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The Process of Parents' Decision-Making to Discharge Their Child against Medical Advice (DAMA): A grounded theory study

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ABSTRACT

Discharge against medical advice (DAMA) refers to the phenomenon that patient or the patient's surrogate decides to leave the hospital before the attending physician confirms the patient is discharged. Children are much more vulnerable to such discharges. This process occurs with different mechanisms that identifying them can be helpful in reducing this phenomenon. We aimed to explore the process of parents' decision-making to discharge their child against medical advice. In-depth, semi-structured interviews were conducted with 10 fathers, 10 mothers, 6 nurses and 3 physician assistants and the data were collected to the point of saturation. Grounded theory methodology was adopted for data collection and analysis. The results of qualitative analysis in the field of the parents' decision-making on the DAMA revealed 4 main themes: "lack of family-centered care", "disruption of the parenting process", "distrust to the medical team and center" and "psychological strategy of shirk responsibility for child care and treatment ". By providing family-centered care, adopting measures to empowering the families, developing the trust of parents to the health care team and developing a discharge plan from the beginning of children hospitalization with the cooperation of health care team and parents and considering all factors such as child's special health condition and parent's health related perceptions and beliefs, children will not be discharged against medical advice and will experience better outcomes.

Keywords: Parent, Decision-making, Discharge against medical advice, Child

INTRODUCTION

Discharge against medical advice (DAMA) refers to the phenomenon that a patient or the patient's surrogate decides to leave the hospital before the attending physician confirms the patient is discharged [1]. Children are much more vulnerable to such discharges because they are less involved in the process of decision-making for their health care [2].

Although the discharge against medical advice suggests that the parents are aware of the child's condition, his/her disease and its consequences and though the physicians are free from legal consequences, but the child who is unable to express his intentions and in some cases, does not have adequate understanding of the such processes may be victims of these decisions [3].

This phenomenon occurs frequently in developed and developing countries, but the reasons behind it are different [4], even within each of these countries have also been reported prevalence of different reasons. For example, in Iran [5] and Nigeria [3], 3.5 and 5.1 to 7.5 percent of children DAMA respectively, happened in different centers.

In fact, this situation can perhaps be considered a case of child neglect because such discharges can induce inadequate care, increased mortality and long-term adverse effects for the children [4]. In many cases, the child's clinical condition deteriorates after such discharges and parents do not refer the children for re-hospitalization because of the fear of being refused by the health care center [6].

Most of patients, who are discharged against medical advice, don't complete the treatment process, don't perform follow-up care and treatment and don't use essential services for their own health. These complications occur with different mechanisms whose identification can be helpful in reducing this phenomenon [7].

Aims of research

Despite the high incidence of child DAMA and its complications, we are still witnessing such discharges in our health care system in Iran [8]. More studies on the DAMA in the world have been conducted retrospectively [9].

Deep insight on the features and reactions of families as well as members of the health care centers about this issue is of particular importance [10]. The aim of this study was to explore the process of parents' decision-making to discharge their child against medical advice.

MATERIALS AND METHODS

Design

To the best of our knowledge, this is the first qualitative study focusing on the process of parents' decision-making to discharge their child against medical advice using an exploratory qualitative design. This allows for deep exploration of the parents' decision-making to discharge their child against medical advice, as experienced and voiced by parents.

Framing of study questions

We framed the research question based on the aim of the study. The central question of the study was "how parents make decisions for discharge their child against medical advice". For answering this main question, we asked participants a series of guiding questions such as: "how did you decide to discharge?", "please talk about the hospitalization of your children", "what happened that you did not continue care and treatment for your child and why do not wait until your child's health care team to provide discharge?, "what factors has strengthened your decision?", "what obstacles do you have for this decision?".

Sampling approach and criteria

For participant selection, the first step was providing the list of parents who were attending to children's hospitals in Tehran, Iran, between 2014 and 2015 and discharged their children from Children's medical center affiliated to Tehran University of Medical Sciences and Ali-Asghar children's hospital affiliated to Iran University of Medical Sciences against medical advice.

