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Barriers Against Providing Home Health Care Delivery to Ventilator-Dependent Patients: A Qualitative Content Analysis

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Abstract

Background: Home health care (HHC) as a part of the health care delivery continuum has continued to be developed over the past decade. The number of patients receiving home mechanical ventilation (HMV) is increasing. The continuity of care from the hospital to the home is very important. However, these patients have various special care needs, and different conditions may affect the quality of care delivered to them.

Objectives: This study was conducted to assess the barriers against service provided to the patients receiving HMV in the distinctive cultural, financial, spiritual, and emotional context of Iran.

Methods: The present study was performed using the method of qualitative content analysis with purposive sampling. In general, 18 participants, including seven nurses, three physicians, and two physiotherapists working in homes, and six family members who each had a patient receiving mechanical ventilation at home, were interviewed during 2013 to 2014. Semi-structured interviews were conducted in quiet places offered by the study participants.

Results: The barriers against home care for patients depending upon mechanical ventilation in this study are classified into three main categories, including policy-based barriers, agency-based barriers, and family-based barriers. The main policy-based barriers were the legal framework restrictions, insurance limitations, and an inefficient social support network. Lack of a professional team, lack of an independent home care organization, and problems related to physician visits were considered as agency-based barriers. Family-based barriers included fatigue and distress of the families and financial drainage.

Conclusions: It seems that providing quality HHC is one of the most important challenges faced by our country's health system, but the relevant infrastructure and policies have not been adequately considered. The results of this study could be used for improving the current challenges in delivering quality care to ventilator-dependent patients at home.

Keywords: Home Health Care, Health Care Delivery, Ventilator-Dependent Patients, qualitative Content Analysis

1. Background

The worldwide trend of avoiding hospitalization by treating patients at home is well established (1). Home health care (HHC) as a part of the health care delivery continuum has continued to be developed in the past decade (2). Home care provides a cost-effective environment that is designed to be clinically appropriate for the treatment of certain patients (3, 4).

In recent years, the number of patients receiving complex therapies such as home mechanical ventilation (HMV) is increasing (5, 6). Technology helps these people to receive these complicated treatments at home, and to have more autonomy (7). As a result, the role of home care for the treatment of intensive care patients is greater than ever.

Continuity of care from hospital to home is very important, so the goal is to provide services at a low cost but without quality reduction (8, 9). Considering the concerns about the quality of services provided in the home, barriers must be identified and appropriate solutions be presented.

Care is usually affected by atypical events and problems in family-nurse communications (2, 10). Based on the available literature, barriers against advanced home care have not been assessed adequately. However, some reports indicate various obstacles to providing quality HHC, such as the difficult conditions of families and patients, and nurses who do not have enough competence or do not have proper training (11-13).

It is very difficult to generalize the HHC studies from one country to another because of differences in resources, health system financing, and service provision. As a result, every system should be studied in its own political, economic, and cultural context (2). Also, the context of the home is quite different from the hospital, and therefore, considering the patient's own biological, spiritual, and cul-

tural context is essential (14).

The population of Iran is aging. Based on the last census, 70.9% of the Iranian population is between 15 and 64 years old, and 5.7% of the country's population is over 65. In recent years, life expectancy has increased. The increase in the elderly population and the growing hospital bed shortage demonstrates the continued importance of HHC. HHC in Iran is not supported by insurance, and costs are paid by family members. Most of the centers that provide HHC services are unspecialized. They thus provide care of a lower cost and quality. Almost all nurses in Iran work in hospitals, and there are no active community health nurses. The Ministry of Health and Medical Education has therefore described the state of home care in Iran as deplorable.

2. Objectives

This study was conducted to assess the barriers against providing service to the patients receiving HMV in the distinctive cultural, financial, spiritual, and emotional context of Iran.

3. Methods

To understand the barriers against HHC delivery to HMV-dependent patients in the Iranian context, a conventional qualitative content analysis method was used. In this study using purposive sampling, 18 participants, including seven nurses, three physicians, and two physiotherapists, as well as six family members who had a patient receiving mechanical ventilation in the home, were interviewed during 2013 to 2014 in Tehran (Tables 1 and 2). Sampling was continued until data saturation. After the 16th interview, no new data was added in the next interviews.

