Original Research Article

Implementation of self-care symptom management program to enhance the quality of life of cancer patients undergoing chemotherapy and their family caregivers

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ABSTRACT

Background: Chemotherapy affects the condition of cancer patients, physically, psychologically, socially and spiritually. The Self-care Symptom Management (SSM) program is a psychoeducation program with the goal of enhancing patients' self-care abilities to manage the side effects of chemotherapy, and thus improve the Quality of Life (QOL) of adult cancer patients and their family caregivers. The objective of the study is to determine the effects of the SSM program on the QOL of cancer patients undergoing chemotherapy and their family caregivers.
Methods: The study adopts a quasi-experimental design, with one group and pre- and post-intervention tests. The study was conducted in a public hospital in Yogyakarta, Indonesia, with 40 cancer patients and 30 of their family caregivers. The QOL of patients is measured using the EORTC QLQ-C30, and for their family caregivers the CQOLC is used. Data analysis are carried out using a paired t-test and Wilcoxon test, with a 95% level of significance.
Results: The data show significant differences between the mean scores on a single item of sleep disturbance (15.84 points) and a single item of financial difficulties (8.34 points) before and after the implementation of the SSM program. Clinical relevance is shown on a single item of sleep disturbance (≥10 points).
Conclusions: The Self-care Symptom Management program represents a promising intervention to promote self-care management for cancer care in Indonesia.

Keywords: Cancer patients, Chemotherapy, Family, Indonesia, Quality of life, Self-care symptom management program

INTRODUCTION

Cancer is a world-wide health problem, and the second major cause of death in developed countries and one of the three major causes of death in developing countries[1]. It is predicted that globally the total number of cancer cases will increase from an estimated 10.9 million in 2002 to 16 million in 2020[2]. In Indonesia, the National Household Health Survey (HHS) in 2002 revealed that cancer was the sixth major cause of death, and that there were 100 new cases of cancer per 100,000 people every year[3]. Over the last few decades there have been dramatical advances in the diagnosis and treatment of cancer, resulting in improved prognosis and increasing numbers of cancer survivors[4]. However, a variety physical and psychological side effects related to both the

disease and its treatment have been reported by cancer patients.[5,6] Cancer patients generally experience a reduced quality of life due to their experiences with the disease and the related therapeutic efforts.[7]

Effective symptom management strategies should be provided to improve the quality of life of such patients, and reduce the adverse impacts of treatment.[8] Oncology nursing plays an important role in providing information about treatments, so that patients can make better decisions. A survey of ten clinical oncology nurses reports that cancer patients need more information about their diseases, treatments, the side effects of treatment, self-care instructions, and advanced care.[9]

The PRO-SELF Program is a symptom management program that was designed for adult cancer patients with the aim of improving self-care.[9] The PRO-SELF Program involves the dissemination of information related to symptoms of the disease and treatment, training in skills to help manage the side effects, and support using the telephone in follow-up activities.[9] A study of the PRO-SELF Program, conducted amongst 127 participants, indicates that 91% of these felt that the program helped them to manage their side effects and identify problems, and 53% of the participants who received support via telephone contacts stated that their problems decreased with help from the program.[9]

A search of online databases indicates that no studies, carried out in the Indonesian context, have examined self-care symptom management strategies for adult cancer patients, which aims to help them deal with the side effects of chemotherapy. With the successes of the PRO-SELF program, we performed study based on the framework of PRO-SELF program.[9] and we modified the program. In a departure from the original PRO-SELF program, in this study, we involve the patients' families as part of the Self-care Symptom Management (SSM) program, since Indonesians have strong family bonds, which is important for cancer care.[10] Therefore, the aim of the study is to determine the effects of the self-care symptom management program on the quality of life of cancer patients undergoing chemotherapy and their family caregivers.

METHODS

This study used a quasi-experimental design with one group and pre- and post-intervention tests, which was conducted in a public hospital in Yogyakarta, Indonesia.

