

Empowerment of the Family Primary Caregiver of Patients with Chronic Obstructive Pulmonary Disease

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Abstract: *Objective:* To evaluate the effectiveness of a family caregiver empowerment intervention for improving the quality of life and anxiety of patients with chronic obstructive pulmonary disease (COPD). *Methods:* A total of 92 COPD patients hospitalized in the Department of Respiratory Medicine of a hospital in Dongguan from November 2018 to August 2019 were enrolled in this study. They were divided into observation and control group (both n = 46). The control group was provided with routine nursing treatment and health education; the observation group was empowered via routine nursing treatment and health education for the main caregivers of COPD patients. The two groups were followed up by telephone, or door-to-door, and data were collected before the intervention and 1, 3 and 6 months after discharge. The data included the COPD Assessment Test (CAT) score, modified Medical Research Council (mMRC) dyspnea scale score and Self-rating Anxiety Scale (SAS) score of the patients, and knowledge level of the main caregivers. *Results:* There was no significant difference in the general characteristics of the two groups of patients or their main family caregivers ($P > 0.05$). After the intervention, there was a significant difference in the quality of life of the two groups, according to the CAT, mMRC dyspnea scale and SAS scores, and in the knowledge levels of the main caregivers ($P < 0.05$). *Conclusions:* In the COPD population, the intervention to empower family caregivers was effective. The knowledge level of the main caregivers was improved, as well as the dyspnea and quality of life of the patients. The anxiety and negative emotions of the patients were also reduced to some extent.

Keywords: Chronic Obstructive Pulmonary Disease, Family Empowerment, Main Caregiver, Quality of Life, Anxiety State

1. Introduction

Chronic obstructive pulmonary diseases (COPD) is a respiratory disease characterized by persistent airflow restriction, which can be prevented and treated. The airway restriction typically shows a progressive course [1]. COPD is the fourth most common cause of death in the world [2]. In China, the prevalence of COPD among people aged 40 years and over is 13.7% [3], and the older the age, the higher the prevalence of COPD; the prevalence in people aged 60 years and over exceeds 27% [4]. In China, although most COPD patients are accompanied by their families when hospitalized, their families often do not participate in taking of them [5], and most patients receive complete care during hospitalization. In

addition, patients have a limited capacity for self-management over the long course of the disease; they often do not know how to take care of themselves, and their families may also not know how to take care of them after discharge; this often leads to low-quality care. Treatment and rehabilitation are very difficult, so family assistance with COPD patient management is particularly important. Family empowerment refers to a process whereby medical staff help family members acquire care knowledge, skills and resources, to enable them to actively control their own lives and improve the quality of life of the patients under their care [6]. Empowerment of family primary caregivers targets their care-related problems; medical staff and primary caregivers jointly formulate individualized care plans to solve these problems, improve care ability readiness for the

provision thereof, and reduce the pressures associated with care [7]. Empowerment interventions have been widely used in the management of chronic diseases in other countries, and have gradually emerged as an effective method to improve the quality of life of patients with chronic diseases [8-10]. In this study, an empowerment program for family primary caregivers after COPD patient discharge was devised to empower the primary caregivers; its application is also discussed.

2. Clinical Data

Using the convenience sampling method, 92 patients with COPD, hospitalized in two wards of the respiratory department of a class III hospital in Dongguan from November 2018 to August 2019, were enrolled in this study. In order to avoid contamination, groups were distinguished according to the research timing. The inclusion criteria for patients were as follows: (1) met the criteria of the 2013 guidelines for the diagnosis and treatment of COPD issued by the COPD group of the respiratory branch of the Chinese Medical Association [11]; (2) presence of family caregivers; (3) family home as the location of rehabilitation after discharge; and (4) provision of voluntary consent to participate (i.e., signed informed consent form). The exclusion criteria were as follows: (1) vision, hearing or severe cognitive impairment such that the patient was unable to cooperate; (2) respiratory failure when using a ventilator; (3) presence of other major organ diseases, such as malignant tumor, heart failure, renal failure, etc.; and (4) unable to continue to participate in this study because of readmission due to disease or death. The inclusion criteria for the main caregivers were as follows: (1) family members of patients, including spouses, parents, children, brothers, sisters, etc.; (2) main patient caregiver during hospitalization (i.e., spend the most time per day caring for the patient, and remaining as the main care giver for at least 3 months after discharge); (3) aged ≥ 18 years; and (4) good awareness, reading comprehension and communication skills. Primary caregivers who had participated in relevant training were excluded. This study has been approved by the hospital ethics committee and obtained the informed consent of COPD patients and their main caregivers.

