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A modified Delphi study to identify strategies to promote health literacy in parents of children with cancer

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Abstract:

BACKGROUND: Parents play a key role in the care, monitoring, management of symptoms experienced in children with cancer, the support, and follow-up of treatment. However, there is a paucity of research as how to improve the health literacy of parents with cancer. The aim of this study was to identify the best and most important strategies to promote health literacy in parents of children with cancer.

MATERIALS AND METHODS: A two-step modified Delphi method was used to establish consensus in Iran in 2021. Fourteen experts representing oncology, clinical nursing, and faculty members of nursing were selected by purposive sampling. In round one, 90 strategies to promote health literacy obtained in the qualitative study were distributed to the experts, which were scored from 1 to 5. In order to discuss statements without consensus in the first round, round two was held in a face-to-face meeting. Descriptive statistics such as mean, standard deviation, and percentage of response frequency were used to calculate agreement levels between experts.

RESULTS: In round one, 57 statements reached a consensus. In round two, 21 statements reached a consensus. Finally, 78 statements reached consensus representing four domains including functional health literacy, interactive health literacy, critical health literacy, and care health literacy.

CONCLUSION: Delphi method helps to identify the best and most important strategies to use in health literacy promotion programs for parents of children with cancer. Identifying these strategies will help health officials, planners, and policymakers.

Keywords:

Child, health literacy, neoplasms, nursing, parents

Introduction

Cancer is the second leading cause of death for children in the world after accidents. Two thousand two hundred nineteen new cases of cancer in Iranian children are diagnosed in 2020.[1] In 2018, the incidence of childhood cancers was reported at 16.8 per 100,000 children for Iranian boys, and 16.56 per 100,000 children for girls.[2] Parents of children with cancer play a direct role in child care and have the most contact with health-care providers (HCPs).[3,4] They have a responsibility to manage treatment appointments, make clinical decisions, and manage the symptoms and complications of treatment at home.[5,6] Parents of children with cancer need specific information about the symptoms, care, and cancer treatments because they deal with them frequently during treatment, particularly as the child experiences symptoms at home and he or she needs immediate help and care.[7] Therefore, parents play a key role in receiving and applying medical and care information about their child's disease.[5]

The essential role of parents in caring for children with cancer has appointed the needs for an adequate understanding of

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health information by them and makes it necessary to pay attention to health literacy in this group.[8] Seeking, accessing, and understanding cancer-related information are important health literacy skills for parents and caregivers affecting the quality of cancer care.[9,10] Due to the increasing complexity in the treatment of childhood cancers, parents' demand to gain information has increased. Meanwhile, researches on parents show that information needs are the most common unmet needs.[9,11,12]

Health literacy skills are very important in caring for children during disease, and about half of people in Iran have inadequate health literacy.[13] Low levels of health literacy in parents are associated with lack of knowledge about disease and care, misunderstanding of drug labels, inability to navigate with the health system, less participation in decision-making for child treatment, difficulty in seeking information, use less of preventive services and more emergency care, increasing health-care costs, increase in adverse clinical outcomes in the child, and poor caregivers' mental and physical health.[8,14,15] Parents' limited health literacy can also negatively affect the provision of information about a child's medical history, participation in clinical decision-making, and adherence to treatment.[7] Yuen *et al*. conducted a study on the health literacy of cancer caregivers, which showed low levels of health literacy among caregivers and the association of that with poor care behaviors. Low health literacy increased the use of health services and high levels of care burden. Parental health literacy is prominent due to long-term treatment and the need for continuous follow-up to achieve maximum results. Therefore, identifying people with a limited understanding of health information among this group and performing targeted interventions can improve clinical outcomes.[16]

Despite the importance of health literacy, no study has been conducted in Iran to assess health literacy in parents of children with cancer. However, studies have been conducted on caregivers of adults with cancer in other parts of the world.[9,16] For example, the results of a systematic review of Lynn *et al*., which examined health literacy in caregivers of children with cancer, show that the field of health literacy in the pediatric oncology population is in its' early stages.[8] Considering the growing importance of health literacy, addressing parental health literacy can be a basis for increasing the role of care and family functioning, increasing the quality of child care, reducing costs, and better allocation of resources in the health-care system. Therefore, this study was designed to identify the understanding of experts about the best and most important strategies to promote health literacy in parents of children with cancer.

