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Author(s): Lappalainen, Päivi; Gallego, Ana; Keinonen, Katariina; Lappalainen, Anna-Lotta; Tolvanen, Asko; Lappalainen, Raimo

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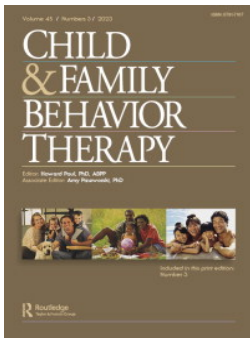
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Online and Self-Help Acceptance and Commitment Therapy for Parents of Children with Chronic Conditions and Developmental Disabilities: What Happens after the Intervention?

Päivi Lappalainen, PhD^a , Ana Gallego, PhD^{a,b} , Katariina Keinonen, PhD^a , Anna-Lotta Lappalainen, MSc^a, Asko Tolvanen, PhD^a , and Raimo Lappalainen, PhD^a 

^aDepartment of Psychology, University of Jyväskylä, Jyväskylä, Finland; ^bFaculty of Education and Psychology, University of Jyväskylä, Finland

ABSTRACT

We investigated the follow-up (3- and 6-month) intervention effects of two ACT-interventions for parents of children with chronic and developmental conditions. Parents ($N = 110$) were randomly assigned to the supported iACT ($n = 57$) or to the Self-help ACT ($n = 53$). At 3-month follow-up, symptoms of burnout decreased more in the supported iACT group, whereas, unexpectedly, psychological flexibility decreased in both groups. However, at the 6-month follow-up, the iACT group reported decreased symptoms and increased psychological flexibility skills. Online and self-help ACT interventions may be beneficial to this population and decrease their risk of psychopathology.

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Introduction

Children with long-term conditions and complex needs require several hours of additional care and assistance on a daily basis compared to their healthy peers (Heyman et al., 2004). Accordingly, research has reported that parents of these children experience higher levels of stress, burnout, and poorer sleep, mental health, and quality of life when compared with parents of healthy children (Cohn et al., 2020; Cousino & Hazen, 2013; Khamis, 2007; Lindström et al., 2010; Piquart, 2018). Parental burnout is defined as a prolonged response to chronic and overwhelming parental stress (Mikolajczak & Roskam, 2018) and refers to a state of intense exhaustion, emotional distancing, and reduced personal accomplishment,

CONTACT Päivi Lappalainen PhD  paivi.k.lappalainen@ju.fi  Department of Psychology, University of Jyväskylä, Jyväskylä 40014, Finland.

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i.e., detachment from children and feelings of incompetence as a parent (Gérain & Zech, 2018; Roskam et al., 2017). Caring for a child with a chronic illness or disability implies an even greater risk of burnout (Basaran et al., 2013; Gérain & Zech, 2018). Indeed, higher levels of burnout have been found in caregivers of children with chronic conditions and developmental disabilities (Ahmadi et al., 2021; Basaran et al., 2013). Parental burnout and distress can have harmful consequences, not only for the parent but also for the children, including depressive symptoms and greater internalizing and externalizing problems (Fang et al., 2022; Fedele et al., 2011; Mikolajczak et al., 2019; Mullins et al., 2004). Owing to this growing burden, parental burnout needs urgent attention (Mikolajczak et al., 2019) as well as interventions to improve the well-being of caregivers of children with disabilities (Basaran et al., 2013). In particular, it is important to explore and better understand long-term effects of interventions supporting parental well-being. There is a limited evidence base regarding the long-term effects of online interventions targeting the well-being of parents of children with chronic conditions.

According to Whittingham (2014), a third-wave approach may be particularly relevant and fruitful to parents of children with disabilities, as it may improve parental adjustment to the child's illness, support parents' grief, encourage flexible parenting, i.e., responding to the needs of their child in the present moment, even when the parent experiences significant stress (see also Blackledge & Hayes, 2006). Acceptance and commitment therapy (ACT) is a model from the third wave of cognitive behavioral therapy, with the ultimate goal to improve psychological flexibility (Hayes et al., 1999), that is, the ability to be mindful of experiences in the present moment, in an accepting and non-judgmental way, while behaving consistently in accordance with one's values and in spite of unhelpful thoughts and feelings (Levin et al., 2014). For parents of children with chronic conditions, increased psychological flexibility may manifest in accepting difficult thoughts and emotions that may arise in caregiving situations and increasing time for personally meaningful activities in accordance with personal values (Han et al., 2020). Studies suggest that interventions with parents based on ACT can lead to positive outcomes that can be maintained in the long term (Chong et al., 2019; Lunskey et al., 2018). The systematic review and meta-analysis by Han et al. (2021) found 24 studies on the effects of ACT interventions on family caregivers, most of whom were parents of the care recipients. The findings showed moderate effects of ACT on depressive symptoms and quality of life, small to moderate effects on stress, and small effects on anxiety. Further meta-analyses and reviews (Byrne et al., 2021; Parmar et al., 2019; Ruskin et al., 2021; Yu et al., 2019) found that ACT and mindfulness-based interventions produced moderate

effects in improving caregiver psychosocial outcomes in pre-post comparisons, whereas social support and psychoeducation showed no effect. In addition, research suggest that the effects of online ACT interventions can be useful independent of the severity of the symptoms of the participants and for many different subpopulations (Pots et al., 2016).

These findings suggest that ACT-based interventions can provide parents with skills that they can utilize in their everyday life as a way of reducing parental stress, anxiety, and depression.

Highly qualified mental health professionals are a scarce resource, suggesting that offering one-to-one psychotherapy to the whole population is not a viable option (Bennet-Levy et al., 2010). Furthermore, traditional face-to-face interventions may be difficult for many parents to commit to due to time constraints and multiple demands at home (Rayner et al., 2016). Therefore, the use of low-intensity self-help formats would provide parents a good alternative to face-to-face psychological support, as these interventions may be delivered in self-paced pieces in the home environment. Low-intensity interventions include, among others, guided or self-guided Internet-based programs and self-help books which are the lowest-intensity type of service (Bennet-Levy et al., 2010). Caregivers of children with special needs and high treatment burden may find a virtual format particularly accessible.

Internet-based interventions have been found to be effective treatments for many populations (e.g., Richards & Richardson, 2012). They can either be delivered with some form of guidance or support from a therapist, counselor, or a coach (guided interventions) or without any support (self-guided interventions, Karyotaki et al., 2019). Guided Internet-based treatments have been found equally effective for psychiatric and somatic disorders as traditionally delivered treatments (Andersson et al., 2014, 2019; Carlbring et al., 2018; Cuijpers et al., 2010). Online interventions with support have been found to be associated with a larger between-group effect size ($d = 0.61$), whereas a smaller effect has been found in unsupported treatments ($d = 0.25$; Andersson & Cuijpers, 2009). Despite of lower effects, the evidence suggests that self-guided Internet-based cognitive behavioral interventions can alleviate symptoms associated with high prevalence disorders to some extent (Karyotaki et al., 2017). However, these come with limitations such as high drop-out rates (Karyotaki et al., 2017).

