 families of children with CP participated in the RCT of PACT (Whittingham et al. 2022) Of those, a total of 55 parents from 50 families provided feedback as they progressed through the PACT course and were hence eligible for the current study. In addition, 23 parents from 23 families

also provided detailed qualitative feedback through telephone interviews. Families of children with CP were recruited through the (removed for de-identification) hospitals around Australia, the Australian Cerebral Palsy Register and word of mouth, with all intervention and assessment completed online. As PACT was delivered online, parents were required to have (1) reliable Internet access for the duration of the study; (2) a mobile phone; (3) an email address; and (4) access to videoconferencing.

2.3 | Procedure

Parental feedback was collected in two ways. Firstly, the ability to give feedback was built into the edX course itself. After every module, parents had the opportunity to rate the content in the module on Likert scales and also provide written feedback. Secondly, parents were invited to participate in a post-intervention interview. Interviews were conducted by the project managers (C.M. and A.W.) and averaged 17 min. Participation in this component of the study was voluntary with 23 parents choosing to participate. The interviews were transcribed by the second author (T.C.). Qualitative analysis was performed on both the written feedback and the interviews combined, firstly by the second author (T.C.), with confirmation by the first author (K.W.). Although both written feedback within edX and the qualitative interviews were used to inform themes, all the quotations used in this paper are from a qualitative interview.

2.4 | Intervention: PACT

PACT is grounded in ACT and focuses on parenting. PACT was delivered as an online course through the edX platform (www.edx.org/) and named PARENT101: Parenting with Purpose.

PACT was structured into four modules. The first three modules were Living a Meaningful Life, Willingness and Relating to Others (see Table 1). Modules were set fortnightly, with a

TABLE 1 | Content of the PACT edX course PARENT101 as delivered over 10 weeks.

Section	Weeks	Length (hours, approx.)	Title	Psychological flexibility process(es) targeted	Content
Module One	1–2	2	Living a Meaningful Life	Values Committed action	Exploring values Differences between values and goals Identifying parenting values Identifying values across life domains Noticing discrepancies between values and life Developing a recipe for a rewarding life
Module Two	3–4	2	Willingness	Experiential acceptance Psychological contact with the present moment (mindfulness) Cognitive defusion	Why do we struggle? Exploring how I struggle Creative hopelessness Willingness/experiential acceptance Cognitive defusion Mindfulness
Module Three	5–6	2	Relating to Others	Experiential acceptance Compassion Psychological contact with the present moment (mindfulness) Flexible perspective taking Committed action	Acceptance of self and others Compassion for self and others Perspective taking Mindfulness while parenting Effective relating to others (child and supports) When you slip
Practice	7–9	Variable	Practice	Practice	No specific content. Participant reviews content and puts aspects into practice in own life, according to their own goals
Review	10	1	Wrap-up	All	Putting the model together Reflecting on values in life again

Table reproduced in full from (removed for de-identification).

4-week practice period after the first 3 modules for parents to apply learnt material in their daily life (total duration of 10 weeks). After the practice period, there was a final review module. The course consisted of videos, written text, experiential exercises, interactive activities and journal exercises. In addition, interaction with other parents was offered through a moderated discussion board. By the end of the study, there were a total of 17 threads on the discussion board with an average of 2 replies.

Parents received three 'check-ins' with a psychologist via phone, email or text (one for each module) to remind them to progress through the course and to offer support in applying the course content and troubleshoot any concerns or issues. Families were encouraged to have a phone consultation if there were any concerns, questions, or difficulties in applying the content. Fifty-seven per cent of families received one phone consultation, and 1% received two. No families accessed all three offered phone consultations. The average length of the telephone consultation was 10 min, and it usually focused on addressing understanding of a specific aspect of the PACT content or tailoring of the intervention and application into the parent's everyday life.

2.5 | Measures

Demographics. Demographics were collected via a Family Background Questionnaire.