Materials and Methods

Study design and setting

This study is part of a sequential exploratory mixed methods study aimed at designing a health literacy promotion program for parents of children with cancer which is based on the pragmatism paradigm. The protocol of this study has been published[17] and the qualitative phase paper is under review. The present study which is a quantitative part of the mixed methods study was conducted using a modified two-step Delphi method. The aim of this study was to determine the most important and best strategies to promote health literacy in parents of children with cancer.

Study participants and sampling

Based on literatures, 7–15 participants in the modified Delphi are recommended. Less than seven may not provide enough variety, and more than 15 make it difficult for everyone to participate in the group discussion in the meeting.[18] In this study initially, 26 selected experts were contacted through E-mail, and 14 people agreed to participate in this Delphi. Experts were selected by purposive sampling as representatives of professional groups that were associated with children with cancer and their parents. The participants were identified from different provinces of Iran including Isfahan, Tehran, Gilan, Mazandaran, and Markazi. They included pediatric oncologists, pediatric oncology nurses, and nursing faculty members. Inclusion criteria included experience in treating, caring, communicating with children with cancer and their parents, and having at least a master's degree. The demographic characteristics of the participants are given in Table 1.

Table 1: Demographic and clinical characteristics of participants

Demographic characteristics	HCPs (*n*=14)
Age (years)	
30-40	3
41-50	6
<51	5
Education	
MSc	3
Ph.D	10
Subspecialist	1
Occupation	
Clinical nurse	2
Faculty member	11
Oncologist	1
Time of clinical experience (years)	
>10	3
10-20	3
<21	8

HCPs=Health-care providers

Data collection tool and technique

In this study, a modified two-step Delphi method was used from April to September 2021. The Delphi method is an effective method for aggregating the knowledge and experience of experts and creating a broad scientific basis for agreeing on issues or procedures, which examines the opinions or estimates of experts in a particular subject.[19] The Delphi method is recommended to determine consensus and agreement in the health-care system.[20,21] The reason for choosing the modified Delphi method was that in this method, one of the rounds is a face-to-face meeting and enables the interaction of experts.[22] Furthermore, consensus is not necessary in this method and the goal is to reach an agreement level. This approach not only analyzes and prioritizes the available evidence but also helps to identify areas for further research.[23]

A qualitative study and literature review was conducted to determine 90 strategies to promote health literacy in parents of children with cancer. Nineteen semi-structured in-depth interviews were conducted with parents of children with cancer (17 mothers and two fathers) and seven interviews with HCPs. Also, to identify strategies to promote health literacy in existing literatures, electronic databases with the keywords including Parent, Caregiver, Neoplasm, and Health Literacy, with Mesh combinations in the title and abstract from 2010 to 2021 were searched.

Round 1

The questionnaire included 90 statements and was E-mailed to all 14 experts in July 2021. This questionnaire consisted of three parts: explain the purpose of the study and the scoring method, the demographic characteristics of the participants, and the tables related to the priority of strategies to promote parental health literacy. Each strategy was evaluated in terms of ease of implementation, cost-effectiveness, time consuming, effectiveness, efficiency, acceptability, and compliance with organizational policies and values. Statements were scored on a 5-point Likert scale from (1) very low to (5) very high. Experts were also given the opportunity to comment and suggest strategies that may not have been included in the questionnaire. Participants were asked to complete and E-mail them within 10 days. During this period, a reminder message was sent to the participants to complete and send the questionnaire.

