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Challenges of home care in patients with burn: Experiences of patients, family caregivers and healthcare providers

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Abstract

Background: Burns are a major health challenge in developing countries. Post-discharge problems of patients with burn are complex and require home care and educational interventions. However, few studies are available in this area.
Objectives: This study explored challenges of home care in burn patients from the perspective of patients, family caregivers, and health care providers.
Methods: This qualitative study was conducted during 2022 and 2023. Participants were purposively recruited from Imam Musakazem Hospital in Isfahan, Iran. Data were collected using semi-structured interviews. The qualitative content analysis approach proposed by Graneheim and Lundman was used for data analysis. The trustworthiness of the data was ensured using the criteria of confirmability, credibility, dependability, and transferability proposed by Lincoln and Guba.
Results: The study comprised 24 participants, including seven patients, four family caregivers, two physicians, two managers, and nine nurses. Three main categories were extracted including "the vague structure of home care," "inefficient home care" and "informal home care." Each category included 2-3 subcategories.
Conclusion: The home care program for burn patients requires reforms, such as changes in the administrative structure of home care, increasing the quality of home care centers, interdisciplinary collaboration between health team members, and boosting patients and their families' awareness about the goals and application of the home care program.

Keywords: Burns, Home care services, Nursing, Qualitative research.

Introduction

Burns are a major public health problem.[1] Every year, more than 300,000 people die from burns worldwide,[2] most of which occur in low- and middle-income countries.[3] In Iran, there are 30,000 burns requiring hospitalization annually, of which about 3,000 people die. About 40-50% of the remaining 27,000 people suffer from disabilities of varying degrees upon discharge, and approximately 13,000 people with disabilities are added to society every year.[4] In Canada, in 2018, the total cost of burns in one year was estimated at $ 299 million.[5] Burns can occur due to fire, hot liquids or vapors, chemicals, electrical sources, and radiation.[6] Regardless of the cause, patients with burns need long-term care.[7] During hospitalization, healthcare providers focus on saving the patient,[8] intensive care, surgery, wound dressing, and management of burns complications.[9]

After the acute phase, at the beginning of the rehabilitation process, healing of the remaining wounds and wound closure are the top priorities in long-term burn care. Dressing changes, cleaning, disinfecting, and debriding the wound, and applying topical ointments are some of the measures that should be performed in wound management, even after hospital discharge.[8, 9] However, mental disorders and physical problems such as scarring, contractures, re-infection, pain, and chronic itching

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continue for months and years after discharge from the hospital. Such problems interfere with a person's family and social roles and ultimately reduce their quality of life, underscoring the need for planning for long-term care planning after discharge.[10]

The post-discharge problems of burn patients are complex and require care and educational interventions at home. Home care (HC), guarantees continuing, safe, and timely care, and prevents dangerous consequences. HC includes five dimensions: increasing patient and family participation in care, educating the patient, family, and care provider, managing the complex health and social needs, promoting health, and ensuring care continuity and availability. High-quality HC has been shown to reduce acute health events in patients.[11] Effective, comprehensive, and family-based HC can promote patient's health, and reduce length of the hospital stay or re-hospitalization.[12,13] However, the lack of an effective HC system causes dangerous health events. The absence of an effective HC system causes 15-20% of patients being readmitted within the first month after discharge. [14] A systematic review has shown that lack of resources, insufficient access to health services, and conflicts in health priorities are barriers to providing long-term rehabilitation care for burn patients.[15] Heydarikhayat *et al.* also investigated burn patients' experiences six months after hospital discharge and receiving HC care, and reported that HC providers need more training.[16] Noting the costs that burns impose on the patient and society, a study of the experiences of burn survivors and caregivers also underscored the need for research on post-discharge care.[17] The lack of qualitative studies on the challenges of rehabilitation programs and HC for burn patients results in a dearth of information in this area and limits the ability to adequately plan and provide quality services for these patients. Thus, the question remains: What are the challenges of home care for these patients from the perspective of burn survivors and their families and formal caregivers?.

Objectives

This study was designed to explore the challenges of in burn patients from the perspective of patients, family caregivers, and care providers.

