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Methods Article

Empowerment of Women to Provide Home-based Supportive and Palliative Care for Patients with Cancer: Participatory Action Research Protocol

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Abstract

Background: Determining the needs and challenges of women, who care for patients with cancer and providing appropriate strategies to empower them in the design and implementation of appropriate change programs pave the way for the promotion of these women's health and empowerment.
Objectives: This study aims at identifying the needs and challenges of women and developing a program to empower women, who care for patients with cancer.
Methods: The present study is based on a participatory action research approach and uses the Kemmis and McTaggart model. The participatory action research of this study will be in 4 phases of planning, action, observation, and reflection. In the planning phase, the needs and challenges of female caregivers are examined from the perspective of women and the health team and, then, women's empowerment strategies in providing home-based supportive and palliative care for patients with cancer are determined, using the results of the qualitative phase and review of the literature by using the decision matrix. In the action phase, the selected strategies are implemented with the help of process owners. In the observation phase, combining different methods, data will be collected to measure the results of change. Finally, in the reflection phase, the results of the implementation of the strategies are evaluated and this cycle continues until the intended results are achieved.
Discussion: Empowerment of the women, who care for patients with cancer requires awareness, motivation, and active participation of women and the health team. As many cultural and social factors affect the health and participation of these women, participatory research can involve them in promoting their health.

Keywords: Empowerment, Women, Home-based Supportive and Palliative Care, Cancer, Participatory Action Research

1. Background

Cancer is the second leading cause of death in the world and about 70% of these deaths occur in middle- and low-income countries (1). Statistics in Iran also show an increasing trend as more than 90000 new cases of cancer are diagnosed each year, which is predicted to reach 130000 new cases by 2025 (2, 3). Given the lack of hospice care centers in Iran, most patients with cancer are frequently hospitalized in the last days of their life and receive specific drugs until the last moments of life, and many of them will finally die on hospital beds and in ICUs. Therefore, despite the low number of personnel and the lack of intensive care beds, the healthcare system is facing a high number of patients, who need to receive services (4). One of the most appropriate strategies for dealing with this challenge is the use of supportive and palliative care services. One type of supportive and palliative care is home-based palliative care services. Among the advantages of this method may be more comfortability of patient compared to other types of care, better protection of the patient's privacy, and active involvement of family members in the patient's care (5). These advantages can increase the satisfaction of patients and caregivers, improve the quality of life of patients and caregivers, and reduce the rate of readmission and the costs of hospitalization (6-8).

For the implementation of supportive and palliative care programs at home, capable and knowledgeable caregivers are required (9). Family caregivers play a pivotal role in providing care for patients with cancer in the area of home-based supportive and palliative care. If the needs of caregivers are not recognized and they cannot adapt to the conditions of home care for the patient, this program will fail (10). Family caregivers have significant needs in the personal, social, physical, psychological, and financial dimensions (11), which can lead to problems such as depression, anxiety, anger, fear, worry, and a sense of guilt. Providing care for patients may also influence the physical health, daily activities, and economic situation of these caregivers.