The population were all patients who were undergoing chemotherapy at the inpatient ward during the study period. Purposive sampling was used to collect the samples, which totaled 40 patient respondents and 30 family caregivers. The inclusion criteria were that the patient respondents were all chemotherapy patients who had undergone hospitalization in the inpatient ward, were under 65 years old, had an ECOG score of 0-2, were able

to communicate and willing to be participants. The exclusion criterion for the cancer patients was a history of psychiatric disorders.

Instruments

A demographic questionnaire was used to obtain the demographic and clinical characteristics of the participants at the beginning of the study.

The EORTC QLQ-C30 (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30) was used to assess the quality of life of the cancer patients. The EORTC QLQ C-30 Indonesian version has been shown to have r =0.18 and 0.48, with an internal consistency >0.70.[11] The EORTC QLQ C-30 Indonesian version is a self-reported scale, consisting of 30 items covering five domains, including physical functioning, mental or emotional functioning, social functioning, fatigue and pain.

The first 28 items are answered with a four-point Likert scale: No, a little bit, frequent and very frequent. The other two items are evaluated with a scale ranging from 1 (very poor) to 7 (very good). The results were then analyzed and the final score converted to a scale ranging from 0-100. Higher scores on the physical scale and global quality of life scale show a good level of functioning, whereas higher scores on the symptom scale indicate more severe symptoms or a lower quality of life. With regard to the statistical significance, a difference of 5-10 points is considered as slightly significant, of 10-20 points as moderately significant, and a change of more than 20 points is considered as significantly large or a clinically meaningful difference. Clinical relevance is shown by a difference in the average score of ≥ 10 points.

The CQOLC (The Caregiver Quality of Life index-Cancer). The quality of life of the family caregiver was measured using the caregiver quality of life-index cancer (CQOLC) questionnaire. The CQOLC questionnaire is a multidimensional and reliable tool which has been designed specifically for caregivers of patients with cancer, with a test-retest reliability of 0.95 and internal consistency of 0.91.[12]

It consists of 35 items divided into four domains (burden, positive adaptation, disruptiveness, financial concern) measured with a five-point Likert scale, ranging from 0 (not at all) to 4 (very much); the total score can thus range between 0 and 140, with a higher score indicating a lower quality of life.

Ethical permission

The Medical Ethics Committee of Universitas Gadjah Mada, Yogyakarta, Indonesia approved the study (Number: KE/FK/463/EC). The participating hospital gave us their permission to perform the study on the basis of the ethical clearance approval.

Procedures

This study performed using the self-care symptom management (SSM) approach based on the modification of the PRO-SELF program. The pre-intervention stage was conducted using a questionnaire that the participants completed in the presence of the researcher or assistants. Cancer patients were given the EORTC QLQ C-30 and the family caregivers were given the CQOLC. The SSM program included the dissemination of information, teaching of skills and provision of support. The disseminated information covered the definitions of cancer, chemotherapy, symptoms of the side effects from chemotherapy, and methods for reducing these. The researchers taught self-care exercises to the participants and their family caregivers that would assist in reducing the severity of the side effects.

These included techniques with regard to washing hands, relaxation in the form of deep breathing, warm and cold compresses to reduce pain, and a technique to prevent mucosity. At the end of the skills learning stage the participants were asked to demonstrate the techniques they had been taught and to review the information they had been given. They were also given a booklet about the methods that had been taught and a mucositis prevention kit. Telephone support is provided after the participants returned home, and this occurred a minimum of two times prior to their return to the hospital.

The patients were asked about the side effects they experienced, how they applied the information and skills that they had been taught, and were requested to give feedback about the program. The post-intervention stage was conducted by giving the EORTC QLQ-C30 and CQOLC questionnaires during the subsequent chemotherapy session for the patient and family caregiver, respectively.

Statistical Analysis

Descriptive statistics were used to describe the study sample in terms of demographic and clinical characteristics. A Wilcoxon test was performed to assess differences in the quality of life before and after the implementation of the SSM program, since the data are not normally distributed. In contrast, the data that are distributed are analyzed using a paired t-test. A p-value of ≤0.05 is considered to be statistically significant.

