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# Web-Based Psychoeducational Intervention to Improve Family Caregiver Preparedness in Specialized Palliative Home Care: A Randomized Controlled Trial

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#### **ABSTRACT**

Objective: Preparedness for caregiving refers to how ready family caregivers perceive themselves for caregiving tasks and stress of the caregiving role. This study investigated whether a web-based psychoeducational intervention could improve preparedness for caregiving among family caregivers of patients receiving specialized palliative home care.

Methods: The intervention "narstaende.se" was provided via a website featuring 23 short videos in which healthcare professionals and family caregivers (actors) discussed key care-related issues. Family caregivers were randomized to the intervention or control group and completed the Preparedness for Caregiving Scale (PCS) at baseline, 4 weeks, and 8 weeks. Data were analyzed using linear mixed models. The intervention effect was assessed based on PCS scores of the entire sample, followed by subgroup analyses based on level of baseline preparedness for caregiving, participation in physical care, and active intervention use, as determined by responses to single-item questions.

Results: A total of 205 family caregivers were recruited (103 intervention, 102 control). The intervention had no significant effect on preparedness for caregiving, including in subgroups based on level of baseline preparedness for caregiving, participation in physical care, or active intervention use. However, all subgroups reported higher levels of preparedness for caregiving at both follow-up assessments than at baseline.

Conclusions: Preparedness for caregiving improved over time in both the intervention and control groups, suggesting other contributing factors. Limited participant engagement may explain the lack of intervention effect. Future studies should evaluate the intervention with more structured and clinically integrated use.

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#### 1 | Background and Aim

Preparedness for caregiving refers to family caregivers' perceived readiness for the tasks and stress of their caregiving role [1]. Recently, the concept has been expanded to include family caregivers' own perceptions of their evolving confidence, practical ability, and ability to handle emotions over time [2]. Preparedness develops through caregiving activities rather than being achieved in advance, and feeling prepared to provide care is essential for managing the caregiver role and enabling homebased care [3]. In this context, family caregivers often undertake complex caregiving tasks, comparable to those of healthcare professionals, when caring for a patient with advanced cancer or other life-threatening illnesses [4].

Many family caregivers feel inadequately prepared, leading to challenges associated with complex responsibilities and concerns about the patient's illness [3]. Consequently, family caregivers often experience significant psychosocial impacts, including anxiety, depression [5], and reduced quality of life [6]. Higher preparedness levels can reduce these negative outcomes [7, 8]. However, as caregivers' needs evolve throughout the patient's illness trajectory [5, 9, 10], adequately addressing their changing needs is a continuous challenge for healthcare services [9].

Preparedness for caregiving can be improved through psychoeducational interventions, traditionally delivered in person [11]. While in-person interventions remain effective, web-based interventions are becoming increasingly common and require user initiative and engagement [12]. They can improve access to self-care, reduce anxiety and depression, and enhance coping skills and overall quality of life [13]. However, limited evidence exists on whether web-based psychoeducational interventions effectively promote preparedness for caregiving in the palliative care setting.

To address this gap, this study aimed to investigate the effect of a web-based psychoeducational intervention on preparedness for caregiving among family caregivers of patients receiving specialized palliative home care. It was hypothesized that the intervention would increase family caregivers' preparedness for caregiving (the primary outcome). Furthermore, family caregivers with lower baseline preparedness, those participating in physical care, or those actively using the intervention were expected to show greater improvement in preparedness for caregiving.

#### 2 | Methods

#### 2.1 | Study Design

This two-arm, non-blinded randomized controlled trial is registered at ClinicalTrials.gov (ID NCT05785494), was approved by the Swedish Ethical Review Authority (2022-02218-02, 2022-06623-02), and described in a previously published study protocol [14]. The study adhered to the UK Medical Research Council's four-phase framework for developing and evaluating complex interventions [15]. A core element of this framework is the use of program theory, which outlines the assumed sequence of activities leading to change and their connection to the anticipated effect (Figure 1).