3. Research Methods

3.1. Intervention for Control Group

The control group received routine treatment and inpatient care, including an introduction to the ward environment, and to competent doctors and nurses when the patients were admitted. A preliminary care plan was formulated, and relevant knowledge of disease treatment and nursing imparted. Controls were also guided in terms of rehabilitation exercises for pulmonary function. Before discharge, a COPD health education manual was provided, and the patient was informed of the follow-up visit times, and regarding appropriate use of drugs and precautions after discharge. A telephone follow-up was conducted after discharge.

3.2. Intervention for Observation Group

3.2.1. Preparation Stage

A family empowerment team was created, comprising two nursing team leaders and a master's tutor, respiratory physician, head nurse, respiratory rehabilitation therapist, master of nursing and a nurse. The team was responsible for the formulation, implementation and evaluation of the family empowerment plan. Through keyword searches of major literature databases such as CNKI, Wanfang, VIP and PubMed, the first draft of the empowerment plan for the main caregivers of the family was obtained. After a group discussion, expert consultation and pre-test, the intervention measures were finally determined. The project leader trained the family empowerment team members. The training covered the purpose, method, and objective of the study, the content of the family empowerment plan, evaluation indicators and tools.

3.2.2. Intervention Phase

(i). Phase I

On the first day of admission, the researcher and nursing team leader met the patients and their main caregivers, discussed the enrollment conditions, supervised the informed consent process, and conducted a general investigation. The researcher or nursing team leader explained the concept and etiology of COPD, and the importance of pulmonary function rehabilitation, and also answered questions from the main caregivers when the patient was hospitalized for the first treatment. Psychological counseling was provided for the main caregivers, along with encouragement to do a thorough job with respect to the management of family nursing (which can greatly improve the prognosis of patients), and help with long-term care preparations.

On the second day of admission, the researcher or nursing team leader communicated in the ward via one-to-one open questions and 10-minute interviews. They listened to the main caregivers of the family, and discussed any negative emotions and problems encountered during the care process. They asked the primary caregiver the following questions and recorded the answers. (1) What problems do you think to arise when taking care of patients? (2) Do you know which adverse lifestyle factors can lead to the onset of COPD? (3) What problems and difficulties do you think you will encounter when helping patients change their unhealthy lifestyle? (4) Do you have knowledge of the dietary management of patients with COPD? (5) Do you feel depressed when taking care of patients? Why did that happen? (6) Do you feel a lot of pressure during the care process, and if so, is it frequent?

(ii). Phase II

From the second day of admission to the first day before discharge, a care plan was formulated according to the identified care problems. During the formulation process, the main family caregivers and researchers collaborated, and the care plan was individualized according to the patient's medical history and disease characteristics. If the patient showed poor compliance with respiratory function exercises and needed the main caregiver to assist them with the exercises, the main

caregiver was instructed such that the patient could carry out the exercises under supervision (to improve patient compliance with the exercises). The investigator or nursing team leader communicated one-on-one with the primary caregiver every Tuesday or Wednesday afternoon. Similar COPD patients with good prognoses were discussed with the patients and their main caregivers. During hospitalization, patients and their main family caregivers could come into contact with some patients with good prognoses through active cooperation with treatment and nursing, to build their confidence with respect to care. Every Thursday afternoon, the main caregivers gathered in the COPD pulmonary functional rehabilitation room to discuss relevant knowledge of COPD, study the theory and demonstrate the pulmonary function exercises. Group study and one-on-one guidance ensured that the main caregivers could master the basic pulmonary function rehabilitation exercises, such as lip contraction breathing, abdominal breathing, other breathing exercises, effective coughing and expectoration, etc.

