

Short-term and long-term effects of a psycho-educational group intervention for family caregivers in palliative home care – results from a randomized control trial

Maja Holm^{1,2*}, Kristofer Årestedt³, Ida Carlander^{2,4}, Carl-Johan Fürst⁵, Yvonne Wengström^{1,6}, Joakim Öhlen^{2,7} and Anette Alvariza^{1,2,8}

¹Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

²Palliative Research Centre and Department of Health Care Sciences, Ersta Sköndal University College, Stockholm, Sweden

³Center for Collaborative Palliative Care, Linnaeus University, Kalmar, Sweden

⁴Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, Stockholm, Sweden

⁵Department of Clinical Science and the Institute for Palliative Care, Lund University, Lund, Sweden

⁶School of Health and Medical Sciences, Örebro University, Örebro, Sweden

⁷Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

⁸Capio Palliative care unit, Dalens Hospital, Stockholm, Sweden

*Correspondence to:

Palliative Research Centre, Ersta Sköndal University College, Folkungagatan 121, 100 89 Stockholm, Sweden. E-mail: maja.holm@esh.se

Abstract

Background: Family caregivers in cancer and palliative care often face heavy responsibilities and feel insufficiently prepared for the situation as caregivers. This study evaluates short-term and long-term effects of a psycho-educational group intervention aiming to increase preparedness for family caregiving in specialized palliative home care.

Methods: The study design was a randomized control trial where family caregivers were allocated either to an intervention or control group. The intervention was delivered as a program including three sessions by health professionals (physician, nurse, and social worker/priest). Family caregivers from 10 specialized palliative home care settings were included. Questionnaires with validated instruments at baseline, upon completion, and 2 months following the intervention were used to measure effects of the intervention. The primary outcome was preparedness for caregiving in family caregivers.

Results: In total, 21 intervention programs were delivered, and 119 family caregivers completed all three measurements. The intervention group had significantly increased their preparedness for caregiving in both the short-term and long-term follow-up compared with the control group. The intervention group also reported significantly increased competence for caregiving in short-term but not long. No effects of the intervention were found on rewards for caregiving, caregiver burden, health, anxiety, or depression.

Conclusions: The psycho-educational intervention has the potential to be used by health professionals to improve preparedness for caregiving among family caregivers in palliative care both in short and long terms.

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Background

Many patients with advanced cancer wish to stay at home throughout the illness trajectory [1,2], and this may impose considerable challenges and burden on family caregivers. In palliative care, the main approach is to improve the quality of life for patients, but also their families, when faced with problems related to advanced illness [3]. Family caregivers are fundamental in palliative home care [4] and could be defined as any friend, relative, or partner who provides care and support [5]. Despite the resources provided by healthcare professionals, family caregivers often have an overreaching responsibility for the patient's care, including medical and personal care and domestic chores [6]. Family caregivers often experience a lack of preparedness for the situation [7], which

is linked to negative effects such as anxiety and depression [8]. Preparedness for caregiving is defined as the perceived readiness of caregivers for multiple domains of the caregiving role, such as emotional and practical support and managing the stressors of caregiving [9]. Preparedness for caregiving is associated with positive experiences such as higher self-perceived hope and rewards of caregiving and less anxiety [8] and could counterbalance negative effects related to caregiving [10]. Promoting caregivers' experience of preparedness for caregiving has therefore been highlighted as an important outcome for intervention studies in palliative care [11].

Psycho-educational group interventions have demonstrated good effects on caregivers' preparedness for caregiving, but also on their competence in caregiving and its rewards [12,13]. Psycho-educational interventions

involve a structured program geared toward providing information about things such as the patient's disease process and related resources while training caregivers to respond appropriately to disease-related problems [14]. They also include supportive activities designed to use dialogues among participants to normalize experiences, give support, and increase connections between participants [15]. Despite the increasing amount of caregiver interventions, there is a lack of theoretically based interventions evaluated in studies with rigorous designs [16,17]. A theoretical framework with particular potential to design interventions aimed at family caregivers is the one of Andershed and Ternstedt, which focuses on the needs of family caregivers in palliative care [18]. Thus, their theory was the base for the development of an intervention. Hence, the aim of this study is to evaluate short-term and long-term effects of a psycho-educational group intervention for family caregivers in specialized palliative home care. The hypotheses are that family caregivers' preparedness for caregiving will increase (main outcome), that their competence and rewards in caregiving will increase, their self-perceived health be preserved, and their feelings of burden, anxiety, and depression decrease (secondary outcomes).