The parents were not suffering from mental, psychological and addiction problems. The parents of hospitalized children aged between one month and 18 years and were not a known case of child abuse, were included. The third author then communicated with parents by telephone to arrange a mutually convenient appointment. They were asked whether they were willing to participate in the study, and an appointment was then made to meet.

Parents were selected using purposive sampling based on their experience on DAMA and the purpose of the study. In order that the data gathered were as rich as possible, we tried to select parents based on the maximum variation of factors that could potentially affect their social interaction. We also sought to involve parents from different social, economic, educational and cultural levels. Children had various diagnoses, age and duration of hospitalization. In order to theoretical sampling, nurses and physician's assistants who had experience regarding DAMA were interviewed. This group had different work experience, age, place of employment and educational level.

Ethical considerations

All participants were informed about the voluntary nature of participation, with the option to withdraw from the study at any time. Moreover, they were assured that their statements would be confidential and their identities would not be revealed in study reports. All participants provided written consent and also provided verbal consent for voice recording at the beginning of each interview. Participants were assured that the voice recorder would be switched off if at any time they felt uncomfortable with recording.

In addition, they were encouraged to contact the researcher to ask questions or be provided with additional data. This study was approved by the Ethics Committee of Tehran University of Medical Sciences.

Data gathering
Data from interviews with 10 fathers, 10 mothers, 6 nurses and 3 physician assistants was collected to the point of saturation. Each interview was scheduled according to the participant's preferences.

Based on the parents' preferences; the interviews were performed in a private room in their house and based on the nurses' and physician assistant's preferences; the interviews were performed in a private room in their workplace.

Face-to-face, semi-structured interviews were held with participants. Interview questions were open-ended to allow participants to thoroughly describe their opinions, perceptions, and experiences on DAMA. Each interview lasted for an average about 60 minutes (ranging from 50 to 80 minutes).

Data analysis
The data were analyzed using the constant comparison method so the data collection, analysis and interpretation occurred simultaneously, in accordance with the grounded theory method. In fact, each interview provided direction for the next one. The data collection and analysis continued until data saturation, that is, no additional data were found for development of the category properties. The data were analyzed for concepts, context, and process and finally integrating for emerging the theory of the process of parents' decision-making to discharge their child against medical advice [11]. MAXQDA software version 10 was used to manage and organize the data.

With the frequent, precise and meticulous reading of the transcripts, concepts were analyzed. All possible meanings of the data were considered and meaning label assigned to the data. High-level concepts were assigned as categories/themes. During the interviews and data analysis, effective contextual factors in the process of parents' decision-making to discharge their child against medical advice such as individual, environmental, organizational, familial, social, political, economic, cultural and historical factors were considered.

By reviewing and comparing the categories and subcategories in terms of their features and dimensions, they reduced to more abstract categories and by drawing diagrams, process of parents' responses to the contextual factors effective on DAMA were discovered. Using memos, prolonged engagement with informants and reflexivity on the data and categories emerged from analyzing the contextual factors effective on DAMA and the process of parents' responses to these factors, the central category was identified. Then, according to the features of this category and respective sub-categories, theoretical story line of the study was written out.

The rigor
To achieve the rigor of this study, the measures introduced by Corbin and Strauss in 2008 were used [11].

To ensure the fit, the results of the study were assessed by the participants, staff of data collection centers, research team members and supervisors of the Graduate School of Tehran University of Medical Sciences. The theoretical storyline developed so that participants could imagine their situation in it and knew that the storyline was right about them. To provide applicability or usefulness of findings, we tried to develop a body of knowledge in nursing, especially issues in admission, treatment and discharge children referred to the health care centers, in other words, all factors associated with the process of parents' decision-making to discharge their child against medical advice were considered.

Development of concepts was conducted during the data collection and analysis and it was tried that the findings organized around concepts and themes that make a common understanding among participants and professionals. The research context described using models and quotations. To provide contextualization of concepts, with a detailed description of the context of the study, we tried to help the reader to better understand the concepts and the background story and finally they fully understand events, specific meanings assigned to those events and underlying experiences.

