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Reflecting Practice Of Integrated Supportive Cancer Care Education Materials For Radiotherapy Patients: A Pilot Study

(Merefleksikan Amalan Bahan Pendidikan Penjagaan Kanser Sokongan Bersepadu Untuk Pesakit Radioterapi: Satu Kajian Rintis)

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Abstract

Patient cancer care education aims to inform and empower patients by providing clear, relevant information about cancer, including its mechanisms, treatment options, and management strategies. This study evaluated the effectiveness and accuracy of existing patient cancer care education materials in Malaysia, specifically assessing patients' understanding of treatment, side effects, and their management. Method: A descriptive, correlational study was conducted involving 20 cancer patients at Gleneagles Penang Medical Center, using the Patient Cancer Education Needs Assessment questionnaire. Data analysis was performed using SPSS version 21.0 and Microsoft Excel 2013. Result: Patient age, education level, occupation, and socioeconomic status were not significant factors influencing understanding. Findings highlight the need to improve existing educational materials to enhance patient comprehension and ensure materials are comprehensive, culturally appropriate, and innovative. Conclusion: Patient cancer care education materials should be comprehensive, interactive, and patient is friendly. Current materials require revision and enhancement to keep pace with technological developments, ensuring they are accessible, understandable, and effective in supporting patients' knowledge of cancer treatment, side effects, management strategies, and psychosocial aspects.

Keywords: Patient Education, Cancer Patient, Patient care, Radiotherapy, Radiation Therapy Patient.

Abstrak

Pendidikan penjagaan kanser pesakit adalah usaha daripada kakitangan penjagaan kesihatan untuk mendidik pesakit dengan menyampaikan maklumat mengenai kanser. Pesakit akan didedahkan kepada mekanisme penyakit, pilihan rawatan, dan pengurusan untuk penyakit tersebut. Penyelidikan ini dibuat untuk menilai bahan pendidikan penjagaan pesakit kanser yang telah dilaksanakan di Malaysia. Khusus untuk menilai keberkesanan maklumat, pemahaman pesakit tentang rawatan, kesan sampingan dan pengurusan untuk kesan sampingan, dan keberkesanan dan ketepatan maklumat bahan pendidikan penjagaan kanser pesakit di Malaysia. Kaedah: Kajian deskriptif, korelasi telah dijalankan dengan meninjau 20 pesakit kanser menggunakan soal selidik Penilaian Keperluan Pendidikan Kanser Pesakit di Pusat Perubatan Pulau Pinang Gleneagles. Program statistik SPSS versi 21.0 dan Microsoft Excel 2013 digunakan untuk analisis data. Keputusan: Umur pesakit, tahap pendidikan, pekerjaan, dan status sosioekonomi bukanlah faktor penting yang mempengaruhi pemahaman pesakit. Terdapat keperluan untuk menambah baik amalan semasa bahan pendidikan penjagaan kanser pesakit di Malaysia untuk meningkatkan pemahaman pesakit dan membangunkan bahan yang komprehensif dan inovatif. Kesimpulan: Bahan pendidikan penjagaan kanser pesakit harus komprehensif, interaktif dan mesra pesakit. Bahan pendidikan penjagaan pesakit kanser yang telah dilaksanakan perlu diperbaiki dan ditambah baik berikutan perkembangan teknologi yang pesat untuk menjadikannya lebih komprehensif, interaktif dan mudah difahami oleh pesakit. Dengan cara ini, pengetahuan pesakit tentang rawatan kanser, kesan sampingan, pengurusan, psikososial bertambah baik.

Kata Kunci: Pendidikan Pesakit, Pesakit Kanser, Penjagaan Pesakit, Radioterapi, Pesakit Terapi Sinaran.

INTRODUCTION

Providing information to patients is not simply about what healthcare providers want them to know, but about addressing what patients need and want to understand. The rapid development of modern medicine sees the evolution of new techniques in treatment and modalities development. There was unlikely no specific guideline for patient cancer care education available in Malaysia. Patient cancer care education programs should not only emphasise side effects and their management only. It should be more comprehensive and easier to understand by patients. Studies show that patients will be more relaxed and reduce their anxiety when they know what they facing and what to expect at the beginning, during, and the end of the treatment. The main aspects that should be in this program are side effects and its management, dietary aspect, psychosocial, and communication.