Method

Trial design

The overall research design is a randomized control trial (RCT) developed in accordance with the CONSORT statement [19] (Registered at <https://www.clinicaltrials.gov/> ID: NCT02482415). Family caregivers were allocated to take part in a psycho-educational intervention, or to a control group with standard support. Data were collected at baseline, upon completion of the intervention, and 2 months afterward.

Participants

Letters with study information were sent to 10 specialized palliative home care settings in a regional metropolitan catchment area in Sweden. All 10 settings agreed to participate. The catchment area covers about 2.2 million citizens, and each setting provided specialized palliative care to a range of 70–200 patients in their own home. The settings had a comprehensive responsibility for the patients' care and assisted with things such as symptom relief, emotional and spiritual support, and medical technical equipment and were all staffed 24 h a day by physicians and nurses. Other professionals included social workers, priests, and physical and occupational therapists. The settings mainly enrolled patients with cancer diseases referred from oncology clinics and sometimes undergoing palliative oncological treatment, but also patients affected by other diseases.

Patients were approached by health professionals at their care setting with a request for permission to invite their family caregiver to the study. Eligibility for patients was as follows: being in receipt of palliative home care with a limited life expectancy that was longer than 5 weeks to increase the chances of family caregivers to complete the intervention. The patients were not included in active data collection, but were asked to give their consent for certain information to be collected from medical records for the study (age, diagnosis, and time of care). If the patient consented, health professionals approached the family caregiver(s) with study information and a request to participate. Inclusion criteria for family caregivers were as follows: being family caregiver to a person in specialized palliative home care, over the age of 18 years, and able to read and understand Swedish. Recruitment took place between January 2013 and March 2014 with intervention delivery between February 2013 and April 2014.

The required power sample size was calculated for linear regression analyses based on the main outcome, the preparedness for caregiving scale [20]. The expected effect size was based on findings from a previous study [12], which found medium effects of a psycho-educational intervention. For the use of a regression model, the required sample was determined to be 55 to detect a medium effect on preparedness for caregiving ($f^2=0.15$, $\alpha=0.05$, $1-\beta=0.80$). As it was expected that each patient should be represented by two family caregivers on average, the required sample size was doubled to 110; 55 in each group.

The intervention

A detailed description of the intervention and a qualitative evaluation have been presented earlier and are therefore presented here in an abbreviated form [21]. The intervention was developed based on the theoretical framework of Andershed and Ternstedt [18] relating to the principal knowledge seeking and support needs of family caregivers. The framework describes family caregivers' involvement in palliative caregiving and focuses on knowing, being, and doing. Knowing is crucial for family caregivers and is connected with an awareness of the patient's serious condition and the caregiver role, knowing what to expect and what to do. Being is related to the management of the caregiver's own emotion as well as the patient's. Doing covers the practical aspects of caregiving and includes various activities. The overall aim of the intervention was to promote preparedness for caregiving (primary outcome) among family caregivers. The intervention program was delivered in a group format including three sessions, covering 2 h once a week over 3 weeks. The program was delivered by the health professionals at each of the palliative home care settings including a physician, nurse, and social worker/priest. It was offered in the afternoon after working

hours to make as many caregivers as possible able to attend. To ensure consistency, the content and structure followed a manual (available in appendix in the Supporting Information) based on the theoretical framework of the intervention. Topics included the following: palliative diagnoses and symptom relief, daily care and nutrition problems, and support and existential issues. The nurse also acted as group leader and participated in every session. Both the control and intervention group received standard support from their palliative settings throughout the patient's period of care, including practical and emotional support within the daily care of the patient and opportunities for individual support, such as supportive talks and information.

