

Effectiveness of symptom management training on caregiving preparedness and burden of family caregivers in-home palliative care: a quasi-experimental study

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ABSTRACT

Introduction: Family caregiving preparedness remains a problem, particularly for those who live in rural areas. Such conditions can cause a high burden for the family caregivers. The purpose of this study was to determine the effectiveness of providing home-based palliative care training for family caregivers (HBPC-FC) on caregiving preparedness and burden.

Methods: This was a quasi-experimental study using a pre-post-test with the control group. There were 50 family caregivers (n=25 in the intervention group, n=25 in the control group) involved. The preparedness for caregiving was measured using the Caregiving Inventory (CGI) and the burden was measured using Caregiving Burden Scale questionnaires.

Results: After four weeks of the HBPC-FC program, caregiving preparedness improved significantly in the intervention group. Statistically significant differences in caregiving burden were also found between-group where caregiving burden in the intervention group decreased significantly ($p < 0.05$). The HBPC-FC program had positive outcomes for family caregivers.

Conclusions: Home-based palliative care training on symptom management could be utilized as a form to improve family caregivers' readiness in providing care for patients at home.

Keywords: caregiving preparedness; caregiving burden; family caregiver; symptom management; training program

Introduction

Providing care to patients with palliative care is a complex process involving not just one family member but the whole family. Therefore, in palliative care, a family-oriented approach is an integral part, as demonstrated by the WHO definition of palliative care (WHO, 2010). The family has an important role in the palliative care setting. Family caregivers are individuals who provide physical, psychological, and psychosocial support as well as support related to health management (Hudson et al., 2012). The family caregivers can have direct kinship or friendship. In

general, family caregivers could be the spouse, child, or parents of the patients (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016).

The majority of patients with palliative care needs prefer to care at home throughout their illness trajectory (Wu, Huang, & Tsao, 2020). Most patients with palliative care needs suffer from more than one physical symptom such as pain, fatigue, and dyspnea (Pidgeon et al., 2016; Rojas-Concha, Hansen, Petersen, & Groenvold, 2020). In addition to physical symptoms, the patients also often experience psychological and



spiritual problems that require more support from their immediate family caregivers in addition to physical symptoms. Such situations may create anxiety, challenges, and burden for family caregivers and Kristanti, Effendy, Utarini, Vernooij-Dassen, and Engels (2019) authors found that family members of patients with life-limiting illnesses such as cancer and dementia stated that they feel confused about how to manage patients' symptoms and their anxiety related to the quality of their care. Grant et al. (2013) stated that the burden experienced by family members who care for patients at home is defined as a problem, difficulty, or detrimental impact. Such a situation will affect the quality of the family's life to carry out its activities so interventions such as education in the family are needed (Grant et al., 2013).

Caring for a sick family member at home can be a challenge for families as most do not have a health education background. Caregivers' preparedness is important to minimize the impact of caregiving (Williams, 2018). Inadequate training across illness trajectory, particularly cancer, is associated with lower self-efficacy and a higher burden in caregiving (Gutierrez-Baena & Romero-Grimaldi, 2022; Havyer, van Ryn, Wilson, & Griffin, 2017). Family caregivers, particularly in rural areas, reported unmet support needs, particularly informational (Brazil, Kaasalainen, Williams, & Dumont, 2014).

Indonesia is a developing country, with 45.3% of the population living in rural areas (Central Bureau of Statistics (BPS), 2020). Caring for a sick family member is seen as an obligation in Indonesian culture (Effendy et al., 2014; Rochmawati, Wiechula, & Cameron, 2016). Study identifies that caregiver preparedness, particularly in rural areas, is still lacking (Rochmawati & Pawitasari, 2021). While there is a national program for patients with chronic illness particularly hypertension and diabetes mellitus. Primary Health Care does not have a specific program to improve family readiness in providing home care for people with a life-limiting illness. In addition, a literature search related to training for families caring for patients with palliative care needs only found two studies. The one identified the need for families who care for HIV / AIDS patients to get an education at home (Ibrahim, Haroen, & Pinxten, 2011) while the other focused more on providing training for caregivers in addressing patients' basic needs (Kristanti et al., 2017). Further, study found that the provision of training improved caregivers' quality of life (Kristanti et al., 2017). From the available literature, it is not clear whether there is an HBP C-FC program to improve

readiness in caregiving among family caregivers in rural areas in Indonesia.