RESULTS

The majority of the participants in this study were female (87.5%), and aged between 40-65 years old (82.5%). All of the participants are Javanese. The majority of the participants have low education levels, with 40% graduating from elementary school and 25% from junior high school only.

Clinical characteristics, as shows in Table 2, reveal that the majority of the participants are suffering from breast cancer (60%), with 70% of these at an advanced stage (stages III or IV), have been diagnosed for less than one year (77.5%), and have received more than five cycles of chemotherapy (25%). With regard to the ECOG score, the largest group (35%) had a score of 1.

Table 1: Characteristics of participants (n=40).

Characteristics	Respondents	
	n	Percentage
Gender		
Female	35	87.5
Male	5	12.5
Age		
17-39	7	17.5
40-65	33	82.5
Ethnicity		
Java	40	100
Education		
No schooling	1	2.5
Elementary	16	40
Junior High School	10	25
Senior High School	10	25
University	3	7.5
Marital Status		
Single	2	5
Married	37	92.5
Widowed/Divorced	1	2.5%
Employment		
Civil Servant	1	2.5
Non-government employee	2	5
Laborer	3	7.5
Self-employed	5	12.5
Other	29	72.5

Table 3 shows the results of the statistical tests before and after the implementation of the SSM program for each variable, and those for the functional scale were not significant at p=0.173 (p >0.05), the global quality of life scale at p=0.802 (p>0.05), the symptom scale at p=0.844 (p>0.05), the single item of dyspnea at p=0.458 (p>0.05), and the significant result was found in the single item of sleep disturbance at p 0.001 (p<0.05). In addition, some single items were found not significant such as the single item of loss appetite at p=0.496 (p>0.05), the single item of constipation at p=0.392 (p>0.05), the single item of diarrhea at p=0.679 (p>0.05), and the single item of financial difficulties at p=0.211 (p>0.05).

Table 4 shows there are no significant differences in the family caregiver's quality of life before and after the implementation of the SSM program (p>0.05) for any of the single aspects of quality of life and the overall value of total quality of life.

Table 2: Clinical characteristics of participants (n=40).

Characteristics	Respondents	
	n	Percentage
Kind of cancer		
Breast	24	60%
Intestinal	3	7.5%
Non-Hodgkin lymphoma	3	7.5%
Nasopharyngeal (NPC)	8	20%
Lung	2	5%
Cancer stage		
II	5	12.5%
III	15	37.5%
IV	13	32.5%
Missing	7	17.5%
Length of time since diagnosis		
<5 months	18	45%
>5 months	13	32.5%
>1 year	8	20%
Missing data	1	2.5%
Chemotherapy cycle		
Cycle 1	6	15 %
Cycle 2	8	20%
Cycle 3	8	20%
Cycle 4	6	15%
Cycle 5	2	5%
>Cycle 5	10	25%
ECOG **Score**		
0	26	65%
1	14	35%

Table 3: Quality of life of chemotherapy patients before and after the Self-care symptom management (SSM) program (n=40).

Variable	Mean (SD)		p-value*
	Before	After	
Functional Scale	84.61(15.30)	82.46 (11.22)	0.173
QOL scale overall	69.79 (17.36)	69.79 (20.38)	0.802
Symptoms scale	22.59(16.74)	26.80 (35.71)	0.844
Shortness of breath	6.66 (20.25)	4.16 (13.47)	0.458
Sleep disorders	28.33 (34.21)	12.50 (23.49)	0.001**
Loss of appetite	21.66 (30.71)	25.83 (29.70)	0.496
Constipation	5.83 (19.81)	8.33 (19.61)	0.392
Diarrhea	2.50 (8.89)	3.33 (14.71)	0.679
Financial difficulties	45.83 (41.13)	37.50 (33.92)	0.211

*Data analysis used the Wilcoxon test (not normally data distribution). ** p-value<0.001 indicates a significant difference in quality of life between pretest and post-test of the SSM program implementation.