There is limited evidence on ACT-based online interventions targeting parents of children with chronic conditions and developmental disabilities (Ahola Kohut et al., 2021; Lappalainen et al., 2021; Sairanen et al., 2019). Ahola Kohut (2021) investigated a three-session online workshop for parents of children with inflammatory bowel disease and found that the brief online ACT was feasible and acceptable in providing parents support,

however, no significant group improvements in any quantitative measures were detected. The study by Sairanen et al. (2019) showed that an ACT-based online intervention for parents of children with type 1 diabetes or functional disabilities was successful without face-to-face contact. Lastly, the study of Lappalainen et al. (2021) compared the effects of supported online ACT intervention with the Self-help ACT for parents of children with chronic conditions and suggested that the psychologist-supported web-based ACT produced broader improvements in parents' psychological well-being than the self-help ACT material offered to parents. Nevertheless, both interventions decreased the symptoms of burnout and showed a beneficial impact on parents' quality of life. The study of Sairanen et al. (2019) found that that all improvements were maintained four months post-intervention. However, the long-term impact of other online ACT interventions for parents of children with chronic conditions and developmental disabilities is not known. After all, caregiver burnout and distress are serious health problems that require more attention. It is imperative to investigate alternative ways of supporting these parents.

The main aim of this randomized controlled trial was to investigate whether the effects of the two differently delivered ACT-based interventions, a supported online ACT intervention (iACT), and an ACT-based self-help (Self-help ACT), were maintained after three months after the intervention (i.e., follow-up 1). For the iACT group only, our aim was also to examine the results at six months post-intervention (follow-up 2). We expected, based on previous research of guided online interventions (e.g., Andersson & Cuijpers, 2009), that participation in a supported web-based intervention would be associated with significantly larger decreases in burnout and depressive symptoms and with significantly larger increases in psychological flexibility and mindfulness skills in comparison to the Self-help ACT group from post to follow-up measurement.

Methods

Participants and procedure

Parents were recruited through advertisements in local newspapers and the Facebook pages of diverse caregiver and family organizations. Those interested in taking part were invited to a telephone screening interview. The eligible participants (1) had a child under the age of 18 with a chronic condition or developmental disability; (2) scored greater than 2.75 points on the Shirom-Melamed Burnout Questionnaire (SMBQ), indicating mild symptoms of burnout (Lundgren-Nilsson et al., 2012; Melamed et al., 1999); (3) had no parallel psychological treatment; (4) did not suffer from a serious mental disorder; (5) had sufficient Finnish language skills; and (6)

had access to the Internet through a computer or other device. Eligible parents ($n = 110$), most of them being females ($n = 103$; 93.6%) and with a mean age of 40.1 years ($SD = 6.68$, range 27–55) were randomized to supported web-based ACT (iACT; $n = 57$) and ACT self-help group (Self-help ACT; $n = 53$, Table 1). Participants were highly educated, with nearly 70% ($n = 76$, 69.1%) of them having a university-level education. Most of the children were male ($n = 76$, 68.5%), with a mean age of nine years ($SD = 4.29$), and with predominantly developmental disabilities. At pre-measurement, more than 60% of the parents were classified as experiencing severe levels of burnout (Shirom-Melamed Burnout Questionnaire; Lundgren-Nilsson et al., 2012; Melamed et al., 1999; $SMBQ \geq 4.47$), and nearly 56% had at least moderate levels of depression (Patient Health Questionnaire-9; Kroenke et al., 2001; $PHQ-9 > 10$). Detailed characteristics are reported in Table 1.

Table 1. Characteristics of parents.

Parental and child variables	All ($n = 110$)	iACT ($n = 57$)	Self-help ACT ($n = 53$)
Age [Mean (SD)]	40.1 (6.69) range 27–55	38.9 (6.9) range 27–53	41.5 (6.3)* range 27–55
Sex			
Female	103 (93.6%)	54 (94.7%)	49 (92.5%)
Male	7 (6.4%)	3 (5.3%)	4 (7.5%)
Marital status			
Married or living together	91 (82.7%)	48 (84.2%)	43 (81.1%)
Single parent	19 (17.3%)	9 (15.8%)	10 (18.9%)
Education ^a			
Primary level	3 (2.7%)	3 (5.3%)	–
Secondary level	31 (28.2%)	13 (22.8%)	18 (34%)
University/college level	76 (69.1%)	41 (71.9%)	35 (66%)
Working status		**	
Full time	48 (44%)	23 (41.1%)	25 (47.2%)
Part time	25 (22.9%)	12 (21.4%)	13 (24.5%)
Unemployed	5 (4.6%)	2 (3.6%)	3 (5.7%)
Student	11 (10.1%)	6 (10.7%)	5 (9.4%)
Sick leave	2 (1.8%)	2 (3.6%)	–
Caregiver/maternity leave	18 (16.5%)	11 (19.6%)	7 (13.2%)
Has own disease or diagnosis	49 (44.5%)	23 (40.4%)	26 (49.1%)
Child's age [Mean, (SD)]	9.0 (4.29)	8.5 (4.3) range 0.8–17	9.6 (4.2) range 1–17
Child's gender	range 0.8–17		
Male	76 (69.1%)	41 (71.9%)	35 (66%)
Female	35 (30.9%)	16 (28.1%)	18 (34%)
Child's condition		***	
Developmental disability	36 (33.3%)	16 (29.1%)	20 (37.7%)
Autism spectrum disorder	20 (18.5%)	14 (25.5%)	6 (11.3%)
ADHD	9 (8.3%)	5 (9.1%)	4 (7.5%)
Diabetes	8 (7.4%)	3 (5.5%)	5 (9.4%)
Gastrointestinal diseases	8 (7.4%)	3 (5.5%)	5 (9.4%)
Coronary diseases	6 (5.6%)	3 (5.5%)	3 (5.7%)
Muscle diseases	5 (4.6%)	4 (7.3%)	1 (1.9%)
Other	16 (14.8%)	7 (12.7%)	9 (17%)

^aPrimary > 9 years; Secondary 9–12 years; University 12 > years (university, college, etc.).

*Missing information: $n = 53$.