Having the roles of wife, mother, and daughter, women play the most important role in providing care for family members, and despite numerous advances in various fields, they are still considered to be a vulnerable group (12). The role of women is more evident in addressing family issues as they always give the least priority to themselves and prioritize the family needs (13, 14). Women care more about others, listen more to others' problems and, as family caregivers, hold the family together (14). Furthermore, according to traditional societies and even the views of some female caregivers, caring is the inherent and main duty of women and they are expected to provide care without having the right to choose. This view has imposed a lot of psychosocial pressures upon women (15). Many studies have shown that caregivers' experiences vary based on their gender. Structural differences between men and women, which are often due to social differences, responsibilities, laws, and cultural norms, have always resulted in lower quality of life in women than men. These factors cause different and distinguished harms between men and women, which prevent women from empowering themselves and affect the health of female caregivers more than that of the male ones, leading to higher levels of anxiety and depression in them. Accordingly, compared to the male caregivers, they experience a lower quality of life (16-19). Additionally, women have a much lower level of access to power and resources than men, especially in traditional societies and less developed countries (12). Women, generally, have lower psychological and social abilities, and their level of education is lower than men. Moreover, low self-esteem and a weak sense of self-worth have reduced women's empowerment (20). All of these underscore the need for empowerment in women. The significance of women's empowerment in providing care for patients with cancer lies in the fact that they have a central position in the family and, thus, their increased awareness and knowledge in various fields can improve the quality of life of family members in times of crisis. Since women are the main caregivers of patients with cancer in the family, their empowerment plays a significant role in the treatment process of patients and their adherence to treatment (21). Additionally, it develops women's ability and freedom in life decisions, which empowers them in gaining opportunities and controlling their resources and choices, thereby affecting the health of them and their families (22). Moreover, identification of the situation and needs of female caregivers and recognizing the factors, which may affect them, can be the basis for planning, policy-making, and appropriate strategies to promote women's health and development. Given the importance of the health of female caregivers and the lack of focused studies in this regard, this study will be an attempt to empower female caregivers through participating these women and process owners in the study.

2. Objectives

- Explaining the needs of women in providing home-based supportive and palliative care for patients with cancer

- Identifying the challenges of women's empowerment in providing home-based supportive and palliative care for patients with cancer

- Developing women's empowerment strategies in providing home-based supportive and palliative care for patients with cancer

- Implementing women's empowerment strategies in providing home-based supportive and palliative care for patients with cancer

- Evaluating the effect of the implemented strategies on the indicators of improving women's empowerment (self-efficacy, self-care, quality of life, etc.) in providing home-based supportive and palliative care for patients with cancer

3. Methods

The present study will be conducted based on a participatory action research approach. This method is based on a full partnership between the researcher and the participants and two-way learning as well. This partnership leads to awareness of the problem and the impact of the problem on it. The researcher and the participants identify the problem and the underlying cause and determine possible changes. In this approach, the subjects will gain a new understanding of their performance and, therefore, the created changes will be more sustainable. This approach emphasizes the learning of the researcher and participants through the interactions created between them and gives participants the right to choose (23). In this research, participatory action research will be used as it is the most appropriate method of creating change and empowering women.

3.1. Phase 1: Planning

The objectives of this phase are as follows:

- Explaining the needs of women in providing home-based supportive and palliative care for patients with cancer

- Identifying the challenges of women's empowerment in providing home-based supportive and palliative care for patients with cancer

- Developing women's empowerment strategies in providing home-based supportive and palliative care for patients with cancer

In this phase, the researchers plan activities to achieve the objectives. The researcher also determines who provides the required information, how many participants are needed, and how to access them. Also, the type of the required data, the methods of data collection, and determining the person or persons for data collection are decided and agreed upon. Moreover, in this phase, face-to-face and focus group interviews will be used to extract women's needs and strategies for women's empowerment.

The research setting in the study is one of the specialized and referral hospitals providing services to patients with cancer in Iran and the only specialized oncology center in the region that accepts and treats these patients from the surrounding provinces. Another setting for this study is the Cancer Prevention and Control Center affiliated with a charity in the region, which provides free specialized treatment and support services to patients with cancer and their families.

The participants of this study will be selected, using the purposive sampling method. After obtaining the necessary permissions and referring to the mentioned centers, interviews will be conducted with women, who meet the inclusion criteria. The interviews will continue until the data saturation is reached (until the new interviews add no data to the previous ones).

In this study, the participants include female caregivers such as spouses, mothers, daughters, and sisters, who provide care to the patients with cancer and need home-based supportive and palliative care, as well as the providers of supportive and palliative care services to patients with cancer, nurses, oncologists, managers, and policymakers.