Methods

Study design and participants

This qualitative study was conducted in 2022-2023. Participants were recruited from Imam Musakazem Hospital in Isfahan Province, Iran. This hospital is one of the main referral centers for burn patients in central and southern Iran, with a total of 120 beds. Approximately, 70 to 80 patients with burn are hospitalized each month. Participants from patients, family caregivers, physicians, managers, and nurses were purposively chosen. The researcher tried to identify and select those individuals who had valuable information or experience relevant to HC in burn patients.[18] For patients, the inclusion criteria were willingness to participate in the study, age of 18 years and older, experience of HC, and no known chronic physical and cognitive disorders. Inclusion criteria for family caregivers were willingness to participate in the study, a close relationship with the patient, participation in patient care, and no physical and cognitive problems. The inclusion criteria for physicians, managers, and nurses were willingness to participate in the study and at least one year of experience in HC for burn patients.

Data collection

Data were collected using in-depth semi-structured interviews. All interviews were conducted by the corresponding author. The time and place of the interview were arranged at the participants' convenience. Interviews with patients were conducted in the clinic after the physician's visit. Interviews with family caregivers, physicians, and nurses were also conducted in a private room at the hospital. The interviews lasted for 30-45 minutes. All interviews began with a general question to make rapport with the participants. Examples of interview questions for patients and family caregivers were as follows: *Please describe your home care experience. What are your concerns about home care? Please explain more. What did you expect from the care provided?* Examples of interview questions for physicians and nurses were: *Please describe your home care experience. What problems have you experienced while caring? Please explain more. What should be done to facilitate home care?*

Participant selection continued until data saturation was reached. Saturation refers to that by continuing data collection, no new conceptual code is obtained.[19]

Ethical considerations

This study was approved by the Ethics Committee of Isfahan University of Medical Sciences (Approval no: IR.MUI.NUREMA.REC.1401.097). Informed consent was obtained from the participants. We used numeric codes in place of personal names to secure the confidentiality of the interviews. The participants were free to withdraw from the study at anytime. All methods were performed in accordance with the relevant ethical guidelines and regulations.

Data analysis

Data analysis was performed using the Graneheim and Lundman (2004) approach.[20] We generated precise transcriptions of the audiotaped interviews and scrutinized all the transcriptions to achieve a common sense with the perceptions of the participants. Firstly, we selected meaning units (sentences or paragraphs that were extracted according to the participants' statements) and condensed them. Then, codes (the words of the participants in a more abstract way) were assigned to those condensed meaning units. Finally, similar codes were grouped into more comprehensive subcategories and categories with an inductive process through constant comparison, reflection, and interpretation.

Data trustworthiness

In this study, Lincoln and Guba's (1981) four criteria, namely, confirmability, credibility, dependability, and transferability, were used to establish trustworthiness.[21] Confirmability was enhanced by keeping a clear audit trail of all research activities. To strengthen the credibility, peer debriefing or reviewing of the data, codes, categories, and subcategories was done. Some interviews, along with the extracted codes, were printed and sent to the relevant participants to be compared to their own experiences. Dependability was achieved through the collaboration of the first and second authors in data analysis. In addition, a sample of coded interviews was presented to an expert in qualitative research to check and verify the coding process. By selecting participants with different demographic characteristics, an attempt was made to increase the transferability of the study results.

Results

The study comprised 24 participants, including seven patients, four family caregivers, two physicians, two managers, and nine nurses (head nurse, supervisor, and nurse) [Table 1]. Three main categories were extracted from the data: "The vague structure of home care," "Inefficient home care," and "Informal home care" [Table 2].

Table 1. Participants' characteristics

Participant number	Gender	Role	Age (year)	Work experience (year)	Degree
P1	Male	Supervisor	49	26	Bachelor
P2	female	Supervisor	37	14	Bachelor
P3	female	Supervisor	47	20	Bachelor
P4	Male	Supervisor	38	13	Bachelor
P5	female	Nurse	32	10	Bachelor
P6	female	Nurse	39	16	Bachelor
P7	female	Nurse	44	24	Bachelor
P8	female	Physician	53	25	Doctoral
P9	Male	Physician	48	-	Doctoral
P10	Male	Patient	37	-	Diploma
P11	female	Patient	32	-	Bachelor
P12	female	Caregiver	27	-	Bachelor
P13	female	Caregiver	43	-	Diploma
P14	female	Caregiver	51	-	Diploma
P15	Male	Manager	55	22	PhD
P16	Male	Manager	57	23	PhD
P17	female	Nurse	41	19	Master
P18	Male	Head nurse	42	19	Master
P19	female	Caregiver	23	-	Diploma
P20	Male	Patient	18	-	Diploma
P21	Male	Patient	25	-	Associate diploma
P22	female	Patient	24	-	Diploma
P23	female	Patient	42	-	Elementary
P24	Male	Patient	53	-	Diploma