Outcomes

Family caregivers were requested to answer questionnaires at baseline, upon completion of the intervention, and 2 months afterwards. The questionnaires comprised self-rated instruments concerning family caregivers' preparedness, competence, reward, and burden in relation to caregiving, health, anxiety, and depression. Baseline questionnaires were distributed by health professionals to family caregivers who agreed to participate. These were returned in postage-paid envelopes to the researchers. For follow-up assessments, questionnaires were sent by mail. If the patient had died, the participants were not included in the analysis for this study because the primary outcome was related to ongoing caregiving.

Primary outcome

The Preparedness for Caregiving Scale is designed to measure caregivers' perceived readiness to provide care in real time [9,22]. It has demonstrated good reliability for caregivers in palliative care [22–24]. It consists of eight items answered on a 5-point Likert-type response scale ranging from 'not at all prepared' (0) to 'very well prepared' (4) with a total score ranging from 0 to 32. Cronbach's alpha was 0.94 in the present study.

Secondary outcomes

The Caregiver Competence Scale measures the adequacy of caregivers in real time and has been found reliable to use in palliative care [12,23–25]. The scale consists of four items on a 4-point Likert-type scale ranging from 'not at all competent' (0) to 'very competent' (3) with a total score ranging from 0 to 12. Cronbach's alpha was 0.90 for the study.

The Rewards of Caregiving Scale was developed to measure personal, self-rated rewards in caregivers [26] and has been found reliable to use in palliative care [23,24]. It consists of 10 items on a 5-point Likert-type scale. The score ranges from 'not rewarding at all' (0) to 'very rewarding' (4) with a total score ranging from 0 to 40 [26]. Cronbach's alpha for this study was 0.94.

The Caregiver Burden Scale was developed to measure burden in caregivers. It is a 22-item scale divided into five dimensions: general strain, isolation, disappointment, emotional involvement, and environment. The items are answered on a 4-point Likert-type scale, ranging from 'not at all' (1) to 'often' (4), where higher scores indicate greater caregiver burden. The item scores of each dimension are summed, and a mean value for each dimension is calculated with scores ranging from 1 to 4. [27]. Cronbach's alpha results were 0.87, 0.72, 0.72, 0.74, and 0.70 for the five dimensions, respectively.

The Health Index has been designed to measure self-perceived health. It consists of 11 items answered on a 4-point Likert-type scale ranging from 1 to 4 with a higher value indicating better health. The total score ranges from 11 to 44. [28]. Cronbach's alpha was 0.85 for this study.

The Hospital Anxiety and Depression Scale was developed to detect anxiety and depression [29,30]. It has previously been used with family caregivers in palliative care [12]. It includes two subscales with seven items for each scale: anxiety and depression. The items are answered on a 4-point Likert-type scale ranging from 0 to 3 with a higher value indicating higher levels of anxiety/depression [30]. For each subscale, the total score ranges from 0 to 21. Cronbach's alpha for the present study was 0.87 and 0.82 for the two subscales, respectively.

Randomization

Randomization was based on a random number sequence, using a computer randomized number generator, and stratified for the 10 home care settings. Randomized permuted blocks of four were used. Each questionnaire had a code number that was unique to the patient. When a family caregiver had completed the baseline questionnaire and returned it, the patient number was used to allocate the family caregiver to either intervention group or control group. When the patient had more than one family caregiver who wished to participate, they were nested to the patient, to ensure allocation to the same group.

Family caregivers were sent a letter by the researchers informing them whether they had been allocated to intervention or control. Those randomized to the intervention also received an invitation to the group sessions. Professionals were informed about allocation in order to prepare for the intervention.

