Internet Interventions 24 (2021) 100382

Contents lists available at ScienceDirect

Internet Interventions

journal homepage: www.elsevier.com/locate/invent

Supporting parents of children with chronic conditions: A randomized controlled trial of web-based and self-help ACT interventions

Päivi Lappalainen [a,b,*], Inka Pakkala [a,b], Juho Strömmer [a], Essi Sairanen [c], Kirsikka Kaipainen [d], Raimo Lappalainen [a]

[a] University of Jyväskylä, Department of Psychology, Jyväskylä, Finland
[b] The Gerocenter Foundation for Research and Development, Jyväskylä, Finland
[c] Karlstad University, Department of Social and Psychological Studies, Karlstad, Sweden
[d] Tampere University, Unit of Computing Sciences, Tampere, Finland

ARTICLE INFO

Keywords:
Acceptance and commitment therapy
Internet
Self-help
Parents of children with chronic conditions
Burnout
Video conferencing

ABSTRACT

Objective: Many parents of children with chronic conditions and developmental disabilities experience high rates of burnout and psychological distress. The aim of the current study was to examine the effects of two differently delivered interventions based on acceptance and commitment therapy (ACT) on symptoms of burnout, depression, quality of life, psychological flexibility, and mindfulness skills.

Method: A total of 110 parents of children aged 0.8 to 17 years with chronic conditions and developmental disabilities participated in a randomized controlled trial lasting 13 weeks with two intervention groups: (1) an iACT intervention, including three psychologist-led video conferencing sessions, and (2) a self-help ACT, which received self-help material: an ACT-based booklet with the possibility of using ACT-based online exercises.

Results: For the main outcome measure burnout, a similar decrease was found in both groups. The supported iACT intervention produced significantly larger improvements in depressive symptoms ($d = 0.49$), psychological flexibility ($d = 0.64$), and mindfulness ($d = 0.55$) compared to the self-help ACT intervention. For health-related quality of life, only the dimension of *role limitations caused by emotional problems* showed a significant difference in favor of the supported iACT ($d = 0.58$).

Conclusions: The results suggest that the iACT intervention including three video conferencing sessions with a psychologist produced broader improvements in parents' psychological well-being than the self-help ACT. Overall, Internet-delivered interventions and video conferencing technology may offer a feasible alternative to psychological support and self-care for parents of children with chronic conditions. Further research is needed to investigate the long-term effects of the current delivery models.

1. Introduction

The number of chronic health conditions and disabilities among children has steadily increased in the last decades (Perrin et al., 2014). Children with long-term conditions and complex needs require several hours of additional care and assistance on a daily basis compared to their healthy counterparts (Heyman et al., 2004), thereby posing extra burdens on their parents' well-being. Parents of children with chronic conditions have been found to experience distress, insecurity, loss of self-esteem, negative emotions, anxiety, disease-related fear, depression, and physical and mental distress (Boman et al., 2004). Burnout symptoms are more typical of parents of chronically ill children than those of healthy children, and mothers, in particular, have been found to suffer from burnout (Lindström et al., 2010). Although the level of distress diminishes over time, some symptoms persist for years after a child has been diagnosed with a serious illness (Boman et al., 2003). In addition, studies show that parents with a child with a developmental abnormality perceive their quality of life to be lower than those whose child develops normally (Huang et al., 2014; Xiang et al., 2009).

As there is abundant research suggesting that parental distress is associated with a large number of adverse family outcomes, including increased mental health problems in children (Amrock and Weitzman, 2014; Merrill et al., 2007) and poorer long-term adjustment to the child's illness (Rabineau et al., 2008), there is a need for interventions

* Corresponding author at: Department of Psychology, FIN-40014, University of Jyväskylä, Finland.
E-mail address: paivi.k.lappalainen@jyu.fi (P. Lappalainen).

https://doi.org/10.1016/j.invent.2021.100382
Received 8 January 2021; Received in revised form 9 March 2021; Accepted 10 March 2021
Available online 16 March 2021
2214-7829/© 2021 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

aimed at reducing parental strain. Parents of children with chronic conditions may engage in a variety of avoidant coping strategies to deal with their child's illness, such as eliminating or avoiding painful thoughts, feelings, and sensations related to the child's condition. Avoidant coping strategies may provide temporary relief but may lead to increased distress in the long term (Bardeen and Fergus, 2016; Hayes et al., 2006). Evidence shows that parents who have poor psychological flexibility, i.e., engage in avoidant coping strategies, may experience challenges when adjusting to caring for their child with a chronic condition and may exhibit psychological symptoms such as anxiety, depression, and stress (e.g., Chong et al., 2017). Increasing parents' ability to take an accepting, non-judging stance toward their own thoughts and feelings and their child's potential behavioral problems may assist parents in regulating their emotions and choosing more appropriate parenting behaviors (Prevedini et al., 2020). A third wave of cognitive behavioral therapy (CBT) or the process-based CBT approach, such as acceptance and commitment therapy (ACT, Hayes et al., 1999), may be particularly useful in addressing avoidant coping strategies and promoting skills that support children's socioemotional development (Lunsky et al., 2018).

In recent years, there has been an increase in the number of ACT-based interventions for supporting parents of children with chronic conditions. These interventions have varied in duration and have been targeted at parents whose children have been diagnosed with a variety of long-term illnesses, such as asthma (Chong et al., 2017, 2019), autism spectrum disorder (Blackledge and Hayes, 2006; Fung et al., 2018; Joekar et al., 2016; Lunsky et al., 2012; Lunsky et al., 2018; Poddar et al., 2015; Zody, 2017), cerebral palsy (Whittingham et al., 2016; Whittingham et al., 2019; Whittingham et al., 2020), intellectual disabilities (Reid et al., 2016), life-threatening illnesses (Burke et al., 2014), diabetes, and other chronic illnesses (Sairanen et al., 2019). According to recent meta-analyses and reviews (Byrne et al., in press; Parmar et al., 2019; Ruskin et al., in press; Yu et al., 2019), interventions based on ACT, mindfulness, and acceptance show promise in helping parents cope with the stress and psychological distress associated with having children with chronic conditions.

As most studies have predominantly examined the impact of individually or group-delivered interventions on the well-being of parents of children with chronic conditions, there is a need for more research on alternative ways to support these parents, who often lack the professional help and services and, owing to time constraints, spend less time on personal care (Brandon, 2007). Furthermore, the barrier of access to support cannot be overcome with the dominant models of delivering psychosocial interventions (Kazdin, 2019).

In countries where caring for chronically ill children often coincides with working life, parents may find it particularly difficult or nearly impossible to incorporate the care of a chronically ill child, employment, and self-care into their schedule. Therefore, parents of children with chronic conditions could benefit from novel models of delivering support that are not tied to time or place, allowing them to devote time to self-care whenever they have the time and opportunity to do so. Feasible options to provide parents support are self-help models or web-based interventions combined with video conferencing technology. Currently, there is substantial research supporting the clinical effectiveness of video therapy (Simpson et al., 2020). So far, only few trials have investigated the efficacy of ACT-based online interventions for parents of children with chronic conditions (Sairanen et al., 2019; Whittingham et al., 2016), and an online parent support program for families of infants identified as at high risk of cerebral palsy, which is currently being implemented (Whittingham et al., 2020). The ACT-based web intervention, developed and tested by Sairanen et al. (2019), produced large between-group effect sizes for burnout, depression and anxiety symptoms, and aspects of mindfulness in comparison to a no-treatment (wait-list control) group. As our research lab participated in the development of the Swedish web-based program utilized in the Sairanen et al. (2019) study, the equivalent web program provided in another language (Finnish) and in another country was utilized in the current study.

