Side effects of chemotherapy in children with cancer: effects of nursing training administered to caregivers

AUTHORS

Zeynep Uzun
RN, Msc
Department of Child Hematology Oncology, Ankara Child Health Diseases Hematology Oncology Education Research Hospital, Ankara, Turkey
zey_tun24@windowslive.com

Sibel Kucuk
Assistant Professor, PhD, RN
Faculty of Health Sciences Nursing Department, Ankara Yildirim Beyazit University, Ankara, Turkey
sibel_9741@hotmail.com

KEY WORDS

caregiver, chemotherapy, child, education, nurse

ABSTRACT

Objective
The present study aimed to assess the consequences of providing nursing training to caregivers of children with cancer on the side effects associated with chemotherapy.

Design
The present study used a pre-test-post-test experimental design.

Setting
The study was conducted in a paediatric hematological oncology hospital in Ankara, Turkey

Subjects
This study was conducted with 40 caregivers responsible for looking after child patients, all of which had been recently diagnosed with cancer, but who had not started chemotherapy.

Primary argument
The knowledge scores of the caregivers on issues related to infection and bleeding risk, nutrition and oral care and total scores were significantly higher than their pre-test scores before undergoing training ($p<0.05$).

Conclusion
Planned training on the problems that may arise due to the side effects of chemotherapy was found to be effective in increasing the knowledge level of caregivers. The authors suggest that training in this subject should be provided before initiating a chemotherapy program, before the occurrence of side effects, and visual and written materials should be used.

INTRODUCTION

Chemotherapy for the treatment of cancer is associated with a wide range of side effects (Carelle et al 2002; De Boer-Dennert et al 1997; Griffin et al 1993). A multidisciplinary approach that involves nurses and other healthcare personnel is recommended for the management of cancer treatment processes and potential complications, and the importance of the caregiver responsible for the care of the child has been emphasised (Kutulu et al 2007; Holm et al 2003).

Patients must be prepared, and training must be provided by the attending nurse before initiating a chemotherapy program (Aranda et al 2012). As caregivers bear the primary responsibility for looking after the child, they should be trained in the prevention, detection and control of side effects associated with the chemotherapy (Kutlu et al 2007). The most significant symptoms and side effects seen in cancer patients could be prevented or minimised through effective and conscious nursing interventions and training programs (Aslan et al 2006). It has, however, been reported that the requirements of the patient are not sufficiently fulfilled despite the patients and their caregivers being given training from the nurses and other healthcare personnel on the side effects of chemotherapy (Aranda et al 2012; Kutlu et al 2007). Training programs that detail the possible side effects of chemotherapy in paediatric cancer patients, as well as preventive measures, may contribute to symptom control.

METHODS

Single-group pre-test-post-test experimental design was planned between 1 December 2014 and 1 December 2015 at a paediatric hematological oncology hospital located in the city center of Ankara. This study aims to assess the consequences of providing nursing training to the caregivers of children with cancer on the side effects associated with chemotherapy.

Participants

This study was conducted after obtaining the voluntary consent of the caregivers responsible for looking after child patients, all of which had been recently diagnosed with cancer, but who had not started chemotherapy and who were not terminally ill.

Study Sample

The study sample comprised the caregivers of 60 children with cancer who were admitted to the study center for cancer therapy during the study period. Twenty caregivers were excluded from this study as they did not fall within the study limitations. Consequently, the final study sample comprised 40 caregivers.

Ethical Considerations

Before starting this study, the ethical approval (Ankara Pediatric Oncology and Hematology Training and Research Hospital: 30.03.2015/2015-007) and the informed consent of the caregivers were obtained.

Research Hypothesis

The provision of planned nursing training on the side effects of chemotherapy provided to caregivers of hospitalised children undergoing chemotherapy can be considered effective.

Limitations

Recent diagnosis of cancer, no previous chemotherapy course, the exclusion of terminally ill patients and the voluntary participation of caregivers were the limitations of this study.

