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The Effect of Intervention Brought about By the LWHP on the Caregivers and Their Advanced Lung Cancer Patients

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Abstract

Objective: Caregiver Hope is the inner strength to achieve good future & to continue care giving. The LWHP is a self-administered intervention that contains of watching an international award winning Living with Hope film and participating in a two week hope activity ("Stories of the Present"). The purpose of this study was to examine the feasibility of this intervention program (LWHP) on family caregivers of lung cancer patients in China which consist of self-efficacy (General Self-Efficacy Scale), loss and grief (Non-Death Revised Grief Experience Inventory), hope (Herth Hope Index) and quality of life (Short-Form 12 version 2 (SF-12v2)

Methods: Sixty family caregivers of patients with advanced lung cancer in Hubei province -China were divided into the experimental group and the control group. However, the differences between two groups were compared using variance analysis of repeated measurements.

Results: 76.6% was the evaluation of the intervention. However, the main effects of hope level, mental health, self-efficacy, anxiety and depression were statistically significant (P<0.05: the time effect self-efficacy and hope level were also statistically significant (P<0.05)

Conclusion: It would appear that LWHP can effectively improve hope level, mental health status; alleviate anxiety, self-efficacy and the depression level of family caregivers.

Keywords: Quality of Life; Living with Hope Program; Lung cancer; Family Caregivers

Introduction

Lung cancer is among the tumours with the highest morbidity and mortality. Family members are the most important people to provide care needs for cancer patients. With long time periods, high load and high mental pressure, the health care can deeply affect the health and living quality of caregivers [1,2], at the same time, it cannot provide patients with care services of higher quality. Study shows [3] that hope is a buffer factor for coping with stress, and it's also an important factor that influences the physical and mental health of caregivers. So increasing the caregiver's hope can not only effectively improve the living quality of caregivers, but also indirectly improve the living quality of patients. The level of hope is a personal experience of the current state of being, which is constantly changing and can be influenced by interventions [4]. However, a few intervention studies aimed at improving the level of family caregivers' hope in China, and this kind of research is still in the stage of continuous exploration in abroad. Among them, "Life Hope Program Intervention" which was developed by the Nursing School of University of Alberta in Canada [5] and applied to the family caregivers of terminal cancer patients, which is an intervention program aimed at improving the level of hope and living quality among family caregivers of terminal cancer patients. Its intervention effect is obvious, but the deficiency is that the study was not compared with the control group. To further validate the effectiveness of the intervention program, and to explore the feasibility of this intervention program in family caregivers of lung cancer patients in China, this study was conducted.

Object and Methods

The objects of study

With the convenient sampling method, the 60 family caregivers of patients with advanced lung cancer (TNM stage IV) were selected and enrolled in the Department of respiration of a three grade hospital in Hubei province- Wuhan city- China from March 2017 to March 2018. 60 patients were selected randomly, 30 were the experimental group 30 were the control group. Inclusion criteria: the family members of terminal cancer patients who are 18 years old or older, and the caring time is equal or more than 72 hours, they don't have mental disorder and can communicate normally, with simple reading and writing ability and singed an informed consent. Exclusion criteria: rejection or death of participants.

Research methods

Mixed method design will be used to achieve the study purpose and aims.

The intervention methods of the test group

Dubbing life hope project video: Life Hope Project Video is recorded by Professor Duggleby, vice-president of the Nursing School of University of Alberta in Canada and her hospice research team, which based on the hope experiences during the period of interviewing family caregivers taking care of the terminal cancer patients. The video describes the family caregivers' understanding of hope, as well as the way to maintain and improve their hopes, lasting for 17 minutes, which has won 2 international awards. Professor Duggleby provided the video for research with no charge, but because of language barriers, in the initial stage of the study, the teams translated, controvert and inserted Chinese subtitles into the video. The specific method is that 2 researchers with years of clinical nursing experience in USA translated

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subtitles into Chinese versions of Ta and Tb; the researchers integrated the translation of 2 researchers into the version of Tab. This version was examined by a nursing specialists who have been engaged in oncology nursing research for many years, and then 2 native English researchers (Senior Specialist in oncology nursing, Hongkong) who did not know the video controverted the Tab version into English, forming the translated versions of BTa and BTb respectively, and then submitted the original English video, the versions of Ta, Tb, Tab, BTa and BTb to the expert committee. The expert committee included 3 specialists in oncology care and 2 specialists in psychological care. On the basis to ensure the accuracy and completeness of the translation for the video content, as far as possible to make the expression of words suit the Chinese style, the Committee of experts determined the final Chinese version and inserted the Chinese subtitles by professional media workers.