1.1. Aim of the study

As the study of Sairanen et al. concluded that Internet-delivered ACT with the guidance of student therapists was effective at enhancing the psychological well-being of parents, we wanted to confirm these results and, furthermore, investigate whether comparable results could be attained with two differently delivered ACT-based interventions. We were especially interested in investigating the impact of a psychologist-supported iACT intervention using video conferencing technology in comparison to a self-help ACT intervention also including ACT-based exercises online but without any guidance. Thus, the aim of the current non-inferiority study was to examine whether the psychologist-supported iACT intervention with three video conferencing sessions would be superior to the self-help ACT intervention in reducing burnout and depressive symptoms and enhancing psychological flexibility, mindfulness, and quality of life in parents.

2. Methods

2.1. Settings and participants

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.

Parents were recruited through advertisements in local newspapers and the Facebook pages of diverse caregiver and family organizations. Interested parents were invited to contact the study team by phone or by sending their contact information via e-mail, after which an appointment for a telephone interview was arranged. In the phone call, preliminary information about the study was provided, and initial inclusion criteria were assessed. Those willing to participate received a link to an online survey, including a questionnaire on burnout that confirmed the suitability of the parent for the study. Parents who fulfilled the following inclusion criteria were eligible to participate: 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.

The data were collected in three phases, with the first wave starting in February 2019 and the last post-measurements taking place in May/June 2020. The randomization in the two groups followed each data collection using a randomization tool (see www.random.org). A total of 119 interested parents contacted the study team (see study flow in Fig. 1). Of these, nine were excluded: four of them did not meet the burnout (SMBQ) inclusion criteria; four dropped out before the pre-measurement; and one could not participate due to time constraints. Altogether, 110 parents comprising 103 females (93.6%) and seven males (6.4%) completed the pre-measurements, including background information (supported iACT, $n = 57$; ACT self-help, $n = 53$, Table 1). The mean age of the parents was 40.1 years ($SD = 6.68$, range 27–55), and close to 70% had a university-level education. A significant difference between the groups was noted in the age of the parents, with the parents in the iACT group being slightly younger ($M = 38.9$ years; $SD = 6.85$) compared to those in the self-help ACT group ($M = 41.5$ years; $SD = 6.29$). However, we considered this difference (39 vs. 41.5 years) as

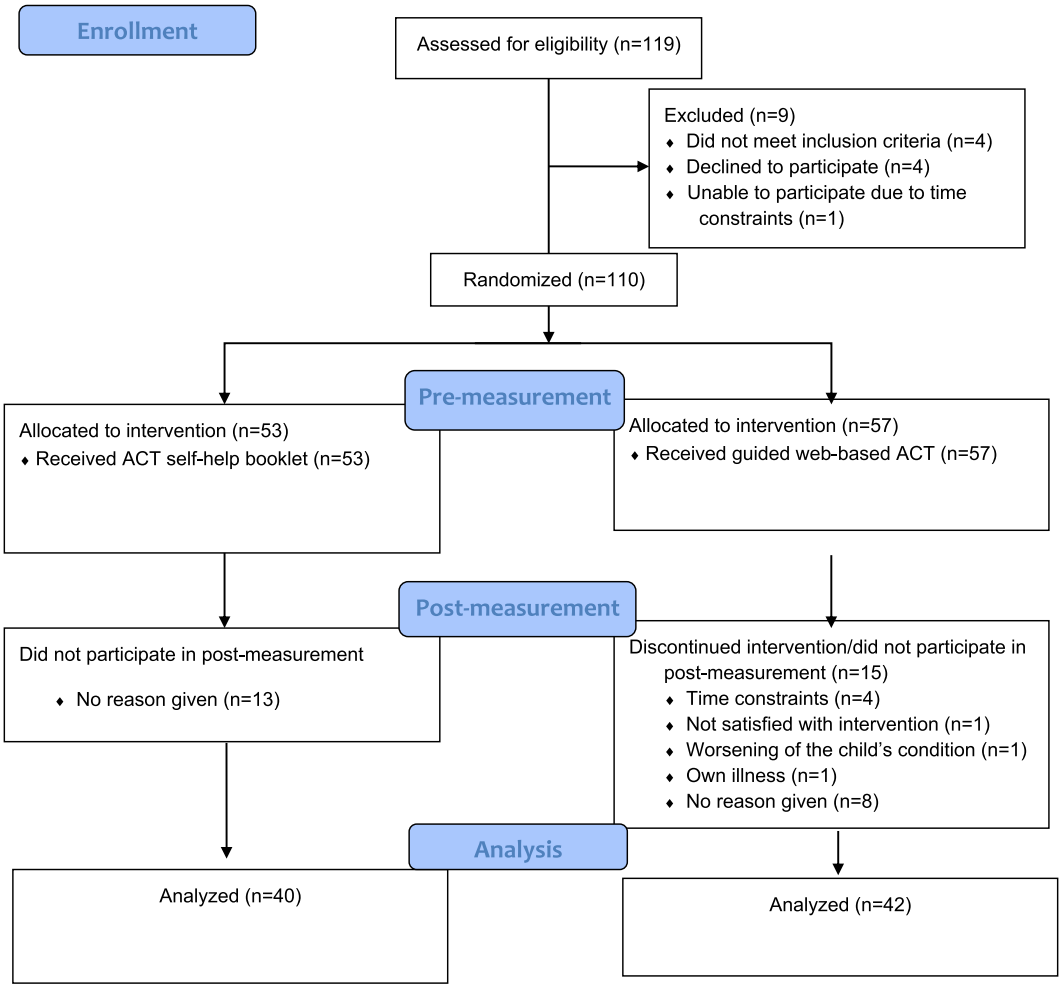

Fig. 1. Participant flow.

clinically non-significant. Sample demographics are presented in Table 1.

2.2. Interventions

2.2.1. Description of the supported iACT intervention

The iACT group (n = 57) participated in a web-based ACT intervention, including a web-program called *Uupu* and three online meetings with a psychologist via the doxy.me telemedicine solution. The parents received credentials to the program website (www.uupu.fi), and the intervention lasted 13 weeks, of which the web-based program lasted 10 weeks and included five modules (2 weeks each), according to an ACT approach: (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). The modules were composed of ACT-related content such as text, pictures, audio exercises, and videos. The content of the web-based program was identical to that in the study of Sairanen et al. (2019), except for changes related to data security according to the wishes of the Ethical Committee: 1) the discussion forum was left out; 2) the program did not include any possibility to write reflections or store any input on the program platform; and 3) email reminders were not sent to the participants. Instead, the parents were encouraged to write and reflect on the two-weekly home assignment for each module in a diary in paper form, which was sent to them by regular mail before the start of the intervention.

In addition, the intervention included three 45-minute online meetings with a clinical psychologist using the Doxy.me telecommunication application (www.doxy.me). The two psychologists, who worked as coaches, had ample experience in ACT. The first virtual session was arranged at the beginning of the intervention—before access to the web-program—the second after the parents had worked through the first two modules (i.e., four weeks from the start), and the third online meeting took place at the end of the intervention (i.e., weeks 11–12). During the first appointment, each parent's set of problems, assets, and circumstances were mapped using the modified psychosocial interview model (see Strosahl et al., 2012), including questions related to family and work life, leisure, and health behaviors. Based on the interview, the psychologist prepared a vector-graphic case formulation of the parent's overall situation (according to the Functional Analytic Clinical Case Model, FACCM; Haynes and O'Brien, 2000; Haynes et al., 2011), which was sent to the parent via regular mail. During the second appointment, the case formulation was discussed, and according to the content of the first two modules, concrete short- and long-term goals were discussed and set to guide the parent toward a valued life. The third online meeting was devoted to sharing experiences and lessons learned, the need for additional practice, and take-home messages for the parent.