Gross Motor Function Classification System (GMFCS). The GMFCS is a classification measure designed to describe the level of gross motor functioning for children (Palisano et al. 1997). It consists of five levels, with Level V reflecting the poorest motor functioning. The parent-reported measure of GMFCS was used in this study and it is considered reliable and valid (Palisano et al. 1997).

Course feedback. Feedback questions were embedded into the end of each of the four PACT modules, as well as at the end of the course itself. Participants rated the module/course on a 10-point Likert scale in terms of (1) usefulness, (2) helpfulness of activities and (3) helpfulness of videos. Participants were also invited to provide written feedback on (1) what they found useful, (2) inclusiveness and (3) suggested improvements.

Post-intervention interviews. Willing participants completed a post-intervention semi-structured phone interview, whereby interviewers asked broad open-ended questions regarding the parent's experiences with PACT including what was helpful, any personal changes experienced, what was difficult, what could be done differently and experiences with the online format. Interviewers were psychologists involved in the study with experience in both ACT and CP (C.M. and A.W.).

Analysis.

The qualitative analysis consisted of a reflexive thematic analysis as outlined by Braun and Clarke (2006, 2021) including an interpretative reflexive process with recursive theme development. The aim was to understand the experiences and perspectives of parents participating in PACT. Analysis was conducted conscious of the subjective positioning of the authors as well as the theoretical assumptions made, including the overall study aim of understanding acceptability and appropriateness as well as contextual factors affecting implementation (Safaeinili et al. 2019). Aligned with this analytic approach, the first and second authors (K.W. and T.C.) read the interview transcripts, and the qualitative participant feedback repeatedly to familiarise themselves with the data. Initial codes were generated by the primary coder (T.C.), reviewed and refined by the secondary coder (K.W.) and then grouped into themes taking into account underlying meanings, and in discussion with co-authors in order to support multi-perspectival analysis. The core study aim of better understanding the implementation of PACT including acceptability, appropriateness, barriers and facilitators (Safaeinili et al. 2019) aided the interpretation and the generation of the themes.

To support qualitative analysis, statistical analyses consisted of descriptive statistics, *t*-tests and an ANOVA to test child age and motor functioning as potential barriers to implementation.

Reporting of this qualitative research has been done in accordance with the Standard for Reporting Qualitative Research (SRQR) guidelines (O'Brien et al. 2014).

3 | Results

3.1 | Sample Characteristics

Of the 67 families participating in the PACT RCT (removed for de-identification), 55 parents gave quantitative feedback on PACT by completing the Likert scales embedded in the course and were, hence, eligible for participation in this study. Of the total of 55, 49 parents gave qualitative feedback (either by providing written feedback to the questions embedded in the course or by participating in the phone interviews or both). The average age of the child was 5.67 years (SD = 2.49), and the sample contained the full range of motor functioning as measured by the GMFCS (GMFCS I = 21, II = 15, III = 8, IV = 8, V = 3). Full demographics for the sample are presented in Table 2.

3.2 | Qualitative Analysis

Qualitative analysis resulted in seven themes in total. There were three themes addressing acceptability and appropriateness and four themes addressing barriers and facilitators.

3.3 | Acceptability and Appropriateness

ACT is an acceptable approach for supporting parents. Parents reported that the ACT principles within the course were acceptable, appropriate and helpful to the challenges of parenting a child with CP. Parents reported attitudes towards ACT and they were willing to engage with ACT concepts. Values and mindfulness were highlighted as being especially helpful, but parents also commented positively on acceptance, cognitive

TABLE 2 | Participant characteristics ($N = 55$; interview participants, $n = 23$).

