



Development of a Health Literacy Program for Parents of Children with Cancer: A Mixed-Methods Study Protocol

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Abstract

Objectives: Parents' health literacy plays an important role in the proper management of symptoms and providing appropriate care for their children living with cancer. However, studies conducted on health literacy in Iranian culture is very limited. Therefore, this study will identify the health literacy needs of parents of children with cancer and will design a program for promoting their health literacy.

Methods: This exploratory mixed-methods study, using qualitative-quantitative methods including 4 consecutive phases. In the first phase, the literature review will be carried out to conceptualize and determine the domains of health literacy. In the second phase, a qualitative study will be conducted to identify and determine the needs and strategies for promoting the health literacy of parents using deep semi-structured interviews. Participants will be selected by purposive and snowball sampling methods and data will be analyzed using the directed content analysis method. In the third phase, participants' needs will be prioritized using a panel of experts and the initial draft of the program will be designed. In the fourth phase, the modified Delphi method will be used to prioritize program strategies and select the final program.

Discussion: Developing a program using a qualitative method and literature review can provide some evidence for promoting health literacy in parents of children living with cancer. Moreover, it is expected that this program promotes knowledge and empowerment of health team members, especially nurses to provide family-centered care for children with cancer. This, in turn, will increase the quality of provided treatment and care and will decrease the costs.

Keywords: Health Literacy, Parents, Child, Neoplasms, Iran, Nursing

1. Background

Today, non-communicable diseases are the main cause of mortality throughout the world and cancer is the basic cause of death and the most important barrier for increased life expectancy in the 21st century. In 2018, about 18.1 million new cases of cancer and 9.6 million cases of death due to cancer have been reported in 185 countries (1). In 2018, the cancer incidence was estimated as 16.8 per 100,000 for boys and 16.56 per 100,000 for Iranian girls (2). Total of 2219 new cases of childhood cancer are being estimated in Iran in 2020 (3). Although the cancer incidence is increasing among children, the 5-year survival rate has also significantly increased in 80% of childhood cancers (4).

Medical advancements like increasing in life expectancy and changing in the treatment system toward outpatient treatments and home care highlight the important role of parents in caring for their children with

cancer (5, 6). In fact, parents are considered as the main caregivers of children in the hospital and the main part of caring at home, managing drug use and their side effects, giving required care, and communicating with the treatment team. Parents have the main role in receiving and processing medical and health information related to the disease and their health literacy is one of the important factors affecting the proper child care (7-10).

However, the health literacy is still a new concept in clinical practice. Some resources considered health literacy as an individuals' ability in receiving, processing and understanding initial healthcare information and services required for making appropriate health decisions (11-13). Some other resources considered it as an active mediator between personal skills and healthcare background that include functional, interactive, and critical domains. Functional health literacy refers to the basic ability to read,

write, and understand the health information provided. This area includes dimensions such as adequate understanding of medical information, having sufficient information to manage health, and the ability to access accurate and quality health information. Interactive health literacy refers to the capacity to combine cognitive, social, and functional skills to extract information and use new information in changing situations. Dimensions in this area include a sense of understanding and support by health care providers, the ability to effectively interact with health care providers, and coordination with the health care system. Critical health literacy refers to the simultaneous application of advanced cognitive skills and social skills to critically analyze the information provided to make health care decisions. This area includes the dimensions of health information evaluation, active health status management, and social health support (14-16). The common point of literature is that health literacy has been considered as the core of knowledge and skills required for function in the healthcare system (11), but there are still inconsistencies in the literature regarding this concept that needs further elaboration.

Ignoring the needs of health literacy can lead to negative consequences in individuals with low health literacy compared to people with sufficient health literacy (17). For example, the low health literacy of caregivers can cause incorrect clinical decisions affecting the child's treatment course. Moreover, the rate of going to emergency and hospitalization increases among them, and in general, they spend more medical costs (12, 18). Health literacy is especially important for patients with cancer because decision-making for prevention, screening, and treatment in the oncology environment is complex. Since parents can directly influence the health literacy needs of children (14, 19, 20) and clinical outcomes of children are affected by parental health literacy, therefore, promoting health literacy is essential for this group (13).

