

Effect of Educational Training Program for Mothers about their Cancer Children Care and its Effect on Children Health Status

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ABSTRACT

Background: Cancer diagnosis and its treatment highly affects negatively on health –related quality of life of children with cancer in physical, social, psychological, and cognitive dimensions in addition to put their care giver in a challenging situation.**The aim:** of this study was to evaluate the effect of educational training program for mothers about care of their children with cancer and its effect on children health status. Quasi-experimental research design was used in the study, a convenient sample of **50** mothers and their children with cancer at inpatient and out- patient departments at Oncology Institute in Mansoura City for six months from November 2013 to April 2014.**The tools:** of data collection were an interview questionnaire form to collect data about socio-demographic characteristics for studied mothers and their children, assessment of knowledge & reported practice related childhood cancer and chemotherapy sheet and assessment of children health status scale. **The results:** revealed that There were statistically significant improvements in mother's knowledge and reported practice with p. value $P < 0.001$. Subsequently, the results lead to a positive impact on their children's health status (physical, psychological, and social status), while there were no statistically significant improvement in children school achievement and their self- care. **The study recommended:** periodic or continuous training program should be applied for mothers and their child in the pediatric oncology departments to improve their knowledge and practice about childhood cancer which can increase improving in physical, psychological and social dimensions for children and subsequently improving of school achievement and self-care as possible.

Key Words: Intervention program, mother's knowledge & practice, childhood cancer, children health status

INTRODUCTION

The health status of children with cancer has been a subject of increasing interest in recent years, it was measured by general health, mental health, functional status, limitation of activity, pain, anxiety and fear as a result of cancer or its treatment (*Ali, 2012*). Also the Health Related Quality Of Life (HRQOL) focused on functional status and sense of well-being and unexpressed perception of both positive and negative aspects of physical, emotional, social, cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease and its treatment (*Bondini et al., 2007; Yeh and Hung, 2011*).

The assessment of health status is a great importance for pediatric cancer and their health care providers as a result of improvement of their survival rates and their quality of life (*Yeh, 2010*). The diagnosis and treatment of cancer is stressful and threatening experience that places children at significant risk for a range of short and long term physical, psychological, social, cognitive, and behavioral difficulties. Subsequently children with cancer usually fail to develop the autonomy and independency as a result of nature of disease and its treatment. Mothers as primary care givers have a dangerous role towards their children to provide the care and improve their health status and their quality of life, therefore, this study evaluates the effect of the intervention program for mothers about care of their children with cancer on their children health status (*Radwan, 2009*).

AIM OF THE STUDY:

Evaluate the educational training program for mothers about care of their children with cancer and its effect on children health status.

Research Hypothesis:

Mother's knowledge & practice of studied mothers and their children with cancer was improved after the implementation of the education program related to the care of their children and health status.

SUBJECTS AND METHOD:

Research Design: A quasi-experimental research design was utilized in the conduction of the study.

Setting: The study was carried out at pediatric inpatient and outpatient departments at Oncology Institute of Mansoura City.

Subjects: A convenient sample of 50 mothers and their children were used in the study according to inclusion criteria which were mothers should be accompanying child during chemotherapy at the study setting; children have any type of childhood cancer; children's age from 6 to 18 years; Children were from both genders; and they were undergoing chemotherapy and received at least two doses.

Tool for data collection:-

Three different tools for data collection were used in this study as following:

TOOL (1): Structured Interview Questionnaire Sheet:

Upon inclusion in the study sample, each mother was interviewed individually. The questionnaire was designed by researcher after reviewing related to literature; it was designed in Arabic language to suit understanding of the study subjects. It contained two parts:

Part (1): Socio demographic characteristics of studied children such as age, gender, birth order and educational attainment.

Part (2): Socio demographic characteristics of mother's such as age, educational level, job status, residence and income, as well as family size.

