



Barriers and Facilitators to Pediatric Oncology Social Work Practice: A Qualitative Study

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Abstract

Background: Childhood cancer is significant due to its high prevalence and its impact on the entire family, resulting in various psychological, social, economic, and communication challenges for the families.

Objectives: The aim of this study was to explore the barriers and facilitators to pediatric oncology social work practices in Iran.

Methods: This qualitative study used a content analysis method and involved 19 pediatric oncology social workers. We used a purposeful sampling method until data saturation was reached. Data were collected through semi-structured interviews and field observations and then analyzed.

Results: This study demonstrated that the factors influencing social workers' practice include personal characteristics and interpersonal communication at the micro level, while barriers mainly consist of cultural, social, economic, organizational, and structural dimensions at the macro level.

Conclusions: In order to better support children with cancer and their families, policymakers and health system managers need to give special attention to the status of social workers. Strengthening support systems and addressing the challenges they face can be effective in protecting the professional practices of these caregivers.

Keywords: Pediatric Oncology, Social Worker, Facilitator, Barriers, Content Analysis

1. Background

Childhood cancer is of high importance because of its high prevalence and its impact on the whole family (1, 2). According to the World Health Organization, the annual incidence of cancer in children is 100 per million (3) and more than 160 000 children are diagnosed with cancer every year (4). In addition to the suffering of their illness, children with cancer incur severe psychological distress (McCaffrey, 2006). Children's families are also usually faced with several issues such as mental and psychological disorders, communication problems, social isolation, financial problems, changes

in work and family duties, leisure patterns, and lack of time to interact with healthy siblings (5-7).

A unique approach is needed to understand and help to solve their problems. As a unique profession, social work has a special place in addressing the needs and issues of children with cancer and their families (8). Oncology social workers are considered the main providers of psychosocial services to patients with cancer and their families in health centers. Their services include psychosocial support, advocacy, empowerment, resource management, the necessary assistance to adapt to the diagnosis and reduce related trauma provide working with dying patients, accompaniment, and counseling for children with

cancer and their families (9). Evidence suggests that some factors (such as individual factors in physical and psychological dimensions, family, cultural, social, and economic factors, as well as health and treatment) have always affected their practices in these fields (10).

These factors sometimes facilitate their actions and in some cases, they also make the service provider face some limitations. So far, few studies have been conducted to identify challenges of social workers' practice in the field of cancer; some of these studies investigated the inhibitors in various fields, such as barriers to accessing health care quality for patients with cancer (6, 11), barriers to discussing fertility capacity preservation in patients with cancer (12), barriers and facilitators to palliative care for children with cancer (13) and in these studies, the barriers and facilitators were explored from the perspective of the interdisciplinary team members, and a few of them included social workers. Other studies examined barriers to care from the medical team's point of view (14) and the perspective of social workers in this field has been neglected. Thus, evaluation of existing knowledge shows limited knowledge and information related to social work practice in the field of childhood cancer. Considering that cancer care is influenced by the powerful forces of cultural and social factors and the context of action (15), these challenges seem to be different according to the field of practice. In Iran, 97 hospitals provide care and treatment to patients with cancer and 130 social workers are working in these hospitals. These social workers have completed palliative care courses and use specialized protocols in this field. Social workers in hospitals carry out interventions such as referral, counseling, individual, group, and family training, crisis intervention, psychological-social-economic support, and home visits. But they also face many challenges in playing professional roles, which this article discusses.

2. Methods

2.1. Study Design

In this study, the qualitative content analysis was considered appropriate to achieve social worker's experiences. Data were gathered directly from the participants without any pre-assumption. Concepts were extracted from the analysis in the form of codes

and categories, which showed the barriers and facilitators of social work practice.

2.2. Setting and Participants

This study was conducted on the experiences of 19 social workers, who were working in public and specialized children's cancer hospitals in Iran. The selection of participants was determined, using a purposeful sampling method. The inclusion criteria consisted of having a B.Sc. or higher social work degree, having at least 5 years of related job experience, and being able to articulate one's experiences. Sampling was continued until no new concepts emerged. In total, 15 women and 4 men participated in the study.