This study was guided by the framework of family involvement in palliative care that was developed by Andershed and Ternstedt (2001). The framework considers the family as the unit of care. This conceptualizes five assumptions in terms of relatives' involvement in palliative care. First, the concept is 'to know,' a crucial part of involvement as it is considered to be both a part of the prerequisite for involvement and also a part of family involvement. In this concept, the family caregivers get 'to know' by either being informed or actively seeking any information by themselves. Family caregivers who had adequate resources would have confidence.

Second, the involvement was affected by the length of the illness. Andershed and Ternstedt (2001) argued that family caregivers' involvement could be promoted; adequate resources and a humanistic attitude of healthcare professionals could promote involvement and make meaningful involvement. The third assumption focused on negative factors that could affect the involvement. Several factors such as inadequate resources, lack of communication, and a negative attitude could reduce family caregivers' confidence in their daily lives.

The fourth assumption indicated the importance of healthcare professionals' attitudes in addition to respect in relative involvement. Support from healthcare professionals could help the relatives get 'to know' and attain information so that the caring situation becomes more manageable. Fifth, a 'partnership' is the highest level of involvement. This should improve healthcare professionals' chances to support relatives in the way they choose. In our study, the assumption of 'to know' is defined as training to be given to the family caregivers to improve their readiness and could also lead to reducing their burden in caregiving.

In the study, we followed the caregiving preparedness framework from Andershed and Ternstedt (2001) which encompasses three concepts of knowing, being, and doing. We applied an educational approach that could increase caregivers' knowledge (knowing), on knowing, ability in providing care (doing), and managing stressors of caregiving (being). Teaching areas to enhance family caregivers' skills included self-care, basic needs, pain, and symptom management, and spiritual support. This is based on a previous study conducted in a rural area in Canada that identified the most prevalent needs were caring for the patient's pain,

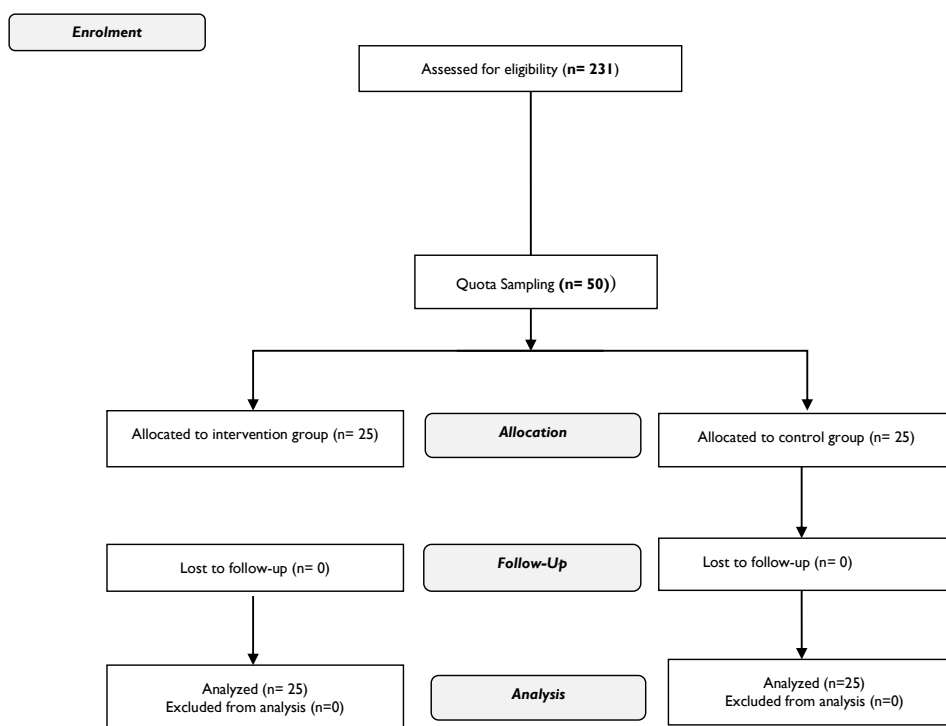


Figure 1 The flow diagram of the study

fatigue, body, and nourishment, and caregivers' personal needs (Robinson, et al., [2012](#)).