Despite the importance of health literacy especially for parents of children with cancer, studies to develop programs for promoting the health literacy for these parents are limited in the world. Most of these studies conducted on the health literacy of parents are descriptive. For example, the study which conducted by Miller et al. showed that the health literacy level was 33% among mothers and 32% among fathers of children with cancer (21). Results of the study by Yin et al. showed that a large portion of American parents have low health literacy skills and need health literacy promotion programs to improve the health conditions of their children (22). Results of a systematic review of Adams et al. showed that information needs of caregivers are more relevant to patient care than medical information (5). Results of a systematic review of Keim-Malpass

et al. showed that promoting the health literacy of caregivers of children with cancer has not been adequately considered in studies (8). In Iran, Khodabakhshi et al. stated that sufficient health literacy among mothers of children with cerebral palsy is 43%, among mothers of children with autism is 49%, and among mothers of children with mental retardation is 42%, and the level of health literacy has been reported insufficient (9).

There are also some research studies outside Iran aimed at promoting health literacy in these parents. For instance, study of Wittenberg et al. who evaluated a health literacy promotion program for family caregivers of patients with cancer. They found that the presented content was very useful and effective for 63% of caregivers. The results of the qualitative part of this study showed that caregivers need to promote health literacy and suggest health literacy promotion interventions in oncology (23). Results of a study by Yuen et al. aimed at designing a conceptual model for health literacy promotion for caregivers of patients with cancer, showed that the health literacy of caregivers is a multi-dimensional concept and includes a wide range of personal and interpersonal elements and is affected by the healthcare system and social factors (24). Other studies revealed that this group still has many ignored needs in terms of health literacy (18, 20, 23, 25).

It can be concluded that health literacy is an important concept which can promote community health and increase the quality of healthcare services. In addition, health literacy affects almost every aspect of health care and is especially important in cancer because decisions about cancer prevention, screening, and treatment are more complex. No research has been found to develop health literacy programs for parents of children with cancer in Iran. Therefore, the current study will be carried out to design a health literacy promotion program for parents of children with cancer in selected centers of cancer treatment in Iran.

2. Methods

The current study is a sequential exploratory mixed methods study that includes qualitative and quantitative steps and it will be based on the paradigm of pragmatism. This study will be conducted in 4 phases to determine the health literacy needs of parents of children with cancer and design a health literacy promotion program for these parents approximately in 2 years. Studies in this area are limited in Iran, and research team members achieve a deeper understanding of the health literacy needs of parents by conducting a qualitative study. Thus, the qualitative step will be given more priority in this study. In the current research, integration of data with the merging data

approach will be done. This integration will be done by reporting results of qualitative and quantitative phases together in a discussion section (26).

2.1. Phase 1: Literature Review

A narrative review will be conducted searching library resources (articles, reference books, and thesis) and electronic databases of Medline, EMBASE, ProQuest, ISI Web of Science, Science Direct, and Scopus with keywords “Health Literacy”, “Cancer”, “Caregiver”, “Mother”, and “Parent”; and with derivations of “Mesh” in titles and abstracts of original articles and review articles from 2010 to 2020. Moreover, Persian literature will be reviewed in iranmedex, SID, and magiran databases with the same keywords from 2010 to 2020. The papers with the following criteria will be excluded: duplicated studies, letters to the editor, and the poster and conference papers. This phase will be done with the aim of identifying models, areas, and dimensions of health literacy in caregivers of children with cancer and using it as a basis for the qualitative phase.

