Published in final edited form as:

J Cancer Educ. 2010 December ; 25(4): 512–517. doi:10.1007/s13187-010-0080-3.

Development and Validation of a Nutritional Education Pamphlet for Low-Literacy Pediatric Oncology Caregivers in Central America

Melissa Garcia, Elisabeth A. Chismark, PhD, RN, Terezie Mosby, MS, RD, CSP, IBCLC, and Sara Day, RN, MSN

Abstract

Background—A culturally appropriate nutrition education pamphlet was developed and validated for low-literacy caregivers in Honduras, El Salvador, and Guatemala.

Methods—The pamphlet was developed after a preliminary survey of pediatric oncology nurses in the 3 countries to assess the need for education materials, caregiver literacy levels, and local eating habits. Experts in nutrition and low-literacy patient education and nurses validated the pamphlet's content and design.

Results and Conclusions—Nurses expressed the need for nutrition-related pamphlets in developing countries. The pamphlet was validated positively by experts and nurses and has been circulated to pediatric oncology caregivers in Central America.

The survival rates of children with cancer have increased in the past few decades [1]. However, this increase is more evident in developed than in underdeveloped and developing countries, where 80% of the world's children currently reside. Worldwide, more than 70% of children with cancer do not have access to the modern treatment essential for their survival. The International Outreach Program (IOP) at the St. Jude Children's Research Hospital (St. Jude) collaborates with several developing countries to increase survival rates by sharing knowledge, technology, and organizational skills.

In developing countries, the prevalence of malnutrition in children with cancer averages 50% [2]. Children diagnosed with cancer are also at an increased risk of infection, the leading cause of death in cancer patients. The introduction of bacteria and contaminants into the gastrointestinal tract can be reduced by practicing strict food safety and excluding certain foods from the diets of immunocompromised patients, thereby decreasing the risk of infection [3].

Discussions during the 10th meeting of the Central American Association of Pediatric Hematology-Oncology (AHOPCA) [4] confirmed that food safety education materials are not available in Central American countries, and their lack leads to uncertainty among patients and families about safe versus unsafe foods and preparation techniques. AHOPCA

nurses identified the limited availability of nutritionists to provide patient and family nutrition education, the provision of unsafe foods for immunocompromised patients by visitors, and the lack of nutrition education materials for caregivers, many of whom are illiterate or low literate, as major obstacles to the nutritional management of children with cancer.

Studies have demonstrated that patients remember only 29–72% of the information verbally presented by health professionals [5]. Health professionals therefore frequently rely on informational pamphlets to enhance the understanding and recall of healthcare instructions. Pamphlets are easy to store, require no special equipment, can be used as reference materials outside the hospital, provide a means for transmitting standardized information, and may be tailored for specific audiences [6]. Many existing pamphlets, however, have a high readability level and may be difficult for illiterate or low-literate caregivers and clients to comprehend, thereby reducing the perceived benefits, hindering client self-care, and compromising the quality of care [7]. However, when low-literacy patients and caregivers receive picture-based materials in addition to spoken medical instructions, home care can be significantly improved [8]. A study by Juarez et al. (1999) assessed the effectiveness of generic cancer education in 3 ethnic groups and found that the groups benefited to different degrees from the education [9]. Sutherland et al. (2008) demonstrated that cancer education assists patients coping abilities and has immediate benefits for family and caregivers [10]. Therefore, it is important for educational pamphlets to reflect the education, religion, values, beliefs, politics, economics, world view, social structure, and healthcare traditions of the population [11].

The goal of this project was the development and validation of a culturally appropriate nutrition education pamphlet by the IOP to be disseminated by pediatric oncology nurses in St. Jude partner sites in Central America. The pamphlet targets the education of low-literate pediatric oncology caregivers, illustrated in Figure 1. and is distributed as a resource for caregivers during treatment and at home. The goal of the development of this pamphlet was to emphasize a cautious approach to bringing food into the hospital. Additionally, it will assist the caregivers in preparing meals for the children at home. The ultimate outcome for the pamphlet will be as an adjunct educational tool to assist in the prevention of infections from food sources.