Characteristic	All ($N = 55$)	Interview ($n = 23$)
Child age in years, mean (SD)	5.67 (2.49)	5.43 (2.55)
Child sex, male, *n* (%)	39 (71%)	15 (65%)
CP motor type, spastic CP, *n* (%)	39 (71%)	16 (70%)
CP motor distribution type (spasticity)		
Quadriplegia/ tetraplegia	10 (18%)	7 (30%)
Diplegia	17 (31%)	5 (22%)
Hemiplegia	25 (45%)	10 (43%)
Ataxia/other motor type	3 (5%)	1 (4%)
Epilepsy, *n* (%)	8 (14%)	2 (9%)
Co-diagnosis of ASD, *n* (%)	7 (13%)	3 (13%)
Co-diagnosis of ADHD, *n* (%)	3(5%)	3 (13%)
Vision impairment n (%)	6 (11%)	5 (22%)
Hearing impairment n (%)	1 (2%)	0 (0%)
Child country of birth, Australia, *n* (5%)	47 (85%)	20 (87%)
Language spoken at home, English, *n* (%)	47 (85%)	20 (87%)
Child Motor Functioning (GMFCS)		
GMFCS I	21 (38%)	8 (35%)
GMFCS II	15 (27%)	7 (30%)
GMFCS III	8 (14%)	2 (9%)
GMFCS IV	8 (14%)	3 (13%)
GMFCS V	3 (5%)	3 (13%)
Parent relationship to child		
Mother	47 (85%)	22 (96%)
Father	7(13%)	0 (0%)
Legal guardian	1 (2%)	1 (4%)
Parent age, mean (SD)	40.14 (6.08)	38.83 (11.50)
Parent relationship status		
Married/de facto/committed relationship	50 (85%)	19 (83%)
Separated/ divorce/widowed	1(2%)	1 (4%)
Single	4 (7%)	2 (9%)
Missing	1(2%)	1 (4%)
Parent highest education		
High school	7 (13%)	4 (17%)
Diploma/ass. degree/certificate/ apprenticeship	12 (22%)	5 (22%)
Bachelor's degree	21 (38%)	8 (35%)
Postgraduate Degree	15 (27%)	6 (26%)
Employment status		
Full time	15(27%)	6 (26%)
Part time/casual	20 (36%)	8 (35%)
Full-time homemaker/carer/ parenting duties	13 (24%)	5 (22%)
Student	4 (7%)	2 (9%)
Missing	3(5%)	1 (4%)
Parent country of birth, Australia, *n* (%)	34 (62%)	16 (70%)
Parent chronic health condition, yes, *n* (%)	8(14%)	1 (4%)
Parent receives psychological or counselling support, yes, *n* (%)	5 (91%)	2 (87%)
Previous engagement in parenting programmes	13 (24%)	3 (13%)

defusion (distancing from thoughts), self-compassion, encouragement of self-care and exploration of feelings and emotions. Parents liked the way that PACT centred around reflecting on themselves as a parent and as an individual. This was felt to be particularly appropriate for this population because the parents did not have as many opportunities to pause and reflect in their daily lives.

> Becoming aware of values and the dissonance between what I'm experiencing in day-to-day life and identifying that dissonance as a source of my dissatisfaction. If I am aware of what is causing dissatisfaction, I am in a better position to change that.
>
> (Mother of 4-year-old child, GMFCS I)

Many parents reported that they had observed positive changes in themselves and as a parent. Parents reported that the course helped to change their perspective, built their resilience or patience and enabled them to apply more supportive approach to their family members. Parents also said that they noticed enhanced family wellbeing, greater connection with their child and positive changes in their child's skills or behaviour as a result of changes they had made during PACT.

> My reactions to particular behaviours have changed. I've tried to reduce my explosive reactions and remain calm.
>
> (Mother of 7-year-old child, GMFCS II)

When supporting parents, be flexible. Parents appreciated the flexibility of PACT, and this was considered key to the goodness-of-fit for their family. They reported that PACT was inclusive and gave a diversity of opportunities to learn. Parents reported that the detailed examples helped them to understand the content as well as how to adapt it to their individual circumstances. Although parents reported that PACT was inclusive, some suggested that it could be made more inclusive by taking care to ensure that all of the examples fit with the full diversity of family circumstances, in particular, the severity of a child's disability.

