



Effectiveness and usability of a web-based mindfulness intervention for caregivers of people with mental or somatic illness. A randomized controlled trial

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1. Background

1.1. Caregiver burden

Approximately 42.1 million family caregivers provided care to an adult with limitations in daily activities at any given point in time in the US in 2009 (Feinberg et al., 2011). The economic value of caregivers' unpaid contributions was estimated to \$450 billion (Feinberg et al., 2011). Younger care recipients most often suffer from mental illness (MI)¹ while older care recipients' problems are commonly aging, chronic diseases, Alzheimer's, dementia/other mental confusion (National Alliance for Caregiving and AARP, 2004). There are approximately 1.3 million caregivers in Sweden who support someone regularly, of whom 900,000 are of working age and 140,000 have stopped or reduced their working hours due to the caregiving situation (Riksförbundet, 2016). Many of the families with a person with MI experience such psychological distress that they require therapeutic intervention. Caregivers of people with other diseases, e.g. stroke (Rigby et al., 2009), dementia (Etters et al., 2008), cancer (Grunfeld et al., 2004), Parkinson's (Schrag et al., 2006), and brain tumors (Schubart et al., 2008) also experience caregiver burden. This entails both an objective and subjective burden, the latter referring to the psychological distress prompted by the illness (Lefley, 1989). It hence includes psychological, occupational and financial burdens, especially in times of illness deterioration (Grunfeld et al., 2004; Schubart et al., 2008). The experience of burden has been found to be enhanced in long-lasting relationships, when the caregiver and his/her relative live together and when the care is given daily and not appreciated (Östman and Hansson, 2004). Caregivers of older adults also report decreases in health due to caregiving (National Alliance for Caregiving and AARP, 2009). For example, role overload (Turcotte, 2013; Adelman et al., 2014) and caregiver burden can be the most important predictors of anxiety/depression (Rigby et al., 2009) and negative stress in caregivers (Turcotte, 2013; Adelman et al., 2014). Furthermore, caregivers report unmet

needs such as finding own time, managing emotional and physical stress, and balancing work and family responsibilities (Longacre, 2013).

It has been proposed that health professionals should include the management of caregiver distress to improve families' quality of life (QoL) (Schrag et al., 2006) and guide them towards effective interventions (Rigby et al., 2009; Adelman et al., 2014). Care duties, carers' fears and worries, and the patient's behavior (Cormac and Tihanyi, 2006) can have negative effects on caregivers' mental health (Schulz and Sherwood, 2008; Phillips et al., 2009; Smith et al., 2014). Family interventions can improve the family's emotional climate (Pharoah et al., 2010), with lower relapse rates, and enhanced outcomes and problem-solving capacities. Transportation issues, fatigue, lack of resources and stigma can be barriers to accessing help, which can be addressed by online solutions. Tailored online interventions that incorporate behavior change techniques such as stress management can have positive effects on caregivers' psychological well-being (Guay et al., 2017). Web-based mindfulness interventions (MBI)² show promising results with beneficial health effects for healthy and clinical samples (de Vibe et al., 2012). A feasibility study and randomized controlled trial of the current online MBI showed positive significant results for families living with MI with enhanced levels of mindfulness and self-compassion, and decreased levels of caregiver burden and perceived stress (Stjernswärd and Hansson, 2016a; Stjernswärd and Hansson, 2017), combined with good usability and subjective value when using the program (Stjernswärd and Hansson, 2016b). Usability refers to the extent to which a specific user can use a specific product to reach specific goals, with purposefulness, effectiveness, and satisfaction, in a given context (ISO, 1998). Ease of access and flexibility of use were strong motivators for use (Stjernswärd and Hansson, 2016b). More studies are called for to verify the intervention's effectiveness for extended groups of caregivers.

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¹ Mental illness (abbreviated MI).

² Mindfulness-based interventions (abbreviated MBI).

1.2. Mindfulness interventions

Kabat-Zinn's Mindfulness-Based Stress Reduction (MBSR) program is a contemporary version of mindfulness stripped of its buddhistic aspects. He defines mindfulness as “the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment” (Kabat-Zinn, 2003). Moreover, mindfulness has been successfully incorporated into evidence-based clinical interventions, i.e. Mindfulness-Based Cognitive Therapy (Segal et al., 2002), Acceptance and Commitment Therapy (Hayes et al., 2006), and Dialectical Behavior Therapy (Linehan, 1993), with subsequent decreases of clinical symptoms, and improved mental health and well-being (Keng et al., 2011; de Vibe et al., 2012; Khoury et al., 2013).

MBI show beneficial effects on mental health outcomes in persons with somatic and mild/moderate psychological problems and for non-clinical samples (de Vibe et al., 2012). MBSR interventions show positive effects on personal development (empathy, coping), mindfulness, QoL and somatic health outcomes (de Vibe et al., 2012). The literature also shows positive psychological effects, improved behavioral regulation (Keng et al., 2011) and effectiveness in reducing caregiver stress as measured by psychological and biological markers (Bloom et al., 2012). MBI have shown to be useful in addressing caregivers' burden, stress (Epstein-Lubow et al., 2011; Pagnini et al., 2015) and mental health (Hou et al., 2014; Paller et al., 2014). The standard 8-week MBI with an instructor requires time for weekly group meetings, daily exercises and one day's silent meditation. However, reduced exercise time does not necessarily affect outcomes negatively (Boettcher et al., 2013), and has been associated with positive results and high program satisfaction. Studies show the feasibility and benefits of MBI online in clinical (Boettcher et al., 2013) and non-clinical (Glück and Maercker, 2011) samples, including reduction in stress (Glück and Maercker, 2011; Krusche et al., 2012), anxiety and depression (Boyer et al., 2012), and increased QoL (Boettcher et al., 2013); this is valid for face-to-face (f2f) and online MBI (Boettcher et al., 2013) despite the lack of contact with an instructor and fellow participants in the latter (Krusche et al., 2012).