Preparation of the Training Manual

The training manual was compiled into two sections. The first section provided explanations of cancer, the chemotherapy process, the side effects of the drugs and the administration of chemotherapy, and contained

a total of seven explanatory diagrams. Details were given on the risks of infection and bleeding associated with chemotherapy, nutritional principles and oral care practices, as well as important considerations, which were explained with a total of 21 explanatory diagrams. The Training Manual was printed using the Arial 14 point font, and bold text was used in key sections to attract attention. The text was supported by explanatory color diagrams. The manual comprised 24 pages of A3-sized paper.

Provision of Training

Training was provided during a single-session face-to-face interview that lasted for 50-60 minutes in a separate room at the clinic, two weeks before the initiation of chemotherapy. Only one caregiver underwent training on a single day.

Before beginning the training session, the training manual was explained and handed to the caregiver for review. Each component of the training was explained practically (using an oral care set, port reservoir, port needle), and the caregiver participated actively in the hands-on training.

Data Collection

Data and sociodemographic characteristics were collected using a caregiver interview questionnaire that contained 52 closed-end questions related to chemotherapy, infection risk, bleeding risk, nutrition and oral care. The pre-test was performed immediately before the training session, and the post-test was performed one month after the training of the relevant caregiver, using a caregiver interview questionnaire. Before starting this study, a preliminary study was conducted with five caregivers with similar characteristics to the study group.

Data Analysis

The statistical analysis included mean, number, percentage, Kruskal Wallis test, Wilcoxon test and in paired comparisons. A Bonferroni test was used with median (interquartile range: IQR), minimum and maximum values, and the level of statistical significance was set at $p<0.05$ (IBM SPSS Statistics 21.0 [IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.] and MS-Excel 2007).

Expected and correct responses given by the caregivers before and after training were coded as 2.5 points, and incorrect and irrelevant responses were coded as 0 points, and a knowledge score was then calculated for each caregiver from the results. The significance of the difference in knowledge scores before and after training was evaluated.

RESULTS

Of the children with cancer, 52.5% were male, 40% were aged 1-5 years, 27.5% were aged 6-10 years, 22.5% were aged 11-15 years, and 10% were aged 16-17 years; 37.5% had AML, 27.5% had ALL, 25% had CML, and 10% had neuroblastoma radiocarcinoma.

All caregivers were female, 32.5% were aged 25–30 years, 47.5% were aged 31–36 years, and 20% were aged 37 years and older; 72.5% were primary school graduates, 20% were high school graduates, and 7.5% were undergraduate or postgraduate students; 85% were housewives, 15% were employed, 95% were the patients mother, 5% were the patients sister, and 15% had another family member with cancer (table 1).

Table 1: Sociodemografic features of caregivers and children with cancer (n=40)

CAREGIVER	n	%
Age		
25-30	13	32.5
31-36	19	47.5
25-30	13	32.5
37 and upper	8	20.0
Education		
Primary school	29	72.5
High school	8	20
Undergraduate	2	5.0
Postgraduate	1	2.5
Profession		
Employed	6	15.0
Housewives	34	85.0
Relationship to child		
Mother	38	95.0
Elder sister	2	5.0
CHILDREN WITH CANCER		
Gender		
Female	19	47.5
Male	21	52.5
Age		
1-5	16	40.0
6-10	11	27.5
11-15	9	22.5
16 -17	4	10.0
Diagnosis		
ALL	11	27.5
AML	15	37.5
CML	10	25.0
Neuroblastoma, radiocarcinoma	4	10.0

The knowledge scores of the caregivers on issues related to infection and bleeding risk, nutrition and oral care and total scores were significantly higher than their pre-test scores before undergoing training ($p<0.05$) (table 2).