Methods

Content, Objectives, and Target Population

The proposed content and objectives for the pamphlet were reviewed by an expert panel from St. Jude. Contents of the pamphlet addressed the 3 obstacles discussed by the participants during the AHOPCA conference. The pamphlet was aimed for illiterate and low-literate caregivers in El Salvador, Guatemala, and Honduras, and featured general food safety guidelines, examples of foods that patients can safely consume, and information on foods to be avoided.

Preliminary Nursing Survey

An initial informal questionnaire was developed by the IOP in Spanish, and disseminated by e-mail to pediatric oncology nurses at 3 Central American hospitals: Hospital de Niños Benjamín Bloom, San Salvador, El Salvador; Unidad Nacional de Oncología Pediátrica, Guatemala, Guatemala; and Hospital Escuela Bloque Materno Infantil, Tegucigalpa, Honduras. The questionnaire surveyed the nurses on the (1) availability of educational materials; (2) need for a nutrition education pamphlet; (3) input from the bedside nurse on content; (4) foods commonly brought into the hospital by caregivers; (5) foods commonly consumed by patients and their families; (6) caregivers' ability to read and comprehend materials; (7) current hospital policy regarding the ingestion of foods; (8) current strategies used to deter the ingestion of unsafe foods; and (9) special ethnic or religious circumstances that affect patients' diets.

Pamphlet Design

Questionnaire responses and research findings were used in the first stage of development of the educational pamphlet; the final product was a 32-slide PowerPoint presentation. The presentation incorporated some text, as well as images, the main component of this pamphlet. The PowerPoint presentation was used to generate the overall design of the pamphlet; it underwent several revisions and resulted in the first draft of the pamphlet.

Assessment of Content Validity

Content validity is the determination of the content representativeness or content relevance of elements of an instrument. This 2-stage process requires validation in the developmental and judgment-quantification stages [11]. During the developmental stage, a panel of 5 experts, including nurses, a dietician, and a translator with expertise in patient education materials, low-literacy education, and nutrition, validated both the accuracy of the information presented and the cultural sensitivity of the pamphlet. The pamphlet was also presented to nurses from El Salvador and Guatemala via a Horizon Live presentation on the Cure4Kids Web site (www.cure4kids.org), a distance-learning initiative of St. Jude. The attendees were solicited for general comments and suggestions.

Content validation during the judgment-quantification stage requires experts to assert the validity of both the content of the items and the instrument [12]. Rating scales were sent to 6 nurses from Honduras, Guatemala, and El Salvador. The panel of experts was required to have the relevant training, experience, and qualifications required for this validation [13]; their clinical expertise was also considered [14]. Experts were selected from various geographic locations to increase the chances of detecting colloquial terms inappropriate for such an instrument [15]. The panel received specific instructions by which to determine the content relevance of items and of the pamphlet as a whole [16]. Item content, item style, and comprehensiveness were assessed by using the rating scale [14], results are provided in Table 1. Results were quantified by applying the content validity index (CVI), which is the percentage of total items that are content valid, on the basis of whether they receive a score of 3 or 4 on a 4-point scale (1 = not representative; 2 = in need of major revisions to be representative; 3 = in need of minor revisions to be representative; 4 = representative) [12]. A new instrument should have a minimum CVI of .80 [17].

A Spanish-language 10-item content validity scale was developed. The scale was distributed to 2 experts in each target country, along with a cover letter stating why they were chosen, general information on the elements they would be addressing, and the significance of their participation in validating the instrument.

