



ASSESSMENT OF FCEM ON THE CONCERN OF PARENTS WITH CANCER DIAGNOSED IN ADOLESCENTS

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ABSTRACT

Families face multiple problems after their children are diagnosed with cancer. This study aims to determine the effect of the Family-Centered Empowerment Model (FCEM) on the care burden of the parents of children, diagnosed with cancer. This quasi-experimental study was conducted with 78 parents, having children with cancer. The FCEM was implemented in the intervention group in four stages, namely perceived a threat, self-efficacy, educational participation, and evaluation during four sessions of 20-40 minutes. The control group only received the usual care. The burden of care of the control and intervention groups were measured one month after filling out the initial questionnaire, and one month after the end of the intervention, respectively. The two groups were similar in terms of demographic variables and level of burden of care. However, a statistically significant difference was observed between the two groups, in terms of the level of burden ($p < 0.001$). The results of this study showed that the empowerment of parents of children with cancer has an impact on reducing their care burden, and using this empowerment model is recommended to the treatment team, especially nurses.

Keywords: *Family-centred empowerment- cancer- burden of care- family-centered care- children.*

1. Introduction

Children and adolescents are at an increased risk of cancer since it is a chronic disease (Siegel et al., 2016). The rapid start of cancer, rigorous long-term therapy, and acute and frequently chronic consequences have elevated cancer to the status of a major public health concern.. concern. Researchers think that cancer should be treated as a family disease since the treatment of children with cancer has a significant impact on their families, particularly their parents. It's important for parents to understand that they continually rethink their duties and functions as



members of the treatment team, as well as their communication patterns both within and outside the home (Crespo et al., 2016). In other words, parents must bear emotional and mental stress while simultaneously carrying out their medical duties, parental supervision, and all of their other roles and obligations, which are clearly defined. Families with cancer-stricken children typically experience greater physical and psychological symptoms, as well as more visits to the doctor as a result.

According to the findings, the care of a chronically sick child placed a significant load on parents. The caregiver burden can be objective or subjective, depending on whether it refers to the physical and/or mental effects of providing care or the negative feelings that the caregiver experiences as a result of providing care (Sav et al., 2015)

Children with cancer, whether they are at home or in the hospital, are affected significantly by their parents' caring practises. Promoting chances for carers to care for children with cancer, join caregiver support groups, and engage in talks with nurses can empower caregivers by improving their competence in caring for them, according to the authors. At the same time, these activities provide caregivers a chance to express their thoughts and feelings and gain from the advantages of working in a group.

1.1FCEM

The load level can be reduced via improved physical and mental function and increased self-ability if the family is empowered. When it comes to the three motivational, psychological (self-esteem, self-control and self-efficacy) and self-problem qualities the FECM is built on the effectiveness of the individual's and other family members' role (like perceived knowledge, attitude and perceived threat). There are several goals of the FECM. The most important one is to help families that have children with cancer (patients and their siblings). Four steps make up the FECM, the first of which is increasing knowledge through educational sessions, using educational support materials like PowerPoint presentations, posters, models and hand-outs, and educational methods like group discussions, questions and answers (Q&A) and lectures. The FECM is divided into four parts. This empowerment programme may reduce the parental burden of care while providing care for their children with cancer who are undergoing chemotherapy, as



the second step is to improve self-efficacy. The third step is to increase self-esteem through educational participation, and the fourth step includes an evaluation process during empowerment sessions (Borhani et al., 2011) There is no empowerment framework for carers of children with cancer being used by the healthcare team in this environment. Sustaining the health of patients will enhance the likelihood that chemotherapy will be completed successfully, reduce its adverse effects, and improve the quality of life for cancer patients and their parents. The goal of this research was to assess the impact of FCEM on the caregiver burden of parents of cancer patients. What we should find out from this study is whether or not the FCEM reduces the care load on parents of chemotherapy-treated children with cancer

.2. Materials and Methods

There were two phases to this quasi-experimental study: pre-intervention and post-intervention. With a confidence level of 95% and an 80 percent test power, the sample size was calculated to be 34.1 in each group, assuming the impact of FCEM on parental burden of care is at least $d=10$. Because of the sample loss, a total of 39 people were included in the study, nine in the intervention group and nine in the control group. The researchers used the continuous sampling approach to identify the parents who satisfied the inclusion criteria by consulting the clinic and department dealing with children's oncology. A 2-way blocking approach was used to separate the parents into two groups: those who were under control and those who were receiving assistance. One-sided blindness was used in this research, thus participants' parents had no idea whether their child was in an intervention or control group. Finally, the study included 78 parents of children ranging in age from one to six years. In both the intervention and control groups, they were included (35 mothers and 4 dads) (35 mothers and 4 fathers).