The cultivation of self-compassion is more or less explicitly interwoven in mindfulness practices (Hölzel et al., 2011), for example, by encouraging a gentle and accepting attitude towards the self during meditations. It can contribute to acceptance and a caring and non-judgmental attitude towards the self and others (Kabat-Zinn, 2009), and to positive effects on psychological functioning (Hofmann et al., 2011). Self-compassion entails three components: self-kindness vs self-judgment, common humanity vs isolation, and mindfulness vs over-identification (Neff, 2003). The practice of mindfulness practice helps break automatic behavior through increased awareness and facilitates responding and coping instead of reacting to stressors, deterring stress reactivity (Kabat-Zinn, 2009), which may enhance families' coping ability and prevent exhaustion. Caregivers' QoL is strongly affected by physical and emotional distress due to unfulfilled needs and caregiving (Caqueo-Urizar et al., 2009). Restoration of patient functioning in family/social roles are good targets for interventions (Caqueo-Urizar et al., 2009), as are coping strategies and the development of personal strength to improve QoL (Boyer et al., 2012). As caregivers can experience an added burden and inter-relational stress, the potential reduction of emotional reactivity, and the enhancement of emotional regulation and positive emotions through MBI (Hofmann et al., 2011; Keng et al., 2011) may be valuable to get a sense of perspective on the situation and enable responding rather than reacting automatically to stressful situations. The cultivation of compassion meditation can further contribute to a more compassionate and caring attitude towards the self and others (Kabat-Zinn, 2009), potentially benefiting both caregivers and patients. Healthy relatives are also better equipped to help the patient, which is why interventions to support burdened caregivers may be valuable to help them cope. The study's aim was to assess the effectiveness and usability of a web-based MBI for families

living with mental or somatic illness.

2. Ethical considerations

The project was approved by the Regional Ethical Committee, Lund, Sweden (dnr 2016/925). Informed consent was obtained from all individual participants included in the study.

3. Methods

3.1. Procedure

The current effectiveness study was designed as a randomized controlled trial with an experimental group and a wait-list control group (WLC), with measurements at baseline (T1), post intervention (T2) and at a 3-month follow-up (T3) on primary and secondary outcomes, and usability, in order to explore the effectiveness of the web-based mindfulness program in supporting caregivers to cope with their situation. The hypothesis was that participation in the program would lead to increased levels of mindfulness and self-compassion, and to decreased levels of caregiver burden and perceived stress in the participants. The WLC was offered the same program after termination of the experiment group's test period, although with a 12-week delay due to semester break. The CONSORT (2010) checklist guided the reporting of the current randomized trial. As the participants could discontinue participation without needing to motivate this, however, reasons for drop-out were not actively registered unless the participants actively informed about the termination of their participation and volunteered this information (as this was done inconsistently, these are not reported here).

3.2. Intervention

The intervention consists of a web-based mindfulness program tailored for families living with mental (MI) or somatic illness (SI), in the sense that its contents are related to caregivers' situation and associated experiences of burden and stress. The audio files for instance take up the fact that being close to an ill person can arouse stressful feelings and thoughts and affect significant others' daily lives. The training is introduced as a potential tool for coping with e.g. stress. The program can be accessed through a computer/tablet/smartphone with Internet access. It contains audio/video files (960 min), including introductory information (initial video and weekly introductions for every new step) and a concluding video (video files) and weekly training advice half-way through the weekly steps (audio files) accompanied by written keywords on the screen, audio files for the daily formal meditations (2 × 10 min/day), descriptive text files and instructions for daily informal mindfulness practice (e.g. notice sounds, scents, etc.), a time log (the training time was registered automatically and displayed on the program website), and a private diary (not visible to the researchers). The recommended training time was set to 2 × 10 min/day, 6 days/week for 8 consecutive weeks. Participants were also encouraged, through a note on the screen once the daily formal meditations were completed, to do daily informal practices (e.g. notice the breath or bodily sensations at some point during the day). The formal training includes basic mindfulness practices such as breathing exercises, body scans, mindful yoga/conscious movements, attention to experiences through the senses, and (self) compassion meditations (Table 1). The exercises are comparable to those in MBSR programs, except that they are kept to a maximum of 10 min/exercise to make them more easily practicable for participants with busy schedules. The test period was set to 10 weeks to allow for individual flexibility. Weekly e-mail reminders, including contact information to the researchers/technical support, were sent to the participants as reminders and motivators for training.

Table 1
The program's 8 weekly steps.

Week	Contents: every step (8 steps, 1 step/week) contains initial introductory audio-files and weekly advice (audio-files) half-way through the respective steps, besides general introductory and concluding video files (at start and finish), and written instructions for daily informal exercises for download. The daily meditation consist of 2 × 10 min audio files.
1	The breathing body
2	Being present in the body
3	Mindfulness in life and movement
4	Compassion with the self – acceptance
5	Wonderful pleasure
6	Being whole
7	Compassion with others
8	To live with the possibility of choosing

3.3. Measures

Participants were sent a link by email for data collection online including a sociodemographic questionnaire (T1) and validated self-assessments scales online at baseline (T1), post intervention (T2), and at a 3-month follow-up (T3), and usability questionnaires (T2, T3).

Five Facet Mindfulness Questionnaire (FFMQ): it consists of 39 items, rated on a 5-points Likert scale (1 = never or very rarely true, 5 = very often or always true), assessing five facets of mindfulness: Non-reactivity to inner experience (7 items), Observing (8 items), Acting with Awareness (8 items), Describing (8 items), Non-judging of Experience (8 items). The scale has shown good internal consistency with alpha coefficients ranging from 0.75 to 0.91 (Baer et al., 2006; Baer et al., 2008). The Swedish version of the FFMQ has shown good psychometric properties, with results comparable to those obtained by Baer et al. (2006, 2008) (Lilja et al., 2011). Cronbach's alpha for FFMQ in the current study was 0.91.

Self-Compassion Scale-Short form (SCS-SF): this 12-item scale measures six components of self-compassion using six subscales with two items each: Self-Kindness, Self-Judgment, Common Humanity, Isolation, Mindfulness, and Over-Identification. Items are rated on a 5-point response scale (1 = almost never to 5 = almost always) (Raes et al., 2011). The scale has shown adequate internal consistency (Cronbach's alpha ≥ 0.86) and a near-perfect correlation with the long form SCS ($r \geq 0.97$) (Raes et al., 2011). The Swedish version of the SCS was translated and back translated by Strömberg (unpublished manuscript) and approved by Neff, the scale's originator. It showed good reliability in a Swedish study (Wallmark et al., 2013). A short version was used, for which Cronbach's alpha in the current study was 0.84.

Perceived Stress Scale (PSS): it is a validated 14-item scale measuring the degree to which situations in life in the past month are appraised as unpredictable, uncontrollable and overwhelming, using a five-point response scale (0 = rarely to 4 = very often) (Cohen, 2013). The scale has shown good reliability and validity. The Swedish version has demonstrated good internal consistency (0.82) and split-half reliability (0.84), and adequate construct validity (Eskin and Parr, 1996). Cronbach's alpha for PSS in the current study was 0.78.

CarerQoL7-D: this self-rating instrument measures seven dimensions of caregiver burden using seven items with a 3-points response scale (1 = no problems to 3 = a lot of problems): fulfillment, relational dimension, mental health dimension, social dimension, financial dimension, perceived support, and physical dimension. It includes the CarerQoL-VAS, indicating the level of happiness with caregivers' experiences and encompassing both negative and positive aspects, ranging from 0 = "completely unhappy" to 10 = "completely happy" (Brouwer et al., 2006). The scale has shown good validity in measuring informal carer effects (Brouwer et al., 2006; Hoefman et al., 2011).