2.2. Phase 2: Qualitative Study

In this phase, a qualitative study will be conducted to analyze the situation, determine the health literacy needs of parents of children with cancer, and identify barriers and strategies to meet health literacy needs. The research environment includes selected centers of cancer treatment affiliated to Isfahan University of Medical Sciences or workplace or house of participants. The schedule, duration, and place of the interview will be determined by participants. This phase will be done with the aim of identifying the needs and strategies to promote health literacy in areas (functional, interactive, and critical) from the perspective of participants.

2.2.1. Participants

Participants are mainly parents of children with cancer (with maximum variation in sex, age, type of childhood cancer, and duration of care). Moreover, health service providers including nurses and oncologist may be interviewed to further understand this concept and related needs. Participants will be selected by purposive and snowball sampling methods. The number of participants is not determined previously and interviews continue until data saturation.

2.2.2. Inclusion Criteria

Parents of Iranian children with cancer who are under the age of 15 (27, 28) are direct caregivers. Children at least one month after cancer diagnosis (24), and hospitalized at least once for diagnostic and therapeutic procedures will

be included in the study. In case of the need to interview with the health service providers, the inclusion criteria will be having at least 6 months of work experience at the oncology wards and desire to participate in the study.

2.2.3. Qualitative Data Collection Method

Data will gather through deep semi-structured individual interviews and field notes. An interview guide questions will be extracted from the relevant literature. Possible questions might be “What problems did you have in receiving information on child disease? (Functional domain)” and “What support have you received from the health care providers? (Interactive domain)”. Ethical considerations will be observed. Research objectives will be described for participants and informed written consent will be taken for participating in the study.

2.2.4. Analyzing Qualitative Data

Data analysis will be performed using Elo and Kyngas directed content analysis method. In this method, the researcher begins the study with a theory or findings of previous research studies, and codes are defined before analyzing data. Then, codes are developed during analysis. It is suggested that the main categories are extracted from the literature. One of the limitations of deductive coding is that newly collected documents or data may contain important ideas or views that have not been identified in previous studies. Thus, these new ideas are added to available categories. Therefore, the directed content analysis generally is a combined deductive and inductive approach for coding (29-31). This approach has been selected because there is no research or framework for analyzing the health literacy needs of parents of children with cancer in our setting (32). In the current study, categories were determined based on health literacy domains in previous research studies and interviews will be coded based on functional, interactive, and critical domains of health literacy. The continuous comparative analysis will be carried out during the study that will allow the formation of new categories (14-16).

2.2.5. The Trustworthiness of Qualitative Data

Guba and Lincoln criteria including credibility, dependability, confirmability, and transferability will be used to assure the trustworthiness of data. Prolonged engagement of the researcher, persistent observation, negative case analysis, peer debriefing, member check, comprehensive description of sampling strategies, methods of data collecting, and analyzing data will increase creditability. A member check will be used to increase researcher creditability. Moreover, events and decisions related to different phases of the study including interviews and data anal-

ysis are precisely recorded to allow inquiry audits by other researchers. The confirmability of results will be achieved by describing the detailed process of data analysis, negative case analysis, and peer debriefing. Moreover, providing a comprehensive description of the study allows readers to follow the study plan and judge the transferability of data to other fields (31).

2.3. Phase 3: Prioritizing Health Literacy Needs and Developing the Program

A panel of Experts will be done to prioritize the health literacy needs of parents resulting from the literature review and qualitative study. In this phase, extracted needs will place on a 5-point Likert scale (from 5 as very important to 1 as very unimportant) to prioritize. Panel members will formally invite and a summary of research objectives and they receive a need prioritizing questionnaire. Then, priorities will be given a score and discussed in the panel meeting. Members of the experts' panel are persons who have experience in the care and treatment of children with cancer and have experience interacting with their parents. Next, the needs of participants will be prioritized based on mean scores obtained and the initial draft of the health literacy promotion program will be developed using Ewles and Simnett's (2010) designing pattern. This model is a suitable method for designing health promotion programs. The main steps of this model are as follows: 1- Identify needs and priorities, 2- Set aims and objectives, 3. Decide the best way of achieving the aims, 4- Identify resources, 5- Plan evaluation methods, 6- Set an action plan (33). This phase will be carried out with the aim of prioritizing the health literacy needs of caregivers of children with cancer and designing an initial version of the program based on prioritizing health literacy needs.

