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Cognitive behavioural therapy and mindfulness for stress and burnout: a waiting list controlled pilot study comparing treatments for parents of children with chronic conditions

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Cognitive behavioural therapy and mindfulness for stress and burnout: a waiting list controlled pilot study comparing treatments for parents of children with chronic conditions

Background: Parents of children with chronic conditions often experience a crisis with serious mental health problems for themselves as a consequence. The healthcare focus is on the children; however, the parents often worry about their children's health and future but are seldom offered any counselling or guidance.

Aim: The aim of this study was to investigate the effectiveness of two group-based behavioural interventions on stress and burnout among parents of children with chronic conditions.

Design, participants and setting: After a waiting list control period (n = 28), parents were offered either a cognitive

behavioural (CBT, n = 10) or a mindfulness program (MF, n = 9).

Results: Both interventions decreased significantly stress and burnout. The within-group effect sizes were large in both interventions (CBT, $g = 1.28$ – 1.64 ; MF, $g = 1.25$ – 2.20).

Conclusions: Hence, the results of this pilot study show that treating a group using either CBT or mindfulness can be an efficient intervention for reducing stress levels and burnout in parents of children with chronic conditions.

Keywords: stress, care giving, chronic illness, cognitive, behaviour therapy, mindfulness, nursing models, burnout, parents of children with chronic conditions.

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Introduction

The family often suffers a crisis when a child is diagnosed with a chronic disease or a functional disability. It is then common that parents worry about their children's health and future, and they are often overwhelmed by the demands to secure the help and support that their children are entitled to (1). Research on parents of children with chronic conditions (chronically ill children and/or children with disability) has identified frequent psychological effects on the parents, for example, deteriorating life quality, stress-related disorders, compulsive thought patterns, evasion, insecurity, fears and despondency (1–5). These symptoms are more frequent among parents of children with chronic conditions, compared with parents in general (5).

Furthermore, long-term stress can lead to some form of chronic stress reaction or burnout or exhaustion disorder (ED) (6–9). Burnout or ED is often the result of ineffective coping with long-term stressors, such stressors as these parents are exposed to, and of the chronic depletion of a person's coping resources (10). The symptoms of burnout are emotional tiredness, cognitive fatigue and distinct bodily weakness or fatigability from which there is no recovery (10).

The challenges that parents of children with chronic conditions struggle with are documented in studies of parents of children with varying diagnoses, for example, cancer, type 1 diabetes, chronic pain, ADHD, asthma, heart disease, brain tumour, autism and schizophrenia (3, 5, 11, 12). Research indicates that the parents' mental health also affect the health, development and adjustment of the child (13). Hence, the parents' stress levels can be harmful to their children (14). Several external stress factors may influence and predict parental distress, such as the number of the child's hospital admissions (15), and Mash and Johnston (16) suggested that parent–

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child interactive stress may be regulated by variables related to 'child characteristics', 'parent characteristics' and 'environmental characteristics'.

Cognitive behavioural therapy (CBT) is an empirically validated form of psychotherapy whose effectiveness has been proven in over 350 outcome studies of mental disorders such as depression, anxiety and eating disorders. Moreover, stress-related problems and relationship problems can be treated individually and in groups (17–21). CBT in groups offers unique therapeutic opportunities: For example, the patient learns to recognise cognitive mistakes made by others, and a group can give more examples of links between thoughts and feelings than is possible in individual therapy (22, 23). Stress management training, as described by O'Donohue and Fisher (19), is a combination of several commonly used techniques to reduce stressors, and the empirical validity of such techniques has been demonstrated by Lehrer and Woolfolk (24). However, while there is no standardised stress management treatment manual that meets all the criteria for inclusion in the APA Division 12 list of empirically validated treatments, other approaches to stress management, such as Meichenbaum's stress inoculation training, are recognised by division 12 (19).

In 1982, Kabat-Zinn introduced a mindfulness-based training programme (25, 26), and in recent years, several forms of therapy based on mindfulness have been developed: among others, mindfulness-based stress reduction [MBSR; (27–29) and mindfulness-based cognitive therapy (MBCT; 30)]. Recent research has shown that mindfulness is effective for many different conditions such as stress, depression and anxiety. Mindfulness emphasises paying attention to the experience of the present moment and the nonjudgmental acceptance of it. However, mindfulness also involves learning to discover bodily signals of extra high stress levels, to identify stress thinking and break the detrimental downward spiral, and to make realistic judgments and find a positive way out (31–34).