#### 2.2 | Intervention

The web-based psychoeducational intervention was provided via the website "narstaende.se" and developed specifically for family caregivers, intending to improve their preparedness for caregiving. A multidisciplinary team of healthcare researchers, clinicians, information systems experts, digital communication strategists, and IT consultants developed the intervention, which was feasibility and acceptability tested [16]. The content was grounded in empirical research [17, 18] and informed by Andershed and Ternestedt's theory on family caregivers'

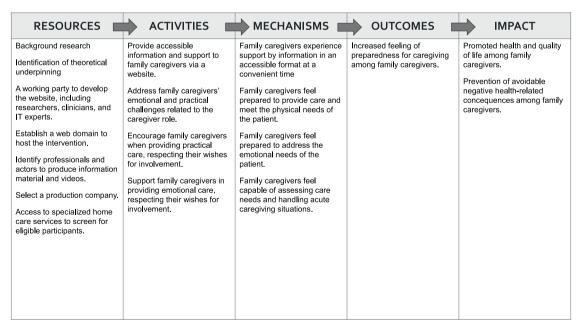


FIGURE 1 | Program theory in accordance with the MRC framework.

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involvement in care [19]. This theory suggests that caregiving can be experienced either "in the light," where family caregivers feel informed and acknowledged, or "in the dark," where they feel isolated and uninformed. Three principal needs shape this experience: knowing (knowledge of symptoms and diagnosis), being (shared time), and doing (practical tasks). Furthermore, this theory aligns with the concept of preparedness, encompassing family caregivers' knowledge, ability to handle emotions, and competence in caregiving [2].

The content of the intervention was divided into three main domains: Support for you-being a family caregiver, How to give support, and Talk about it (Figure 2). It included 23 videos, each averaging 4 min, depicting conversations between family caregivers and healthcare professionals regarding key care-related issues. The principal needs described by Andershed and Ternestedt were reflected across website domains, for example: "Knowing" includes education about symptoms, the grief process, and emotional reactions; "Being" includes communication about illness-related issues, future life, and bereavement; and 'Doing' includes practical care and support. Each video had a descriptive title and a brief introduction to help family caregivers identify relevant topics based on their preferences. This allowed them to navigate the intervention website freely, engage with the chosen content at their own pace, and access it anytime and as often as needed. Informative texts supplemented the videos in each domain. These included, for example, information about assistive devices to facilitate personal care, such as transfer aids or pressure-relieving seat cushions, and guidance on how to access them. The texts also provided information about the social support system, along with web links to relevant stakeholder organizations in family caregiving and social welfare. The intervention delivery relied on family caregivers' own responsibility, willingness, and motivation to engage with the content. The study design did not monitor participant engagement.

#### 2.3 | Context

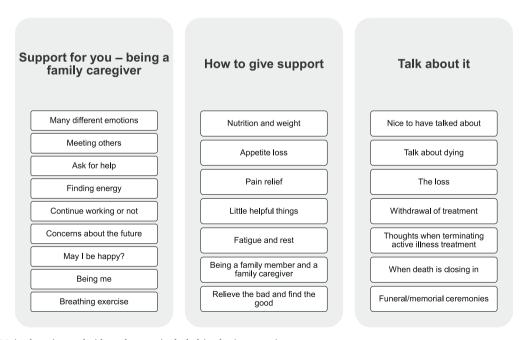
Five specialized home care services formed the recruitment base. These services, among the largest in Sweden, serve most of the Stockholm metropolitan area. Together, they comprised 18 teams with varying catchment areas, each caring for 35 to 220 patients. The teams comprised approximately 15–100 healthcare professionals, including registered nurses, physicians, physiotherapists, occupational therapists, and healthcare social workers. They provide 24-h multifaceted home care to patients with various conditions, including palliative care at a specialized level, based on the patient's needs. Home care visits are scheduled according to patient and family requirements, with urgent visits provided when necessary. While supporting family caregivers is part of the services' mandate, no specific guidelines dictate what it should entail, leading to potential variations between services and individual healthcare professionals.

#### 2.4 | Participants

The inclusion criteria required participants to be family caregivers of patients receiving specialized palliative home care. Patients were included if they had a life-threatening illness and palliative care needs. Additionally, patients and family caregivers had to be at least 18 years old, and family caregivers needed to communicate in Swedish.