**Missing information: $n = 56$.

***Missing information: $n = 55$.

Among the parents who participated in the 6-month follow-up (follow-up 2; iACT, $n = 28$), all except for one parent ($n = 27$, 96.4%) were female, and their age was, on average, 39.1 years, ($SD = 7.3$). Nearly all of them were married or co-habiting ($n = 26$, 92.9%), had a university education ($n = 21$, 75%), and worked fulltime ($n = 14$, 50%). The most common diseases in their children were autism spectrum disorders ($n = 7$, 25%) and developmental conditions ($n = 6$, 21.4%).

Data on parents' psychological well-being were collected at baseline (pre-measurement; $n = 110$, Figure 1), at 10-week post-measurement ($n = 82/75\%$), three months after the post-measurement (follow-up 1;

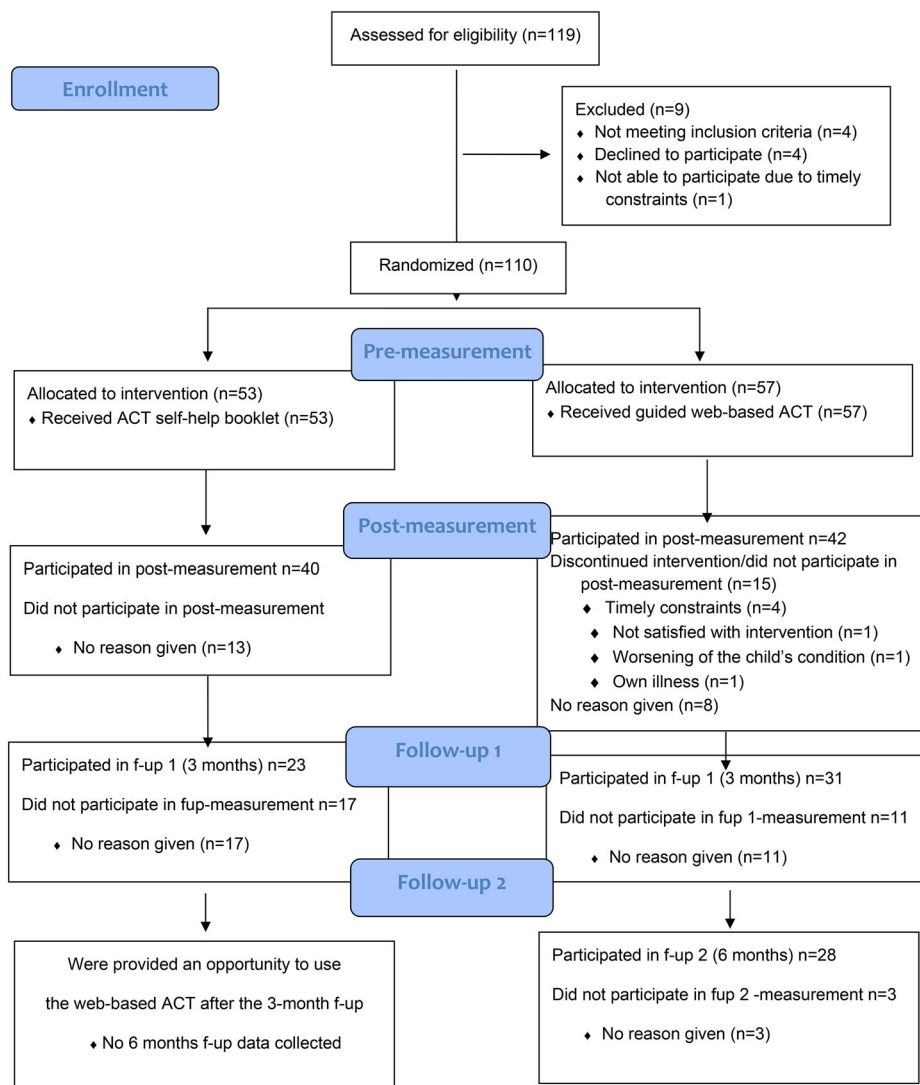


Figure 1. Participant flow.

$n = 54/49\%$; iACT, $n = 31/54\%$; Self-help ACT, $n = 23/43\%$), and for the supported iACT group only, six months post-intervention (follow-up 2; $n = 28/49\%$). For the flow of the intervention, see [Figure 1](#). As the Self-help ACT group was offered the intervention after the first follow-up measurement (follow-up 1, three months), the six-month follow-up (follow-up 2) could not be conducted for this group.

The study was conducted in the Psychology Department Clinic at the University of Jyväskylä in 2019–2020. Ethical approval for the study was obtained from the Ethical Committee of the Central Finland Health Care District (board affiliation: Central Finland Central Hospital; approval number 12/U2018 on November 6, 2018, registered at www.clinicaltrials.gov; ClinicalTrials.gov, Identifier: NCT04250012, Protocol ID 18/26/2018). The participants took part in the study on a voluntary basis and gave written informed consent for their participation.

Interventions

A detailed description of the interventions has been provided elsewhere (Lappalainen et al., 2021). In short, the supported iACT intervention consisted of a web program and three videoconferencing meetings with a psychologist. The program included five modules, and the participants were instructed to spend two weeks per module (10 weeks in total). The modules were based on the processes of ACT: (1) What is important to you? (2) meaningful actions; (3) present moment; (4) distance to thoughts and feelings; and (5) acceptance and self-compassion (see [Table 2](#) for the program content). The iACT intervention included three 45-min videoconferencing meetings with a clinical psychologist using the Doxy.me telecommunication application (www.doxy.me). Two clinical psychologists with several years of experience in ACT worked as coaches. The first videoconference meeting was arranged at the beginning of the intervention—before access to the web program—the second after the first two modules (i.e., four weeks from the start), and the third took place at the end of the intervention (i.e., weeks 8–9).

The parents in the self-help group ($n = 53$) received a 20-page self-help booklet highlighting the ACT approach, which was sent to them by regular mail. In addition, the participants in this group were encouraged to visit the *Oivamieli* website (www.oivamieli.fi), a publicly accessible web page that included a series of ACT-based exercises. The participants in the Self-help ACT group did not have access to the same website as the supported iACT group, neither did they not receive any professional support during the intervention period (see [Table 3](#)).

Table 2. Content for the supported iACT online intervention.