About the logical process of the ideas expressed in this study, we tried to continue the research process until its gap in terms of its logic improved and findings understood by the participants, staff in the data collecting centers and research team. Decisions about the appropriateness of the research methodology well explained so that reflects its appropriateness to collecting and analyzing the data. To provide the depth of the results, in addition to providing relevant concepts we tried to present descriptions along with details, so that the research findings will be able to participate in the necessary changes in policies and practices relating to the child's admission, caring and discharge.

Using sampling with maximum variation, we tried to acquire data with varied dimensions and characteristics and in fact, as far as possible, reflect the complexity of participants. For the creativity in the findings of the study, we tried that required procedures in research process such as appropriate sampling methods are compatible with each other

and to be used flexibly. For example, following purposeful sampling, to complete creatively developing theory, theoretical sampling was used when necessary.

Table1. Participants' Characteristics

Number	Age	Sex	Relativity with child	Education level	Job	Address	Child's age	Child's diagnosis
1-a	40	Male	Father	High school diploma	Self-employed	Urban	3 YO	Tetralogy of Fallot
1-b	34	Female	Mother	Junior high school	unemployed			
2-a	30	Male	Father	Bachelor's degree	Government employee	Village	2 MO	Congenital short bowel syndrome
2-b	23	Female	Mother	High school diploma	unemployed			
3-a	34	Male	Father	Bachelor's degree	Government employee	Urban	1 MO	seizure
3-b	29	Female	Mother	Associate's degree	Government employee			
4-a	40	Male	Father	Junior high school	Self-employed	Village	2 YO	Foreign body aspiration
4-b	36	Female	Mother	Junior high school	unemployed			
5-a	36	Male	Father	Associate's degree	Self-employed	Urban	6 YO	appendicitis
5-b	28	Female	Mother	High school diploma	Government employee			
6-a	22	Male	Father	Elementary school	Self-employed	Village	4 MO	Gastroenteritis
6-b	21	Female	Mother	Elementary school	unemployed			
7-a	35	Male	Father	Bachelor's degree	Self-employed	Village	10 MO	Fever
7-b	30	Female	Mother	Bachelor's degree	unemployed			
8-a	36	Male	Father	Elementary school	Self-employed	Urban	4 YO	Febrile convulsion
8-b	28	Female	Mother	Elementary school	unemployed			
9-a	37	Male	Father	Junior high school	Self-employed	Urban	3 YO	Achalasia
9-b	32	Female	Mother	Associate's degree	unemployed			
10-a	43	Male	Father	High school diploma	Self-employed	Urban	2 YO	Neutropenia
10-b	38	Female	Mother	High school diploma	unemployed			
11	30	Female	Nurse	Bachelor's degree	5 years' experience			
12	34	Female	Nurse	Bachelor's degree	9 years' experience			
13	50	Female	Nurse	Bachelor's degree	23 years' experience			
14	30	Female	Nurse	Bachelor's degree	6 years' experience			
15	34	Female	Nurse	Bachelor's degree	8 years' experience			
16	27	Female	Nurse	Master of science	4 years' experience			
17	30	Female	Physician's assistant	Student of pediatrics	2 years' experience			
18	34	Female	Physician's assistant	Student of pediatrics	4 years' experience			
19	28	Female	Physician's assistant	Student of pediatrics	1 years' experience			

In observance of the researcher's sensitivity to the participants and the data, using semi-structured interviews to collecting data, we tried to remain faithful to the data utilizing probing questions and proposing the questions that emerge at the time of writing memos and in fact, stimulating questions for data collections, emerged from data analysis. The research team tried to use less the previous data available in the literature to extract concepts related to the study context. To avoid the problem of relying only to the recalling the content and observance of accuracy of

the findings and precision in regard to attention to the all aspects of the process of parents' decision-making to discharge their child against medical advice, documents relating to memos discussed in the research report and along with the progression of the research became more abstract.

Findings

Participant's characteristics, including age, sex, educational level, type of disease, duration of hospitalization and job experience are presented in table 1.

