Hindrances to the implementation of family-centered care approach: a grounded theory study

Obstáculos a la implementación del enfoque de atención centrada en la familia: un estudio de teoría fundamentada

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Abstract

Introduction: Family centered care is one of the caring approaches which support patient and family members and reduce their stress level caused by illness. This study aims to explain the challenges of family centered care approach implementations in Iranian health care settings.

Methods: This article is a part of grounded theory study. Participants were selected through purposeful sampling method; the data was collected conducting an in-depth semi-structured interview with each participant. Participants were family members, nurses, clinical supervisors and physicians of educational hospitals affiliated to Khuzestan University of Medical Sciences. Data analysis was conducted using constant comparative analysis method.

Results: Five challenges to implementation of family centered care were extracted in the process of data analysis including: healthcare resources limitations, health professional patient dependency, time constraints for providing care, nature of chronic diseases and medical paternalism.

Conclusions: Implementing this approach is facing with some issues. It needs to develop a partnership between patients' family members and healthcare providers. Health care system can achieve a range of potential benefits with the implementation of family centered care.

Keywords: family centered nursing, Grounded theory.

Resumen

Introducción: la atención centrada en la familia es uno de los enfoques de cuidado que apoyan a los pacientes y los miembros de la familia y reducen su nivel de estrés causado por la enfermedad. Este estudio tiene como objetivo explicar los desafíos de las implementaciones del enfoque de atención centrada en la familia en entornos de atención médica iraníes.

Métodos: este artículo es parte del estudio de teoría fundamentada. Los participantes fueron seleccionados mediante un método de muestreo con propósito, los datos fueron recolectados realizando una entrevista semiestructurada en profundidad con cada participante. Los participantes fueron miembros de la familia, enfermeras, supervisores clínicos y médicos de hospitales educativos afiliados a la Universidad de Ciencias Médicas de Khuzestan. El análisis de datos se realizó utilizando un método de análisis comparativo constante.

Resultados: Se extrajeron cinco desafíos para la implementación de la atención centrada en la familia en el proceso de análisis de datos, que incluyen: limitaciones de los recursos de atención médica, dependencia del profesional de la salud del paciente, limitaciones de tiempo para brindar atención, naturaleza de las enfermedades crónicas y paternalismo médico.

Conclusiones: la implementación de este enfoque enfrenta algunos problemas. Necesita desarrollar una asociación entre los familiares de los pacientes y los proveedores de atención médica. El sistema de atención médica puede lograr una gama de beneficios potenciales con la implementación de la atención centrada en la familia.

Palabras clave: enfermería centrada en la familia, teoría fundamentada.

Introduction

Family is one of the most influential factors during illness of a family member. During hospitalization, the presence of family members is crucial, and they are considered as an important source of information. They are also the most important source of emotional support for patients[1]. In recent years, the caring approach in most of health care systems in developing and developed countries has changed from disease-centered approach to family-centered approach.

Family participation in planning, delivery and evaluation of health care increases their satisfaction, and improves mutual trust between family members and health professionals[2] which is an important aspect in assessing the quality of care provided by health centers and hospitals[3]. Besides, lack of family members' participation in the care plans can lead to unsatisfactory outcomes of interventions and makes patients and family members face many challenges such as increased stress, miscommunication and dissatisfaction with provided services. Since family members play a vital role in patients' recovery and improving their physical and mental condition, they should be involved in provision of care plans[4].

Family-centered care (FCC) is defined as a partnership between health professionals, patients and their family members which is a model of care that all family members are considered in the development of the care plan. This approach is in close interaction with empowerment, respect for individual autonomy, and recognition of human rights[5]. FCC can apply to patients of all ages in any health care setting[6].

Although many studies have discussed the benefits of FCC, there are still many limitations for implementing this approach in different hospital settings. There is a need for comprehensive quality studies for honoring human values, appropriate cultural contextualization, acquiring standard clinical findings and attention to existing ambiguities, because the proposed solutions have not yet been able to guarantee the full implementation of this kind of care. In addition, due to the process and multidimensionality of FCC, the effect of different conditions and platforms influencing key people, a qualitative approach helps to obtain reliable contextual information about the barriers to implementing of FCC approach in hospitals. The purpose of this study was to explore the barriers to the implementation of FCC approach in Iranian health care settings.