Home health workers who had been working in homes for more than two years, and who had extensive firsthand experience in caring for the HMV patients, were included. To enhance the maximum variation of HHC professionals of both genders, those with different work experiences and different educational levels were selected. In addition, family members from different cultures and socioeconomic levels providing care for patients with conditions of different levels of complexity were asked to participate.

Semi-structured interviews were used for data collection, and each lasted from 30 to 70 minutes. Interviews were conducted in quiet places which were offered by the study participants. Most of the interviews with health care professionals were done in their workplaces, and interviews with family members were done in their homes.

The first author of this article conducted the interviews. After several warm-up questions, the interviews were started with an open ended question which respondents were asked to answer in as much detail as possible about their own experiences.

The data analysis was conducted using a qualitative content analysis method. Immediately after each interview, the contents were transcribed verbatim and then read several times for obtaining a general sense of the participant's words. Then, using MAXQDA 10 software, the data was divided in meaning units, then coded and arranged in different categories and subcategories based on their similarities and differences. The underlying implications of the study are expressed in terms of themes and categories.

The Lincoln and Guba criteria for rigor and trustworthiness were used in this study (15). The researcher had long-term engagement with the data and the research field. Member-checking was done by giving a summary of the primary result of each interview and the final results to the participants. Also, the analytical process was conducted in accordance with the agreement of two members of the research team, and was audited by two external supervisors.

The ethical and research committee of the University of Social Welfare and Rehabilitation Sciences in Tehran approved of this study. After clarifying the aim and objective of the study, informed written consent was obtained from the participants.

4. Results

The barriers against home care for HMV-dependent patients in this study were classified into three main categories, including policy-based barriers, agency-based barriers, and family-based barriers (Table 3).

4.1. Policy-Based Barriers

Problems that seemed to be related to certain health policies were included in this category. This category includes the following three main subcategories of legal framework restrictions, insurance limitations, and inefficient social support networks.

4.1.1. Insurance Limitations

Keeping the patients with medical complications at home is costly. Despite the passage of several years from the enactment of tariffs for home care services, insurance still has not accepted them. As a result, most of the costs must be paid by the client's family. The burden of the costs on families is the prevailing reason for the reduced quality of care. Participants claimed that coverage by insurance is

Table 1. Characteristics of the Patients' Family Members

Age	Gender	Relationship With the Patient	Duration of Involvement in Care	Patient's Diagnosis	Marital Status	Duration of Interview	Economic Status
65	Female	Patient's wife	6 mo	CVA	Married	30	Good
44	Male	Son	3 mo	CVA	Married	45	Not bad
31	Male	Father	6 mo	ALS	Married	52	Poor
56	Male	Son	5 y	Brain ischemia	Married	55	Poor
44	Female	Patient's wife	8 mo	COPD	Married	48	Good
29	Male	Father	1 y	ALS	Married	39	Rich

Table 2. Characteristics of Professional Health Care Workers

Age	Gender	Position	Experience in Home Care, y	Duration of interview, min
40	Male	Nursing manager	12	70
37	Male	Nurse	10	45 and 62
45	Male	Nurse	5	52
33	Female	Nursing assistant	3	32
41	Male	Nurse	11	68
32	Female	Nurse	4	43
35	Female	Nurse	2	32
44	Male	Physician	8	35
31	Male	Physiotherapist	10	45
29	Male	Physiotherapist	2	37
41	Male	Physician	6	52
39	Male	Physician	7	49

the only way to improve the service quality. As one study participant stated, "The insurance did nothing to help us. Hence, we had to reduce the quality of care. The nurses were replaced with nursing assistants. At the moment, we are seeking a full-time caregiver". There is no special organization that is responsible for supporting these families. Organizations such as Red Crescent and Welfare sometimes support these families, but the support provided by these organizations is not enough. Family members also receive different support from the treatment team, including informational support, emergency equipment, and sometimes financial support in the form of reduced or waived fees. Patients' families describe this support as helpful.

4.2. Agency-Based Barriers

The HHC agencies have an important role in transferring the patient from critical care units to the home. There are many agencies in our country, but most of them are doing general work. They cannot help the families in their efforts to keep the patients with complications at home. Agency-based barriers can be categorized into three main categories: lack of a professional team, lack of independent HHC agencies, and problems related to physician visits.