Table 2: The correct answers and knowledge scores of caregivers after and before education (n=40)

Education subjects	Before education		After education	
	Correct answer (n)	Score	Correct answer (n)	Score
Infection Risk				
Using mask	40	100	40	100
Ventilation of room	39	97.5	40	100
Taking baths every other day	34	85	40	100
Changing the bed linen	27	67.5	40	100
Separating personal items	26	65	40	100
Bathroom / toilet cleaning	26	65	40	100
Ironing of clothes	17	42.5	40	100
Reporting of IV/port catheter changes	26	65	40	100
Hand washing	25	62.5	40	100
Proper hand washing	26	65	39	97.5
Do not enter other patient rooms	32	32	39	97.5
Do not accept visitors	23	23	39	97.5
Choosing the right toy	8	20	39	97.5
Chaning clothes when return from outside the hospital	25	15	36	90
Total		**805**		**1380**
Bleeding risk				
Do not bath glove	22	55	40	100
Using moisturizer after bathing	20	50	40	100
Daily gaita follow-up	24	60	40	100
Keeping the bed locked	22	55	40	100
Do not toothbrush	14	35	39	97.5
Report changes in the body (bruise, redness, etc.)	24	60	39	97.5
Do not give foods that can cause oral irritation	20	50	38	95
Report blood presence in urine / stool	20	50	38	95
Observing changes in the anal region	21	52.5	37	92.5
Learning thrombocyte value before procedures that can disrupt skin integrity	16	40	35	87.5
Total		**507.5**		**965**
Nutrition				
Reporting when undernutrition	18	45	40	100
Often and often, little by little eating	19	47.5	39	97.5
Reporting factors influencing eating	23	57.5	39	97.5
Report diarrhea / constipation	22	55	39	97.5
Consumption of plenty of water	9	22.5	39	97.5
Fruit washing right	5	12.5	39	97.5
Fruit-feeding with the knowledge of the health team	2	5	38	95
Do not buy ready food	18	45	36	90
Total		**290**		**772.5**

Oral care				
Observation of mouth and oral mucosa	1	2.5	40	100
Time for oral care	1	2.5	39	97.5
Swallowing the fungostat while oral care	2	5.0	39	97.5
Making oral care within half an hour after eating	1	2.5	39	97.5
Using mouthwash in oral care	0	0.0	38	95
Make the mouthwash for 30 seconds	1	2.5	38	95
Do not give food / drink for 30 minutes after oral care	0	0.0	37	92.5
Reporting when oral care can not be done	0	0.0	35	87.5
Total		**15**		**762.5**
FINAL TOTAL		**1617.5**		**3880**

Table 3: The knowledge scores of the caregivers about infection risk, bleeding risk, nutrition and oral care before and after education.

Education subjects	Median score		Test	
	Before education	After education	Z*	p
Infection Risk	23.7 (7.5)	35.0 (7.5)	5.182	0.001
Bleeding Risk	12.5 (10.0)	25.0 (7.5)	5.385	0.001
Nutrition	7.5 (10.0)	20.0 (0.0)	5.533	0.001
Oral care	0.0 (0.0)	20.0 (0.0)	5.785	0.001
Total	43.7 (19.4)	100 (5.0)	5.514	0.001

* Wilcoxon test

DISCUSSION

Neutropenia is a common side effect of cancer therapy (Lustberg 2012). Compliance with hand and general hygiene principles in neutropenic areas (WHO; Gencer 2008), wearing face masks (Raad et al 2002) and providing easily disinfectable toys available in childrens rooms (Randle et al 2006) are recommended approaches to reduce infection rates. Isolation is another means of preventing infections, and has been reported to be successful in the prevention of nosocomial infections (Ostrowsky et al 2001). Invasive interventions and the presence of an indwelling IV/port catheter increase the risk of infection (Lustberg 2012) and it is important to provide training in catheter care to families (Gordon et al 2003). The rooms of patients with neutropenia must be arranged in accordance with hygiene principles, and particular measures must be put in place, such as limiting the number of visitors (Gonderen et al 2009). Providing training to caregivers in infection risks increased the level of knowledge in all sections, particularly on isolation and toy selection, and the training proved to be effective (table 1, table 2).

Chemotherapeutic drugs may predispose to bleeding by decreasing the platelet count. It was suggested that preventing the patient from engaging in activities in which there is a risk of soft tissue injury, using a soft toothbrush, avoiding the use of nail clippers and the monitoring of bleeding are recommended during periods when the patient has a low platelet count (Can 2005). The knowledge scores of the caregivers on bleeding risk increased in all training sections (table 1), and the difference between the scores before and after training was statistically significant (table 2). Findings suggest that increasing the knowledge level of caregivers on bleeding risks and prevention and protection measures may facilitate the protection of the child.