#### 2.5 | Procedure

Family caregivers were recruited through a stepwise procedure. First, after approval from service managers, the researchers screened patient records to identify patients who met the inclusion criteria. Identified patients received an information



 $FIGURE\ 2\ \mid\ \text{Main domains and videos that are included in the intervention}.$ 

letter about the study along with a separate letter to share with a family caregiver of their choice. Approximately 1 week later, the researchers contacted patients by telephone to provide verbal information about the study and obtain approval to approach their family caregivers. Patients provided written consent for the researchers to retrieve their age and diagnosis from medical records. Once patients agreed to participate, their family caregivers were contacted by telephone for information and gave verbal consent to participate. Online questionnaires were sent to participating family caregivers via e-mail at three time points: baseline, follow-up 1 (after 4 weeks), and follow-up 2 (after 8 weeks). Written consent for study participation was obtained in connection with the completion of the baseline questionnaire. Those family caregivers who had access to the intervention received one telephone call each from a researcher who provided initial login assistance. Recruitment occurred between October 2022 and December 2023.

## 2.6 | Statistical Power

Statistical power was calculated for the primary outcome variable, the *Preparedness for Caregiving Scale* (PCS), based on findings from a previous study using the same outcome in a similar population of caregivers [17]. Using a two-way repeated measures ANOVA for three assessments and two groups, a total of 134 participants (equally distributed between groups) were required. The calculation was based on a medium effect size ( $f^2 = 0.15$ ), a 5% significance level ( $\alpha = 0.05$ ), a power of 90% ( $1 - \beta = 0.9$ ), and a correlation of 0.3 among repeated measures. Considering a 30% attrition rate, as previously observed in palliative care research, the target sample size was set at 180 participants.

## 2.7 | Randomization

Once the baseline questionnaire was submitted, family caregivers were randomized to either the intervention or control group. A computer-based stratified block randomization procedure was used to ensure a balance between the intervention and control groups across services, with participating family caregivers randomized in blocks of four (allocation ratio 1:1). The randomization was not blinded. Both intervention and control groups received standard care from one of the aforementioned specialized home care services where the patient was admitted.

# 2.8 | Measures

The primary outcome, preparedness for caregiving, was assessed using the PCS. This scale measures family caregivers' self-rated preparedness across multiple domains, along with an additional overall assessment. Originally developed for family caregivers of older adults [1], the PCS was later adapted and validated for use in palliative and cancer care [20, 21]. The scale consists of eight items rated on a five-point Likert-type scale with the following response categories: *not at all prepared, not too well prepared, somewhat prepared, pretty well prepared*, and *very well prepared* 

(scored 0–4). The total score ranges from 0 to 32, with higher scores indicating greater preparedness. In the present study, the Cronbach's alpha was 0.92.

The questionnaires also included *sociodemographic questions*, such as sex and age, along with two *single-item questions*: one measuring participation in physical care and the other measuring active intervention use. Family caregivers self-reported their participation in physical care on a 5-point Likert-type scale with the following response categories: *never*, *occasionally*, *1–2 times/week, every day*, and *several times/day* (scored 1–5). Active intervention use was self-reported on a four-point Likert-type scale with the following response categories: *not at all, once, 2–4 times,* and *five times or more* (scored 1–4).

# 2.9 | Data Analysis

Missing items in the primary outcome, PCS, were imputed using a person's median score if the number of missing responses did not exceed 25% (i.e.,  $\geq$  3 missing item responses). In total, nine missing values were imputed for eight individuals. Analyses followed the intention-to-treat (ITT) principle. Descriptive statistics were conducted using SPSS (IBM Corp., Armonk, NY, USA), whereas all remaining analyses were conducted in R (R Foundation for Statistical Computing, Vienna, Austria) using the lme4 (1.1–35.3) and lmerTest (3.1–3) packages. Pearson's chi-square tests, Mann-Whitney U tests, or unpaired t-tests were applied as appropriate, depending on data level and distribution.

Linear mixed models were used to evaluate the intervention effects on preparedness over time, both within and between groups. The models included fixed effects (group and time) and random effects (individuals). According to the ITT approach, all participating family caregivers were included in the analyses, regardless of whether they completed all follow-up assessments. Sensitivity analyses were conducted to adjust for baseline differences in family caregivers' relation to the patient between the intervention and control groups.

Subgroup analyses were performed to further investigate the effect. First, the intervention effect was investigated based on baseline preparedness levels. Family caregivers with the highest baseline preparedness were excluded because improvements were assumed to be unlikely in this group. Three different cutoff scores were used: the first group consisted of family caregivers whose preparedness scores were below Q1 (PCS < 12), the second group included family caregivers with scores below Q2 (PCS < 17), and the third group included family caregivers with scores below Q3 (PCS < 22).