Materials and methods

This study has been a part of larger grounded theory study. Participants in this study were patients, their family members, nurses and other members of healthcare professionals that were recruited and selected from teaching hospitals affiliated to Khuzestan University of medical Sciences, Khuzestan province. In order to collect data, after having approval from the Ethics Committee of Iran University of Medical Sciences and presenting it to the vice chancellor of Ahvaz Jondishapour University of Medical Sciences, the researcher referred to Medical-Surgical units. The principal researcher introduced herself to the potential participants and informed them about the research objectives. Potential participants who were happy to participate in the study were selected, and they were asked to sign an informed consent form.

The participants were face-to-face in-depth semi-structured interviewed. The interview sessions were conducted in a quiet room participants found convenient to attend. All interviews were audiotaped and transcribed verbatim immediately after the interview sessions. The principal researcher rechecked the transcripts for accuracy while she was listening to audiotapes carefully. The data were also collected through the direct observation of Medical-Surgical units after obtaining the permission from the nursing staff by the principal researcher. Besides, the researchers used field notes, methodological and theoretical memos throughout the research process.

Data analysis was performed simultaneously with data collection using constant-comparative method provided by Corbin and Strauss (2015). This method includes data analysis to identify concepts; conduct the comparative analysis of concepts based on similarities, differences, descriptions and details; analyze for background; analyze the process; and combine the categories, background and process. In the data analysis process, open codes were extracted from the transcripts and then they were categorized into categories using the constant-comparative method.

To achieve credibility and trustworthiness in this study, eight follow up strategies were used. These strategies were: 1) prolonged engagement and persistent observation in the field; 2) triangulation; 3) using peer review or debriefing; 4) negative case analysis; 5) clarifying researcher bias; 6) in member checks; 7) rich thick description; and 8) external audit[7].

The number of participants was 10 individuals (five males and five females) including two patients, three family members, three nurses, one clinical supervisor and one physician. The hindrances to implementation of FCC, which were extracted in the process of data analysis, were: 1) limited healthcare resources; 2) health professional/patient dependency; 3) Time constraints for providing care; 4) nature of chronic diseases; and 5) medical paternalism.

Limited healthcare resources

This category included three subcategories of organizational constraints, human resource constraints, and educational constraints. About organizational constraints, nurse no.1 stated: "We have 2-3 work shifts. There aren't enough staff and there is no plan. If we get less work and have less patients, we can do our job better." The supervisor said: "Verbal guidance may not be used because it's really crowded, and the workload is high. There is too much traffic and high patient transfer that you're usually not allowed to enter. There is so much noise. The number of patients is also high". Patient no.1 complained: "I was in emergency section for 4 days. There was only one endoscopy device for 200 patients! If there were more devices, I could have been discharged earlier." "Number of patients is high and the environment is so boring and dirty that when one of my relatives becomes sick, I prescribe the same medications used in hospital, and if they need an injection, I do it for them at home. When I see some patients that are from a rich family, I prefer not to hospitalize them as far as possible; because when they see patients lying on bed next to them smell bad or have psychiatric problems, they complain in a loud voice and disturb other patients. Most of them also don't like hospital foods. Anyway, it's not a favorable place, although for some patients that come from a family with low-level economic status, it may not be a bad place. But, you know, it's not good. We have no choice though and we have to cope with such conditions, facilities, and place." the physician told us.

Regarding human resource constraints, the researchers asked the participants: "To what extent do you respect the opinions of your patients or their family members? Do you listen to them?" Nurse no.1 replied: "well, yes if we had free time, but we don't! We can't always stay beside the patient!" Family member no.1 disagreed: "no! They aren't at this level as all!" Supervisor argued: "they've taught them, no matter it's low or high. I mean, they teach them as far as they can, but I can't say it exactly; all I can say is that there's a lack of time and energy, and the number of patients is high. Another factor is the tiredness of nursing staff." The physician told: "They share their experiences but most of them are not important. This information should be such that can guide us, correct us. When they say that they did something and it healed them, it does not necessarily show that their practice was right. That's why they are in hospital! Since patient turnover is high, I think, we can't do anything unless, for example, they tell the patient to come back one day after discharge for training, counseling, or anything related to psychotherapy as outpatient, but in these patients, it's not applicable."