4.2.1. Lack of a Professional Team

Due to the tendency to reduce the costs of care and the corresponding lack of adequate supervision, persons with inadequate skills are often sent to the patients' homes. Most of them are not health care staff. Also, the professional health care workers usually see home care as their second job. They are often tired and often are not providing quality care. Some nurses have technical problems with executing procedures, and others do not have enough knowledge to manage the patients' problems. In addition to reducing costs, institutes and families are also relying on unprofessional staff given that most of them are not familiar with the basic principles of home care provision. Ultimately, a full-time professional HHC team who have the

Table 3. List of Codes and Categories

Category/Subcategory	Code (Examples)
Policy-based barriers	
Legal framework restrictions	Lack of a clear framework for home care
	Home care is not supported legally
Insurance limitations	Inappropriate coverage by insurance
	All costs to be covered by family members
Inefficient social support networks	Dissatisfaction from the support for welfare
	Disproportion of support to the needs of patients
Agency-based barriers	
Lack of a professional team	Technical problems of nursing staff
	Nurses who are unable to manage emergency situations
Lack of an independent home care organization	Unavailability of home care agencies
	Unavailability of full-time staff
Problems related to physician visits	Prescription without seeing the patient
	Difficulty in accessing specialist physicians
Family-based barriers	
Fatigue and distress of the family	Sleep deprivation of family members
	High levels of tension in the patient's family
Financial drain	Selling things to pay for care
	Money as the major problem for families

required knowledge and skills is simply unavailable.

4.2.2. Lack of an Independent HHC Organization

When the family wants to transfer the patient home, they must look for someone who will be able to do it. There are agencies that provide HHC services. The home care agencies are licensed by the Ministry of Health and Medical Education, but their interventions in the home are not supported by any legal institutions. Some of them have establishment licenses, but most of them do not. Adequate supervision does not take place with respect to the performance of these agencies.

4.2.3. Problems Related to Physician Visits

The transfer of a patient dependent on HMV usually occurs when the patient has a complex situation. Therefore, the patient needs to be visited by different physicians. Usually the visits are coordinated by team leaders. They report the situation to the specialist in charge of the patient's particular problem. In most cases, the physicians provide some advice. In special circumstances, the patient needs to be visited by a physician. Families usually have difficulty in this situation. The cost of a physician visit is high, and most of the families cannot afford it. In addition, most of the specialist physicians refuse to visit the patient at the home and want the family to bring the patient to the clinic. Transferring the patient in this situation is very difficult. Also, most physicians who come to the home do not assess the patient's problems very effectively.

4.3. Family-Based Barriers

The family is the host of HHC and has a great effect on the quality of service delivery. For a successful HHC program, a supportive family context should be provided. If the home environment is not prepared for care, the process will fail. The main subcategories of family-based barriers are classified into two general domains: (1) fatigue and distress of the family, and (2) family financial drain.

4.3.1. Fatigue and Distress of the Family

The family is forced to participate in the process of patient care, with some family members even leaving their jobs to care for the patient. Some of them do overtime work to pay for the costs. During this complex process, families experience various types of physical and emotional distress. There is the stress involved with the advent of a critical incident regarding their patient, the disappointment

in the patient's lack of improvement, the stress of independent care giving, general psychological distress due to taking on the full-time role of an entire HHC team, and sleep deprivation. They may also experience different physical symptoms including low back pain, headache, hypertension, and the requirement of different medications. They often describe caring for the patient as problematic and tedious, and many experience boredom and frustration.

4.3.2. Financial Drain

Before transferring the patient to the home, usually family members have already paid a high price for ICU, and most are not in good financial shape. Now, they must pay all of the costs of caring for a patient with different needs. The family must pay the costs of medicine and medical equipment, nurses, and other health care staff by itself. Another problem is that the price of HHC services has not been regulated. Most families cannot afford the costs and therefore have to acquire the means through other sources, such as the sale of their home appliances.

5. Discussion

In the current study, the main barriers against effective service delivery to intensive care patients at home are categorized into three main groups: policy-based barriers, agency-based barriers, and family-based barriers. In the policy-based category, the focus is on the inappropriate legal frameworks, followed by incomplete insurance coverage and inefficient social support networks. It seems that this category is the main category of concern that emerged from this research.