Second, the intervention effect was investigated based on the family caregivers' baseline reports of participation in physical care. Thus, family caregivers were divided into subgroups based on their reported participation in the physical care of the patient. The variable was dichotomized, with responses *never* and *occasionally* coded as 0, and *1–2 times/week, every day*, and *several times/day* coded as 1. In the analysis, Group 1 was combined with subgroups based on levels of preparedness for caregiving at baseline.

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Third, the intervention effect was evaluated based on family caregivers' self-reported active intervention use at follow-ups 1 and 2. Thus, the intervention group was divided into subgroups based on participating family caregivers who reported active use of the intervention. The variable was dichotomized, with responses not at all coded as 0, and once, 2–4 times, and five times or more coded as 1. In the analysis, Group 1 was combined with subgroups based on levels of preparedness for caregiving at baseline.

#### 3 | Results

#### 3.1 | Sample Characteristics

A total of 243 family caregivers were recruited (Figure 3). Of these, 205 completed the baseline data collection (n = 103 in the intervention group and n = 102 in the control group). The first follow-up assessment was completed by 162 family caregivers. Since the present study focused on preparedness for caregiving, responses from those caring for a patient who had died after the previous assessment were excluded from the analysis, leaving 155 family caregivers (n = 76 in the intervention group and n = 79 in the control group). The second follow-up assessment was completed by 131 family caregivers. After exclusion due to patient death, 117 family caregivers remained (n = 56 in the

intervention group and 61 in the control group). Participants could withdraw from the study at any time without giving a reason, however, some participants reported that their withdrawal was due to deterioration of the patient's condition.

The baseline characteristics of the family caregivers and patients are presented in Table 1. Among the family caregivers, 62.4% were female, with an average age of 64.0 (SD = 13.1) years. The majority (68.8%) were partners of the patient, 47.8% were retired, and 42.9% were employed. Nearly half of the family caregivers reported participating in physical care every day (27.8%) or several times per day (20.0%), whereas fewer reported participating one to two times per week (16.6%), occasionally (19.0%), or never (15.1%). No significant differences were observed between the intervention and control groups, except for the relationship with the patient. Partner relationships were more common in the control group, whereas parent or other relationships were more common in the intervention group (p=0.020). Sensitivity analyses adjusting for family caregivers' relation to the patient did not alter the results.

Among the patients, 52.7% were female, with a mean age of 70.1 (SD = 12.3) years. The most common diagnosis was malignant disease (94.1%), with gastrointestinal cancer being the most frequent (40.5%). The duration of the patient's incurable illness ranged from < 1 year to  $\geq$  10 years, most commonly between 1 and 2 years (37.0%). No significant differences were observed

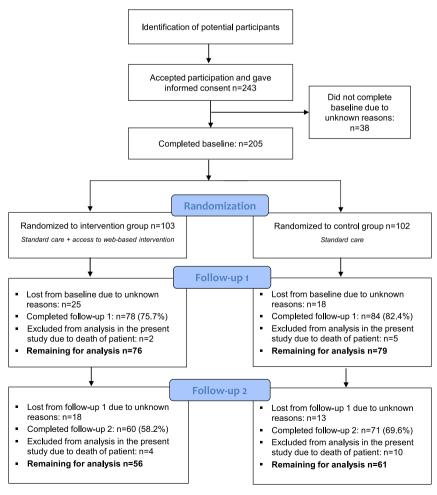


FIGURE 3 | Study flow diagram.

 $\textbf{TABLE 1} \hspace{0.1in} \vdash \hspace{0.1in} \textbf{Family caregiver and patient baseline characteristics.}$ 