Table 2. Categories and subcategories

Categories	Subcategories	Examples of initial coding
The vague structure of home care		
	- Deficient referral process	- Ignorance of patients about home care - Absence of a home care center representative in hospital
	- Lack of financial transparency	- Obscurity of costs - Undefined tariff
Inefficient home care		
	- Providing home care by an individual rather than a team	- Weak interaction between nurse and health care provider - Lack of feedback about patients' condition
	- Underqualified home care providers	- Weak knowledge of burns and related problems - Poor skill about burn care
	- Considering home care equivalent to wound management	- Low pay attention to patients' pain - Ignoring mental needs of patient
Informal home care		
	- Home care by paramedics and nurses outside the administrative system	- Attempt to attract patients - Encourage patient to early discharge - Dressing by service personnel. - Dressing by local people.
	- Consequences of informal care	- Re-hospitalization - Wound infection

Category 1: The vague structure of home care

One of the critical challenges in providing HC to burn patients was its unclear structure, implying the deficient HC referral process and lack of financial transparency.

Deficient referral process

The referral process was inefficient due to the lack of a follow-up agent in the hospital, the lack of competition between HC centers, absence of a HC center representative in the hospital, and poor interaction between the hospital and HC centers. Supervisors merely introduced the patients seeking HC to one of the three HC agencies approved by the treatment deputy of Isfahan University of Medical Sciences, and the hospital did not supervise the performance of the HC centers. In addition, the patient's condition was not reported to the hospital by HC centers. A supervisor said, *"Home care centers do not provide us (the hospital) with a report on the patient's condition, cannot we monitor their activities"* (P2).

Lack of financial transparency

One of the structural problems of HC was the obscurity of costs and revenues. The incomplete setting of HC services tariffs, patient and family unawareness of care costs, and failure to provide the hospital with a financial report of services provided by HC centers were the causes of this challenge. Referring to the unclear tariff for HC services, a patient commented, *"In the first few days after discharge, Ms. A came to change the dressing and charged a little money. In addition to changing the dressing, she also did physiotherapy for me. A few days later, Ms. B came to do the same, but charged me much higher"* (P21). A supervisor made a similar point, stating, *"Some nurses charge a higher rate; tariffs aren't specified. We have had the necessary correspondence with insurance organizations, but it hasn't been fruitful"* (P1). As participants' experiences showed, the structure and process of HC for burn patients face challenges such as the lack of a HC agency in the hospital, lack of hospital supervision over HC providers, and the lack of transparency in financial issues.

Category 2: Inefficient home care

Another challenge in HC for burn patients was incomplete and non-standard HC. HC was provided by an individual rather than the care team. On the other hand, in some cases, the individuals lacked enough qualifications to provide HC, and in most cases, there was no correct and professional understanding of the concept of HC.

Providing home care by an individual rather than a team

There was no team to provide HC to burn patients. Rather, after the patient was referred to a HC center, an individual (a paramedic or nurse) was appointed to visit

the patient at home, and communication was established between the patient, the family, and the appointed individual. However, no feedback was given to the center or hospital, and no assistance was received from other health team members, such as physiotherapists, nutritionists, infectious diseases doctors, and general or cosmetic surgeons. A supervisor said, *"The person who visits the patient at home to change the dressing should contact a doctor to report the patient's and wound's condition to the doctor to schedule the next visit. But the decisions are made personally"* (P4). A nurse involved in HC also commented, *"In most cases of changing the dressing, I needed to consult an infectious disease doctor, but there was no formal communication between us. Quality and standard care could be provided if a team of a physician, a physical therapist, a dietician, and other nurses worked together"* (P5).