Concepts such as "behavioral tension of staff", "cumbersome rules", "parents physical fatigue", "sense of empowerment in home care", "lack of coordination between the health care team" and "medical errors" refers to the context. The data analysis for the context revealed that the main concern of parents regarding the DAMA was "distrust to the health care team and centers". This concern was created following the effect of the child's hospitalization to the different aspects of families such as physical, emotional, mental and social.

After identifying strategies that parents used in response to the context, such as "prejudice on improper mental beliefs related to health" and "indecision and uncertainty to continue care and treatment", we tried to discover the main strategy/process of parents to decide on the DAMA. The issue of "psychological strategy of shirk responsibility for child care and treatment "was the main process of parents' decision-making on the DAMA. "Distrust: shirk responsibility" was emerged as core category.

The results of qualitative analysis in the field of the parents' decision- making on the DAMA, revealed 4 main themes: "lack of family-centered care", "disruption of the parenting process", "distrust to the medical team and center" and "psychological strategy of shirk responsibility for child care and treatment ". (Table 2)

Table2. The results of qualitative analysis in the field of the parents' decision- making on the DAMA

Subcategories	categories	Core category
Lack of respect for the family	Lack of family-centered care	Distrust: shirk responsibility
Lack of family support		
Lack of parent participation in the child care		
Concerns within the family	Disruption of the parenting process	
Financial concerns and social responsibilities		
Not justifying the child's disease course and care plan	Distrust to medical team and center	
Failure to receive expected care		
Fear of worsening clinical condition of the child		
Clinical uncertainty and despair of parents		
Irresponsible consultations		
Special clinical condition of children	Psychological strategy of shirk responsibility for child care and treatment	
Feeling exiting from the crisis		
Prejudice on improper beliefs related to the health		
Indecision and uncertainty to continue care and treatment		

Lack of family-centered care

Lack of respect for the family

"Merely because the staff mistreated with me, I decided to discharge my child against medical advice…" (Participant 5-mother)

Lack of family support

"I'm a mother, a mother needs someone to comfort and support her psychologically while there is no such support here…" (Participant 15-nurse)

Lack of parent participation in the child care

"I want to say that during the two years that my child was sick, we have experienced many things better than health care workers, so it is annoying that your experiences do not observe by health care workers…" (Participant 1-father)

Disruption of the parenting process

Concerns within the family

"Two of my children are at home, I more miss my home, I was more worried about my children, and this was one of the factors that motivated me to discharge my child…" (Participant 10-mother)

Financial concerns and social responsibilities
"Because it's really hard, because you should be regardless of your life, my own job situation so I must devote time for it, we have a life outside these walls that we need to handle it…" (Participant 2-father)

Distrust to medical team and center
Not justifying the child's disease course and care plan
"Maybe, in some cases, they have a right to be distrusted to the health care team, for example, a consultant doctor says something else, doctors are not God, and anybody may make a mistake…" (Participant 16-physician assistant)

Failure to receive expected care
"I saw that medical errors happened in some cases, they were upset and want to discharge, I mean that they do not trust to me…" (Participant 11-nurse)

Fear of worsening clinical condition of the child
"The truth is that most of the reason that we decided to discharge is admitting the children suffering from different types of disease over there, we are afraid that our kid get sicker and disease transmitted from other children…" (Participant 7-father)

Clinical uncertainty and despair of parents
"My child has already undergone surgery twice, forty days is in the hospital, and has not the growing trend, for how long my child should stay undecided…" (Participant 3-father)

Irresponsible consultations
"Finally, the parents say that our family physician outside the hospital suggested that for your child it is not necessary to stay in the hospital, then the parents distrust of us…" (Participant 19- physician assistant)

Psychological strategy of shirk responsibility for child care and treatment
Special clinical condition of children
"If our child did not suffer from additional skin problem and was healthy with regard to his/her other organs, we could stay in the hospital and not discharged…" (Participant 9-mother)

Feeling exiting from the crisis
"We are now working in the pediatric ward, sometimes the family thinks her child's clinical condition has improved and discharging the child will not be a problem…" (Participant 12-nurse)

Prejudice on improper beliefs related to the health
"We have satisfied ourselves for discharge, we have certain beliefs, I generally do not believe in illness, we discharged our child with trust in the belief that, God willing, our child will be recovered…" (Participant 10-father)