If a similar efficacy in terms of therapeutic effect can be established for mindfulness group treatment compared with CBT group treatment, mindfulness would appear to be an alternative intervention option for stress reduction and burnout prevention in parents of chronically ill children. Mindfulness intervention offers some advantages in comparison with the CBT intervention. A mindfulness intervention is a relatively simple approach compared to a CBT approach. When a CBT intervention often requires a highly trained expert, a mindfulness intervention can be carried out after a more limited training. However, while the two treatments have not been directly compared, there have been several studies of CBT and mindfulness-based treatments applied to parents and/or caregivers of children with disabilities (35–37). A careful review of the literature indicates that these studies either focused on the child's behaviour and well-being or had limited experimental control conditions (36, 38–42).

Thus, more studies are needed to investigate the effectiveness of psychological interventions on parent's well-being having children with chronic conditions.

Aims of the present study

The purpose of this pilot study is to investigate whether CBT and mindfulness group treatment can reduce symptoms of stress and burnout in a population of parents of children with chronic conditions. We expected both intervention to have a positive impact on stress and burnout.

Method

Participants

Parents of children under the age of 18 with chronic conditions (chronic disease and/or functional disability) who were suffering from stress and burnout symptoms were recruited to the project via advertisement in the local press. For participation, an average of above 2.75 points on the Shirom-Melamed Burnout Questionnaire (SMBQ) and/or a sum above 25 points on the Perceived Stress Scale (PSS) was required. Parents with insufficient knowledge of Swedish (i.e., who needed an interpreter to fill out the questionnaires) were not invited to participate in the study. Also parents undergoing psychological treatment were excluded.

Initially, 28 participants took part in the baseline phase of the study. Of those, seven (23.3%) did not complete the postmeasurements of the baseline (waiting list) condition. Two participants (6.7%) withdrew during the treatment phase (did not complete the post measurement after the interventions. A total of nine participants (32.1%) dropped out of the study during the study period. Participants' demographic data are presented in Table 1.

Each participant was informed about the study both orally and in writing. They were also informed that participation was voluntary and that they could withdraw from the study at any time.

Procedure

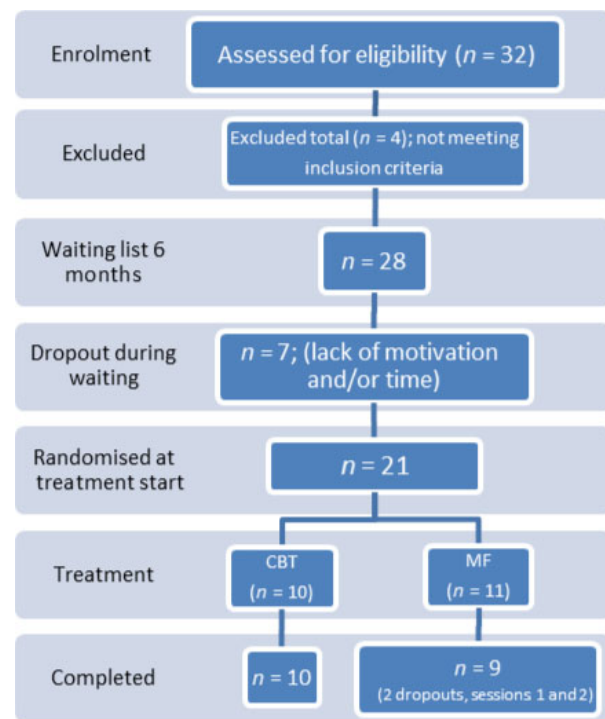
Study design. The study started with a baseline period ($n = 28$). The baseline (waiting list) period lasted for 6 months before they were randomised into one of the two treatment groups: mindfulness (MF, $n = 9$) or CBT ($n = 10$), see Figure 1. The purpose of the baseline period was to investigate the effect of measurements, and the impact of participation and attention on measures of stress and burnout.