Modules (ACT processes)	Program content
Introduction	Welcome to the program
Module 1: What Is Important to You? (Values)	Text, video on “Important to You” experiential exercises
Assignment, weeks 1–2	Reflect on your life values and formulate them. Choose one or more areas of life and life values that feel/s right for you right now. Act! Think about what little action you can perform today.
Module 2: Meaningful Actions! (Value-based actions)	Text, experiential exercises
Assignment, weeks 3–4	Select the three most important life values and goals, and make a plan to start the journey toward them. Create a calendar, and schedule some activities tomorrow, next week, next month, etc. Write down your plan, as in the example below: ● My life value (what matters to me) is: ... ● My intermediate goals toward this value are as follows: 1 ... 2 ... 3 ... ● When will you take the first step? Today, tomorrow, next week?
Module 3: Present Moment (Present moment)	Text, video, experiential exercises
Assignment, weeks 5–6	(1) Apply the SOAL (Stop, Observe, Accept and Let go) method in your everyday life. (2) Fill a “present moment thermometer” every night, and note how present you have been during the day. Note the activities that have helped you be more present (e.g., a hobby, mindful shower, mindful eating, music, dance, yoga, exercise). Try to increase the frequency of the activities that make you focus more on the moment and feel good. (3) How can you influence your well-being? What actions that promote the good life for you are you willing to choose today or tomorrow?
Module 4: Distance To Thoughts and Feelings (Defusion)	Text, video, experiential exercises
Assignment, weeks 7–8	(1) Put a label on your thoughts, feelings, and body sensations as they appear. Speak loudly for yourself, for example: <i>Now, I've got the feeling that I'm sad</i> Now, I've got the idea to (describe the idea) Now, I've got the feeling to (describe the feeling) Now, the memory that comes to me (describe the memory) Now, it feels like this in the body (describe the sensation)
Module 5: Acceptance (Acceptance and Self-Compassion)	Text, video, experiential exercises
Assignment, weeks 9–10	(1) Is there anything in your life that you need to learn to accept? Select any of the acceptance exercises above or apply the general model of acceptance to what you have difficulty accepting. Practice acceptance several times a week. 1. Note and describe the present moment. 2. Accept what you note. 3. Accept your painful and unpleasant thoughts and feelings. 4. Do not avoid. (2) Be compassionate with yourself and others. Reflect and tell how it feels and affects you and people who are close to you. Seek deliberate pleasures in your life every day.
Closing words	The journey continues ...

Symptom measures

The Shirom-Melamed Burnout Questionnaire (SMBQ, Lundgren-Nilsson et al., 2012; Melamed et al., 1999) was used as the main outcome measure to assess parental burnout symptoms. The measure comprises four subscales: emotional exhaustion, physical fatigue, listlessness, and tension. The statements are answered on a 7-point Likert scale, ranging from 1 (almost

Table 3. Content of the self-help booklet, 20 pages with text and pictures.

Chapter	Content
Introduction to the value-, acceptance, and mindfulness-based approach (2 pages)	
The Mindful mind (4 pages)	Being present: Be present, live in this moment. Thoughts as traps and double-edged sword. The skill of being present
The Wise mind (6 pages)	Observing mind: Take a flexible stance to your thoughts. You are not your thoughts. (3 pages) Accepting mind: What is acceptance? Accept your thoughts and emotions. Accept what you can not change. (3 pages)
The Valuing mind (3 pages)	What are values? Reflect on your own values and act accordingly. What is important to you?
Healthy Body (2 pages)	Relaxation Exercise Mindful eating

In addition, parents in the Self-help ACT group were encouraged to visit a website with a series of ACT-based MP3exercises (www.oivamieli.fi).

never) to 7 (almost always). Based on the SMBQ, burnout can be divided into low (2.75–3.74), high (3.75–4.46), and pathological (≥ 4.47) levels. The validity and reliability of the SMBQ have been found to be good in previous studies (Lundgren-Nilsson et al., 2012). In this study, Cronbach's alpha at baseline was excellent, 0.92.

Depressive symptoms were measured by the Patient Health Questionnaire-9 (PHQ-9; Kroenke et al., 2001), which is used for diagnosing and assessing the severity of depressive disorders. The PHQ-9 contains nine items, which are answered on a 4-point Likert scale, ranging from 0 (not at all) and 3 (almost every day). The total score on the PHQ-9 ranges from 0 to 27, with a higher score indicating more depressive symptoms. PHQ-9 scores of 5 (5–9), 10 (10–14), 15 (15–19), and 20 (20–27) represent mild, moderate, moderately severe, and severe depression, respectively. The validity and reliability of the PHQ-9 have been found to be good (Kroenke et al., 2001). In this study, Cronbach's alpha indicated adequate reliability, $\alpha = 0.78$.

Process measures

Psychological flexibility was measured with the Comprehensive Assessment of ACT processes (CompACT; Francis et al., 2016), a 23-item questionnaire that includes three subscales: openness to experience (CompACT-OE), behavioral awareness (CompACT-BA), and valued action (CompACT-VA). The items are answered on a 7-point Likert scale ranging from 0 (strongly disagree) to 6 (strongly agree), with higher scores representing greater levels of psychological flexibility (openness, awareness, action). The total score of the CompACT ranges from 0 to 138, with the CompACT-OE ranging from 0 to 60, the CompACT-BA ranging from 0 to 30, and the CompACT-VA ranging from 0 to 48. In this study, the CompACT showed

adequate to good internal consistency for the total score ($\alpha=0.83$), $\alpha=0.79$ for the CompACT-OE, $\alpha=0.76$ for the CompACT-VA, and $\alpha=0.80$ for the CompACT-BA.

The Five Facet Mindfulness Questionnaire (FFMQ) was used to assess mindfulness skills (Baer et al., 2006). The measure includes five aspects of mindfulness: observing (noticing internal and external experiences), describing (naming and labeling internal experiences), acting with awareness (paying attention to one's activities in the present moment), non-judging of inner experiences (having a non-evaluative stance toward inner experiences), and non-reactivity to inner experiences (ability to let thoughts and feelings come and go without struggle). The scale comprises 39 items rated on a 5-point Likert-type scale ranging from 1 (never or very rarely true) to 5 (very often or always true), with higher scores indicating higher levels of mindfulness. The reliability and validity of the FFMQ have been found to be good (Baer et al., 2006). In this study, the FFMQ showed adequate to high reliability for the total score ($\alpha=0.87$), with $\alpha=0.74$ for observing, $\alpha=0.91$ for describing, $\alpha=0.79$ for non-judging and non-reacting, and $\alpha=0.82$ for acting with awareness.