Nutritional problems may have unfavorable consequences in cancer patients (Andreyev et al 1998), and chemotherapy may affect the child's nutritional status by causing nausea, vomiting, taste changes and diarrhea (Can 2005). Furthermore, 66 % of children experience fluid volume deficit, although fluid resuscitation is important in the treatment (Gonderen et al 2009). Although no relationship has been identified between a neutropenic diet and infection (DeMille et al 2006; Wilson 2002), a neutropenic diet is administered in most hospitals when a patient is undergoing chemotherapy (Jubelirer 2011). Certain rules are applied in the center associated with the present study which the caregivers and children are asked to comply with.

A significant increase in awareness in all training sections has been noted after training, particularly on the consumption of plenty of water, washing, and eating fruit, which was relatively unknown before training (table 1). The difference between the scores before and after training were statistically significant (table 2).

Oral complications may occur in children within 1–2 weeks after initiating a chemotherapy program (Chen et al 2004). Following oral care protocols during courses of chemotherapy has been reported to reduce incidences of mucositis (McGuire et al 2006; Chen et al 2004). A daily check of the oral mucosa (Harris 1980) and oral care at night (Sweeney et al 1995) are recommended. Oral care is important for the prevention of mucositis, pain, loss of taste and difficulty in swallowing (Kıkınc 2012), however informing the caregivers about correct oral care practices is important to prevent complications, as the child will be unable to perform these activities unattended.

The knowledge level of the caregivers on oral care was low before training but showed a significant increase after training. Of all the training sections, the most remarkable increase was noted in the oral care segment. Before the training, caregivers had little knowledge about oral care solutions, the time required to avoid consumption of food/beverages after oral care and informing the healthcare team when mouth care is not performed. These were training themes, the level of knowledge was higher after the training (table 1). This was thought to be related to the chemotherapy having not commenced, and that caregivers had not performed oral care. The difference between the oral care scores before and after training was statistically significant (table 2).

The findings showed that training proved to be effective in all training subjects, and that the level of knowledge and the knowledge scores increased after training (table 1). A significant difference was noted between the scores before and after training (table 2).

CONCLUSION

Planned nursing training on the problems that may arise as side effects of chemotherapy was found to be effective in increasing the knowledge level of caregivers. The authors suggest that training in this subject should be provided before initiating a chemotherapy program, before the occurrence of side effects, and visual and written materials should be used. The knowledge levels of nurses working in paediatric oncology clinics regarding the side effects of chemotherapy should be increased, and the training should be provided by the specialist nurses.

REFERENCES

Andreyev, H.J., Norman, A.R., Oates, J. and Cunningham, D. 1998. Why do patients with weight loss have a worse outcome when undergoing chemotherapy for gastrointestinal malignancies? *European Journal of Cancer*, 34(4):503-509.

Aranda, S., Jefford, M., Yates, P., Gough, K., Seymour, J., Francis, P., Baravelli, C., Breen, S. and Schofield, P. 2012. Impact of a novel nurse-led prechemotherapy education intervention (ChemoEd) on patient distress, symptom burden, and treatment-related information and support needs: results from a randomised, controlled trial. *Annals of Oncology,* 23(1):222-231.

Aslan, O., Vural, H., Komurcu, S., and Ozet, A. 2006. Effect of education on chemotherapy symptoms in cancer patients receiving chemotherapy. *Journal of Cumhuriyet University School of Nursing,* 10(1):15-28.

Can, G. 2005. Side Effects of antineoplastic drugs and nursing approaches. *Journal of Education and Research in Nursing* 2(2):8-15.

Chen, C., Wang, R., Cheng, S., Chang, Y.C. 2004. Assessment of Chemotherapy-Induced Oral Complications in Children With Cancer. *Journal of Pediatric Oncology Nursing*, 21(1):33-39.

Carelle, N., Piotto, E., Bellanger, A., Germanaud, J., Thuillier, A. and Khayat, D.2002. Changing patient perceptions of the side effects of cancer chemotherapy. *Cancer*, 95(1):155-163.