TOOL (2): Assessment of mother's knowledge and reported practice about childhood cancer sheet, it included:

Part (1): Assessment of mother's knowledge about childhood cancer

This part was intended to assess mother's knowledge about cancer such as definition, risk factors, symptoms, and spread of disease, investigations, complications, and treatment. It also had questions for mother's knowledge about chemotherapy definition, duration, routes, action, and side effects, in addition to dealing with child under chemotherapy and the home precautions.

Scoring system: For each question, a correct answer was scored 1 and zero for correct answer. For each area of knowledge, the score items were summed-up and the total divided by the number of items, giving mean scores for the part. These scores were converted into percent score. Knowledge was considered satisfactory if percent score was 50 % or more and unsatisfactory if less than 50 %.

Part (2): Assessment of mother's reported practice while caring of their children with cancer and undergoing chemotherapy.

This tool was aimed at assessing mother's reported practice while caring for their children with cancer. It involved questions about the care provided for side effects as bone marrow, skin, and gastrointestinal, respiratory, urinary, muscle-skeletal, neurological and psychological side effects of chemotherapy. The mother was asked whether the steps of care for each side effect was done or not done.

Scoring system: The steps reported to be done were scored (1) and the items not done were scored (0) for each area, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into percent scores. The reported practice was considered adequate if the percent score was 60% or more and inadequate if less than 60%.

TOOL (3): The Pediatric Health Status Assessment Tool

This tool intended to assess the level of activity and health impairment of the child. It consisted of the following parts:

Part (I): Lansky Play Performance Scale

This scale assesses the performance status and activity of daily living of children used this tool. It was initially developed by *Lansky (1997)*, and modified by *Yaris et al (2001)* and *Ali (2012)*. The scale and was consisted of eleven levels or grades ranging from 0 to 100%.

Part (2): Health related Quality of Life

This part of the tool was used to assess the health related quality of life of the child with cancer. It was initially developed by *Verny(2003)*, and modified by *Radwan (2009)* then by researcher. The tool consists of 49 statements assessing impairment in physical, psychological, social, school achievement, and self-care areas.

Method of study

- An official permission was obtained from the directors of oncology institute in Mansoura city through an official formal letters from the dean of The Faculty of Nursing Port Said University.
- The tools were tested for their content validity and clarity by seven experts in nursing and medical pediatrics and oncology for face and content validation. The tools were then adjusted based upon their recommendations.
- Informed consent was obtained from each mother in the study after explaining its purpose and importance. Confidentially of the information was assured by the researcher.
- A pilot study was carried out after review of data collection tools by seven experts. It was applied on 10% of study sample (five mothers and their children with cancer attending the Oncology Institute in Mansoura City). The purposes of the pilot study were to test the applicability, clarify, and feasibility of the data collection tools.
- The actual study was conducted through four phases: assessment phase, program development phase, implementation phase and evaluation phase.

Assessment Phase (Pretest): This phase-involved preparation of the tools and assessment of the mothers' knowledge and practice regarding the care of their children with cancer undergoing chemotherapy and assessment children health status. After obtaining the mother's consent, the researcher conducted an individual interview with her in the study setting according to hospital policy .Each interview questionnaire took approximately 35 to 40 minutes using an individual interview questionnaire form.

Planning Phase: the researcher developed the educational program using the baseline information gathered in the assessment phase.The program aimed at improving mothers' knowledge and reported practice for provision of care to their children with cancer and evaluate the effectiveness of the program on children health status. The program included materials to improve mothers' knowledge regarding the definition of childhood cancer, its types, clinical manifestations, predisposing factors, investigations and treatment. It also covered instructions concerning the preparation of the child before, during, and after chemotherapy doses and the precautions to protect other children at home. The program also included reported practice related to

care of chemotherapy side effects such as disturbances of bone marrow, gastrointestinal tract, respiratory system, hair and skin, urinary system, musculoskeletal system, nervous system, and psychological impairment.

