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Characteristics of family caregivers who did not benefit from a successful psycho-educational group intervention during palliative cancer care: a prospective correlational study

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Conflict of interest

The authors have no conflicts of interest to disclose

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Abstract

Background: Although there has been a steady increase in intervention studies aimed towards supporting family caregivers in palliative cancer care, they often report modest effect sizes and there is a lack of knowledge about possible barriers to intervention effectiveness.

Objective: To explore the characteristics of family caregivers who did not benefit from a successful psycho-educational group intervention compared to those who did.

Intervention/Methods: A psycho-educational intervention for family caregivers was delivered at 10 palliative settings in Sweden. Questionnaires were used to collect data at baseline and following the intervention. The preparedness for caregiving scale (PCS) was the main outcome for the study and was used to decide whether or not the family caregiver had benefited from the intervention (PCS difference score ≤ 0 vs ≥ 1).

Results: 82 family caregivers completed the intervention and follow up. Caregivers who did not benefit from the intervention had significantly higher ratings of their preparedness and competence for caregiving and their health at baseline compared to the group who benefited. They also experienced lower levels of environmental burden and a trend towards fewer symptoms of depression.

Conclusions: Family caregivers who did not benefit from the intervention tended to be less vulnerable at baseline. Hence, the potential to improve their ratings was smaller than for the group who did benefit.

Implications for practice: Determining family caregivers in cancer and palliative care who are more likely to benefit from an intervention needs to be explored further in research.

Background

There has been an increasing focus on interventions directed at family caregivers in palliative cancer care as they often assume the role as primary caregiver and have the need for both information and practical support.^{1,2} A growing number of intervention studies aiming to improve family caregiver outcomes in cancer and palliative care have been identified³ and there has not only been an increase in quantity, but also in quality, with more studies identified with a higher grade of evidence.⁴

However, research regarding the most effective ways to provide support for family caregivers is still in its infancy.⁴ Interventions directed at family caregivers in cancer and palliative care have typically demonstrated modest effects while sample sizes have been small with high levels of attrition and thus the generalizability of the results has been limited.⁵⁻⁷ There is also a lack of consensus regarding which outcome measures should be applied³ as well as a lack of rigorous interventions based in theoretical and conceptual work.⁵ A randomized psycho-educational group intervention in palliative home care based on the theories of Andershed and Ternstedt⁸ had significant positive effects on family caregivers' feelings of preparedness for caregiving.⁹ Preparedness for caregiving has been defined as the perceived readiness to provide emotional and practical support and to manage the stressors of caregiving.¹⁰ Preparedness is associated with higher self-perceived health and rewards of caregiving and less anxiety,¹¹ burden and depression.¹² That intervention study had sufficient sample power and included validated statistical outcome measurements.⁹ However, the effect sizes on preparedness were also quite modest, indicating that all participants might not have benefited from the intervention. Increasing knowledge about barriers to intervention effectiveness could be an important factor in the development of new tailored interventions in palliative cancer care.¹³ Hence, there is a need to focus on caregivers who benefit from an

intervention and on those who do not. Therefore, the aim of this study was to explore the characteristics of family caregivers who did not improve their preparedness for caregiving by participating in a psycho-educational intervention in palliative cancer care compared to those who did.

Method

Design and setting

This study used a prospective correlational design and data from a previously conducted psycho-educational intervention study. The intervention was delivered at 10 different specialized palliative home care settings in a regional metropolitan area in Sweden which had between 70 and 200 patients enrolled. A majority of the patients were in different stages of an advanced cancer trajectory and were cared for in their own homes with health professionals making regular visits. Patients often had various and complex needs, including advanced symptom management, palliative oncological treatments and existential and practical support. The study settings mainly enrolled patients with various cancer diagnoses, but also patients with coronary and pulmonary diseases. Health professionals at the settings included physicians, nurses, social workers, priests and occupational and physical therapists.

