DEVELOPMENT OF EDUCATIONAL MATERIAL FOR HEALTH LITERACY AND PATIENTS WHO RECEIVE CHEMOTHERAPY IN TURKEY

Duygu CEVEN OZTURK [ID][1], Emine SENYUVA [ID][2]

[1] Service Nurse, Istanbul University – Cerrahpasa Cerrahpasa Medical Faculty Hospital, Istanbul, TURKEY

[2] Nursing Education Department, Istanbul University – Cerrahpasa Florence Nightingale Faculty of Nursing, Istanbul, TURKEY

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ABSTRACT

Aim: The aim of the study was to determine the health literacy levels of patients receiving chemotherapy in Turkey, to develop written educational material considering the health literacy level and to evaluate the appropriateness.

Methods: 360 patients who received chemotherapy at the Istanbul University Cerrahpaşa Medical Faculty Medical Oncology Outpatient Clinic. Descriptive and methodological research method was used. The data were collected using the DISCERN, Patient Data Form, Turkish Health Literacy Scale-32, Evaluation of the Conformity of Written Materials Form. "Chemotherapy Patient Education Guide" has developed. The data were evaluated by using descriptive analysis, parametric, non-parametric and advanced analysis in IBM SPSS Statistics 21 program.

Results: 72.2% of the patients receiving chemotherapy have a poor health literacy level and 6.1% are excellent. The developed "Chemotherapy Patient Education Guide" was found to be high in reliability and information quality by experts and patients.

Conclusions: With cooperation of health care professionals work on the development and growth of written training materials in different disciplines and health policy regulators, it can be advised planning and organizing training activities, development of written training materials and evaluation of the readability level, reliability and information quality of the developed written training materials in accordance with results obtained from the research. Nurses should plan educational activities that will increase the health literacy levels of patients receiving chemotherapy, and develop written education materials taking into account their health literacy levels.

Keywords: Health literacy, written education material, patient education, chemotherapy, nurse

Corresponding Author: Emine SENYUVA esenyuva@iuc.edu.tr

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Introduction

Cancer, due to the rapid increase in incidence and mortality in recent years has been seen as one of the most important health problems in the world and in our country in recent years (1-3). In this process, chemotherapy prevents the growth and proliferation of both normal and cancerous cells, and may cause side effects such as nausea, vomiting, loss of appetite, constipation, diarrhea, cardiac problems, bone marrow suppression (anemia, leukopenia, thrombocytopenia), hair loss, etc (4, 5). Minimizing or eliminating these side effects, healthcare professionals, especially nurses who are in constant interaction and communication with the patients and families considered as the most accessible source of information have important responsibilities (6, 7).

Patient education comes first among these responsibilities. During the education applied by nurses, different educational materials are used to facilitate the learning of the patient and families and to increase their interest on the subject (6-8). However, to make understandable those education materials such as posters, brochures, books, booklets etc. used in patient education those educational materials need to be developed/prepared pursuant to literacy level of patients and their families (9).

According to the World Health Organization (WHO, 2013), health literacy; "Health literacy is associated with general literacy and it is their ability and capacity that enable them to correctly perceive and understand health-related information and messages, to have access to health-related information resources to protect, maintain and improve their health, and to improve the quality of life (10).

According to UNESCO (2009) report; 776 million adults in the world are not primary health literate. In the case of low levels of health literacy, the process of

benefiting from health care for patients begins again. Repeating this process causes social and economic effects, increased workload, the need for more staff than the existing, individual and institutional loss of time and financial loss and so on. Low/inadequate level of health literacy also causes individuals to have problems in hospital admissions, spending more on health care, understanding the educational materials provided, adapting to their treatment and chronic disease management, and expressing information about their health conditions appropriately. In related studies, it is stated that low health literacy level increases cancer incidence and mortality and decreases quality of life (11, 12). Most of the researches conducted in our country and in the world shows that most written education materials used in patient education are difficult to understand for patients with low levels of health literacy and do not comply with the principles of preparing written education material (4, 5). For this reason, it is important that nurses improve their communication with patients and their families, determine their health literacy levels, and develop written education material by considering the determined health literacy levels and the principles of preparing written education material (6, 7).

METHODS

Study Design

The research was carried out according to the descriptive and methodological research method. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)-Cross-sectional studies guideline was followed.