The existing literature emphasizes the importance of educational preparation for family members (Borneman et al., [2011](#); Ibrahim et al., [2011](#)). In addition, a framework developed by Andershed and Ternstedt ([2001](#)) proposes that interventions should focus on promoting preparedness. The provision of training or education is suggested for families because of its benefit in strengthening their capacity, particularly for managing symptoms at home (Putranto & Rochmawati, [2020](#)). Support programs and increasing caregiver preparedness are priorities for intervention studies in caregiving (Harrop, Byrne, & Nelson, [2014](#); Lambert et al., [2019](#)). Support programs include home care, practical training, and caregiver coaching. Home-based education for caregivers of patients with a life-limiting illness is important and suggested in a limited-resource setting (Kizza & Muliira, [2019](#); Williams, [2018](#)). Therefore, the current study aimed to investigate the effect of providing HBPC-FC training for family caregivers in rural areas on their preparedness and burden of caregiving with the following hypotheses:

1. Mean scores of caregiving readiness in the intervention group would be significantly higher than that of the control group measured at week 4 of the intervention program and would be significantly higher than pre-intervention.
2. Mean scores of the caregiving burden in the intervention group would be significantly lower than

that of the control group measured at week 4 of the intervention program and would be significantly lower than pre-intervention

Materials and Methods

A quasi-experimental with data collection at baseline and immediately after training was employed for the study. We reported using the Consolidated Standards of Reporting Trials (CONSORT) guideline.

Sample and Setting

The sample was relatives who were the primary caregivers of patients with a life-limiting illness. The sample size was calculated using G*power, with the level of significance (α) = .05, power of test = .80, and an estimated effect size of 0.9 (Rivera, Elliott, Berry, & Grant, [2008](#)). Following the calculation, we added 10% to anticipate potential dropouts. Given the possible attrition rate, a minimal sample size of 50 was considered adequate. We recruited 50 family caregivers divided into 25 people in the intervention group and 25 people in the control group ([Figure 1](#)). Eligible family caregivers were as follows: being a primary family caregiver of the patient; 18 years or older; not diagnosed with life-limiting illness; and willing to spend time for the training.

Table 2 Characteristics of the family caregivers

Characteristic	Intervention group		Control group	
	n	%	n	%
Gender				
Female	21	84	22	88
Male	4	16	3	12
Age				
26-35 y	7	28	3	12
36-45 y	7	28	13	52
46-55 y	6	24	6	24
56-65 y	4	16	3	12
>65 y	1	4	0	0
Relationship with patient				
Spouse	11	44	7	28
Children	9	36	15	60
Parents	1	4	0	0
Sibling	3	12	2	8
Other (niece)	1	4	1	4
Support from other family member				
Yes	18	72	21	84
None	7	28	4	16
Employment				
Government employee	1	4	0	0
Private employee	5	20	2	8
Self-employed	5	20	3	12
Housewife	13	52	19	76
Other	1	4	1	4
Length of caregiving				
<1 year	7	28	2	8
>1 year	18	72	23	92
Patient's medical diagnose				
Diabetes	7	28	5	20
Stroke	4	16	5	20
Cancer	4	16	6	24
COPD	6	24	6	24
Heart Failure	4	16	3	12

Ethical Considerations

The semi-structured in-depth interview method was We conducted the study after approval from the University Ethics Committee in Research (No.023/EC-KEPK/II/2019). We recruited family caregivers using data from the Primary Health Care center. The researchers explained the study to the family caregivers and included study objectives, process, potential benefits, and risks. Following that, participants who agreed to be involved in the study provided their consent. We assured the participants that they could withdraw at any time and this would not affect the healthcare service. We kept all participants' data confidential without individual identification in any form.

Research Instruments

The research instruments consisted of three parts: (i) a demographic information questionnaire; (ii) caregiving preparedness and (iii) caregiving burden). The

Table 1 Schedule, content and activities of HBPC-FC training

Time	Contents	Method
Week 1 (1-2 hours)	Basic needs (personal hygiene, discussion of medication regimen for patient). pain control (assessment, pain medication management and non pharmacological interventions).	- Trust establishment - Program overview - Teaching and providing information - Breathing exercise - Providing feedback and encouragement
Week 2 (1-2 hours)	Symptom management: - nausea - loss of appetite	- Teaching, demonstrating - Evaluating participant's understanding, - Providing feedback and encouragement
Week 3 (1-2 hours)	Dyspnea management Spiritual support	- Teaching - Demonstrating deep breathing exercise - Asking participants to redemonstrate - Providing feedback and encouragement - Program evaluation

demographic information questionnaire was developed to obtain the participants' age, gender, relationship to the patients, and type of employment. In addition, we also developed illness-related questions: type of disease, length of illness, and availability of support.