2.4. Phase 4: Prioritizing Strategies of the Program and Final Confirmation of The Program

The Delphi modified method will be used to the prioritize strategies of the program. In this stage, a list of extracted strategies from findings of qualitative content analysis of interviews and literature review will be prepared in the form of a questionnaire. Each strategy is investigated in terms of ease for implementation, cost-effectiveness, simplicity, efficiency, and acceptability in a 5-point Likert scale (very high = 5 to very low = 1). The number of panel members will be between 7 and 15 and experts in various specialties who are familiar with caregivers for children with cancer will be invited and they will receive a summary of the research objectives and the questionnaire and according to the schedule, they will send the completed questionnaires. The researcher analyzes the questionnaires and enters the data into SPSS software (version

19) and calculates mean and standard deviation for each strategy. Then, strategies will be prioritized based on the mean scores. The results of the experts' agreement will be sent to them. Next, a session will be held at the Nursing and Midwifery Faculty of Isfahan with experts' panel members to discuss the priority of strategies face to face and complete the questionnaires again. Finally, the mean score of each strategy and agreement level will be determined based on the variance of answers and quartile range. If more than 80% of members agree on a subject and the quartile range is 0, the agreement level will estimate very high. If more than 60% of members agree on a subject and the quartile range is 1, the agreement level will estimate medium. If less than 60% of members agree on a subject and the quartile range is more than 2, the agreement level will estimate weak. When the agreement level is very high, there is consensus and the strategy is accepted (33-36). This phase will be done with the aim of prioritizing the program strategies using the Delphi modified method and the final confirmation of the health literacy promotion program for caregivers of children with cancer.

3. Discussion

Since health literacy dimensions have not yet been investigated in parents of children with cancer and no action is taken to promote their health literacy, conducting a sequential exploratory study and developing a program is a useful step in this regard. We believe that this program will be a basis for supporting and promoting health literacy among parents of children with cancer. Various studies have emphasized the necessity of investigating the information needs of caregivers and promoting their health literacy (13, 23, 25). Promoting health literacy of caregivers will increase their capability to make informed decisions, decrease health risks, increase prevention of diseases, safety, quality of life, and quality of care. High quality of care is very important for patients with cancer, because it warrants better outcomes for the patient and reduces costs, and makes possible the better allocation of resources in the healthcare system (37, 38).

Moreover, the Ministry of Health and Medical Education and other related institutions can use the results of this research in policy-making and planning for promoting the health literacy of parents of children with cancer. Focusing on the promotion of health literacy can help policymakers in different health care sectors access to appropriate healthcare services including adherence to treatment, reduce emergencies, reduce the length of hospitalization, reduce mortality, and increase the use of health care services. In addition, negative economic effects resulted from low health literacy on patients and the health-

care system cannot be ignored (39). Effect of the mental status of parents on providing information during the interview is among the potential limitations of this study that we will try to control this limitation by selecting participants one month after diagnosis when the critical period of accepting cancer has been passed.

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Footnotes

Authors' Contribution: S.S., M.B., A.A.E. and A.M. were involved in study conception, design and drafting of the manuscript. S.S. wrote the first draft of this study protocol. M.B., A.A.E. and A.M. reviewed the first draft of the protocol and manuscript. M.B. provided the qualitative design. M.B. and A.M. were responsible for coordinating the study. S.S. will be responsible for interview with participants, description and data analysis. M.B. will review and will involve in data analysis and qualitative phase. S.S. and M.B. will provide the quantitative design. S.S., M.B., A.A.E. will involve in program design. All authors have read and approved the final version of the manuscript.

Conflict of Interests: The authors declare that they have no conflicting interests

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