	All (n = 205)	Intervention $(n = 103)$	Control $(n = 102)$	Missing data	<i>p</i> -value
Family caregiver characteristics					
Sex, family caregivers, $n$ (%)				1	0.514 <sup>a</sup>
Female	128 (62.4)	62 (60.2)	66 (64.7)		
Male	76 (37.1)	40 (38.8)	36 (35.3)		
Age family caregiver, mean (SD) [min-max]	64.0 (13.1) [19–88]	64.4 (12.6) [19–88]	63.7 (13.6) [24–87]		0.726 <sup>b</sup>
Relation to patient, $n$ (%)					0.020 <sup>a</sup>
My partner	141 (68.8)	68 (66.0)	73 (71.6)		
My parent	47 (22.9)	21 (20.4)	26 (25.5)		
Other <sup>e</sup>	17 (8.3)	14 (13.6)	3 (2.9)		
Participated in physical care of the patient during the past month, $n\ (\%)$				3	0.134 <sup>c</sup>
Never	31 (15.1)	16 (15.5)	15 (14.7)		
Occasionally	39 (19.0)	23 (22.3)	16 (15.7)		
1–2 times/week	34 (16.6)	19 (18.4)	15 (14.7)		
Every day	57 (27.8)	26 (25.2)	31 (30.4)		
Several times/day	41 (20.0)	17 (16.5)	24 (23.5)		
Occupation, n (%)				2	0.460 <sup>a</sup>
Employed	88 (42.9)	43 (41.7)	45 (44.1)		
Retired	98 (47.8)	48 (46.6)	50 (49.0)		
Other <sup>f</sup>	17 (8.3)	11 (10.7)	6 (5.9)		
Preparedness for caregiving score, mean (SD) [min-max]	17.4 (6.4) [3–32]	17.9 (6.3) [3–32]	17.0 (6.6) [4–32]	1	0.279 <sup>b</sup>
Patient characteristics					
Sex, patient, n (%)					0.519 <sup>a</sup>
Female	108 (52.7)	52 (50.5)	56 (54.9)	1	
Male	96 (46.8)	50 (48.5)	46 (45.1)		
Age patient, mean (SD) [min-max]	70.1 (12.3) [21–93]	70.0 (13.1) [21–93]	70.1 (11.4) [21–90]		0.977 <sup>b</sup>
Patient's diagnosis, n (%)					
Hematological cancer	14 (6.8)	11 (10.7)	3 (2.9)		0.028 <sup>a</sup>
Gastrointestinal cancer	83 (40.5)	40 (38.8)	43 (42.2)		0.628 <sup>a</sup>
Lung cancer	20 (9.8)	10 (9.7)	10 (9.8)		0.982 <sup>a</sup>
Gynecological cancer	19 (9.3)	10 (9.7)	9 (8.8)		0.827 <sup>a</sup>
Breast cancer	12 (5.9)	7 (6.8)	5 (4.9)		0.564 <sup>a</sup>
Prostate cancer	12 (5.9)	6 (5.8)	6 (5.9)		0.986 <sup>a</sup>
Other cancer	33 (16.1)	12 (11.7)	21 (20.6)		0.082 <sup>a</sup>
Cardiovascular disease	2 (1.0)	1 (1.0)	1 (1.0)		1.000 <sup>d</sup>
Pulmonary disease	3 (1.5)	3 (2.9)	0		0.246 <sup>d</sup>
Amyotrophic lateral sclerosis (ALS)	6 (2.9)	3 (2.9)	3 (2.9)		1.000 <sup>d</sup>
Liver cirrhosis	1 (0.5)	0	1 (1.0)		0.498 <sup>d</sup>
Duration of incurable illness, $n$ (%)				5	0.974 <sup>c</sup>
< 1 year	54 (27.0)	26 (26.3)	28 (27.7)		
1–2 years	74 (37.0)	39 (39.4)	35 (34.7)		

(Continues)

**TABLE 1** | (Continued)

	All $(n = 205)$	Intervention $(n = 103)$	Control (n = 102)	Missing data	<i>p</i> -value
3–4 years	32 (16.0)	14 (14.1)	18 (17.8)		
5–9 years	24 (12.0)	11 (11.1)	13 (12.9)		
≥ 10 years	16 (8.0)	9 (9.1)	7 (6.9)		

aChi2-test.

between the groups, except that hematological cancer was significantly more common in the intervention group than in the control group (10.7% vs. 2.9%, p = 0.028).

# 3.2 | Intervention Effect

At baseline, the mean preparedness level did not significantly differ between the intervention and control groups (17.9 vs. 17.0; p = 0.279) (Table 1). When analyzing the entire sample, no significant differences in preparedness were observed over time (p = 0.781 and p = 0.112, respectively) or between the intervention and control groups (p = 0.375). Similarly, no significant interaction effect was observed between time and group (p = 0.217 and p = 0.289, respectively) (Table 2).

# 3.2.1 | Subgroup Analyses Based on Baseline Preparedness

No significant differences were observed between the intervention and control groups based on family caregivers' baseline preparedness levels. However, family caregivers overall reported higher levels of preparedness for caregiving at both the first and second follow-up assessments than at baseline (all p < 0.001).