2.3. Data Collection

The data were collected through semi-structured interviews and field observation. The research team used a few open-ended questions to guide the interviews. Complementary probe questions were added when needed. To identify the perception and experience of the participants, the following general questions were used:

- Please describe the experience of serving in the field of childhood cancer.
- Which factors help you to work with children with cancer and their families?
- Which factors are considered barriers to the appropriate practice?

On average, interviews lasted for about 40 to 60 minutes and were conducted in the workplaces of the social workers. All interviews were conducted by the first author and were recorded with the consent of participants, and transcribed and analyzed in accordance with the nature of the content analysis method.

2.4. Data Analysis

In this study, data were analyzed according to the principles of the content analysis method. First, interviews were transcribed verbatim. During the open coding phase, all interviews were reviewed several times, and words and phrases, consequences, and facts in the text were considered. The initial codes were extracted. The codes and data were compared for similarities and differences; then, concepts were

developed. From the first interview, a preliminary set of codes, categories, and sub-categories were created.

2.5. Rigor

Similar to other qualitative approaches, the results of content analysis must be reliable, and the results should be evaluated based on the method of data collection. Spending enough time to collect and analyze data as well as using multiple methods were considered to collect data to ensure the validity of findings (triangulation). The acceptability of data was checked by two Ph.D. candidates of social work, who had the necessary expertise in qualitative studies (peer-check). Data were coded independently and extracted concepts were compared and classified. A summary of the findings was presented to subjects to ensure that the findings were derived from their experiences (member-check).

2.6. Ethical Considerations

Considerations and codes of ethics of the study were verified by the Ethics Committee. Consent was obtained, and all participants were informed that they could refuse to participate or withdraw from the study at any stage.

3. Results

This study explored challenges to social work practice in the field of childhood cancer. Participants' ages ranged from 25 to 55 years old, and their work experience was between 5 and 30 years (Table 1).

Through text analysis, interviews, and field observations, Problems experienced and facilitators were extracted (Table 2).

3.1. Problems Experienced

This category includes 4 sub-categories including "Cultural Problems," "Structural Problems," "Institutional Problems," and "Socioeconomic Problems".

3.1.1. Cultural Problems

Based on the experience of the participants, the strategies of patients facing cancer were affected by their beliefs and stereotypes, and some of these beliefs and attitudes affected social workers' practice. The main

concepts of this sub-category include cancer-related stigma and beliefs for the treatment of cancer.

3.1.2. Cancer-Related Stigma

The term "cancer" is accompanied by fear in Iran. Even most people consider the detection of cancer as "death." Working in such conditions that the family is even unwilling to hear the name of the disease causes the treatment to face more difficulty. Two participants talked about the negative feelings of families about the impact of cancer on the future of their children and they addressed the concerns of the families about existing stereotypes and wrong attitudes towards the disease.

"In our society, the term cancer is so terrible that people face it for fear of losing someone, and some do not say the name of the disease and do not want to face it, let alone accept the disease".

"In cases of girls, conditions become more complex, and the family hides disease because it may impact her future and marriage. Sometimes the families fear the judgment of others who say "What did they do that their children caught this disease?"

3.1.3. Beliefs in the Treatment of Cancer

Social workers pointed out patients using unusual treatments for childhood cancer that are rooted in their attitudes and superstitious beliefs. A social worker described her experience:

"We had a child with a malignant tumor in his eyes, but his family did not want their child to go through surgery. The doctor asked us to speak with the family, but it was useless since they did not want to get help, they used herbal remedies and prayer. Unfortunately, it was too late."

3.1.4. Structural Problems

Social workers, in the expression of inhibitors, refer to the problems rooted in the lack of proper infrastructure in the health system in Iran. This sub-category consists of "difficulty of medicine procuring under sanction conditions, the throng of patients at large cities, and lack of integrated care program".