The intervention was delivered as a randomized controlled trial with two arms at each of the 10 settings where family caregivers within each setting were randomized either to the intervention or to a control arm with standard support. The trial took place over fifteen months in 2013 and 2014. Each of the 10 settings participating in the trial delivered the intervention between 1-4 times and in total, 21 intervention programs were held. On average, 4 family caregivers participated in the intervention sessions. Questionnaires encompassing socio-demographic questions and statistical instruments were used to collect data at baseline

and upon completion of the intervention. Ethical approval was granted by the regional ethical review board.

Intervention description

The intervention has been thoroughly described previously¹⁴ and has a psycho-educational design, including both supportive and educative components; the primary aim is to improve preparedness for caregiving. The intervention was developed based on the theoretical framework of Andershed and Ternstedt⁸ that conceptualizes the involvement and principal needs of family caregivers in palliative care to be *knowing*, *being* and *doing*. *Knowing* represents the family caregiver's need for information about things such as the patient's condition, symptoms and prognosis. *Knowing* could also be viewed as a prerequisite for *being* and *doing*. *Being* concerns the family caregiver's emotional needs; how to manage his or her own feelings as well as the patient's feelings. *Doing* has a practical dimension and involves the things the family caregiver needs to do for the patient, such as helping with medications and practical nursing care. The intervention is delivered as a program in group format by health professionals (nurse, physician and social worker/priest) at the palliative care setting where the patient is enrolled. The program entails three sessions which are planned to last two hours. Each session starts with coffee/tea and snacks being served, followed by a presentation of topics from an intervention manual by health professionals. The manual has been jointly developed by health professionals and researchers and consists of a compendium of evidence-based knowledge including topics focusing on the informational (*knowing*), emotional (*being*) and practical (*doing*) needs of family caregivers. Apart from the presentation, the sessions also include discussions and reflections about the topics between the family caregivers and health professionals and a short relaxing exercise. The intervention has an approach that is based on information and education (*knowing*). Through increased

knowing family caregivers could become better prepared to manage practical caregiving (*doing*) and their own emotions as well as the patient's emotions in the situation (*being*). Throughout the intervention delivery, a nurse acts as group leader (Table 1).

Sample and procedure

Inclusion criteria for family caregivers were: being a family caregiver to a person in specialized palliative home care, over the age of 18 and able to understand Swedish. Patients and family caregivers were approached by health professionals at the settings with an invitation to the study. The patient was asked to give his/her permission to include the family caregiver(s) in the study and consent to some information being collected from patient records. If this was granted, the family caregiver was invited and asked to complete a baseline questionnaire. In total, 270 family caregivers accepted to participate. Each questionnaire had an ID number linked to the patient and was used to randomize family caregivers to one of the two arms; intervention or control. If the patient had more than one family caregiver who wished to participate, they were given questionnaires with the same ID number, to ensure allocation to the same arm. The allocation of family caregivers was made with the use of a random number sequence which had been generated through a computer program with the help of an independent statistician and stratified for each of the 10 palliative care settings. The number sequence included randomized permuted blocks of four.

148 family caregivers were randomised to the intervention arm and 122 to the control arm. No significant differences were found between these two groups at baseline. Because focus was on the characteristics of family caregivers who participated in the intervention, the control arm was excluded from this study. In total 89 family caregivers completed their participation in the intervention and measurements at baseline and upon completion. Because

the primary outcome was related to preparedness for ongoing caregiving, caregivers of patients who had died before the follow-up had to be excluded, leaving 82 family caregivers as the final sample for this study (Figure). Even though the trial design allowed family caregivers of the same patient to participate, it was decided not to use nested data for the analysis because very few patients were represented by more than one family caregiver (n=6) and hence it was considered that this would not influence the results.

The questionnaires

The questionnaires included socio-demographic questions and self-reported instruments. The variables for this study were chosen on the basis of being considered important for whether or not the family caregiver had benefited from the intervention. The socio-demographic questions included the caregiver's age, sex, marital and financial status, education, occupation, morbidity and relation to the patient. Data were also gathered from patient records regarding patient diagnosis, years since diagnosis and time in palliative care.

The Preparedness for Caregiving Scale (PCS) was the primary outcome for the intervention. It measures perceived readiness for various domains of caregiving^{10,15,16} on a five-point Likert-type scale ranging from 'not at all prepared' (0) to 'very well prepared' (4) with a total score ranging from 0-32.