Regarding educational constraints, supervisor said: "There's very little talk about diseases. For example, when the patient strokes, we say that he's bleeding or something like that instead of explaining the patient about the disease and its adverse effects and talking about its prognosis or diagnosis. We inform them about these when they are discharged. During an inpatient admission, nurses give some pamphlets to them which explains what's the policy? Where's the prayer room? Where's the toilet? How many rooms are there? How many patients do we have? What's patient capacity? There are also other pamphlets that introduce the disease. For example, if the patients have CVA diagnosis, these pamphlets explain the characteristics of this disease. Or if a patient is going to be treated by NG TUBE, the pamphlets describe this treatment method and its care needs to them. These printed pamphlets exist in all departments. Verbal guidance may not be used because the hospital is really crowded and the workload is high; you need 30-40 min to 1 hour to talk with a companion, while we have other clinical works. We distribute these pamphlets for their knowledge and not asking any more questions. Unfortunately, most of the families aren't alert and without reading them, they come on the door complaining and asking loudly about their patient status and quarreling why we haven't done anything for their patient! But we had already told them!". Nurse No.1 explained: "Sometimes in morning shifts, it is quiet with no mess and we can teach them in peace, while in some morning shifts, we don't even have time for writing reports! I do my work as far as I can. I am an active person but not fully, as 50-60%! Because the workload is really heavy. We have time only for writing reports and medication administration. We have 11 patients and this makes it difficult". Nurse No.2 complained: "In each shift, in our nursing report, we should write one or two training; work load is high and is increased day by day and most of which is paperwork. It really annoys me. Of course, the officials are getting busy as well. Patients need clinical care not this! It could be better if there was no paperwork". She also said: "We have to repeat it in each shift. It annoys us. We write and say it to them from the first day. For example, when their blood sugar is high we verbally warn them; or when they have bedsore, we verbally teach them what to do; or we ask the companion to help the patient or change the patient's position. But, it makes it difficult if we teach them in the written form. There're also so much rigor in internal department. I mean patients are more sensitive, and they need more care. For example, a patient in this sector may have a heart problem, lung

problem, diabetes, infection or other diseases altogether; so it's hard to handle all of these! Treating 13 patients makes us tired".

Health professional/patient dependency

In terms of healthcare team's group dependency, the physician answered: "If I do my job well; if the nurse teaches well; if the patients help and acquire information about their disease and its side effects, and their family supports them, the cycle will be completed, technically. A physician should have a disease knowledge as well. He can't do it all alone and only by administrating medications." Nurse no.3 replied: "We all are a team for treating one patient. We all have the same goal and work as a team. If one of us doesn't do her work in time, others can't do their work in time; so the patient will not receive the treatment in time".

Time constraints for providing care

Regarding the allocation of time to provide care for patients, the participants said: "Nurse comes and says something but forgets to record it, because of high workload. Or when she is talking to me, other one interrupts us and thus forgets what she was talking about!" (Quoted by family member no.3). "I think if the nurse has more time or spends more time on the families, they can definitely learn better and provide better assistance for their patients" (quoted by the supervisor). "Look, If the doctor comes on time for visiting patients, we can write our reports, give them medications, and also teach them. For instance, the patient asks: what did the doctor prescribe for me? Why the doctor prescribed CT? Why sonography? We can answer them. In the evening shifts, we also have very sick patients." (Quoted by nurse no.1).

Nature of chronic diseases

Regarding the nature of chronic disease, the participants argued: "I had put an oxygen mask on patient, but he removed it and threw it back! Neither the companion nor the patient got what we said! One patient needed a nuclear scan. He asked us to inject him a morphine. We did it! But he said: I don't feel good. Then we injected Pethidine. Again, he wasn't satisfied! He fooled us!" (Quoted by nurse no.3). "Two doctors told me that I needed a surgery but this thermos that they put here (on the stomach) looks bad and I'm supposed to have diarrhea for 4-5 months until they fix the intestines. This means, this thermos is going to be here for 4-5 months!" (Quoted by patient no.1). "Unfortunately, the patient does not comply with the treatment. He walks barefoot for example, while he has diabetes! Diabetic foot ulcers can cause amputation. It's not up to the physician, family or nurse. This is the patient's negligence. We really have a lot of such patients. Some of them think that something that happens to others is not going to happen to them! One said: I hate injection! That man died because of insulin injection! Or said: doctors amputated that man's leg after the injection! But he doesn't understand that the man died or his leg got amputated because of the delay in injection. They think that everything is about dying, but they don't understand that the dialysis is more painful than death" (quoted by physician no.1).