3.1.5. Difficulty of Medicine Procuring Under Sanction Conditions

Table 1. Demographic Characteristics of Participants

Row	Position	Age	Gender	Job Experience
1	Supervisor	45 - 36	Female	20
2	Supervisor	45 - 36	Female	10
3	Supervisor	35 - 26	Female	9
4	Supervisor	35 - 26	Female	5
5	Social worker	35 - 26	Female	7
6	Social worker	35 - 26	Male	5
7	Social worker	35 - 26	Female	6
8	Social worker	35 - 26	Female	6
9	Social worker	35 - 26	Female	9
10	Social worker	45 - 36	Male	8
11	Supervisor	35 - 26	Male	8
12	Social worker	35 - 26	Female	5
13	Supervisor	55 - 46	Female	25
14	Social worker	35 - 26	Female	8
15	Supervisor	55 - 46	Female	30
16	Supervisor	45 - 36	Female	9
17	Supervisor	45 - 36	Female	14
18	Social worker	45 - 36	Female	9
19	Social worker	35 - 26	Male	12

Table 2. Samples of Extracted Codes, Subcategories, and Classes from Data

Categories and Subcategories	Codes
Problems experienced	
Cultural barriers	Cancer-related stigma; beliefs in the treatment of cancer
Structural barriers	Difficulty of medicine procuring under sanction conditions; throng of patients in big cities
Organizational barriers	Lack of integrated care program; lack of coordination among team members; the ambiguity of roles and expectations; shortage of resources
Socio-economic barriers	The low economic status of clients; family social problems
Facilitators to practice	
Personal characteristics	Patience; enthusiasm and commitment
Effective relationships	Relationships with clients; relations with other workers
Religious beliefs	Perceive service as worship trust
Supporting clients	Gratitude; cooperation in care

In some medical centers in Iran, coordination for the preparation of medicines is the responsibility of social workers, and by engaging in the process of preparing drugs, they understand the limitations of sanctions. A social worker said:

"Sometimes medicine could not be found easily, and anxiety of the family goes too high. We now put more time and manpower into finding medicine".

3.1.6. Throng of Patients in Large Cities to Access Services

Inappropriate distribution of medical services between the provinces in Iran and the accumulation of health facilities in the capital and big cities causes the movement of patients and families to these areas and faces social workers with more service requests. A participant said:

"We have patients from all the provinces in Tehran. They come from Lorestan, Kermanshah, Golestan, and Ilam provinces because they don't have facilities, which has difficulties for both the families and us... We should work with more patients. We should manage these displacement problems".

3.1.7. Lack of Integrated Care Program

Deficiency of policy in the field of childhood cancer and lack of integrated care programs throughout the country were other limitations referenced by the social workers. A participant in this field said:

"We have no integrated national program for childhood cancer at all. Hospitals do things for adult cancers, but they do not have a program for young

children, they act by their own measures. In Tehran, the situation is better than other cities".

3.1.8. Organizational Problems

Lack of coordination among team members, the ambiguity of roles and expectations, and limited resources were extracted from data as organizational problems.

3.1.9. Lack of Coordination Among Team Members

Social workers reported that low engagement and lack of coordination between the members of the team caused unnecessary and repetitive activities and inappropriate responses to the needs of patients. A social worker said:

"Anyone here works for himself on an island, physicians and nurses do their own work, the social workers and the psychologists also do the same. In this way, we don't know what we can do to help medical staff in treating patients, and they do not want us to help families. Sometimes, we do some repetitive things to the patient's needs, and their real needs are not met well".

3.1.10. The Ambiguity of Roles and Expectations

Participants considered the ambiguity of roles and expected tasks as barriers to their practice. A social worker, in this case, said:

"We don't know how to do the right job. The hospitals' administrators handle our tasks for us; they assign unrelated work to us. Our duties are old and incomplete".

3.1.11. Shortage of Resources

Social workers have limitations considering family accommodation, travel expenses, job security for fathers, and meeting the needs of other healthy children. A social worker said:

"Some families come from another city to treat their children, they don't have a place to stay, and they also have transportation difficulty. The father loses his job and we cannot give him a job, housing, or travel expenses."