Implementation phase: The implementation of the program was carried out at the inpatient and out-patient departments in the study setting. The program was administered in five sessions; the duration of each session lasting from 45 to 60 minutes. The sample of mothers was divided into 10 groups; each session of the program included five mothers. At the beginning of the first session of the program, mothers were oriented about program objectives, contents, and procedures. The program was implemented two days per week during a period of 6 months from November 2013 to April 2014.

The educational program was presented in a clear and concise form, following the principles of adult learning, focusing on interactive learning and active participation. It was implemented using different teaching methods such as short lectures, group discussion, practice, demonstration and re-demonstration. In addition, different audiovisual materials were used as pamphlets, pictures, posters and video to facilitate the teaching of each topic.

Evaluation Phase: The effectiveness of the program was based on assessing the improvement in mother's knowledge and reported practice and of children's health status.. This was achieved through comparing the pre-test with post- test immediately done after the implementation of the program, and the follow- up test carried out three months later.

Statistical analysis of data:Up completion of data collection, variables included in the structured interview sheet, were coded prior to computerized data entry. The raw data were coded and transformed into coding sheets. The results were checked. Then, the data were entered using SPSS 20.0 statistical software package. Output drafts were checked against the revised coded data for typing and spelling mistakes. Finally, analysis and interpretation of data were conducted.

RESULTS:

Table (1) demonstrates socio-demographic characteristics of the studied children with cancer, children's age ranged between six and sixteen years, with more males (60.0%). Slightly more than one-third of them (42.0%) were firstborn. As for their educational level, approximately two-thirds (68.0%) were in the primary level, whereas only 4.0% were in secondary education.

Table (2) shows socio-demographic characteristics of studied mothers, it illustrated that mother's age ranged between 25 and 55 years, with median 35. They mostly had secondary education (64.0%). As, the family size ranged between three and six members, with median five, and the great majority (92.0%) having insufficient income.

Figure (1): shows total mother's knowledge about childhood cancer throughout the study phases. It clarified that 14% of the studied mothers had satisfactory knowledge pre the intervention, while post the intervention immediately and at follow up, majority of the studied mothers had satisfactory knowledge (96 %, 94%) respectively. There was statistically significant improvement ($p < 0.001$).

Figure (2): illustrates total reported practice of the studied mothers related to their children care of chemotherapy side effects throughout the study phases. It clarified that only 34.0% of the studied mothers had total adequate reported practice at the pre-intervention phase. Meanwhile, majority of them (96.0%) had adequate reported practice at the post- intervention and 90.0% of them at the follow up phase. These improvements were statistically significant ($P < 0.001$).

Table (3): shows Performance and activity score of the studied children according to Lansky- Scale pre the intervention and at follow – up. Illustrates performance and activity score of the studied children with cancer according to Lansky- performance Scale pre the intervention and at follow –up. It pointed that a slight increase children's activity score in the follow up phase compared with pre- intervention phase. However, this difference was not statistically significant.

Table (4): illustrates health impairment among studied children pre the intervention and at follow-up phase. The follow up phase showed statistically significant decreases in the percentages of children having severe physical ($p = 0.04$), psychological ($p = 0.03$), and social ($p = 0.03$) health problems. On other hand, no significant changes were revealed in the cognitive/school or self –care impairment.

Figure (3): shows total health impairment among studied children pre the intervention and at follow-up, it demonstrated improvement of children's health impairment at follow–up compared with pre-intervention phase. The percentage of children with severe impairments decreased from 60% to 40% respectively.

Table (1): Percent distribution of studied children related to socio-demographic characteristics

Socio-demographic Characteristics	N = (50)	%
Age (years):		
<12	34	68.0
12+	16	32.0
Range	6.0-16.0	
Mean± SD	9.5±3.2	
Median	8.5	
Gender:		
Male	30	60.0
Female	20	40.0
Birth Order:		
First	21	42.0
Second	20	40.0
Third	6	12.0
Fourth	3	6.0
Level of Education:		
Primary level	34	68.0
Preparatory level	14	28.0
Secondary level	2	4.0

Table (2): percent distribution of studied mothers related to Socio-demographic characteristics.