Cancer patients usually have problems understanding cancer itself, the treatment for cancer, the side effects of the treatment, and also how to manage the side effects (Cardenas et al. 2016). Several studies have shown that the need for information is one of the most important issues faced by a cancer patient (Matsuyama et al., 2013). Medical information given by the medical personnel using jargon words and unclear explanations about the procedure makes the patient confused. Thus, patients have difficulty following the instructions given to them. In Malaysia, most of the cancer centers have their patient education programme with several materials for cancer patients since there is no specific guideline available in Malaysia that can be referred to.

Patient education helps improve patient awareness of the symptoms and treatment side effects. It promises to facilitate desired changes in patient behaviour and attitudes toward their daily care (Cardenas et al. 2016). The studies show that in Haiti, the patient is more alert about changes that they have and also knows how to manage the side effects after receiving the patient education program. The limitation of current cancer care education is that patients themselves lack knowledge about cancer. Clinicians do not have enough time to entertain the patient and family by explaining the procedure and plan in detail. Unfortunately, patients do not understand the treatment and its side effects, resulting in misunderstanding, which is the main limitation of patient cancer care education. Currently, some patient education materials have been developed. However, it is unsuitable due to cultural content, socioeconomic condition, and specific scientific domain in middle-income and low-income countries. A study was done to investigate the need for patient care education for cancer patient who undergoes radiation treatment, chemotherapy, hormonal therapy, and brachytherapy and founds that most of the patients demand a better understanding of their disease and are willing to learn about the management of side effects and skin care(Zheng et al. 2014). Patient education is an effective way to improve the daily lives of patients. By knowing more about the illness, it can improve adult patients' self-management and thereby improve their quality of life (Laine et al. 2015). For instance, an educational program may provide information on the lymphatic system, the symptoms and signs of lymphedema, and suggestions for preventing lymphedema (Lu et al. 2015).

Each treatment and site of cancer can lead to variable types of side effects and management for pre, during, and post-treatment. C. Cardenas suggests an adjustment of the set of the patient education program to improve the cultural relevance that can be tested during implementation by evaluating patient understanding of the program or module. Some of the patient education available was not suitable for Malaysians in the sense of culture, religious beliefs, and daily lifestyle. Thus, some adjustment is recommended, and the type of materials that are suitable for multiple ages. By using familiar words to replace the technical term and simple language, avoiding long words and complex sentences, and using examples. Emphasis on a simple and clear header, balanced white space, and put some visual content and readable fonts are recommended. In this journal, they suggest having an extended type of patient education materials that can be developed, including other printed formats and an alternative media format to support patient education.

Lack of knowledge about the disease symptom, side effects, and its management were the main problem that led to misunderstanding and misinterpretation in patient education (Cardenas et al. 2016). The method of delivering the information and the materials used in the education program must be effective in order to enlighten patients about cancer. Most patients, especially geriatric patients, need help understanding the complex procedure and terms used by the medical personnel, causing them to fail to do it so. On the other hand, for young adults, the current approaches used are no longer fit for them because they are more attractive to high technology and interactive ways.

Effective communication between medical personnel and a patient, there is a huge barrier. As patients, they face difficulties in understanding medical terms and abbreviations. It is inappropriate for medical personnel to use those terms to explain the procedure or the treatment to a patient. Thus, misunderstanding could be a major setback in having good communication. Ineffective communication, both parties should be actively involved in achieving satisfaction which leads to better health and psychosocial outcomes (Van Bruinessen et al., 2013). Unfortunately, patients continue to experience unmet communication needs in terms of medical information and understanding of the procedure. Apparently, patients are hindered by barriers to participating actively during consultation with medical personnel. Specific communication behaviours of physicians, for example, keeping the conversation too general, not responding to patient's notice of vague physical or psychological complaints, not apologizing for mistakes, and blunt delivery of bad news, are frequently mentioned as a problem in patient-doctor communication barrier. Patients mentioned that it helped when a physician showed a reflective communication style and addressed the communication rules between them. Frequently mentioned by patients, by keeping the conversation too general, not responding to patient's notice of vague physical or psychological complaints, not apologizing for mistakes and blunt delivery of bad news as a barrier. Proximal outcomes might be improved, such as increasing patients' satisfaction, reducing patients' anxiety, and improving patients' trust and emotional health via patient-centred communication, which in turn may lead to increased adherence to medical treatment and patient recovery. (Dong et al. 2014) On the other hand, terms of patient readiness emotionally and physically are questionable because the patient will not know what to expect throughout the treatment. (Li et al., 2018)