The Caregiver Competence Scale (CCS) measures competence/knowledge for caregiving.^{15,17} It consists of four items on a four-point Likert-type scale ranging from 'not at all competent' (0) to 'very competent' (3) with a total score ranging from 0-12.

A modified version of the Rewards for Caregiving Scale (RCS) was used to measure personal rewards for caregiving.^{15,18} It consists of 10 items on a five-point Likert-type scale. The score ranges from ‘not rewarding at all’ (0) to ‘very rewarding’ (4) with a total score ranging from 0-40.

The Caregiver Burden Scale (CBS) measures burden in caregiving.¹⁹ It consists of five subscales; general strain, isolation, disappointment, emotional involvement and environment. The 22 items are answered on a four-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 1-4.

The Health Index (HI) was used to measure self-perceived health.²⁰ It consists of 11 items answered on a four-point Likert-type scale ranging from 1-4 with a higher value indicating better health. The total score ranges from 11-44. For this study, HI was measured both as a total score but also with two single items asking about family caregivers’ health in the last week and their overall health.

The Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and symptoms of depression in family caregivers through two subscales.^{21,22} The seven items of each subscale are answered on a four-point Likert-type scale ranging from 0-3 with a higher value indicating higher levels of anxiety/depression respectively. For each subscale, the total score ranges from 0-21.

The Multiple Scale of Perceived Social Support (MSPSS) measures social support.²³ It consists of 12 items ranging from 1-7 where higher values indicate a higher perceived social support. It includes three subscales: family, friends and significant others. The subscales have a total score of between 4 and 28 each.

Analysis

Analysis for this study was undertaken by using data from the intervention group. To identify family caregivers who did and did not increase their preparedness for caregiving by participating in the intervention, difference scores of the PCS were calculated between baseline and follow-up. If the difference was 0 or below, the family caregivers were considered not to have benefited from the intervention. If the difference was 1 or above, they were considered to have benefited from the intervention. These two groups are hereafter referred to as the non-benefit group and the benefit group.

Different statistical methods were used, depending on the level and distribution of data. The characteristics between the non-benefit and benefit groups were compared using baseline data. Chi-squared tests were used for categorical socio-demographic variables (sex, marital status, education, occupation, and illness) and unpaired *t*-tests for continuous variables (age, years since patient diagnosis). If the expected values of contingency cells were below 5, the Fisher's exact test was applied for categorical variables (relation to patient, financial status, patient diagnosis and time in palliative care). For continuous self-reported instruments, the non-parametric Mann-Whitney U-test was used (PCS, CCS, RCS, CBS, HI, HADS, MSPSS) as most of them were skewed and it could be argued that they could be classified as either numerical or ordinal data. The statistical significance level was set at $p < .05$, while $p < .1$ was

set as a considerable trend towards significance. All statistical analyses were carried out using the STATA version 13.1 for Windows (Stata Corp LP, College Station TX, USA).

Results

Sample characteristics

Of the 82 family caregivers included in this study, 26 (32%) were men and 56 (68%) were women. They had a mean age of 62 years and 90 % cared for a patient with a cancer diagnosis. A majority of the family caregivers were spouses or partners (59%) of the patient and lived in the same home (64%) (Table 2). Calculations of differences between baseline and follow-up measurements revealed that 45 (55%) had improved their ratings in the PCS by participating in the intervention (benefit group), while 37 (45%) had not (non-benefit group).

Differences in characteristics between benefit and non-benefit group

No significant differences were found in socio-demographic variables such as the family caregiver's age, sex, marital and financial status, education, morbidity and relation to the patient between the benefit and non-benefit groups, or in variables such as the patient's diagnosis or amount of time in palliative care. However, there was a considerable trend towards significance, indicating that family caregivers who did not work (retired, unemployed, on sick-leave) were more likely not to benefit from the intervention compared to those who were working or studying ($p=.058$) (Table 3).