(iii). Phase III

On the day of discharge one-on-one health education was provided, to inform the main caregivers about the risk factors for COPD recurrence, precautions for commonly used drugs, adverse reactions, pulmonary function rehabilitation exercises, dietary education, precautions when returning to the hospital for reexamination, and effective communication, so that the main caregivers of the family were confident in terms of the provision of care.

(iv). Phase IV

At discharge, a rehabilitation management manual was issued to record changes in COPD patient status at home, and some objective indicators were used as a reference when returning to the hospital. By empowering the main caregivers to supervise patients, and applying the knowledge obtained during hospitalization, the main caregivers could encourage the patients to take their drugs daily according to the doctor's instructions, and do not stop the drugs by themselves; they could also observe the adverse reactions of the drugs. They were also able to understand the patient's psychological and physiological needs, improve their mood, care for and comfort the patient, prevent negative emotions, and give the patient confidence to overcome the disease. Through WeChat and 317 nursing platforms, the patients continued to receive education and timely feedback regarding problems after discharge, so as to ensure effective care. If the main caregivers were older and restricted in terms of information acquisition and feedback, explanations were provided via telephone or by watching educational videos repeatedly through their children's mobile phones.

3.3. Research Indicators and Tools

- (1) The questionnaire used to obtain general patient and family main caregiver information was designed by the research group according to the research purpose.
- (2) The Self-rating Anxiety Scale (SAS) was created by William W. K. Zung, and comprises 20 items scored on a 4-point scale. The scores on all 20 items are added to

obtain the rough score, which is then multiplied by 1.25. The integer part is then taken as the standard score; the higher the score, the more anxious the individual. The cut-off value for the SAS standard score is 50 points, where 50~59 points indicate mild anxiety, 60~69 points moderate anxiety, and 70 points and above severe anxiety. The SAS is applicable to adults with anxiety symptoms, is widely used in the clinic, and has good reliability and validity [12].

- (3) To evaluate the quality of life of the patients, the COPD Assessment Test (CAT) and modified Medical Research Council (mMRC) dyspnea scale were used. They are both fast and simple scales with good reliability and validity, and are well accepted by the participants in this study.

3.4. Data Collection

Before the start of the study, the researcher first explained its purpose, significance and importance to the COPD patients and main caregivers, who then signed the informed consent form. Within 48 hours after patient admission to the hospital, the researcher issued unified and standardized guidelines to the main caregivers, helped them fill in the general questionnaire and SAS, and collected the completed questionnaires on the spot. One, three, and six months after discharge, follow-up data were collected via telephone or home visits, to ascertain how the care was being implemented of the main caregivers, and strengthen the intervention through re-empowerment again.

3.5. Statistical Methods

SPSS software (ver. 13.0; SPSS Inc., Chicago, IL, USA) was used for data analysis. The general demographic data and clinical data are described as frequency and percentage. The measurement data are expressed as mean \pm standard deviation, and a two-sample t-test or Wilcoxon rank sum test was used for group comparisons; the χ^2 test was used to compare count data between the groups. For the repeated-measures data with an approximately normal distribution (i.e., the CAT and SAS scores), repeated measurement design analysis of variance with control was carried out first. However, because of the non-parallel control group, ensuring balance between the groups was not easy. Therefore, the analysis of variance was repeated separately for the observation and control groups. For the "grade" repeated-measures data (i.e., the mMRC data), Friedman's m test was performed for comparison of the observation and control groups. Then, taking 3 months after discharge as the efficacy evaluation timepoint, the Wilcoxon signed rank sum test was performed on paired samples (before the intervention and 3 months after discharge); $P < 0.05$ was taken to indicate a statistically significant difference.

4. Results

4.1. General Data of the Two Groups

The general data was not statistically significantly different between the two groups ($P > 0.05$). There were 96 patients with COPD overall (48 in the observation group and 48 in the

control group). One month after discharge, data for 95 of the cases were obtained; one patient in the observation group withdrew voluntarily for personal reasons. Three months after discharge, the data for 92 cases were obtained, including 46 cases in the observation group (in which one patient died), and

46 in the control group (two patients were rehospitalized). In total, four cases were lost to follow-up 3 months after discharge, including two each in the observation and control groups (loss rate = 4.1%). Thus, 92 cases were included in the final analysis (Tables 1 and 2).