Statistical analysis

All statistical analyses were conducted using Mplus version 8 (Muthén and Muthén, 2017). Descriptive statistics were carried out to provide an overview of the mean and change scores of the process and outcome measures. Path model using change scores was used to analyze the group x time interaction, i.e., whether the groups changed differently between the measured time points (Pre, Post, Fup). If there was a difference, post hoc tests were conducted to determine between the groups whether the difference was during the intensive intervention period or after the intensive intervention period. HLM accounts for missing values at random (MAR) and includes all available data. The parameters were estimated using the full-information maximum likelihood method (MLR estimation in Mplus). Separate within-group analyses were done in the supported iACT group investigating changes from Pre to Post, and to Follow-Up at three months and six months. Effect sizes (ES) between groups at post- and follow-up 1 measurements were investigated using the pre-measurement corrected Cohen's d values to consider the possible difference between the groups before the intervention. Effect sizes within the supported web-based iACT were also investigated. Effect sizes (ESs) were reported using Cohen's d . An effect size (d) value = 0.20 was considered small, $d=0.50$ medium, and $d=0.80$ large. Because the within-group effects sizes tend to be larger than the between-group ES, we interpreted that a change had occurred when the

with 95% Confidence Interval of the ES did not include zero. In our data, this change was equal to at least medium-size ES ($d > 0.50$).

Results

Before treatment, a significant difference between the groups was observed in age, with the parents in the supported iACT group being slightly younger (iACT, $M = 38.9$ years; $SD = 6.85$; Self-help ACT, $M = 41.5$ years; $SD = 6.29$, Table 1). However, this difference (39 vs. 42 years) was considered as clinically non-significant.

Dropouts

Among the supported iACT group, the dropout rate from the pre-measurement to the three-month follow-up measurement was 45.6% ($n = 26$) compared to 56.6% ($n = 30$) in the self-help condition. For the iACT condition only, the dropout rate from the pre-measurement to the six-month post-intervention measurement was 50.9% ($n = 29$).

Changes in symptoms at the three-month follow-up

Significant time-by-group interactions (from the pre-measurement to the three-month follow-up) were found in burnout (SMBQ) total, SMBQ physical fatigue, SMBQ emotional exhaustion, and depression symptoms (PHQ-9). At the three-month follow-up, when compared with parents who had participated in the self-help condition, parents in the supported iACT group reported having significantly fewer symptoms of burnout (SMBQ total score: the between-group effect size, $d_b = 0.44$). In particular, the parents in the iACT condition experienced less physical fatigue with medium effect size (ES, $d_b > 0.50$) and emotional exhaustion ($d_b = 0.44$), as well as fewer symptoms of depression, with small ES ($d_b = 0.29$; see Table 4). In addition, based on the within-effect sizes (95% CI), the self-help ACT produced beneficial changes for up to three months in SMBQ total ($d_w = 0.57$; 0.07; 1.06) and SMBQ tension ($d_w = 0.66$; 0.16; 1.16). Overall, as shown in Table 4, symptoms for participants in both interventions remained at a lower level at follow-up compared to the pre-measurements.

Changes in process measures at the three-month follow-up

The participants' scores for psychological flexibility (their CompACT total scores) as well as their scores on the three subscales—Openness to Experiences (OE), Behavioral Awareness (BA), and Valued Action (VA)—

Table 4. Symptom measures, estimated mean values, and standard deviations, p -values, between (d_b) and within (d_w) group effect sizes at Pre, Post, and 3-month Follow-up.

Measure	Supported iACT			Self-help ACT			Pre, Post, Fup1*	Post, Fup1**	Pre-Fup1 Between d_b	Within d_w , 95% CI
	Pre (n = 57)	Post (n = 42)	Fup (n = 31)	Pre (n = 53)	Post (n = 40)	Fup (n = 23)				
Burnout (SMBQ Total)	4.51 ± 0.88	3.55 ± 1.07	3.71 ± 0.97	4.76 ± 0.75	4.04 ± 1.09	4.32 ± 0.81	PrePostFup $p = .03$	$p = .03$ $d_w = -0.16$ to 0.28	$d_b = 0.44$ iACT > Self-help	iACT $d_w = 0.88-$ 0.41;1.32 Selfhelp $d_w =$ 0.57, 0.07;1.06
SMBQ Physical fatigue	4.68 ± 0.98	3.51 ± 1.17	3.70 ± 1.05	4.84 ± 0.82	4.01 ± 1.14	4.44 ± 0.95	PrePostFup $p = .06$	$p = .02$ $d_w = -0.17$ to 0.40	$d_b = 0.64$ iACT > Self-help	iACT $d_w = 0.98-$ 0.51;1.43 Selfhelp $d_w =$ 0.46-0.03;0.95
SMBQ Listlessness	4.67 ± 0.85	3.84 ± 1.07	4.02 ± 0.93	5.02 ± 0.94	4.23 ± 1.27	4.61 ± 1.02	PrePostFup $p = .04$	$p = .06$ $d_w = -0.18$ to 0.32	$d_b = 0.27$ iACT > Self-help	iACT $d_w = 0.74-$ 0.28;1.18 Selfhelp $d_w =$ 0.43-0.07;0.91
SMBQ Tension	4.25 ± 1.18	3.45 ± 1.19	3.76 ± 1.32	4.60 ± 0.99	4.02 ± 1.45	3.92 ± 1.10	PrePostFup $p = .2$	$p = .16$ $d_w = -0.25$ to 0.07	$d_b = -0.18$ iACT < Self-help	iACT $d_w = 0.40-$ 0.05;0.84 Selfhelp $d_w =$ 0.66-0.16;1.16
SMBQ Emotional exhaustion	4.33 ± 1.25	3.49 ± 1.43	3.47 ± 1.31	4.56 ± 1.04	3.96 ± 1.41	4.20 ± 1.17	PrePostFup $p = .04$	$p = .03$ $d_w = 0.01$ to 0.18	$d_b = 0.44$ iACT > Self-help	iACT $d_w = 0.68-$ 0.22;1.12 Selfhelp $d_w =$ 0.33-0.16;0.82
Depression (PHQ-9)	9.61 ± 4.97	6.46 ± 5.08	6.47 ± 4.53	9.21 ± 4.40	8.31 ± 4.95	7.43 ± 4.47	PrePostFup $p = .10$	$p = .27$ $d_w = 0.00$ to 0.18	$d_b = 0.29$ iACT > Self-help	iACT $d_w = 0.65-$ 0.20; 1.09 Selfhelp $d_w =$ 0.40-0.09;0.89

SMBQ: Shirom-Melamed Burnout Questionnaire with subscales Physical fatigue, Listlessness, Tension, and Emotional exhaustion; PHQ-9: Patient Health Questionnaire-9.

*PrePostFup1 = interaction effect Pre, Post, Follow-up; interaction effect Pre, Post, p -values based on Wald -test.

**PostFup1 = interaction effect Post, Follow-up1, and within group d PostFollow-up1, iACT (upper), Self-help (below).

Table 5. Process measures, estimated mean values, and standard deviations, p -values, between (d_b) and within (d_w) group effect sizes at pre, post, and 3-month follow-up.