The Montgomery-Borgatta burden scale: this self-rating scale measures stress/subjective burden (affect component of burden), relationship burden (the extent to which caregivers perceive the care recipient's

behavior as manipulative or overly demanding), objective burden (the extent to which care relationships impose on observable aspects of a caregiver's life, e.g. time for self/others), and uplifts. It includes 22 items with a response set ranging from 1 (a lot less) to 5 (a lot more) assessing to which level aspects of their life had changed because of caregiving (Montgomery et al., 2000). The four subscales' total scores are calculated, with higher scores indicating higher levels of burden or uplifts. The reliability of all forms of burden range from 0.83 to 0.89 (Savundranayagam and Montgomery, 2010). Cronbach's alpha in the current study was 0.82.

Usability, confounding factors and negative effects of training: A Swedish version of the System usability scale (SUS) (Brooke, 1996) was used to assess the program's usability. It is a 10-item 5-point Likert scale giving a global view of subjective assessments of usability. Possible scores range between 0 and 100 with higher scores indicating better usability. A system with a SUS value > 70 can be estimated as good and > 85 as excellent, although it doesn't guarantee high acceptability in the field (Bangor et al., 2008). SUS has been used extensively, displaying good reliability and validity across a variety of assessed systems (Sauro, 2011). Additional questions with room for free-text answers about usability, confounding factors (other sources of support, negative life events, patient's health status) and negative effects of training were also included for separate analysis.

3.4. Participants

Participants were recruited (January–February 2017) through advertisement in papers, newsletters, online, social media, and clinics/organizations with interests in caregivers. On the question "where did you first hear about the project" respondents in the experiment and the WLC groups answered: newspaper advertisement (directly or through tips) (74%), Facebook-social media/advertisement on website (18%), tips from friend (5%), through care organization/family consultant (2%), and other/don't remember (1%). Information about the study and informed consent were available online. The inclusion criteria were: age (> 18), being a relative/significant other to a person with MI or SI (mixed diagnoses/as reported by participants), having access to a computer/Internet, and understanding Swedish. The exclusion criteria were having prior experience of mindfulness meditation and an own severe MI that requires other professional treatment. A power calculation based on the primary outcome measure (mindfulness) from the previous feasibility study showed that 100 participants (50 per arm) would be an adequate sample size to identify a medium effect size using a 80% probability and $p < 0.05$ as a marker of significant differences. We intended to include 140 persons, accounting for a drop-out rate of around 30%.

Of the 443 participants who fulfilled the inclusion criteria and were registered in the study using the online consent form, 398 completed the sociodemographic and baseline questionnaires (T1), after which all participants were randomized (allocation sequence generated by the first author through randomizer.org) into an experiment group ($n = 196$) and a WLC ($n = 202$) (Fig. 1). As registration to the study implied that the inclusion criteria were met, none of the registered participants were excluded. After randomization, participants in the experiment group were sent an e-mail with instructions for registration to the web-based mindfulness program. Participants in the WLC were sent similar instructions once the post-test questionnaires following the first test period (T2) were completed, which also represented their baseline assessments prior to their own test period with the same program as the experiment group.

There were no significant sociodemographic differences between the groups. The majority of participants were women, aged 50–69 (mean = 52.5), and a parent to the patient (47% and 51% in the respective groups), but also partners (21%/23%), adult children (17%/12%), siblings (9%/7%) and persons with another relationship to the patient (4%/3%) were represented (Table 2). A majority of participants

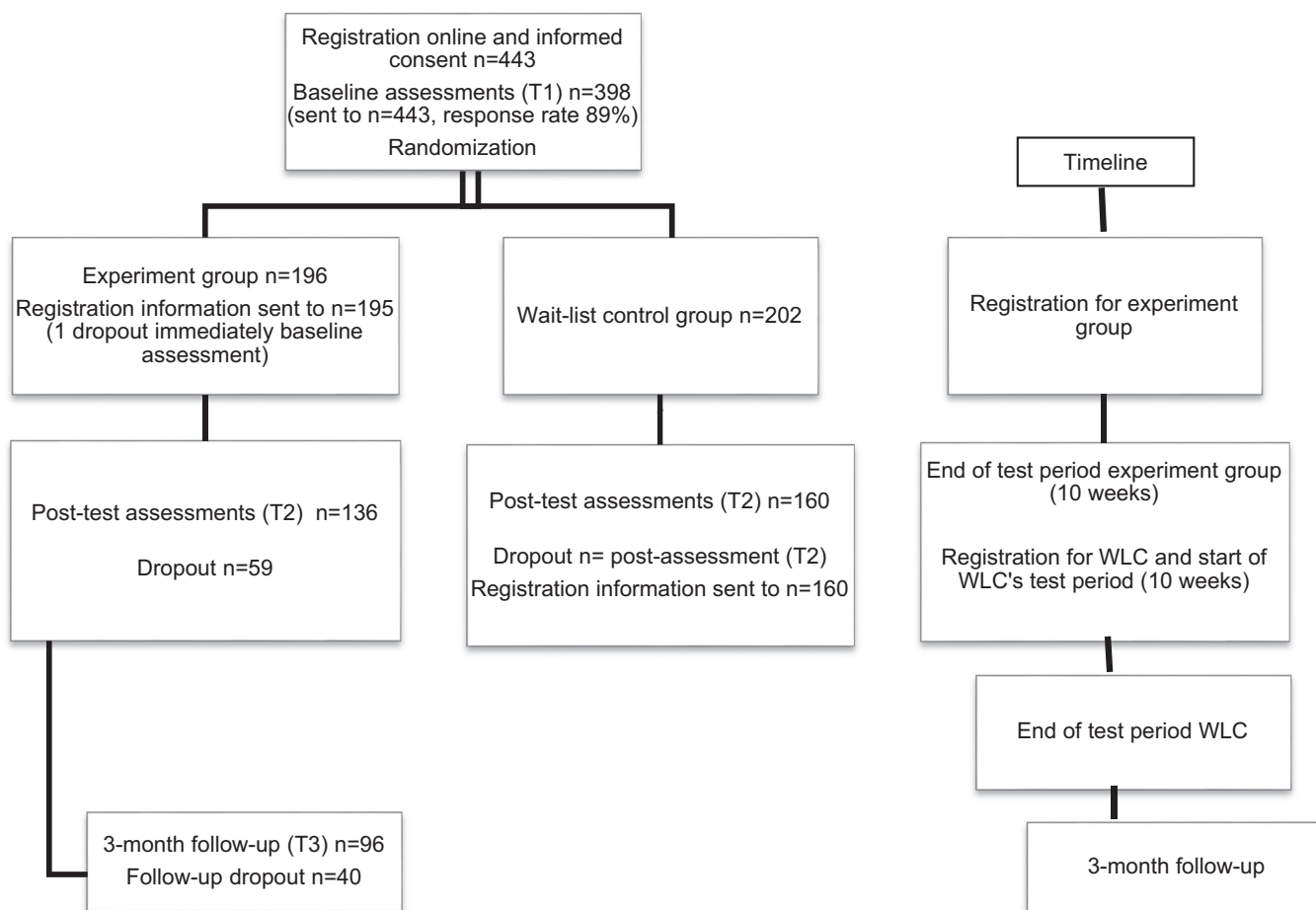


Fig. 1. Total sample and dropout.