Interventions

One group was offered the structured CBT intervention and the other group the structured mindfulness

Table 1 Descriptive data for study participants

	Baseline	CBT	MF	<i>p</i> ^a
Parents				
Gender (female/male)	26/2	9/1	8/1	ns
Age (M and SD)	41.0 ± 6.1	40.4 ± 3.0	46.3 ± 4.7	0.05
Range of age variation	30–54	36–45	41–54	–
Acad. education				
>4 Terms	16	5	7	ns
~3 Terms	5	1	1	
<1 Term	6	3	1	
Missing	1	1	0	
Children				
Age (M and SD)	9.8 ± 4.6	9.9 ± 4.8	11.4 ± 4.0	ns
Range of age variation	1–18	1–15	6–18	–
Diagnosis (Soma/Psych/Both)	6/17/5	1/6/3	2/6/1	ns

^aComparison between CBT and MF.**Figure 1** Flow diagram depicting the recruitment process.

intervention. The group treatments went on for 8 weeks with one two-hour session per week. The two study-therapists who conducted the respective intervention had undergone basic therapy training in CBT (both had a master degree in psychology and step 1 in CBT, *i.e.* they have studied CBT half-time for one term prior to the psychotherapy treatment sessions conducted during terms 2–

4). The study-therapist who conducted the mindfulness intervention was also a step 1 mindfulness instructor, that is 6 days (1 + 2+2 + 1) during 3–4 months. Each study-therapist had supervision from a certified therapist twice, and after each session the study-therapists wrote a short summary of the session.

The structured mindfulness programme used was the Here and Now Version 2.0 developed by Dr Ola Schenström (43). The programme is derived from MBSR and MBCT with the same basic exercises comprised eight sessions, and the main theme for each session is listed in Appendix S1. The programme included training observing sensations and awareness of body as well as training of acceptance, some elements of psycho-education on stress, and different homework assignments. During the intervention, the members of the MF group committed to practise exercises at home for 15 minutes per day using self-instructing material. Each participant received a CD with these guided assignments at the start of the therapy.

The CBT intervention was based on cognitive theory (44, 45) to change thoughts and emotions in relation to stress-related problems (19) and on behavioural techniques to enhance behavioural change (44). Some exercises describing personal values and value-based action were included in the programme based on Acceptance and Commitment Therapy (ACT; *e.g.*, 46). In this study, however, techniques promoting mindfulness and acceptance strategies were omitted from the CBT intervention due to overlap with the mindfulness programme (47). The intervention was developed by the present authors who have experience of both CBT and of this specific population from previous research and clinical work. The CBT intervention was based on the findings of Grossi (48) and Anclair and Hiltunen (49) and was structured as presented in Appendix S2. The members of the CBT group committed to perform homework assignments estimated to take 15 minutes per day. Thus, both intervention groups met once a week during 2 hours and were instructed to carry out home practice about 15 minutes a day.

Measures

The parents filled out a questionnaire at inclusion (6 months before the intervention), at the start of the intervention, and at the end of the intervention to measure the degree of perceived stress and fatigue. In addition, information regarding the degree of awareness, dispositional optimism, and positive and negative affects was collected.

Stress and burnout were measured with the Shirom-Melamed Burnout Questionnaire (SMBQ) and the Perceived Stress Scale (PSS). The SMBQ is a general (nonoccupational specific) self-assessment instrument that has been widely used both in Sweden and other

countries (10, 45, 50). The instrument consists of 22 items forming four subscales with the factors Emotional exhaustion and physical fatigue, Listlessness, Tension and Cognitive weariness. All items are rated on seven-grade scales. Mean scores in the present study are calculated for an overall burnout index (SMBQ-Global) score (i.e. the mean of all items). High scores correspond to more burnout symptoms. The cut-off score for burnout on the SMBQ-Global is 3.75, with high burnout, pathologic, at ≥ 4.47 and low burnout, healthy, at ≤ 2.75 . Previous research has shown high levels of homogeneity with Cronbach's α values of 0.95–0.98 for SMBQ-Global (50).

The Perceived Stress Scale [PSS; (51)] consists of 14 items designed to measure the degree to which stress is experienced in different situations. The PSS measures both the psychological and physiological symptoms that arise from stress. The instrument is a self-assessment questionnaire with five-grade Likert scales for each item. The minimum total sum is 0 points, and the maximum total sum is 56 points, where higher values correspond to higher degrees of experienced stress. The PSS has been translated into Swedish and validated in Sweden, and its homogeneity has shown to be good with a Cronbach's alpha of 0.82 and a split-half reliability of 0.84 (52).