2.2.2. Description of the ACT self-help material

The parents in the self-help group ($n = 53$) received a 20-page self-help booklet highlighting an ACT approach, which was sent by regular mail (see Table 3). In addition, they were encouraged to visit a website called Oivamieli (www.oivamieli.fi), a web page accessible to the public that included a series of ACT-based exercises (to read or listen) on topics such as values, acceptance, and the present moment (see Table 4). The

Table 1
Characteristics of parents.

Parental 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 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) range 0.8–17	8.5 (4.3) range 0.8–17	9.6 (4.2) range 1–17
Child's gender			
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%)

[a] Primary > 9 years; secondary 9–12 years; university 12 > years (university, college, etc.)
* Missing information: $n = 52$.
** Missing information: $n = 56$.
*** Missing information: $n = 55$.

participants in this group did not have access to the same website as the supported iACT group, neither did they receive professional support during the intervention period.

2.3. Measures

2.3.1. Symptom and quality of life measures

The main outcome measure was the Shirom-Melamed Burnout Questionnaire (SMBQ, Lundgren-Nilsson et al., 2012; Melamed et al., 1999). The questionnaire contains 22 statements measuring different aspects of burnout. The measure comprises of four subscales: emotional exhaustion, physical fatigue, listlessness, and tension. The statements are answered on a 7-point Likert scale, where the response options range from 1 = "almost 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 has 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) questionnaire (Kroenke et al., 2001), which is a dual-purpose instrument for making preliminary diagnoses and assessing the severity of depressive disorders. The PHQ-9 contains nine

Table 2
Content of the web-based program (supported iACT group).

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: Curtains in your life's window A meaningful moment 90th birthday party
Assignment, weeks 1–2	Reflect on your life values, and formulate them. Choose one or more areas of life that feel/s right for you right now. Do what it takes!
Module 2: Meaningful actions! (Value-based actions)	Text, experiential exercises: Do it now! Relieving stress Focus on breathing A place to rest Tired Passengers on the bus But-stories On your life's journey
Assignment, weeks 3–4	Choose at least two important life values, and make a plan. Write down your plan, as in the example below: My life value (what matters to me) is: … What do I choose to do?
Module 3: Present moment (Present moment)	Text, video, experiential exercises: Senses Breathing exercise Mindful listening Mindfulness in daily life Mindfully washing the dishes Mindful eating Mindful walking Mindful body
Assignment, weeks 5–6	1. Apply the SOAL (stop, observe, accept, and let go) method in your everyday life. 2. Choose a daily chore, and do it mindfully. 3. How can you influence your well-being? What actions are you willing to choose during the next two weeks
Module 4: Distance to thoughts and feelings (Defusion)	Text, video, experiential exercises: The little man Leaves in the stream The sky and the weather Observer
Assignment, weeks 7–8	1. Stop once in a while, and focus on what you are feeling or thinking. Label your thoughts, feelings, and body sensations as they appear: *Now, I've got the feeling that I'm sad* Now, I've got the feeling to … Now, the memory that comes to me … Now, it feels like this in the body …. 2. Train distance to your thoughts by asking yourself *Who is in charge here; me or my thoughts?* Or *Is this thought helpful? Has it helped me to live a good life?*
Module 5: Acceptance (Acceptance and self-compassion)	Text, video, experiential exercises: Köydenveto Hillomunkit Broken machine Let it be Compassionate hand Stone on the beach A good friend The guesthouse
Assignment, weeks 9–10	1. Is there anything in your life that you need to learn to accept? Apply the general model of acceptance to what you have difficulty accepting: 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. Which small acts of kindness can improve your well-being and that of others?
Closing words	The journey continues…

Table 3
Content of self-help booklet (self-help ACT group).

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 on your thoughts. You are not your thoughts (3 pages). Accepting mind: What is acceptance? Accept your thoughts and emotions. Accept what you cannot 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

items, which are answered on a 4-point Likert scale, where the answer options range 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 meter have been found to be good (Kroenke et al., 2001). In this study, Cronbach's alpha indicated high reliability, 0.78.

Health-related quality of life was measured with the Finnish version of the SF-36 measure (Dempster and Donnelly, 2000; Ware and Sherbourne, 1992) RAND-36 (Aalto et al., 1999). The RAND-36 measures the following eight dimensions: physical functioning, role limitations due to physical health problems, bodily pain, social functioning, general mental health, psychological distress and well-being, role limitations due to emotional problems, and vitality, energy. Each dimension is measured with Likert scales and "Yes" or "No" questions and forms its own entity. The original numeric values are recoded to give a value of 0–100. Regarding the scoring, index values were calculated, which were obtained by summing the number of questions for each dimension divided by the number of questions answered, with high scores indicating good health and quality of life. The validity and reliability of the RAND-36 have been found to be good in the Finnish population (Aalto et al., 1999). Cronbach's alpha for the RAND-36 in this study was high, 0.89.

2.3.2. 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, activation). The total score of the CompACT ranges from 0 to 138, with CompACT-OE ranging from 0 to 60, CompACT-BA ranging from 0 to 30, and CompACT-VA ranging from 0 to 48. In this study, the CompACT showed good internal consistency for the total score ($\alpha = 0.83$), $\alpha = 0.79$ for CompACT-OE, $\alpha = 0.76$ for CompACT-VA, and $\alpha = 0.80$ for CompACT-BA.

Mindfulness skills were assessed using the Five Facet Mindfulness Questionnaire (FFMQ, Baer et al., 2006), which measures five aspects of mindfulness: observing (noticing internal and external experiences), describing (naming and labeling internal experiences), acting with awareness (paying attentions to one's activities in the present moment), non-judging of inner experiences (having a non-evaluative stance toward inner experiences), non-reactivity to inner experiences (ability to let thoughts and feelings to 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 structure, reliability, and validity of FFMQ have been found to be good (Baer et al., 2006). In this study, the FFMQ showed 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.

Table 4
Content of the self-help ACT material on the web.

Process	MP3 exercises
1. The mind	
Present moment	Introduction
Focus on what you are doing.	Follow your breath
	Mindful sitting
	Connect with sounds around you
	Drop the anchor
	Mindful chores
	Summary
Observing	Introduction
You are not the same as your mind	Observer
	The bird
	Leaves in the stream
	Terrier thoughts
	The little man
	I have a thought
	Summary
Acceptance	Introduction
Accept what you cannot change	Warm jelly doughnuts
	Tug-of-war
	Stone on the beach
	Broken machine
	Compassionate hand
	Summary
2. Values and choices	
Values	Introduction
Find what is important to you	Your life now
	Epitaph
	Important in life
	Value domains
	Six months to live
	Notice the little things in your life
	Summary
Value-based actions	Introduction
Act according to your values	Set a goal
	Value-based action
	Do it now!
	Mindful listening
	Appreciate a loved one
	Passengers in the bus
	I cannot do it
	Summary
3. Body wellness	
The sensing body	Introduction
Feel the calm and peace in your body	Breath in, breath out
	Release your tensions
	Be a mountain
	Accept your body
	Massage the pain away
	Relaxation exercise
	Summary
Mindful eating	Introduction
Nutrition to your body, mind and heart	Mindful eating
	Who is hungry?
	Individual eating rhythm
	The value of food choices
	Barriers to eating choices
	Mindful groceries
	Summary
The moving body	Introduction
Take care of your body	The value of exercising
	Barriers to exercising
	Choose the stairs!
	Dance your troubles away
	Mindful exercise
	Summary

2.3.3. User activity and intervention satisfaction

In addition to the standardized instruments, we collected data on user activity and participant satisfaction. In the supported web-based group, user activity was determined as a percentage of the *Uupu* web program, which each parent had completed based on the log data. In the self-help group, the usage of the publicly accessible *Oivamieli* website could not be tracked, and instead, the parents were asked to report with "Yes" or "No" whether they had used the self-help booklet and the website, including the MP3 exercises. Overall satisfaction with the support received (web-based group) was measured using 0–10 visual rating scales (0 = not at all satisfied with the support model, 10 = very satisfied with the support model). Both groups of parents were also asked to evaluate with "Yes" or "No" whether they would recommend this kind of support (web + psychologist support or the self-help material) to other parents.