Medical Paternalism

Regarding patronizing attitude of healthcare team, the participants stated: "the behavior of nurse or anyone that is addressed is important. Some of them even don't look at us to listen what we want to say. Maybe this is because of cultural, political or social problems. Nurses rely on the doctor's order, and don't ask the patients to explain their conditions. I don't judge them but they should admit that they may make a mistake theoretically or practically. They must not decide before listening to the patients and understanding their problems. They must not decide based on their wrong perception. Whatever they want to do, they should think before for a moment. They should ask families for advice. It would be better if you (doctor) know the attitudes of nurses as you ask mine. The head of nurses once came and asked me what the problem of my patient was. This is a systemic weakness!" (Quoted by family member no.1). "Well, doctors don't treat patients based on the advice of families, but, come on! They ask them about some habits of patients" (quoted by nurse no.2). "... no, that one who perform sonography. I asked her why the patient should come back. She replied: I doubted something! Then I said something to her and maybe I was wrong. Then, another doctor came and performed sonography. She didn't say anything to me either. They had a discussion that I didn't get!" (Quoted by family member no.2). "I think they don't give us any information because it may cause a problem! Sometimes, they had no sense, somehow like a machine! A nurse needs both technique and feeling to be successful in her work! (Quoted by family member no.3).

Discussion

At the time of hospitalization, family members tend to have an effective role in accelerating the patients' recovery and participate in the care of the patients. The patient also needs the presence of family members along with the treatment team. While the current care approach is traditional, and the healthcare team members focus on the patients' needs and physical problems with regard to the barriers and limitations. The condition of hospitals and care facilities for the involvement of the patients and family members in the care process is not appropriate. Considering the increase of chronic diseases, the high cost of care and treatment, and the emotional attachment of chronic patients on family members, FCC approach can reduce the challenges of patients and family members with healthcare team, especially nurses who spend the most time with the patients and their families, by rewarding the patients' cultural values and family members. According to the studies, one of the challenges of implementing this approach are its preventive factors[6]. The findings of this study also showed that one of the important challenges

in implementing all the aspects of FCC is deterrent factors, because in Iran, there is still no standard guidelines for the involvement of patients and family members in the patient care process. The presence of family members in Iran's educational hospitals is still controversial, and there are diverging views on this issue. Despite the positive effects of family participation in the patient care plan and family members' desire to help accelerate patient recovery, their presence in hospitals is still limited[8].

In this study, regarding the deterrent factors of FCC implementation, the limitations of healthcare system were organizational, human resources, and educational constraints. In many studies, these factors have been indicated. For example, in the study by Davidson et al. (2017), it was emphasized on the attention and support of family members and identifying related hospital policies. To achieve this goal, factors such as communication, training for staff and family members, involvement of families in patient care, providing counseling services, and facilitating environmental and organizational conditions for implementing a FCC program are important[10]. In Barreto et al. (2017)'s study, the participants perceived that FCC was about confirming the presence of family members in a care setting that could provide more friendly care, although its implementation in the emergency department seems difficult because of the current physical space, unpreparedness of the staff on the subject, the high flow and turnover of patients and the sociocultural conditions[6]. The existing social conditions for communication between patients and family members were also important, and the possibility of a visit between them should be provided. The results of this study were consistent with their results where the participants emphasized on organizational constraints of the healthcare system, such as work pressure and lack of workforce, high number of patients, inability to give verbal information to the patient and families due to overcrowding and heavy workload, not allowing the families to enter the unit due to the heavy congestion, and the insufficient hospital resources[6]. In line with the results of this study, Boztepe and Kerimoğlu Yıldız (2017) concluded that the implementation of all aspects of FCC is difficult and, in addition to positive views of nurses, the environmental and organizational factors of care providers should also be conducive[10]. To practice FCC appropriately, nurses need to have sufficient resources, appropriate education, and support from their managers. There are no standard clinical guidelines in this area which should be designed and used. In the study by Azami- Aghdash et al. (2015), the awareness level of nurses about the involvement of families in the treatment of patients was low, and further studies are needed to understand the lack of participation of families in the care of patients, because despite the employees' awareness about the benefits of family participation in the patient treatment, there are policies restricting family members, and there is no guideline to educate how family members should be involved in patient care[11].