3.1.1. Inclusion Criteria for Women Caregivers

The inclusion criteria for women caregivers include willingness to participate in the study, being above 18 years old, providing at least 33 hours of care per week, being literate, lacking major psychiatric disorders (mood disorders, bipolar disorder, and psychotic) according to the DSM-5 criteria for those who provide care for the over 18-year-old patients with advanced cancer.

3.1.2. Inclusion Criteria for the Treatment Team

The inclusion criteria for the treatment team include willingness to participate in the study, providing healthcare and supportive and palliative care services to patients with cancer, nurses, oncologists, and managers, who have at least 6 months of experience in the field of supportive and palliative care or home care.

3.1.3. Exclusion Criteria

The exclusion criteria include reluctance to continue cooperation and withdrawal from the study at any stage of the research.

3.1.4. Data Collection

The data collection method at this stage includes open and semi-structured interviews, focus group discussion, and literature review.

3.1.5. Semi-structured Individual Interviews

Face-to-face and semi-structured interviews are used as the main and initial method of data collection. After obtaining informed consent, the eligible participants are purposefully invited to record in-depth, semi-structured, and individual interviews. The interview begins with general questions such as "tell us about your experiences as a female caregiver, who cares for a patient with cancer at home." and "what are your needs as a woman, who cares for a patient with cancer in the family?" Then, based on the participants' answers, a series of open-ended questions will be asked. The setting of the interview for the sake of convenience will be selected based on the opinion of the participants (caregiver's home, hospital, or participant's workplace) and should have the conditions for the interview (quiet place and privacy).

3.1.6. Focus Group Discussion

Given its flexible nature, the focus group discussion helps to recall information and provides rich data, which are valuable for collecting qualitative data. In this research, focus group meetings are used to complete the data. Individuals who can be present at the interview site at the same time are interviewed in a focus group not only to get familiar with other members of the research team but also to collaborate in developing solutions for empowering women through the method of brainstorming.

3.1.7. Inclusion Criteria for Focus Group Discussion

The inclusion criteria for focus group discussion include willingness to participate in the study, providing healthcare and supportive and palliative care services to patients with cancer, nurses, oncologists, and managers, who have at least 6 months of experience in the field of supportive and palliative care or home care.

3.1.8. Literature Review

In this section, to achieve the existing knowledge in the field of empowerment of female caregivers, studies conducted in the world will be retrieved and reviewed. To search the databases, keywords are determined based on the title of the research and MeSH terms and, then, a literature review is performed by combining the existing keywords. For this purpose, using the keywords of "needs, family caregivers, cancer, empowerment, gender, and supportive and palliative care" from 2010 to 2020 will be searched in PubMed/Medlin, Scopus, ProQuest, ISI Web of Science, Elsevier, and CINAHL databases. Moreover, Persian literature will be reviewed in Iranmedex, SID, and Magiran databases with the same keywords from 2010 to 2020.

3.1.9. Qualitative Data Analysis Method

The conventional content analysis method is used for qualitative data analysis (23).

In this method, all descriptions and stories of the participants are read to gain insight or a general understanding of what they have said. The text is, then, re-read for open coding, and the topics being studied are noted as they are read. This step is repeated several times until the relevant titles are written in the margins of the text as much as possible so that it can cover all aspects of the text. All of these titles are, then, written on coding sheets and are categorized into groups. There is a title for each group that includes all the titles of the group. Eventually, these groups and classes contract as much as possible in the larger classes. The purpose of creating larger classes is to acquire new knowledge and increase the full understanding and description of the phenomenon (23).

3.1.10. Trustworthiness of the Qualitative Data

Guba and Lincoln proposed 4 criteria of credibility, dependability, confirmability, and transferability for the trustworthiness of the qualitative data.

3.1.11. Credibility

In the present action research study, the methods of participant evaluation, peer evaluation, and self-evaluation will be used to increase the credibility of the findings (23).

To evaluate the participants, group meetings with the participants in all phases of the study and receiving their opinions will help increase the validity and reliability of the findings and actions. Moreover, the results of data analysis in each phase will help to confirm the accuracy of the data and extracted codes through the continuous engagement of the participants in the stages of action, reflection, and review of the findings by the participants.