reported that they provided between 1 and 15 h of caregiving per week, including different kinds of support, with emotional followed by practical support being the most common. A majority of the participants helped with contacts with health care/other organizations, and about 40% provided financial support. The most commonly reported time since diagnosis was 1–5 years (37%/32%), followed by > 15 years (28%/27%) in the respective groups. The majority of participants reported good physical health, while a more or less equal number of participants reported good or bad own mental health in both groups.

A link to the post intervention assessments (T2) was sent to all participants in both groups who had not actively dropped out, regardless of training time (Fig. 1). This included registered participants with 0 min's training time who had not actively dropped out. The assessments also included questions about usability, confounding factors and negative effects of training. Of the 179 participants in the experiment group and the 201 in the WLC who received a link to the post intervention assessments (T2), 75% (n = 136) and 79% (n = 160) respectively completed the questionnaire. Follow-up assessments (T3) were sent to the participants 3 months after termination of the test period, at which point 96 participants in the experiment group completed these.

Daily formal practice time was registered online for all participants on the program website (120 min = 1 week's training). The number of missing cases regarding training time for the experiment group was 10. This is due to participants not registering, or registering to the program website but not initiating their training. These cases have been included in the 0–120 min interval below. If training was initiated, but did not proceed up to the fulfillment of the first 10 min' exercise, the training time was registered as 0 (experiment group n = 21) (=pre-treatment

drop-out). In the experiment group at T2 (n = 136), 16% (n = 22) had a training time between 0 and 120 min (0 min: n = 6, included in the analyses), 27% (n = 37) between 121 and 480 min, and 57% (n = 77) between 481 and 960 min, whereas the figures in the respective training time intervals at the 3-month follow-up (n = 96) were 21% (n = 20), 22% (n = 21) and 57% (n = 55).

4. Data analyses

General linear models with repeated measures analyses of variance were performed on the responses of completers to evaluate between group comparisons of the intervention's impact on primary (FFMQ) and secondary (SCS-SF, PSS, CarerQoL-7D, Montgomery-Borgatta Caregiver Burden) outcomes as compared to the WLC. A GLM model was used to analyze whether drop-outs at T3 differed from remainders on changes in overall mindfulness scores between T1 and T2. Independent samples *t*-test was performed to investigate baseline differences between completers and dropouts at T2. In addition, an intention-to-treat analysis using GLM models was performed including the subscales and global scale of the primary outcome measure. In order to perform this, data for participants who completed the T1 measures but not the T2 assessments were imputed using the multiple imputation module in IBM SPSS.

Paired sample *t*-tests were carried out to compare means on primary and secondary outcomes between pre-intervention and follow-up for the experiment group. Between-group effect sizes for primary and secondary outcomes for the experiment group and the WLC post intervention were calculated, and within-group effect sizes for the experiment group at follow-up, using Cohen's *d*. Effect sizes below 0.5 were considered as small, between 0.5 and 0.8 as medium, and above

Table 2
Background characteristics of the baseline sample (n = 398).

Baseline n = 398	Experiment group n = 196		WLC n = 202	
	n	%	n	%
Men/Women	29/168	15/85	27/175	13/87
Age				
20-29	12	6	14	7
30-39	20	10	24	12
40-49	34	18	30	15
50-59	79	40	62	30
60-69	39	20	56	28
≥ 70	12	6	16	8
Married or in a relationship/Single	163/33	83/17	167/35	83/17
Relationship to the patient				
Father/mother	7/85	47	6/96	51
Son/daughter	13/21	17	7/17	12
Brother/sister	2/15	9	1/13	7
Partner (male/female)	23/19	21	27/20	23
Other relationship	7	4	7	3
Non valid answers	4	2	8	4
Shared household with the affected person				
Yes	85	43	91	45
No	80	41	84	42
Sometimes	31	16	27	13
Living situation				
In a city/town	183	93	185	92
On the country-side	13	7	17	8
Education				
Elementary school	9	5	14	7
Upper secondary school	35	18	34	17
University/higher education	150	76	149	74
Other	2	1	5	2
Work situation				
Employed	153	78	147	73
Not working	43	22	55	27
Main diagnosis as reported by participants				
Somatic diagnosis	25	13	35	17
Psychiatric diagnosis	171	87	166	82
Depression/anxiety disorders	74	38	54	27
Schizophrenia spectrum/psychotic disorders (incl. bipolar disorder)	33	17	43	21
Autism spectrum/neurodevelopmental disorders	33	17	38	19
Other (including personality disorders)	28	14	30	15
Missing	-	-	1	1
Time since diagnosis (in years)				
< 1	9	4	15	8
1-5	72	37	65	32
6-10	37	19	41	20
11-15	23	12	27	13
> 15	55	28	54	27
Type of support to patient (several answers possible)				
Emotional support	185	94	186	92
Help with daily care (e.g. hygiene, dressing)	31	16	27	13
Practical support (e.g. cleaning, transportation)	125	64	134	66
Economical support	86	44	85	42
Contact with health care/other organizations	99	51	112	55
Other help	60	31	55	27
Caregiving in hours/week				
≤ 1	7	3	13	7
1-15	112	57	122	60
16-30	30	15	25	12
31-45	9	5	10	5
> 45	8	4	10	5
“feels like 24/7”	9	5	4	2
“difficult to say/don’t know”	21	11	18	9
Self-rated own physical health				
Very good	30	15	31	15

Table 2 (continued)

Baseline n = 398	Experiment group n = 196		WLC n = 202	
	n	%	n	%
Good	127	65	131	65
Bad	34	17	38	19
Very bad	5	3	2	1
Self-rated own mental health				
Very good	15	8	13	6
Good	93	47	91	45
Bad	84	43	92	46
Very bad	4	2	6	3

0.8 as large (Cohen, 2013). Spearman correlation analyses were used to investigate the association between amount of exercise reported and outcome of the intervention. IBM SPSS Statistics package version 24 was used in all statistical analyses.

A total score was calculated to obtain an overall value of system usability (SUS) (Brooke, 1996). Qualitative data from the usability questionnaires (T2, T3) was analyzed with content analysis (Graneheim and Lundman, 2004) and quantitative data is reported with descriptive statistics (Tables 4 and 5).

