

Wimpfheimer-Guggenheim Essays Competition

Winning essay from 2013

Development and Testing of Educational Tool for Low Literacy caregivers of Children with Cancer Teaching About Food Safety

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Introduction

Author together with co-authors of this essay developed an educational material for low literacy caregivers of children with cancer in Guatemala (residence of co-authors) and El Salvador (residence of a co-author). This program is very successful and was presented at the 41st [SIOP \(International Society of Pediatric Oncology\)](#) congress (1). Please, see the copy of the educational material attached to this essay.

Background

The author was invited to give a presentation for nurses at the 2006 meeting of [Association of Pediatric Hematology-Oncology of Central America \(AHOPCA\)](#). During the 10th meeting of AHOPCA, the local nurses identified the most common problems they deal with when taking care of patients with cancer (2). The two main problems were that parents are bringing unsafe food to patients and that there are no educational materials available for illiterate or low literacy caregiver about food safety. Nurses from each Central American country participating in that meeting recognized food safety as being one of the main problems they have to deal with on daily bases while taking care of children with cancer. Strict Food Safety or Low Bacteria Diet is recommended for children undergoing treatment for cancer due to their immuno-suppression. Following the Low Bacteria Diet may help to reduce risk of bacterial infections in immuno-compromised patients. Participating nurses determined that food safety education materials are not available in the Central American countries, and their lack leads to uncertainty among patients and their families about safe versus unsafe foods and their preparation techniques.

AHOPCA nurses identified the limited availability of nutritionists to provide patient and family nutrition education. The ingestion of unsafe foods for immuno-compromised patients by their parents, and the lack of nutrition education materials for caregivers, many of whom are illiterate or low literate, are major obstacles to the nutritional management of children with cancer. Current report showed that children who live in the same community and share the same resources are less malnourished, if the mother has education. This observation demonstrates the importance of caregivers' education for health of their children.

Description of educational program

To meet this need we decided to develop a food safety educational program for low literacy caregivers of children with cancer to teach about food safety. Patients who are undergoing treatment for cancer are immuno-compromised and have to follow a strict food safety diet (neutropenic diet/ low bacteria diet), to prevent dying due to a food-borne infection. Most of caregivers in Guatemala and El Salvador are either illiterate or have a low literacy. Therefore, educational material has to be simple, in pictorial form and using local food (3,4). Both of those countries are low income countries and limited finances are available for development of educational material. Ana Lucia Molina Linares from Guatemala is the head of nutritional department in Guatemala and played a key part in the development of the "food safety" handout for her hospital (4).

This program had several parts: 1. Development and validation of a culturally appropriate nutrition education booklet and distribution of the booklet "Alimentación del Niño con Cáncer". 2. Training nurse educators on how to provide food safety education using this booklet. 3. Testing the efficacy of this booklet as an educational tool for low literacy population and for information acquisition and information retention, using a pre- and post-test.

Development of the booklet had to meet several criteria: it had to be targeted to illiterate and low literacy caregivers, local foods had to be used in the booklet, it had to address main food safety issues and it had to be attractive and readable for children.

The booklet was developed in several steps.

- Step 1: we surveyed local hospitals about the main food/dishes patients are consuming in each country (in Guatemala and in El Salvador).
- Step 2: Development of the booklet.
- Step 3: We validated the booklet with board of experts from Guatemala, El Salvador and U.S.A.

The goal of the booklet was to emphasize a cautious approach to bringing food into the hospital and preparing meals for the children at home.

To assess efficacy of the nutrition booklet, pre- and post-tests were developed to measure information acquisition and retention in caregivers in Guatemala and El Salvador. The test

contained 10 multiple-choice questions and content was validated by a team of experts. We also developed educator's speech for consistency of education. The test was administered by nurse educators trained to provide food safety education using the booklet. Pre-test was administered prior to any educational intervention. The post-test was administered immediately after education, and again after one and three months. Demographic questionnaire were also developed and administered to find out living, cooking conditions, and education level.

There were 198 caregivers of newly diagnosed pediatric patients with leukemia from two public hospitals in El Salvador and Guatemala participated in the evaluation study. There were 162 caregivers were from El Salvador and 36 caregivers from Guatemala.

Summary of results

The booklet was found to be an excellent educational tool to teach illiterate and low literacy caregivers about food safety. Significant differences in scores between pre-test1 and post-test1, pre-test1 and post-test2 at one month were found.

There was no significant difference in scores between post-test1 and post-test2 at one month, post-test1 and post-test3 at 3 months or between post-test2 at 1 month and post-test3 at 3 months. It signifies a high information retention rate and that one education is enough and re-education is not necessary.

Pre-educational knowledge was not associated with the gender of caregiver, socio-economic status, relationship of caregiver to patient, person which usually cooked for patient, source of drinking water used, age of caregiver, number of persons living in the same house as patient, monthly income per family and number of persons being supported from this income.

El Salvador caregivers who had the ability to read had higher pre-educational knowledge than caregivers who were unable to read. However, caregivers in Guatemala, had no significant relationship existed between the ability to read and the pre-educational knowledge.

There was no significant difference in pre-intervention knowledge between the two countries. Information acquisition of caregivers in El Salvador was significantly higher than that of caregivers in Guatemala. There was no significant association between learning and demographic variables in El Salvador and Guatemala. There was no significant difference in socio-economic status between El Salvador and Guatemala caregivers.

Education provided by nurse educators using the nutritional education pamphlet significantly improved food safety knowledge and knowledge levels were sustained at one and three months after intervention.

Conclusion

This program is a great example of international collaboration in nutrition. The project benefits local caregivers of children with cancer, because the education and booklet are provided for free and it serves their needs using local food and being developed for illiterate population.

Future plans

Because of the successfulness of this program and our experience in this field, we would like to extend this program to additional countries in Central America that are members of the AHOPCA consortium.