For peer evaluation, review of the research process and implementation of strategies by members of the research team and receiving their feedback will help increase the credibility of the data. Possible strategies are also provided to action research experts and respected professors so that the right steps can be taken.

Self-evaluation in this study will be created through the researcher's efforts to continuously examine her biases and assumptions in the research process and to pay constant attention to the correct understanding of the situation.

3.1.12. Transferability

It means the provision of a complete and clear description of the study so that another person can implement and use it in another context. Generally, while the results of a functional study are not generalizable, the obtained information can be used in other contexts.

3.1.13. Dependability

Dependability in this study will be achieved by involving more than 1 person in data analysis. To this end, the researcher and the research team will study the results separately. The data are also studied and coded, and the obtained results will be compared by the researcher and the supervisor. Additionally, all actions and decisions in the action research process are precisely recorded so that others can audit the research.

3.1.14. Confirmability

Confirmability is also ensured through auditing. The researcher tries to provide other researchers with enough information so that they can reach similar results if they read her study. In this regard, the researcher tries to preserve the documents in all stages of the research and provide a clear description of all stages. For confirmability, the researcher also provides several extracted codes and categories to colleagues, who are familiar with qualitative data analysis to verify the accuracy of the coding process.

3.1.15. Prioritization of Strategies

In this stage, the obtained strategies, which are the result of literature review and qualitative content analysis, are combined and used to develop the program. Since it is not possible to implement all the obtained strategies, the proposed ones should be prioritized by experts through using the decision matrix. The criteria for the prioritization of the strategies (ease of implementation, cost-effectiveness, time-consuming, effectiveness, and efficiency) should be set and the members of the expert panel are asked to give a score of 1 to 5 to each strategy based on a 5-point Likert Scale. Then, the mean scores of the available strategies are determined and the program is developed based on the obtained scores. If it is impossible to hold panel meetings or the final result is not possible at the end of the meetings, this stage will be held in the form of the Delphi method.

3.2. Phase 2: Action

The objective of this phase is to implement women's empowerment strategies in providing home-based supportive and palliative care for patients with cancer.

In this phase, the strategies, which have been developed and agreed upon in the planning phase, will be implemented by the participants. The setting of the research is the specialized oncology center and the supportive-palliative charity center for cancer or any other setting that participants may wish. During the empowerment program, educational programs may be held for female caregivers, nurses, and physicians in hospital wards. Possible strategies can include educations in the areas of care for patients with cancer, implementation of life skills, coping skills, self-care strategies, and so forth.

During this phase, after the implementation of the program and at different time intervals, feedback and reflection of the participants will be obtained. Reflection clarifies the impact of the action on the insights and actions of the participants, identifies and modifies problems of the program, and increases the likelihood of success. Feedback and reflection will be assessed through self-report techniques, field notes, and review sessions.

3.3. Phase 3: Observation

This phase will be conducted by collecting the data and, like the initial review, information should be collected by combining different methods to measure the results of change. The phase aims at collecting data about the impact of actions by identifying the factors that need to be modified in the designed program. Therefore, combining different quantitative and qualitative methods such as the General Self-efficacy Scale, Caregiver Quality of Life Index-Cancer (CQOLC) Scale, as well as individual and group interviews, we will measure the results of change.

3.4. Phase 4: Reflection

The objective of this phase:

This phase aims at evaluating the effect of the implemented strategies on the indicators of women's empowerment (self-efficacy, self-care, quality of life, etc.) in providing home-based supportive and palliative care for patients with cancer.

Reflection is used to reflect program, action, and observation, and continuous reflection is used to form effective evidence for preserving the cyclical nature of action research. It is a mental process, in which situations are reexamined to gain a better understanding of the situation and this understanding helps to improve the process. Reflection takes place in the formative and summative stages.