External Beam Radiation Therapy (EBRT) may affect the patient's diet due to dysphagia, and dietary changes can exacerbate other treatment-related symptoms, for example, chemosensory alteration, distorted taste, and increased taste sensitivity (Coa et al. 2015). The common side effects faced by head and neck cancer patients undergoing radiotherapy treatment are dysphagia, loss of appetite, and loss of weight. In current patient education practice, the dietary perspective needs to be highlighted. For the inpatient, the food will be provided by the hospital under the supervision of the dietician. In contrast, for the outpatient patients, they need to manage their own dietary needs by themselves. Studies show that some food consumed could lead to a patient's loss of appetite. Patients in a study conducted by Coa have many food preferences and aversions in terms of cuisines, textures, and flavours. Each patient has their preferred foods and taste, and this has been found to change throughout treatment. (Coa et al. 2015) Nutrition assessment, education, and dietary interventions should be proactively done in order to have early prevention of malnutrition and its undesirable clinical outcomes, leading to poor quality of life for pelvic cancer patients. Nutrition assessment, education, and dietary interventions should be proactively done in order to have early prevention of malnutrition and its undesirable clinical outcomes, leading to poor quality of life (Dzairudzee et al. 2017).

Psychosocial support is an element that usually takes for granted among cancer patients and caregivers. Currently, patients who are diagnosed with cancer tend to have post-traumatic stress disorder (PTSD). It not just affecting the patient but their family members. A patient will face depression, anxiety, hopelessness, and stress related to physical and psychosocial changes (Mizota et al., 2018). Thus, psychosocial support helps the patient, family member, and also caregiver facing the distress. A high level of stress was faced by the cancer patient who was illiterate and unemployed. A patient is recommended to have cognitive behavioral stress management after effective treatment. It has been proven that patient who undergoes behavioural stress management will have a better quality of life and lower symptoms of depression 15 years after treatment (Hisam et al. 2018). Patient with end-stage cancer needs targeted, child-centered, family-focused psychosocial intervention support (Steiner et al. 2017).

From a clinical perspective, this research would develop a new module for integrated supportive cancer care education which is more comprehensive and more effective educational material in which patients have an adequate amount of knowledge and understanding about cancer. The results from this research would be a catalyst for new research and develop and improve the current practice and might be considered as a standard operating procedure in Malaysia.

This research focused on integrated supportive cancer care education to evaluate the supportive cancer care education materials that have been implemented. Specifically, to evaluate the information effectiveness of cancer care education that has been practiced, patient's understanding, and information effectiveness.

MATERIALS AND METHODS

This study was conducted at Gleneagles Penang Medical Center and involved 20 cancer patients selected using simple random sampling. Participants were not limited to any specific cancer type. Before participation, patients were provided with an information sheet and consent form explaining the study purpose and procedures. Participation was entirely voluntary and anonymous, and patients were informed they could withdraw at any time without consequence.

Ethical approval was obtained from the Universiti Kebangsaan Malaysia Research Ethics Committee (UKMREC) (Ref. No.: JEP-2019-145) on 29 March 2019. Data collection took place between April and May 2019. Questionnaires were distributed in hard copy form to accommodate the study's geographically localized sample and to improve accessibility for participants. Patients were given approximately one hour to complete the questionnaire while waiting for their clinical appointments.

Several challenges were noted during recruitment. Some patients declined participation due to emotional distress, mental readiness, or offense taken at sensitive questions. Language barriers also emerged, as many patients at the center were Indonesian nationals who did not speak Malay or English fluently, and some were illiterate.

The Patient Cancer Education Needs Assessment Questionnaire was used, adapted with permission from the original version developed by Johnson and Grahn and later modified by Zheng et al. The instrument includes 26 items: 18 original questions plus 8 new items relevant to local contexts. The questionnaire covered demographics (sex, race, age, education level, occupation, monthly income, and treatment type) and assessed patients' knowledge needs about cancer.

For knowledge assessment items, response options included: "I know enough about it," "I know a little, but need to learn more about it," "I know nothing but would like to learn more about it," and "I do not want to learn it." Patients were required to answer the questionnaire prior to the patient education received by them.

Data analysis was performed using SPSS version 21.0 and Microsoft Excel 2013. Chi-square tests were used to examine associations between patient characteristics (age, education, occupation, socioeconomic status) and levels of understanding. Given the small sample size (n=20) and the ordinal, categorical nature of responses, non-parametric tests were deemed appropriate, as parametric tests would violate normality assumptions.