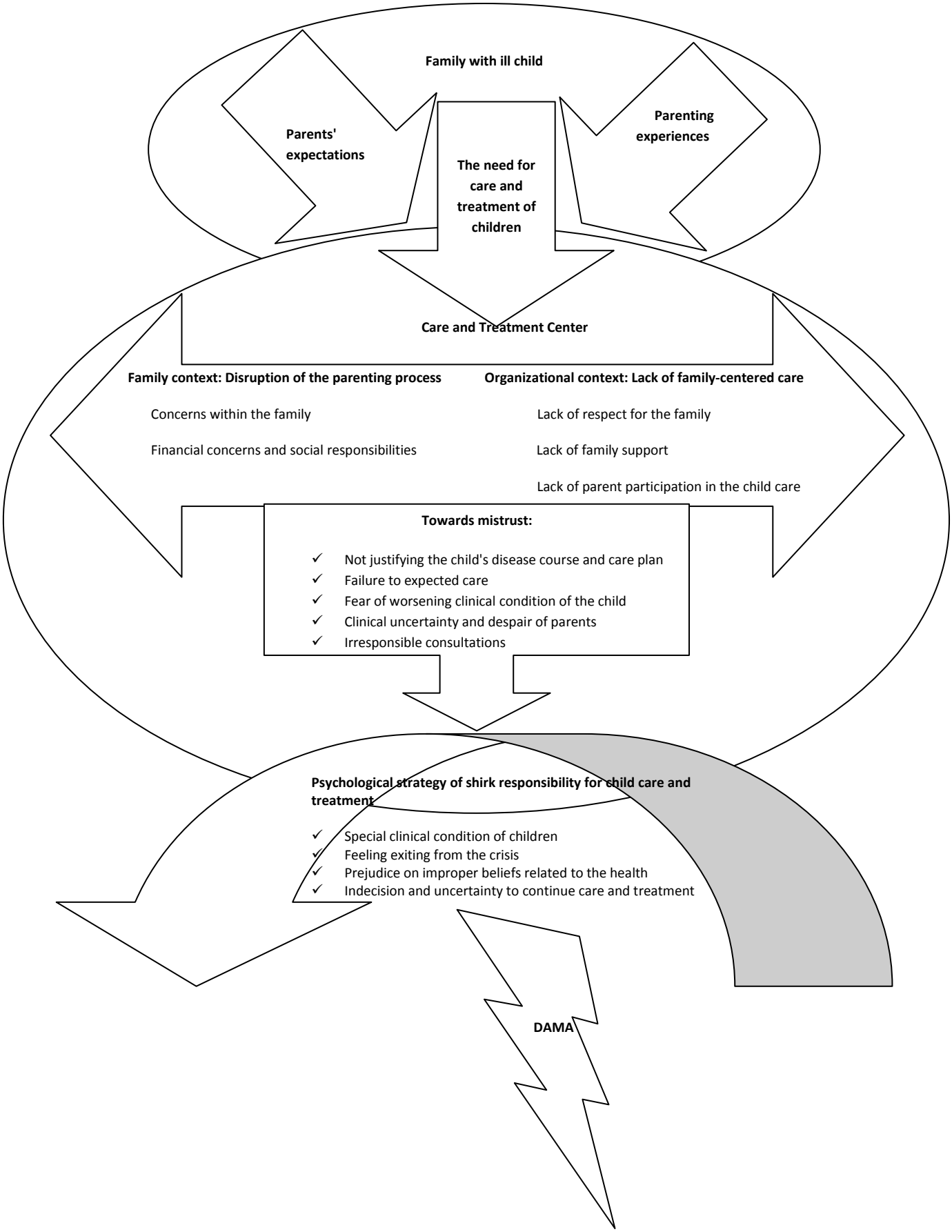
Indecision and uncertainty to continue care and treatment
"I insisted I had to discharge the child, yet it is not the time for discharge, I accept that I was wrong, it was better to stay in hospital…" (Participant 4- mother)

DISCUSSION

Parents with the ill child having parenting experiences, expectations and the need for care and treatment of their children refer to the health care centers (figure 1).