2.4. Statistical analysis

Latent change score (LCS) modelling (Wald test) was used to analyze the Group × Time interaction, i.e., whether the groups changed differently from the pre- to post-measurement (Klopack and Wickrama, 2020). LCS modelling applies structural equation modelling (SEM) and is equivalent to repeated measures ANOVA. It accounts for missing values at random (MAR) and includes all available data. The parameters were estimated using the full maximum likelihood (MLF) method (robust maximum likelihood (MLR) estimation in Mplus) (Muthén and Muthén, 1998–2015).

Effect sizes (ESs) are reported using Cohen's d. This was calculated from the baseline to post-measurements within, and corrected between, groups to estimate the ESs using estimated values. ES was calculated by dividing the difference between the means by the average of the standard deviations. When calculating the between-group ES at post-measurement, we took into account the possible pre-measurement difference between the groups. An ES of 0.2 is considered small, 0.5 medium or moderate, and 0.8 large (Roth and Fonagy, 2005). The power analysis suggested that in the current study we needed a sample size of 128 participants given the effect size (d) = 0.25, α = 0.05, power = 0.80. Thus, the between group effect size $d > 0.20$ was the lowest effect size of interest, and our sample $n = 110$ was large enough to detect the difference between the groups.

3. Results

3.1. Baseline psychological distress and dropout rates

Regarding burnout (SMBQ), the majority of the parents in the iACT group were classified as experiencing pathological levels of burnout (≥4.47, $n = 34$, 59.6%); 12 parents (21.1%) had high burnout (3.75–4.46); and 11 parents (19.3%) experienced mild burnout (2.75–3.74). In the self-help ACT group, the equivalent values were 35 (66%), 13 (24.5%), and 5 (9.4%). With regard to depression (PHQ-9), mild depression was reported by 21 (36.8%) parents in the iACT and 26 (49.1%) in the self-help ACT group; moderate depression was reported by 18 parents (31.6%) in the iACT and 14 (26.4%) in the self-help group; moderately severe to severe depression was experienced by 10 parents (17.6%) in the iACT group and six parents (11.4%) in the self-help ACT group.

Out of the 110 parents who participated in the pre-measurement, a total of 28 (25.5%) dropped out at the post-measurement, leaving 42 parents in the supported iACT group (dropout 26.3%) and 40 in the self-help ACT (dropout 24.53%) at post-measurement. Fig. 1 presents the flow of the study.

3.2. Symptom, quality of life, and process measures

The effects of the two interventions on the symptom and process measures are summarized in Table 5, and those regarding the quality of life measures are summarized in Table 6. For the main outcome measure, symptoms of burnout (SMBQ), there was no significant interaction effect. Instead, the groups showed relatively similar and significant within group decreases ($p < 0.01$) in burnout symptoms (SMBQ), and the within group effect sizes were medium in both groups (iACT: d = 0.63–0.99; self-help ACT: d = 0.48–1.10). In terms of depressive symptoms, a comparison revealed that the two groups changed differently (PHQ-9; a significant interaction effect, $p = 0.021$), with a larger decrease in the supported iACT group. For the process measures, we observed the following significant interaction effects: the supported iACT produced larger changes for the total CompACT score ($p = 0.039$) and its subscale *valued action* ($p = 0.039$) as well as for the total mindfulness score (FFMQ; $p = 0.047$) and its subscale *describing* ($p = 0.007$). These significant interactions showed medium-sized differences (d = 0.49–0.64) in favor of the supported iACT intervention. For health-related quality of life (RAND-36), both groups showed significant positive changes in vitality and general mental health (Table 5). The within-group ESs indicated large changes in the iACT ($d = 0.94/0.84$ for vitality and general mental health, respectively) and small to medium changes in the self-help ACT for vitality and mental health (d = 0.42–0.55). However, the RAND subscale *role limitations caused by emotional problems* showed a significant medium-sized ($d = 0.58$) difference between the groups in favor of the supported iACT (significant interaction effect, p = 0.021). An investigation of the between- and within-group ESs revealed that the changes in several symptom, process, and quality of life measures were somewhat larger in the supported iACT than in the self-help ACT.

3.3. User activity

In the supported iACT group, a great majority (69%, $n = 29/42$) of the parents completed the whole program or most of it (76–100%); 11.9% ($n = 5$) completed between 51 and 75%; and 19.1% completed 50% or less. Overall, approximately 80% of the parents completed more than 50% of the web intervention. Further, the log data indicated that approximately 62% had been using the web program over five to eight weeks (45.2%) or longer (16.7%, over 9–12 weeks). For the self-help ACT, no user activity data were available, but following the intervention, 62.5% of the parents reported that they had used the self-help booklet, while 32.5% had used the website with the ACT-based exercises. More precisely, 30% of the parents in the self-help ACT group (n = 12/40) had used both the self-help booklet and the website.

3.4. Intervention satisfaction

The parents in the supported iACT gave a rating of 7.8 (scale 0–10) for their satisfaction with the overall support. In the self-help ACT, their satisfaction with the self-help material was rated 5.4, on average, using the same scale. The participants were also asked to evaluate with "Yes" or "No" whether they would recommend this kind of support (web + psychologist support) to other parents of children with chronic conditions. In the iACT group, 95% of the parents would recommend the intervention to other parents, whereas in the self-help ACT, 65% of them would recommend the self-help material to other parents.

4. Discussion

Parents of children with chronic conditions have been found to experience physical and mental distress, which can have harmful consequences for the entire family. The aim of the present study was to examine two types of interventions with the purpose of supporting such families, namely the impact of a psychologist-supported iACT intervention and self-help ACT regarding burnout, depressive symptoms, quality of life, and psychological flexibility among parents of children with chronic conditions. With regard to the main outcome measure

Table 5
Estimated sample statistics (mean ± standard deviation (SD)) and the effect of the intervention on outcomes.

	Supported iACT				Self-help ACT				Interaction p[a]	d[d]
	Pre	Post	p[b]	d[e]	Pre	Post	p[c]	d[e]		
SMBQ	4.51 ± 0.88	3.57 ± 1.08	<0.01	0.99	4.76 ± 0.75	4.04 ± 1.11	<0.01	0.77	0.27	0.29
Phys.fatigue	4.68 ± 0.98	3.52 ± 1.19	<0.01	0.84	4.82 ± 0.81	3.99 ± 1.15	<0.01	1.10	0.14	0.39
Listlessness	4.67 ± 0.85	3.84 ± 1.06	<0.01	0.89	5.02 ± 0.95	4.20 ± 1.28	<0.01	0.72	0.86	0.05
Tension	4.25 ± 1.18	3.45 ± 1.19	<0.01	0.68	4.60 ± 0.99	4.04 ± 1.15	<0.01	0.55	0.47	0.19
Emot.exhaust.	4.33 ± 1.25	3.53 ± 1.40	<0.01	0.63	4.56 ± 1.04	4.00 ± 1.44	<0.01	0.48	0.35	0.21
PHQ-9	9.61 ± 4.97	6.61 ± 5.13	<0.01	0.63	9.21 ± 4.40	8.15 ± 4.75	0.26	0.19	0.02	0.49
CompACT	77.20 ± 18.65	91.61 ± 18.16	<0.01	0.76	75.24 ± 14.01	78.95 ± 11.72	0.22	0.27	0.04	0.64
OE	32.59 ± 11.25	40.18 ± 10.20	<0.01	0.65	33.08 ± 8.54	35.84 ± 8.34	0.15	0.28	0.09	0.47
BA	13.75 ± 6.17	15.43 ± 5.97	0.16	0.30	12.53 ± 5.25	12.21 ± 3.20	0.74	0.07	0.18	0.37
VA	30.86 ± 7.13	36.00 ± 5.76	<0.01	0.74	29.63 ± 6.44	30.90 ± 4.99	0.18	0.25	0.04	0.49
FFMQ	125.72 ± 16.62	138.07 ± 17.69	<0.01	0.72	126.37 ± 14.00	129.47 ± 13.87	0.15	0.27	0.05	0.55
OBS	25.82 ± 5.36	28.39 ± 4.75	<0.01	0.49	26.41 ± 4.92	26.63 ± 5.32	0.31	0.19	0.18	0.30
DESC	28.46 ± 5.92	31.29 ± 7.09	<0.01	0.40	28.98 ± 5.49	28.37 ± 5.10	0.41	0.15	<0.01	0.59
AWA	22.75 ± 5.12	24.43 ± 5.25	0.04	0.34	21.55 ± 4.06	22.55 ± 3.70	0.35	0.25	0.74	0.17
NJ	28.04 ± 7.34	31.11 ± 7.39	0.02	0.41	28.29 ± 6.53	29.90 ± 6.05	0.12	0.28	0.39	0.20
NR	20.66 ± 4.40	22.86 ± 3.17	0.01	0.58	21.14 ± 3.54	22.05 ± 4.07	0.39	0.19	0.21	0.38