Socio-demographic Characteristics	(n= 50)	%
Mothers Age (years):		
<35	22	44.0
35+	28	56.0
Range	25.0-55.0	
Mean± SD	35.6±7.4	
Median	35	
Mothers Education:		
Basic education (primary& preparatory)	3	6.0
Secondary education	32	64.0
University education	15	30.0
Mother's job:		
House wives	45	90.0
Employed mothers	5	10.0
Residence:		
Urban	26	52.0
Rural	24	48.0
Family size		
<5	8	16.0
5+	42	84.0
Range	3.0-6.0	
Mean ±SD	5.0±0.6	
Median	5.00	
Income		
Sufficient	4	8.0
Insufficient	46	92.0

(*) Statistically significant at $p < 0.05$

Figure (1): Total mother's knowledge score about childhood cancer throughout the study phases.

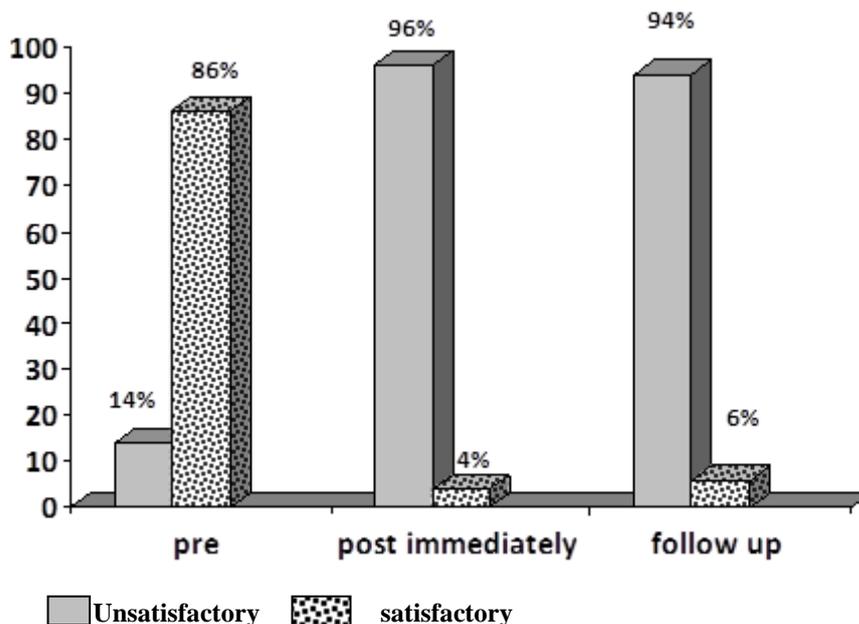


Figure (2):Total reported practice score of the studied mothers related to their children care of chemotherapy side effects throughout the study phases.