5. Results

Mindfulness (FFMQ) significantly improved pre-post intervention in comparisons between the experiment and the WLC group. This was the case for both the overall score and all subscale scores (p = 0.001) with effect sizes mainly medium in size (range 0.51–0.74), except for the Acting with Awareness and the Describing subscales, which were small (0.33 and 0.30 respectively). An intention to treat analysis verified these results, showing no differences in results concerning outcome regarding the primary measure. There were significant and positive improvements in the experiment group between pre-intervention and follow-up in both the overall and the subscale scores with P-values 0.001 and within-group effect sizes were in the range 0.40–0.82 (Table 3). It is noticeable that most effect sizes except for the Observing subscale are larger at follow-up than post intervention, with a large size effect for the FFMQ global sum (0.82). With the means of a general linear model we examined whether there was a significant difference in outcome for the mindfulness global sum pre-post intervention between caregivers of a person with mental illness (85% of the T2 sample) compared to caregivers of a person with somatic illness (15%), which there wasn't.

There were significant improvements pre-post intervention regarding self-compassion in comparisons between the groups. The experiment group showed significant changes in the global SCS-SF score and in several of the SCS-SF's subscales at the p = 0.001 level, except for the Isolation (p = 0.003) and Over-Identification (p = 0.007) subscales. Effect sizes for the global sum score and all subscales were small (range 0.30–0.43). Comparisons pre-intervention and follow-up showed significant within-group improvements in the experiment group in all subscales, with effect sizes in the range 0.35–0.77.

Significant decreases in favor of the experimental group were observed in the perceived stress scale (PSS) in pre-post intervention comparisons between the groups (p = 0.001 and ES = 0.46). Within-group comparisons in the experimental group showed a significant improvement between pre-intervention and follow-up (p = 0.001 and ES = 0.53).

Comparisons between the groups pre-post intervention on caregiver burden (CarerQoL-7D) showed no significant improvements in favor of the experimental group in any of the 7 dimensions nor the VAS scale. The latter indicates levels of happiness with caregiving experiences. However, within-group comparisons pre-intervention and follow-up in

Table 3

Outcome of pre-post intervention comparisons between groups regarding Mindfulness, Self-Compassion, Perceived Stress, CarerQoL-7D and Montgomery-Borgatta Caregiver Burden Scale (repeated measures ANOVA) and pre-intervention follow-up in the experimental group (paired samples *t*-test).

Outcome measure	Baseline		Post intervention		Pre-post-intervention		Follow-up		Pre-intervention-follow-up	
	Experiment group (n = 196)	WLC (n = 202)	Experiment group (n = 136)	WLC (n = 160)	p-value	Effect size	Experiment group (n = 96)	p-value	Effect size	
	M ± SD	M ± SD	M ± SD	M ± SD			M ± SD			
FFQM Global Sum	119.7 ± 20.2	116.8 ± 19.7	133.4 ± 18.9	116.7 ± 21.2	0.001	0.69	134.7 ± 19.9	0.001	0.82	
Non-reactivity	18.8 ± 4.7	18.5 ± 4.4	21.3 ± 4.1	18.45 ± 4.7	0.001	0.56	21.9 ± 4.1	0.001	0.71	
Observing	24.5 ± 5.8	24.1 ± 5.9	28.4 ± 4.9	23.9 ± 5.5	0.001	0.74	27.7 ± 5.6	0.001	0.61	
Acting with Awareness	23.8 ± 6.6	22.3 ± 6.1	26.0 ± 5.6	22.6 ± 6.2	0.001	0.33	26.8 ± 5.7	0.001	0.60	
Describing	27.7 ± 6.5	27.6 ± 6.1	29.2 ± 5.6	27.3 ± 6.3	0.001	0.30	29.5 ± 5.9	0.001	0.40	
Non-judging	24.9 ± 7.1	24.2 ± 7.2	28.5 ± 6.7	24.5 ± 7.5	0.001	0.51	28.8 ± 7.0	0.001	0.58	
SCS-SF Global Sum	33.2 ± 8.2	32.7 ± 8.5	38.0 ± 8.7	33.2 ± 9.0	0.001	0.43	38.8 ± 9.9	0.001	0.65	
Self-Kindness	5.5 ± 1.9	5.5 ± 1.8	6.1 ± 1.7	5.5 ± 1.7	0.001	0.38	6.2 ± 1.9	0.001	0.37	
Self-Judgment	5.8 ± 2.2	6.2 ± 2.4	5.0 ± 2.3	6.1 ± 2.3	0.001	0.36	7.0 ± 2.3	0.001	0.45	
Common Humanity	5.9 ± 1.8	6.0 ± 1.9	6.8 ± 1.7	6.1 ± 1.9	0.001	0.39	7.0 ± 1.9	0.001	0.58	
Isolation	7.3 ± 1.9	7.4 ± 2.0	6.5 ± 2.1	7.2 ± 2.0	0.003	0.32	5.6 ± 2.1	0.001	0.43	
Mindfulness	6.6 ± 1.8	6.6 ± 1.8	7.1 ± 1.6	6.5 ± 1.8	0.001	0.42	7.2 ± 1.9	0.001	0.35	
Over-identification	7.6 ± 1.9	7.9 ± 1.9	6.6 ± 2.2	7.5 ± 2.1	0.007	0.30	5.8 ± 2.2	0.001	0.77	
PSS	33.3 ± 7.2	34.9 ± 6.7	29.2 ± 7.5	34.1 ± 7.1	0.001	0.46	29.3 ± 8.3	0.001	0.53	
Montgomery-Borgatta Caregiver Burden										
Relationship burden	13.8 ± 5.2	13.4 ± 4.8	13.6 ± 5.2	13.2 ± 4.7	0.709	0.03	12.9 ± 4.9	0.110	0.12	
Objective burden	20.2 ± 5.6	19.5 ± 5.4	19.3 ± 5.6	19.4 ± 5.7	0.102	0.12	18.5 ± 5.7	0.001	0.26	
Stress/subjective burden	19.1 ± 3.8	19.3 ± 3.8	17.7 ± 4.1	18.4 ± 4.2	0.141	0.12	17.0 ± 4.4	0.001	0.55	
Uplifts	14.2 ± 4.8	14.5 ± 5.0	15.1 ± 5.2	14.7 ± 5.4	0.062	0.15	15.5 ± 5.3	0.002	0.25	
CarerQoL-7D										
Fulfillment	1.93 ± 0.63	1.87 ± 0.58	1.97 ± 0.58	1.86 ± 0.59	0.419	0.08	1.98 ± 0.66	0.196	0.12	
Relational problems	2.13 ± 0.76	2.11 ± 0.70	2.01 ± 0.74	2.06 ± 0.69	0.312	0.10	1.97 ± 0.70	0.004	0.12	
Mental health problems	2.24 ± 0.63	2.29 ± 0.66	2.11 ± 0.60	2.26 ± 0.61	0.184	0.16	1.94 ± 0.66	0.001	0.50	
Problems with daily Activities	1.94 ± 0.65	1.94 ± 0.69	1.84 ± 0.71	1.92 ± 0.71	0.312	0.11	1.64 ± 0.63	0.001	0.44	
Financial problems	1.32 ± 0.54	1.28 ± 0.49	1.35 ± 0.61	1.34 ± 0.55	0.587	0.05	1.25 ± 0.52	0.580	0.06	
Support	1.72 ± 0.68	1.84 ± 0.72	1.82 ± 0.71	1.84 ± 0.69	0.175	0.14	1.86 ± 0.73	0.021	0.21	
Physical problems	1.79 ± 0.64	1.85 ± 0.64	1.78 ± 0.68	1.91 ± 0.70	0.291	0.10	1.65 ± 0.63	0.057	-0.19	
CarerQoL-VAS	4.27 ± 2.21	3.87 ± 2.23	5.19 ± 2.38	4.51 ± 2.24	0.229	0.20	5.07 ± 2.23	0.001	0.37	