Watching life hope project video: The experimental group was scheduled to make an appointment to watch the video, in the patient's reception room. Except for the researcher himself, no other personnel were allowed to enter the reception room. During the video viewing process, the members of the experimental group were required to wear earphones, throughout the intervening period; the video was broadcast only once. Before watching the video, researchers gave instructions for controlling the volume and pause the video just in case the watchers needed them while watching. During the video viewing process, if the members of experimental group have any questions, the researchers will give the answers according to the video, and assist them in understanding the content of video correctly. When the video was over, the test group completed the content approval questionnaire as required.

Recording hope diary: After completing the content approval questionnaire, handing out the hope diary book, informing the recording method and attentions, the participants were required to write a hope diary at that day and every day for the following 2 weeks. The selection of hope dairy uses Professor Duggleby's previous research findings [6] for reference. The recording content contains three questions: What challenges are you facing today? What are your hopes for today's life? What are the things that will bring you hope? The aim of the repeated answers of these three questions in the diary was to know the own predicament clearly and understand what can bring hope for life. What are the ways which can make someone more clear about solving or alleviating this situation? What are the resources that can be used and that can continue to strengthen this positive attitude for solving problem every day? At the end of the first week of the dairy and at the end of the second week, the researchers asked for the caring difficulties faced by the test group during the course of recording the diary either by a field visit or by telephone follow-up, giving professional guidance to patients regarding symptom management issues. When it comes to psychological problems, the researchers were patient and listen to them, and recommend various ways shown in video leading to a life of hope. For example, hobbies can create good memories with patients.

The intervention method of control group

The control group carried out publicity and education on caring knowledge. After research, the videos were sent to the control group, informing them of different ways of recording hope diary to ensure the fairness.

Evaluation Tools

General information questionnaire: There were two parts, including general data of caregivers (Gender, age, religious belief, hobbies, educational background, employment status, marital status, number of children, total monthly income of families, Degree of financial difficulties) and the relevant information of care (the relationship with the patients, the total caring time, the way of care and the caregivers' self - assessment for the patients).

Herth Hope Index (Herth Hope Index, hope HHI) uses the Chinese version translated by Zhao Haiping and others [6], the scale includes a positive attitude toward reality and the future (temporality and future T), taking positive attitude (positive readiness and expectancy, P), have an attitude of keeping close relationship with others (interconnectedness, I). Three dimensions, 12 entries. Each entry is scored at 1~4 points, with a total score of 48. The higher score, the higher level of hope. The Cronbach's alpha coefficient of the scale is 0.87, and the test-retest reliability is 0.90 [7].

The Chinese version of the general self-efficacy scale (General Self-efficacy Scale, GSES) translated and revised by Wang Caikang and others [8]. A total of 10 entries, each entry are scored at 1~4 points, the highest score is 40, and the higher the score, the higher the self-efficacy. The Cronbach's alpha coefficient of the scale is 0.87, and the test-retest reliability is 0.83.

The hospital anxiety and Depression Scale (Hospital Anxiety and Depression Scale, HADS), this study uses the HADS of Chinese version translated by Ye Weifei and others. A total of 14 items, 7 items are assessed for depression, 7 items are assessed for anxiety, 4 grade scoring method (0~3 score) is adopted. The score of anxiety and depression subscale is from 0 to 7, which is symptomless. The score is from 8 to 10, which has the possibility of suffering anxiety and depression. The score is from 11 to 21, which shows that a person has suffered from anxiety and depression. The Cronbach's alpha coefficient of the total scale is 0.862, and the Cronbach's alpha coefficient of each dimension is from 0.797 to 0.800 [9].

The concise questionnaire of living quality (Short Form 12-item Health Survey Version 2, SF-12v2), this scale is a simplified version of SF-36, with a total of 12 entries. The total score of physiology can be obtained by the standard scoring method (physical component summary, PCS) and total psychological score (mental component summary, MCS), the calculated scores of PCS and MCS are very close to the SF-36 [10]. In the Chinese general population survey, Lamand and others approved that the Cronbach's and alpha coefficients of the physiological and psychological dimensions of SF-12v2 in the Chinese version are 0.67 and 0.60, respectively. The test-retest reliability is 0.82 and 0.81, respectively.