At baseline, family caregivers in the non-benefit group had significantly higher levels in the PCS ($p<.001$) and CCS ($p=.003$) compared to the benefit group. They had also significantly higher levels in the HI scale, both in the total score ($p=.039$) and in the single item about overall health ($p=.030$). They had significantly lower ratings of their CBS-environment

($p=.048$) while a considerable trend towards significance was found for lower ratings in the HADS-symptoms of depression ($p=.098$). We found no differences between the groups with regards to their rating of the RCS, the remaining CBS subscales, HADS-anxiety, HI-last week or any of the MSPSS subscales (Table 4).

Discussion

This is, to the authors' knowledge, the first study investigating the characteristics of family caregivers who did not benefit from a psycho-educational intervention during palliative cancer care compared to those who did by looking at the differences in their baseline ratings.

The major finding of this study was that family caregivers who did not benefit from the intervention generally scored “better” in the self-rated instruments at baseline. In several of the scores, there were either significant differences or a considerable trend towards significance between the groups with the non-benefit group scoring “better” in instruments measuring things such as preparedness, competence, health, environmental burden and symptoms of depression. These results could indicate that because the non-benefit group was less vulnerable at baseline it might have been difficult to improve their scores compared to the benefit group. It has also been found that the PCS may not have the ability to capture changes in family caregivers with very high or very low scores.¹⁶ Previous research has found that well-adapted family caregivers are more likely to be included in research studies in cancer and palliative care, which could affect the outcome of interventions and reduce potential effects.^{5,24} Therefore, a way to enhance effect sizes could be to focus interventions on more vulnerable family caregivers.^{25,26}

Screening instruments have been developed to identify the supportive and educative needs of family caregivers in cancer and palliative care^{27,28} and these could be used to target family caregivers in special need of an intervention. The primary outcome for this intervention was preparedness for caregiving and the PCS could also be used as a possible screening instrument. Preparedness for caregiving has been suggested as something that could moderate negative aspects of family caregiving and promote supportive factors.^{11,12} Hence, it could be important to identify low-scorers of the instrument who might benefit from an intervention aiming to promote preparedness for caregiving. Because resources in clinical practice are often limited, it has also been suggested that the health professional support mainly should target family caregivers who are in most need of it.²⁹

However, it is difficult to recommend screening based only on these results, because it is unknown how the preparedness for caregiving in the non-benefit group would have developed if they had not taken part in the intervention. Preparedness for caregiving has previously been described as an ongoing movement with fluctuating needs,³⁰ indicating that it should be measured continuously. It is also possible that the non-benefit-group would have benefited more from other kinds of support or could have benefited from the intervention in other ways than how was measured in this study. Qualitative studies of group interventions in cancer and palliative care have shown that one of the main rewards was meeting other family caregivers and creating a basis for future networking^{14,31,32}, something that was not studied in this paper.

It is noteworthy that no significant differences in socio-demographic characteristics of family caregivers were found between the non-benefit group and the benefit group. It could be considered a strength of this intervention that its potential benefits to family caregivers were

not depending on variables such as their age or sex which has previously been found influential to intervention results.²⁵ Earlier research has indicated that the wellbeing of family caregivers are influenced by a diversity of variables such as their relationship to the patient³³ and the patient's condition,³⁴ however, in this study it could not be pinpointed that these variables influenced the results of the intervention on their own.

Limitations

This study has several limitations which should be considered in relation to the results presented. The sample was limited and power analysis was not calculated as only family caregivers who had completed the intervention and the questionnaires were included. Because this could increase the risk of Type II errors, the decision was made to describe the variables that showed trends towards significance ($p < .1$). However, these results should be interpreted with caution. Another limitation of the study is that there is no data on family caregivers who refused to participate in the intervention study. It would have been valuable to investigate the characteristics of this group in comparison to the two groups in the study especially with regards to perceived vulnerability. The division between the non-benefit and benefit group (PCS difference score ≤ 0 vs ≥ 1) represents another potential weakness of the study. This difference was not based on stated guidelines, because it could not be found in the literature. Therefore, the use of this measurement should be considered tentatively.