2.1 Intervention

The primary investigator and experts developed an empowerment programme based on the Alhani empowerment model to help caregivers become more competent in caring for children with cancer who are undergoing chemotherapy. The Alhani empowerment model includes four steps: 1) perception of threat, 2) acquisition of skills and self-efficiency, 3) building self-confidence through educational participation, and 4) evaluation. Ultimately, the goal was to



better equip caregivers to care for children with cancer by providing them with the knowledge and skills they need to do so. A committee of experienced nurses has evaluated and approved the instructional content. "Children with Cancer: A Guide for Parents- National Cancer Institute, 2014" served as the inspiration for this booklet's material (diagnosis, treatment, adaptation strategies, life and care follow-up). Each session in this booklet includes a number of open questions that the researcher used to gauge the effectiveness of the procedure and also to provide input for the final report. Before the FCEM could begin, parents were required to complete a questionnaire regarding their child's burden of care, and the model was used to guide its execution, which included four 40-minute sessions spread over four weeks (one session per week, per day). Prior to each session, a schedule was worked up with the parents, and classes were held at times that worked for everyone. A study room next to a cancer department at two hospitals was used for all sessions, both individual and group. As part of the empowerment programme, the researcher spoke face-to-face with parents about childhood cancer types, common signs and symptoms, diagnostic methods and treatment programmes based on the stage and condition of the child's illness for 40 minutes, using an educational booklet. These parents were then given the necessary trainings in those areas. They received the study guide at the end of the session.

It's important to note that each parent in the intervention group received this session on their own. In order to execute the second stage of the empowerment model, the parents were divided into groups of 3-6 and requested to speak with the hospital treatment team about communication methods and exchange ideas with the team during the second session lasting 40 minutes. They discussed the treatment, assessment, and management of chemotherapy side effects during this meeting. Aside from infection prevention and pain control and relief, additional topics covered in this session included immunisation, increasing self-control when dealing with unwell children and their concerns, as well as strategies to assist other family members. There was a lot of indirect leadership throughout this session, as the researcher tried her best to help the group feel more self-efficacious. Participants were asked to teach a member of their family who was in charge of caring for the child what they had learned in the previous two sessions and answer his/her questions under the researcher's indirect supervision during the third session, which



implemented the third step of the empowerment model. As soon as the trained parents made a mistake or transferred erroneous knowledge, the researcher rectified it promptly throughout this session. Final assessment sessions are held in the fourth session, and at this time the researcher assesses each participant's knowledge of all topics presented and concerns raised in the previous sessions. Finally, any remaining misunderstandings are clarified.

3. Instrument

There were two sections of the questionnaire utilised in this investigation. In the first section, questions were asked regarding the subjects' demographics, including two different kinds: the child's belongings, and the parents' and other family members' belongings. The second portion of the questionnaire contained questions about the financial hardship parents bear in providing care for their children. The Zarit caregiver burden self-report questionnaire was used to gather data. The caring load for parents was assessed using a scale with 22 questions concerning psychological stressors. (Zarit et al., 1980) created it to gauge the emotional strain caused by the illness. These questions were answered on a 5-point scale by family caregivers who were interviewed. The questions ranged from "never" to "rarely" to "occasionally" to "frequently" (always). According to the sum of each caregiver's scores, the amount of caring work they were facing. It was found that a total score of 30, 31-60, and 61-88 indicated low to moderate and high loads. The lowest and highest possible grades were 0 and 88, respectively, for each subject. The higher the score, the greater the burden of caring; the converse is also true. (Schreiner and colleagues, 2006) For the original Zarit burden interview questionnaire, reliability was found to be 0.71% (test-retest) and internal consistency was found to be 0.91% (Schreiner et al., 2006)

Caregiver burden	Pre-intervention				After intervention			
	Intervention Group N=39		Control Group N=39		Intervention Group N=39		Control Group N=39	
	Number	Frequency	Number	Frequency	Number	Frequency	Number	Frequency
(88-0)								
Weak	19	48.7	17	43.6	28	71.8	15	38.5
(0-30)								
Moderate	19	48.7	21	53.8	11	28.2	22	56.4
(31-60)								
Severe	1	2.6	1	2.6	0	0	2	5.1
(61-88)								
Sum	39	100	39	100	39	100	39	100
Fisher's Exact Test	p=0.908				p=0.008			

Table1:Frequency of caregiver burden in intervention and control groups (N=78) among parents of cancer patients(Siegel et al., 2016)

3.1Control group

Parents in this group completed the burden of care questionnaire twice, once at a month interval and once without any additional intervention. It's important to note that throughout this one month, the parents in this group got all of the regular standard hospital care.