The Method of Data Collection

The data of two groups are collected by researchers through the methods of field or telephone follow-up at the time of admission, first week, second week, first month and third month. The data collection includes general data and HHI, GSES, HADS and SF-12v2 scores. The researchers also have to collect the hope diary from the trial group at the time of first week and second week by taking pictures on the spot or sending them back to the researcher himself through the caregivers' reserved QQ, We Chat or MMS. After watching video and diary, the researchers also evaluated the immediate effects of intervention in the trial group by field or telephone follow-up.

Quality Control

The translation and retroversion of video contents were completed

by professionals, and discussed by several experts to ensure the accurate delivery of video content. The researchers participated in the patient care such as nurses have and established a full trust relationship with the subjects, which improved the compliance of caregivers. All interventions were completed independently by the investigators themselves, ensuring the homogeneity of intervention.

Statistical Methods

Using Epidata 3.0 to establish database, the data is checked and input by two people, using SPSS 17 statistical software for data analysis. The enumeration data uses the number and percentage to count and describe, using $\chi 2$ to examine or the Fisher exact probability method is used for statistical analysis, Measurement data uses the $x \pm s$ to count and describe, t test and repeated measures analysis of variance were used for statistical analysis, regarding $P<0.05$ as the difference with statistical significance (Table 1).

Results

Comparison of general data between two groups

The comparison of general data between two groups, the difference doesn't have statistical significance ($P>0.05$).

The completion status of intervention in the test group

The experimental group completed to watch the Life Hope Program video and record the 2-week hope diary. Video recognition was 73.3%, the number of people of basic recognition and recognition are 22, 8 people didn't support. We received 306 hope diaries, with an average of 5.1 records per person per week (there were 2 people whose number of diary was less than 5, there were 12 people whose number of diary was 5~10, there were 16 people whose number of diary was more than 10, the least number of diary was 3, the most number of diary was 14). The immediate effect of intervention of Life Hope Program was 76.6%, the number of people thought it effective was 23, and the number of people thought it invalid was 7. The total follow-up was 224 cases, of which 96 cases were field followed-up and 128 cases were followed up by telephone. During the follow-up period of 3 months, 3 patients in the trial group and 2 patients in the control group died, and their caregivers dropped out. The follow-up data of third months were not collected, so they were eliminated. The sample size of the final data analysis was 27 in the experimental group and 28 in the control group.

The comparison of the scores of each evaluation index between the two groups before and after intervention

The correction result of Greenhouse-Geisser was adopted through

Variables	Experimental group n=27	Control group n=28	Statistic value	P value
Gender				
Male	11(40.74)	7(25.00)	1.54	0.21
Female	16(59.26)	21(75.00)		
Age (years)				
18~	4(14.81)	4(14.29)	1.57	0.7
35~	13(48.16)	15(53.57)		
50~	4(14.81)	6(21.43)		
≥60	6(22.22)	3(10.71)		
Educational background				
High school	15(55.55)	10(35.71)	2.2	0.33
Collage	7(25.93)	10(35.71)		
Graduation school	5(18.52)	8(28.58)		
Working status				
Working	10(37.04)	12(42.86)	0.19	0.66
Not working	17(62.96)	16(57.14)		
Marital status				
Unmarried	3(11.11)	5(17.86)	-	0.7
Married	24(88.89)	23(82.14)		
Hobbies				
Yes	20(74.07)	18(64.29)	0.61	0.43
No	7(25.93)	10(35.71)		
Religion Affiliation				
Yes	5(18.52)	3(10.71)	-	0.46
No	22(81.48)	25(89.29)		
Number of Children				
0	3(11.11)	6(21.43)	1.12	0.66
1	9(33.33)	9(32.14)		
≥2	15(55.56)	13(46.43)		
Household monthly income(Yuan)				
<1000	4(14.81)	5(17.86)	1.96	0.95
1000~	14(51.86)	10(35.71)		
3000~	4(14.81)	4(14.29)		
>5000	5(18.52)	9(32.14)		
Level of financial difficulties				
No difficulty	2(7.41)	5(17.86)	4.23	0.35
Slight difficulty	1(3.70)	0		