	Supported iACT			Self-help ACT			Pre, Post, Fup1*	Post, Fup1**	Pre-Fup1 Between (d_b)	Pre-Fup1 Within d_w 95% CI
	Pre (n = 56)	Post (n = 28)	Fup1 (n = 31)	Pre (n = 51)	Post (n = 18)	Fup1 (n = 23)				
Psych.flex. (CompACT)	77.20 ± 18.65	92.30 ± 18.63	72.35 ± 13.06	75.08 ± 14.03	78.75 ± 11.96	70.42 ± 5.13	PrePostFup $p = .01$	$d_w = .48$ $d_w = 1.25-0.95$	$d_b = 0.01$ iACT < Self-help	iACT $d_w = 0.29-0.16, 0.73$ Selfhelp $d_w = 0.37-0.17, 0.91$
Openness to Experiences (OE)	32.59 ± 11.25	40.70 ± 10.80	31.69 ± 6.40	33.01 ± 8.53	35.37 ± 8.07	29.59 ± 3.39	PrePostFup $p = .04$	$d_w = .19$ $d_w = 1.03-0.98$	$d_b = -0.26$ iACT < Self-help	iACT $d_w = 0.09-0.35, 0.53$ Selfhelp $d_w = 0.45-0.09, 0.99$
Behavioral Awareness (BA)	13.75 ± 6.17	16.50 ± 6.64	16.75 ± 4.90	12.51 ± 5.25	12.26 ± 3.27	17.39 ± 2.73	PrePostFup $p = .05$	$d_w = .41$ $d_w = -0.04$ to 1.72	$d_b = 0.33$ iACT < Self-help	iACT $d_w = -0.52-0.96, -0.07$ Selfhelp $d_w = -1.03-1.58, -0.45$
Valued Action (VA)	30.86 ± 7.13	35.42 ± 5.75	24.88 ± 6.85	29.50 ± 6.49	30.92 ± 5.03	23.52 ± 3.40	PrePostFup $p = < .01$	$d_w = .19$ $d_w = 1.66-1.77$	$d_b = 0.00$ iACT < Self-help	iACT $d_w = 0.85$ Selfhelp $d_w = 1.02-0.45, 1.57$
Mindfulness (FFMQ total)	125.73 ± 16.62	136.96 ± 17.43	120.38 ± 10.22	126.39 ± 13.94	130.35 ± 14.80	114.02 ± 5.64	PrePostFup $p = < .01$	$d_w = .43$ $d_w = 1.18-1.53$	$d_b = -0.45$ iACT < Self-help	iACT $d_w = 0.36-0.08, 0.80$ Selfhelp $d_w = 1.00-0.43, 1.54$
Observing (OBS)	25.82 ± 5.36	28.31 ± 4.62	26.44 ± 4.27	26.41 ± 4.90	27.23 ± 5.18	26.58 ± 3.66	PrePostFup $p = .25$	$d_w = .43$ $d_w = 0.42-0.15$	$d_b = -0.09$ iACT > Self-help	iACT $d_w = -0.12-0.56, 0.32$ Selfhelp $d_w = -0.04-0.57, 0.50$
Describing (DESC)	28.46 ± 5.92	30.81 ± 6.48	26.57 ± 5.44	28.98 ± 5.47	28.12 ± 5.51	24.77 ± 2.55	PrePostFup $p = < .01$	$d_w = .41$ $d_w = 0.71-0.82$	$d_b = -0.41$ iACT < Self-help	iACT $d_w = 0.33-0.12, 0.77$ Selfhelp $d_w = 0.86-0.29, 1.40$

(continued)

Table 5. Continued.

	Supported iACT			Self-help ACT			Pre, Post, Fup1* PrePostFup PrePost p = .13	Post, Fup1** Fup1**	Pre-Fup1 Between (d _b)	Pre-Fup1 Within d _w 95% CI
	Pre (n = 56)	Post (n = 28)	Fup1 (n = 31)	Pre (n = 51)	Post (n = 18)	Fup1 (n = 23)				
Acting with Awareness (AWA)	22.75 ± 5.12	24.61 ± 5.30	21.94 ± 3.42	21.55 ± 4.06	22.40 ± 3.51	21.28 ± 3.66	PrePostFup p = .27	p = .39 d _w = 0.61–0.31	d _b = 0.12 iACT > Self-help	iACT d _w = 0.18–0.26, 0.61 Selfhelp d _w = 0.07–0.47, 0.60
Non-Judging (NJ)	28.04 ± 7.34	32.71 ± 8.03	21.43 ± 8.03	28.29 ± 6.50	30.17 ± 5.36	19.42 ± 3.74	PrePostFup p = .05	p = .08 d _w = 1.41–2.38	d _b = –0.33 iACT < Self-help	iACT d _w = 0.87–0.41, 1.32 Selfhelp d _w = 1.49–0.89, 2.06
Non-Reacting (NR)	20.66 ± 4.40	23.33 ± 3.21	23.67 ± 4.10	21.17 ± 3.54	21.97 ± 3.84	23.37 ± 3.41	PrePostFup p = .18	p = .48 d _w = –0.09 to 0.39	d _b = –0.20 iACT > Self-help	iACT d _w = –0.70 to 1.15, –0.24 Selfhelp d _w = –0.63 to 1.16, –0.08

CompACT: Comprehensive assessment of ACT processes with subscales: OE: CompACT Openness to Experiences; BA: CompACT Behavioral Awareness; VA: CompACT Valued Action. FFMQ: Five Facet Mindfulness Questionnaire with subscales: OBS: FFMQ Observing; DESC: FFMQ Describing; AWA: FFMQ Awareness; NJ: FFMQ Non-Judging; NR: FFMQ Non-Reacting.

*PrePostFup: interaction effect Pre, Post, Follow-up; interaction effect Pre, Post.

**PostFup: interaction effect Post, Follow-up1, and within group Effect Sizes (d) PostFollow-up1, iACT (upper), Self-help (below).

changed differently in the two intervention groups from the pre-measurement to the three-month follow-up (Table 5). However, this difference was due to a larger increase in their CompACT scores from pre- to post-measurement. From the post-intervention measurement to the three-month follow-up, the iACT and self-help ACT groups did not change differently in psychological flexibility (their CompACT total scores). Interestingly, psychological flexibility skills decreased to the pre-measurement level or below during the three-month follow-up period in both groups. This was especially true for the Valued Actions subscale, where the decrease was large ($d > 0.80$) from pre-measurement to follow-up 1. Mindfulness skills as measured by the FFMQ Total and FFMQ Describing increased significantly more from the pre- to post-measurement in the iACT group compared to the self-help ACT, but from the post-intervention measurement to the three-month follow-up, they decreased in both groups, with larger decreases in the self-help ACT group with small ES ($d = 0.20\text{--}0.49$). The decreases in psychological flexibility and mindfulness skills were significant in both groups; within ES, this decrease was large ($d > 0.80$; CompACT Total, with a 95% CI: iACT, $d = 0.68$; 1.79, self-help, $d = 0.28$; 1.58; FFMQ Total, iACT, $d = 0.60$; 1.71, self-help ACT, $d = 0.81$; 2.21).