> I have found the whole program very inclusive and very open-minded, so it suits a broad range of personalities and parenting styles.
>
> (Mother of 3-year-old child, GMFCS II)

> I like that you could choose how you absorb the information.
>
> (Mother of 3-year-old child, GMFCS IV)

Online intervention suits parents but make it more interactive. Parents appreciated the online nature of the course. They liked being able to take the course at their own pace, and they found the flow between activities made the course more engaging. The fact that it was an online intervention increased the flexibility of PACT for some parents, including enhancing their ability to integrate PACT into already busy lives, although some parents would have liked additional flexibility. Parents particularly liked the interactive aspects of the online course and stated that the interactive elements made the course engaging. Some parents reported that they would have liked more interactive elements, as well as effects, captions and animated figures in the videos to make these more engaging too. Parents particularly appreciated the ability to connect with other parents who are going through a similar situation on the discussion board. In fact, some parents suggested encouraging further use of the discussion board to make it livelier or setting up an online group that they could use to chat or connect with each other.

> Doing it online just makes it, I think, easier to fit in with everything else going on.
>
> (Mother of 3-year-old child, GMFCS V)

> I liked to read the discussion board. It helps to be able to relate to others and to see that we aren't alone in this.
>
> (Mother of 3-year-old child, GMFCS I)

3.4 | Barriers and Facilitators

ACT can be psychologically challenging. Parents described PACT as being psychologically challenging at times, even confronting. For many, PACT a re-evaluation of their life or parenting and that could be painful and required courage. Importantly, the parents who reported that they found PACT confronting also said that this confrontation was necessary and, ultimately, helpful because it allowed them to re-orientate their life and parenting to better align with their values. That is, the gains of the intervention outweighed this particular cost. In addition, some parents reported that the experiential exercises were not always helpful, and one parent reported a negative reaction consistent with a paradoxical reaction where experiences increased anxiety during experiential exercises normally associated with relaxation (Solomen and Aaron 2015). Paradoxical reactions are known to be present in a minority of the population, particularly in populations with a history of trauma.

> I had to look inside me. I get short with them, I get sarcastic and they're not really doing anything different to what they normally do - it's just today, it's annoying me. So, I'm finding that I'm crossing boundaries that I shouldn't be doing, like I'm being disrespectful to them as well.
>
> (Mother of 9-year-old child, GMFCS I)

> [The breathing exercise] makes me more anxious than it helps me cause then I think I can't get enough air in my lungs.
>
> (Mother of 3-year-old child, GMFCS IV)

Pitching the content to fit everyone. Some parents felt that the course was too academic, that the language could be simplified or that the amount of content was overwhelming and yet other parents would have liked the content to be expanded upon and explored in a deeper way. In addition, some parents reported that they remained unsure of how to apply strategies from the course into their everyday life.

> There were probably some parts of it that would've been better if I had some idea of how to apply it to our particular situation.
>
> (Mother of 3-year-old child, GMFCS V)

Technological difficulties are a barrier for online intervention. Although overall the online format was liked and it enhanced flexibility, some parents reported technological difficulties when completing the course and these were a barrier.

Some parents recommended the course be made accessible on their phone through a mobile application and suggested that alternatives could be made available for those with technological issues, including face-to-face and group options.

Reminders are important for online intervention. Follow-ups were suggested by some parents who were interested in re-engaging with the course at a later date to refresh their knowledge. Although the programme did use reminders throughout, individual parents noted that they would have appreciated more frequent reminders to prompt them to practise the exercises or to complete the modules.

3.5 | Quantitative Analysis

Overall, parents gave positive feedback on PACT with mean ratings of usefulness of the content and the helpfulness of videos and activities ranging between 7 and 9 on a 10-point Likert scale (see Tables 3 and 4).