Moderate difficulty	7(25.93)	11(39.28)		
Difficult	4(14.81)	4(14.29)		
Very difficult	13(48.15)	8(28.57)		
Relationship with patient				
Spouse	13(48.15)	11(39.29)	0.43	0.5
Children	14(51.85)	17(60.71)		
Total care per month				
<1	2(7.41)	8(28.57)	6.3492	0.09
1～	11(40.74)	6(21.43)		
3～	6(22.22)	3(10.71)		
>6	8(29.63)	11(39.29)		
way of care				
All day alone	5(18.52)	7(25.00)	0.64	0.88
Not all day alone	9(33.33)	7(25.00)		
The main day shift	7(25.93)	7(25.00)		
Non	6(22.22)	7(25.00)		
caregivers' self -assessment				
Range	3(11.11)	2(7.14)	2.24	0.57
Poor	3(11.11)	7(25.00)		
Good	18(66.67)	15(53.57)		
Very good	3(11.11)	4(14.29)		
Excellent	0	0		

Table 1: Comparison of general data of two groups.

Groups	Entering group	1 week into the group	2 weeks into the group	1 month into the group	3 months into the group	F Group	P value	F Time	P value	F Interaction	P value
Experimental group	35.44 ± 4.19	35.81 ± 3.70	37.56 ± 3.36	39.04 ± 3.73	39.22 ± 4.01	5.675	0.021	9.559	0.001	15.627	0.001
Control group	35.46 ± 3.80	35.50 ± 4.49	34.89 ± 4.14	34.39 ± 3.84	35.61 ± 3.46						
Experimental group	23.81 ± 7.19	26.81 ± 6.44	29.63 ± 4.66	30.37 ± 4.38	30.33 ± 3.71	4.76	0.034	12.811	0.001	23.676	0.001
Control group	25.75 ± 7.80	25.54 ± 6.59	24.93 ± 5.17	24.46 ± 4.61	25.14 ± 3.87						
Experimental group	10.07 ± 4.04	8.74 ± 3.96	8.52 ± 3.36	8.37 ± 3.43	8.30 ± 3.54	5.017	0.029	0.484	0.692	12.505	0.001
Control group	9.11 ± 4.60	10.82 ± 4.74	11.32 ± 3.95	11.68 ± 3.3	11.67 ± 3.70						
Experimental group	9.67 ± 3.51	8.22 ± 4.06	7.85 ± 3.43	7.22 ± 3.37	7.26 ± 3.63	5.178	0.027	1.937	0.13	15.249	0.001
Control group	9.43 ± 4.40	9.92 ± 4.49	9.93 ± 4.59	10.64 ± 4.31	11.82 ± 4.48						
Experimental group	48.26 ± 9.28	47.22 ± 9.17	46.70 ± 9.87	49.41 ± 7.98	49.85 ± 8.06	2.437	0.124	2.654	0.059	1.548	0.21
Control group	45.14 ± 8.45	43.75 ± 9.61	45.39 ± 9.07	44.64 ± 7.87	45.61 ± 8.13						
Experimental group	42.33 ± 8.95	43.59 ± 6.55	45.74 ± 6.61	45.78 ± 4.89	46.67 ± 5.92	5.835	0.019	0.347	0.789	8.662	0.001
Control group	43.39 ± 9.41	41.14 ± 7.38	40.21 ± 7.49	40.27 ± 7.45	39.43 ± 5.2						

Note: the experimental group was n=27; the control group n=28

Table 2: Scores of each evaluation index before and after intervention in the two groups.

analysis of variance measured repeatedly. The result of this study shows that the difference between the two groups in the score of levels of hope, self-efficacy, anxiety, depression and mental health has statistical significance (P<0.05). The time effect of score of hope level and self-efficacy was statistically significant (P<0.05). There were interaction between intervention factors and time factors on the level of hope, self-efficacy, anxiety, depression and mental health (P<0.05) are shown in Table 2.

Discussion

The intervention of Life Hope Program can increase the level of hope and general self-efficacy in the family caregivers of advanced lung cancer patients