Statistical analysis

Data validation was conducted before analysis, and one independent person manually verified the data file against all questionnaires. Missing items were replaced if they did not exceed 20% for each scale. In total, 52 missing items were replaced in the questionnaires using person mean imputation [31]. A sensitivity analysis on the unimputed

dataset showed that this procedure did not bias the findings. Statistical analysis was carried out using Stata version 13.1 (StataCorp LP, College Station, TX, USA). All tests were performed, assuming $p < 0.05$ to be statistically significant.

Baseline characteristics of the intervention and control group were compared using chi-squared tests for categorical variables and t -tests for continuous variables. Intraclass correlations (ICC) were calculated, using multilevel modeling, to evaluate if the assumption of independency was violated as some participants were nested to the same patient. The ICC deviated from zero for general strain ($icc=0.16$), isolation ($icc=0.29$), and self-perceived health ($icc=0.42$) for the short-term follow-up and preparedness ($icc=0.10$), general strain ($icc=0.42$), emotional involvement ($icc=0.82$), self-perceived health ($icc=0.76$), and anxiety ($icc=0.73$) for the long-term follow-up. As the assumption was violated for these outcome variables, we used linear regression analyses based on robust variance estimates for clustered data, that is, family caregivers of the same patient, to test the effects of the intervention. This technique relaxes the assumption of independence, and only standard errors are affected, not the estimated coefficients [32]. The difference between the baseline and follow-up scores was included as an outcome variable,

while the group scores (control group as a reference category) were included as predictor variables. Cohen's f^2 was calculated to assess the effect size with 0.02 considered a small effect size, 0.15 medium effect, and 0.35 large effect [33]. Analyses were undertaken based on per-protocol approach.

Ethical considerations

Family caregivers of patients in palliative home care could be considered a vulnerable group, and consequently, much attention was placed on ethical issues. Patients and family caregivers were informed that participation in the study was voluntary and that consent could be withdrawn at any time. Approval was granted from a regional ethical review board (2012/377-31, 2012/2191-32, 2013/934-32).

Results

Sample characteristics

A total of 270 family caregivers were included in the study at baseline, 122 allocated to control and 148 to intervention. Because of attritions, mostly due to the deterioration or death of the patient, the final baseline sample was 194 family caregivers, 96 in the control group and 98 in the intervention group (Figure 1). There were no