TABLE 3 | Summary of means and standard deviations of ratings of module usefulness, video helpfulness and activity helpfulness based on age group.

Age group	Ages 2–5		Ages 6–10	
(*N* = 55)	M	SD	M	SD
Module usefulness				
Module 1 Living a Meaningful Life	8.05	1.53	8.19	1.21
Module 2 Willingness	8.09	1.34	8.08	1.29
Module 3 Relating to Others	8.26	1.46	8.19	1.10
Module 4 Review	8.26	1.35	7.97	1.29
Overall	8.16	1.20	8.11	1.00
Video helpfulness				
Module 1 Living a Meaningful Life	8.37	1.84*	7.12	1.84*
Module 2 Willingness	8.18	1.65	7.37	1.55
Module 3 Relating to Others	8.07	1.61	7.72	1.68
Module 4 Review	7.19	1.86	7.09	1.30
Overall	7.95	1.42	7.32	1.22
Activity helpfulness				
Module 1 Living a Meaningful Life	7.75	2.18	7.67	1.79
Module 2 Willingness	7.64	1.45	7.37	1.69
Module 3 Relating to Others	8.00	1.37	7.78	1.10
Module 4 Review	7.30	2.07	7.07	1.67
Overall	7.67	1.52	7.47	1.15

Note: Scale ranges from 1–10, where 1 indicates a low score of usefulness/helpfulness, and 10 indicates a high score of usefulness/helpfulness.
*$p < 0.05$ significant difference between groups.

Impact of child age. Independent t-tests found no significant differences in Likert ratings between parents of younger (2–5 years, $n = 29$) and older (6–10 years, $n = 26$) children on module usefulness ($t(53) = 0.187$, $p = 0.852$), activity helpfulness ($t(53) = 0.542$, $p = 0.590$) or video helpfulness, ($t(53) = 1.748$, $p = 0.086$) for overall course ratings.

Breaking down the ratings by module, no significant differences were found for module usefulness or activity helpfulness between the two age groups across any of the four modules. Analyses found a significant difference in video helpfulness ratings between parents of younger (2–5 years) and older (6–10 years) children for Module One Living a Meaningful Life. Video helpfulness was rated significantly higher by parents of younger (2–5 years) children than parents of older (6–10 years) children, $t(53) = 2.527$, $p = 0.015$, although parents of older children still rated the video as helpful (M = 7.12, SD = 1.84). No significant differences between parents of younger (2–5 years) and older (6–10) children were found for video helpfulness ratings for Modules 2, 3 and 4.

Impact of child motor functioning. ANOVAs revealed no significant univariate effects of child motor functioning as measured by the GMFCS for module usefulness, $F(2, 52) = 0.505$, $p = 0.607$, video helpfulness, $F(2, 52) = 0.037$, $p = 0.964$, or activity helpfulness, $F(2, 52) = 0.744$, $p = 0.480$. A further series of ANOVAs found no significant impact of child motor functioning on parental ratings for module usefulness, video helpfulness and activity helpfulness for any of the individual modules.

4 | Discussion

Overall, the response to PACT was positive, both in terms of quantitative and qualitative feedback, PACT was found to be acceptable, appropriate and inclusive. Parents reported positive changes from participating in PACT, including greater family wellbeing, calmer parenting, an enhanced sense of connection between parent and child, improved parental resilience and positive changes in child behaviour with reductions in misbehaviour and improvements in family quality of life. They found ACT-based principles a good fit for parenting support, particularly values and mindfulness. They also had positive attitudes to the online format and the flexible delivery that this enabled. These qualitative reports are consistent with the results of the RCT (Whittingham et al. 2022). Ratings of usefulness and helpfulness were high, regardless of the child's age or motor functioning as measured by GMFCS level. Thus, child age and motor functioning level should not be considered barriers. There was only one exception: Parents of younger children (2–5 years) rated the videos in Module One Living a Meaningful Life as more helpful than parents of older (6–10 years old) children, although parents of older children also rated the videos as helpful overall. This is interesting as values was especially liked in the qualitative feedback and was novel for some parents. It is possible that the concept of parenting values was less novel for parents of older children.