3.1.12. Socioeconomic Problems

These problems refer to the challenges of patients and social workers involved with their multi-dimensional problems. The low economic status of clients and their social problems are concepts that were placed in this sub-category.

3.1.13. Low Economic Status of Clients

Social workers referred to the economic deprivation of patients. In these circumstances, to manage the basic needs of these families, they face trouble.

"Most of our clients are from disadvantaged social class. Some of the heads of households are unemployed. Some families are living in absolute poverty; they want money to pay living expenses. They even spend allowance for the child with cancer to feed and clothe other siblings. They constantly ask for financial help".

3.1.14. Social Problems

Participants expressed their experiences of the diversity of social family problems they have faced, and they considered the cancer disease of the child as the smallest problem. In many cases, they are involved in many problems to reduce the negative impact of these issues on the treatment of children. In this regard, a participant said:

"Cancer is the smallest problem in these families. They may have other problems; in some cases, the father is addicted, the parents are separated from each other and the mother has so much anxiety that she cannot attend to the sick child. In one case, the parents of a child had left him in the hospital, and they went their way. You could not say that you can only focus on cancer, other factors also affect it".

3.2. Facilitators to Practice

Concepts of personal characteristics of social workers, establishing effective relationships, religious beliefs, and supporting clients are considered facilitators of the experiences of social workers.

3.2.1. Personal Characteristics of Social Workers

Some features of the character of social workers, including patience enthusiasm, and commitment to serving clients were identified as effective facilitators.

3.2.2. Patience

Participants considered tolerance and resilience in the face of demanding emotional conditions in this field as a protective factor. A participant said:

"The social worker who does work here must be very patient to endure all the emotional challenges. Usually, a patient worker lasts longer and works more efficiently in this field".

3.2.3. *Enthusiasm and Commitment*

Social workers work with the interest to improve the conditions of children with cancer. A social worker said in this regard:

"I love my job, and I'm doing something that helps children have a better condition. I would forget my hardships in this way. When I wanted to set up a project of teaching children during treatment, my supervisor said, 'Why do you want to do so much work? I said I want children to have a normal life and I do everything necessary".

3.2.4. *Effective Relationships*

Effective communications of social workers with other social workers and patients are considered to be other facilitators to their practice.

3.2.5. *Relationships with Clients*

The formation of close and empathic relationships with the child and family was part of the experiences of social workers. A social worker said:

"Children and families feel very close to us. They do not just consider us a specialist, sometimes they feel so comfortable with us and have confidence that they look at us as a friend or family member, they talk about their problems with us and ask for help".

3.2.6. *Relations with Other Social Workers*

Creating a network of inter-group relations between social workers, their intimacy, establishing effective collaboration, and supporting each other in difficulties were some facilitators of social work practice. A social worker said:

"We have a very great relationship with each other in the work division, and help each other to solve the client's problem. This relationship is not limited to a hospital; we have contacts with other social workers in other hospitals and institutes. We support each other".

3.2.7. *Religious Beliefs*

One of the supports of social workers for resilience and continuation of activity in challenging situations is their religious beliefs. Perceptions of service as worship and trust were extracted from the analysis of social workers' experiences.

3.2.8. *Perception of Service as Worship*

Oncology social workers perceive serving children with cancer and their families as worship and talk about receiving God's satisfaction. In this regard, one of the participants said:

"When you help them, they pray for you with different accents, or they say this is the real worship of God. It's a good feeling when you know you are helping people, and making God satisfied".

3.2.9. *Trust*

Social workers trust in God and seek help from holy Imams in overwhelming work situations. For example, one participant said:

"I am religious and always ask God to ease the difficulty I face in my works".

3.2.10. *Supporting Clients (Support of Family)*

Social workers reported gratitude for clients and their cooperation in care as facilitators of their practice.