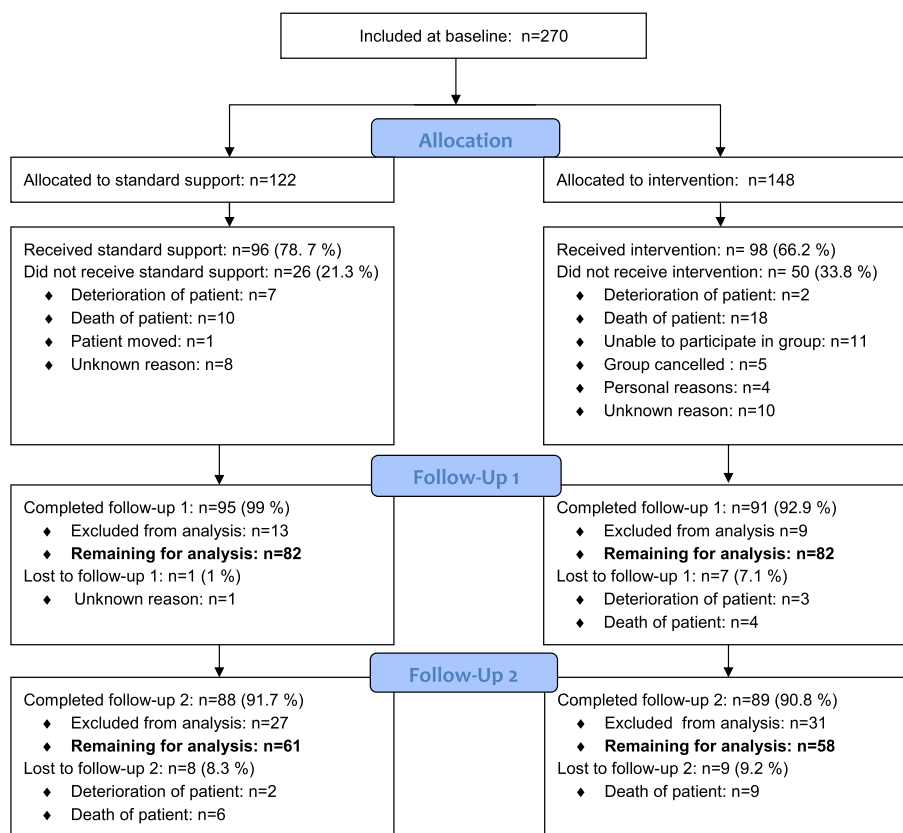


Figure 1. The trial process

significant differences found between the two groups at baseline (Table 1). Every setting delivered the intervention program one to four times before the trial ended according to plan. In total, 21 intervention programs were held. On average, the sessions consisted of four family caregivers. Seventy percent attended all three sessions, while 20% attended two, and 10% one session. One hundred and seventy-five patients were represented (15 patients represented by >1 caregiver), and 90% had a cancer diagnosis. The mean age for patients in the study was 72 years; 53% were women and had been enrolled at the palliative care setting for a median time of 4 months before the study.

Short-term effects

In the first follow-up, between February 2013 and April 2014, 186 family caregivers completed questionnaires

(return rate 95.9%). Of these, 22 were excluded because of the patient's death, because the primary outcome was preparedness for ongoing caregiving, with 164 family caregivers remaining (82 in control and 82 in intervention). The intervention group had significantly increased their preparedness for caregiving between baseline and the first follow-up, compared with the control group ($\beta=1.51$, $t(1)=2.06$, $p=0.041$, $f^2=0.02$). They had also significantly increased their competence for caregiving ($\beta=1.04$, $t(1)=3.24$, $p=0.001$, $f^2=0.06$). No significant effects were found on rewards for caregiving, caregiver burden, health, anxiety, or depression (Tables 2 and 3).

Long-term effects

In the second follow-up, between April 2013 and June 2014, 177 family caregivers completed questionnaires (return rate 91.2%) of which 58 were excluded because of the patient's death, resulting in a final sample of 119 (61 in control and 58 in intervention). The intervention group had significantly higher preparedness for caregiving than the control group ($\beta=2.25$, $t(1)=2.57$, $p=0.012$, $f^2=0.05$). No significant effects were found on competence or rewards for caregiving, caregiver burden, health, anxiety, or depression (Tables 2 and 3).

Discussion and conclusions

This relatively short psycho-educational intervention in palliative home care led to significant improvements in family caregivers' preparedness for caregiving both in short and long terms. This intervention also demonstrated a short-term effect on caregivers' perceived competence for caregiving. The effects demonstrated in the study were quite small. However, no reference in the literature to clinically meaningful differences for the Preparedness for Caregiving Scale has been found.

The results could be compared with a previous psycho-educational intervention study in palliative care, which was delivered in six sessions with a quasi-experimental design and had medium effects on preparedness, competence, and rewards for caregiving [12]. This could possibly be attributed to the longer duration of the intervention [14]. The fact that the effect on competence was not maintained at the second follow-up could perhaps also indicate that there would have been a need for the intervention to take place over a longer duration in order to provide a deeper knowledge for the changing phases of palliative care. However, the often limited care time in palliative care makes briefer interventions necessary [34], which is demonstrated in this study's large number of patient deaths. No negative effects of the intervention