In the early stages of child's hospitalization and attending of the parents in the health care centers, due to factors related to the context of the health care centers such as "lack of respect for the family", "lack of family support" and" lack of parent participation in the child care" they experience lack of family-centered care. Core concepts of patient and family-centered care (PFCC) are "dignity and respect", "information sharing", "participation" and "collaboration" [12]. PFCC is more successful when information is shared in an unbiased manner and without prejudice approach so that families are supported to use that information to make decisions related to their family's health [13].

Figure 1: The model of parents' decision making to discharge child against medical advice.



Following this process, due to the factors related to the context of the family, such as "concerns within the family" and “financial concerns and social responsibilities" parents experience disruption of the parenting process for their family. During child hospitalization the entire family are affected, happen the maternal role conflict and must adjust to a new conditions related to the child's disease so that, parents need emotional, informational, familial, social and psychological support [14, 15]. Family empowerment in a supportive caring environment by increasing family members' knowledge, competencies and self-efficacy may motivate them to acquire the needed skills, resources, authority, opportunity and motivation to achieve desired outcomes for their family and their children [16].

In addition, because of some factors related to the context of health care centers such as "not justifying the child's disease course and care plan", "failure to receive expected care", "fear of worsening clinical condition of the child", "clinical uncertainty and despair of parents" and " irresponsible consultations" parents progress towards mistrust to health care team and centers. Recently, increased attention has been given to the issue of medical mistrust [17]. Health care encounters that have higher levels of trust to the health care team more likely to seek health care services will be satisfied from health care services and accept health care recommendations [18].

During mentioned events in the process of hospitalization and discharge the child, parents because of the crucial and vital need for their child care and treatment are still responsible and do not finalize their decision to discharge their children.

Finally, due to some factors related to the context of the family, such as "special clinical condition of children", "feeling exiting from the crisis", "prejudice on improper beliefs related to the health" and "indecision and uncertainty to continue care and treatment", parents relying on their psychological strategy of shirk responsibility for their child care and treatment, finalize their decision on DAMA. Discharging the children with complex chronic condition is a challenging condition so that some of these children transported to a subacute pediatric hospitals for focused discharge preparation program [19]. Continuity of care for children with special health care needs is a key factor representing health care provision. In this regard, parent's perceptions and experiences have a critical role and they should be actively involved in the assessment and improving the continuity of care for their children [20].

The process of discharge from hospital is complex and challenging for health care workers and patients. Therefore, an effective and holistic discharge plan can significantly improve outcomes such as patient's health. Adverse effects of improper decisions for discharge represent a sub-optimal assessment of readiness for discharge and a breakdown in communication, interaction and information transfer within health care workers and between them and their patients [21].

Limitations

Because the protesting nature of DAMA for parents, difficulty of their cooperation in participating in the study was the limitation of this study. By establishing appropriate relationship with parents and explaining the process of the study, we tried to overcome this limitation. The need to conduct interviews with the parents at their home was a challenge for this study. By spending time proportional to time of parents, we tried to overcome this challenge. Lack of the time of the nurses and physician assistants for interviews and the challenging nature of DAMA for them, were another challenge for this study. By spending time proportional to the time of the nurses and physician assistants for interviews and explaining the process of the study, we tried to overcome these challenges.

CONCLUSION

It seems that providing family-centered care through respectful behavior with family members, support parents mainly informational support and involve them in the care of hospitalized children can help parents to make the best and appropriate decision regarding continuity of care and treatment of their child or discharge them from the hospital. By adopting the measures to empower the families using informational and motivational support of parents to use health care related resources such as social worker's office and health care counselors, parents can focus on the health care of their child without additional family and social concerns.

With providing honest information regarding children clinical condition and his/her care and treatment progress and thus developing the trust of parents to health care team, parents are less likely to discharge their children against medical advice. By developing a discharge plan from the beginning of children's hospitalization with the cooperation of the health care team and parents and considering all factors such as child's special health condition and parent's health related perceptions and beliefs, children will not be discharged against medical advice and will experience better outcomes.

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