Underqualified home care providers

Some HC providers were not adequately qualified to provide HC for burn patients. They did not have higher education or sufficient knowledge in burn care, which in some cases, caused harm to the patient. One of the family caregivers said, *"My child's wound was festering under the silver dressing, and the person who came to change the dressing did not notice. We went to the doctor, and he hospitalized my son"* (P19). One nurse pointed out the need for qualified HC workers, *"The person who provides home care should be fully aware of burns and related problems. Now most of them are paramedics who only have empirical knowledge about dressings resulting in incomplete care"* (P6). Highlighting the consequences of HC by unqualified people, a hospital manager also commented, *"Currently, home care centers lacks qualified burn care providers such as doctors and nurses experienced in burns. We see the results in the readmission of patients with a bad general condition"* (P16).

Considering home care equivalent to wound management

One of the most fundamental challenges of HC for burn patients was the inaccurate and unprofessional understanding of the concept of HC for burn patients. The HC for burn patients was considered synonymous with burn dressing, in which patients' psychological and social needs were ignored. In addition, education to the patient and family was insufficient, and were not referred to other professionals in a timely manner by HC providers. One of the patients commented about the shortcomings in patient education and referral, saying, *"The paramedic who came to my home only changed the dressing. I asked her several times about physiotherapy for my hand, but she didn't answer me. Home care should include all kinds of care so that we can raise our questions. She must either answer herself or consult a doctor"* (P22). One of the managers also highlighted the need for teamwork of burn care experts in HC by saying, *"In the home care process, burn patients must be supported financially, physically, psychologically, and socially after discharge with the help of a home care provider. They will assess the patient and refer them to the hospital if necessary"* (P15). A supervisor also pointed out the same point and lamented, "*However, in our hospital, home care means change dressing only!"* (P3). Participants' experiences showed that the quality of HC for burn patients was compromised by the fact that care was provided by an individual rather than a team, that HC workers were inadequately qualified, and that only the physical dimension was considered in HC.

Category 3: Informal home care

The HC program for burn patients was largely informal, consisted mainly of dressing changes, and was mostly performed by paramedics or nurses outside the administrative system or by nonprofessionals. This approach to HC had negative consequences for patients and the health system.

Home care by paramedics and nurses outside the administrative system

Many paramedics and nurses at the burn hospital have informally informed patients that they can change their dressings at home after discharge. They even encourage patients and their families to voluntarily leave the hospital and entrust their care. One physician pointed out, *"The patient never tells us who changes the dressing at home, although we've told them that if the person changing the dressing is not approved by the hospital, the hospital has no liability for complications. As a doctor, I still face this problem"* (P8). Sometimes even unprofessional people such as service personnel working in burn centers or local people performed dressing changes for burn patients at home, as one of the managers said, *"In several cases, service personnel have done dressings for burn patients at home. This is not safe for the patients"* (P15).

Consequences of informal care

The negative consequences of informal HC included increased costs, the inability to monitor informal care, and threats to patient safety. In most cases, HC results in

patient harm, readmissions, and increased costs for the patient because the performance of HC providers is not monitored and care is provided by lay people. A supervisor commented in this regard, *"Many patients who were discharged without receiving official home care have been readmitted in bad conditions. This is the result of the involvement of amateur profiteers. There are even cases where patients entrusted to these amateurs died at home a few days after discharge"* (P1).

Discussion

The "vague structure of home care," "inefficient home care" and "informal home care" were the challenges associated with HC for burn patients. The unclear structure of HC negatively affected its implementation. Designing and implementing a straightforward, explicit referral process and financial transparency are essential for consistent care providers' performance. Heydarikhayat also emphasized the need for appropriate policies and structures for HC implementation by studying the experiences of burn survivors from the nursing telephone follow-up program.[22] Another study also have cited structural deficiencies as one of the main obstacles to HC.[23] In the present study, the hospital introduced the agencies providing HC to patients. However, the hospital should play the role of advocate for the patient during the HC process. To fulfill this role, it would be beneficial to develop a system to design individualized HC programs for patients and to designate a follow-up nurse to check the patient's post-discharge HC status.

Centers providing HC and the quality of the services they provide must be supervised by health authorities. The quality of care provided by these centers can be ensured by creating a competitive atmosphere between them. These centers should provide HC services for burn patients by a specialized burn care team, consisting of burn nurses, physiotherapists, internists, infectious disease specialists, plastic surgeons, psychiatrists, and nutritionists. All these people must have ethical competence, professional communication skills, honesty, good manners, compassion, patience, and adherence to professional codes.