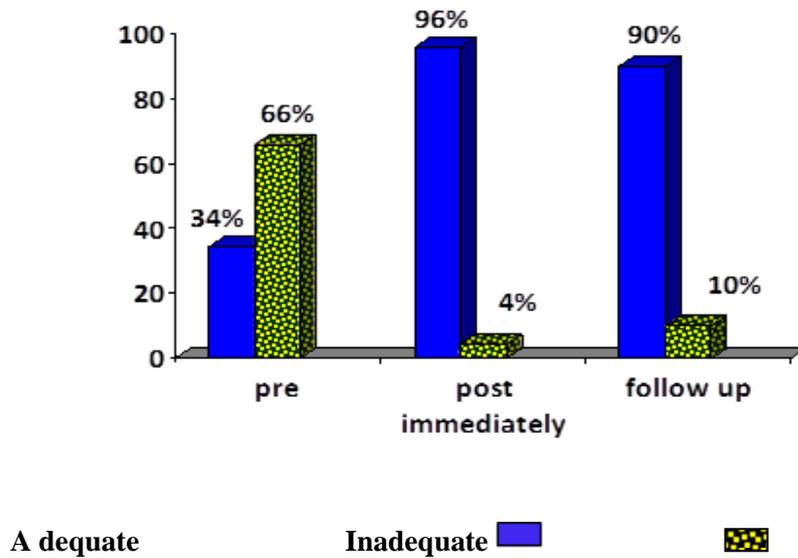


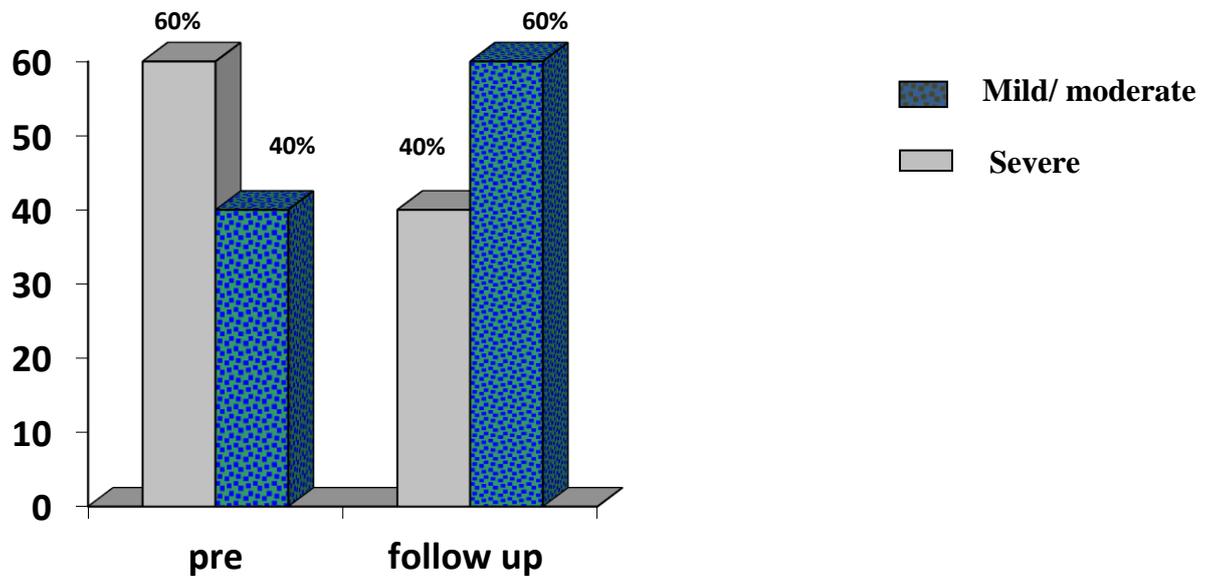
Table (3): Percent distribution of the studied children related to practice and activity score using Lansky- Scale pre the intervention and at follow – up.

Activity and performance scale	Program phases				Mann Whitney Test	p-value
	Pre		FU			
	No.	%	No.	%		
Activity score :						
+ 70	34	68.0	36	72.0	0.19	0.66
< 70	17	32.0	14	28.0		
Range ±SD	10.0-90.0					
Median	65.8±20.6					
	70.0					

Table (4): percent distribution of studied children related to health impairment pre the intervention and follow-up.

Severe impairment of:	Program phases				X ² Test	p-value
	Pre		FU			
	No.	%	No.	%		
Physical health impairment	33	66.0	23	46.0	4.06	0.04*
Psychological health impairment	19	38.0	9	18.0	4.06	0.03*
Social health impairment	32	64.0	13	26.0	4.06	0.03*
Impairment of cognitive /school achievement.	38	76.0	42	84.0	1.00	0.32
Self-care	8	16.0	8	16.0	0.00	1.00

Figure (3): Total health impairment among studied children pre the intervention and at follow-up.