The results of this study showed that the inter group effect of scores in the level of hope and self-efficacy have statistical significance, which is similar to Duggleby's [11] research results of intervention of Life Hope Program on the female caregivers of advanced cancer patients. The possible reason is that hope is an organic combination of goals, motivation and path thinking, the goal of value for the individual is the starting point of hope, dynamic thinking drives individuals to search for more effective ways to pursue their goals, and at the same time, periodic feedback through effective methods will further stimulate individual motivation [12]. The videos in the experimental group were recorded by real-life family caregivers of advanced cancer patients, the main description of their understanding of the hope, and various methods of maintaining and enhancing the level of hope, the biggest advantage of the video is its exemplary role [13]. When the test group considers the individual in the video to be similar to their situation, they will realize that they should have the ability to accomplish similar tasks. If there is the same goal, then it is easier to motivate them into dynamic thinking. The video content can precisely to provide them with the means to improve the individual level of hope. The study was conducted with a self-managed intervention requiring caregivers to log daily. The advantage of daily journaling is to help individuals to systematically sort out cognitive and stressful events [14]. It helps the caregivers to systematically comb and rethink the challenges they face from cognition, including a new cognition of things that give them hope. Bally found from the research of parents' hope experience on cancer children that many parents believe recording hope diary is

helpful in maintaining and improving self hopes. At the same time, research [15] shows that self-efficacy is one of the factors that influence the level of hope, and the higher the score of self-efficacy, the higher the score of hope level. Caregivers are able to effectively improve their self-efficacy by repeating 3 questions in the journal daily and strengthen their problem-solving skills, thus, self-efficacy has been effectively improved. At the same time, in the gradual exploration, when found a really suitable way for them to maintain and enhance the level of hope, to further improves its level of hope. The promotion of self-efficacy and the promotion of the level of hope complement each other.

The intervention of Life Hope Program can reduce the level of anxiety and depression of family caregivers of advanced lung cancer patients

The results of this study showed that the inter group effect of anxiety and depression scores among caregivers have statistical significance. With time, the anxiety and depression scores of the experimental group showed a downward trend, and the control group showed an upward trend, which was similar to the results of Duggleby [5]. The reason might be that the process of expressing positive emotions and related events helped guiding the individual's attention to the positive aspects of life events, and to find and learn the positive meaning of daily events and hence, to adjust cognitive structure, improve the ability of emotion regulation, improve coping style, improve positive quality and reduce negative emotion. Research [16] showed that the expression of positive emotions can promote the physical and mental health of the intervention subjects (including healthy people and patients); it can significantly improve their emotional status, reduce the level of anxiety and depression, and also improve their ability of self-adjustment and self-efficacy. Hope is a concept in positive psychology. Through writing the diary, the test group reflects the feelings and expectations of the day, which gives them a chance to look forward to the good things for a short time. The record repeats and strengthens the desire for the positive things in mind. This strengthens the positive psychological quality to some extent, and relieves the negative emotions such as anxiety and depression.

The intervention of Life Hope Program can improve the living quality of family caregivers of advanced lung cancer patients

The results of this study showed that the inter group effect and interaction effect between the two groups of mental health scores have statistical significance ($P<0.05$, which is similar to the result of the research of hope from family caregivers of terminal patients, but differ from Duggleby's research results. After 12 months' intervention, the physiological health of caregivers in Duggleby's research was lower than baseline. Although there was no statistical significance in the group effect of physiological health score, it still shows an upward trend. The possible reason was that the research subjects of Duggleby were on average of 59 years old, however, the age of caregivers included in this study was mostly 30~44 years old. They are in better health, stronger ability to accept new things and their self-health regulation and recovery is faster. Although the physiological condition of the experimental group was improved, it was not as obvious as that of the mental health. The possible reason is that this study is an intervention program that mainly meets the needs of social psychology in the experimental group. The promotion of the level of hope enhances self-efficacy and improves anxiety and depression. This therefore helps to improve the overall psychological state of individuals and thereby improves their mental health status. After the improvement of the mental health status of the subjects, the physical health status may be affected over time. However, the follow-up time of this study is only 3 months, so it was not possible to exclude the fact that improvement of physiological health status wasn't obtained. It is suggested that the follow-up study can continue to explore this problem.

The Limitations of the Study

Due to constraints of research time and funding, the sample size of this study was small. During the follow-up period of 6 months, 17 patients died, 10 caregivers were lost, and total of 27 were eliminated, so we lost a large amount of samples [17,18], resulting in some demographic data and baseline level of evaluation index of the remaining two groups becoming uneven. So the data of 6 months follow-up could not be analysed. It is suggested that further follow-up studies should increase the sample size and prolong the duration of follow-up to observe the intervention effect of middle and short term and long term intervention on life hope program.

Conclusion

The intervention of Life Hope Program can effectively improve the short-term hope level for family caregivers of advanced lung cancer patients as well as self-efficacy and mental health status. At the same time, it can also alleviate anxiety and depression and can be used by many medical workers to provide intervention pathway for family caregivers of advanced cancer patients.

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