	Intervention Group		Control Group		Independent t-test
	Mean	SD	Mean	SD	
Caregiver burden					
Pre-intervention	33.28	12.65	34.03	12.17	t=0.264 p=0.792 ES: 0.059
After-intervention	24.67	9.01	34.13	11.79	t=3.980 **p<0/001 ES:1.04
Differences between Groups	-8.61	10.2	0.102	6.37	t=4.547 **p<0/00 ES=0.854

Table2:The difference between intervention and control groups in terms of caregiver burden for parents of cancer patients(Siegel et al., 2016)

4. Results

Seventy-nine mothers (90.7%) and eight dads (10.3%) were randomly assigned to one of two groups: intervention or control. A breakdown of the family's demographics can be found in Table 1 and Table 2. There were more females (53.8 percent) than boys in the intervention group, and there were more girls than boys in the control group, according to the findings (51.3 percent). More than 40% of the children in the intervention group were 3-4 years old, whereas 53.8% were in the control group. The intervention group had a higher percentage of siblings (64.1 percent) than the control group (69.2 percent). To the best of our knowledge (Table 1), there was no significant difference between groups in terms of gender, age, or whether or not someone had siblings.

The intervention group had a higher percentage of 31-40-year-old moms, whereas the control group had a higher percentage of 50.0 percent-old mothers. More than eighty-nine percent of intervention group moms (89.7 percent) were homemakers, whereas over seventy-nine percent of intervention group mothers (76.2 percent) had a high school education or above. Pre-intervention differences in the ages, occupations, and educational attainment of mothers were non-existent between the groups. The results show that before the intervention, caregiver load was low (48.7%) for most parents in the intervention group and moderate (53.8%) for most parents in the

control group. Parental caregiver load was not significantly different across groups, according to the Fisher exact test ($p=0.908$). After the intervention, caregiver load was low for most parents in the intervention group (71.8 percent) and moderate for most parents in the control group (56.4 percent). Parental caregiver load was significantly different across groups, according to the Fisher's exact test ($p=0.008$) (Table 3). Parents in both control and intervention groups did not have significantly different mean caregiver burden scores pre-intervention based on independent t-test results ($p=0.792$), however this difference became statistically significant after intervention ($p<0.001$). According to the comparison of the two groups, the mean parental burden of care was higher in the control group after the post-test than it was before. The intervention group's mean parental care burden, on the other hand, significantly decreased after the test (Table 3).

Caregiver Burden	Intervention group N=39		Control group N=39	
	Mean	SD	Mean	SD
Pre-intervention	33.28	12.65	34.03	12.17
After-intervention	24.67	9/01	34/13	11.79
t-test	t=5.272 df=38 **p<0.00		t= -0.100 df=38 **P<0/00	

Table 3: Mean and Standard Deviation of Caregiver Burden for the Parents of Children with Cancer before and after the Intervention in Intervention and Control Groups (Inter-Group)(Siegel et al., 2016)

5. Discussion

The goal of this research was to assess the impact of FCEM on the caregiver burden of parents of cancer patients. The intervention group's caregiver burden decreased when the FCEM was implemented, according to the findings. In other words, following the intervention, caregiver burden was lower for parents of cancer patients in the intervention group than for parents in the



control group. The findings confirmed the prediction that caregiver involvement in an empowerment programme would enhance their competency in caring for chemotherapy-treated children with cancer. Enabling caregivers to have a better actual perspective and develop critical reflection were beneficial parts of the empowerment programme. As a result of the empowerment framework, caregivers now have a better grasp of cancer and chemotherapy symptoms and side effects. These insights aided caregivers in making judgments about care options that were most suited to their circumstances. Finally, building self-confidence via educational involvement was the third step. According to the model, step four was the evaluation, in which the parents were given the chance to discuss what they had learned about caring and speak with each other in order to guarantee that they could take care of the child.

6. Conclusion

Educating and motivating parents to learn more about caregiving is an excellent strategy for easing the caregiving strain on them. Increased parental impression of the current danger is likely to result from education about sickness and treatment, as well as issues that might arise if patients don't follow their health care provider's recommendations. When parents assemble to discuss and prepare solutions to their difficulties, it increases their likelihood of involvement since they are around others who are experiencing the same issues. They are also more compassionate and less burdened when they participate in educational talks that address their own needs and convey their knowledge to another family member. Nurses who are aware of the value of caring can have a positive impact on the families they serve. They found that nurses may use FCEMs to help patients who are dependent on the medical team by reducing their reliance on them and giving them more autonomy in their care by consulting with them and addressing problems with them in an active way. Patients' families will be empowered and their adherence to treatment regimens will be improved by family-centered care programmes, which will play an important part in the management of physical and mental health of patients



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