Table 1. Comparison of general demographic data between the two groups ($n = 46$ in each group).

Variable	Classifications	Observation group		Control group		$\chi^2 (t)$	P
		Number (n)	Constituent ratio (%)	Number (n)	Constituent ratio (%)		
Gender	Male	34	73.9	33	71.7	0.055 ^a	0.815
	Female	12	26.1	13	28.3		
Age (years)		73.50±9.31		75.89±9.40		1.226 ^b	0.223
Place of residence	Urban	7	15.2	13	28.3	2.300 ^a	0.129
	Rural	39	84.8	33	71.7		
Level of education	Primary school and below	37	80.4	37	80.4	0.136 ^c	0.892
	Junior high school	4	8.7	7	15.2		
	High school or technical secondary school	4	8.7	1	2.2		
	University	1	2.2	1	2.2		
	Master's degree or above	0	0	0	0		

Note: A denotes the χ^2 test, B the two-sample t-test, and C the Wilcoxon rank sum test for the comparison of two independent samples.

Table 2. Comparison of the general demographic data of the main caregivers between the two groups ($n = 46$ in each group).

Variable	Classifications	Observation group		Control group		$\chi^2 (Z)$	P
		Number (n)	Constituent ratio (%)	Number (n)	Constituent ratio (%)		
Gender	Male	16	34.8	8	17.4	3.61 ^a	0.058
	Female	30	65.2	38	82.6		
Age (years)	18-25	0	0	1	2.2	0.41 ^b	0.686
	26-30	0	0	1	2.2		
	31-40	6	13.0	3	6.5		
	41-50	8	17.4	7	15.2		
	≥51	32	69.6	34	73.9		
Employment status	Employed	11	23.9	16	34.8	1.31 ^a	0.252
	Unemployed	35	76.1	30	65.2		
Education level	Primary school and below	15	32.6	9	19.6	1.34 ^b	0.179
	Junior high school	22	47.8	25	54.3		
	High school or technical secondary school	9	19.6	12	26.1		
	University	0	0	0	0		
	Master's degree or above	0	0	0	0		
Relationship	Spouse	32	69.6	26	56.5	1.68 ^a	0.195
	Child	14	30.4	20	43.5		
	Parent	0	0	0	0		
	Other	0	0	0	0		

Note: A denotes the χ^2 test, and B the Wilcoxon rank sum test, for comparison of two independent samples.

4.2. Comparative Analysis of CAT Scores Between the Two Groups Before and After Intervention

The normality test showed that the CAT scores were normally distributed at each time point. Therefore, the t-test was used for comparison of the CAT scores between the two groups before the intervention; There was no statistical difference between the observation and control groups before the intervention ($t=0.565$, $P=0.573$).

The family empowerment CAT scores of the two groups

showed a normal distribution at each time point. Therefore, the scores were analyzed by repeated-measures analysis of variance. The results showed that the main effect of time was statistically significant ($F=115.730$, $P < 0.001$), indicating that the CAT score of the COPD patients changed with time. The interaction effect between time and treatment was also statistically significant ($F=30.244$, $P < 0.001$), indicating that the change in CAT over time differed between the observation and control groups. The CAT score of the observation group was lower than that of the control group ($F=4.821$, $P=0.031$).

Table 3. Repeated-measures analysis of CAT scores of the two groups at each time point ($\bar{x} \pm s$).

Group	Number of participants	Before intervention	1 month after discharge	3 months after discharge
Observation group	46	21.54±4.48 ^a	18.52±3.32	17.98±3.12
Control group	46	22.09±4.75 ^a	22.09±4.10	21.28±4.35

Note: ^aTwo-sample t-test, $t = 0.565$, $P = 0.573$.

4.3. Comparative Analysis of mMRC Grades Between the Two Groups Before and After Intervention

A rank sum test of two independent samples was used to compare the two mMRC grades of the two groups of subjects before the intervention. There was no significant difference in mMRC grade between the observation and control groups before the intervention ($z = 1.32, P = 0.185$).