DISCUSSION:

Mothers of children with cancer may suffer from various forms of distress in regards to the child's illness, side effects of treatment. They have serious duties and roles toward their children because children with cancer often fail to develop independency and autonomy as result of their illness nature, treatment and complication of disease. Meanwhile, mothers as primary care givers have roles to promote the care of their children and to improve their quality of life (*Roddenberry & Renk, 2008; Thompson et al., 2009*). The present study was carried out to evaluate the intervention program for mothers about care of their children with cancer and its effect on their children health status.

The implementation of the current study intervention led to significant improvements in mothers' knowledge. This was noticed in most areas related to cancer itself and chemotherapy. Thus, by the end of the intervention, majority of the studied mothers had satisfactory knowledge, which points to the effectiveness of the educational program in achieving its first specific objective. The present study findings are in agreement with those of *Rodrigues et al. (2010)* who demonstrated a lack of mothers' information about childhood cancer, and recommended an educational intervention based on identification of mothers' information needs during the hospitalization with their children in order to understand the disease nature to be able to support their children. On the same line, *Juma et al. (2010)* found that the majority of the mothers had no knowledge of cancer and chemotherapy in children before implementing their program. After the educational program, 94% of the mothers had correct knowledge about childhood cancer and chemotherapy. Similar successes of educational interventions targeting the parents and siblings of children

with cancer were reported from Iran (*Hashemi & Sokrpour, 2010*), Malaysia (*Othman et al., 2010*), Sweden (*Ringner et al., 2015*) and (*Lindsey et al., 2014*).

After the implementation of the present study intervention, the practices of the mothers improved in all the aspects tested. This was assessed as self – reported practice. Hence majority of them had adequate reported practice at the post- intervention and 90.0% of them at the followup phase of the educational intervention demonstrated total adequate practices. This is undoubtedly attributed to the effect of the educational program as shown by the results of the multivariate analyses, which identified the attendance of the program as the main and independent factor positively influencing mothers' practice scores. The result is also in partial agreement with (*Ringner et al., 2014*) and (*Gangane & Sebastian, 2015*) in India which demonstrated high satisfaction of parents of children with cancer with personalized intervention.

The ultimate goal of the present study was to improve the health status of children with cancer through improving their mothers' knowledge and practices. The univariate analyses demonstrated slight improvement in children's activity scores following the intervention. However, the univariate analysis, there was a significant improvement in this score, and this was mostly induced by the attendance of the intervention program as the main significant positive predictor. The finding is in congruence with that of *Elsayed & Mahmoud (2012)* who demonstrated significantly less restriction in children's performance of activities following their educational intervention. A similar improvement in Lansky performance scale among children with cancer was shown following an intervention program in a study in India (*Batra et al., 2014*).

The current study also was aimed at improving the Health-Related Quality of Life (HRQL) of children suffering from cancer as a consequence of their mother's improved knowledge and practice. The results of the study actually demonstrated significant improvements in their HRQL, with decreases in their health impairments. This was noticed in most aspects of (HRQL), particularly regarding the physical, psychological, and social aspects. The findings are in agreement with the study done in Germany, which demonstrated significant improvements in the physical and psychological aspects of the (HRQL) of children with cancer (*Beulerz et al., 2016*). On the same line, a randomized clinical trial conducted in Hong Kong reported the effectiveness of a health education program in enhancing the physical, psychological, and social aspects of the HRQL of children with cancer; these improvements were sustained through a follow-up period of 18 months (*Chung et al., 2015*). Similarly, *Gibson et al. (2010)*, who found that children with cancer engaging in regular physical activity after intervention showed better health outcomes, including better HRQL, better functional capacity and better mood states. However, a study carried out in the Netherlands demonstrated only a slight improvement in physical aspect of HRQL of children with cancer (*Van Dijk-Lokkart et al., 2015*). This lack of considerable improvement was attributed to the burden of attending the training program, which negatively influenced children's participation (*Van Dijk-Lokkart et al., 2014*).