Data analysis

We examined within-group changes during the baseline period and changes during the intervention periods separately. First, we investigated whether the changes from pre to post during waiting period (baseline) were statistically significant. Second, we examined separately with in the CBT and mindfulness groups, whether changes from pre to post during the intervention period were significant. All the analyses were calculated using Mplus

(version 7) statistical program (53), which allows all clients taking part in the premeasurement to be included in future analyses. Thus, the full information maximum likelihood (FIML) estimation method was used, on the assumption that there would be few values 'missing at random' (MAR). The pre-post changes were tested using the Wald test. Mean values and standard deviations (SD) were calculated using Mplus to correct the means for missing values. Thus, the corrected mean values and standard deviation are reported. The magnitude of change was reported using within-in group effect size (ES) values. The with-in group effect sizes (ES) were calculated using Hedges' g due to small number of participants. They were calculated as follows: The ES was calculated by dividing the mean change from the pre- to the postmeasurements by the combined (pooled) standard deviation (SD) (54, 55). In purpose to avoid overestimation of the treatment effects, a within-group ES of 0.5 was considered small, 0.8 was medium and 1.1 large (20, 21).

Results

Comparative analyses of participants' symptom rates during baseline, and before and after the interventions

Table 2 shows that during the baseline period stress as measured by PSS, decreased significantly from pre to post. However, during the baseline, the pre to post with in group effect size was relatively small ($d = 0.48$) and nonsignificant [95% confidence interval (CI) = -0.17 ; 1.01 , see Table 2]. Significant decreases were observed also both for the CBT and mindfulness groups from pre to post when the participants were offered interventions after the baseline. The within-group effect sizes were

Table 2 The clients' (CBT and MF) mean scores, standard deviations and within-group effects sizes (95% confidence intervals in the parenthesis) for the Perceived Stress Scale (PSS), and for the Shirom-Melamed Burnout Questionnaire (SMBQ Global), during the baseline period as well as before (Pre) and after (Post) interventions

	Pre	Post	Wald-test	Effect size
PSS				
Baseline	38.02 (6.70)	35.18 (6.42)	5.34 $p < 0.02$	0.48 (-0.17 ; 1.01)
CBT	34.50 (5.01)	24.20 (6.82)	23.99 $p < 0.001$	1.64 (0.63 ; 2.66)
Mindfulness	35.44 (5.10)	24.00 (4.79)	23.32 $p < 0.001$	2.20 (1.03 ; 3.37)
SMBQ (Global)				
Baseline	4.98 (1.01)	4.95 (0.98)	0.06 $p < 0.81$	0.03 (-0.55 ; 0.61)
CBT	4.62 (0.75)	3.44 (1.00)	32.35 $p < 0.001$	1.28 (0.32 ; 2.24)
Mindfulness	4.91 (0.80)	3.79 (0.90)	15.39 $p < 0.0001$	1.25 (0.24 ; 2.26)

large and significant both for the CBT ($d = 1.64$; 95% CI = 0.63; 2.66) and mindfulness ($d = 2.20$; 95% CI = 1.03; 3.37) groups from pre to post. Thus, although there were positive changes in all groups regarding stress, the within-group effect sizes were considerably larger in the CBT and mindfulness groups as compared to the baseline condition. According to effect sizes, the impact of the two interventions on stress was equivalent.

Burnout symptoms as measured by SMBQ-Global decreased significantly both in the CBT and mindfulness conditions from pre to post, but not during the baseline (Table 2). The within effects sizes were large and significant for both interventions groups (CBT, $d = 1.28$, 95% CI = 0.32; 2.24; mindfulness, $d = 1.25$, 95% CI = 0.24; 2.26). Effect sizes suggested that the changes were equivalent in the two intervention groups. The within-group effect size was very small and nonsignificant from pre to post during the baseline condition ($d = 0.03$, 95% CI = -0.55; 0.61).

In summary, the results showed that both CBT and mindfulness interventions were effective with statistically significant improvements on outcome measures with large within-group effect sizes suggesting that the changes were clinically relevant. In both groups, parents' stress and burnout symptoms were reduced. In contrast, markedly smaller changes were observed during the baseline period.

Discussion

This study applied CBT and mindfulness as methods for treating stress-related problems of parents of children with chronic conditions. The parents constituted their own controls and were wait-listed for 6 months before they were randomised into one of two treatment groups.

The results show that perceived stress and the degree to which situations are perceived as stressful, decrease significantly irrespective of the form of treatment received (CBT or MF). Within-group effect sizes (ES) were large in both interventions. During the baseline period, they were small. Thus, the study suggests that it is possible to obtain clinically relevant changes in stress and burnout symptoms either with CBT or mindfulness interventions. This can be seen in Table 2 which shows relatively large changes in stress and burnout as described by using 95% confidence intervals for within group effect sizes from pre to postmeasurement.