Results

Preliminary Nursing Survey

Three nurses (one from each target country) were sent and completed the preliminary nursing survey by email. All surveyed nurses stated that their respective hospitals did not currently have any type of nutrition education materials available for pediatric oncology patient caregivers, and that most nutrition education is offered through informal talks with caregivers. All nurses also expressed that an educational pamphlet would be welcomed and useful. They suggested the following topics for inclusion in the pamphlet: nutrient-rich foods, general food safety, basic diet guidelines, nutrition content of foods, and prevention of food contamination. The nurses emphasized the importance of including local foods in the pamphlet to enhance relevancy and effectiveness. The estimated percentage of caregivers who could read at any of the given hospitals ranged from 60% to 85%. However, the nurses commented that most caregivers dislike long educational materials because they are unaccustomed to reading.

Foods commonly brought into the hospital by the caregivers include tortillas, fast food, soup, candy, juice and other beverages, fruit, vegetables, salad, *elotes* (roasted or boiled ears of corn smeared with butter or mayonnaise and topped with cheese, salt, lime juice, and chili powder), and *pupusas* (thick corn tortillas filled with cheese, beans, or meat). Common items consumed by patients and their families include beans, tortillas, eggs, cereal, bread, rice, pasta, meat, seafood, soup, vegetables (greens, potatoes, carrots), fruits (bananas, oranges), pancakes, fast food, cheese, *pupusas*, juice, milk, and coffee. Foods best tolerated by patients during treatment include salad, soup (made with macuy herb), fruit shakes, fruit, beef tacos, chicken, French fries, plantains with beans and butter, and tortilla with cheese.

Hospitals varied in their policy regarding the food brought in by caregivers. The hospitals in El Salvador and Guatemala allow the ingress of homemade foods under special circumstances and with authorization from the nutrition department or the physician, whereas the hospital in Honduras does not allow the ingress of street-bought or homemade foods. All nurses expressed that ingress of street-bought or homemade food is a common practice at their hospitals, despite the hospital policies. When caregivers bring in food to the hospital without permission, nurses verbally instruct them about the health risks and consequences of food poisoning and infection for the patient.

The nurses felt ethnic and religious circumstances affected the patients' diets, such as religious beliefs requiring a vegetarian diet. Most nurses also cited economic hardship and discrepancies between foods offered in the hospital versus those commonly consumed in the patients' homes as other factors that affected patient diets. An effort was made to include foods that both vegetarians and persons from lower socioeconomic classes typically consume.

Content Validity Index

Three of the 6 evaluation surveys were returned: 1 nurse from Guatemala and 2 nurses from El Salvador studied the pamphlet and completed the rating scale. The number of experts needed for content validity determination is arbitrary and depends on the ability to locate content or domain experts and obtain their cooperation [12]. In content or domain areas that are restricted enough to preclude a large number of experts, a minimum of 3 experts should be used [12]. At the time of evaluation survey, the 3 nurses completing the survey had 3.6 years of experience (range, 6 months to 6 years and 10 months) working with pediatric oncology patients. Nurses scored all items as a 3 or 4 on the 4-point scale.

All 3 nurses stated that no important food safety recommendations had been omitted, and no portions of the pamphlet should be removed from the publication. One nurse noted the exclusion of a widely-consumed fruit (*nance*) and requested its inclusion in the final draft. Additional comments, not addressed by the evaluation survey, included: 1) the need for feedback from caregivers who receive the pamphlet, and 2) the need to include a specific fruit commonly consumed in Central America. There were queries by some of the evaluators on why certain food safety recommendations were listed in the pamphlet. A St. Jude Children's Research Hospital nutritionist was consulted to provide nursing education about the latest food safety guidelines.

The CVI score (the percentage of components rated by the experts as either a 3 or 4) for the pamphlet is 1.0, as the 3 nurses who returned the survey scored all items as a 3 or 4.

Discussion

The concern raised by nurses at the 2007 AHOPCA conference over the unavailability of nutritional education materials on food safety in hospitals in Central America prompted the IOP at St. Jude to develop a culturally appropriate nutrition education pamphlet. The pamphlet was targeted for use by pediatric oncology nurses in Honduras, El Salvador, and Guatemala to assist in the education of low-literate pediatric oncology caregivers. These 3 countries are official partners with the IOP, and their patient populations have similar dietary habits. Nurses in the participating hospitals responded to a preliminary survey to assess: the availability of and need for nutritional pamphlets, food practices of caregivers, caregivers' ability to comprehend educational material, and hospital policy on ingestion of food. The final pamphlet was assessed for content validity by nurses from El Salvador and Guatemala.