For comparison of the mMRC grades of the two groups at each time point, Friedman’s m test of multiple related samples was used. There was no significant difference in mMRC grade

at any time point in the observation group ($\chi^2 = 66.07, P < 0.001$), but there was a significant difference for the control group ($\chi^2 = 35.62, P < 0.001$). The proportions of mMRC grade 3 in the observation group before the intervention, and 1 and 3 months after discharge, were 32.61%, 6.52% and 4.35% respectively, compared to 23.91%, 10.87% and 19.57%, respectively, in the control group. After the empowerment (of the main family caregivers) intervention in the observation group, the downward trend in severe disease was more pronounced than in the control group.

Table 4. Comparison of mMRC classifications between the two groups at different time points.

mMRC grade	Observation group			Control group		
	Before intervention	1 month after discharge	3 months after discharge	Before intervention	1 month after discharge	3 months after discharge
0	0	5	5	0	5	2
1	9	21	17	15	17	11
2	22	17	22	20	19	23
3	11	3	2	7	5	6
4	4	0	0	4	0	3
≥ 3 (%)	32.61	6.52	4.35	23.91	10.87	19.57

Note: mMRC grade ≥ 3 (%) denotes extremely serious diseases.

4.4. Comparison of SAS Scores Between the Two Groups Before and After Intervention

The SAS scores of the two groups exhibited a normal distribution at each time point. Therefore, the two-sample t-test was used to compare the SAS scores of the two groups before the intervention; there was no statistically significant difference ($t = 0.99, P = 0.325$).

The SAS scores of the two groups were compared at each

time point by repeated-measures analysis of variance. The results showed a main effect of time ($F = 44.317, P < 0.001$). The interaction effect between time and treatment was also statistically significant ($F = 60.552, P < 0.001$), indicating that the trend of SAS score over time was different between the observation and control groups. There was also a significant difference in the proportion of SAS ≥ 50 scores between the two groups ($P < 0.05$).

Table 5. Results of repeated-measures analysis of the SAS scores of the two groups at each time point ($\bar{x} \pm s$).

Group	Number of participants	Before intervention	1 month after discharge	3 months after discharge
Observation group	46	44.76±7.04 ^a	40.89±5.68	39.74±5.67
Control group	46	43.17±8.28 ^a	42.65±7.55	43.96±7.03

Note: ^a Two-sample t-test, $t = 0.99, P = 0.325$.

4.5. Comparison of the Knowledge Level of the Main Caregivers Before and After the Intervention

The knowledge level assessment scores of the main caregivers before (59.22 ± 10.64) and 6 months after the intervention (81.29 ± 5.78) were statistically significantly different ($P < 0.05$).

5. Discussion

5.1. Family Empowerment Can Improve the Quality of Life of Patients with COPD

Studies have shown that family empowerment can improve the quality of life and social function of stroke patients [13]. Family empowerment was the focus of this study. The CAT score and mMRC grade of the patients in the two groups

decreased 1 month after discharge; thus, after hospitalization, the quality of life of the patients improved. However, the scores of the patients decreased to different degrees after 1 and 3 months, according to the intervention measures. The score of the observation group was significantly lower than that of the control group, and the improvement of quality of life was significantly better than that of the control group. This shows that routine health education can help improve the quality of life of patients to some extent, but compared with routine health education, the quality of life improvement in the observation group after family empowerment was greater than that in the control group. After the family empowerment intervention, the sense of responsibility of the main caregivers was enhanced, and the care efficiency improved. Under professional guidance, the main caregivers assist the patients in terms of pulmonary function rehabilitation, the number of exercises is increased, symptoms are reduced, and the

confidence to go out is enhanced; all of these factors improve the quality of life of the patients.

According to the analysis of CAT scores, after the main caregiver empowerment intervention, the patients' energy levels, sleep, confidence to go out, degree of disease, cough, expectoration, chest tightness, and exercise habits, etc., all improved. The reasons for this may be as follows: (1) after hospitalization, cough, expectoration and chest tightness all generally improved, perhaps because the main caregivers guided the patients regarding how to cough and expectorate effectively, and encouraged them to take their medications and oxygen on time. (2) The main caregivers also helped the patients with their daily pulmonary function exercises, spent more time with them (i.e., provided companionship), strove to understand the psychological status of the patients, gave the patients support, and improved their exercise habits and confidence to go out. (3) As the main caregivers care about and understand the patients, they encouraged them in terms of active rehabilitation, sleep habits and diet, etc.