Changes in the iACT group at the six-month follow-up (follow-up 2)

When investigating the change in the supported iACT group only ($n = 28$) from the pre-measurement to the six-month follow-up (follow-up 2; Table 6), the results showed significant changes over time in both symptom and process measures. Burnout and depression symptoms decreased during the iACT intervention and remained at a lower level up to six months following the intervention ($d_w = 0.69\text{--}0.86$). As described above, psychological flexibility (CompACT) and mindfulness (FFMQ) increased significantly from the pre- to the post-intervention measurement, decreased from the post-intervention to the three-month follow-up (follow-up 1), but increased again between the three-month and six-month follow-ups. The levels of CompACT and FFMQ were higher at the six-month follow-up (follow-up 2) compared to the pre-measurement levels (within ES, CompACT Total, $d = 0.21$; 1.14; FFMQ Total, $d = 0.08$; 1.00). The mean scores, standard deviations, and effect sizes for the supported iACT condition are presented in Table 6.

Discussion

Parents of children with chronic illnesses and developmental disabilities may be at risk of suboptimal health outcomes. Therefore, interventions

Table 6. The follow-up (Fup1 = three months; Fup2 = six months post-intervention) results of the supported iACT intervention for parents of children with chronic conditions.

Measure	Supported iACT				Pre-Post-Fup1-Fup2 Fup2 p-value	Pre – Fup2 Within d _w 95% CI	Pre-Post within p-value	Pre – Post Within d _w 95% CI	Post – Fup2 Within d _w 95% CI
	Pre n = 57	Post n = 42	Fup1 n = 31	Fup2 n = 28					
Burnout(SMBQ)	4.51 ± 0.88	3.56 ± 1.07	3.71 ± 0.97	3.75 ± 0.90	< .001	0.86–0.38;1.32	< .001	0.98–0.56;1.40	0.19–0.29;0.67
Depression(PHQ-9)	9.61 ± 4.97	6.48 ± 5.08	6.41 ± 4.46	6.21 ± 4.75	< .001	0.69–0.22;1.15	< .001	0.62–0.21;1.03	0.05–0.42;0.53
Psych.flex total(CompACT)	77.20 ± 18.65	92.69 ± 18.17	72.27 ± 13.05	89.65 ± 17.43	< .001	0.68–0.21;1.14	< .001	0.84–0.42;1.25	0.17–0.31;0.65
Mindfulness total (FFMQ)	125.73 ± 16.62	137.39 ± 17.89	120.24 ± 10.07	134.60 ± 15.63	< .001	0.55–0.08;1.00	< .001	0.68–0.27;1.09	0.16–0.32;0.64

SMBQ: Shirom-Melamed Burnout Questionnaire; PHQ-9: Patient Health Questionnaire-9; CompACT: Comprehensive assessment of ACT processes; FFMQ: Five Facet Questionnaire.

Mean values (± standard deviation), p-values, and within-group effect sizes (d-values with 95% Confidence intervals).

aimed at improving their health and well-being are warranted. There is limited evidence regarding the effects of online ACT interventions targeting the well-being of parents of children with chronic and developmental conditions. Therefore, it is important to explore and better understand what kinds of interventions are effective in maintaining positive parent outcomes over a longer period.

The current study set out to investigate the three-month follow-up results of a web-based, psychologist-supported ACT intervention (iACT) for parents of children with chronic conditions and developmental disabilities in comparison to the results of an ACT-based self-help intervention (self-help ACT). The primary aim of the study was to examine whether the effects of (1) a supported iACT intervention and (2) a self-help ACT intervention were maintained at three months post-intervention for both intervention groups and at six months post-intervention for the iACT group only. Our hypothesis was that participation in a 10-week web-based intervention would be associated with significantly larger decreases between the pre-measurement and the follow-up measurements in burnout and depressive symptoms and significantly larger increases in psychological flexibility and mindfulness skills in comparison to participation in the ACT self-help intervention.

Our hypothesis was partially supported. The supported online iACT intervention produced larger changes in the main outcome of burnout symptoms, including physical fatigue and emotional exhaustion as well as depressive symptoms from the pre-measurement to the three-month follow-up compared to the self-help ACT condition, showing small to medium-sized differences between the groups ($d_b = 0.29\text{--}0.64$). Regarding the symptoms of burnout and depression, these results are partly in line with earlier findings from studies on online ACT interventions for parents of children with chronic conditions and developmental disabilities. For example, these results are congruent with the results obtained by Sairanen et al. (2019) in their online intervention for parents of children with chronic conditions, which showed a decrease in symptoms of burnout and maintenance of depressive symptoms between the pre-measurement and the four-month follow-up measurement. Our results are also consistent with earlier findings suggesting that the effects of online ACT interventions are maintained for between one and six months (Karekla et al., 2022; Kiuru et al., 2021) and that these interventions can be useful independent of the severity of the symptoms of the participants and for many different subpopulations (Pots et al., 2016). Importantly, although the supported online iACT resulted in a larger decrease in burnout symptoms at the three-month follow-up, the self-help ACT without any support also resulted in a decrease in burnout symptoms. As our study did not include a non-

treatment comparison group, the results were compared with a similar study by Sairanen et al. (2019) which used a waitlist control condition. Consequently, at the four-month follow-up in the Sairanen et al. (2019) study, the within ES in the wait list control group was very small or non-existent ($d = 0.09$, 95% CI, -0.42 ; 0.59), whereas it was considerably larger in the self-help as well as in the online group at the three-month follow-up in the current study (Self-help: $d = 0.57$, 95% CI, 0.07 ; 1.06 ; Online: $d = 0.88$, 95% CI, 0.41 ; 1.32). However, it should be remembered that these results were obtained from participants in different countries and at different time points.

In addition, our findings indicated that both psychological flexibility and mindfulness skills increased more during the intervention period in the iACT group compared to the self-help ACT group; however, these changes were not maintained three months post-intervention.