RESULT

Demographic Data

The demographic characteristics of the 20 respondents are shown in Table 1. The sample included 40% male and 60% female participants. The majority (55%) identified as "Others" in terms of race, with smaller proportions of Malay (20%) and Chinese (25%). The largest age group was 41–60 years old (60%), followed by 61–80 years old (20%). Regarding education level, 45% had completed secondary school, 15% held a diploma or equivalent qualification, 35% had a degree, and 5% held a Master's or PhD. In terms of occupation, 55% were unemployed, 40% employed, and 5% students. Monthly income distribution was skewed toward lower-income groups, with 55% earning below RM2,000. Most patients received radiotherapy alone (55%), while 45% received combined chemotherapy and radiotherapy.

TABLE 1. [Patient Demographic]

Variable	Number	Percent
Sex		
Male	8	40.0
Female	12	60.0
Race		
Malay	4	20.0
Chinese	5	25.0
Others	11	55.0
Age		
Below 20 year old	1	5.0
21 - 40 year old	3	15.0
41 – 60 year old	12	60.0
61 - 80 year old	4	20.0
Education		
Secondary school	9	45.0
Matriculation/Foundation/STPM/Diploma	3	15.0
Degree	7	35.0
Master/PhD	1	5.0

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Occupation		
Student	1	5.0
Employed	8	40.0
Unemployed	11	55.0
Monthly Income		
Below RM2,000	11	55.0
RM2,000 – RM5,000	6	30.0
RM5,00 – RM10,000	2	10.0
More than RM10,000	1	5.0
Treatment		
Radiotherapy	11	55.0
Chemotherapy + Radiotherapy	9	45.0

Patient Understanding by Demographic Factors

The data from the Patient Cancer Education Needs Assessment Questionnaire are summarized in Tables 2–5, which present patients' self-reported levels of understanding across four response options ("Know Enough," "Know a Little," "Know Nothing," "Do Not Want") broken down by age, education level, occupation, and socioeconomic status.

TABLE 2. Patient Understanding by Age Group (n = 20)

Age Group	Know Enough (%)	Know a Little (%)	Know Nothing (%)	Do Not Want (%)
<20	5	0	0	0
21–40	10	15	0	0
41–60	35	30	15	5
61–80	10	10	10	5

Across age groups, understanding levels varied, but no statistically significant differences were observed. For example, respondents aged 41–60 showed the highest proportion reporting "Know Enough" (35%), while younger and older groups reported lower levels. In addition, 45% of patients know about it in question 23, and 45% of respondents know little and need to learn about it in question 8. There is a significant difference for some questions between ages in questions 7 (), 11 (), and 24 ().

TABLE 3. Patient Understanding by Education Level

Education Level	Know Enough (%)	Know a Little (%)	Know Nothing (%)	Do Not Want (%)
Secondary School	20	25	15	5
Matriculation / Foundation / STPM / Dip.	5	15	5	0
Degree	5	5	0	5
Master / PhD	5	0	0	0

Education as a factor of patients' understanding is 40% for question 26 (, where Secondary school and degree holders had similar distributions of "Know Enough" (20% and 5%, respectively) but both groups also expressed substantial interest in learning more, indicating unmet educational needs.

TABLE 4. Patient Understanding by Occupation

Occupation	Know Enough (%)	Know a Little (%)	Know Nothing (%)	Do Not Want (%)
Student	0	5	0	5
Employed	20	30	5	5
Unemployed	30	25	20	5

For the occupation factor, 35% of respondents know that for question 7 (, 25% were unemployed, and 10% were employed. 25% of employed respondents know little about the role of food/vitamins, while 20% of unemployed respondents answered the same. They wanted to learn more about the role of food/vitamin in cancer treatment. In addition, for questions 4 (and 21(, 35% and 20% of respondents, respectively, know enough about it. Unemployed respondents reported higher rates of “Know a Little” (25%) and “Know Nothing” (20%), suggesting potential barriers to information access in this group.

TABLE 5. Patient Understanding by Socioeconomic Status

Income Level	Know Enough (%)	Know a Little (%)	Know Nothing (%)	Do Not Want (%)
< RM2,000	20	30	15	5
RM2,000–5,000	15	20	5	0
RM5,000–10,000	5	5	5	0
> RM10,000	5	5	0	5

In terms of socioeconomic status, Lower-income groups (<RM2,000) had the highest proportion reporting “Know a Little” (30%) and “Know Nothing” (15%), underscoring disparities in understanding related to income level.