Table 1. Participant characteristics

Baseline characteristics of family caregivers	Control (n = 96)	Intervention (n = 98)	p-value
Age, mean (SD)	60 (14.3)	63 (13.4)	0.225 ^a
Gender, n (%)			0.388 ^b
Women	61 (63.5)	68 (69.4)	
Men	35 (36.5)	30 (30.6)	
Social status, n (%)			0.127 ^b
Married/partnership	68 (70.8)	75 (76.5)	
Unmarried	28 (29.2)	23 (23.5)	
Employment, n (%)			0.612 ^b
Employed	44 (45.8)	40 (40.8)	
Retired	40 (41.7)	45 (45.9)	
Other	12 (12.5)	13 (13.3)	
Cohabit, n (%)			0.254 ^b
Yes	49 (51.0)	58 (59.2)	
No	47 (49.0)	40 (40.8)	
Relation to patient, n (%)			0.129 ^b
Spouse	40 (41.7)	54 (55.1)	
Adult child	35 (36.5)	32 (32.7)	
Other	21 (21.8)	12 (12.2)	
Education level, n (%)			0.829 ^b
University degree	46 (47.9)	41 (41.8)	
Other	50 (52.1)	57 (58.2)	
Outcome measurements at baseline, mean (SD)			
Preparedness	17.4 (6.9)	16.8 (6.4)	0.548 ^a
Competence	6.5 (3.1)	6.4 (2.7)	0.842 ^a
Rewards	28.6 (7.8)	28.0 (7.8)	0.605 ^a
Burden			
Strain	2.4 (0.7)	2.3 (0.7)	0.637 ^a
Isolation	2.4 (0.8)	2.4 (0.9)	0.846 ^a
Disappointment	2.1 (0.7)	2.1 (0.7)	0.703 ^a
Involvement	1.8 (0.7)	1.9 (0.7)	0.547 ^a
Environment	2.1 (0.7)	2.0 (0.7)	0.486 ^a
Health	33.6 (4.7)	34.1 (5.0)	0.499 ^a
Anxiety	7.6 (4.4)	8.0 (4.3)	0.578 ^a
Depression	5.3 (3.6)	5.2 (3.5)	0.852 ^a

SD, standard deviation.

^at-test.

^bChi-squared test.

Table 2. Mean ratings at baseline and follow-ups

Outcomes	Control			Intervention		
	Baseline (n = 96) mean (SD)	Follow-up 1 (n = 82) mean (SD)	Follow-up 2 (n = 61) mean (SD)	Baseline (n = 98) mean (SD)	Follow-up 1 (n = 82) mean (SD)	Follow-up 2 (n = 58) mean (SD)
Preparedness	17.4 (6.9)	16.9 (6.5)	16.9 (5.4)	16.8 (6.4)	18.4 (5.2)	17.9 (5.6)
Competence	6.5 (3.1)	5.8 (2.9)	6.2 (2.9)	6.4 (2.7)	6.8 (2.7)	6.5 (2.8)
Rewards	28.6 (7.8)	27.5 (7.7)	26.3 (8.5)	28.0 (7.8)	26.2 (8.0)	24.6 (9.1)
Burden						
Strain	2.4 (0.7)	2.5 (0.6)	2.5 (0.7)	2.3 (0.7)	2.5 (0.7)	2.6 (0.7)
Isolation	2.4 (0.8)	2.5 (0.8)	2.5 (0.9)	2.4 (0.9)	2.5 (0.9)	2.6 (0.9)
Disappointment	2.1 (0.7)	2.2 (0.6)	2.3 (0.7)	2.1 (0.7)	2.2 (0.7)	2.3 (0.7)
Involvement	1.8 (0.7)	1.9 (0.7)	1.9 (0.7)	1.9 (0.7)	1.9 (0.7)	1.9 (0.8)
Environment	2.1 (0.7)	2.2 (0.6)	2.2 (0.7)	2.0 (0.7)	2.0 (0.7)	2.1 (0.8)
Health	33.6 (4.7)	32.9 (4.8)	32.6 (4.6)	34.1 (5.0)	33.6 (5.1)	32.6 (5.7)
Anxiety	7.6 (4.4)	7.9 (4.0)	7.6 (4.1)	8.0 (4.3)	8.1 (4.4)	7.7 (5.0)
Depression	5.3 (3.6)	5.6 (3.7)	5.6 (3.9)	5.2 (3.5)	5.9 (4.2)	6.1 (4.5)