Sample and Setting

The population of the study consisted of patients who applied to the Medical Oncology Policlinic of the

Internal Medicine Department of a university hospital for chemotherapy treatment.

The sample of the study consisted of 360 who applied to the Istanbul University Cerrahpaşa Medical Faculty Medical Oncology Outpatient Clinic for chemotherapy treatment for the purpose of determining the health literacy levels of patients receiving chemotherapy and developing written education materials and evaluating their suitability. Power of 0.05 effect size and 95% confidence interval determined with 5% error level with unknown sample size. The patients to be sampled were selected by random sampling method among the patients who met the research criteria.

Inclusion criteria in the study sample;

- Receiving chemotherapy treatment
- Agreeing to voluntarily participate in research
- Being 18 years and older
- Being able to read and write
- To be able to communicate verbally
- Not having any disability that would hinder learning / communication

Instruments

Patient Information Form: It is developed by the researcher pursuant to the literature. Form; consists of 14 questions, 9 of which are intended to determine age, gender, marital status, educational status, socio-demographic characteristics and 5 of which are to determine the need of having knowledge about chemotherapy, the state of finding it sufficient, the sources of access to information and chemotherapy-related education needs (13).

Turkey Health Literacy Scale-32 (TSOY-32): Scale aiming to determine health literacy levels of patients, it is developed based on the conceptual framework of the European Health Literacy Survey (HLS-EU). Scale consists of 32 questions and of eight components: two of which basic dimensions (Treatment and service, Disease prevention/health promotion) and four processes (access to health information, understanding health information, evaluating health information, using/applying health information

Response options of five-point Likert scale is sorted as; Very easy (5), Easy (4), Difficult (3), Very difficult (2) and No idea (1) In the calculation of the scale score; Index = (average-1) x (50/3) formula was used.. The lowest score is 0 and the highest score is 50.

Scores refer as;

(0-25): inadequate health literacy

(>25-33): problematic - limited health literacy

(>33-42): adequate health literacy

(>42-50): expresses excellent health literacy.

The total cronbach's alpha coefficient of the scale ranged from 0.95 and its subscales ranged from 0.86 to 0.91 (14).

Total cronbach's alpha coefficient was 92 in the study. The total cronbach alpha coefficient of the Treatment and Services sub-dimension was 92 and the coefficients of the sub-processes ranged from 67 to 81. Disease Prevention/Health Promotion subscale total cronbach's alpha coefficient was 92 and the coefficients of the sub-processes ranged from 71 to 75.

Development of Chemotherapy Patient Education Guide (CPEG): CPEG was developed in John Hopkins University Communication Programs

Center (JHU/PCS) by considering the stages of the development of written education material (15).

Analysis stage; the aims and objectives of the material were determined by considering the knowledge, skills and attitudes expected of patients to gain. Costs were determined by contacting the relevant printing centers.

Planning stage; Patient Information Form and TSOY-32 knowledge related to chemotherapy, education needs and health literacy levels are determined by using chemotherapy socio-demographic characteristics of the patients

Material Development stage; "Chemotherapy Patient Education Guide" has been developed taking into consideration the health literacy levels of patients receiving chemotherapy and the principles of preparing written education material. It was developed in accordance with the relevant literature and the opinion of three experts, two oncologists and one oncology nurse.

CPEG; was presented to the specialists and chemotherapy patients for the evaluation of language, content and technique of it.

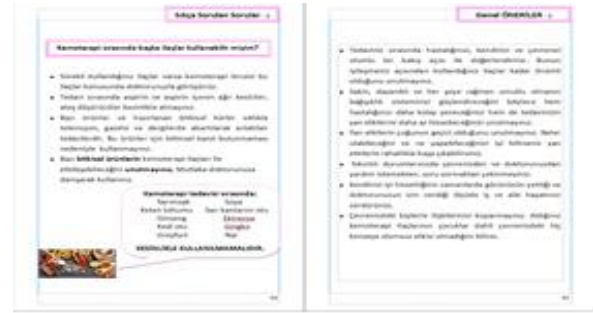

Figure1. Text (Content) Page

Figure2. CPEG Source - Back Page

Implementation and Monitoring stage; According to the opinions of oncologist, oncology nurse, educational scientist, academician, dietitian, 14 specialists and 14 chemotherapy patients CPEG , has been revised in terms of language, content and technique and has been finalized.