De Boer-Dennert, M., de Wit R., Schmitz, P.I., Djontono, J., v Beurden, V., Stoter, G. and Verweij J. 1997. Patient perceptions of the side-effects of chemotherapy: The influence of 5HT3 antagonists. *British Journal of Cancer*, 76(8):1055-1061.

DeMille, D., Deming, P., Lupinacci, P. and Jacobs, L.A. 2006. The Effect of the Neutropenic Diet in the Outpatient Setting: A Pilot Study. *Oncology Nursing Forum*, 33(2):337-343

Gencer, S. 2008. Prevention and Control of Hospital Infections: Hand Washing. I.U. Cerrahpaşa Medical Faculty Continuous Medical Trainings Hospital Infections Prevention and Control: Symposium Series, 60:71-78.

Gonderen, H.S. and Kapucu, S. 2009. Evaluation Criterion in Neutropenic Patient and Nursing Care. *Hacettepe University Faculty of Health Sciences Nursing Journal*, 69-75.

Gordon, K. and Dearmun, A,K. 2003. Occlusion Problems in Central Venous Catheters: The Child and Family Perspectives. *Journal of Child Health Care*, 7(1):55-69.

Griffin, A.M., Butow, P.N., Coates, A.S., Childs, A.M., Ellis, P.M., Dunn, S.M. and Tattersall, M.H. 1996. On the receiving end. V: Patient perceptions of the side effects of cancer chemotherapy in 1993. *Annals of Oncology*, 7(2):189-195.

Harris, M. 1980. Tools for mouth care. *Nursing Times,* 76:340-342. PMID: 6899174

Holm, K.E., Patterson, J.M., Gurney, J.G.2003. Parental involvement and family-centered care in the diagnostic and treatment phases of childhood cancer: results from a qualitative study. *Journal of Pediatric Oncology Nursing,* 20(6):301-313.

Jubelirer, S.J. 2011. The Benefit of the Neutropenic Diet: Fact or Fiction? *The Oncologist*, 16:704-707.

Kılınc, G. 2012. Oral comlications associated with chemotherapy and radiotherapy in children. *Journal of Dokuz Eylul University Faculty of Medicine,* 26(1):75-83.

Kutlu, L., Mutlu, L. and Kabaoglu, A. 2007. Evaluation situation informed of parents of children with leukemia. *Journal of Education and Research in Nursing*, 4(1):32-39.

Lustberg, M.B. 2012. Management of Neutropenia in Cancer Patients. *Clinical Advances in Hematology & Oncology,* 10(12):825-826.

McGuire, D.B., Correa, M., Johnson, J. and Wienandts, P. 2006. The role of basic oral care and good clinical practice principles in the management of oral mucositis. *Support Care Cancer*, 4:541-547.

Ostrowsky, B.E., Trick, W.E., Sohn, A.H., Quirk, S.B., Holt, S., Carson, L.A., Hill, B.C., Arduino, M.J., Kuehnert, M.J. and Jarvis, W.R. 2001. Control of Vancomycin-Resistant Enterococcus in Health Care Facilities in a Region. *The New England Journal of Medicine*, 344:1427-1433.

Raad, I., Hanna, H., Osting, C., Hachem, R., Umphrey, J., Tarrand, J., Kantarjian, H. and Bodey, G.P. 2002. Masking of neutropenic patients on transport from hospital rooms is associated with a decrease in nosocomial aspergillosis during construction. *Infection Control & Hospital Epidemiology*, 23(1):41-43.

Randle, J. and Fleming, K. 2006. The risk of infection from toys in the intensive care setting. *Nursing Standard,* 20(40):50-54.

Sweeney, M. and Bagg, J. 1995. Oral care for hospice patients with advanced cancer. *Dental Update,* 22(10):424-427

WHO Guidelines on Hand Hygiene in Health Care. Patient: Safty. http://apps.who.int/iris/bitstream/10665/44102/1/9789241597906_eng.pdf (accessed 06.06.2018).

Wilson, B.J. 2002. Dietary recommendations for neutropenic patients. *Seminars in Oncology Nursing*, 18:44-49.