Group dependency of healthcare team is another deterrent factor identified in this study. Belanger et al. (2018) suggested that families need to be adequately recognized and supported and have access to information so that they can contribute to their loved ones' care in a timely manner, and reduce the burden of this stressful experience[12]. In the present study, the participants also needed for sharing information with the healthcare team, and expected the healthcare team to involve them in the treatment process so that they can observe the reactions and conditions of their patients and, if necessary, report a problem to the healthcare team. This requires staff to respect the values and needs of patients and family members. This shows the necessity of information and communication between the patients and family members by the healthcare team. So, the members of the care team should provide more opportunity for family members to contribute to the care of their patients.

Another barrier was the time constraint. Lioyd et al. (2018) also indicated high staff workloads and time pressures as a barrier to FCC. The participants frequently mentioned to high workload (clinical and supervisory duties) and time pressure. They stated that lack of time in a crowded department is a problem, and patient satisfaction could be improved if the physician and nurse had the sufficient time to provide the patient and family with explanations; but, the nurse has to take on some works, discharging patients, clerical issues and non-nursing duties, and treat the clinical problems of the patients. In such situation, it is difficult for the nurse to give all the information the patient needs. These were in agreement with the results of the current study[13]. In the present study, the participants indicated some issues such as forgetting to write the medication instructions due to the hurry and high workload; the nurses' need for time to teach, learn, and have more efficiency; and taking a time for family members if the conditions are favorable. Given the evidence of FCC benefit for the patients, family members and health care system, it is necessary to pay attention to the high workload and time constraints of the staff, and take appropriate measures to resolve or mitigate these problems, because they are barriers to FCC implementation.

The nature of chronic diseases was another identified barrier. Khachian et al. (2016) showed that FCC education had a positive effect on the self-care behaviors of the patients with chronic diseases. With regard to Iranian culture and the importance of family, it is suggested that this approach be used to improve self-care behaviors in these patients, because the incidence of chronic diseases in Iran is increasing, and these patients have many problems in this area. They need self-care to adapt to their conditions. It is also recommended to teach their family members which can play a positive role in reducing their stress, and increasing their awareness about the disease and how to control it[14]. In the present study, it was found out that some chronic patients and their family members did not pay enough attention to their disease and did not follow instructions. They did not care to control their disease. Teaching chronic patients and caring for the role of

family members as a valuable resource can be helpful in achieving therapeutic goals.

Regarding patronizing attitude of healthcare team as another barrier, in addition to the results of the current study, most studies have shown that the lack of family involvement in care planning has undesirable consequences for patients and families, and faces them with many challenges such as increased tension, communication problems and dissatisfaction with the healthcare team[4]. Despite the emphasis on the benefits of implementing FCC and honoring their cultural values, in the study of Teymouri et al. (2014), the implementation of FCC increased the Knowledge and self-efficacy, self-esteem and quality of life in parents of children with asthma[15]. It should be noted that in recent years, many studies such as the above mentioned studies, have been carried out on different patients and their family members; however, the implementation of these interventions, despite the benefits, is not very permanent, and there is no standard guideline for its permanent implementation, and after the end of the study, its implementation also ends up. Moreover, according to the participants of this study, the healthcare team members had patronizing attitude towards the involvement of patients and family members. They do not consult with family members, and families' advices and opinions are not considered. There is a systemic weakness. They feel something is missing. The nurse is dependent on the instructions of the physician and does not consider the families' advices. Hart et al. (2013) The healthcare team does not explain the patients and families about the used diagnostic techniques, and nurses have different views about having a family in the patients' bedside. These indicate the patronizing attitude of medical professionals in Iran which should be corrected, because, given the increasing number of people with chronic diseases and the elderly people, and the willingness of patients and family members to participate in the patient care process, if it is revised and updated, the unique capabilities of patients and family members will be used for their own benefits[16]. Moreover, in addition to increasing the satisfaction of patient/family members/staff, it reduces stress, the length of hospitalization, chronic disease recurrence and re-hospitalization, improves the human communication, and empowers patients and family members for the time after the discharge from the hospital and for the home-based disease control.

Conclusions

Although the implementation of FCC for Iranian health system is valuable, there are several barriers to its implementation. It is imperative that the healthcare policy makers take action to eliminate or reduce these factors in order to benefit from the potential of patients and their family members. The findings of this study are useful for policy makers to identify and resolve the barriers to the implementation of FCC.

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Ethical considerations: Ethical considerations were obtaining permission to enter the research location, explaining the purpose of the study and the interview and the right to participate in the study or withdraw it at any time, assuring participants of the confidentiality of their information, and obtaining informed consent for interviewing and recording conversations

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