Evaluation stage; CPEG published to be used for the patients receiving chemotherapy. Necessary works will be continued by returning to the planning phase from time to time to apply possible updates.

Form of Evaluation of the Compliance of Written Materials: It is developed by Doak et al. (1996) (16). It is used for the first time in our country, by Gokdogan et al. (2003) (17) and Demir et al. (2008) (18) in their research. Form consists of 27 questions, 4 of literacy status (5), pictures, graphics, tables and lists (5), plan and type (8), learning and motivation (3), cultural appropriateness (2) consists of six sub-dimensions. The form is evaluated on a total of 1-27 points by giving 1 point for Yes and 0 points for No. Scoring more than the form indicates that the readability of the educational material is high.

DISCERN (Quality Criteria for Consumer Health Information) Scale: The scale used to evaluate the reliability and quality of knowledge of the educational material was analyzed by Charnock et al. (1999) (19). Turkish validity and reliability study has been made by Gokdogan et al. (2003) (17). The scale consists of 15

items. The lowest score that can be obtained from the scale is 15 and the highest score is 75. Obtained 15 points indicates that the information quality of the education booklet is low and the 75 points indicates that the quality of information is high (17).

Statistical Analysis

The data obtained were transferred to the computer by the researcher. Analyzed by statistical expert in IBM SPSS Statistics 21 (Statistical Package for Social Sciences) software licensed by Istanbul University. Data were evaluated at $p < 0.05$ significance level and 95% confidence interval. Descriptive analyzes (number, percentage, mode, mean and standard deviation) were performed to determine the socio-demographic characteristics of chemotherapy patients, the status of finding sufficient information about chemotherapy, the sources of access to information, and the education requirements related to chemotherapy. To test TSOY-32 total and internal consistency coefficient for testing the validity and reliability of its dimensions, TSOY-32 material, descriptive analysis to determine the average scores obtained from the total and the dimensions (number, percent, lowest-highest values, mean and standard deviation) were used. Parametric (one-way analysis of variance and t-test in independent groups) and non-parametric (Kruskal Vallis and Mann Whitney U) to determine whether the socio-demographic characteristics of chemotherapy patients and their knowledge of chemotherapy make significant difference on the mean scores of TSOY-32; and advanced analyzes (Tukey HSD for one-way analysis of variance and Mann-Whitney U with Bonferroni correction for Kruskal Wallis) were used. Descriptive analyzes (number, percentage) were performed to determine the opinions of specialist and chemotherapy patients about CPEG.

Ethical Consideration

Prior to the study, the approval of the Ethics Committee (date: 07.12.2016 and number 442908), permission to use the institution and scale was obtained. Written and verbal consent was obtained from chemotherapy patients who agreed to voluntarily participate in the study.

RESULTS

Socio-demographic characteristics of chemotherapy patients

37.8% of patients receiving chemotherapy are 51 years or older, 36.1% are 40 years and under. The mean age was 45.46±12.96 years. 53.3% are women, 73.1% are married, 33.6% are primary school, 24.4% are high school, 21.7% are university graduates.

Chemotherapy related knowledge levels and education needs of chemotherapy patients

73.6% of chemotherapy patients stated that they had information about chemotherapy and while 19.2% of them found their information sufficient, 29.4% of them found it insufficient.

55.6% of chemotherapy patients stated that they received information about chemotherapy from the internet, 51.7% from the physician, 21.7% from a nurse.

Table1: Chemotherapy education needs of patients receiving chemotherapy (n: 360)

Chemotherapy Education Needs of Patients	n	%
Subjects (s) needed for chemotherapy education*		
Side effects of chemotherapy and coping methods	250	69,4
Nutrition	218	60,6
Home care after chemotherapy	215	59,7
Protection from infection	206	57,2
Ways of coping with hopelessness / stress for the future	206	57,2
Conditions that may arise during the during chemotherapy	203	56,4
By whom, when, how long, where to receive chemotherapy	170	47,2
Emergency numbers	167	46,4
Examinations and controls	161	44,7
Basic hygiene and skin care	151	41,9
Protection from bleeding	145	40,3
Sex life	133	36,9
Others	56	15,6
The ways or persons that the chemotherapy will be given *		
I would like to receive from physicians	309	85,8
I would like to receive from nurse	165	45,8
I would like to be given written sources (brochures, booklets).	157	43,6
I would like to share the experiences with the patients who have had the same experience before.	95	26,4
Others	13	3,6

* Multiple options were checked.