Interestingly, the two interventions seem to work equally well for these parents. The reason why mindfulness seems to affect stress and burnout can be explained by the emotional regulation system, and by the fact that mindfulness has been reported to impact well-being positively (56–60). Based on biological, evolutionary and social psychological theories, Gilbert has developed a model for how people regulate their emotions. The three systems are the alarm system, the drive system and the

soothing system. The alarm system is activated when a threat is perceived, and its function is to get people to seek protection. Emotions linked to this system are worry, anxiety, stress, fear and shame. The drive system is an energising and motivational system striving to achieve rewards and activating well-being. This system gives rise to joy, euphoria and pleasure. The soothing system is activated when the other two systems are passive (i.e. when people are not striving to achieve something or do not need to deal with various threats). When this system is activated, feelings of calmness, happiness and contentment are experienced. People, especially those with high demands, self-criticism and shame, can have an overactive alarm system, often leading to an inactive soothing system that is difficult to access. In these cases, the systems no longer function to help people act goal oriented or to protect them from threats. However, mindfulness training helps activate the soothing system, which balances the parents' negative thoughts and emotions and calms down the alarm system (61). This results in parents accessing their strengths and coping strategies to handle the demands and additional stressors that come with being a parent of a child with a chronic condition. Instead of years of training to become a certified instructor in mindfulness, the training of instructors in the Here & Now programme is of 6 days over a period over 3–4 months (62).

Earlier research shows that CBT appears to have an effect on stress and fatigue (63). CBT is an active method focusing on psychoeducation, problem solving, practical objectives and on achieving greater psychological flexibility and behavioural changes through cognitive interventions (19).

Clinical experience has shown that this group of parents seek health care for stress-related problems (such as headache, shoulder pain, neck pain, anxiety, depression and sleep problems) although many of them meet the criteria for burnout or ED. One study showed that 98% of people with burnout or ED suffer from at least one somatic symptom, of which nausea, gastrointestinal problems and headaches are the most common ones (64).

The dropout rate in this study was 32.1% after the baseline period, before the interventions were offered. That is consistent with research literature on dropout analysis (65). The bulk of psychotherapy research is pursued in atypical settings, such as clinical tests, academic centres and student clinics. Data from such settings show that 25–50% of the participants drop out of psychotherapy interventions in the course of the five-first sessions. The research available in the field shows that early dropout is associated with lower age, low income, low education, substance abuse and insufficient social support (65–70). A study by Cane and Williams (71) indicates that persons with high levels of cognitive reactivity, depressive dwelling and brooding had difficulties completing and engaging in mindfulness-based cognitive therapy

(MBCT). Paradoxically, these are the persons who may benefit the most from completing MBCT. It is therefore of utmost importance to figure out how to motivate and support this group to complete MBCT treatment. In their review, Santana and Fontenelle (72) show that between 10% and 57% of the anxiety, patients drop out before the end of treatment. Comorbidity with depression was the factor that caused the greatest dropout rate.

This study has certain limitations. Because of the restricted population size and time limits, this pilot study had to settle for 19 participants when investigating the effects of the interventions. Although significant results were observed, the reader needs to observe that several parents dropped out after the baseline period. Low-powered studies may also result in overestimates of effect sizes or unreplicable effects. Further, the parents constituted their own controls and were wait-listed for 6 months, which were not ideal control conditions. For these reasons, the present results should be replicated in an RCT study, but also qualitative studies might be of importance for the understanding of how these treatments help the focus population. Also, studies focussing both on children and on parents by behavioural parent training are needed and the first results from mindfulness training for children with ADHD and parallel mindful parenting training are promising (73).

In conclusion, the results show that group treatment with either CBT techniques or a mindfulness programme can be efficient for reducing stress and burnout or ED in parents of children with chronic conditions. It is our hope that these interventions can be used more

extensively (e.g. in child health care and in mental health nursing) and that they could be generally available to parents suffering from parental stress. In a wider perspective, children will benefit from having parents who have learnt to identify stressors and found functional coping strategies preventing the stress from turning into clinical burnout or depression (74).

Author contributions

Malin Anclair has contributed to study conception/design, data collection and to drafting of manuscript. Malin Anclair and Joona Muotka have contributed to data analysis. Arto Hiltunen and Raimo Lappalainen have contributed to critical revisions for important content.

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Ethical approval

The study was approved by the regional Ethics Board (approval number 2011/358).

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. The structured Mindfulness programme Here and Now Version 2.0.

Appendix S2. The structured CBT- intervention for stress-related problems based on cognitive theory and behavioural interventions.