3.2.11. *Gratitude*

The experiences of participants showed a great sense of gratitude and received positive feedback from children and families. They describe the family's gratitude as a motivating factor. In this regard, a participant said:

"Mother of a child gave me a bouquet of flowers and said that she'd picked them from plains and another mother brought me some dates from the yard of their house, with the gratitude of families, we are encouraged to continue working."

3.2.12. *Cooperation in Care*

Social workers described that the participation of families in supporting each other is a contributing factor to their practice. A social worker stated:

"Families who stay here, not only help us in the care of their children but also they help other families. They assuage others' grief, share their information, and help each other. This way reduces our task volume".

4. Discussion

The present study is the first qualitative study that aims at exploring challenges to pediatric oncology social workers in Iran. Cultural problems, structural problems, institutional problems, and socio-economic problems are derived from the analysis of the experiences of social workers as inhibitors to their practice. The concepts of personal characteristics of social workers, religious beliefs, and supporting clients are identified as facilitators of their practice.

The first problem of social workers in providing services to children with cancer and their families was their cultural beliefs. Experiences of social workers showed that due to the stigma associated with cancer and taboos families did not discuss the disease or declined to accept it; therefore, they do not receive support from relatives and professional caregivers. In line with these findings, studies by Neimeyer and Holland and Else-Quest and Jackson showed that because of the relationship between cancer and death, patients often did not discuss the disease (16, 17). Else-Quest and Jackson considered this stigma an obstacle to the treatment of patients with cancer, and it is leading to their isolation (17).

According to the results, the family's belief in ineffective treatments has disrupted the process of social work and even put children's lives at risk. A study by Okagbue et al. showed that affected by superstitious beliefs, cancer survivors had turned to using traditional methods and herbal cancer treatment to keep body and avoid surgery (18).

The second inhibitors to social work practice were structural obstacles, including the difficulty of procuring medicine in sanction, the throng of patients in big cities, and the lack of integrated care programs. The social workers participating in this study, given the scarcity of some drugs, spent time and effort looking for the medicine and did not go through their professional tasks. Due to the lack of drugs needed for children with cancer as a result of sanctions on Iran, this experience can be unique to social workers who participated in this study.

Participants also considered the unequal distribution of health facilities and services in the provinces of Iran and the accumulation of patients in big cities, especially Tehran. Families who moved from their places and came to big cities faced many problems including losing jobs, travel and accommodation costs, being away from family members, and taking care of siblings. These problems affected providing proper service to clients and the social worker involved in managing a large number of patients with different needs. The results of Zahedi Asl and Rasti and Jahantigh on indicators of access to medical care and health development in Iran showed that there is inequality of opportunities to access health services between provinces of Iran and, therefore, patients have to travel to big cities to access medical facilities (19, 20). Junger et al. showed the gap in the provision of care and access to services as the inhibitor of the provision of palliative care to patients (21).

Lack of integrated care programs for children with cancer and their families in Iran was another problem presented by pediatric oncology social workers that resulted in disruption of services, and parallel and non-planned practice in organizations and NGOs. The non-integrated health system in Iran always has been discussed as one of the challenges in service delivery to patients (22).

Organizational problems that affect social workers serving children with cancer and their families include a lack of coordination between care team members, the ambiguity of roles, and a lack of resources. Social workers reported that limited interactions among team members and poor cooperation between them have caused repetitive, non-essential activities, and a lack of accountability for the needs of patients and families. According to Brueckner et al., the main problem with providing palliative care to patients was poor teamwork and role conflict among members of the medical team (23).

Based on the findings, in Iran, there is no particular plan on how social workers are involved in the process of psychosocial care of children with cancer and their families, and their role is not clear. In this regard, it is known that the social work profession is full of stress, because of unclear and conflicting roles, tasks, statuses, and background (24, 25). Ambrose-Miller and Ashcroft also explain the challenges of social workers in teamwork and note the ambiguous role of social

workers in the health sector as one of these challenges (26).