SMBQ = Shirom-Melamed Burnout Questionnaire.
SMBQ Phys.fatigue = physical fatigue.
SMBQ Emot.exhaust. = emotional exhaustion.
PHQ-9 = Patient Health Questionnaire (depressive symptoms).
CompACT = comprehensive assessment of ACT processes.
CompACT-OE = openness to experiences.
CompACT-BA = behavioral awareness.
CompACT-VA = valued action.
FFMQ = Five Facet Mindfulness Questionnaire.
FFMQ-OBS = observing.
FFMQ-DESC = describing.
FFMQ-AWA = acting with awareness.
FFMQ-NJ = non-judgement.
FFMQ-NR = non-reactivity.
[a] p-Value for differences in changes between the groups using estimated parameters (Latent Change Score, Wald test). Bold text indicates significant p-value < 0.05.
[b] p-Values of the change between pre and post within the supported iACT group.
[c] p-Values of the change between pre and post within self-help ACT group.
[d] Cohen's d from baseline to post-measures between the supported iACT group and the self-help ACT group using estimated parameters.
[e] Cohen's d from baseline to post-measures within the group using estimated parameters.

Table 6
Estimated sample statistics (mean ± standard deviation (SD)) and the effect of the intervention on Health-related quality of life (RAND-36).

RAND-36	Supported iACT				Self-help ACT				Interaction p[a]	d[d]
	Pre	Post	p[b]	d[e]	Pre	Post	p[c]	d[e]		
Physical function.	85.61 ± 16.61	86.19 ± 20.41	0.05	0.13	85.00 ± 14.01	86.83 ± 14.35	0.90	0.02	0.33	0.13
Role limit./phys. health	75.00 ± 10.69	77.98 ± 33.27	0.27	0.14	61.79 ± 37.49	62.81 ± 36.68	0.97	0.01	0.56	0.12
Role limit./emot. probl.	39.18 ± 35.39	61.11 ± 37.03	<0.01	0.60	45.28 ± 38.90	46.34 ± 41.57	0.99	0.00	0.02	0.58
Vitality	34.91 ± 14.49	50.00 ± 19.24	<0.01	0.94	33.89 ± 14.88	44.02 ± 21.56	<0.01	0.55	0.17	0.38
Mental health	54.18 ± 14.80	66.00 ± 13.81	<0.01	0.84	51.93 ± 14.27	57.76 ± 16.03	0.01	0.42	0.10	0.39
Social functioning	58.77 ± 22.70	69.05 ± 27.45	<0.01	0.46	60.82 ± 21.38	65.94 ± 18.75	0.15	0.24	0.20	0.30
Bodily pain	67.50 ± 26.04	72.08 ± 28.08	0.06	0.22	66.70 ± 22.10	71.95 ± 20.69	0.12	0.26	0.99	0.02
Health perceptions	54.12 ± 18.52	59.17 ± 21.01	0.03	0.22	51.60 ± 18.78	57.76 ± 20.13	0.07	0.26	0.96	0.02

Physical function. = physical functioning.
Role limitat./phys. health = role limitations due to physical health problems.
Role limitat./emot. probl. = role limitations due to emotional problems.
Vitality = vitality, energy.
Mental health = general mental health covering psychological distress & well-being.
Social functioning.
Bodily pain.
Health perceptions = general health perceptions.
[a] p-Value for differences in changes between the groups using estimated parameters (latent change score, Wald test). Bold text indicates significant p-value < 0.05.
[b] p-Values of the change between pre and post within supported iACT group.
[c] p-Values of the change between pre and post within self-help ACT group.
[d] Cohen's d from baseline to post-measures between the iACT group and the self-help ACT group using estimated parameters.
[e] Cohen's d from baseline to post-measures within the group using estimated parameters.

burnout, the results showed that both the psychologist-supported iACT and the self-help ACT intervention reduced burnout symptoms. However, regarding depressive symptoms, psychological flexibility, mindfulness, and in one dimension of health-related quality of life, the supported iACT produced significantly larger improvements compared to the self-help ACT intervention. In these measures, the between group

effect sizes showed medium-sized differences ($d = 0.49–0.64$) in favor of the supported iACT intervention. In an examination of psychological flexibility (CompACT) and mindfulness skills (FFMQ) at the subscale level, the *valued action* and *describing* (*labeling feelings, thoughts and experiences with words*) subscales showed larger changes in the iACT group compared to the self-help ACT group. In an examination of the within-group effect sizes, small or very small effects in mindfulness skills were generally observed in the ACT self-help group, however, larger changes were recorded in the supported iACT group. This may be due to the fact that only one third of the parents undergoing the self-help approach had undertaken the experiential exercises of teaching value-, acceptance and mindfulness skills, which may have reflected in the outcomes in these constructs. One explanation why no significant changes in other mindfulness and flexibility skills were detected in the supported iACT group could be that skills such as *observing* (noticing or attending to internal feelings and thoughts), *acting with awareness* (attending to what is happening in the present), and *non-reacting* (allowing emotions and thoughts to come and go) may require more practice and take more time to appear, which is similar to the argument regarding the subskill of *non-judging* (Hofer et al., 2018). The same may apply to other psychological flexibility skills measured by CompACT, such as *openness to experience* and *behavioral awareness*, which are very close, if not overlapping, constructs to mindfulness skills. The change in *valued actions* may be due to the fact, as a construct, it is easier to understand and to promote compared to mindfulness constructs, which require more practice. This, potentially, suggest that the parents – who were reminded by the psychologist – had more actively committed to exercises dealing with value work, and, consequently, may have engaged in value-based actions.

Interestingly, both interventions had an impact on burnout symptoms. In the past years, research has been inconclusive in terms of whether or not burnout and depression are the same construct or not and whether burnout is a risk factor in developing depression (Kaschka et al., 2011; Koutsimani et al., 2019). According to Koutsimani et al. (2019), burnout and depression seem to be different constructs that share some common characteristics and may develop in parallel. Given that burnout is an antecedent of depression, a possible explanation could be that the self-help ACT intervention had started to have an impact on burnout, but had not yet affected depressive symptoms. An alternative explanation is that provided by Baer et al. (2012) who stated that before learning any mindfulness skills, other factors such as coming to a treatment group and sharing with fellow participants with similar problems may lead to small decreases in perceived stress. In this study, being allocated to a research group and received attention may have also induced changes in burnout in the self-help ACT group. As mindfulness and flexibility skills begin to develop, additional decreases in burnout may be expected (see Baer et al., 2012).