56.4% of chemotherapy patients stated that they needed to be educated about the conditions that may be experienced during chemotherapy application, 69.4% had side effects and coping methods of chemotherapy, 60.6% had nutrition, 59.7% had home care after chemotherapy, and 57.2% had protection from infection and coping with hopelessness stress for the future. (Table1).

85.8% of chemotherapy patients indicated that they wanted to get the education about chemotherapy from the physician, 45.8% from the nurse 43.6% of them arefrom brochures, booklets and the written sources (Table 1).

Health literacy levels of chemotherapy patients

It was found that 38.6% of chemotherapy patients had poor health literacy, 33.6% were problem-limited and 6.1% were excellent (Table 2).

Table2. Health literacy scores of patients receiving chemotherapy from Turkey Health Literacy Scale – 32 (n: 360)

Health Literacy Scores of Patients Receiving Chemotherapy	n	%	Index Value
Poor Health Literacy	139	38.6	≤25
Problem-Limited Health Literacy	121	33.6	between 25.1-33
Adequate Health Literacy	78	21.7	between 33.1-42
Excellent Health Literacy	22	6.1	between 42.1-50

The lowest score from the treatment and service subscale was 16, the highest score was 33, and the mean total score was 23.28±10.12. Among the processes under this sub-dimension, the highest average score was"Health-related Knowledge Assessment" (10.71±2.76), the highest average score "Evaluating Health Related Information" was (10.71±2.76), the lowest mean score was found to be Use/Apply Health Information" (9.29±2.76).

The lowest score obtained from the Disease Prevention/Health Promotion sub-dimension was 16, the highest score was 31 and the total score average was 24.50±9.99. Among the processes under this sub-dimension, was Evaluating Health Related Information in (10.51±2.79), the lowest mean score was Understanding Health Information" (9.56±2.86).

Comparison of socio-demographic characteristics and knowledge of chemotherapy and health literacy levels of patients receiving chemotherapy

There was not found statistically significant difference between ages of patients receiving chemotherapy and with TSOY-32 total mean score (p<0.05) (Table 6). The difference was found to be due to the fact that patients aged 40 had a higher mean score than those aged 51 and over (Table 3).

Table3. Comparison of total average score socio-demographic characteristics and knowledge levels of chemotherapy and Turkey Health Literacy Scale – 32 (n: 360)

Comparison of total average score socio-demographic characteristics and knowledge levels of chemotherapy	X±SD	
Age		
≤40 [a]	43.52±9.71	**F=4,831**
Between 41-50[b]	41.35±10.11	**p=0.003**
≥51[c]	38.51±9.29	**a>c**
Gender		
Female	41.12±8.73	t=-0.503
Male	41.52±8.85	p=0.584
Education status		
Primary education [a]	37.73±9.85	**F=27.505**
Secondary education	43.41±9.25	**p<0.001**
High education[c]	46.36±8.62	**b,c>a**

***p<0.001 F= One-way analysis of variance; t= t-test in independent groups; KW= Kruskal Wallis; z= Mann Whitney U; Adj. p= Bonferroni corrected significance for corrected Mann Whitney U

There was not found statistically significant difference between gender of patients receiving chemotherapy and with TSOY-32 total mean score (p>0.05) (Table 3).

There was not found statistically significant difference between educational status of patients receiving chemotherapy and with TSOY-32 total mean score (p<0.05) (Table 3). The difference was found to be as secondary education and higher education graduates had a high average score from primary school graduates.

Opinions of experts and patients receiving chemotherapy on CPEG

It was determined that the lowest score obtained from the opinions of the experts in line with the Evaluation of the Suitability of the Written Education Material on the CPEG was 15, the highest score was 26 and the total score average was 22.86±3.57.

When the total score mediations of the experts in the DISCERN scale regarding the CPEG were examined, total score of the scale was found to be 66.50±7.23, reliability score 32.50±8.36, knowledge quality score 29.14±7.97, overall quality score 4.57 ±0.51.

When the cultural suitability of CPEG is examined; It was found that 92.9% of chemotherapy patients stated that the language and logic of the material were appropriate to the society and that 78.6% stated that the images were positive, realistic and appropriate.