This questionnaire can be divided into 3 section, which is general knowledge about cancer, side effect and management for cancer, and patients’ psychosocial. Analysis of responses revealed patterns across the three thematic sections of the questionnaire. For general knowledge of cancer, approximately 30% of respondents across age groups reported “Know a Little but Need to Learn More,” with similar patterns seen by education, occupation, and socioeconomic status.

Side effects and management of cancer section, in terms of age of the respondent, Around 35% of respondents in all demographic categories reported needing to learn more, indicating a consistent gap in understanding of side effect management.

Psychology section for age factors, 30% and above are answered. Responses suggested lower baseline knowledge overall, with 30% or more indicating limited understanding and a desire for more information.

DISCUSSION

Accurate, clear, and culturally appropriate cancer education materials are critical to improving patient understanding and self-management. This study found that patient age, education level, occupation, and socioeconomic status were not statistically significant factors in understanding, likely due in part to the small sample size and recruitment challenges. However, analysis of the questionnaire responses revealed consistent gaps in knowledge across all demographic subgroups, particularly regarding side effects, management strategies, and psychosocial aspects of cancer care.

Several barriers to effective patient education were identified. Language differences and literacy limitations were significant challenges, particularly in a setting with many foreign patients. Many participants faced difficulties understanding Bahasa Malaysia or English, and some were illiterate. This highlights the need for multilingual, culturally adapted education resources that are accessible to diverse patient populations.

Another barrier was patient readiness and emotional state. Some patients declined participation due to emotional distress or felt offended by sensitive questions. Others may have been in denial about their diagnosis or experienced anxiety and depression that limited their willingness to engage with educational materials. Previous research shows that cancer-related post-traumatic stress disorder (PTSD) is common and can interfere with patients’ ability to process and use health information (French-Rosas et al., 2011). Integrating mental health support into education programs may help address these barriers.

Current education practices in Malaysia often use one-way delivery methods with limited opportunity for interaction or personalization. This approach can be particularly ineffective for patients with limited health literacy or those unfamiliar with medical terminology. Interactive, patient-centered education approaches—such as visual aids, culturally adapted illustrations, mobile apps, or video-based materials—have been shown to improve patient understanding, reduce anxiety, and increase satisfaction (Dahodwala et al., 2018).

Dietary guidance also emerged as a critical, under-addressed component. Patients undergoing radiotherapy, especially for head and neck cancers, face significant nutritional challenges, including dysphagia, taste changes, and loss of appetite (Coa et al., 2015). Nutrition assessment and counselling should be incorporated into education programs to prevent malnutrition and support quality of life (Dzairudzee et al., 2017).

Psychosocial support is equally important yet often overlooked. Cancer patients and their families may experience high levels of stress, anxiety, and hopelessness, particularly among those who are illiterate or unemployed (Mizota et al., 2018). Evidence suggests that interventions such as cognitive-behavioral stress management can significantly improve quality of life and reduce depression symptoms over the long term (Hisam et al., 2018). Education materials should therefore address not only clinical and practical information but also emotional and psychosocial needs.

Finally, the lack of standardized, culturally relevant patient education guidelines in Malaysia results in inconsistent practices across centers. Developing comprehensive, standardized, and culturally sensitive education modules is essential to ensure equitable access to high-quality information. Such modules should be multidisciplinary, involving oncologists, nurses, dietitians, radiation therapists, and mental health professionals.

Despite the limitations of this pilot study—including the small sample size, time constraints, and recruitment challenges—the findings provide valuable insights. They highlight clear opportunities to improve patient cancer care education in Malaysia, making it more comprehensive, interactive, patient-friendly, and culturally appropriate. Future research should expand on these findings with larger, more diverse samples and evaluate the impact of improved education materials on patient outcomes

CONCLUSIONS

Patient cancer care education materials in Malaysia require significant improvement to ensure they are comprehensive, interactive, culturally appropriate, and patient-friendly. This study highlights consistent gaps in patient understanding across demographic groups, underscoring the need for educational resources that address treatment, side effects and their management, dietary guidance, and psychosocial support.

To be effective, education materials must keep pace with technological advancements, using interactive formats such as mobile applications, videos, and culturally adapted illustrations to enhance accessibility and engagement. They should also be available in multiple languages to accommodate diverse patient populations and overcome language barriers.

Furthermore, the development of comprehensive patient education programs should adopt a multidisciplinary approach, involving oncologists, nurses, radiation therapists, dietitians, and mental health professionals to ensure holistic support for patients. By improving the quality, clarity, and cultural relevance of cancer care education, we can empower patients with the knowledge they need to manage their treatment journey confidently and improve their overall quality of life.

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