**p* < 0.05.

the experiment group showed significant improvements in Mental Health Problems (*p* = 0.001, ES 0.12), Problems with Daily Activities (*p* = 0.001, ES 0.44) and the CarerQoL-VAS (*p* = 0.001, ES 0.37).

Regarding the Montgomery-Borgatta Caregiver Burden Scale, comparisons between the groups pre-post intervention showed no significant improvements for the experimental group on any of the subscales. Within-group comparisons pre-intervention and follow-up, however, showed significant improvements in objective (*p* = 0.001, ES 0.26) and stress/subjective burden (*p* = 0.001, ES.55), and uplifts (*p* = 0.002, ES.25), but no improvements in relationship burden.

Of the 136 participants in the experiment group completing the usability questionnaire at T2, 133 (*n* = 3 missing) reported rather low overall SUS scores (range 5–40, mean = 21). Additional questions on usability, also including free-text answers, illuminated motivators and barriers to use, which related to technical aspects (e.g. flexibility of use vs technical hitches), program contents (e.g. type of exercises and delivery format) and the participants' life situation (e.g. life events) (Tables 4–5). Effects of training were described as motivating and perceiving the training as another daily demand was stressful. Over half of the participants experienced the weekly e-mail reminders as positive for their training. While 71% answered “no” to whether their training had any negative effects, 22% answered “yes”. As to potential confounders, mental and/or physical health fluctuations in the patient during the test period were reported in both groups. A majority reported not having additional sources of support during the test period, while 32% and 21% in the respective groups did. As to life events

occurring and affecting the participants negatively during the test period, 33% and 40% respectively answered “yes”. A majority of participants who completed the T3 assessments reported that they had maintained their training after the test period, although with varying intensity and 60% experienced their training as (partly or very) valuable. Most participants in the experimental group at both T2 and T3 reported that they were open to pursuing their training and that they would/had recommend(ed) the program to others (see Table 5).

Amount of exercise: We examined whether there was a relationship between the amount of exercises performed during the intervention and changes in mindfulness through a correlational analysis. It showed a significant small association of 0.29 pre-post intervention and 0.33 between pre-intervention and follow-up, indicating that amount of exercise accounted for around 8% and 11% respectively of the variation in mindfulness changes.

No significant differences between completers and drop-outs at T2 were found on sociodemographic variables such as gender, age, employment status, or relationship to the patient. There were however significantly more participants with a higher education level (university/higher education) (*p* = 0.24) among completers at T2. Considering the sizeable number of participants dropping out from the investigation between assessments at T2 and T3, we analyzed whether dropouts differed from remainders with regard to outcome pre-post intervention in the primary outcome measure mindfulness (global sum). The analysis showed no differences between the groups regarding changes in mindfulness, which indicates that those participating in the

Table 4
Aspects of usability and value as extracted from the free-text answers at T2/T3 (experiment group).

Technical advantages and motivation to use	<p><u>Related to technology:</u> Easy access and use, independence and flexibility of use (place, time, technical platform, independent use) Easy access as a safety, “a coach in my pocket”</p> <p><u>Related to contents:</u> Speaker's voice, guiding voice - agreeable and easy to follow Type and variation of exercises (including mindful yoga), easy to grasp</p> <p><u>Effects as motivator:</u> Positive effects of training (e.g. relaxation, calmness, better sleep, energy, conscious awareness, reflection, supportive tool, break automatic behavior/reactions, kinder with myself, better balance, feeling that I can influence my situation/well-being, reminder to self-care)</p>
Disadvantages and barriers to use	<p><u>Related to technology:</u> Technical difficulties (e.g. log-in procedure, insecurity regarding registration of training time online) Navigation difficulties Inability to browse among exercises and choose freely (note: can be done once the whole program has been completed) Dependence on Internet connection</p> <p><u>Related to contents:</u> Lack of variation (exercises, instructions, speaker's voice) Too much talking (wish for more silent periods), wording, speaker's voice Certain contents provoking/difficult to relate to/not experienced as relevant for one's situation Difficulties with certain parts of the self-compassion exercises and conscious movements Commercial feel</p> <p><u>Related to own situation:</u> Lack of time and/or peace and concentration to do the training Lack of motivation and/or support Life situation/events (e.g. move, stress at work, family conflicts, fatalities, health issues: own or/and patient's) Falling asleep during training</p>
Other feedback and suggestions	<p><u>Related to technology:</u> Internet-independent application Possibility to browse through the exercises (not possible before completion of full program) Easier navigation Clearer instructions</p> <p><u>Related to contents:</u> More varied exercises and speaker voices Shorter daily training or longer test period</p>
Negative effects of training	<p>The training as another stressful demand, not keeping the pace induces negative feelings (failure, guilt, stress) Stirs up strong and sometimes negative feelings (can be experienced as negative, but also as positive and soothing) Periodically diminished well-being</p>
Confounding factors	<p><u>Other sources of support:</u> Own support from health professional (e.g. psychologist, counselor, physician) Emotional and/or practical support from friends/family/colleagues More support from other family members towards the patient (unburdening the participating caregiver) Professional support for the patient (e.g. medication, housing) Other sources of support (e.g. yoga, holiday)</p> <p><u>Negative life events:</u> Ill health, conflicts or fatalities in family Deterioration in patient's and/or own health Work-related stress Economic deterioration due to own or/and patient's illness Other stressful life events (e.g. move, relationship break-up)</p>

follow-up assessments were representative for the sample participating in the intervention.