Unexpectedly, and opposite to earlier studies (e.g., Sairanen et al., 2019), we noticed a dramatic decrease in psychological flexibility during the three-month period following the intervention. Interestingly, this decrease was not reflected in the level of symptoms of burnout or depression. The large decreases in both psychological flexibility and mindfulness from post-intervention measurement to the three-month follow-up may indicate that many parents either stopped applying psychological flexibility skills when the intervention period ended or were not able to apply them in their daily life. An alternative or additional explanation is that the COVID-19 pandemic possibly affected this unexpected change. The decrease in psychological flexibility scores may have been a consequence of the outbreak of the COVID-19 pandemic as most of the three-month follow-up data was being collected during the COVID-19 pandemic. Previously, we have observed that psychological flexibility and self-compassion skills may have protected against the psychological distress caused by the COVID-19 pandemic in adult and adolescent populations (Dawson & Golijani-Moghaddam, 2020; Lappalainen et al., 2023; McCracken et al., 2021). Interestingly, and in accordance with earlier studies (Lappalainen et al., 2023), parents' burnout and depressive symptoms remained at a lower level throughout the study and during the pandemic. In terms of psychological flexibility and mindfulness, as well as symptom outcomes, our results are consistent with earlier studies showing that the effects of an ACT-based online intervention for parents of children with chronic conditions were maintained following the intervention (see Sairanen et al., 2019). In line with a study by de Wit et al. (2019), this study suggests that delivering online support seems to be beneficial in supporting parents and caregivers of children with chronic illnesses.

Adherence, which is the degree to which users engage with the content of an intervention as intended, is a critical topic in digital interventions (Karekla et al., 2019), as greater adherence leads to improved health outcomes (Donkin et al., 2011). In contrast, low adherence impacts the effectiveness of the intervention and increases the dropout rate (Hilvert-Bruce et al., 2012; Trompetter et al., 2015). In this study, the dropout rates were relatively high over the study period. In the iACT condition, more than 40% of the parents dropped out between the pre-measurement and the three-month follow-up, whereas in the self-help condition, the dropout rate was more than half, 56.6%. An adherence rate of this size is not rare in online interventions (Christensen et al., 2009), however, this is a relatively low percentage. Lack of time is a commonly reported dropout reason in caregiver studies (Blom et al., 2015), which may also have been one of the most common reasons for dropout in the current study. As some of these parents were caregivers of more than one child with special needs, they may have been so occupied by caregiving that any more obligations were perceived as burdensome. This is a common finding in studies with caregivers (see, e.g., de Wit et al., 2020).

Limitations

Although the results of the current study confirm earlier findings of studies of online interventions supporting parents of children with chronic conditions and developmental disabilities, definitive conclusions cannot be made based on the limited number of studies conducted thus far. In the current study, we are not able to rule out the possibility that changes could have occurred without any intervention. However, in their study, Sairanen et al. (2019) observed no changes in the non-treatment control group. A further limitation concerns the study sample. It must be noted that the investigated sample of children included a wide range of conditions, and in the current study, it was not possible to study the effectiveness and the acceptability of the intervention in different subgroups of children. Although we intended to recruit mothers and fathers in the same proportion, nearly all the participants were mothers (94%). Thus, future studies should include an equal number of mothers and fathers to assess gender differences more accurately among parents of children with chronic conditions and developmental disabilities. In addition, the representativeness of the sample may be compromised because nearly 70% of the parents were highly educated. Participants from more heterogeneous social backgrounds would ensure a more representative sample of parents. Also, the large number of dropouts during the follow-up period is a problem, and more attention should be paid to how to motivate parents to participate in follow-up measurements. However,

there were no differences at pre-measurement between those participated in the 6-month follow-up and drop-outs in terms of burnout symptoms, symptoms of depression, psychological flexibility age, gender, and education level. Finally, the use of self-report questionnaires should be considered a limitation. Therefore, a multi-method measurement approach should be considered in future studies.

Future directions and conclusions

The present study is one of the first to provide evidence that a brief online ACT intervention with minimum support may decrease the pathological symptoms of burnout among parents with children with chronic conditions and developmental disabilities in the long term. Our results are in line with earlier research suggesting that online interventions with support have been found to be associated with larger between-group effect sizes compared to unsupported online treatments (Andersson & Cuijpers, 2009). Andersson and Cuijpers (2009) found, on average, a between-group effect size of $d=0.61$ for guided and $d=0.25$ for unsupported online interventions. It must be noted that our iACT online intervention for parents was brief and included, in addition to the online program, only three videoconferencing sessions facilitated by a psychologist, implying that it offered fewer resources than the traditional support provided to parents. In addition, this study suggests that if supported or face-to-face interventions are not available, a cost-effective self-help ACT delivered without any professional contact may also bring some, although limited, health benefits to parents who are struggling to care for their children with special needs. Our results are in accordance with findings showing that, despite lower effects, low-intensity self-guided interventions, such as the self-help ACT condition in the current study, can bring benefits (Karyotaki et al., 2017; Richards & Richardson, 2012). Self-guided interventions, such as the self-help ACT intervention, may be a viable alternative as a first-step treatment approach for symptoms of burnout and depression. In addition, the two low-intensity treatment options described in the current study can provide treatment access at low cost to large numbers of parents worldwide.

In accordance with earlier studies (e.g., Bradshaw et al., 2019), the current study revealed that over half of the parents reported severe levels of burnout and moderate depression, and, therefore, significant support needs must be addressed to improve parent outcomes. These two examples of remote and flexible interventions demonstrate that geography or busy schedules do not need to be a barrier to delivery or prevent parents from participating in psychological intervention. This study also suggests that distressed parents may benefit significantly from cost-effective

interventions where support can be provided through minimal contact videoconferencing sessions.

As research to reduce health care costs over the long term should be promoted (Cohn et al., 2020), the current two interventions could be offered for delivery within routine care settings, without any support or including minimal contact from health professionals. However, these two approaches are unlikely to meet the needs of all parents. Therefore, further development of these interventions is needed to make them relevant and meaningful and to maximize the intervention effects for parents of children with chronic conditions and developmental disabilities. To ensure that interventions are acceptable and meaningful to parents, parents should be involved in the development of interventions in future studies. Overall, future research is needed to better understand the short- and long-term health outcomes of parental caregiving and the optimal ways to deliver online support for parents. Online interventions based on an acceptance and mindfulness approach—such as ACT—may form part of the support offered to these parents and may decrease their risk of psychopathology. At the same time, these interventions may also assist parents in flexible parenting—responding to the needs of their child, even in the presence of significant parental stress.

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ORCID

Päivi Lappalainen  <http://orcid.org/0000-0001-9038-894X>

Ana Gallego  <http://orcid.org/0000-0002-8060-2495>

Katariina Keinonen  <http://orcid.org/0000-0003-3228-5357>

Asko Tolvanen  <http://orcid.org/0000-0001-6430-8897>

Raimo Lappalainen  <http://orcid.org/0000-0001-6683-134X>

Data availability statement

The data supporting the conclusions of this article will be made available by the authors by request.

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