CONCLUSION:

Based on the findings of the present study, it was concluded that knowledge and reported practice of the studied mothers related to care of their children with cancer and undergoing chemotherapy were deficient pre-the intervention program. While after developing educational intervention program to them, the results revealed that there were statistically significant improvement in mothers' knowledge and reported practice .Subsequently, this lead to a positive impact on their children's Health status (physical, psychological, and social status).

RECOMMENDATIONS:

Based on the findings of the present study, the following recommendations are to be considered: periodic or continuous training program should be applied for mothers and their child in the pediatric oncology departments to improve their knowledge and practice about childhood cancer which can improve children health status.

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تأثير برنامج تعليمي تدريبي للأمهات حول رعاية أطفالهن المصابين بالسرطان وتأثيره علي حالتهم اطفالهن الصحية

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الخلاصة

تهدف هذه الدراسة شبه التجريبية إلي تقييم برنامج تداخلي للأمهات حول رعاية أطفالهن المصابين بالسرطان والخاضعين للعلاج الكيماوي وتأثيره علي حالتهم الصحية . أجريت هذه الدراسة في معهد الاورام بالمنصورة في العيادات الخارجية وقسم الداخلي للاطفال وشملت العينة ٥٠ من الأمهات و أطفالهن المصابين بالسرطان والخاضعين للعلاج الكيماوي أثناء فترة جمع البيانات خلال ستة اشهر وذلك من نوفمبر ٢٠١٣ - ابريل ٢٠١٤ . كما استخدمت ثلاثة أدوات لجمع البيانات من الأمهات، الأداة الأولى وهي استمارة استبيان مصممة بواسطة الباحث وتحتوي على البيانات الشخصية والاجتماعية للطفل والأسرة ،الأداة الثانية وتشمل معلومات ومهارات الامهات المرتبطة بمرض السرطان والعلاج الكيماوي ،اما الاداه الثالثة فهي تشمل مقياس الحالة الصحية للطفل. ولقد أوضحت الدراسة ان ١٤% فقط من الامهات لديهن معلومات كافية قبل تلقي البرنامج التعليمي بينما الغالبية العظمي منهمن اصبحن لديهن معلومات كافية سواء بعد تلقي البرنامج مباشرة او بعد ثلاثة اشهر، كما اوضحت ايضا النتائج ان الغالبية العظمي منهن اصبحن لديهن مهارات كافية حول رعاية اطفالهن بعد تلقي البرنامج التعليمي مباشرة وبعده بثلاثة اشهرمقارنة بمهارتهن قبل البرنامج حيث ان ٣٤% منهن فقط لديهن مهارات حول رعاية اطفالهن .كما اوضحت النتائج ايضا وجود تحسن ذو دلالة احصائية مرتبطة بمعلومات الامهات ومهارتهن حول رعاية اطفالهن الخاضعين للعلاج الكيماوي بعد البرنامج مباشرة وايضا بعده بثلاثة اشهر مقارنة بمعلوماتهن قبل البرنامج التعليمي .وايضا اسفرت تلك النتائج عن وجود تحسن ذات دلالة احصائية للحالة الصحية للاطفال وجودة حياتهم .لذا فقد اوصت الدراسة الي اقامة برامج تعليمية بصفة مستمرة لامهات الاطفال الذين يعانون من السرطان وتكرار هذا البحث على عينة كبيرة و في أماكن مختلفة في مصر وجعل أمهات الأطفال المصابين بالسرطان محور اهتمام فريق الرعاية الصحية من خلال النشرات المحدثه والملصقات و الكتيبات التي تساعد علي تحسين معلوماتهن ومن ثم تحسين الحالة الصحية لاطفالهن .

الكلمات المرشدة : برنامج تعليمي- معلومات ومهارات الامهات – سرطان الطفولة - علاج كيماوي