A low-bacteria diet and strict food safety can reduce the number of bacteria and contaminants that enter the body, thereby decreasing the incidence of food poisoning and infection in patients [3]. Because it is common practice in Central America for caregivers to bring foods from the street or home to the patient at the hospital, patients in these countries are at a high risk of acquiring infections from food sources. A simple pamphlet containing important nutrition information that is both easily understandable and visually attractive can help ensure that caregivers are more informed about safe and unsafe food practices. The healthcare provider should go over the pamphlet with the caregiver and patient to ensure that it has been clearly understood and not discarded or ignored. Healthcare providers should

note that the pamphlet is a simplified representation of select guidelines and is not meant to be all-inclusive; additional restrictions should be discussed if necessary.

Several elements can affect patient education such as low literacy levels, cultural customs, and socioeconomic status of patients and their caregivers. These were considered while developing this pamphlet. The pamphlet was tailored to a low-literacy audience and created in agreement with the design and readability recommendations from previous literature [5–8, 11, 18–22] as well as the feedback provided by nurses in the preliminary questionnaire. A bulleted question-and-answer format was used, and the use of italics and all-caps type was avoided to enhance comprehension. The pamphlet was uncluttered and its information was in large print and included culturally relevant graphics [23]. The final version of the pamphlet was validated positively by 3 nurses and the minor changes they suggested were incorporated.

Nurse educators at the participating institutions will be trained on how to provide food safety education by using this pamphlet. Future research will assess the efficacy of the pamphlet as an educational tool by using pre- and post-tests to measure information acquisition and retention in low-literacy caregivers in the target countries. Caregivers of pediatric patients undergoing treatment for leukemia in El Salvador and Guatemala will participate in the pilot study.

Acknowledgments

Received from the International Outreach Program, St. Jude Children's Research Hospital, Memphis, TN (SD, LC, TM), and the University of Pennsylvania School of Nursing, Philadelphia, PA (MG*)

*Studies reported in this paper done as part of the POE (Pediatric Oncology Education) and CURE (Continuing Umbrella of Research Experiences) funded by the National Cancer Institute. Additional funding in part by grants 5R25CA023944 and 2P30CA021765 from the National Cancer Society and ALSAC (American Lebanese Syrian Associated Charities).

References

1. O'Leary M, Krailo M, Anderson JR, et al. Progress in childhood cancers: 50 years of research collaboration a report from the childhood oncology group. *Seminars in Oncology*. 2008; 35(5):484–493. [PubMed: 18929147]
2. Sala A, Pencharz P, Barr RD. Children, cancer, and nutrition - A dynamic triangle in review. *Cancer*. 2004; 100(4):677–687. [PubMed: 14770421]
3. Todd J, Schmidt M, Christain J, et al. The low-bacteria diet for immunocompromised patients: Reasonable prudence or clinical superstition? *Cancer Practice*. 1999; 7(4):205–207. [PubMed: 10687586]
4. Nursing Meeting: Nutrition in Pediatric Oncology. Central American Association of Pediatric Hematology-Oncology (AHOPCA). Dominican Republic. 2007 Feb 17.
5. Houts PS, Bachrach R, Witmer JT, et al. Using pictographs to enhance recall of spoken medical instructions. *Patient Education and Counseling*. 1998; 35(2):83–88. [PubMed: 10026551]
6. Developing health and family planning print materials for low-literate audiences: a guide. Revised ed. Seattle: Program for Appropriate Technology in Health (PATH); 1996.
7. French KS, Larrabee JH. Relationships among educational material readability, client literacy, perceived beneficence, and perceived quality. *Journal of Nursing Care Quality*. 1999; 13(6):68–82. [PubMed: 10476626]