3.4.1. Reflection in the Formative Stage of the Program

To identify issues and problems of the formative stage, feedback is obtained from the participants including the female participants of the study and members of the research and health teams. To reflect the formative stage, the Gibbs framework will be used. This framework has 6 steps that are useful for reflection. In the first step, the event, upon which the reflection should be done (women's empowerment program), will be described in full detail. The second step examines the feelings and thoughts in the minds of the research team, the executive team, and the female participants. The evaluation is performed in the third step. In this step, an evaluative judgment is made about the good and bad aspects of the experience. In the fourth step, the women's empowerment program in providing home-based supportive and palliative care for patients with cancer is broken down into its components and each component is considered separately. Conclusions are made in the fifth step and planning for the next cycle is designed in the sixth step.

3.4.2. Summative Reflection

For the summative reflection of the program, both quantitative and qualitative methods are used. For the qualitative evaluation, using individual interviews with the participants, their experiences about the implementation of the program, and the impact of the empowerment program are examined and the data obtained from the interviews are analyzed, using the conventional content analysis method. For quantitative evaluation of the program, after its implementation, the impact of the program on the empowerment indicators such as self-efficacy, quality of life, and self-care is evaluated by using the General Self-Efficacy Scale ($r = 0.76$ to $r = 0.90$) (24) and CQOLC Scale ($r = 0.754$ to $r = 0.832$) (24) to determine the effectiveness of the program.

4. Discussion

Numerous studies have emphasized gender differences in the discussion of providing care for patients with cancer as the health of female caregivers is more affected than the male ones. Accordingly, it is suggested that support and empowerment programs be provided to female caregivers in this regard (18, 25, 26). Stress, anxiety, depression, fear of loss, decreased life expectancy, decreased quality of life, decreased social participation, and various physical problems are the most important challenges in the empowerment of women (16, 21, 25). Given the prevailing culture in Iranian society and the expectation that care should be provided by the Iranian women and lack of attention to their physical and mental health together with the prioritization of family over women, there is a necessity for a comprehensive program with the participation of women, who care for patients with cancer and the owners of the process according to the cultural, social, and economic conditions of Iran.

A literature review shows that the use of various in-person and virtual educational programs in the fields of information and concerning the mental, psychological, physical, and spiritual health of caregivers can effectively contribute to their empowerment. Although in the participatory method, the program is not predetermined, the literature review will help us a lot in this regard, and these methods will probably be used in this research as well. In this study, the needs and challenges of empowering female caregivers are determined by considering the context and review of the literature, as well as through the participation of women and, then, the development and implementation of the program lead to women's empowerment and promotion of their physical, mental, and spiritual health. Moreover, the findings of this study can help oncology nurses, physicians, psychologists, social workers, and health policymakers to understand the essential role of effective empowerment strategies based on culture and social structure, as well as the needs of female caregivers. Moreover, they can use the findings to improve the function of these women in individual, family, and social dimensions. This empowerment change program is also designed to promote the health of women, who care for patients with cancer, their families in Iran, and other women around the world.

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Footnotes

Authors' Contribution: All authors fulfill the criteria for authorship. They have read and approved the presented manuscript. Sh.M wrote the first draft of the manuscript. All other authors revised the manuscript critically. Sh.M and FT were responsible for the original set-up of the study design, which was discussed with another author during subsequent meetings. This paper is the outcome of these discussions and the written comments of all authors. All authors provided consent to publish this protocol manuscript.

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Data Reproducibility: The research team will have access to interim results and the final data set. Every 6 months, Isfahan University of Medical Sciences will receive aggregated interim results. The results of the study will be disseminated via open-access, peer-reviewed publications, and conference presentations. Study materials are available on request.

Ethical Approval: This study was approved by the Ethics Committee of Isfahan University of Medical Sciences, No. IR.MUI.RESEARCH.REC.1399.234.

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Informed Consent: Before each phase, the participants were orally briefed on the objectives of the study, and their informed written and verbal consent was obtained for participating in the study. They were also told that they could freely withdraw from the study at any stage they desired.

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