DISCUSSION

Chemotherapy-related knowledge and education needs of patients receiving chemotherapy

Approximately three-quarters of patients receiving chemotherapy reported that they have knowledge about chemotherapy. However, only 19.2% of patients of them found that their information is sufficient. Özdoğan and Kav (2014) (13) found that while the majority of cancer patients found their knowledge of chemotherapy insufficient, a very few of them found it sufficient. Wittenberg et al. (2018) (20), found that cancer patients do not have enough information about the management and treatment of the disease, they have difficulty in accessing the information they need and they need information about the management, treatment and side effects of the disease. This finding, It was evaluated that nurses' patient education activities should be planned on subjects such as treatment, side effects of patients to improve their adaptation and quality of life, to manage the disease.

It was determined that the chemotherapy patients mostly obtained their information on chemotherapy from the internet, physician and another patient. Tengilimoglu et al. (2015) (21) that individuals follow health-related developments primarily through social media and health personnel. Ozdogan and Kav (2014) (13) that the patients and their relatives first received information from the physician, another patient and from the internet they prefer to be given the written and verbal information together when receiving this information. Ballard and Hill (2016) (8) with the

developing technology these days, many cancer patients use the internet as a source of information and cancer patients have stated that they obtained information via the Internet. Eysenbach (2003) (22) found that internet use is quite common among cancer patients. It was interpreted that individuals would use the Internet to obtain more comprehensive information on health issues and health-related developmentsin this context, the finding was interpreted as with the rapid development of technology and the increasing use of the internet and health-related information.

The majority of chemotherapy patients stated that they needed education on subjects such as the side effects and coping methods of chemotherapy, nutrition, home care after chemotherapy etc. that may be experienced during chemotherapy application (Table1). In related studies, has identified that the patients firstly, wanted to be informed about the side effects of treatment, the probability of recurrence, psychological effects, prognosis, when the treatment would end and the causes of this disease, but the information needs to be reevaluated when the patient's knowledge and experience increases during the long illness period (23). In general, it is emphasized that the chemotherapy patients often want to receive education on disease, chemotherapy treatment and effects, disease management and home care. This finding suggests that patients receiving chemotherapy want to receive education in chemotherapy-related subjects (treatment and side effects, etc.), therefore, it was considered that nurses should determine the priority education needs of patients and plan the patient education according to these needs.

It was determined that the majority of chemotherapy patients wanted to receive education from physicians, nurses and written sources such as brochures and

booklets (Table1). As patient advocates, oncology nurses must attend to varying levels of health literacy among patients and families (20) Ballard and Hill (2016) (8), stated that the majority of cancer patients and their relatives prefer to receive information from physicians, nurses, books and individuals who have the same disease. This similar finding to the results of the research, was evaluated that the chemotherapy patients wanted to get the information about the disease from physicians and nurses that they thought to have more accurate and reliable information. It is considered that Chemotherapy patients who want to get information from written education materials choose them because with these materials they have access to the necessary information in a short time and they allow them to read the information over and over and reinforce verbal education.

The majority of the chemotherapy patients had poor health literacy level and limited-problematic (72.2%) and very few (6.1%) were excellent (Table 2). There is a paucity of data relating health literacy to cancer treat-ment, and health literacy is likely very important in the context of patients navigating through cancer treatment (24). Tanrıover et al. (2014) (14) in Turkey 24, 5 % of the population is insufficient, of 40.1% problematic, 27.8% adequate, while the 7.6% that has excellent health literacy level, in other words, approximately 3 million individuals are inadequate and problematic health literacy level. In European Health Literacy Project (2009-2012) (25) it is determined that 12.4% of the population in Europe is inadequate, 35.2% is problematic, 36% is sufficient, 16.5% have excellent health literacy level, ıt was determined that individuals with low health literacy applied to the hospital/emergency department three or more times and physician examination six and more times. Özdoğan and Kav (2014) (13), it was found that the health literacy levels of cancer patients and their relatives are low. This finding shows that as a result of

the low level of health literacy, all the negativities (prolonged hospital stay of individuals., unnecessary emergency room uses, unnecessary labor losses, increase in health expenditures, increase in unnecessary inspection rates, Inability to effective management of chronic diseases and difficulties in adapting to treatment, increase in mortality and morbidity, individuals limited communication with nurses and other health professionals, difficulty in understanding health etc.) mentioned in the literature may be experienced and this may affect both health care services and the adaptation of the patient and family to the disease (26, 27). Therefore, it is important to plan educational activities that will increase the health literacy levels of individuals.