Table 3. Intervention effects based on simple linear regression analysis

Outcomes	Predictor	Follow-up 1 (n = 164)		Predictor	Follow-up 2 (n = 119)	
		Unstandardized B (SE)	p-value		Unstandardized B (SE)	p-value
Preparedness	Intervention	1.51 (0.7)	0.041	Intervention	2.25 (0.9)	0.012
Competence		1.04 (0.3)	0.001		0.51 (0.4)	0.194
Rewards		−0.03 (0.8)	0.968		0.30 (1.2)	0.805
Burden						
Strain		0.03 (0.1)	0.605		0.06 (0.1)	0.506
Isolation		0.04 (0.1)	0.605		−0.03 (0.1)	0.811
Disappointment		0.03 (0.1)	0.642		0.07 (0.1)	0.376
Involvement		−0.01 (0.1)	0.843		−0.05 (0.10)	0.621
Environment		−0.04 (0.1)	0.597		−0.01 (0.1)	0.819
Health		−0.04 (0.5)	0.933		−1.03 (0.7)	0.140
Anxiety		0.08 (0.4)	0.856		0.14 (0.6)	0.829
Depression		0.45 (0.44)	0.316		0.61 (0.6)	0.290

were found, although we failed to find any effects on rewards for caregiving, caregiver burden, health, anxiety, or depression. Baseline ratings show that family caregivers in the study generally reported low to moderate levels of burden, anxiety, and depression, and high levels of self-perceived health, giving small potential for improvements. There is a risk that more vulnerable caregivers might not participate in this type of intervention. It is important to consider what interventions directed at family caregivers can realistically accomplish [35], and it is possible that this kind of brief group intervention did not have potential to improve outcomes such as health, burden, and depression, indicating that they were too far-fetched in this study.

This RCT has several limitations. Because of an oversight, the trial was not registered until post-analysis. It was not blinded to the participants because it was delivered in the context of clinical care where blinding was not possible. The standard support offered to both the intervention and control group could vary between the palliative care settings and thus influence the result.

Attritions are a common problem in trials in palliative care because of the unpredictable illness trajectory and the vulnerability of family caregivers [36,37]. Reasons for attritions in this study were mainly due to patient deterioration or death. In addition, family caregivers were excluded if the patient had died or if they failed to receive the intervention, which makes the analysis per-protocol and not intention-to-treat based. This could have increased the risk of bias in the analysis. However, using the intention-to-treat approach could have created a risk of underestimating the effects of the intervention [38].

We suggest that the theoretical framework by Andershed and Ternstedt [18] is an appropriate theory on which to build interventions focused on promoting preparedness. It could be argued that the primary outcome measurement, the preparedness for caregiving scale, encompasses the three concepts of knowing, being, and doing because the items refer to both practical and mental preparedness as well as dealing with emotional stress related to caregiving. The intervention manual has an educational approach, based on knowing, which could

improve caregivers' doing (how to provide care) and being (manage the stressors of caregiving) and thereby promoting their preparedness for caregiving.

Strengths of the study include the RCT design, indicating a high standard of evidence. The fact that it was delivered in 10 different settings adds to the strength and makes it plausible to assume that the results could also be generalized to other palliative care settings. The intervention was delivered using an intervention manual [18], which facilitates implementation in other settings. It could be used internationally, although with some societal adaptations. Intervention studies with randomized designs [39] based in theory have previously been found lacking in palliative care [40]. Although the intervention is complex, incorporating several different components, its delivery is simple and demands few resources. The group design and

the short duration make it possible for professionals to support many family caregivers simultaneously over a short period.

In conclusion, the results from this RCT show that a relatively short psycho-educational intervention for family caregivers led to a small, but significant, increase in their preparedness for caregiving, both in short and long terms. Therefore, the intervention has the potential to be used by professionals in palliative care settings to support family caregivers.

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