Social workers have identified the lack of resources to accommodate the patients and their families, paying the cost of medicine and other expenses of family life, finding jobs for the head of the family, and finding resources to meet the needs of the siblings as obstacles in providing appropriate services to patients. Jones and Novak suggested that the lack of resources leads to limited control and less autonomy of social workers (11).

Based on the results, the poverty of the patients and their low financial power to handle living costs have caused restrictions on social workers to spend the funds provided for health care costs and the welfare of children with cancer. Social workers are normally involved with the financial difficulties of clients (27), but in this study, the poverty of the clients and lack of resources have made it more difficult for social workers to manage and prioritize family problems. They believe that family problems are caused by structural problems in society. Social workers are trying to solve these problems to reduce the consequences of them on improving the treatment of children.

According to evidence, working in the field of cancer is stressful and exhausting for social workers (25, 28-30). In this regard, some factors facilitate their practice. In this study, some of these facilitators were identified by analyzing social workers' experiences. The individual characteristics of social workers such as patience and tolerance provide better compatibility with stressful and demanding situations. Kapoulitsas and Corcoran suggested that resilience is an important factor in reducing fatigue and stresses of working with distressed patients. Empowering the child and family to have a natural life is a motivating factor for social workers (31).

In the study, establishing effective relationships with clients and other social workers was identified as another facilitating factor. Nelson et al. (32) pointed out effective communication between patient and therapist as a facilitator in providing palliative care. The intended results of content analysis by De Graaff et al. suggested that members of the medical team believe that a good relationship between patients and their professional caregivers is one of the facilitating factors for curing cancer (33).

In this study, social workers have established appropriate professional relationships with social workers from other health centers and social service

institutions. They considered the support of their colleagues as a protective factor against their hardships. Also, to approve the results of this study, Yi et al. considered the appropriate linkage between social workers and receiving support from them to be a resiliency factor (25).

Religious beliefs of social workers, such as serving as worshiping and achieving God's satisfaction and trust in God and resorting to Imams facilitate social work practice. According to Neimeyer and Holland, religious beliefs and daily religious activities decrease a variety of physical, cognitive, and emotional fatigue in the workplace. In this regard, Forootan et al. suggested that trust in God and resorting to Imams increase the resilience of professionals and facilitate the provision of pre-hospital care (16, 34).

Gratitude, participation, and contribution of families in care were considered other supporting factors for social work practice. Families' satisfaction and their gratitude to social workers in various ways encourage them to continue serving in this field. Emotional and informational support of other patients and taking care of each other have made a positive impact on the provision of service. In this regard, Mok and Chiu considered confidence in the ability of caregivers and supporting them as a facilitating factor in palliative care (35).

The present study focused on perceived problems and facilitators of pediatric oncology social work practice in Iran. It provides an important insight into providing a suitable platform for caring for children with cancer and their families. Based on the results, facilitators of social work practice in Iran encompass personal characteristics and interpersonal communication at the micro levels, while the problems are considered cultural, social, economic, organizational, and structural at macro levels. Thus, according to the macro-level problems, it seems that the formulation and implementation of the national care plan for children with cancer, and the design of protocols for psychosocial care for them may lead to the unity and integrity of service in all provinces and explain the role and extent of participation of interdisciplinary team members in the care program.

Also, regarding the status of social workers in addressing the needs of children with cancer and their families, the special attention of policymakers and health system managers to strengthen facilitators and

reduce the problems of their practice can be effective in protecting the professional practices of these caregivers. Ultimately, this will improve care and the quality of services for patients.

In this study, given the small number of specialized hospitals of pediatric oncology in Iran, all of the participants were not necessarily oncology social workers, but according to the specified inclusion criteria, only hospital social workers who had at least 5 years of job-related experience participated in the study. Although according to the method of data collection and qualitative research principles, the results of the study cannot be generalized to other countries; some of the findings may be shared by similar cultures. It is also suggested that future research explore the experiences of oncology social workers in other cultures. Moreover, due to differences between the care of adults with cancer and children with cancer, research on adult oncology can be effective in identifying barriers and facilitators to social workers' practices.

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Footnotes

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