Conclusion

It is difficult to draw conclusions from this prospective-correlational study of a psycho-educational intervention aiming to promote preparedness for caregiving during palliative home care. Many different variables probably work together to influence family caregivers' benefit or non-benefit of an intervention. However, the results indicate that family caregivers

who did not benefit from the intervention were less vulnerable than the benefit group at baseline and that they might have been in less need of the intervention. Intervention trials in palliative and cancer care often report modest effect sizes and this study could provide knowledge about the sampling of family caregivers in order to promote greater effects. However, it is still possible that the non-benefit group benefited from the intervention in other ways than how it was measured.

Clinical and research implications

The results of this study provide insights that point towards a possible need for health professionals to target and invite vulnerable family caregivers in palliative cancer care to psycho-educational interventions because they might benefit more from them. Considering the often limited resources in clinical practice, it could be reasonable to focus interventions on family caregivers who would be expected to need them most. However, it is still necessary to develop further knowledge before stating such clinical implications. To capture an overreaching image of family caregivers who do and do not benefit from an intervention in palliative cancer care, it might be necessary to adapt multi-faceted research strategies, including qualitative and quantitative methods.

The trial has been registered at www.clinicaltrials.gov; ID: NCT02482415.

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Table 1: The data collection and intervention process

Table 2: Family caregiver characteristics at baseline

Table 3: Differences in socio-demographic variables between non benefit/benefit group

Table 4: Differences in self-reported instruments at baseline between non benefit/ benefit group

Figure: Inclusion in the study

Table 1. The Data Collection and Intervention Process

Baseline Questionnaire - Before Intervention Start				
Time Frame of The Intervention	Session Number	Health Professionals	Main Topic	Examples of Content
3 weeks	Session 1	Group leader (nurse) + physician	Palliative care and symptom management.	<ul style="list-style-type: none"> • Palliative care philosophy • Common patient symptoms such as pain, nausea and anxiety and their management • The very last phase of life, how the body changes and the process of preparing for death
	Session 2	Group leader (nurse)	Daily life and practical nursing care	<ul style="list-style-type: none"> • Being a family caregiver; changing roles and relations • Nutritional problems such as lack of appetite, constipation and xerostomia; explanations and management • Helping with personal and intimate care; how to manage practical and emotional aspects
	Session 3	Group leader (nurse) + social worker or priest	Emotional reactions and grief	<ul style="list-style-type: none"> • Grief reactions and the individual variations • Coping, hope and resilience • Perspectives on death and dying in the modern developed world • Support systems in society
Follow-Up Questionnaire - Upon Completion of The Intervention				

Table 2. Family Caregiver Characteristics at Baseline

Characteristics	Family Caregivers (n=82)
Caregiver age Mean (SD)	62.2 (12.9)
Sex n (%)	
Male	26 (32)
Female	56 (68)
Education n (%)	
University degree	35 (43)
Below university	46 (57)
Marital status n (%)	
Married/cohabiting	65 (79)
Unmarried	17 (21)
Relation to patient n (%)	
Spouse/partner	48 (59)
Parent	24 (29)
Other	10 (12)
Living with patient n (%)	
Yes	52 (63)
No	30 (37)
Occupation n (%)	
Working/studying	36 (44)
Not working/retired	46 (56)
Financial situation n (%)	
Good/very good	72 (89)
Bad/very bad	9 (11)
Presence of mental/physical illness in caregiver n (%)	
Yes	45 (55)
No	37 (45)

Patient diagnosis n (%)	
Cancer diagnosis	74 (90)
Other diagnosis	8 (10)
Instrument ratings Mean (SD)	
Preparedness for caregiving	17.05 (6.77)
Competence for caregiving	6.41 (2.85)
Rewards for caregiving	27.58 (8.20)
Caregiver Burden -general strain	2.35 (0.70)
Caregiver Burden-disappointment	2.12 (0.68)
Caregiver Burden-isolation	2.43 (0.90)
Caregiver Burden-emotional involvement	1.85 (0.69)
Caregiver Burden-environment	1.99 (0.72)
Health Index – total score	34.29 (5.28)
Health Index – general	3.29 (0.58)
Health Index – last week	3.23 (0.67)
Anxiety	7.85 (4.44)
Depression	5.19 (3.53)
Social support – family	22.10 (5.93)
Social support – friends	20.99 (6.01)
Social support – significant others	22.48 (6.11)