# 3.2.2 | Subgroup Analyses Based on Participation in Care

No significant differences were observed between the intervention and control groups regarding family caregivers' participation in the physical care of the patient. However, family caregivers overall reported higher levels of preparedness for caregiving at both the first and second follow-up assessments than at baseline. Preparedness levels of family caregivers increased in both groups, regardless of baseline preparedness level  $(p=0.01\ {\rm to} < 0.001)$ .

### 3.2.3 | Subgroup Analyses Based on Intervention Use

No significant differences were observed between the intervention and control groups based on family caregivers' active intervention use. However, family caregivers overall reported higher levels of preparedness for caregiving at both the first and second follow-up assessments than at baseline. Preparedness

levels of family caregivers increased in both groups, regardless of their baseline preparedness levels (all p < 0.001).

#### 4 | Discussion

To the best of our knowledge, this is the first trial to evaluate the effect of a fully web-based psychoeducational intervention on preparedness for caregiving among family caregivers of patients with predominantly advanced cancer. Despite developing an empirically and theoretically grounded intervention that underwent feasibility testing, no effect on preparedness for caregiving was observed, and the study hypothesis could not be confirmed. Similarly, no significant effects were observed based on caregivers' baseline preparedness levels, participation in physical care, or active intervention use. However, preparedness for caregiving significantly increased over time, as family caregivers in both the intervention and control groups reported higher levels of preparedness at both follow-up assessments than at baseline.

Previous studies on this intervention have shown that family caregivers found it useful, appreciating its flexibility in tailoring content to their needs [16]. Findings also suggest that it provides guidance in the caregiver role [22], indicating potential benefits for those who engage with the intervention. However, these effects were not observed in the trial reported herewith.

The lack of a significant intervention effect on preparedness for caregiving raises questions about the web-based intervention design and calls for careful interpretation to understand why the intended effect was not achieved. While web-based interventions are generally accepted among family caregivers in palliative care [23], evidence on the most effective delivery format (whether in-person, digital-only, or a combination) remains limited, with no single approach proving superior [24, 25]. Previous interventions that effectively improved preparedness for caregiving among family caregivers of patients with cancer or other life-threatening illnesses were delivered inperson [17, 26, 27]. In-person formats may provide personal encouragement and interaction that help family caregivers stay engaged in the intervention, an element lacking in fully webbased intervention designs. Web-based alternatives designed to integrate a digital format with means for interaction between participants and professionals increase engagement compared with fully self-guided interventions [28]. Nevertheless, regardless of the intervention design or delivery format, supportive

bt-test.

<sup>&</sup>lt;sup>c</sup>Mann-Whitney *U* test.

dFischer's exact test.

<sup>&</sup>lt;sup>e</sup>My child, my friend, or other.

fStudent, unemployed, on parental leave, or other.

TABLE 2 | Intervention effect based on linear mixed models with random intercepts and unstructured covariance matrix.