After the intervention, the proportion of extremely severe cases in the observation group was significantly lower than in the control group. Studies have shown that [14], patients engaging in less exercise have more severe symptoms of dyspnea and a lower quality of life. From a mechanistic perspective, through family empowerment, the sense of responsibility of the main caregivers is enhanced and care efficiency is thus improved. Under professional guidance, the main caregivers trained the patients to carry out pulmonary function rehabilitation exercises, helping them to increase the number of exercises engaged in per day and enhance exercise tolerance.

5.2. Family Empowerment Can Help Alleviate the Anxiety of COPD Patients

Some studies have pointed out that family empowerment can effectively alleviate the anxiety of elderly patients with depression [15]. This study showed that, 1 month after discharge, the SAS scores of the observation and control groups decreased to a certain extent, which was related to the increase of social and family support and improvement of the general situation of the patients after hospitalization. Three months after discharge, the SAS scores of the observation group continued to decline more than those of the control group, in which the patients were in a state of mild anxiety. After effective nursing treatment, the mild anxiety state of most patients was relieved; however, the SAS score of the control group increased 3 months after discharge, even exceeding that before intervention, which may be related to a lack of effective family psychological support for patients via the traditional health education and nursing model, poor treatment compliance, repeated illness, hospitalization (for serious cases), and increased economic burden. Over the intervention, the scores of the observation group showed a gradual downward trend, and the gap with the scores of the control group widened. Family empowerment, delivered with professional guidance from medical staff, increased the familial support and care for patients, improved their attitudes,

and allowed them to actively participate in the whole treatment process. Most of the main caregivers in this study were older adults with a lower education level, Their ability to obtain resources and process information may have been limited, so attention must be paid to educating the main caregivers. Most of the main caregivers were the spouses of the patients, and were mainly unemployed. They thus had time to spend with the patient, and could actively participate in the rehabilitation process, effectively communicate with the patient and actively feed back to the medical staff, which had a very positive effect on the emotional status of the patients (including improvement in anxiety symptoms and negative emotions).

5.3. Family Empowerment Can Improve the Knowledge Level of Primary Caregivers

Studies have shown that guidance from medical staff directly affects the level of care readiness of main caregivers [16]. For the treatment of COPD, patients and main caregivers often rely on medical staff. Regarding patient care after discharge, the main caregivers need to have a sufficient understanding of the disease and be able to apply basic nursing skills. Our family empowerment program enhanced the enthusiasm of the main caregivers in this respect; they actively acquired disease-related knowledge and skills, and sought out relevant resources to improve them further [17, 18]. In this study, the knowledge level of patients was compared before and 6 months after the intervention, and was found to have improved. Routine health education often involves patient-centered health education based. After receiving health education, main caregivers, who play an important role after patient discharge and may continue to encounter problems during the care process, acquire new knowledge, accumulate practical care experience, and communicate with medical staff. Electronic and video resources improve their knowledge and reduce the burden of care.

6. Conclusion

For the care of COPD patients, our intervention to empower the main family caregivers was effective; dyspnea was reduced, and quality of life improved. The intervention can improve the anxiety of patients, reduce negative emotions, and improve the knowledge of primary caregivers to some extent. However, due to its limited length and small sample size, this study lacked long-term post-intervention follow-up. In the future, we will expand the sample size and carry out a long-term follow-up study to verify the long-term effects of the family empowerment program. As COPD patients tend to be older adults, most of the main caregivers are also older adults, as they are usually spouses, such that their capacity to understand and memorize information may be reduced; thus, the collection of more relevant indicators regarding the status of the main caregivers is recommended to objectively evaluate their role and enhance cooperation with community nurses, Health education regarding family empowerment for patients and their main caregivers can increase social support, resolve

problems encountered by their main caregivers in a timely manner, and allow for more rapid and convenient patient support.

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