With regard to the amount of support, our findings are consistent with previous research suggesting that unsupported treatments are less effective than treatments that incorporate support (e.g., Andersson and Cuijpers, 2009; Farrand and Woodford, 2013). The current study is also in line with meta-analyses that have compared guided Internet-based treatments with unsupported control conditions and indicated larger effect sizes in favor of guided Internet-based treatments in which a therapist or coach supports the client through the treatment program (between-group $d = 0.42–0.78$; Andersson and Cuijpers, 2009; Richards and Richardson, 2012). At the same time, the results also indicate that pure self-help ACT may produce positive outcomes in parents. Despite of the differential design, this study can be compared with that of Hofer et al. (2018) which concluded that ACT delivered through a self-help book without contact from a therapist reduced stress and burnout for individuals among working population compared to those in a waiting-list control group.

An important aspect was the satisfactory user activity in both intervention groups. In the supported web-intervention group, approximately 70% completed all or nearly all of the program, and only 5% ($n = 2$) took very little advantage of the program (1–25% usage observed). Conversely, self-help material, which was provided with no support, was utilized by over 60% of the parents. These numbers can be regarded as encouraging. To attain even better adherence to the web intervention (iACT) and self-help material (self-help ACT), some parents may have needed more professional support, peer support, and/or email-reminders inviting them back to the program. Therefore, there is a need to examine in greater detail parents' usage activity in terms of reflecting their engagement and patterns of usage in the current iACT and self-help ACT interventions. In addition, future studies should pay attention to remaining sensitive to parental needs and wishes for support. Support for families—as Coyne et al. (2020) suggest—should be provided in small, doable doses. Even when the dose is small, it can still make a difference (Coyne et al., 2020). The current interventions are one step in this direction, providing parents with flexible tools for managing their own distress and promoting self-care.

The study by Sairanen et al. (2019) offers an interesting comparison to the current study as it applied a comparable web-based ACT intervention in a different country and language. Juxtaposing the results of the current study with those of the equivalent study by Sairanen et al. (2019), comparable changes were observed in the context of burnout (within-group effect size, $d^w = 0.99$ (FI) versus 0.70 (SWE)). Interestingly, these ESs were comparable to burnout decrease in the self-help group ($d^w = 0.77$). Although different measures for depression were used, the magnitude of the change was also similar in both iACT interventions ($d^w = 0.63$ (FI) versus 0.45 (SWE)). Moreover, regarding mindfulness, the impact was equal in the two interventions ($d^w = 0.63$ (FI) versus 0.72 (SWE)). In addition, the percentages for dropouts were equal at post-measurement, with 26% ($n = 15$) in the current iACT intervention compared with 27% in the Swedish treatment group. Both percentages are in accordance with the findings of a meta-analysis of computer-based interventions for depression, showing dropout rates of 28% for therapist-support treatments (Richards and Richardson, 2012). Interestingly, the dropout rate for the self-help group (25%) was comparable to that of the supported iACT group and, therefore, was not consistent with dropout evidence for non-supported treatments (74%, Richards and Richardson, 2012). In conclusion, the current study confirmed the results observed in the previous study by Sairanen et al. (2019), which showed that a psychologist supported ACT intervention delivered via the Internet can decrease symptoms of burnout and depression among parents of children with chronic conditions.

4.1. Limitations

Several limitations need to be considered in interpreting the results of this study. First, the recruitment method and data collection may limit the generalizability of the results. By conducting the recruitment through family and parent organizations, we may have excluded parents who were not actively engaged in these organizations and who may not use the Internet. Second, the current study reports only the pre- and post-intervention results. However, the ongoing follow-up period will determine whether the changes were maintained over a longer period of time. Third, the lack of a waiting-list control group (WLC) that did not undergo intervention suggests that we cannot draw firm conclusions from the results of the study, neither can we exclude that other factors might have impacted the results. It is possible that the improvements in the outcomes of the two groups were caused by repeated measures or spontaneous recovery effects. However, changes in a WLC group were verified in the Swedish study by Sairanen et al., 2019, showing no or minimal changes in the no-intervention group, with a web-based ACT intervention showing significantly larger improvements. Fourth, all the assessment scales were self-report questionnaires. Ecological momentary assessment through smartphones could have given additional information on the impact of the study. Fifth, given the large number of significant test performed, and the increased risk of type I and type II errors (and in purpose to ensure that our conclusions were reliable), the

conclusions were based both on statistical differences and corrected between group effect sizes. Thus, among those variables that showed significantly different changes between the groups, the corrected between group effect sizes were at medium size level (d = 0.49–0.64) indicating clear differences at the end of the intervention. Finally, the sample identified themselves mainly as highly educated, most of whom were mothers. The above-presented findings can only be generalized to a group of highly educated and motivated parents reporting high levels of burnout and depression symptoms. Consequently, future research should aim to investigate parents with a greater heterogeneity of participant characteristics, including males and parents from different backgrounds and minority populations.

5. Conclusions and future directions

Many parents experience burnout and other mental health problems in caring for children with chronic conditions. However, the severity of these parents' symptoms is rarely recognized or treated by health professionals. Many parents wait too long before seeking treatment for their symptoms of burnout, which often results to a prolonged recovery (Glise et al., 2012). Therefore, it is important to continue to develop and evaluate relevant interventions for this vulnerable group of parents, who often lack access to services. Supporting them is vital because of the crucial role they play in the lives and well-being of their children. These parents need treatments or self-care-providing skills to manage distress and promote well-being. As they deal with several challenges regarding combining childcare with work and leisure time, they need self-care tools that can easily be integrated into their daily life. Furthermore, as there are barriers in the provision of support services for these parents, digital health interventions may offer a feasible alternative to psychological support and self-care, which are readily accessible. Video conferencing opens the lines of communication for parents to be put in touch with a psychologist for a virtual therapy session, independent of geographic location.

While we need to be cautious about the conclusions herein due to some limitations in the current study, our findings suggest that parents of children with chronic conditions may be able to alleviate their symptoms of burnout by participating in either the psychologist-supported web-based ACT intervention or a self-help ACT intervention. A relatively brief (three months) web-based ACT intervention with totally three virtual sessions with a psychologist may offer additional benefits such as reduced symptoms of depression and increased psychological flexibility and mindfulness skills. Since the ACT self-help delivery model showed nearly equivalent improvements in burnout symptoms, the self-help guide combined with ACT-based experiential exercises in the Internet can also be considered a feasible option for distressed parents as it uses fewer resources than supported interventions. Based on our findings, however, we propose that whenever possible, a supported iACT intervention should be prioritized over a self-help ACT intervention as the supported model produced broader changes and was overwhelmingly accepted by the parents. In addition, our findings suggest that video conferencing technology can bring opportunities to work with this population and support them in virtual settings regardless of physical location.

There are grounds to explore in greater detail how the current ACT interventions could be improved to guarantee the best way to deliver psychological support to parents of children with chronic conditions. In particular, it is worth exploring how the support provided via video conference calls could be improved to provide more convenient and adequate support for parents of children with chronic conditions. The importance of including peer support in the intervention should also be examined. Moreover, the effectiveness and acceptability of interventions developed in collaboration with parents should be investigated, and further research should investigate the long-term effects of the current delivery models. Both parents and health professionals should be informed that there are feasible alternatives to support, such as web-based programs combined with support using video conference sessions or pure self-help models which may help in reducing the distress of parents of children with chronic conditions.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

Funding for this project was provided by the Social Insurance Institution of Finland (Kela), grant number 18/26/2018. The funding source had no involvement in the conduct of the research (study design, analysis, interpretation of data), the preparation of the article, or in the decision to submit the article for publication.