6. Discussion

In accordance with the literature, significant improvements were found in the primary outcome mindfulness, currently with mainly medium effect sizes in both the global sum scale and all subscales both post intervention and at follow-up. The effect size increase for all the FFMQ subscales except one (Observing) and the large effect size of the global sum scale at follow-up is, however, noticeable. Similar improvements were found in previous studies with the same intervention (Stjernswärd and Hansson, 2016a; Stjernswärd and Hansson, 2017), although effect sizes were slightly weaker in the current study compared to the earlier effectiveness study (Stjernswärd and Hansson, 2017). Significant improvements in benefit for the experimental group were also found for perceived stress, with a small effect size post intervention and medium effect size at follow-up. Previous studies showed medium effect sizes already post intervention (Stjernswärd and Hansson, 2016a; Stjernswärd and Hansson, 2017). MBI such as MBSR

have been associated with lowered levels of perceived stress and negative affect, with linear decreases as a function of both time and cumulative number of days of mindfulness training, suggesting a dose-effect relationship (Snippe et al., 2017). Nevertheless, even shorter interventions show beneficial health outcomes (Carmody and Baer, 2009; Zeidan et al., 2010; Krusche et al., 2012; Boettcher et al., 2013; Stjernswärd and Hansson, 2017), which is also the case in the current study. Current associations between training time and effect were smaller compared to previous studies (Stjernswärd and Hansson, 2016a; Stjernswärd and Hansson, 2017). Nevertheless, the enhanced effect sizes at follow-up may speak for the value of maintained training, although there is an insecurity as to how much more the remaining participants had practiced by the time of the 3-month assessment. Training time was registered until T3, however training time > 960 min (complete program) could not be registered online and the amount of self-reported maintained training was not specific enough to draw any further dose-effect related conclusions.

The current intervention was targeted at a wider audience of caregivers, speaking for generalizability of the results. Half of the participants reported low levels of mental health speaking for the relevance of

Table 5

Usability aspects and potential confounding factors as experienced during the test period and by the 3-months follow-up (free-text answers and descriptive statistics, T2/T3).

Assessments at T2 - after the experiment group's test period	Experiment group n = 136	%	WLC n = 160	%
Mental health fluctuations in the patient during the test period				
Improved	16	12	30	19
Unchanged	58	43	43	27
Deteriorated	8	6	24	15
Fluctuated (better and worse)	26	19	44	28
Don't know	15	11	15	9
Not relevant	13	9	4	2
Physical health fluctuations in the patient during the test period				
Improved	9	7	19	12
Unchanged	76	56	65	41
Deteriorated	10	7	25	16
Fluctuated (better and worse)	13	9	32	20
Don't know	13	10	12	7
Not relevant	15	11	7	4
Support from other sources during the test period with potential positive effects				
Yes	44	32	34	21
No	90	66	116	73
Don't know	2	2	10	6
Life events during the test period with potential negative effects				
Yes	45	33	64	40
No	91	67	87	54
Don't know	–	–	9	6
<hr/>				
Assessments at T2 – after the experiment group's test periods	Experiment group n = 136			%
Negative effects of training				
Yes	30			22
No	97			71
Don't know	9			7
e-mail reminders positive for training				
Yes	73			54
No	7			5
Neither nor	52			38
Don't know	4			3
Potentially pursue training with a similar program (T2)				
Yes	100			74
Maybe	26			19
No	8			6
Don't know	2			2
Would/has recommend(ed) the program to others				
Yes	100			74
Maybe	26			19
No	5			4
Don't know	5			3
Assessments at T3–3 months after termination of the test period				
Continued training after test period				
Yes, 4–7 days/week	6			6
Yes, 2–3 days/week	16			17
Yes, 1–7 days/month	35			36
No, hardly ever	39			41
Experienced continued training after test period as valuable				
Yes, very	23			24
Yes, partly	35			36
No, hardly or not at all	5			5
Don't know	12			13
Not relevant (did not pursue training)	19			20
Missing	2			2
Potentially pursue training				
Yes	66			69
Maybe	20			21
No	3			3
Don't know	7			7
Would/has recommend(ed) the program to others				
Yes	68			71
Maybe	19			20
No	4			4
Don't know	5			5

targeting this population with supportive interventions such as MBI, which can help decrease stress reactivity (Kabat-Zinn, 2009) and enhance the ability to communicate and respond constructively to stress, including relationship stress (Barnes et al., 2007). Increased self-compassion can also improve interpersonal relationships (Hofmann et al., 2011; Jazaieri et al., 2014; Yadavaia et al., 2014). It can help reduce shame, negative affect and emotional exhaustion, while increasing positive affect (Leary et al., 2007; Neff et al., 2007; Neff and Vonk, 2009). In accordance with previous findings (Stjernswärd and Hansson, 2016a; Stjernswärd and Hansson, 2017), significant improvements were found for self-compassion including most of its subscales. A number of participants, however, commented on difficulties with the self-compassion exercises, such as difficulties with including “all humanity” or “others” in their training, or feeling provoked because they already cared a lot for others. Additional (virtual) support may be valuable in addressing such resistance, which may activate a threat response (Rockliff et al., 2008) and increase the vulnerability to mental health problems (Gilbert et al., 2011) instead of opening up for the beneficial effects of compassion.

Regarding caregiver burden, the study showed no significant improvements post intervention in the CarerQoL-7D, although some dimensions showed significant improvements at follow-up. Previous findings were mixed, with significant but small improvements on some dimensions of caregiver burden (Stjernswärd and Hansson, 2016a; Stjernswärd and Hansson, 2017). As previously discussed (Stjernswärd and Hansson, 2017), the CarerQoL-7D does not appear to capture central effects of the intervention, although the latter may have indirect positive effects on the caregivers' situation and experiences of burden. The Montgomery-Borgatta Caregiver Burden Scale was added to investigate the appropriateness of a different instrument to measure potential changes in burden. Although no significant changes in any of the subscales were found post intervention, significant but mostly small improvements were found at follow-up for uplifts, objective and subjective burden, but not for relationship burden. Coping is viewed as a central mediator that can affect the outcomes of stress (Pearlin et al., 1990). In the process of decreasing stress reactivity (Kabat-Zinn, 2009), MBI can help caregivers cope more constructively with stress. Such strategies may help reduce the negative effects of stress on caregivers' health and relationships, which in turn may indirectly contribute to alleviate the caregivers' situation. Potential direct effects on caregiver burden is, however, an issue for further research. As reported in the free-text answers, the training was a reminder and opportunity for respite and to make own time without feeling guilty. The positive effects of training can contribute to increase caregivers' well-being and QoL, which also goes in line with previous findings (Banerjee et al., 2017).