After collecting the questionnaires, they were entered into the SPSS software (Statistical Product and Service Solutions) version 24 (Made by IBM company, location in New York City, USA) and analyzed. Using descriptive statistics, the mean, standard deviation, and the percentage of response frequency of each statement were calculated. The definition of consensus level in Delphi studies depends on the question and the concepts of research and is also used to determine agreement.[24] In the present study, the agreement level in both rounds was considered more than 70% based on the percentage of responses frequency. In other words, in cases in which more than 70% of experts agreed and gave homogeneous answers, a consensus was stablished.[18,25] Statements with mean in the upper third of the scores (5–3.66) are appropriate, statements with mean in the middle third of the scores (3.65–2.33) are indeterminate, and statements with mean in the lower third of the scores (2.32–1) were considered inappropriate.[18] We only accepted statements in appropriate range as strategies to improve the health literacy of parents of children with cancer. The results of the first round, including the total mean of each statement and the mean score given by each expert to all statement aspects, were prepared in the form of a table and sent to each expert. Providing statistical feedback on individual responses compared to the responses of other participants helps to modify the results and revise the answers given in the second round.[23]

Round 2

After providing feedback to the experts, statements that did not reach a consensus in the first round were included in the second-round questionnaire. This questionnaire was evaluated in terms of feasibility and importance. Statements were scored on a 5-point Likert scale from (1) very low to (5) very high. The second round was held on September 14, 2021, as a face-to-face meeting for 2 hours. This meeting was held at Isfahan School of Nursing and Midwifery. Nine experts from the participants in the first round attended the meeting. They included one oncologist, two clinical nurses, and six faculty members, of which four of them were present by video conference. Five experts were not present in the meeting due to time constraints.

At the beginning of the session, all participants were introduced. Then, the moderator explained the objectives and framework of the session. The second-round questionnaire was provided to the experts. Experts were asked to discuss separately the feasibility and importance of each strategy in promoting the health literacy of parents of children with cancer and to state their reasons. During the session, the moderator tried to focus the experts' discussion on the statements. At the end of the session, the experts were asked to rate their questionnaires individually. Then, questionnaires were entered into SPSS software version 24 and analyzed. Using descriptive statistics, the mean, standard deviation, and the percentage of response frequency of each statement were calculated. Statements that reached more than 70% of the experts' agreement and their mean in the range of 5–3.66 were considered as strategies to promote parental health literacy and the rest of the statements were eliminated.[18,25]

Ethical consideration

The study objectives were explained to all participants before participating in the study and they were assured that their information would be kept confidential. Written informed consent was obtained from all of them. This study has been approved with ethical code IR.MUI.RESEARCH.REC.1398.368 by the Ethics Committee of Isfahan University of Medical Sciences.

Results

Round 1

After analyzing the qualitative data and reviewing the literatures, 90 strategies were selected to improve the health literacy of parents of children with cancer. There were 31 strategies related to promoting functional health literacy, 24 strategies related to promoting interactive health literacy, 11 strategies related to promoting critical health literacy, and 24 strategies related to promoting care health literacy. These 90 statements were included in the first-round Delphi questionnaire and were sent to 14 experts.

After analyzing the first-round questionnaires, the mean of 86 statements was in the appropriate range (5–3.66) and the mean of 4 statements was in the indeterminate range (3.65–2.33). After calculating the percentage of responses frequency, 57 statements reached more than 70% of the experts' agreement and reached consensus (≥10 participants voted homogeneously). Among these strategies, 14 strategies were related to promoting functional health literacy, 19 strategies were related to promoting interactive health literacy, 7 strategies were related to promoting critical health literacy, and 17 strategies were related to promoting care health literacy. Given that the average of all 57 consented strategies was in the appropriate range, these were accepted as strategies to promote health literacy in parents of children with cancer and were removed from the second-round questionnaire.

Round 2

Thirty-three statements without consensus in the first round were discussed in a face-to-face meeting of experts. The statements that were included in the second-round questionnaire include 17 strategies were related to the promotion of functional health literacy, 5 strategies were related to the promotion of interactive health literacy, 4 strategies were related to the promotion of critical health literacy, and 7 strategies were related to the promotion of care health literacy.

After analyzing the second-round questionnaires, the mean of 23 statements was in the appropriate range (5–3.66) and the mean of 10 statements was in the unclear range (3.65–2.33). After calculating the percentage of responses frequency, 21 statements reached more than 70% of the experts' agreement and reached consensus (≥6 participants voted homogeneously). Therefore, 21 statements were accepted in the second round and 12 statements were eliminated. After analyzing the first and second rounds of Delphi, a total of 78 strategies to promote health literacy in parents of children with cancer reached consensus and accepted.