		Subgroup	Subgroups based on baseline preparedness	baseline	Suborouns 1	Subgrouns based on narticination in care	tion in care	Suborouns	Subgroups based on intervention use	ention use
		74	a de la companya de l		Participated in	Darticinated in	Darticinated in	Active	Active	Active
		PCS < 12	PCS < 17	PCS < 22	physical care	physical care	physical care	intervention	intervention	Active
		at	at	at	and	and	and	use and	use and	use and
	All (n = 205)	baseline $(n = 55)$	baseline $(n = 112)$	baseline $(n = 154)$	PCS < 12 $(n = 29)$	PCS < 17 $(n = 63)$	PCS < 22 $(n = 91)$	PCS < 12 $(n = 41)$	PCS < 17 $(n = 83)$	PCS < 22 $(n = 108)$
Score distribution of PCS, mean (SD)	of PCS, me	an (SD)								
Baseline intervention	17.9 (6.3)	9.8 (2.4)	12.7 (3.4)	15.3 (4.6)	10.5 (1.8)	13.2 (3.0)	15.9 (4.2)	9.7 (2.7)	13.2 (3.7)	15.1 (4.3)
Baseline control	17.0 (6.6)	9.8 (1.9)	12.4 (3.3)	13.9 (4.2)	9.4 (2.1)	12.8 (3.6)	14.4 (4.3)	9.8 (1.9)	12.4 (3.3)	13.9 (4.2)
Follow-up 1 intervention	17.5 (5.8)	17.5 (5.8) 16.0 (5.8)	17.0 (5.8)	17.4 (5.5)	17.0 (4.1)	17.7 (5.3)	18.1 (5.3)	14.3 (6.3)	17.0 (5.9)	17.9 (5.9)
Follow-up 1 control	17.0 (6.0)	17.0 (6.0) 18.3 (6.8)	17.2 (5.8)	17.0 (5.5)	17.5 (6.8)	17.0 (5.5)	16.5 (5.2)	18.3 (6.8)	17.2 (5.8)	17.0 (5.5)
Follow-up 2 intervention	18.4 (5.8)	18.4 (5.8) 17.5 (5.2)	17.7 (5.0)	18.3 (5.1)	18.3 (6.1)	18.3 (5.0)	19.1 (5.1)	16.6 (5.2)	17.7 (4.1)	18.1 (4.6)
Follow-up 2 control	18.6 (5.9)	19.3 (6.6)	19.4 (6.1)	18.9 (6.0)	18.2 (6.9)	19.0 (6.2)	18.5 (6.0)	19.3 (6.6)	19.4 (6.1)	18.9 (6.0)
Model coefficients	\$									
Main effect of group	roup									
Intervention group	-0.57	1.17	0.41	-0.56	-0.44	-0.02	-1.1809	2.31	0.19	-0.53
Main effect of time	ime									
Baseline (reference)	rence)									
Follow-up 1	-0.16	7.66***	4.58***	2.66***	7.67***	4.32***	2.1175**	7.57***	4.61***	3.06***
Follow-up 2	1.03	8.72***	5.99***	3.97***	8.46***	5.70***	3.5930***	8.79***	6.23***	4.27***
Interaction effect of group and time	ct of group	and time								
Follow-up 1 intervention group	0.36	2.16	0.67	0.95	1.76	-0.07	0.1727	3.86	1.01	0.31
Follow-up 2 intervention group	1.28	1.94	2.15	1.96	96.0	1.28	1.0653	2.92	2.42	1.92

p < 0.01. p < 0.001. p < 0.001.

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interventions for family caregivers of patients with advanced cancer have demonstrated the potential to improve psychosocial health [29]. This highlights that engagement and outcomes are also influenced by factors beyond just the mode of delivery. Considering the diverse needs of family caregivers, interventions must be designed to offer flexibility in both delivery and content. A key advantage of web-based interventions is their accessibility, as they can be used whenever needed. This may partly explain the lower attrition in this study compared to prior in-person interventions in a similar context [17]. We anticipated a 30% attrition rate between baseline and first follow-up, but actual attrition was lower. Since participants could withdraw without stating a reason, the slightly higher attrition in the intervention group remains unexplained, though some may have felt uncomfortable with the web-based format.

It is reasonable to assume that the family caregivers with the lowest levels of preparedness at baseline were more likely to improve their preparedness levels. However, no intervention effect was observed. Instead, preparedness increased over time in both the intervention and control groups. These results should be interpreted with the understanding that preparedness is a process that evolves throughout the caregiving journey [2], as family caregivers have described how active caregiving contributes to their sense of preparedness [30]. Additionally, longer caregiving duration has been associated with higher levels of preparedness [31], suggesting that both caregiving experience and the passage of time can contribute to increased preparedness. Importantly, as many as 34.1% of family caregivers reported that they had either never or only occasionally participated in the physical care of the patient. Thus, preparedness for caregiving may not have been relevant for this group, which may have influenced the extent to which they perceived the need to prepare. Family caregivers who participate more frequently in patient care and support tend to gain greater caregiving experience and report higher levels of preparedness for caregiving [32]. The intervention's program theory anticipated that certain sequences of activities would promote preparedness. These activities rely on family caregivers to engage with the intervention and integrate it into their daily caregiving for change to occur. This may explain why some changes did not occur as expected. However, according to Andershed and Ternestedt's theory [19], preparedness for caregiving includes not only the provision of physical care (doing) but also knowing and being. Since this study focused primarily on participation in physical care, it may have provided an incomplete representation of caregiving, as it did not sufficiently reflect social and emotional aspects. Therefore, it may not have fully captured all the dimensions of caregiving that could have contributed to family caregivers' preparedness.