8. Houts PS, Doak CC, Doak LG, et al. The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling*. 2006; 61(2):173–190. [PubMed: 16122896]
9. Juarez G, Ferrell B, Borneman T. Cultural considerations in education for cancer pain management. *Journal of Cancer Education*. 1999; 14(3):168–173. [PubMed: 10512335]
10. Sutherland G, Dpsych LH, White V, et al. How does cancer education impact on people with cancer and their family and friends? *Journal of Cancer Education*. 2008; 23(2):126–132. [PubMed: 18569249]
11. Leininger M. Culture Care Theory: A major contribution to advance transcultural nursing knowledge and practices. *Journal of Transcultural Nursing*. 2002; 13(3):189–192. [PubMed: 12113148]
12. Lynn MR. Determination and quantification of content validity. *Nursing Research*. 1986; 35(6): 382–385. [PubMed: 3640358]
13. Standards for educational and psychological testing. Washington, DC: American Educational Research Association, American Psychological Association, National Council on Measurement in Education; 1985.
14. Grant JS, Davis LL. Selection and use of content experts for instrument development. *Research in Nursing & Health*. 1997; 20:269–274. [PubMed: 9179180]
15. Grant J, Kinney M, Guzzetta C. A methodology for validating nursing diagnoses. *Advances in Nursing Science*. 1990; 12(3):65–74. [PubMed: 2107792]
16. McCain, NL. A test of Cohen's developmental model for professional socialization with baccalaureate nursing students. University of Alabama in Birmingham; 1984.
17. Davis L. Instrument review: getting the most from your panel of experts. *Applied Nursing Research*. 1992; 5:104–107.
18. Aldridge MD. Writing and Designing Readable Patient Education Materials. *Nephrology Nursing Journal*. 2004; 31(4):218–224. [PubMed: 15114804]
19. Cutilli CC. Do your patients understand? Providing culturally congruent patient education. *Orthopaedic Nursing*. 2006; 25(3):218–224. [PubMed: 16735855]
20. Doak LG, Doak DC, Meade CD. Strategies to improve cancer education materials. *Oncology Nursing Forum*. 1996; 23(8):1305–1312. [PubMed: 8883075]
21. Hubley J. Patient education in the developing world - A discipline comes of age. *Patient Education and Counseling*. 2006; 61(1):161–164. [PubMed: 16533684]
22. Ngho LN, Shepherd MD. Design, development, and evaluation of visual aids for communicating prescription drug instructions to nonliterate patients in rural Cameroon. *Patient Education and Counseling*. 1997; 31(3):245–261. [PubMed: 9277247]
23. Massett HA. Appropriateness of Hispanic print materials: a content analysis. *Health Education Research*. 1996; 11(2):231–242. [PubMed: 10163408]

Figure 1.
Nutritional Education Pamphlet for Low-Literate Pediatric Oncology Caregivers in Central America

Table 1

Rating scale to assess the item content, style, and comprehensiveness of the nutritional education pamphlet.

Item	Mean Content Validity Score (1–4)
1. This pamphlet provides good recommendations about food safety for children diagnosed with cancer.	3.33
2. This pamphlet will be helpful for families of all ethnic, religious, and economic groups represented in your hospital.	3.67
3. Foods are representative of those available to parents/caregivers.	4.00
4. Foods are typical of those commonly consumed by families.	4.00
5. Recommendations are presented in a clear manner.	3.33
6. Parents/caregivers are likely to understand the content presented in the pamphlet.	3.67
7. Parents/caregivers will be more informed about what foods they can give their children.	3.67
8. Parents/caregivers will be more informed about what foods they should not give their children.	3.67
9. Recommendations are feasible for parents/caregivers to follow.	3.67
10. I would use this pamphlet to educate parents/caregivers about the nutrition of their child with cancer.	4.00

Note: 1 = the item is not representative of the educational pamphlet; 2 = the item needs major revisions to be representative of the educational pamphlet; 3 = the item needs minor revisions to be representative of the educational pamphlet; 4 = the item is representative of the educational pamphlet