The majority of participants reported spending 1–15 h weekly caring for the affected person, which is not uncommon (National Alliance for Caregiving and AARP, 2004; Turcotte, 2013). Caregivers also report spending care time equaling a full-time job (Turcotte, 2013), representing a source of worry and stress. MBI can help increase psychological flexibility (Hayes et al., 1999), and the ability to accept and connect with the present moment, including negative thoughts, feelings and bodily sensations (Hayes, 2002), potentially addressing caregiver distress (Jansen et al., 2015; Jansen et al., 2017). Mindfulness can contribute to an increased and non-judgmental acceptance of what is, and an enhanced ability to be in the present moment rather than to ruminate about the past or worry about the future (Kabat-Zinn, 2009). MBI may help caregivers come to an acceptance of the situation, while also making space for grief and other negative emotions related to their kin's illness (Jansen et al., 2017). Although many of the problems associated with being a caregiver cannot be solved with MBI, such intervention may be an additional coping tool.

There is a need for identifying central key components and mechanisms of change in web-based caregiver-targeted interventions (Guay et al., 2017). Theoretically grounded interventions (Webb et al., 2010) and interventions including behavior change techniques (BCT)

(Guay et al., 2017) appear to be more efficacious in improving caregiver outcomes. Moreover, interventions providing stress management techniques – which caregivers covet (National Alliance for Caregiving and AARP 2015) – appear to have the greatest effect on behavior (Webb et al., 2010). The current intervention has its theoretical underpinnings in the beneficial effects of MBI, for which the underlying effective mechanisms still need to be illuminated, especially when adapted to new populations and contexts (Crane et al., 2017). In MBI, however, a relationship change towards one's experiences, whether pleasant or unpleasant, is associated with decreased levels of distress (Kabat-Zinn, 2009; Crane et al., 2017). There is evidence for the association of MBSR/MBCT with reduced cognitive and emotional reactivity, and reduced rumination and worry (Gu et al., 2015). In this respect, stress management through MBI may represent a potential mediator of burden for caregivers.

A fifth of the participants reported negative effects of their training, which is important to bear in mind. Anxiety about not succeeding in maintaining the training pace was a source of stress that can decrease motivation and adherence. Other reported negative effects were the surfacing of strong emotions, anxiety from a participant in crisis, and at times reduced well-being. Awareness about unpleasant thoughts, feelings and experiences, idealizing practice or setting impossible standards, and sleepiness (Kabat-Zinn, 2017a) can be obstacles to (but also opportunities for) training, similarly as self-criticism for disengaging from practice (Banerjee et al., 2017). Discipline and motivation to engage in mindfulness practice are key and obstacles can be turned into opportunities if embraced in awareness (Kabat-Zinn, 2017b). Although severe mental illness was an exclusion criterion and the participants were informed that the training can give rise to strong emotions, crises can occur at any time during the test period, which requires vigilance.

Lack of motivation is a barrier in e-health interventions (Kampmeijer et al., 2016), as also seen in the current study, which is why ways of upholding motivation may improve adherence and the potential beneficial effects of training. Human support is commonly used in caregiver interventions online (Guay et al., 2017) and can enhance adherence (Kelders et al., 2012; Kampmeijer et al., 2016) and intervention efficacy (Webb et al., 2010). Moreover, reminders (Fry and Neff, 2009; Webb et al., 2010) and the RCT format appear (for different potential reasons) to increase adherence (Kelders et al., 2012), which was also mentioned by participants in a previous study (Stjernswärd and Hansson, 2016b). Lack of support and feedback can be further barriers, while ease of use, prompts and personal support may facilitate the use of such interventions (Kampmeijer et al., 2016), as partly illuminated in the current study. A possibility for the participants to discuss their practice may be a valuable complement to the web-based program.

The SUS scores were surprisingly low, especially in comparison with earlier high usability scores (Stjernswärd and Hansson, 2017), although many participants commented upon the program's ease and flexibility of use. The supplementary usability questions may help shed light onto factors affecting these ratings negatively and areas for enhancements. Weaving in an even clearer rationale in the program, among others, may help clarify the mindfulness principles and uphold motivation, as seen in previous studies (Banerjee et al., 2017).

6.1. Limitations

Although the current design was a RCT, the intervention was not compared against an alternative control intervention. The use of self-report measures is a potential limitation, as is the potential selection bias, limiting generalizability of the results. The participants consisted of a majority of middle-aged women and mothers to an ill person, which also goes in line with previous studies (Guay et al., 2017; Stjernswärd and Hansson, 2016a; Stjernswärd and Hansson, 2017), the literature on caregiving (e.g. Fox and Brenner, 2012) and engagement in online interventions. There was also a significant overrepresentation

of participants with a higher education among the completers at T2, limiting representativity and generalizability of the current findings. The presence of potential confounders was explored, such as the occurrence of support or negative life events during the test period, or health fluctuations in the patient – which were present in both groups. Slightly more participants in the experiment group reported additional sources of support compared to the WLC and fewer also reported negative life events, possibly affecting the interpretation of the current results.

Dropout rates for the experiment group were 30% (n = 59) and 20% (n = 40) at T2 and T3, respectively. Dropout rates in earlier MBI online range between 7.7 and 52.3% (Fish et al., 2016) (Fish et al., 2016) and the average dropout rates for internet-based treatments for psychological disorders is 35% (Melville et al., 2010). Kelders et al. (2012) found an average adherence of 50% to web-based health interventions (range < 10%– > 90%), further illuminating challenges with adherence and motivation in online interventions. Due to the high drop-out rate, an ITT analysis was performed on the primary outcome mindfulness, resulting in equivalent findings, which indicates the validity of the results. A majority of the participants in the present study completed between 50 and 100% of the suggested training dose, and several participants reported that they worried about not being able to complete the full program within the study's test period, creating additional stress. Training undeniably requires motivation, time and discipline (Stjernswärd and Hansson, 2016b; Kabat-Zinn, 2017b). The potential value of including further psychoeducation (clearer rationale) and virtual support to address difficult experiences that emerge during practice (Banerjee et al., 2017) and self-criticism (e.g. related to non-adherence to suggested training dose) (Langdon et al., 2011) should be explored. Feedback on usability of the program also highlights areas for improvement in future MBI online.

6.2. Conclusions

Web-based mindfulness programs can be a potentially cost-effective tool to support caregivers coping with stress and burden, preventing further ill health and costs to society. Further research is needed to corroborate and explore the effectiveness and usability of such interventions, possibly adding instructor support (e.g. online or by phone) to enhance the program's beneficial effects. Caregiver interventions can be tailored to better suit their users and enhance their beneficial outcomes through an understanding of potential barriers and facilitators of use. Attention to ways of supporting motivation and adherence to the programs may contribute to enhanced benefits of mindfulness practice, such as increased levels of mindfulness and self-compassion, and decreased levels of perceived stress, and indirectly of caregiver burden.

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