Discussion

According to our best information, this is the first study to identify strategies to promote health literacy in parents of children with cancer in Iran. Currently, parents of children with cancer in Iran suffer from unawareness of the child's disease and treatment process, unknowing the various sources of information, inability to communicate properly with HCPs, unfamiliarity of HCPs with strategies to promote health literacy, inefficient use of health care and support resources, inability to recognize accurate and valid information, and unawareness about providing care to the child and managing the side effects of chemotherapy at home. Studies show that the informational needs are similar in most caregivers and most of their search and information request are about cancer and related treatment.[11,12,16,26] In this study, strategies to promote parental health literacy in four domains of promoting functional health literacy, promoting interactive health literacy, promoting critical health literacy, and promoting care health literacy reached consensus. This reflects the multidimensional nature of health literacy concept according to existing health literacy models.[16,27,28]

Strategies for promoting functional health literacy are considered in issues such as understanding medical information, the ability to access accurate and quality health information, and having sufficient information for health management. Osborne *et al*. also considered having sufficient information for health management and the ability to find appropriate health information and understand health information necessary to promote functional health literacy.[29] In other studies, seeking, accessing, and understanding of health information related to the patient was one of the important skills of caregivers' health literacy that affects the quality of care provided.[9,16,28] The use of plain language, written educational materials, limiting specialized words, using short sentences, and teach-back technique are recommended to achieve a better understanding of the provided information,[9,15] which was similar to the strategies obtained in our study. Interactive health literacy promotion strategies include dimensions of caregiver support by HCPs, the ability to interact effectively with HCPs, and health social support. Studies show that communicating with the HCPs is especially important for

parents and helps to promote interactive health literacy, increase parental trust in HCPs, and the ability to seek help and advice from HCPs.[16,29] Unfamiliarity of HCPs with the concept of health literacy is one of the factors causing poor communication with parents. The results of the study by Macabasco-O'Connell and Fry-Bowers showed that many HCPs were not familiar with the concept of health literacy or considered it insignificant compared to other patient problems,[30] while Goldsmith and Terui considered parent interactions with HCPs a key factor in receiving support and increasing adherence to the treatment regime.[31]

Critical health literacy promotion strategies include issues such as health information evaluation and active health status management. In the field of active health status management, the results of the study by Lambert and Keogh also emphasized the participation of parents in clinical decisions-making, accepting responsibility for child care, and the ability to coordinate with the health system to improve health literacy.[32] The results of the Osborne study showed that the ability to evaluate the received information, identify useful and valid sources of information, and navigating in the health-care system is essential to promote health literacy in parents.[29]

Strategies for promoting care health literacy included such as adapting to the role of caregiver, accepting responsibility for child's health, participating in care, and managing care challenges. The results of other studies also consider adaptation to the role of caregiver by parents and related acceptance and support to promote health literacy. Parents' awareness of their rights as a caregiver, parents' participation in care, and having a caring attitude increase their adaptation with their role.[16,33] The results of the Goldsmith study showed that parents' informational care need to provide optimal care has increased and they needed support to develop health-care literacy skills and provide high quality care.[31] Therefore, support and education for parents by HCPs and preparing them to provide safe care for the child is important.[34]

Limitations and recommendations

One of the limitations of the modified Delphi method is the elimination of the anonymity of experts in face-to-face meeting. Attending a meeting, in addition to all the benefits, may force some participants to conform to the group's point of view. We tried to select specialists with maximum variety; however, there may be bias in selecting experts. Finally, only nine experts were able to attend the meeting and some of them also attended via video conferences. It is suggested that strategies to promote health literacy in parents of children with cancer be implemented and evaluated in future studies.

Conclusion

The results of this study provide important reflections on the best and most important strategies to promote health literacy in parents of children with cancer in Iran from the time of diagnosis to follow-up after the end of treatment period. These strategies can be used in designing health literacy promotion programs to meet the health literacy needs of these parents in a targeted manner.

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Conflicts of interest

There are no conflicts of interest.

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