Barriers and implementation strategies. In re-evaluating their life through the lens of their own values, parents became aware of discrepancies between their desired and present life, and, for some, this was distressing. This reaction is to be

TABLE 4 | Summary of means and standard deviations of ratings of module usefulness, video helpfulness and activity helpfulness based on GMFCS.

GMFCS level	GMFCS Level I	GMFCS Level II	GMFCS Levels III and V
(*N* = 55)	M (SD)	M (SD)	M (SD)
Module usefulness			
Module 1 Living a Meaningful Life	7.99 (1.47)	8.51 (1.26)	7.94 (1.37)
Module 2 Willingness	8.14 (1.08)	8.02 (1.36)	8.08 (1.54)
Module 3 Relating to Others	8.12 (1.20)	8.55 (1.12)	8.09 (1.52)
Module 4 Review	8.10 (1.45)	8.44 (0.90)	7.91 (1.46)
Overall	8.09 (1.12)	8.38 (0.96)	8.01 (1.22)
Video helpfulness			
Video 1 Living a Meaningful Life	7.87 (2.08)	7.23 (1.85)	8.12 (1.80)
Video 2 Willingness	7.75 (1.63)	7.76 (1.76)	7.89 (1.64)
Video 3 Relating to Others	7.82 (1.47)	7.93 (1.66)	7.98 (1.86)
Video 4 Review	6.97 (1.60)	7.71 (1.29)	6.89 (1.80)
Overall	7.60 (1.43)	7.66 (1.37)	7.72 (1.33)
Activity helpfulness			
Activity 1 Living a Meaningful Life	7.33 (2.30)	8.28 (1.51)	7.69 (1.94)
Activity 2 Willingness	7.62 (1.51)	7.63 (1.74)	7.31 (1.53)
Activity 3 Relating to Others	7.80 (1.15)	8.32 (1.00)	7.68 (1.47)
Activity 4 Review	7.07 (1.86)	7.54 (1.59)	7.04 (2.14)
Overall	7.45 (1.49)	7.94 (1.03)	7.43 (1.42)

Note: Scale ranges from 1 to 10, where 1 indicates a low score of usefulness/helpfulness and 10 indicates a high score of usefulness/helpfulness.

expected. The shift in perspective facilitated by ACT can be a major adjustment. Importantly, the parents who reported that they found PACT confronting in this manner also said that this confrontation was necessary and, ultimately, helpful because it allowed them to re-orientate their life and parenting to better align with their values. That is, they reported that the benefits of ACT outweighed the costs. That said, it is important for clinicians to be aware of this experience when implementing ACT-based interventions, especially when implementing them online.

One of the parents reported that they experienced a paradoxical reaction, a documented experience where an individual, due to their own personal history, experiences increased anxiety during experiential exercises normally associated with relaxation (Solomen and Aaron 2015). Paradoxical reactions are known to be present in a minority of the population, particularly in populations with a history of trauma. This underscores the importance of providing an explanation of paradoxical reactions in all online interventions incorporating mindfulness or relaxation exercises as part of trauma-sensitive care (Treleaven 2018).