References

Aalto, A.-M., Aro, A.R., Teperi, J., 1999. RAND-36 terveyteen liittyvän elämänlaadun mittarina: mittarin luotettavuus ja suomalaiset väestöarvot [Verkkokirja]. Helsinki, Stakes, Tutkimuksia, p. 101. http://www.julkari.fi/bitstream/handle/10024/76006/Tu101.pdf?sequence=1&isAllowed=y.

Amrock, S., Weitzman, M., 2014. Parental psychological distress and children's mental health: results of a national survey. Acad. Pediatr. 14 (4), 375–381 (doi:10.1016/j).

Andersson, G., Cuijpers, P., 2009. Internet-based and other computerized psychological treatments for adult depression: a meta-analysis. Cogn. Behav. Ther. 38, 196–205. https://doi.org/10.1080/16506070903318960.

Baer, R.A., Smith, G.T., Hopkins, J., Krietemeyer, J., Toney, L., 2006. Using self-report assessment methods to explore facets of mindfulness. Assessment 13 (1), 27–45. https://doi.org/10.1177/1073191105283504.

Baer, R.A., Carmody, J., Hunsinger, M., 2012. Weekly change in mindfulness and perceived stress in a mindfulness-based stress reduction program. J. Clin. Psychol. 68 (7), 755–765.

Bardeen, J.R., Fergus, T.A., 2016. The interactive effect of cognitive fusion and experiential avoidance on anxiety, depression, stress and posttraumatic stress symptoms. J. Contextual Behav. Sci. 5, 1–6. https://doi.org/10.1016/j.jcbs.2016.02.002.

Blackledge, J.T., Hayes, S.C., 2006. Using acceptance and commitment training in the support of parents of children diagnosed with autism. Child Fam. Behav. Ther. 28 (1), 1–18. https://doi.org/10.1300/J019v28n01_01.

Boman, K., Lindahl, A., Björk, O., 2003. Disease-related distress in parents of children with cancer at various stages after the time of diagnosis. Acta Oncol. 42 (2), 137–146. https://doi.org/10.1080/02841860310004995.

Boman, K.K., Viksten, J., Kogner, P., Samuelsson, U., 2004. Serious illness in childhood: the different threats of cancer and diabetes from a parent perspective. J. Pediatr. 145 (3), 373–379. https://doi.org/10.1016/j.jpeds.2004.05.043.

Brandon, P., 2007. Time away from "smelling the roses": where do mothers raising children with disabilities find the time to work? Soc. Sci. Med. 65 (4), 667–679. https://doi.org/10.1016/j.socscimed.2007.04.007.

Burke, K., Muscara, F., Mccarthy, M., Dimovski, A., Hearps, S., Anderson, V., Walser, R., 2014. Adapting acceptance and commitment therapy for parents of children with life-threatening illness: pilot study. Fam. Syst. Health 32 (1), 122–127. https://doi.org/10.1037/fsh0000012.

Byrne, G., Ghráda, Á.N., O'Mahony, T., Brennan, E., 2021. A systematic review of the use of acceptance and commitment therapy in supporting parents. Psychol. Psychother. Theory Res. Pract. https://doi.org/10.1111/papt.12282 (in press).

Chong, Y.Y., Mak, Y.W., Loke, A.Y., 2017. Psychological flexibility in parents of children with asthma: analysis using a structural equation model. J. Child Fam. Stud. 26 (9), 2610–2622. https://doi.org/10.1007/s10826-017-0757-x.

Chong, Y.Y., Mak, Y.W., Leung, S.P., Lam, S.Y., Loke, A.Y., 2019. Acceptance and commitment therapy for parental management of childhood asthma: an RCT. Pediatrics 143 (2), 1–16. https://doi.org/10.1542/peds.2018-1723.

Coyne, L.W., Gould, E.R., Grimaldi, M., Wilson, K.G., Baffuto, G., Biglan, A., 2020. First things first: parent psychological flexibility and self-compassion during COVID-19. Behav. Anal. Pract. 1–7. Advance online publication. https://doi.org/10.1007/s40617-020-00435-w.

Dempster, M., Donnelly, M., 2000. Measuring the health related quality of life of people with ischaemic heart disease. Heart 83 (6), 641–644. https://doi.org/10.1136/heart.83.6.641.

Farrand, P., Woodford, J., 2013. Impact of support on the effectiveness of written cognitive behavioural self-help: a systematic review and meta-analysis of randomised controlled trials. Clin. Psychol. Rev. 33, 182–195. https://doi.org/10.1016/j.cpr.2012.11.001.

Francis, A.W., Dawson, D.L., Golijani-Moghaddam, N., 2016. The development and validation of the comprehensive assessment of acceptance and commitment therapy processes (CompACT). J. Contextual Behav. Sci. 5 (3), 134–145. https://doi.org/10.1016/j.jcbs.2016.05.003.

Fung, K., Lake, J., Steel, L., Bryce, K., Lunsky, Y., 2018. ACT processes in group intervention for mothers of children with autism spectrum disorder. J. Autism Dev. Disord. 48 (8), 2740–2747. https://doi.org/10.1007/s10803-018-3525-x.

Glise, K., Ahlborg Jr., G., Jonsdottir, I.H., 2012. Course of mental symptoms in patients with stress-related exhaustion: does sex or age make a difference? BMC Psychiatry 12, 18.

Hayes, S.C., Strosahl, K.D., Wilson, K.G., 1999. Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change. Guilford Press, New York, NY.

Hayes, S.C., Luoma, J.B., Bond, F.W., Masuda, A., Lillis, J., 2006. Acceptance and commitment therapy: model, processes and outcomes. Behav. Res. Ther. 44 (1), 1–25. https://doi.org/10.1016/j.brat.2005.06.006.

Haynes, S.N., O'Brien, W.H., 2000. Principles and Practice of Behavioral Assessment. Springer, New York.

Haynes, S.N., O'Brien, W.H., Kaholokula, J.K., 2011. Behavioral Assessment and Case Formulation. John Wiley & Sons, Hoboken, NJ.

Heyman, M.B., Harmatz, P., Acree, M., Wilson, L., Moskowitz, J.T., Ferrando, S., Folkman, S., 2004. Economic and psychologic costs for maternal caregivers of gastrostomy-dependent children. J. Pediatr. 145 (4), 511–516. https://doi.org/10.1016/j.jpeds.2004.06.023.

Hofer, P.D., Waadt, M., Aschwanden, R., Milidou, M., Acker, J., Meyer, A.H., Lieb, R., Gloster, A.T., 2018. Self-help for stress and burnout without therapist contact: an online randomised controlled trial. Work Stress 32 (2), 189–208.

Huang, Y.-P., Chang, M.-Y., Chi, Y.-L., Lai, F.-C., 2014. Health-related quality of life in fathers of children with or without developmental disability: the mediating effect of parental stress. Quality Life Res. 23 (1), 175–183. Advance online publication. https://doi.org/10.1007/s11136-013-0469-7.

Joekar, S., Farid, A.A., Birashk, B., Gharraee, B., Mohammadian, M., 2016. Effectiveness of acceptance and commitment therapy in the support of parents of children with high-functioning autism. Int. J. Human. Cult. Stud. 2, 2763–2772.

Kaschka, W.P., Korczak, D., Broich, K., 2011. Burnout: a fashionable diagnosis. Deutsches Arzteblatt International 108 (46), 781–787. https://doi.org/10.3238/arztebl.2011.0781.

Koutsimani, P., Montgomery, A., Georganta, K., 2019. The relationship between burnout, depression, and anxiety: A systematic review and meta-Analysis. Front. Psycho. 10 (284).

Kazdin, A.E., 2019. Annual Research Review: Expanding mental health services through novel models of intervention delivery. J. Child Psycho. Psychi. 60 (4), 455–472.