We assessed family caregivers' preparedness using the Caregiving Inventory (CGI) developed by Merluzzi et al. (2011) We received permission to use and translate the CGI. The CGI consists of 21 items and is categorized into four subscales that include: managing medical information, caring for the care recipient; caring for oneself, and managing difficult interactions and emotions. The questionnaire has a 9-point Likert scale (1 = "not at all confident" to 9 = "totally confident"), with a higher score reflecting a higher preparedness in caregiving. The CGI was translated into Indonesian, with a reliability score of 0.856 (Rochmawati & Pawitasari, 2021).

Caregiving burden was measured using Zarrit Burden Index (ZBI). We utilized the Indonesian version of ZBI with a Cronbach's alpha score of 0.93 (Tristiana, et al., 2019). The ZBI has 22 items rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly always). The sum score ranges between 0–88, with higher scores, indicating a greater burden. A score of 61 or more was considered a high burden. Data on caregiving

preparedness and burden were collected at baseline and upon completion of the intervention

Data Collection Procedures

We conducted the study in February 2020-May 2020. We divided the caregivers' group based on the location of their homes. The intervention group received HBPC-FC which was delivered in the form of one-on-one training using the structured module, while the control group did not receive any training during the study. After obtaining written consent and completing baseline assessments, the researchers' scheduled one-on-one sessions with the caregivers for training. The researchers were postgraduate students in nursing. The HBPC-TC training was conducted at the caregiver's home. The training was offered based on the family caregivers' availability to participate. The researchers delivered the HBPC-FC training to the intervention group for three weeks. In the study, we provided education to enhance family caregivers' skills, including self-care, basic needs, pain, and symptom management, and spiritual support. This is based on a previous study conducted in a rural area in Canada that identified the most prevalent needs were caring for the patient's pain, fatigue, body, nourishment, and caregivers' personal needs (Robinson et al., 2012).

Table 1 shows detailed contents and methods in our HBPC-FC training. In the first week, we trained family caregivers on patients' basic needs (personal hygiene, discussion of medication regimen for patients) and pain control (assessment, pain medication management, and nonpharmacological interventions). Each meeting ranged from 1-2 hours. We provided information on managing nausea, such as providing small and frequent meals, and maintaining preferred meals, fatigue (an example is pleasant activity scheduling), and loss of appetite in the second week of the training. In the third

week, we trained the participants to manage dyspnea and provide spiritual support for patients. We taught strategies for managing psychological distress by conducting deep breathing and progressive muscle relaxation

Data Analysis

Statistical analysis was performed using SPSS 23.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics were utilized to describe participants' demographic and background variables. All tests were performed, assuming $p < 0.05$ to be statistically significant. Independent t-tests were used to measure the statistical difference of the mean scores of caregiving preparedness and burden. Wilcoxon Signed Ranks Test was used to test the difference in caregiving burden and preparedness in the experimental group between pre- and post-intervention.

Results

In the current study, a total of 50 family caregivers were divided into intervention group (25 participants) and control group (25 participants). None of the family caregivers withdrew from the study. The comparison of demographic and clinical findings of the study population is displayed in Table 2. Overall, there were no significant differences in the study participants' demographic characteristics and disease-related data. The data showed that most family caregivers were female both in the intervention and control group. Most of the caregivers were the patient's spouse or children (intervention group: 80%, control group: 88%). The majority of caregivers in the intervention group were 26-35 years and 36-45 years. The primary caregivers in both groups had support from other family members.

Table 3 shows the difference in outcomes after three weeks of HBPC-FC training intervention in the

Table 3 Preparedness and burden of providing care to patient at home pre-post-test in intervention and control group

Variable	Intervention group		Control group		P-value
	Min-max	mean±SD	Min-max	mean±SD	
Caregiving preparedness					
Pre-test	55-94	66.53±10.947	50-92	68.12±9.382	0.000
Post-test	84-174	131.56±29.551	51-90	71.20±9.513	
Caregiving burden					
Pre-test	57-93	79.32±8.966	61-87	78.52±7.332	0.000
Post-test	24-71	41.32±15.569	68-87	79.84±5.778	