Socio-demographic characteristics of patients receiving chemotherapy and comparison of chemotherapy knowledge and health literacy levels

When comparing average scores of TSOY-32 and ages of chemotherapy patients it is found that average health literacy score of patients aged 40 years and younger was higher than those aged 50 years and older ($p<0.05$), (Table 3). Sequeira et al. (2013) (28), Özdemir et al., (2010) (29) found that health literacy levels of individuals older than 60 years were lower than those of other age groups. Safeer and Keenan (2005) (30) have determined that 80.0% of individuals over 60 years of age, especially those with chronic diseases, have limited health literacy levels, therefore, individuals have problems in filling out hospital forms and answering questions about their health and they were unable to ask the health personnel important questions about their health because of their hesitation. This finding similar to the results of the research shows that, especially those who are over 50 years old who have chemotherapy will have problems

in the follow-up of health care services, filling in consent forms to save appointment dates, o be able to read prescriptions and drug leaflets and understand this information, to manage and cope with diseases at home, read and understand written educational materialsthus, the rate of hospital admissions and health expenditures of patients will be increased.

When comparing average scores of TSOY-32 and gender of patients receiving chemotherapy It is found that there is no statistically significant difference (p>0,05), (Table3). Almaleh et al., (2017) (31) that only 10.2% of female patients have adequate health literacy, Ozdemir et al., (2010) (29) found that women's health literacy levels were lower than men's. In the European Health Literacy Project (2009-2012) (25), it was found that health literacy was higher in women than in men. Although there are studies showing that women's health literacy levels are high in general there are also studies showing that women have lower health literacy levels than men.However, in the researches it was found that there was no relationship between gender and health literacy level.This finding was evaluated that the level of health literacy of chemotherapy patients did not change according to gender.

When comparing average scores of TSOY-32 and education status of patients receiving chemotherapy It was determined that the average health literacy score of the secondary and higher education graduates was higher than the basic education graduates (p<0.05), (Table3). In Turkey Health Literacy Project study made by both Tanrıover et al. (2014)[14] and European Health Literacy Project (2009-2012)[23]. It was determined that health literacy level increased as individuals' education level increased.

Copurlar and Kartal (2016) (32), Sorensen et al. (2015) (33), reported that health literacy level decreased as education level decreased, this finding

was interpreted as it was evaluated that patients receiving chemotherapy with low educational level may have hesitation with health personnel on subjects such as use their medication, to request the repetition of the information given or to ask questions.

Opinions of experts and patients receiving chemotherapy on CPEG

It was determined that the written education material developed in the research was high in terms of content, literacy status, pictures, graphics, tables and lists, planning, learning and motivation, cultural readability, reliability and quality of knowledge according to experts and patients receiving chemotherapy. It is stated that most of used written education materials also used in the research examining written education materials are insufficient in terms of reliability, knowledge quality and content (pictures, graphics, writtings and planning conditions). It is highlighted that these materials can only be understood by the help of a nurse or physician since they contain intense medical terms and therefore suitable only those for high level of health literacy (9, 17, 34). This finding indicates that written education material developed considering the patients with poor health literacy levels and limited-problematic patients will be high in terms of readability and comprehensibility by patients.

Limitations

The study was limited to patients who applied to the Medical Oncology Policlinic of the Internal Medicine Department of the university hospital between January and March 2017 and met the criteria for the study.

There have been many patients under the age of 18 who are illiterate or who do not want to participate in the research because of their personal fears.

CONCLUSION and RECOMMENDATIONS

The health literacy level of 38,6% of patients receiving chemotherapy is insufficient and 6,1% of them are excellent. The developed CPEG has a high level of readability, content, literacy, pictures, graphics, tables and lists, planning, learning and motivation, readability in terms of cultural relevance, reliability and quality of information according to experts and patients receiving chemotherapy.

According to results of the research;

- in collaboration with healthcare professionals from different disciplines and health policy makers, development of written educational materials considering the health literacy levels of the society and healthy/sick individuals, evaluation of written education materials in terms of readability, reliability and quality of knowledge,

- CPEG developed for patients receiving chemotherapy. Can be recommended.

Conflicts of Interest

None of the author has any conflict of interest to disclose

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