Table 4: Quality of life of family before and after the Self-care Symptom Management (SSM) program implementation (n=30).

Domain	Mean (SD)		p-value*
	Before	After	
Positive Adaptation	14.10 (SD:3.20)	14.37 (SD:4.09)	0.736
Burden	26.93 (SD:8.14)	24.73 (SD:8.07)	0.192
Disruptiveness	14.20 (SD:3.80)	15.13 (SD:5.33)	0.266
Financial worries	10.17 (SD:2.65)	10.43 (SD:2.48)	0.601
Other factors	39.98 (SD:4.45)	39.13 (SD:3.36)	0.278**
Total quality of life	104.93 (SD:15.53)	103.80 (SD:17.51)	0.751

Analysis used paired t test (normal distribution of data) **Data analysis used the Wilcoxon test (not normal distribution of data). A p value<0.001 indicates a difference in the quality of life between pretest and post-test of the SSM program implementation

DISCUSSION

The SSM program implemented in this study consists of providing information, teaching skills and giving support through telephone calls or home visits to a sample of Indonesians suffering from various types of cancer. Overall, there were no significant differences in the cancer patients' quality of life or that of their family caregivers (p=0.802) after taking part in the program. The factors that influence the overall quality of life are: age, cancer type, stage of cancer, length of time since diagnosis, chemotherapy cycle and general condition.[13-15]

The finding of no significant difference in the overall quality of life scores could possibly be influenced by the fact that all of the participants in this research were Javanese. In Indonesian culture, Javanese people tend to be accepting of their health conditions and to perceive a positive value in their health and life conditions, regardless of any illness or difficulties they are experiencing. Moreover, since we did not have a comparison group we cannot conclude whether cancer patients who did not receive SSM program would have had a different quality of life or not.

However, even though there were no significant differences between the pre- and post-intervention scores, a fall was found in the functional score (84.61 vs 82.46); the patients' and their family caregivers' perceptions with regard to the relative inactivity of the former during their illness may have contributed to this. During telephone counseling, some participants stated that their family caregivers advised them to reduce or avoid physical activity during the treatment period. The majority of the participants (67.5%) have a low education level, and this may indicate that they held some misconceptions about

the benefits and dangers of physical activity. This should be addressed by nursing staff, as maintaining physical activities can prevent muscle weakness and problems that are caused by long periods of inactivity, such as constipation, loss of appetite, and exhaustion, and can also reduce stress.[16]

A decrease in functional status can also be influenced by exhaustion related to the cancer treatments. Exhaustion can then further decrease the patient's quality of life, regarding their physical functioning and ability to carry out daily activities, as well as adversely affect their emotional, cognitive and social functions and roles.[17] Exhaustion can occur prior to chemotherapy and in patients with stage I-III breast cancer.[18]

The majority of participants in this study suffer from breast cancer (60%) in stages II and III (49%), were diagnosed over five months ago and having received multiple cycles of chemotherapy. Breast cancer patients who receive chemotherapy following an operation report greater exhaustion, a decline in daily activities, an increase in daytime sleeping, and an increase in periods of wakefulness during the night throughout the period of chemotherapy.[18]

Symptom scales assessed fatigue, nausea, vomit and pain, and the results showed an overall increase in the symptoms score but no significant difference between the pre- and post-intervention test scores (22.59 vs 26.80, p=0.884). This could have been influenced by treatment-related factors, e.g., the majority of participants received >5 cycles of chemotherapy. Research shows that approximately 25-30% of cancer patients who undergo chemotherapy experience symptoms of moderate to severe nausea, as well as a high probability of anticipatory nausea after 3-4 cycles of chemotherapy.[19] However, each patient responds differently to the side effects of chemotherapy.