While the passage of time and caregiving experience may be important factors, other external factors triggered by study participation could have contributed to the observed increase in preparedness. One such factor is the completion of questionnaires on caregiving, which may have prompted self-reflection on preparedness and the caregiver role. Responding to questionnaires can evoke emotions but may also have a therapeutic effect by encouraging reflection [33]. This phenomenon, known as the mere-measurement or question-behavior effect, refers to a methodological bias in which responding to questionnaires

influences behavior [34]. Thus, the observed increase in preparedness in this study may be a result of this effect, impacting both the intervention and control groups. This warrants specific consideration, as most family caregivers in the present study cared for a patient who had lived with a life-threatening illness for over a year.

The results of this study reflect a pragmatic design, as family caregivers were free to engage with the intervention in a way that suited their individual preferences. Engagement and use were not monitored in real-time, instead, data were collected through a single self-reported question at follow-up. Consequently, assumptions about dose and fidelity cannot be made, as it remains unclear how much or which content family caregivers accessed. Pragmatic trials evaluate whether an intervention can be effective in real-world settings [35] and are particularly relevant in cancer care, where simple, affordable, and feasible interventions are needed across clinical settings [36]. A common challenge in pragmatic trials is maintaining intervention fidelity [35]. Web-based interventions for family caregivers are often pragmatic because they allow flexibility in adherence [37, 38], which in turn affects outcomes and effect sizes [35, 37, 38]. To enhance relevance and accessibility for family caregivers, this study adopted a strategy of offering free access without monitoring adherence. This pragmatic design allowed family caregivers to engage in the intervention according to their individual needs. Previous results showed that family caregivers could avoid emotionally challenging parts of the intervention while still participating in the study [22]. While this flexibility may not have optimized the overall results, it may have benefited some family caregivers on an individual level by allowing them to tailor the intervention to their specific process of preparedness.

#### 4.1 | Clinical Implications

These findings reinforce the understanding that family caregivers' preparedness for caregiving is an ongoing process that evolves over time. Solely web-based interventions may be insufficient to improve preparedness in a population as varied as family caregivers. Instead, web-based interventions should complement the support provided by healthcare professionals in clinical settings to offer tailored support to family caregivers. Clinically, this underscores the need to deliver digital support as an integrated part of, rather than in parallel with, clinical practice to ensure adherence while maintaining personalized care. These findings emphasize the importance of maintaining fidelity in web-based interventions without compromising flexibility.

#### 4.2 | Study Limitations

The web-based intervention design may have excluded family caregivers who were either uncomfortable with or lacked access to digital technology, potentially limiting inclusivity and, consequently, the external validity of the findings. Statistical power was calculated for a two-way repeated measures ANOVA, whereas linear mixed models were used in the present

study. The use of multiple subgroups may have resulted in insufficient statistical power, reducing the likelihood of detecting a significant effect and influencing the internal validity of the findings. The lack of fidelity monitoring during the trial may have affected the results. Moreover, in the questionnaires, the wording of the single-item question assessing family caregivers' active intervention use was suboptimal, limiting the conclusions that can be drawn from these responses.

## 5 | Conclusions

This randomized controlled trial found no significant effect of the intervention on preparedness for caregiving; however, a significant increase in preparedness was observed over time in both the intervention and control groups. This suggests that factors beyond the intervention may have contributed to this improvement. Limited engagement with the intervention may have contributed to the lack of a significant difference between the intervention and control groups. As family caregivers represent a diverse population, interventions targeting this group must be flexible to address their varying needs. Ensuring fidelity while maintaining flexibility can better support efforts to improve preparedness for caregiving. Future studies should evaluate the intervention "narstaende.se" when it is delivered with structure and guidance as part of clinical care. Interventions need to be flexible enough to meet individual needs while ensuring consistent delivery to maintain adherence, which remains a challenge.

#### **Author Contributions**

Cecilia Bauman: conceptualization, data curation, formal analysis, investigation, methodology, validation, visualization, writing – original draft, writing–review and editing. Kristofer Årestedt: conceptualization, formal analysis, methodology, validation, visualization, writing – original draft, writing – review and editing. Viktoria Wallin: data curation, investigation, project administration, validation, writing – review and editing. Louise Häger Tibell: validation, writing – review and editing. Peter Hudson: validation, writing – review and editing. Ulrika Kreicbergs: conceptualization, methodology, validation, writing – review and editing. Anette Alvariza: conceptualization, formal analysis, funding acquisition, investigation, methodology, project administration, supervision, validation, visualization, writing – original draft, writing – review and editing.

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## **Conflicts of Interest**

The authors declare no conflicts of interest.

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