Although some parents wanted additional content and further in-depth explanation, others found the existing content overwhelming and overly academic. In addition, some parents felt that they were still unsure of how to apply the content in their lives. Getting the level of depth right is a challenge in developing an online course. It was our intention that the telehealth consultations would support the parents in adapting the content for their own specific circumstances and address any remaining questions, with parents self-regulating in accessing the degree of support needed. In fact, there was low uptake for the psychological consultations. Combined with the qualitative feedback, this suggests that some parents who required more individualised support did not access it, despite consultations being regularly offered. The parents who most need individualised support may not be able to self-regulate in accessing the level of support needed, or they may be feeling swamped by the number of medical and therapy appointments they have for their child and not able to consider further involvement. This could be addressed in part by building additional supports or scaffolding into the course itself to assist parents in understanding when individualised support is needed or by making the telehealth consultations routine. It may also be possible to build additional tailoring and support into the course itself through expanding the interactive elements and/or the discussion board as parents suggested. Regardless, tailoring and the provision of sufficient support to those who need it is a general challenge to online intervention.

Finally, some parents experienced technological difficulties and others would have liked additional reminders to help them in moving through the course. Both points are important for any online intervention. Going forward, it is important to have clear resources and strategies for when technological difficulties are

experienced and to build effective reminders into the intervention protocol itself.

Clinical implications. Overall, this study suggests that ACT is appropriate and acceptable for parents of children with CP and that values and mindfulness are two aspects of ACT that are particularly relevant for this population. That said, increased awareness of the discrepancy between the values underpinning meaningful living and the degree to which such values are currently being lived was distressing for some. Clinicians should rest assured that parents believed this initial distress to be necessary and, ultimately, helpful, as parents used this awareness to make fruitful change in their lives.

This study also suggests that online intervention is both acceptable to parents and inclusive. In designing online interventions, care should be taken to build flexibility into the programme, to scaffold parental ability to know when and how to seek individualised support or to use some other means to identify parents with greater need. This is challenging because it is not merely a matter of identifying parents with more severe concerns at the outset although that could be one reason to ensure a parent receives individualised support. It is also a matter of identifying the parents who are not able to independently adapt the content and apply it in their lives. This challenge impacts on all online interventions. Further, consistent with trauma-sensitive care, information on paradoxical reactions should be available in any online programme with mindfulness or relaxation exercises for those who may experience these reactions.

Strengths and limitations. This study employed a mixed methods design, looking at both qualitative and quantitative feedback of parents to ascertain a more detailed view of their experiences participating in PACT. This allowed for a deeper understanding of the parent experience. Unfortunately, not all families participated in giving feedback, and that is a limitation of the current study (50 of 67 families or 75% response). Additionally, the qualitative interviews were conducted by the research managers (C.M. and A.W.) of the study, which may have unintentionally introduced bias into the parental report. Qualitative data were also collected through the course itself.

5 | Conclusion

Overall, parents found PACT appropriate and acceptable, both in terms of the application of ACT principles to parenting and developing parenting support in an online format. Implementation should focus on understanding that ACT can be psychologically challenging, ensuring that parents who need individualised support for intervention adaptation receive it, providing good support to address technological difficulties, building effective reminders into the intervention protocol and maintaining a strong process of programme evaluation.

Author Contributions

Koa Whittingham: conceptualization, funding acquisition, writing – review and editing, methodology, formal analysis, supervision, investigation. **Tara Crandon:** writing – original draft, formal analysis, data curation. **Catherine Mak:** data curation, writing – review and editing, investigation. **Jeanie Sheffield:** conceptualization, writing – review and editing, formal analysis. **Ashleigh Wright:** data curation, investigation. **Grace Kirby:** writing – review and editing, formal analysis. **Roslyn N. Boyd:** conceptualization, writing – review and editing, methodology, investigation.

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Ethics Statement

Ethics approval was obtained through the Children's Health Queensland Hospital and Health Service Ethics Committee (HRC/15/QRCH/115) and the University of Queensland Behavioural and Social Science Ethical Review Committee (2015001743).

Conflicts of Interest

Koa Whittingham and Jeanie Sheffield both developed the PACT intervention. PACT was developed using the free platform edX with no intention to commercialise. The other authors declare no conflicts of interest.

Data Availability Statement

Access to data collected for this project is restricted to the original research team as participants did not consent to have their data shared publicly. De-identified individual participant data will not be made available.

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