Table 3 Preparedness and burden of providing care between groups

Variables	Intervention (n=25)	Control (n=25)	T test	P-value
Caregiving preparedness	131.56 (29.55)	71.20(9.51)	9.72	*.000
Caregiving burden	41.32 (15.57)	79.84(5.77)	11.59	*.000

*Correlation is significant at the 0.05 level (2-tailed).

intervention and control group. The family's preparedness in providing caregiving increased significantly in the intervention group. There is also a significant difference between the intervention and control groups regarding caregiving preparedness (Table 3). The caregiving burden decreased significantly in the intervention group. Statistically significant differences in caregiving burden were found between groups ($P < 0.05$).

Discussions

The findings of previous studies are similar to this study (Duimering et al., 2020; Petruzzo et al., 2019). The majority of family caregivers in our study were female. This study was undertaken to assess the effectiveness of HBPC-FC training for family caregivers in rural areas on their caregiving preparedness and burden. Providing training at home is suggested in limited-resource settings (Kizza & Muliira, 2019). In Indonesia, where the study was conducted, the resource is still limited in some areas, particularly rural areas. Therefore, we conducted a HBPC-FC training session for family caregivers at their home as suggested by previous study. In addition, due to the characteristics of the family caregivers, the researcher followed suggestions from two previous studies to provide information for families in simple language; we also provided written instruction on administering medication and evaluating symptoms (Dionne-Odom et al., 2018; El Osta & Bruera, 2015).

Findings from the study have highlighted that caregiving preparedness among family caregivers in the intervention group was significantly improved by HBPC-FC training. We conducted the intervention in the form of one-on-one training. Such form of intervention was highlighted by participants in Hendrix et al. (2016) study). Previous related studies in the field confirm the results of the present study (Chi, et al., 2016; Hendrix et al., 2016; Mollica, et al., 2017). For example, in their study, Hendrix et al. (2016) delivered enhanced training that included two components symptom management for patients and managing stress for family caregivers and found that the training significantly improved the caregiving preparedness. The two components were similar to materials of HBPC-FC training that we provided in our study. Further, many studies indicate that caregiving preparedness is associated with other positive outcomes. For example, although we did not measure in our study, previous study indicates that a higher preparedness associates with higher competence and quality of life (Winterling, Kisch, Alvariza, Årestedt, & Bergkvist, 2021).

Family caregivers experienced a high burden due to the lack of real support in managing patient symptoms at home. The caregiving burden mean scores in both groups before the intervention were considered high. This is different to the previous study. A cross-sectional survey of family caregiver's burden in a specialized palliative care unit in Malaysia found that the caregiving burden was low (Ahmad et al., 2020). The difference could be due to different setting, as, in our study, the family caregivers provided care to the patients at home where they cared for the patients 24/7. Following the HBPC-FC training, we found the caregiving burden score in the intervention group had decreased compared to the baseline values. This suggests that HBPC-FC training was instrumental in influencing the caregiving burden. Furthermore, similar results are found in previous study. Although, previous study focused on caring specifically for patients with cancer, it was shown that education training had a direct impact on the perception of burden among family caregivers (Mollica et al., 2017). Support is needed by family and it can be provided in several forms such as training or café meeting (Finley, 2018). Our study showed that HBPC-FC significantly decreases family caregivers' burden. This confirms the previous study that lack of receipt of training increases the burden among family caregivers (Hendrix et al., 2016; Mollica et al., 2017). In addition, a systematic review found that experimental interventions slightly reduce caregivers' burden (González-Fraile et al., 2021).

The study has several limitations. First, we conducted our study with primary family caregivers at home. There was variety in terms of supports of family caregivers at home (availability of other members to be a proxy caregiver) that could contribute to a different level of caregiving burden. Secondly, the type of disease and complexity of the patient's symptoms varied, thus the needs and burden could also vary.

Conclusions

A three-week HBPC-FC training is an effective approach to improve caregiving preparedness and reduce the caregiver burden of the family caregivers in rural areas. For nursing practice, particularly in community and adult nursing, nurses can provide HBPC-FC training for family caregivers in the current practice. In addition, primary healthcare nurses can implement sustainable empowerment for caregivers or partnerships with community health workers to assist palliative patient care. Further studies can adopt technology to support caregivers, such as developing mobile apps that can be used to increase caregivers'

preparedness and reduce the level of family stress in providing care independently.

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