Klopack, E.T., Wickrama, K., 2020. Modeling latent change score analysis and extensions in Mplus: a practical guide for researchers. Struct. Equ. Model. Multidiscip. J. 27 (1), 97–110. https://doi.org/10.1080/10705511.2018.1562929.

Kroenke, K., Spitzer, R.L., Williams, J.B.W., 2001. The PHQ-9: validity of a brief depression severity measure. J. Gen. Intern. Med. 16 (9), 606–613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x.

Lindström, C., Åman, J., Norberg, A., 2010. Increased prevalence of burnout symptoms in parents of chronically ill children. Acta Paediatr. 99 (3), 427–432. https://doi.org/10.1111/j.1651-2227.2009.01586.x.

Lundgren-Nilsson, Å., Jonsdottir, I.H., Pallant, J., Ahlborg, G., 2012. Internal construct validity of the Shirom-Melamed Burnout Questionnaire (SMBQ). BMC Public Health 12 (1), 1–8. https://doi.org/10.1186/1471-2458-12-1.

Lunsky, Y., Fung, K., Zurowski, M., 2012. Acceptance and commitment therapy (ACT) for parents of youth with autism spectrum disorders: preliminary findings. J. Intellect. Disabil. Res. 56 (7–8), 743–748.

Lunsky, Y., Fung, K., Lake, J., Steel, L., Bryce, K., 2018. Evaluation of acceptance and commitment therapy (ACT) for mothers of children and youth with autism spectrum disorder. Mindfulness 9, 1110–1116. https://doi.org/10.1007/s12671-017-0846-3.

Melamed, S., Ugarten, U., Shirom, A., Kahana, L., Lerman, Y., Froom, P., 1999. Chronic burnout, somatic arousal and elevated salivary cortisol levels. J. Psychosom. Res. 46 (6), 591–598. https://doi.org/10.1016/s0022-3999(99)00007-0.

Merrill, R.M., Brown, R.J., Alder, S., Baker, R.K., Byrd, A.D., White Jr., G.L., Lyon, J.L., 2007. Psychological disorders among children and the parents of children undergoing cancer workup. J. Psychosoc. Oncol. 25, 1–18. https://doi.org/10.1300/j077v25n03_01.

Muthén, L.K., Muthén, B.O., 1998–2015. Mplus User's Guide, 7th ed. Muthén & Muthén, Los Angeles, CA.

Parmar, A., Morinis, L., Barreira, L., Miller, D., Major, N., Church, P., Cohen, E., Orkin, J., 2019. 24 acceptance and commitment therapy (ACT) for parents of children with a chronic medical condition: a systematic review. Paediatr. Child Health 24 (Suppl. 2), e10. https://doi.org/10.1093/pch/pxz066.023.

Perrin, J.M., Anderson, L.E., Van Cleave, J., 2014. The rise in chronic conditions among infants, children, and youth can be met with continued health system innovations. Health Affairs (Project Hope) 33 (12), 2099–2105. https://doi.org/10.1377/hlthaff.2014.0832.

Poddar, S., Sinha, V., Urbi, M., 2015. Acceptance and commitment therapy on parents of children and adolescents with autism spectrum disorders. Int. J. Educ. Psychol. Res. 1, 221. https://doi.org/10.4103/2395-2296.158331.

Prevedini, A., Hirvikoski, T., Holmberg Bergman, T., Berg, B., Miselli, G., Pergolizzi, F., Moderato, P., 2020. ACT-based interventions for reducing psychological distress in parents and caregivers of children with autism spectrum disorders: recommendations for higher education programs. Eur. J. Behav. Anal. 21 (1), 133–157. https://doi.org/10.1080/15021149.2020.1729023.

Rabineau, K.M., Mabe, P.A., Vega, R.A., 2008. Parenting stress in pediatric oncology populations. J. Pediatr. Hematol. Oncol. 30, 358–365. https://doi.org/10.1097/MPH.0b013e318168e76b.

Reid, C., Gill, F., Gore, N., Brady, S., 2016. New ways of seeing and being: evaluating an acceptance and mindfulness group for parents of young people with intellectual disabilities who display challenging behaviour. J. Intellect. Disabil. 20, 5–17. https://doi.org/10.1177/1744629515584868.

Richards, D., Richardson, T., 2012. Computer-based psychological treatments for depression: a systematic review and meta-analysis. Clin. Psychol. Rev. 32 (4), 329–342. https://doi.org/10.1016/j.cpr.2012.02.004.

Roth, A., Fonagy, P., 2005. What Works for Whom: A Critical Review of Psychotherapy Research, 2nd ed. Guilford Publications, Guildford.

Ruskin, D., Young, M., Sugar, C., Nofech-Mozes, J., 2021. Mindfulness and acceptance interventions for parents of children and adolescents diagnosed with chronic medical conditions: a systematic review. J. Altern. Complement. Med. https://doi.org/10.1089/acm.2020.0191 (in press).

Sairanen, E., Lappalainen, R., Lappalainen, P., Kaipainen, K., Carlstedt, F., Anclair, M., Hiltunen, A., 2019. Effectiveness of a web-based acceptance and commitment therapy intervention for wellbeing of parents whose children have chronic conditions: a randomized controlled trial. J. Contextual Behav. Sci. 13, 94–102. https://doi.org/10.1016/j.jcbs.2019.07.004.

Simpson, S., Richardson, L., Pietrabissa, G., Castelnuovo, G., Reid, C., 2020. Videotherapy and therapeutic alliance in the age of COVID-19. Clin. Psychol. Psychother. https://doi.org/10.1002/cpp.2521. Advance online publication.

Strosahl, K., Robinson, P., Gustavsson, T., 2012. Brief Interventions for Radical Change: Principles and Practice of Focused Acceptance and Commitment Therapy. New Harbinger Publications, Oakland, CA.

Ware, J.E., Sherbourne, C.D., 1992. The MOS 36-ltem Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. Med. Care 30 (6), 473–483 (PMID: 1593914).

Whittingham, K., Sheffield, J., Boyd, R., 2016. Parenting acceptance and commitment therapy: a randomised controlled trial of an innovative online course for families of children with cerebral palsy. BMJ Open 6 (10), e012807. https://doi.org/10.1136/bmjopen-2016-012807.

Whittingham, K., Sanders, M.R., McKinlay, L., Boyd, R.N., 2019. Parenting intervention combined with acceptance and commitment therapy: a trial with families of children with cerebral palsy. J. Pediatr. Psychol. 41, 531–542. https://doi.org/10.1093/jpepsy/jsv118.

Whittingham, K., Sheffield, J., Mak, C., Dickinson, C., Boyd, R.N., 2020. Early parenting acceptance and commitment therapy 'early PACT' for parents of infants with cerebral palsy: a study protocol of a randomised controlled trial. BMJ Open 10, e037033. https://doi.org/10.1136/bmjopen-2020-037033.

Xiang, Y.-T., Luk, E., Lai, K., 2009. Quality of life in parents of children with attention-deficit-hyperactivity disorder in Hong Kong. Aust. N. Z. J. Psychiatry 43 (8), 731–738. https://doi.org/10.1080/00048670903001968.

Yu, Y., McGrew, J.H., Boloor, J., 2019. Effects of caregiver-focused programs on psychosocial outcomes in caregivers of individuals with ASD: a meta-analysis. J. Autism Dev. Disord. 49, 4761–4779. https://doi.org/10.1007/s10803-019-04181-z.

Zody, M.C., 2017. Acceptance and Commitment Therapy (ACT) as a One-day Workshop for Parents of Children With an Autism Spectrum Disorder (ProQuest Dissertations and Theses). The Wright Institute, Ann Arbor. http://ulib.iupui.edu/cgi-bin.