Another factor that may influence the emergence of exhaustion is the time spent waiting for a room for the next chemotherapy session. Moreover, the lack of physical activity can result in participants being less energetic with regard to managing the side effects that arise after treatment. Pain may also be caused by the treatment, and the majority of the participants were 40-65 years old (82.5%). In this context, it should be noted that physiological changes related to aging and comorbidity can also increase the risk of toxicity of chemotherapy.[20]

The use of antiemetics and analgesics prescribed by the doctor, teaching the skills needed to manage side effects (e.g. better oral hygiene and the use of warm compresses), as well as providing information to eat small meals or drink warm ginger drinks when nauseous, could be useful in decreasing the severity of their symptoms for the majority of this study's participants. However, these strategies are still not sufficient to eliminate the side effects of chemotherapy, and this may

be related to how many of these techniqes were used and how well they were applied; such details were not recorded in this study.

Single items that examined shortness of breath, sleep disorders, loss of appetite, constipation, diarrhea, and financial difficulties reveal some interesting results. Shortness of breath, loss of appetite, constipation and diarrhea showed no significant differences between the pre-and post-intervention scores, with p =0.458, 0.496, 0.392, and 0.679 respectively. The increase in the degree of loss of appetite was likely influenced by the side effects of nausea and vomiting, which occurred with the majority of participants. The side effects of cancer treatment also affect the body's ability to absorb nutrients from food.[21] With regard to the financial difficulties score, this fell by around 8.33 points (45.83 vs 37.50, p =0.211) after the intervention, and while this is not significantly different it does have a moderate clinical relevance.

Most of the participants stated that the health facility they visited paid for their medical expenses, and that they had also sought to obtain loans to overcome the financial difficulties they faced. The results of another study showed that there was a significant improvement in the single item of financial difficulties if the patients knew the total costs incurred during chemotherapy after being discharged from hospital.[22] Financial problems are also closely related to a patient's decision to continue or postpone medical care after being diagnosed with cancer[23].

There was a clinically significant difference in sleep disturbance symptoms before and after the intervention (28.33 vs 12.50, p=0.001). The 15.83 points (28.33 vs12.50) are considered clinically moderate differences. A significant change in the sleep disturbance score after the implementation of the SSM program may indicate that the majority of participants tend to accept their condition, and thus did not experience greter anxiety or take more rest. Anxiety is associated with an increase in cortical and peripheral stimulation that can lead to sleep disturbance.[24] The lower levels of anxiety found in this study may be because all the participants were Javanese (100%), with a culture that leads them to accept the conditions they experience and have confidence that the disease and the side effects of its treatment were part of a test given by God.

The quality of life of family caregivers is influenced by various factors, such as the quality of life of the patients.[25,26] This study found no significant difference between the pre- and post-implementation scores for the caregivers. This is supported by research conducted by Tang et al among patients and family caregivers of cancer patients in Taiwan. Their study found that the family burden, which is part of the domain of quality of life, has a positive relationship with the severity of the family's condition.[27] The current study assessed the quality of life

of the family caregivers before implementation of the SSM program (i.e., the period prior to the patients' chemotherapy) and immediately after the implementation of the program (after the patients' chemotherapy).

This might the reason why there is no significant difference in the quality of life of family caregivers after the implementation of the program, because of the high burden faced by family caregivers who were still caring for the post-chemotherapy patients when completing the second survey (the average value of burden 24.73; SD = 8). Periodic assessments of the quality of life for family caregivers may thus still need to be done for several weeks after the patient receives chemotherapy, or when the patient's condition improves.

Limitations

This study has the following limitations that should be noted. First, the sample is small, which limits the generalizability of the findings. Moreover, the quasi-experimental design and lack of a control group make it difficult to assess the benefits of the SSM program compared with standard care. There were also no records taken to assess whether the participants actually applied the skills that they had been taught or not, and this would also impact the study's findings. However, our results do show an improvement in quality of life, in terms of sleep disturbance, and the participants said that the intervention was valuable with regard to addressing the side effects of treatment. It can thus be concluded that the SSM program represents a promising intervention to promote self-care management in cancer care in Indonesia.

ACKNOWLEDGEMENTS

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