Abbreviations: SD, standard deviation

Table 3. Differences in Socio-Demographic Variables Between Non-benefit/Benefit Group

Socio-demographic Variables	Non-benefit (n=37)	Benefit (n=45)	P-value
Caregiver age Mean (SD)	64.76 (10.63)	60.10 (14.25)	.1014 ^a
Sex n (%)			.545 ^b
Male	13 (35)	13 (29)	
Female	24 (65)	32 (71)	
Education n (%)			.913 ^b
University degree	16 (43)	20 (44)	
Below university	21 (57)	25 (56)	
Marital status n (%)			.360 ^b
Married/cohabiting	31 (84)	34 (76)	
Unmarried	6 (16)	11 (24)	
Relation to patient n (%)			1.000 ^c
Spouse/partner	22 (59)	26 (58)	
Parent	11 (30)	13 (29)	
Other	4 (11)	6 (13)	
Living with patient n (%)			.831 ^b
Yes	23 (62)	29 (64)	
No	14 (38)	16 (36)	
Occupation n (%)			.058 ^b
Working/studying	12 (32)	24 (53)	
Not working/retired	25 (68)	21 (47)	
Financial situation n (%)			.724 ^c
Good/very good	33 (92)	39 (87)	
Bad/very bad	3 (8)	6 (13)	
Presence of mental/physical illness in caregiver n (%)			.450 ^b
Yes	15 (41)	23 (51)	
No	22 (59)	22 (49)	

Patient diagnosis n (%)			.132 ^c
Cancer diagnosis	31 (84)	43 (96)	
Other diagnosis	6 (16)	2 (4)	
Patient time in palliative care n (%)			.230 ^c
<3 months	14 (38)	16 (35)	
3-6 months	9 (24)	13 (29)	
6 months-1 year	12 (32)	8 (18)	
>1 year	2 (5)	8 (18)	
Years since patient diagnosis Mean (SD)	4 (4.55)	5 (5.64)	.1984 ^a

Abbreviations: SD, standard deviation

a: t-test

b: x2-test

c: Fisher's exact test

Table 4. Differences in Self-Reported Instruments at Baseline Between Non-benefit/ Benefit Group

Variable	Non-benefit Md q1-q3	Benefit Md q1-q3	Z-value	P-value
Preparedness for caregiving	22 (16–24)	14 (10–18)	4.856	<.001
Competence for caregiving	8 (6–9)	6 (4–8)	2.950	.003
Rewards for caregiving	28 (21–33)	28.5 (22–35.5)	-1.000	.281
Caregiver Burden – general strain	2.5 (1.6–3.1)	2.38 (2–2.8)	0.779	.391
Caregiver Burden – disappointment	2 (1.4–2.6)	2.2 (1.8–2.6)	-0.362	.758
Caregiver Burden – isolation	2.33 (1.7–3)	2.67 (1.7–3)	-0.243	.903
Caregiver Burden – emotional involvement	1.67 (1–2.7)	1.67 (1.3–2.3)	-0.034	.959
Caregiver Burden – environment	1.67 (1.3–2.3)	2 (1.7–2.7)	-1.930	.048
Health Index – total score	36 (34–39)	34 (31–37)	2.063	.045
Health Index – general	4 (3–4)	3 (3–3)	2.177	.026
Health Index – last week	3 (3–4)	3 (3–4)	1.062	.349
Anxiety	6 (5–8.5)	9 (5–10)	-1.651	.146
Depression	4 (2–6.5)	6 (3–7)	-1.714	.098
Social support – family	25 (20–28)	23.5 (19–26)	1.175	.190
Social support – friends	23 (18–26)	21 (16–25)	0.643	.432
Social support – significant others	25 (22–28)	24 (18–28)	0.240	.704

Abbreviations: Md, median q1, quartile 1, q3, quartile 3

Figure. Inclusion in the study