Our findings showed that these health care services are provided with no clear legal framework, and the needed support to make these services more widely available is not provided. These services are, however, more widely available in other countries. In the U.S., these services have been insured by Medicare since 1965. Medicare determines the legal circumstances, the target group, and the covered services (16). When a service is covered by insurance, usually the legality of the provision, the eligibility of the patient, and the minimum standards are determined.

In Iran, HHC service arose as an issue of legal concern in 1999. Despite the passage of more than 15 years since this time, insurance refuses to cover these services. Also, due to the diversity and complexity of these services, many of the procedures are not covered. In other words, the initial legal interest has not been acted upon or enforced.

In Iran, instead of an emphasis on the transformation of the health system and the reintegration of these HHC services within it, the contribution to these services in the health budget is negligible. In the U.S., 24% of the health budget is allocated to HHC, as is 5% in Canada.

Another barrier to service provision is related to agencies. The lack of a professional team, the lack of an independent HHC agency, and problems related to the physician visits were the also important barriers found in this study.

In a hospital, the nurses usually have a support framework, including a health care team and backup equipment. However, at home, neither the necessary equipment nor colleague support exists. The availability of sufficient specialist nurses in the ICU is necessary for patient safety and quality of care (17), and nursing staff's inexperience leads to decreased quality of care (18). In this study, most of the health care workers were not professionally trained in this specific line of work. In other words, while the team leader may have had the required professional knowledge, most of the staff were inexperienced. In other studies on the role of a professional team in ensuring proper care, problems have also been reported. For instance, the skills of experienced RN nurses in many areas were reported to have been low (19), and in another study, most of them did not have the experience of working with a tracheotomy patient (20).

During the phase of transition from the hospital to the home, patients reported discontinuity in the health services provided (21). As the results show, full-time staff were not provided in our teams. This may be because HHC is the second line of work for most nurses. The nurse who cares for the patient in the hospital should continue to deliver the same quality of service to the same patient at home. Because the continuity of care is very important, coordinating these two roles of the nurse may improve the general quality of care.

The family is the host of this process, and so they must be prepared well. One of the most important barrier categories in this study was family-based. The families experienced loss of work, loss of social opportunities, and general distress. Anxiety, depression, and post-traumatic stress disorder have been reported in both patients and family caregivers (22), since service delivery to the chronic patients could affect the physiological and psychological health of caregivers (23, 24). Family members also experience financial problems. Other studies report that financial stress is the strongest factor affecting quality of life among these caregivers (25). Family income adequacy has a direct effect on both the patients and families' quality of life and clinical outcomes (25). It seems that in other countries, the physical and psychological pressures are also prominent, but in our country, families mention financial constraints as the main source of stress. The continued decrease in proper health service coverage is lead-

ing to increased pressure on patients and family members.

Furthermore, the physical and psychological side effects may interfere with the quality of care. The patient and family should therefore receive support for reducing the physical, emotional, social, and financial burdens (26). In our country, the external support is not sufficient, but the support of the family members does seem to be quite high.

5.1. Study Limitations

Because of cultural barriers, gaining access to the homes for doing the interviews was one of the hardest parts of this study. The families would not allow the researcher to enter their homes. Since the team leaders had a close relationship with family members and in most cases were respected by them, we wanted the team leaders to coordinate the time of the interviews.

5.2. Conclusions

Despite the extent of HHC services, they are still in their initial developmental steps in Iran. It seems that home health care is one of the most important challenges faced by our country's health system, but the suitable infrastructure and policies have not been adequately considered. It is hoped that the results of this study could be used for improving the current status of HHC delivery to ventilator-dependent patients at home.

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Footnotes

Authors' Contribution: Study concept and design: Seyed Tayeb Moradian and Hamid Reza Khankeh; acquisition of data: Seyed Tayeb Moradian and Abbas Ebadi; analysis and interpretation of data: Seyed Tayeb Moradian, Abbas Ebadi, and Kian Norouzi; drafting of the manuscript: Seyed Tayeb Moradian; critical revision of the manuscript for important intellectual content: Hamid Reza Khankeh, Kian Norouzi, and Abbas Ebadi; study supervision: Hamid Reza Khankeh, Kian Norouzi, and Abbas Ebadi.

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