By defining the required infrastructure and linking the HC providing centers, HC agents, and the hospital's follow-up nurses, the hospital becomes aware of the patient's HC status. This allows the hospital to monitor and evaluate the performance of the HC providers and the outcomes for the patient, and provide them with consultation and hospital services needed for patients or the HC provider as needed. In addition, specific forms need to be designed for HC documentation, to assess, review, recognize, and record HC needs and care services provided. Designing and using these forms can contribute to improving the quality of HC, care evaluation, and audit of these cares.

Financial management of HC is a crucial issue in defending the rights of patients and HC providers.[23] Financial problems, including lack of insurance coverage and supportive social networks, were among the obstacles to HC. In one study, burn patients and their families considered it a pleasant experience to receive assistance in solving financial issues associated with HC and burn treatment, which could be a powerful motivator to continue the rehabilitation program.[24] Measures required for financial management of HC include determining tariffs for HC services, notifying patients and family caregivers of care tariffs, recording received fees, having centers provide financial reports to the hospital, and encouraging charitable organizations to contribute to the expenses.

The lack of clarity in the structure of HC resulted in poor and informal HC. Burn victims and their families experience acute trauma. The long-term treatment process, post-discharge wound care, possible reconstructive and cosmetic surgeries, long-term rehabilitation programs, and socio-psychological and occupational issues are among their concerns.[25-27] In a study in Sweden, the HC team's focus on issues such as the parental role of the burn survivor was a positive experience for patients and families.[24] Burn survivors and their families deal with various needs; therefore, comprehensive physical, psychological, social, financial, spiritual, and cultural care should be tailored to the patient's needs.[28] Nevertheless, in the present study, HC was only considered equivalent to dressing change.

HC is a novel experience in Iran,[22] and patients' and families' unawareness of its nature and importance has caused patients not to receive care after wound repair. If we can change the attitude toward HC dimensions, the concept of providing HC by a team will be more tangible. In other studies, burn patients have indicated the need for a HC team.[23,30] The HC team needs to be highly knowledgeable and skilled in caring for burn patients. An earlier study from Iran also reported that patients and families considered the presence of a physician in the HC team as a strong point.[22] A specialized homecare team for burns can help provide comprehensive care.[29] The care team jointly examines, diagnoses, plans, implements, and evaluates patients resulting in safe and high-quality care and preventing many burn-related complications. In the

study by Wu et al., nurses providing palliative HC considered support from the hospital's care team essential for HC.[30]

Burn patients require post-discharge care from health care providers,[25] but informal HC jeopardizes the patient's health and safety.[31,32] The current structural deficiencies of HC in Iran have laid the groundwork for the presence of unprofessional profiteers.[22] Developing an appropriate structure for HC and rehabilitation of burn patients will help diminish the risks associated with informal HC.[33] The hospital must have a HC team. This team must collaborate with the department responsible for educating patients and families about the importance of planning for HC after admission. During this process, patients needing HC should be initially identified; afterward, the care needs should be determined and prioritized, and finally, the HC team should be selected with the participation of family members. In Iran, the family plays a significant role in making decisions about patients,[34] and their lack of participation can affect the HC program.

To better understand the challenges of HC, the researchers in this study attempted to analyze the perceptions and experiences of family caregivers and the care team rather than limiting themselves to the experiences of the patients. Nevertheless, our findings, like those of other qualitative studies, may not be highly generalizable.

Conclusions

Given the needs and problems of burn patients and their families, the HC program for burn patients is considered a priority for reform, such as changing the administrative structure of HC in hospitals, increasing the quality of HC centers, interdisciplinary collaboration between health team members, and boosting patients and their families' awareness about the goals and application of the HC program. Moreover, the participation of charitable organizations, government assistance, and insurance coverage to support the HC program is indispensable.

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Competing interests

The authors declare that they have no competing interests.

Abbreviations

Home care: HC.

Authors' contributions

All authors read and approved the final manuscript. All authors take responsibility for the integrity of the data and the accuracy of the data analysis.

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Role of the funding source

None.

Availability of data and materials

The data used in this study are available from the corresponding author on request.

Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki. This study has been approved by the ethics committee of Isfahan University of Medical Sciences (Approval no: IR.MUI.NUREMA.REC.1401.097). Informed consent was obtained from the participants.

Consent for publication

By submitting this document, the authors declare their consent for the final accepted version of the manuscript to be considered for publication.

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